
LAMENTATIONS

Issue 101

middle

May, 2006

The month of May... May 20th, Young Jim's angel date... his 15th... I miss him terribly, but I feel he has become part of me and is with me constantly as well as with our children. I feel certain that Jim and our children know each other, because we are put together by someone, so it must be them. May you feel your child near you today. This poem is to you for Mother's Day:

**Heaven lit up with His mighty presence,
As all the Angels looked down,
Today the Lord was placing the jewels,
In all the mother's crowns.
As He held up a golden crown,
As all the mother's looked on,
He said in His gentle voice,
"I just want to explain each stone".**



**He held the first gem in His hand
But the radiance couldn't match His own.
For He was the light of Heaven,
Reflecting off each of the stones.
"The first gem," He said, "is an emerald,
And it's for endurance alone,
For all the nights you waited up.
For your children to come home.
For all the nights by their bedside,
You stayed till the fever went down,
For nursing every little wound,
I add this emerald to your crown."**



**"A ruby, I'll place by the emerald,
For leading your child in the right way,
For if you hadn't taught them about me,
They wouldn't be here with you today.
For always being right there,
Thru all life's important events,
I give you a sapphire stone,
For the time and love you spent."**



**"For untying the strings that held them,
When they grew up and left home,
I give you this one for courage."
Then the Lord added an amethyst stone.
"I'll place a stone of garnet," He said,
"For all the times you spent on your knees,
When you asked me to take care of your children,
And them for having faith in me."**



**"I have a pearl for every little sacrifice,
That you made without them knowing,
For all the times you went without,
To keep them happy, healthy, and growing."
"And last of all I have a diamond,
The greatest of all gems,
For those mother's who lost their children,
When they came home to heaven before them."**



**"This is the most precious sacrifice,
So I give the most precious stone,
For I know just how you felt,
I too lost a child of my own."
After the Lord placed the last jewel in,
He said, "Heaven is now complete,
For every mother has her crown of jewels,
And all her children are at her feet."
(author unknown)**

Grief Grafts

**Ian & Brenda Verdiel's son, Justin (4-28-95), died from cancer,
3-5-01.**

Brenda is an amazing writer and I hope you will click on this email and read Justin's story. It is amazing what this family has done as a family:



When Tragedy
Strikes.doc

She wrote the following poem to her sons:

A Mother's Love:

I Too CRY...

*Sitting alone with just my thoughts,
My memories of you shine through.
Watching you play and run so free
When life didn't leave a clue.*

*Your eyes, so blue as the sky above.
Your hair blowing in the wind.
Your screams fill the air
As you rode your horse
With a smile and a grin.*

*Mommy, look at me...
Look and see... what I can do.
I picked this flower just for you.
Keep it close so when we are apart,
You will always remember me in your Heart.*

*Little did I know that flower would be
A treasure Forevermore.
I cling to your gift with all of my Might
Remembering your days before.*

*Life has its trials and tribulations,
But losing a child seems More.
Your heart is broken, the pain so real,
As Life continues on.*

*I too do cry...for you each day.
My memories get me through.
But the flower you gave me,
I keep so close,
It reminds me of YOU.*

*When I see a dandelion,
I smile through my tears...*

*Although you are gone from me today,
I know I will see you Play.
With each coming spring,
Through the summer time too
Your gift grows to the skies
And when it seeds and blows with the wind,
I feel you glide by.
Butterflymom 2003*

She wrote the following poem to her sons:

***To My SONS:
(Jeremy, Spencer, Michael, Brent, and Wade)***

*All five of you were with us,
When the diagnosis came.
You stood tall and brave,
And had to Grieve on your own again.*

*You all found your place,
And did what had to be done.
For this my Sons I am grateful
And I thank you each and everyone.*

*You gave me the strength to carry on,
When life was upside down.*

*You all stood your ground so strong,
And helped your Mom go on.*

*There were times when I could not be there,
And Times I was but...
You never once turned away.
And stood beside me all the way.*

*For this My SONS...
I Thank You.*

*Then came the time for us all to know,
That Justin's time had come.
He would leave this world of ours
We would lose our brother and son.*

*Again you stood there,
Side by side Not even swaying in the wind.
With Courage and Strength,
You held on till the inevitable end.*

*If I could change our days before,
With a blink of an eye I would.
But my sons you showed the world,
What MEN you all have become.*

*Your Love is real and genuine,
And your future will be yours.
For going through what you all endured,
Shows you can open all the doors.*

*So to you my sons,
Jeremy, Spencer, Michael, Brent, and Wade.
I Love You...
With all my heart.*

**AND...
I THANK YOU ONCE AGAIN!
Love MOM!**

Written Jan 27th 2004 Butterflymom

Brenda set this website up for other parents:

<http://groups.msn.com/ParentSupportConnection>

Justin's symbol is a butterfly.

**Larry & Ginger Katz & Louis Eaccarino's son, Ian (12-31-75),
died from a heroin overdose, 9-10-96.**

Ian James Eaccarino was the much-loved son of Ginger Katz and Louis Eaccarino, step-son of Larry Katz, brother of Candace Eaccarino and dear friend to the many people he made part of his short, but vibrant life. As a kid, he liked to cuddle up on the couch with his mom, sister and step-dad. At age eight, he was captain of the soccer team. Two years later, he earned a black belt in karate and at eleven, came in second to a fourteen-year-old in a competition at Madison Square Garden. As a 5th grader, he was voted most popular boy of his class.

In high school, Ian played baseball, basketball and lacrosse. The semester before he died, he was an honor student at the University of Hartford. In September of 1996, Ian died of a heroin overdose at the age of 20 years old.

Shortly after his death, Ginger Katz founded The Courage to Speak Foundation, Inc. Speaking as a parent who has experienced a loss every parent fears, Ginger inspires people to step forward, assess their situation, and address their problems. Rather than speaking from a place of sadness, however, Ginger speaks words of hope and promise that the courage to speak - about fears, drug dependence, or any troubling issue - presents an ideal opportunity for healing. Ginger chose the sunflower as a logo because the sunflower looks up to heaven.

Through Ginger's story, students and parents begin to recognize the telltale signs of alcohol and other drug use. She also describes the veils behind which those signs hide: anger, denial, fear, pain and deception.

Ian James Eaccarino was born December 31, 1975 and died September 9, 1996. He loved sports...soccer, baseball, lacrosse, basketball, running and more... The symbol is our sunflower. Every time I see a sunflower it reminds me of Ian's life,bright and beautiful, and now it looks up to heaven.

God Bless you with your work. This is an articles I wrote for my town newspaper.....it describes a lot of why I do what I do in memory of my son.

<http://www.ucumberlands.edu/lamentations/Housefire.html>

We are dedicated to....."Saving Lives by Empowering Youth to be Drug Free" 1-877-431-3295 Visit our "NEW" Website www.couragetospeak.org

I invite you to visit SAMSHA website. The Courage To Speak has the honor of being featured on its site since May 2003 sponsored by the US Dept. of Health and Human Services. Please [Partners for Substance Abuse Prevention | Highlighted Partner](#)

Drugs don't discriminate!

Dear Friends,

Ten years ago, we established an organization to help save kids' lives. The Courage to Speak Foundation grew out of a personal and family tragedy: the loss of our son, Ian, to a drug overdose. Since then, Courage to Speak, a nonprofit foundation, has reached out and touched the lives of tens of thousands of children and families with over 700 prevention presentations given nationwide and with educational programs being delivered in middle schools, high schools, and parent groups.

*"I am changed from hearing Ian's story. I shall no longer do drugs."
- a student at Staples High School, Westport, CT.*

Ian died September 10, 1996, the day before he was to enter a rehabilitation program. He was 20 years old. His drug problems had begun in high school, and when my husband and I discovered them and insisted that he enter counseling, we thought we had caught his addiction early. Then I received a phone call from his biological Dad: Ian was snorting heroin in college.

My breath was taken away, my life changed. My friends saw that there was something different about me. And then, as we were trying to help Ian

with his problem, the worst happened. I found him as I was leaving to meet my friend for our morning run – Ian had died in his sleep.

We are not alone. I received an email from another parent recently, who wrote “You have no idea how similar your story is to the loss of my son. _____ was also 20, he was also scheduled to enter a rehab the day following his final heroin use, he was also scolded by police and sent home.....so many similarities! I feel your pain and I know how you miss your precious son. But most of all I KNOW that addiction does not discriminate.”

Once every parent’s worst nightmare became our reality, we promised Ian that we’d do everything in our power to prevent the same fate from befalling others. It was in that spirit that we developed an award-winning community drug education strategy based on Ian’s story - because for most people, especially children, a single true story can outweigh a hundred scientific facts.

Our presentations and programs uniquely touch the hearts and minds of children and adults with candor, credibility, concern, and tools for making healthy life choices. With children as young as nine being offered drugs today, new programs are in the pipeline for elementary students and parents to help families start early to keep their children safe from the crippling effects of drug use.

Drugs and drug dealers do not discriminate!

- ***It takes courage*** to refuse something your friends are doing.
- ***It takes courage*** to be an individual.
- ***It takes courage*** for a parent to say, “I’m here for you; don’t go in that direction.”

*And it takes courage to recognize that no family, no matter how blessed, is immune from the dangers of drugs. **It takes Courage to Speak!***

We give children and parents that courage. Teachers and students invariably respond not with a “heard it already” reaction, but with enthusiasm for what Courage to Speak brings into their midst. Parents, too, report having gained the “Courage To Speak” to their children and loved ones about the dangers of today’s frighteningly pure drugs – and we all know by now that the single most potent weapon against drugs is discussion between parent and child.

Listen to what they are saying about us:

“Courage to Speak is on the cutting edge of a new parent movement, picking up in a way where Nancy Reagan and the parent movement in the 1980’s left off ... CTS offers creative thinking, a highly credible message, forward thinking and vocal leadership at a time when America’s parents and kids need help ... While most kids do NOT do drugs, today’s middle and high

schoolers are more at risk than ever - they and their parents face record drug purity levels, a rise in meth, diversion of prescription drugs, new use of dangerous inhalents, and a creeping return of cocaine ... Policy makers, parents and anyone who cares about America's future is well advised to see what the CTS curriculum and leadership offers - Taking time, could make all the difference ..”

-- Bobby Charles, former Assistant Secretary of State for Narcotics and Law Enforcement, former Staff Director and Counsel to Speaker Hastert's Task Force on Drugs, current president of The Charles Group, LLC, a Washington-based strategic planning and consulting group.

Drug addiction destroys not only the users, it destroys their entire families. It robs you of everything, until you have nothing left. Our son Ian was a good, kind person who suffered from a terrible disease, and we miss him every day of our lives.

The mission of the Courage to Speak Foundation is to save as many children and as many families as we can. You can help us. Please, visit our website @ www.couragetospeak.org Read what our children have to say. If you are a parent, please remember that there are worse things than your child getting caught with drugs, it is their not getting caught. Have the Courage to Speak because it is ok to ask for help. Find a trusted relative, a favorite teacher, a coach or clergy, and talk to them. Above all, talk to your child and give them the strength to have the Courage to Speak.

Ian's symbol is a sunflower.

David & Cindy Jo Greever's daughter, Michelle (8-24-84), died in a school bus related accident, 11-5-93.

Cindy Jo has a Healinghearts Ministry for Bereaved Parents offering on-line group support via her grief group and websites for our Angels. For more information you can contact Cindy Jo: cindyjo@msn.com This is her newest website: www.geocities.com/michellesangelfriends

Cindy wrote this poem:

~ The Coleus Seed ~

*Once upon a time ~ A long, long time ago
There lived the sweetest little girl that you could ever know ~*

*This little girl was a treasure to her family and friends
Always loving beyond measure and steadfast to her ends ~*

*One day at school she planted a tiny little coleus seed
Her plant grew so beautifully, then she proudly gave it to her beloved
Mommy ~*

*It was long ago on Mother's Day Back in 1993
Who then would have ever known ~
What joy this plant would always be ~*

*She was only eight when she planted that tiny little seed
None of us then knew her fate,
What a few more months would bring*

*The plant was nurtured and adored with every fiber of her mother's being
And when this little girl had died,
What comfort and joy this plant would bring*

*The years went on and the plant stayed strong,
It grew with such beauty and meaning,
And continued to daily touch the very core of her Mother's being*

*Some fourteen years had come and gone,
One day it seemed the time had come
The plant was bound to die,
It had Lived its life, and there were no questions why*

*But could they be given some renewed hope, some faith to assure them now
As this plant had served so long and it's continued life was this mother's
vow?*

*What that they could find another to somehow tide them along
A new beginning perhaps, as a reminder of the old?*

*A cherished living reminder of her sweet love and song
The very seed that she had planted such a very long time ago?*

*Hearts searched on for a new seed but one could not be found
To ever come close to the one, she so long ago had planted lovingly in its
ground*

*Days went by, hope diminished, they'd have to settle for another
To remind them of the "One" seed brought long ago to her beloved Mother*

*That Mother's Day back in 1993 when the little girl now in Heaven
This plant had so joyfully nurtured and then so lovingly given*

*But this story is not over for there is joy yet waiting to be discovered
And when they thought all had been tried an Angel led a new seed to her
very Mother!*

*Found tucked inside a can that had been closed up tight for years
Long forgotten by her Mother were the very seeds from the plant of her tiny
little peer*

*From a past time so dear when the plant grew and prospered here
The Angel had spoken and led her Mother there*

*The message from her Daughter, it was so loud and clear
Life does not end Mom! It just starts over! She said with a cheer!*

*And so the seed was planted, the one from its mother's vine
It would grow and prosper to forever remind*

*That life is Eternal and Forever, so never lose hope!
The little girl was still working from her place in Heaven called Home!*

*And so it was decreed for this tiny little seed
Because you see it truly happened, and it happened to me!*

***Lovingly Written
In Loving Memory of
My Youngest Daughter
Michelle Marie
August 1984 ~ November 1993***

© CindyJo Greever
March 4th 2006

**Michelle's symbols are a 5-point star with a heart and a flower
in the center.**

**Scott & Carol Plaisted's son, Joshua (7-25-97), died from
Bacterial Meningitis, 3-28-00.**

Carol sent me pictures of Joshua and his sister with this note:

Dinah,

I want to thank you for always thinking of Joshua and sending the beautiful notes with the flag that he so loved.

We can't believe that six years have passed-it still seems like yesterday.

We are now in our sixth year of "Joshua's Book of Dreams" and over 17,000 books have been donated in his memory. The program grows with each year and we have met so many inspirational people.

Our beautiful daughter, Lindsey, is now 6 and in kindergarten ~ she is such a blessing. We will always miss Joshua so very much. God is so good and has blessed us with so much. We are grateful we had him for as long as we did and we are grateful to be able to watch our daughter grow. Your kindness touches us ~ thank you.

I have enclosed pictures of both of my angels, one here and one in heaven.

*Love,
Carol*

The Plaisteds have a wonderful ministry in collecting and distributing new and gently used books to school-age children. As Carol stated, they have given over 17,000. Their community has also become involved and there is an annual 5-K race to raise money for "Joshua's Book of Dreams." Scott and Carol just spoke at a Literacy Conference and are very involved in this important project also.

Joshua's symbol is the American Flag.

**Don & Sandy Drake's son, Eric (1-22-81), completed suicide,
2-3-05.**

Sandy explains the packet she sent me and tells us about Eric:

Dear Dinah,

First let me say thank you for remembering our Eric's birthday on January 22nd of this year. That date almost coincides with his year anniversary death date on February 3rd. The clouds on your card were especially nice because Eric had a meteorology emphasis when he graduated from Western, along with a degree in Geography and a minor in Broadcasting. The surprise of the smiley face confetti did bring a smile.

I actually began this letter last fall, but being able to complete projects has been a weakness, my mind, heart, and hands do not seem to want to work together anymore. Did you ever go through that?

Eric, Lee Eric Drake, was a May 2004 Western Kentucky graduate. The following October he became depressed. He had never had emotional or mental issues, and we as his parents knew nothing about depression. Drugs and alcohol were not part of Eric's life style. For sometime Eric had been searching for God's will for his life. He had even asked our congregation at Franklin First Baptist Church to pray for him. I have since learned that he asked other churches, friends and our pastor to pray for him as well.

A member of our community described Eric as a "people magnet". He was a spontaneous, fun loving, creative, talented, handsome young man who was everyone's best friend. He was always giving of himself.

As November and December passed, Eric began showing signs of a very bad depression. We were trying to get him help, and we had seen a Psychologist and a Psychiatrist, but Eric did not respond to either. Finally in early January he admitted himself to Parthenon Pavilion for help. After a three week stay in this facility, Eric came home to our house in Franklin. Eight days later he shot himself.

We were and still are devastated. Our son's loss was so great. As Eric was going through whatever it was that consumed him, he was constantly praying and writing notes and letters to God. I am still finding these prayers everywhere, in his bathroom, in his bedroom, in his car, in my husband's shop, on post it notes, and on backs of pictures. Eric was running to God with the problem that engulfed him, he was trying so hard to get his life back.

We are dealing with so many issues surrounding our wonderful son's death. My husband, Don, and I are Christians. We always felt that we were grounded in the Word of God. We always had answers for Eric or Ben, our other son, when they asked questions about God, faith or whatever else they happened to ask. We thought we knew answers, and we used biblical references, quoted famous pastors and evangelists, etc.

Just this morning, I read Mark 11:24. Before this happened to Eric, I had no problem believing any part of the Bible. But now, knowing that Eric was praying to God to take thoughts away from him, as well as our prayers and the prayers of our pastor and family, mine and Don's faith has been absolutely shattered. The "Rock" I once claimed is no longer there. I know God could have healed Eric. I know depression is a terrible illness, but I do not understand how God could allow a Christian person to take their life, especially when Eric was running to God for help! I don't understand how God could allow this precious child to take his own life when he was so desperately crying out to God for help. We have probably found 100 notes, letters, and prayers from Eric to God. I honestly do not know how to deal with this. Our pastor is supportive and offers what comfort he can, but he too has no answers.

Every day is a struggle because I never know which issue will compete for my attention. Whether it's the fact that I will not see Eric again, or the thought that God did not help Eric, or that we as parents failed Eric, that Eric took his life, that God allowed one of his own children to take their own life, or the grief that his brother and friends are trying to cope with, or how totally irresponsible his medical help was.

So I hate to minimize Eric's cause of death to suicide, because I feel it was so much more. I want to say that The JIMS Conference was such a help and blessing. I attended at the invitation of Sue and Ray Hutchenson. Even though Don would not attend, I came alone because as I had learned early on husbands and wives handle grief differently. Truly this conference has been my biggest help. Meeting you and so many others and hearing their heart breaking stories have given me the strength and courage to keep on going. As I looked at each one of you those two days, I thought to myself,

that is where I want to be ten years from now. I do not want to stay where I am today. I see smiles on their faces; they have joy in their lives again. I too want that.

The two symbols I selected to represent Eric were the “piano” and a “smile.” Eric could not read or write music, but he could play what he heard and compose his own arrangements—totally unique to even trained musicians. Our minister of music at First Baptist even said, “Eric’s music was not of this world.” If there was a piano around, Eric would draw a crowd and all would be having fun - he was such an entertainer! The “smile” was because Eric always had a smile and you could not be around him without smiling too. In one of Eric prayers I found, he had written, “My purpose in life is to make people smile. I can no longer do that because I have lost my smile.”

I have enclosed a CD that a friend of Eric’s and Don Phillips, our minister of music were able to make from compositions that Eric had recorded for himself personally. I know he had not considered putting them on a CD, let alone to be given out as a memorial to him by Don and Janis Phillips. The CD was played at his funeral. Friends and family have also used his music in a wedding, a dance recital, at his great grandmother’s funeral, and often at the beginning of our church service. The “Brown Paper Sack” poem was also written by Eric for an assignment at Western. Don and I happened to have found it in some things that Eric had moved home in November before his death. I thought it was so “Eric,” which is why we gave a copy to everyone at the funeral, and his college roommate read it as part of his eulogy.

This is the poem:

Brown Paper Sack

By Eric Drake

*Time takes it’s time when I’m sitting in class,
Five minutes can seem as an hourglass.
My eyes become heavy, can’t stay awake anymore,
I jerked when I dropped my pencil on the floor.
It didn’t land on the floor, but fell in my backpack,
Where in it I found a brown paper sack.
“In this you could put a lot of things,” I said,
But I’d rather wear it around on my head.
I’ll cut out some eyes, draw some glasses and hair,*

*I could go to the mall, and sit in a chair.
People would walk by and glance, and then glance again,
The looks that they'd give me, like what I'm doing is a sin.
It might even make someone angry, but they fail to see,
I'm just trying to brighten a day, for someone other than me.*

(Sandy had the poem pasted on a brown bag with a ribbon tied around it)

I am sorry this has been so lengthy, but I have wanted to share Eric with you and I guess, as you well know, there is never enough we can say about our children. I learned that at your JIMS Conference. Finally, thank you for caring, reaching out, and being concerned for others. I know Eric would have loved Cumberland College (now University of the Cumberlands). The campus is so special. All the many wonderful memorials have enhanced its beauty and sensitivity. It is such a treasure in that part of our state.

Since reading Rosemary's book, Children of the Dome, I feel as if I know those children and their parents. I am sorry for the tragic loss of your son. I do want you to know how personally grateful I am for all your efforts in keeping his memory alive.

*With Sincere Thanks and Love,
Sandy Drake*

This was also included in the packet:

All of the recorded selections that will be played in the Memorial Service today are original compositions and sequences by Eric Drake.

Some were recorded at my studio and others on his workstation at home. He only had titles for a few of his compositions, but one that he did name was appropriately entitled "Sanctuary."

For Eric, music was his sanctuary, and he was happiest when he was improvising at a piano or keyboard.

Music is truly the language of the emotions, and the music you will hear today ranges from light and carefree to profoundly beautiful and moving.

Don Phillips

This email was sent later:

I enjoyed reading the comments about last year's conference and the picture. I have an awesome picture of the stained glass window I will have to send you. Even though I made the picture when the sun was out, the entire window is surrounded by black, making the colors of the window really stand out. My pastor thought it was a postcard that I had picked up. Every once in a while I capture something in a picture that surprises me. My photography skills consist of simply luck. Again, let me say how much the J.I.M.S. conference meant to me. The brick we purchased for Eric and the coincidence of it being placed with some of the students from Columbine was truly overwhelming to me because the year that happened, Eric was a senior in high school. Never would I have ever thought I would have any connection with that event. I even had the opportunity to talk to those parents at the conference. There are so many ways today that I still draw help and strength from my experience at the Conference. I did hear from Becky Greer. I still don't know how she makes it through a day, and Jan Ulrich I've spoken with in Bowling Green. Both Nathan and Eric were at Western at the same time. Eric was a basketball player in high school and had a desire to play on the college level, but never did. However, he was a Big Red mascot for a brief time at Western - the season Nathan was on scholarship at Western. I know for a fact Eric was Big Red at one of the games in February 2002. I told Jan that Eric probably knew Nathan, because he liked to play in pick up games with the players at Preston, Western's activity center. So here I am back at the topic of suicide - it never goes away!

A later email:

Although I have no proof of Eric and Nathan knowing each other, I do know of Eric's love for basketball and that he was involved in pick up games with some of the Western players. He was also Big Red during one of the 2002 February basketball games at WKU. At the J.I.M.S. conference last year, Nathan's mom displayed a picture of Nathan featured in a 2002 February WKU basketball game. I also had a picture, but not a good one, of Eric as Big Red in a 2002 Western game in February. Obviously this coincidence captured my attention and gave us some conversation material.

Eric's symbols are a piano and a smile.

Robert & Jackie Searl's son, Dan (Woody) Harbison (4-6-61), died from an inoperable brain tumor, 4-30-00.

Jackie challenges us:

April is a month filled with assorted memories...some sad and some beyond belief. April is a new beginning for all creation. A canvas of colors and sounds of delight fill the environment and atmosphere...God is at work once again doing only what He and He alone can do...His plan in daily action.

His mission statement to the world! He is predictable and consistent, reliable, trustworthy and His attention to detail is unsurpassed.

April is the birth month of my first born Dan...it is also the anniversary month of his passing to be with his heavenly father and brother Alex.

The month of April represents many endings and such blessed beginnings. Easter is the way God decided to paint this blessed experience with our Savior's passing His sacrifice for you and me and His transformation. Again, here is His attention to detail at such a meaningful time of His season.

I got to thinking what way would help me with this anniversary of Dan's passing and the following came to mind while driving to work today. I know it would be something our Dan would encourage each of you to do if you can.

Dan's birthday is Thursday, April 6th, 11:07 AM (born on a Wednesday). Mothers have the memory of an elephant sometimes and this is one of those times.

*We all have heard of **Random Acts of Kindness**...if not just look it up on the web and if you don't have that available...it is something you do for someone else without expecting any recognition in return...do something anonymously for someone else.*

Example...drive thru one of those coffee places and pay for the car behind you or pay something ahead for the person behind you in line or leave some money in a vending machine or phone stand. One day I did the coffee thing and the party asked the coffee attendant "Why would she do that?"

Some would ask "Why would He do that?"because He loves us. He went to the cross for us and those of us yet to be. What a wonderful gift!

So, I pass this along in memory of so many wonderful blessings this month brings.

A Random Act of Kindness in memory of our Dan

May God continue to love and bless you and your family.

Jackie Searl...mother of Daniel Gregory Harbison ("Woody")

April 6, 1961-April 30, 2000

Jackie

Dan's symbol is his dog, Buddy.

Herschel & Shirley Mincks's son, Loyde (12-26-59), was murdered, 4-5-02.

Shirley wrote:

Thank you so much for remembering Loyde I have to believe someday it will get easier. I know Loyde is with our Lord and sure wouldn't want to be back here but I sure want him back at times. Have you heard the song "Now that you know where Heaven is?" It was played at Loyde's memorial when they dedicated a cross made into benches and flags at his church.

Please if you can have an old fashion picnic in the park and not worry about sessions just let's have a potluck we that travel can buy our foods at the deli. For me being one of the new ones I sure am trying hard to come down there again. It was such a blessing to be there.

We have started having people at our house that do not attend the group we used to. A lot have stopped going but still want to be with people that care about their feelings. We have had a wonderful time doing this, hoping it will help those new ones. We try to invite persons that have recently lost children. We put out a bulletin and we have one of our ladies send cards to everyone on their birthday and anniversary of their child's death.

I will close for now, thanking you again for your kindness.

Shirley and Herchel Mincks

Loyde's Mom and Dad (Eagle 4-5-02)

Loyde's symbol is an eagle.

Mary Treadway and Robert Allen Joseph's son, Robbie Joseph (8-9-71), died in an auto accident while drinking, 12-14-05.

Mary talks about her first Mother's Day since Robbie's death:

Dear Dinah,

Thank you for the time and emotion that you put into the newsletter. My thoughts on Mothers Day 2006. I will not hear from or see Robbie unless the wind sounds different or one of the other things happens that I know he is close by. This will be my first Mothers Day since his death December 14th 2005.

Christmas was a blur, we only went to church on Christmas Eve I don't remember much about it. Valentine's Day, I was at the cemetery with a heart wreath for Robbie's grave. I took a picture and e-mailed it to his brother, Heath, who is only eleven months younger than Robbie. Heath made Captain this week in the United States Air Force. His brother would have been proud. He often jokingly called him "Colonel."

Last night Heath, who lives in Florida, and I talked for over an hour on the phone. Due to Heath living away from Kentucky since he was eighteen years of age, he has lost his "Kentucky" accent as I remind him. To make me happy last night on the phone he said, "listen to this I can sound just like Robbie." Sure enough, he came out with a Robbie line with his "Kentucky" accent and we cracked up laughing. I laughed so much that he did it again.

Yesterday the Cincinnati Reds won the game and I wanted to talk to Robbie about it. Perhaps on Mother's Day I will selfishly ask him to sound like his brother again; that is if he is not in another country or a desert somewhere.

Robbie's son is eleven years of age and is doing well. I try to see him every other week. When I leave there the tears start and my husband is afraid that I may not pay attention when I drive.

On Mother's Day, May 14, 2006, Robbie will have been dead five months to the day. We plan to have his monument complete by his birthday in August; his brother and I are working on it now. I found a poem I would like to share. I will pray for all of us on Mother's Day and probably will go to Robbie's grave as I try to go every week.

Mary Treadway
Mother of Robert "Robbie" Allen Joseph II

This would be a good poem to share with others who "don't understand:"

BEING THERE by Debi L. Pettigrew

*Do you know of someone whose precious child has died?
Perhaps she is a neighbor or friend with whom you can confide.
You assume that she is suffering a tragedy so deep,
That there is nothing you can do since all she does is weep.
You feel that if you see her there is nothing you can say
That would make her precious child come back or make the pain go away.
And if by chance you meet her and have to face her grief,
You'll do your very best to make this meeting brief.
You'll talk about the weather or the lady down the lane,
But you'll never mention her child- That would cause her too much pain!
And when the funeral's over and all is said and done,
You'll go home to your family and she'll be all alone.
She'll go on, we'll be all right, time heals- Or so it seems,
While she's left alone to pick up the pieces Of her shattered life and dreams.*

-OR-

*You can open up your special place
Where compassion and true giving are awaiting your embrace.
"Today I'm thinking of you in a very special way,"
Or, how about "I love you!" one some loving things to say.
Sometimes a very simple task like picking up the phone,
Can help her feel not-so-quite desperately alone.
Whatever comes from a genuine heart cannot be said in vain
For the truth is, it's these very things that lessen her great pain.
And when you let her talk about her child who is now dead,
You'll know this is far greater than anything you've said.
So will you reach out with all your soul and let her know you care?
For in the end there's not substitute for simply BEING THERE*

Robbie's symbol is a baseball.

Janet Mart's son, Marc Schuster (7-30-75), was accidentally shot, 3-22-93.

Janet works with KODA (Kentucky Organ Donation Association):

Hello,

You are so kind to continue to remember that day with your warm, inspiring words. I often paraphrase your words from the very first card you sent me when I work with the families facing death. You wrote, "I feel certain that Marc and Jim are smiling down upon us." It never fails to bring a smile and a look of relief to the faces of family members. I bet you never thought the winding road of your life would have such an impact on so many strangers, especially the indirect effect. I can't speak for you, but I feel that my son still directs my life in so many ways. Due to changing responsibilities, I don't speak to groups as much as I used to. When I do, I always share that most people would agree that our children, especially the first born, define our lives with their birth. In my case, as well as yours and too many others, my son defined my life with his death. Those who have not lost as we have may look confused, thinking that I am stuck in grief or the "morbidity" of death. Not so, I continue, because look at what my son's death has meant for me in finding a true calling and for so many other people that are affected by the work I do. You, Dinah, are the same. I feel certain that not only is Jim smiling down upon you, but he is guiding you, sustaining you and encouraging you to go on. I believe that our sons are still very much a part of us, just in a different way.

I'm still working for KODA, specifically with families facing eminent brain death. Sad as these situations are, I still love what I do. Marc's death has taught me to accept death as part of life and my ability to do this helps me to start families on their assimilation journey. The other positive side of all this is that donation brings a sense to senseless tragedy and literally saves lives for recipients. Last year, my consent rate was 77% as compared to the national average of 55%! That equates to a lot of families that receive some peace knowing that their loved one is still impacting lives, not to mention the lives saved through transplantation.

I hope you and yours are well. I especially hope you know the value of your support, friendship and first-hand knowledge of the grief journey in maintaining my sense of perspective for the last 13 years.

Thank you and please continue.

Love,
Janet

**Starla Sutherland's son, Joshua (2-9-83), died of cancer,
11-19-00.**

I hope each of you will encourage your church to do this. Starla sent this information about a wonderful ceremony they are having at her church:

Dear Dinah,

I want to start off by thanking you for all that you do. My name is Starla Sutherland. I met you 5 years ago after my son Joshua left. I am from Dayton, Ohio. The church that I started attending 1 year ago, is putting on the First Annual Mother's Day Bereavement Ceremony. The date is May 13, 2006 at 11:00 am. The web site is www.vctchurch.com or <http://vctchurch.com/MothersDay.html>. Mother's day is a hard day for all of us. This year I will be honored as a Mother and not forgotten. I want to pass this ceremony on to you and your friends. I want to give you, your Mother's Day back. This is a day for only special "mothers." Please visit the web site. I hope to see you there. If you cannot make it, I will send a special prayer to you & your son.

*God bless you,
Love, Starla*

Joshua's symbols are a football and a ladybug.

**Semih & Holly Mutlu's daughter, Mia, was stillborn,
1-9-99.**

Holly sent the flyer and I asked her if she had lost a child:

Dinah,

Attached is our flyer...I'm sending you the large copy. I appreciate you taking the time to help us out by putting our info in your newsletter. I think it's great how the parents are so willing to help each other out. I guess we all know too well the pain and try to just offer encouragement and support to each other!

Yes, I have lost a child...I lost my only daughter, Mia, she was stillborn...I have four boys so I miss out on what could've been with my daughter. But I do have the hope of being reunited with her one day in heaven! So what I'm missing out on here, I will one day have the opportunity to make up for in eternity! Right now, she's just waiting for us to join her!

I did receive Jim's picture and I'll be sure to include him in the video tribute and in our list of names of those we are honoring!

Thank you again for all your support!
Holly Mutlu,
Director, Women's Ministries, VCT

**Mia's symbol is an angel.
Carson and Freda Allen's daughter, Christy (2-14-81), died in
an auto accident, 2-1-04.**

Freda shared:

Dear Dinah,

Just a few lines to say thank you for thinking of me and my family because of our loss. I am sorry for not writing you sooner, but there has been a lot of things going on since Christy's death.

*comfort,
peace,
hope*

*There is a place for you
A place of comfort,
peace and of hope*

**Vandalia Christian Tabernacle's
1st Annual Mother's Day
Bereavement Ceremony**

Our journeys are different, we have walked with our children down the paths of illness, disease, tragedy, suicide, miscarriage, stillborn and abortion. Yet we find ourselves at the same turning point, ready to fully embrace our breakthrough!

If you are a Mother who has experienced this pain, you feel lost, your basket of hope is empty, perhaps your basket is full of sadness or anger, feeling there is no place to begin the healing process God wants for your life, know THERE IS A PLACE FOR YOU!

There will be a balloon launch at this event and a free luncheon immediately following the service.

Please join us!
To register or for more information visit www.vctchurch.com
or call 937-898-4384 Registration is free

Saturday May 13, 2006 11am
836 S Brownschool Rd
Vandalia, OH 45377

We are not on the internet so we don't have a website. I have chosen a butterfly for Christy's symbol. The reason for that is because one of the doctors she worked for said she was like a butterfly. Every time she came into a room, she would light it up with her smile.

Here is a picture of my family and one of Christy. I will close for now. May God bless you and your family.

*Love,
Freda*

Christy's symbol is a butterfly.

**Martha Ann Lynn's daughter-in-law, Rhonda Sue (5-30-68),
and her granddaughter, Heather (7-5-91) died in an auto
accident, 3-27-94.**

Martha shared:

Dear Dinah,

Thank you for the card and message. You are a blessing to many people.

Rhonda Sue was a blessing to our family. She married our son, Michael, in August, 1987. We loved her as our own daughter. Michael and Rhonda met their first year at Campbellsville College in 1985. They married in 1987 and continued their education. Little Heather was born in 1991. They were a perfect little family. We all loved them dearly.

God took them March 27, 1994. Rhonda and little Heather had gone to visit her parents and they were on their way home. Michael was waiting for them. It was raining very hard.

I appreciate your Christian Testimony. I thank God for your Ministry. May God continue to bless and use you.

*God Bless you,
Martha*

**Esther Fitch's son, David (10-20-56), died in an auto accident,
3-28-04.**

Esther shares how Maureen Hanna reached out to her:

Dear Dinah,

Thank you for writing to me. I've often wondered how others have managed to go on with living life and doing what seems normal every day while all the time there's an ache inside of you that never goes away.

Maureen Hanna has been such a blessing. She reached out to me in spite of her own pain she carries inside. You also are doing the same thing. I feel your loss also. My oldest son, David, was also killed in an auto accident.

My oldest son was born October 20, 1956 and his death date was March 28, 2004. His name is David John Fitch, II. The symbol I would pick for David would definitely be birds. Since his death, I've had experiences with birds that I never had before. I'm convinced it's my son's way of letting me know that he is around me. I never paid much attention to birds before my son's death, but now, when they fly around me in a flock, I get a peaceful feeling inside of me. No matter where I'm walking, I will get the urge to look up and out of nowhere, will come a flock of birds and they circle above me three times and then disperse. Others who are with me are amazed that this happens. This has been going on for two years. David and I were very close. He had so much love and caring for people.

People like you and Maureen are truly doing God's work. I am learning from all this. Thank you once again and God bless you.

*Love,
Esther Fitch*

David's symbols are birds.

My email address is: dinah@ucumberlands.edu

The website's address is <http://www.ucumberlands.edu/lamentations/>

Hello:
I'm Butterflymom and I would like to share Justin's story.
Many people have asked me to share some words...
So I will. Over the next few weeks...add to this story.

This journey...is a rough one, so there will be days
When the anger and fear will come forward again.
But I thank you for allowing me to move further
In my healing...yet at the same time...
Knowing that these words will reach those who need to hear them.

I will start with...
I am a wife and mother of 6 sons,
And our 6th son was diagnosed with cancer in 1999
Cancer took our son and brother March 5th 2001 at the age of 5.

Cancer did not just affect Justin...but the whole family and our friends
Cancer KNOWS No age...and treatment dictates every minute and second of your life.
With any disease that strikes families...
Life does go on...just never the way it was!

Until Tomorrow
Hugs
Butterflymom

TRIBUTE TO:

To my Husband Ian,
Who stood beside me each step of the way,
Even when I didn't want him too.

To my son's,
Jeremy, Spencer, Michael, Brent, and Wade
Who without them not too sure if I would have wanted to survived.

To Jennifer,
Who was apart of Justin's life from the start.

Auntie Ev
Who loved him as her own.

To my Dear Friend Corinne
And her family for just being there.

My Extended Family,
From the Ronald McDonald House in Toronto.
Who stood by, through the good and bad.
Who to this day remain in my life and heart forevermore.

To the Families,
From our Home away from Home.
Your love, compassion, and understanding got me through.

To
Judy, Kathleen, Cheryl, Anita, Sheila, Kimberly (Justin's Angel Friend forevermore), Joan,
Gramma Vivian, Gisele, Anna, Angie (Justin's Girlfriend for Life), Loretta, John, Anita,
Polo, Marc, Dan the Man, Chantal, Story teller Pat (Just press here to start), Cher
And all the volunteers and staff from the HOUSE...
I love you all and Thank You!

To
Silken, Chris, and Bryan the 'Rat' (Toronto Fire Department) and George Cohon
You kept that smile on Justin's face right to the end!

When Tragedy Strikes:

(Written by Butterflymom November and December 2003.)

Well as I said...Things WILL come up,
And why NOT start with today???

I received a call early this morning.
From a Friend I met at the Ronald McDonald House.
Her son Darryl earned his WINGS this morning.

Grief creeping in...Trying to take away...
BUT...NO...For I have something to say!!

Oh how this cancer...ravages so many lives...
BUT...today...IT LOSES once again.
For Darryl has joined a MIGHTY Army...

Emotions are raw once again...feeling my Friend's pain...
Knowing what lies ahead...
Also realizing...this is her journey of grief.
I will be there for when she needs me.
My hand out stretched...ready to hold on.
Pick her up...when the pebbles turn to boulders...
BUT...to allow her to grieve...in her own way!

I feel I must talk about Darryl right now.
YES...he did join my family along with his family,
When we met at the "HOUSE"
A common bond...these families shared...
One we WISHED did NOT!

Darryl is a young man...who battle this disease
For 10 years. Off and on it would come forward once again.
Each time...Darryl saying...Here we go again.
Give up NEVER...fight to the end.

Last year almost to the day...
Darryl was sent back home to die.
Talked for hours with his mom...saying...
Take this time for you and yours.

**Darryl will decide when it is time.
Continue on...live each day...to the fullest.**

**Exactly what was done...
So Darryl joined his class for grade 8 graduations,
Darryl did get his beginners, and this summer drove to B.C.
To attend a family's wedding.
Darryl lived his life...and in this past year...lived it to the fullest.
Bringing his Mom, Dad, and brother along for the ride!**

**Although he is gone from Earth this morning...
He did what he had to do...
He too taught many lessons...and his family will have this to hold on to
In the coming days, months, and years!
He showed strength and courage...and gave that too his family.**

**Darryl we love you we thank you
And WE CELEBRATE your LIFE...
A new life will now begin...
And I know you will guide us all through this pain.**

**Darryl...Justin waits for his hockey buddy!
In Tears...BUT JOY...
Butterflymom**



*The Angels have gathered once again
To welcome another SOUL
Darryl your life here on earth is done,
But you life anew will begin.*

*You brought such joy to all around
You will remain forevermore in our hearts.
Although you have left us today...
We will never be apart.*

Another Child has earned his wings

Through our tears...
We hear the heavens sing
For Darryl you continue to stand strong
And NOW you are FREE
Our LOVE TO YOU!

written Oct 17th Butterflymom

Good Morning:

**Well today I start...although I must admit...
I would rather just think...Think of yesterday.
So instead of just thinking...I'm writing too.**

**Justin as mentioned already was the youngest of 6 boys.
The first 5 were in 7 years and then a gap...
You see Justin came to us when our youngest at the time
was 10. Justin was a foster child that came into our home
just under a month of age...He was born out of LUST with 2 very young children
themselves 15 and 16, who didn't want the responsibility of a child.**

**Justin came to our home...under nourished...dirty...and NO Love.
He entered our lives...Needing us so.... and brought nothing BUT unconditional Love.**

**The day Justin came home...the boys were ecstatic...for we fostered older children.
In fact at that time we had 13 boys in our home.
Everyone was so thrilled and the look in their eyes...said it all.
Little did we know at that time...that YES...Justin was truly HOME
with his NEW family.**

**Justin was so mal nourished and weak that he could not even suck.
So hours were spent holding cradling...feeding drop by drop
and loving him....more and more each day.
The boys...would not even let him root (LOL) without running to see if all was well.**

**Justin brought to the lives of so many boys...'the throw away baby syndrome'.
I know this sounds harsh...but think about it...
a quick moment of LUST...not Love and a child...Not wanted
Needing...but not receiving.
A lesson for all who came to know our son!**

**Justin progressed very well and with in 2 weeks...
Our Family Dr. made the comment...that he looked like my first 5.
Great job...he is progressing well.**

**Justin was the joy of everyone's life...he smiled... he giggled... and he laughed.
He was loved by so many...a child...I know now...
who needed to come back to this world For his own lessons...
of receiving Unconditional Love...was getting JUST what he needed.**

**A child that came in to our lives...needing Love...
Little did we know what this child would bring to us all?**

My husband got word of a transfer...having us to leave our hometown.

Believe it or not...Children's services...was not sure if Justin could leave with us.
After 2 years...a child only knowing us as a family...and they did not know.
Adopting was NOT an option at this time as they were working with Justin's
biological mother to see if she could take him back.

The Monday...3 days before were to leave for the move the call came in YES...Justin could
come with us.

But...I would have to bring him back... for visits with his biological MOM...
No problem...I would cross-mountains and storms to give Justin what he needed
so a 4 hour drive each way is Nothing.

The move was made and yes...then the trips...first 6...
No visit from Mom... 4 hours both ways...and No call and no visit.
Well time for 7th and this lady says...Is the Mom coming??? Call me if Yes...then we will
come.

Well several weeks went by...no visits...then the call...Mom is pregnant again and really
doesn't like boys...so she has given up her rights...Justin was now a Crown Ward...and
was up for adoption. Well O.K. then...Yes...we want to adopt. Let us know.

Several weeks went by again then I received a call...well not sure if our family was the one
for Justin...they will come and visit and see. I must add that the organization had Justin
classified as slow. As both natural parents were classified, so the label was passed on to
Justin. Well...I couldn't believe it...the only family this child ever knew...and they were not
sure if we were adequate...Yeah...sure...want to play games...you got it...NOW I fight for the
right of a small child...

Now...Listen to what this woman did...

The call came in to tell me when the visit would be for the Agency to come and talk to us
about adopting Justin. Call me when you get to the Mall and I will give you directions to
our house. Now the plan...the agency has already classified Justin so...I will give them
what they have assumed.

I kept Justin up till 3 in the morning playing with toys...games and just plain playing. The
poor child was exhausted. The next morning let him sleep till the call came in woke him
up...gave him his bath...and knock, knock...Went to the door...new workers as usual and
then the fun began.

Workers trying to pick Justin up...Justin wondering whether or NOT he was having a bad
dream or something...and looking for me every time one of them went anywhere near. The
workers tried everything to get Justin to walk...smile...or even talk...he just sat there
looking at them searching for me...and crying for me to hold him.

Soon hubby and boys had to come home for this interview...so enters Dad. He looks
around says his HELLO's comes over to Justin and I and just looks at Justin wondering
what was wrong. I gave the look...you know the one Mother's come up with that
says...quiet PLEASE!

Mean while now comes the boys... all 5. Justin by this time is really starting to wake up
and once the boys come in that is it... So meeting quick...
The agency says what they have to about adopting then adds...And we feel that since you
and hubby are older...there is a great chance that someday Justin may have to come back
to our agency. If something ever happened to you who would take care of Justin.

WELL...I sat back...smiled as my second son piped in as if on key..."EXCUSE>>>>ME>>>> you and who's army will try to take our brother from us?" The boys just looked at each other...then at the workers then took Justin and went down stairs.

Well I must add...no one in the house...knew what I was doing...so this was my own plan of attack. The meeting didn't last too much longer...Workers headed back on their 4 hour drive and said we would hear from them soon.

Boys were playing down stairs with Justin...'BUCKETS' a game you put on hockey helmets and hit each other...I know not great...but that is the game. LOL Justin was beating all of them up when the workers called down to say goodbye. The boys came to the bottom of the stairs and waved bye...Justin again in the arms of number 3 son just looked at them...and they left.

The next day...early morning...I received a call..."we (the agency) did not know how delayed Justin is...we would have problems finding a home for him so if you would like to adopt YES you can"

Thank You Very Much
A Mother Does what a Mother has to do!

So Adopt we did...and within the month all was finalized...and the priceless thing was...the agency from our hometown came as well. I wish you could have seen the faces of the workers. Here is a little 2 year old...running all over...dressed to the nines...with all his 6 foot brothers and Mom and Dad there...running to everyone saying..."I'm being dopted today, we is having a party"

Did he know what adopted meant NO...He only knew we were having a party!.

See...when people assume things...it usually is wrong. They assumed Justin was delayed...so I just helped them to see what they already believed... BUT...Justin was far from delayed...he was a child born... Out of Lust... not Out of Love...but given so much that he caught right up and surpassed many children his age...because of it. I guess you can say...he was OVERDOSED with Love...everywhere he looked.

That is it for today...Till tomorrow I Wish you Enough!

Hugs
Butterflymom

Got a bit of time...so thought I would continue.

Now where was I...oh yes...Justin is ours...

But...he was all along. From the moment I went to the agency to pick up this precious bundle... He was OURS!. Just now we have all the legal papers. Not born of me...but instead...born deep in the soul of my heart...a bond forevermore...a mother and her child!

Now life went on...Justin grew to a beautiful well-rounded child. Always loving the company of people. He went to school on his first day...so excited...but complaining of a sore arm. Thought perhaps through all his dreams of school and friends, his tossing and turning that he slept funny on the arm. His day was great and his excitement wasn't complete until he came home on the school bus. Coming off the bus...I noticed again...that he was holding his arm funny. But said nothing at that time...as he was too excited...had to tell me about his day...his new friends and his teacher... Mr.J. So much to say...not enough breath to get it all out.

Walking the length of our driveway I heard about 3 different classmates that were his friends...his teacher who really likes him but he likes everyone...but he likes me...I think ME the best...as he sniggered and showed me some work he had done. Justin was just so excited to be finally at school.

That night he complained about his arm being sore...we check the full range and all was working so we again let it go. But that night he awoke in pain. His arm was so sore...he could hardly hold it up. I decided to drive him to Emergency department to have it looked at. Thoughts of perhaps in his play he dislocated it and it popped back into place. There was no swelling, hot spots, or bruising, but not normal for a young boy to have such pain. 5 hours in emergency...waiting to be seen, then the Dr. on call comes over...does the same range of motion and checks for any indication of problems. All looked well. I asked for an X-ray...and with some hesitation on her part...we finally headed off to x-ray. By the time all was done we had spent 7 hours at the hospital and it was now 4 in the morning and we were still waiting to talk to the Dr. She finally came over and by this time Justin had fallen back to sleep. Her exact words..."He looks fine now...can not see too much...X-rays fine...so maybe see your family Dr. perhaps he has Juvenile Arthritis. Hmmm was a long day for me as well...so this comment didn't go over well. Why would you make a statement like that??? Perhaps we should have blood test or something done. There are NO signs of Arthritis and this pain is real. Well I guess that was my first mistake...I questioned.

Well boy was she upset...just take some painkillers and see your Dr. I told you what I thought. Not RIGHT...why would you say that...because I cannot find anything wrong...What??? This is even more frustrating than the actual diagnosis...which has no findings behind it. BUT NO BLOOD WORK...didn't feel it was necessary.

Went home and put Justin to bed by this time it was 6:30 a.m. so no school today for him. I waited till 8:30 to call the Dr to make an appointment. 3 weeks...I explained that we were in Emergency last night and that we needed to see him. Told sorry...if we needed to see a Dr. that bad...then go back to Emergency or go to the walk in clinic.

Oh boy...never had this problem back in our hometown...but here we are...waiting. Watched Justin the next day and noticed now a leg was sore...there is something definitely wrong here. Was extremely upset...so called my cousin who could get us in touch with a Master Herbalist. Which she did...I talked to him...ended up crying and having to call back...just explaining how NO-ONE was listening. Told him something was very wrong...what... I was not sure...but a very healthy young boy...cannot go from running around one day to aches and pains the next. Wanted to know if he had some immune boosters I could have...as when someone gets sick the first to go is the immune system.

By the end of this conversation...we were making plans to leave to see this Dr. who was first a General Practitioner, then Surgeon and now Master Herbalist. So he has both sides of the medical story here.

Off the next day...by bus for an 8-hour long drive. Got to see the Dr. and we talked for about 1 hour. Justin was assessed and had some immune boosters for him to take.

For the next 3 weeks before we got to see our family Dr. Justin had another sore arm...opposite one...then the opposite leg. By the time we got to see the Dr. he had gone through all the limbs one at a time being sore...and crying with the pain.

Explaining to the Dr. what was going on...and in fact keeping notes. I knew in my heart something was very wrong. Again...this lady does the wrong thing in the eyes of the Dr. I gave him my notes...Short sweet and to the point. He looked at me...just put them down...looked at Justin and started to move his arms in a range of motion gestures...and looked at Justin... struggling to move his arms in every direction the Dr. asked BUT...with HUGE tears in his eyes.

The Dr. then looked right into Justin's eyes and said..."Hey there...you are a BIG BOY...don't you cry!" I wanted to punch the man in the face. I had to take a deep breath...he wasn't crying...he was doing his best to move his arms in all directions and the pain was so much that he had tears.

Gosh here is man that should have some compassion and tact...and this is what he says???
Oh brother...He said to me he didn't know...looks good to him. I then said well maybe we should get blood work done...and again a 'booboo' a mother...giving suggestions about her child who she knows better than anyone else. The look...well who cares...I'm upset now...so I want something done...you don't know... so get me somewhere who can figure this out. With some hymning and humming he was going to make an appointment for us to see the Paediatrician. So wait for a call.

Well that is it for today...Until tomorrow ENOUGH!

Good morning well almost noon and by the time I write this part...will be after noon for sure!

Surprisingly I received a call with in 2 days. I was shocked when I heard the receptionist say this is the Pedestrians Office and want to give you Justin's appointment time. First however, we need more information. Answered her questions and then was told Oct 28th. Hello this is Sept I need to see him before that...Well...if you need to see the Dr. before then you will have to go to Emergency or a local walk in clinic. Oh brother here we go again...WAIT!...Will anyone ever listen???

The next month was terrible. Did go to Emergency and walk in clinics...and got no where...Never once would anyone give us some blood tests...That is all I wanted...BUT NO...Not necessary, and of course the good old Juvenile Arthritis was coming up...You were told that was the problem. Hello...don't you think we need more tests then??? At least blood works...NOT just the word of one Dr.

Justin awoke one morning crying in pain. Justin was the type of child that never cried...so when he did you ran...you knew something was VERY wrong. As I picked him up...he screamed..."EVERYTHING HURTS ME MOM HELP ME PLEASE HELP ME" My heart broke...I'm doing everything I possible can and no one will listen.

**Grabbing at straws I decided to take Justin to a Chiropractor in our area...perhaps he can do something to alleviate the pain...Just let my little one be pain free for one day. We went...I explained the problem and as the Dr. was assessing him...he looked at me and said...I would love to work with Justin but only after he sees a Medical Dr.
Again Wait...
I NEED HELP NOW!**

Calling everyone I could think of...even calling the Family Dr. again...but being given an appointment in Nov. Why would I come to that appointment in Nov. when I see the Paediatrician in Oct??? Well then go to Emergency or the walk ins...I have...Nothing. What is wrong with you people??? Well very clearly and to the point...Mrs.V. you can bring Justin in Nov. if this is not good for you...I'm sorry then. I just hung up...I was crying...mad and frantic trying to find help for my son.

Then I remembered seeing something about another Chiropractor in the down town area that also did alternative procedures. After rummaging through the weeks papers...I found her number and called.

As soon as the receptionist said hello...I started crying...trying to get out what I had to. Crying and sobbing saying I need HELP for my son. I soon was on my way to see at least someone who took the time to listen.

The receptionist who had Level 1 Reiki and the Chiropractor who was a Master in Reiki were waiting for us. As we entered...me carrying Justin as he could not walk now, and when I stood him up I could with a finger touch one hip and have it dislocate then put it back and do the same to the other one.

The 2 of them along with myself did Reiki on Justin for 1 hour. I had my Level II and although I was using Reiki daily on Justin needed HELP! Justin for the first time in a week...appeared relaxed and free of pain during the treatment and then again for 3 hours after. When he would cry out again because of the pain...and yes...he was taking Tylenol for the pain but it was doing nothing. He would call to me...Mom I need more Reiki!

This went on with daily visits to the only Dr. who would listen and Justin actually was getting relief. Then came the Paediatricians appointment. Before we went there we went for our daily dose of Reiki then off to the Dr's for his long awaited appointment.

I kept one of my son's at home from school that day to help me get to the appointment. My back was broken from carrying Justin and besides...I was an emotional wreck. Now I should explain here...when I get really upset...two things happen...I curl up or I fight...words are my weapons and I use them well. Not always helping us to get ahead...but certainly letting people know where I stand. I find it easier telling the people I am upset with face to face confrontations...so believe me...now some people were interfering with my son's Health...so I am a Momma Bear protecting her own!

So with an extra 2 hands and muscles with me off we headed for our appointment. Got in had to fill in a form...did that then went into a room. Soon a Dr. came in but a Resident in training...he was there to ask the questions and then tell the Dr. what the reason for our visit was once he comes in.

I started to explain...in fact like before keeping a diary of events. Short and sweet. I guess I should also add that I am a Registered Nurse...so what I presented was factual. The First Dr. looked at the sheets then looked at me... put them down...then proceed with his questions. My Son who came with me...just kept looking at me...saying nothing and wondering why I was so calm.

Finally the Dr. came in. The first Dr. started to repeat what I said...and I would say..."I never said that!" continue on..."I NEVER said that"...this went on for a few minutes. The Dr. asked me...then you tell me in less than 1 minute. Hmm...Again parents who explain facts and truths are considered...irresponsible neurotic fools. Well NOT THIS TIME. 1 minute or less. O.K. "I had a Healthy child running and playing now I have a very sick child that has pain every part of his body! That about does it...and in less than 1 minute." The Dr. just looked at me...and by this time my 5th son was backing away. Mom is building up for the KILL...Yes KILL...this time someone is GOING TO LISTEN. Because if they don't No-one is leaving this room!

The Dr. asked me to place Justin on the examination table...pushed and prodded and then said..."He certainly does not have pain now!" Said nothing... as I knew that he was going to get Justin to stand, which he could not do! Yep I was right...O.K. could you please have Justin stand in front of your knees. Have him hold your knees I want to see about this hips stuff you said. As I was getting Justin up...the Dr. added "You know Mrs.V hips do not move around like you said, and sometimes kids can pull the wool over their parents eyes!" Daggers...my look could have **stuck** him right there...BUT...you want him to stand...O.K. then stand he will try!

I stood Justin in front of me...with all his might...his arms trembling he stood with NO pressure on his legs...his eyes filling with tears because of the pain...but doing exactly what the Dr. ordered. I then with my finger lightly touched one hip...put it back... touched the other then put it back again.

THEN...I looked up...Looked at the Dr. and said..."It Isn't Suppose To Be Like THIS!"

Well now I had someone's attention. He just stood there. I called to number 5 son and asked for him to give me the diary and passed into the hand of the Dr. saying..."maybe NOW you will read this. I WANT Blood WORK and NOW!!!"

That's it for today...
Feelings of Anger and frustration are coming flooding back...
But don't you worry...
This Too Shall Pass.
Hugs
Butterflymom

It is with heavy Heart that I write today. For today is the day my Friend lays her son to rest. Oh how grief, fear and anger can creep in so suddenly.
But today...I take another step...For I will conquer this part of my grief....

Down we went to the lab to get the blood work that now was being requested. The one that I asked for since the middle of Sept and had to wait until my son could no longer walk to get it. Down we go with a list as long as my arm. I just hope my poor child has enough blood to give.

We left after the tests were all done. Justin tired and feeling rotten. We drove the 45 minutes back to our house in silence. Wade was sitting right next to Justin with tears in his eyes...knowing too that his little brother was very sick. Me just trying to remember to breath...tears coming and going...driving...hoping our home would bring some refuge to this crazy world that was now before us.

We walked into the House...me carrying Justin and number 4 son, Brent says the Dr.'s office called. He wants you to call back right away...something about Justin's blood work he just got taken. Here we go again...now that I have someone's attention...the calls are coming in. Putting Justin down on the couch and making sure he was comfortable I made the call. Taking a deep breath when I waited for the Dr. to come to the phone. Many things went through my mind in the last month. Thought perhaps Justin had C.P or another neurological disorder. Not sure what...BUT knew in my hearts of hearts that MY SON...was seriously ill.

The Dr. finally came to the phone and said...Mrs.V we need you to take Justin to the main hospital as his blood tests show he is very low in calcium. Not sure what the problem is but we will have to do more tests immediately. Well... make all the arrangements and I will bring him in first thing in the morning. Mrs.V. I believe that you should bring him in now...Well...one more night is certainly not going to hurt...remember Dr. no-one thought there was a problem for a month...so as I said I will see you tomorrow morning at 8:00 a.m. The Dr. agreed and I just broke down in tears. Trying so hard to contain myself...but everything over the full month coming to a head. Glad that something was finally going to be done...yet at the same time...FEAR...Not knowing...but in my heart knowing something is terribly wrong.

My other son's gathered round. Hugging and telling me it is going to be O.K. trying to help this Mom who always was strong...always with answers and solutions to the problems that come up in our household. The ROCK...Well this rock was falling apart...and she needed time to think...so the boys went to over see Justin's needs and I went for a walk out back.

When I returned hubby had come home from work. Boys had told him what they knew and he came with a hug and kiss...as though he could make it better. Stop...this is NOT his fault...but GOSH...I need someone to be mad at. Again...tears...saying we are in BIG trouble here...I can feel it. Hubby doing the best he could to comfort me...yet knowing how I am and I needed my space to figure things out for myself. In my own way and in my mind.

Supper was quiet...Justin seemed to have a good night as I prepared to bring my son to the

Hospital.

Next morning off everyone went and I took Justin to the Hospital. All paper work in order and so it went quite fast. We were on the floor within 1/2 hour.

On the floor now starts all the picks and pokes...Poor Justin's veins were just as bad as he felt so picking and prodding they did. Finally at one point I said...HEY...if you cannot get it this time...forget it. Or else give me the darn I.V and I will do it myself. The look came again...One asked if I had medical background. Said yes...Specialized in Peds...so really could do this stuff myself. Poor Nurse...perspiration dripping...she finally got the vein and we went back to the room.

Shortly after the lab now came in. Oh brother...more picks and pokes. At this time...the technician asked..."When did you find out your son was diabetic?" What??? He is not diabetic...yes he is that is what is on his admission sheets. Let me see that...this is WRONG...He is NOT hypo glycaemia...he is hypocalcaemia. That is why we were told to come here. Sorry that is it...No More blood nothing...get the Dr. there is something wrong here.

Soon the room was full of nurses from the floor telling me that I had to let them do what they are suppose to...OH NO YOU ARE NOT...he was not admitted for diabetes so until I talk to the Dr. that is it. So good BYE!

Later that evening the Dr. came in. First question from me ...what is this stuff about Diabetes? He was wondering what I was talking about. They did not even call. No Mrs.V. not hypo glycaemia...hypocalcaemia...well you better tell the staff then because someone wrote the diagnosis down wrong. He then grabbed the admission sheets and shook his head...NO...this is wrong.

I feel compelled to write today...perhaps it is just a way of keeping my mind off of Darryl's funeral. So instead of curling up today...I will write some more.

With the diagnosis now in tact the lab returned to do the blood test the Dr. had order. Since the Dr. was present when they arrived...a quick...make sure you get everything you want...because this is the last time Justin gets picked for a few days. So check the order and add if you want now...because in an hour or tomorrow the answer will be NO.

Dr. checked the order...added a few more things and said he would see us in the morning. Justin was just exhausted with all the goings on so rested what seemed to be rather peaceful. Soon all 5 brothers and Dad came in for a visit and Justin really seemed to perk up. This was my cue to run down stairs for a break and a long awaited smoke break. Hubby came with me we grabbed a coffee smoke 2 cigs very fast and headed back up the stairs.

It was nearly time for visiting hours to end...so the boys and Dad bid their farewells and told both of us they would see us tomorrow.

After they left Justin and I played a few board games then read a story then lights out. Well anyone who has been in the hospital knows there is no such thing as lights out. People in and out all night long. Then comes the Pick Lady...no way...told you No more for a few days...no discussion JUST no more!

Now I think I had a name there...probably one that should not be repeated but non-the less...that is it. I really didn't care.

Next morning the Dr. came in bright and early told me that he was hoping to receive the results today of all the blood tests. I asked him if he had ordered more...he said NO and then I told them they had come back. He said he would check why...Well back to the wrong diagnosis on the chart on admission...came to check his blood sugars...Oh well...better get that changed...because I said NO MORE PICKS for awhile!

The day was very long...just waiting and waiting. Soon hubby and boys came in again and at least again another chance for me to run outside. They came in...I ran outside.

I went back upstairs to find the Dr. there. He began by saying that for some reason that they were NOT aware of Justin was losing calcium from his body. He was consulting with some colleges and would get back to us the next day in what they want to try. We agreed...off went boys and Dad and Justin and I settled in for another night at the hospital.

The next morning the Dr. came in and said "we are going to release you until we get more conclusive tests back" I agreed and began to pack up some of our stuff. Called Dad at work and he was going to pick us up in 2 hours.

Home we went...Halloween night...Justin not feeling great but wanting to put on his costume. Not going trick or treating just wanted to wear his costume.

The next morning the phone rang. Mrs.V. we need you to bring Justin back to the hospital. Just go straight to the floor as all the paper work is still there. O.K. and again prepared for another trip to the Hospital. Left a note for Dad and boys and off Justin and I went.

Got to the hospital...and soon once back in the same room a nurse comes for me to sign for a Lumbar Puncture...NO WAY...will not... want to talk to the Dr. first. Mrs.V. That is why you were re-admitted. Sorry...I guess he should have said something before he told me to come back. If you would like us to leave...so be it...BUT I'm telling you right now... NO Lumbar Puncture! Nurse left, quite upset I must add...muttering something about not letting the staff do their job. Sure they can do their jobs...but someone better inform me first. That is my job to make sure my son is well and safe...so take the time to explain what and when you are going to do things then this lady and you will get along fine. Until that time...BYE!

The Dr. came in about 5 and shortly after Justin's brothers and Dad also came in. The Dr. was trying to explain to me that maybe they could find something that way. I said definitely NOT...have a better reason...not checking reason...then maybe...but NO. Hubby at this time...piped in that perhaps we should go a head and get it done...just get as much as we can right now...Daggers...NO WAY...I'm the one with the medical back ground NOT YOU...so right now not in the mood. NO! Dr. said something to Dad then said bye. I needed a ciggy butt real bad so decided to go out for one while Justin had family next to him. My last words to brothers, as Dad had decided to come with me...was DO NOT LET THEM DO ANYTHING TILL I GET BACK! Agreed so off I went to sit and NOT think...just try to slow my mind down...DO NOT THINK!!! But...Dad had other ideas...wanted to talk about the Lumbar and getting it done. I was mad as H*** God...I just want to sit here. Don't talk. Well the next words pierced my heart...Well I'm the Dad I have some input here! That was it...all that had gone on...now when I needed my hubby the most just to support and say nothing...this is what I hear. Then it hit me like a ton of bricks...that is what the Dr. was talking to my husband about...getting me to agree with the procedure. Again...now really angry...I have the medical background...not you...when he wants to explain to me WHY...then I will think about it. Lumbar's are painful and you sign a form...they can cause permanent damage...so this is one I will wait...until I feel it is right! Dad was NOT too happy but again knowing me...and seeing the She Bear come forward in full force...backed off. We sat in silence for one more cigarette then went upstairs.

The Dr. rushed in almost right behind us...I turned and said..."You lose...The answer is NO and Don't ever play my husband and I against each other again" Boys knowing mom too well came and stood on each side of me. Gently rubbing my back and making sure I knew they were there. You know that pushing right in next to you feeling. The Dr. looked said nothing was said until my older son said...Mom said NO...so I guess that is it for tonight! Silence...and off he went.

Finally morning came...after another long and sleepless night...waiting wondering and crying to my self...realizing that we were in big trouble...and how was I going to fix this one. BREATH...just BREATH!

The Dr. came in early as other days and said perhaps I would agree to a full body X-ray. I agreed right away...just set it up and Justin will be ready. That afternoon they came to get Justin so I decided to run again outside...for some air and a cigarette. It would take about 1/2 hour...so just needed 'Me' time. Had 2 just sitting by myself...not looking at anyone...because I didn't want anyone to talk to me. So I was trying to keep my eyes down as not to make eye contact with anyone.

Went back upstairs and just sat next to where Justin's bed would be and within minutes he was back. Big smile Hi mom I'm back.

Did whatever for the rest of the afternoon. Justin had a couple of little sleeps and I just sat there...a lot of times just staring at the walls...trying not to let my mind wonder about...had enough right now...certainly could not deal with more thoughts of what could be.

Boys and Dad came in for visit...told them all that Justin went for X-rays and Justin began to chat like no-one's business. My time to again get outside for a while. Dad came again...got our coffee and just sat...at first saying nothing...then...we have to do this together...I agreed, but added...you like to see things on paper...I go with gut feelings and what I know with my background. You have to trust me...and let me make the decisions unless you want to take my place here at the hospital. I really do not have the energy to explain everything to you...step by step...you ask the Dr.'s if you want more answers than what I give... I just do not have the energy. We seemed to understand each other sat for another cigarette then went back upstairs.

The boys left and Dad stayed longer...him and Justin just reading playing games and me sitting in the corner watching. Then the Dr. came in...hmmm strange...but there he was. Came in with that...Oh Boy We Have A Problem Look. I took a deep breath...he said he wanted to talk to us in another room I said no here was fine...then he preceded by adding,

Justin shows a fast growing malignancy...we are going to make arrangements for you and Justin to go to Sick Kids or Ottawa your choice" woooooow thought of everything else but...Never CANCER! My heart started to pound...I had to leave the room. Nurses were watching from the station and I just needed to get away...go by myself and try to Breath...just needed to breathe.

Not sure how I found some empty conference room but I did...went in there...looked out the window and cried...what the H*** is going on??? Bad dream that is it... all a Bad dream....God this cannot be happening. Not sure how long I was there then made my way back to the room. The Dr. was still talking to hubby and I came back. Justin was just going about his business playing. Dad was talking and I just watched...wondering if soon I would wake up...this is not happening.

Dr. asked me if I was O.K. said yes...then when do we leave for Toronto? I pick Toronto? Said that he would make the arrangements tonight and we should be leaving first thing in the morning.

Gosh got to go home and get some things...need to pack or something...Dr. left said he was sorry...and Hubby and I decided he would drive me home get my stuff I would fly with Justin he would come by bus the next morning and together we would see what the Dr's in Toronto had to say.

Went home...made a few calls...My friend Corinne came over with her husband...Boys had called some people as well...still not sure who called who. Corinne was really supportive asking if there was anything...and not to worry about home, as she would make sure boys are eating. Said I cannot believe Justin has Cancer...Hubby said...why are you saying that??? We do not know that for sure. Hmmm can't go there...you heard what you heard and I heard what I heard. I packed or thought I did...thank goodness hubby checked...because I have 1 underwear for me 1 new pair of socks and that is it...I had tons for Justin. Hubby threw in a few more things for me and off I went back to the hospital. Boys were great as usual...telling me not to worry...they would come up in the morning if we were still there.

Well yes there we were...believe it or not...first snowstorm of the year...and everything was cancelled...another day and night in the hospital here...more waiting and waiting. Even the busses were cancelled...so hubby spent most of the day and into the wee hours of the night at the hospital with Justin and I.

Next morning looks like it is a go...so Hubby left to get the bus and Justin and I waited...yes you guessed it... waited and waited...finally word came they are coming for us now...Ambulance transfer to airport. Off we were...Justin again...taking everything in stride..."yepii MOM we are going in the amboolunce this is fun...think they can make it sing???" Don't think so Justin...they do that to make people get out of their way for emergencies. "Mr...hey Mr...I'm a mergeny eh???" could you make the amboolunce sing?" The attendant smiled and said let me see what I can do...talked to the driver and before long...the Ambulance was indeed singing...and Justin was just ecstatic...smile and giggling to himself!

Finally on our way...plane in the air...again Justin just so excited with all that was going on...and talking to everyone...asking tons of questions...and half the time not even waiting for answers before the next question came flying in. The flight was good...attendant and pilot were just great...and Justin got some Pilot Wings to put up on his wall...which again had him so happy!

Arrived at Sick Kids...and ready for what ever lies ahead...or so I think...

Thanks that is it...for today...Thanks for listening. Hugs Butterflymom

The next week and a half was unbelievable. Tests and pokes...more tests and X-rays. Everyday something else...and the Waiting...that is what really got me...waiting for answers and results from all the tests.

Justin went for body x-rays, he had MRI, Cat Scan, Ultrasound, Bone scans, Echo, Heart monitoring, Kidney function tests... liver functioning tests...and you know what...I'm forgetting tons. Each day something repeated or something new...this child was a pincushion...just waiting for the next attack. But through it all he just took the picks and pokes...didn't like them...but took them. With a deep breath he would close his eyes and say...go! One of the Lab technicians came in one day and said...I know Justin you probably hate to see me...His answer stunned ever me. "...NO I just hate the Picks...I like to see you" With tears she picked him again. I just looked the other way...tears streaming down my face...amazed at how well he was taking everything.

Then the dreaded day...Dr's came in by the 9's...Oh, oh we are in trouble again. Mr. and Mrs. V we will have to schedule surgery tomorrow...it does appear that Justin has a Sarcoma and that we need to biopsy it and also place his 'Port' in. A Port is a small gizmo that is placed usually on the right side of the child's chest, under the skin. This is where all the treatment and also blood tests would be taken from most of the time. Helps a little in the picks and pokes. Oh brother...and his legs???? Why is he still not walking? We have Ortho coming in some time today to look at that.

What do you say??? Just take in the words...place them where ever and look blindly into space.

Ortho did come in about 1 hour after that visit...Still in shock and disbelief...3 of them come in. We are here to check out Justin...From top to bottom...pushing here asking him to push... pull stand... sit...you see Justin had progressed now to having to have assistance to sit...or he would topple over. They checked him from head to toe and did it again. Being a Nurse...I knew that either this is the BEST hospital in the world or they found something else and were trying to figure out what to do. Again I'm right...within 1/2 hour...in came tons of Dr.'s again. Please both of you come with us...we would like to discuss what we would like to do right now. Taking a deep breath and really looking around for an escape route...I really didn't feel I could take any more. But followed them all to the 'Chat" room. Hated that room immediately. The room where the hammer falls and there is absolutely Nothing we can do.

In the room our Primary Dr. began to talk...not even sure what he was saying...I was just looking at all the people and trying to read something in their eyes...the eyes tell it all and believe me the eyes were trying NOT to look at me. My husband was listening intently and then like a BONK...I focused on the Dr's and their words. By this time I think 3 had already talked, and now it was the Orthopaedics that were talking. I turned and listened...Justin has many tumours on his spine. We need to do surgery right away...as soon as possible...if we don't do it now then he will be paralysed from the neck down and we would then have to put him on a respirator. I squinted...I

remembered squinting...I guess hoping that maybe my ears were hearing wrong and that this was just another terrible dream and that I would wake up. Mrs.V. do you hear us...we need to do surgery right away. As crazy as it sounds I said...But he is going tomorrow can it not wait? NO Mrs.V Justin's tumours are spreading very quickly...they are spreading daily. Oh brother...I looked at my husband as though to ask...hey do something here...don't sit there...do something...Struggling to hold back the tears...that lump in the throat had now spread to my chest...THIS CAN NOT BE HAPPENING...Dear GOD...Do something.

About a few minutes passed, Hubby spoke first and said we have to do what is right by Justin...he looked at me and I agreed. Then 'Primary' said O.K. we are going to start Justin on Morphine for the pain...Oh No You Are NOT...he has had none all the way... he is not going to start now. After surgery yes for 24 hours... when needed and I'll tell you when, but before that NO WAY!

NO...NO...NO... Guess my mind clicked back in but I was adamant...NO Morphine right now. Hubby looked...Dr's looked and I said I have to go back to Justin... when is this surgery... in one hour we are just setting up...and we will do everything at the same time...so no surgery tomorrow. How many Dr's 4 teams...each would be doing their own thing. Gosh that is all I could take right then so I left.

I looked over my shoulder and saw hubby talking to 'primary' and 2 other Dr's just kept walking...dear God on Heaven Take care of my BOY!

I was in the room when a nurse came...she said nothing quickly went to Justin's I.V. and I turned around to see her inject something...what is that??? Morphine the Dr. ordered Morphine and your husband just agreed.

WELL...this lady went bonkers...get out...out the door I stomped...Look at my husband and said this is the last time you will ever... do you hear me... ever...over step me in the medical field. And you...all of you listen good...You ever do this again...I swear I will take my son out of here and you will never see us again. I was so angry that I had to leave...get out of the hospital.

I had stayed next to Justin all the way. Going out maybe 2 times except at night when he was sleeping...this is when I would go out and sit at the pillar next to the hospital and just smoke my brains out...looking into the dark skies...smoking... crying and smoking again.

Hubby's place of work when they heard of Justin's transfer to Sick Kids...immediately got a room at a hotel for us to stay in. They were covering the costs and Hubby was staying there most nights. I just walked...headed to the hotel...got a key and went to the room.

Scared out of my Wits...Angry and frustrated and NOW...NOW this...I cannot even trust my husband. And this is exactly how I felt.

I paced...I swore...I swung my arms...the phone rang...Hubby...Justin needs to go for another MRI are you coming back to go with him...No I Am NOT...you know everything, you do it...and hung up. Again all the anger came rushing in like tidal waves rushing over me...but unfortunately not wiping me under which right now...I wished it would. Just get me out of here...what the H*** is going on?

Before long the boys started to call...I guess Dad called and told them what had happened...Mom you O.K. was the question I heard over and over...O.K. NO I am NOT...and now I have to fight your Dad too...I'm fed up...he is dead meat when I see him again...I just hate everyone right now...and really do not want to talk to you. Hung up again...phone rings another son...hung up phone... rings and now my Mother...I do not even want to talk to you...why are you calling???

Didn't hang up on her...she is my MOM and I could never do that to my Mom...I guess this is where reality slipped back in. Mom called and I had to listen...Hubby is trying Hun...he is just as scared as you...you know he needs to see things on paper and that he trusts those who have gone to school to learn specialties...Doesn't make them right...I piped in...I know...but you have to give a little too...I know you...your kids are your life and you will fight the world for them...Remember Justin is also hubbies. So take time...think...he wants what is best for Justin too. K...tears flowing too freely now... don't want to talk anymore...she was making sense to me...and right now...I needed to be mad at someone...so hubby is the closest right now.

Hung up then the phone rang again...GOD this D** thing...I wanted to rip it out of the wall. HELLO...Justin is going for surgery in 15 minutes...he needs you here we could not even do the MRI...he kept saying no way where is my MOM. I hung up the phone...ran to the hospital one block away and to his room. As I entered on the floor...nurses and staff were staying far away...I

ran to his room and Dad stood up...Justin was crying and he was trying to sooth him...then I hugged Justin and told him Mommy was here...don't cry....

It was 10:00 p.m. when they came for Justin. We went to the operating waiting room where the children wait until the room it totally ready. I was explaining to the best of my ability to Justin what was going on. He just kept saying..."Mom I need you ...don't ever go away again!" Trying to be strong for my son...my heart breaking...not knowing what will happen tonight...I just kept hugging and kissing him...him in return giving back the hugs and kisses. Then the Nurse came Justin you ready? He looked at me...with BIG tears...yes...Love you MOM...and Dad Love you too. That was it for me...I just broke down sobbing...hubby tried to hold me...but I just pushed him away...he had me so mad...that I did not want him touching me at all. The nurse came and lead us to a waiting room for parents waiting for their child during surgery. It was late...so the room was rather empty. A few people here and there...all sleeping. I just went to sit...my mind totally confused and thoughts running in every direction...not really knowing what is right or wrong. The nurse said that she would come out ...off and on to tell us what was happening but that we were in for a long night...so try to sleep some here.

SLEEP...Right...what was that? I don't think I have slept now for more than 2 hours at a time...and that was a good night, if I got 2 hours...SLEEP NOW...not me.

Hubby asked if I wanted coffee...everything was closed up tight at the hospital so he would go and find some coffee shop that was open and bring it back. I said yes...and he left.

Now alone...and feeling totally useless...I just sat. Thoughts of me as the nurse comforting others...helping them to get through their ordeal...holding sick children rocking them telling them it will be O.K. hugging Mom's letting them know that they are NOT alone...but here I am...my child...I can not do anything right now for him...Comforting...no way...my life was in a whirlwind and I could not find a way out!

The nurse came back in to tell me they were starting Justin's surgery now...so if I wanted to go for coffee or a sleep that now was the time. She would not be back for at least 1 hour.

Sleep NO...Coffee yes...and hubby was off doing that...and cigarette...that is what I needed. Out I went to sit next to my Pillar...one that many parents sit next too when their world is falling apart.

Smoked 2 cigarettes when I saw hubby coming back with super large coffee's He saw me sitting and came to sit with me. Told him the nurse would not be back for about 1 hour to give us an update. We were good here till around midnight. Sat in silence smoking ciggy butt after ciggy butt.

Then hubby said... "I'm sorry...The Dr's felt it was best for Justin...I just want things to be right!" Anger...but understanding at this time...yes...I know...but I know what I am doing...PLEASE let me do what I do well. Over and above a mother...I am a GOOD nurse...I know my stuff and I also know that sometimes...Dr's feel and make parents feel that they are the only ones that can make medical decisions...Let me do MY job!" Silence...then yes...agreed. Hugged...but one of those...O.K. enough hugs...I was still upset and angry and I could not just forget!

Went upstairs...nurse came by about 15 pass midnight and said all was well...one team was just finishing up and the next is just getting ready...Oh brother...how long is this going to be??? Well we have the room till 5:30 a.m. Oh my GOD...tears...no words.

Hubby decided to get some sleep...I paced...and paced went out for more cigs and paced some more. Came in saw the nurse and sometimes some of the Dr's from the team that had just finished on Justin...all is well Justin is doing well...I heard about 5 times that night...deep breath...pace and smoke.

It was about 3:30 a.m. when I saw a man coming down the street...he was checking the ashtrays for butts...I just watched him...and in turn he just watched me. Came close to where I was...and he started to go through the ashtrays...I reached into my pack of smokes and took out 2 cigarettes...here I said...he stopped looked at me...said I didn't ask for that...I said I know JUST TAKE THEM! I guess I must have had my crazy eyes look because he took them...said nothing...kept walking looking over his shoulders...stopping at the corner to look again at me...then disappeared into the night.

Into the hospital I went...out I came...paced walked smoked...paced some more. Finally at about 5:45 a.m. The Ortho Dr. came out...Mrs.V Justin did extremely well. They are just starting to

close...so you should be able to see Justin in about an hour's time. He will be in recovery for about 4 hours. Thank you I said...then the tears again...over one hurdle how many more to go???

Checked on hubby he was sound asleep so I just left him till the Nurse came out to say that we could go and see Justin now. Both of us went in...Looked at our poor son...I.V's bandages all over the place...sleeping...at least he is sleeping...Kissed his head...he looked at me said "Hi mom...I'm tired!" We both sat with Justin till the next morning...making sure that he was O.K. Then in came a round of Dr's. Sick Kids is a teaching hospital...so one thing for sure...there are many Dr's all over the place. This group had their instructor with them and they all came into Justin's room. Hello I'm so and so...this is whatever...Do you have any questions on what your son had done yesterday...No thank you I know...what about ...is he in pain...no that is being monitored and also under control...please...you must have questions...no I do not. Then Dear I must tell you how important it is to make your son cough...what??? You know...I've been up all night...and right now...I really do not want to talk right now...BUT DEAR...it is important to make your son cough...listen...thank-you...but not right now...BUT DEAR...GET THE H*** OUT OF HERE all of you GET OUT!...I think she understood that one...for they all left. Just as hubby was bringing in coffee...Poor guy...he looked at them said my wife is very upset and tired...sorry about that...Oh boy...don't apologize for me...I meant it...she was deaf or something...so I told her very simply to get out!

Silence again...and the day went on.

3 days went on here...then the Primary Dr. came in...Yes Justin indeed had cancer...Rhabdomyosarcoma Stage IV waiting for microbiology for molecular type. Going to move to you the 8th floor that is the cancer floor...

What that all meant...I didn't have a clue...only heard YES... CANCER!

That is it for today...

Walking onto the 8th floor was something that is hard to explain. We all hear of a child with cancer...and our hearts go out. Thinking to ourselves...Terrible... So young. Now I am living it... and seeing it with my eyes, and realizing we now belong to this group. Looking around and seeing all the children...the rooms are full...parents walking about with their MASKS on ...so tightly tied around their faces...Fear and sadness in each and everyone eyes. Oh my GOD...Reality sets in... Justin has cancer.

You get to the point that you have to blank out things that are going to make you cry...or make you feel like you have NO control. You walk about...smiling when you have to...knowing every inch of floor space on that floor. Eyes peered to the floor...looking up only when spoken too and slowly drifting...that is it...I was drifting. Having NO direction...No thoughts right now...No idea what was to come. Seeing children everywhere...no hair...some in wheelchairs...eyes darkened from all the treatment and the results of this fight they were battling...Children of all ages, all races, girls, boys, teenagers and young adults...all with Cancer...fighting one of the greatest battles of their lives.

BREATH....

The next 2 more weeks were again somewhat of a blur...doing what we were suppose to...trying to get information...reading all night long...talking to nurses and Dr's but at this time staying very much so away from other parents. Not really wanting to hear their stories...not wanting to really KNOW! Just cannot handle this right now.

Spent most of my time in the room with Justin...Doing tons of range of motion on his feeble legs and arms...trying to gain any strength we can. Been seen by TONS of Dr.'s not even sure who they are half the time...and to tell the truth NOT even caring at this point. In and out... all day... all night. Up down...here there...more tests... try to nap...that happened with my head on the side of Justin's bed for minutes at a time. Just rest my head...still praying that this is a nightmare...and I will soon wake up. But knowing in my heart...SH** has hit the fan...and the fan is full speed! We had physio come up and start to work with Justin...I would do exercises each day...many times a day and then he would go down for 1/2 hour session. I of course am not leaving his

side...in fact...my night smokes were even less as the Dr's were coming in at all times. I did not want to miss a thing...and besides...this is MY child...I CANNOT leave him. Our primary Dr and Primary Nurse came in sat down...and I knew...here we go again. Hubby and I were sitting there just looking...Dr. began...Justin has Rhabdo like I said...still do not have molecular studies back but expecting them any day. I want to sit with you and plan our attack. He explains the treatment...Chemo weeks and weeks of chemo...the news that he will lose his hair...he may be sick to his stomach...may not...problems that can arise from the treatment...Gosh I went blank again...can't keep all this in...Shut my ears off...sat there looking at him...but not letting one thing go in. Just cannot handle this. Then after a while...not sure how long...but I kept wishing he would just SHUT UP...but talking he continued. Hubby was asking a question then I came back. What are his chances...That is what I heard...10% at this time but depending on molecular that could drop to 1%. Well blank city again. I remember just saying...I have to go for a cigarette now...BYE...just got up and left!

I had smoked about 2 when hubby came down to MY Pillar...believe me this Pillar was many Mom's special Pillar but right now...it was MINE and I swear if anyone came near I think I was ready to PUNCH...LOL... think of it now...but that Pillar was my strength. Besides it was a great backrest. LOL

Hubby and I talked...wondering what will happen now. No decision to make really...I was staying with Justin and Hubby was going to have to go back with 5 other son's. Both agreed with no thoughts. Then the question when??? Well, Justin was going to start Chemo next week...so perhaps after the first bout. That too was agreed upon and we then sat in silence again...smoking our heads off wondering what ever happened.

The following day...I was talking to Justin and was explaining as best I could about what he had...what was going to happen and what treatment and what it was suppose to do. Justin just looked at me and said..."Don't worry Mom...Justin is O.K!" Ahhhh...tears are coming I have to go out of the room...Justin cannot see his Mom falling apart here. Out I go... back I come. Then as quick as I got back...Justin in a very stern voice says...."MOM why do you go out of my room to cry? I know you are sad because Justin is SICK...But you can cry right here!" Well how-do-you-do...Here I am trying to hide my fear, pain, and tears from Justin and he is only all too well aware of what is going on. I looked at him started to ball my eyes out and he just held my head...rubbing my hair telling ME it was O.K.

Wow...what a lesson...regardless of the age...they KNOW...you are NOT protecting...actually it makes them very sad and uneasy...Share...Share your fears...Anger...and Tears...for THEY KNOW!

Well from that moment on...time to wake up...Yes this is Justin's body...he knows only too well what is going on inside of him...I can only assume...so from now on...Right here Right now. Well don't think that things happen bit by bit...OH NO...Everything all at once...O.K. here come the Ortho Dr.'s All three in their white gowns...green paper shoes green hats and charts...tons and tons of charts! Good Morning...How are you Justin? Feeling a little better...yep was the answer...I'm sitting right next to him...eyes red from my tears...looking like I just got in the biggest fight of my life and LOST!...but none the less I'm there. They looked at me...ask how physio is going?...Tell them fine...then they proceed to check Justin...Incisions...strength in legs and arms neck reflexes etc...All three were doing it so just thought perhaps some more teaching stuff...BUT NO...Mrs.V. is your hubby around...no he is at the hotel...Oh... well...we are here to inform you that we removed 3 very large tumours from Justin's spine. The bottom one actually fractured his spine and that is why Justin cannot walk...put pressure on his legs. It seems however he is getting some of the strength back in his arms and neck area. We really do not know if he will get much more than he has already as it has been 2 weeks since surgery. Yes and??? And we believe that Justin will never walk again. Well hammer down right on the head...what??? Sorry Mrs. V. I guess the strength that Justin had just given came flooding in all at once...I looked at Justin again just going about his business as though these Dr's were talking about someone else...I looked back at them...as they asked do you have any questions??? No I said a comment...First thank so much for all you did...we are really thankful...But for Justin NOT walking...sorry...will NOT accept that...This family has enough to tend with right now...with this 10% or less survival rate so never to walk again...NO WAY! Dr's looked at me...said this is what we feel and know Mrs.V there is always a miracle! Yes there are ...and you know what...it starts

today! Again thank you...The Dr's left wishing us all the luck in the world and telling me if I ever need to ask questions etc.etc.etc...you know how it is just call.

Sat there again...wondering why all this was happening...not one thing but one thing after another after another...Just at this time Hubby came in and behind him our primary Dr. Thinking again...Our primary was coming in just to confirm what the Ortho's had to say...But oh no...Just to add some more to the boiling pot...for it is not quite over flowing...Hi...how are you??? Well...not too good thanks and you? Hubby asked who the Dr's were that were leaving...told him and repeated what they had said. Our primary said nothing...then sat down...I looked at him and said Oh no...Every time you come in this room you have more bad news...now what??? He just looked at me...and said the Molecular studies from Justin's biopsy had come back...Justin had the Alveolar type not the Embryonic that they were hoping for...so what does that mean...Justin's chances of surviving the treatment is now 1% let alone surviving Cancer. It is the treatment now I have to be worried about. I just looked up...quickly looking over to Justin who looked up smiled and continued to look through his book. Looked at my hubby who now was just sitting there...looked at the Dr...And said...wow...from now on when you come here to tell me something...PLEASE let's go outside of the room...maybe then we will get some good news. He just looked at me...I had to smile...almost a survival smile...then said...O.K. Chemo starts in 3 days...I have to try and place this stuff somewhere in my head...so right now...I can really not think. I'll need to talk to you in 3 days! He agreed...told us just to call if we need him before...and left.

Hubby looked at me...I said Don't Talk...I have to think...you know... I have to go...Justin I have to go for a walk...Mommy will be back...but I have to go for a walk..."O.K. Mommy you go think K!" and I left...by myself...just me and my thoughts...or the jumbled mess of thoughts.

Today is a busy run around day but...felt I needed to write something just for me.

The next few days were just days...the hospital routine stuff. Cancer was slowly dictating what we do, when and why. Just getting use to it now. So that is our life right now.

Then one day before Chemo was going to start...Justin and I talked about his hair falling out. He really didn't comprehend what I was saying...so asked if there was a hairdresser who could come and shave his head. Yes there was and she came in about 10 in the morning. Justin was all excited as he was going to have a "Bruce Paris Cut" now no-one else knew what that was...but number 2 son, Spencer's friend who played hockey with him shaved his head...so to Justin ...this is what he was having done. The lady came in...pleasant as all get out. Asked how short we wanted to go...I said shaved to the scalp...Justin said "Bruce Paris cut" Didn't have the energy to explain to her...but she shaved, and shaved and shaved.

Justin had wavy blond hair Beautiful hair...with the biggest sky blue eyes you have ever seen. Many people commented on his eyes...Ice blue...that pierced your heart when you see him. There he was tied in his wheel chair...getting shaved. Just before however we took a picture, and when she was done we took the same pose but hair gone.

I think it was at this time that things really started to hit me...I looked as his beautiful hair was falling to the ground...looked out the window...tried desperately not to sob...but cried...the tears would not stop. Hair is just hair and it will eventually grow back in...but I cried. Realizing that we were in for a long haul. No bandage is going to fix this.

All done and then nurses came in to tell Justin how handsome he looked. Each time someone came in he just said Yeah I know...I have a "Bruce Paris cut" Don't think I ever told anyone about what the cut name was really about.

The next day was chemo day...first chemo day...and the beginning of our long treatment.

In came the nurses...setting things up. Hubby came in early that day so we could be together. Important to really watch for any reactions so we were not leaving Justin alone for one minute. Justin as usual just took everything in stride. By now, I too was getting use to all the picking and pokes so again when they came in I would hold Justin... talk and we would get things done quickly and out of the way. Had to be...so might as well get it done fast!

By the evening Hubby and I were just sitting and Justin playing in his bed...then I heard..."HI GUYS!" I looked up and all the boys were here...oh my gosh...what a wonderful feeling it was to have everyone here all together for Justin's first chemo. As if that would not happen...the boys were waiting for the right time to come and this was it. After all the hugs tears and I'm so glad you are here...I went for a smoke...Again needing time for just me.

Came back to "LOOK MOM Mr.J is here...he's my teacher...and Look Mom he gave me a puppy...I call him PuppyLOVE!" I was shocked...there was Justin's teacher all the way

5 hours away...and he was here to see Justin. Justin was so thrilled to have all these people here...and then he looked at me and said..."See I told you Mr.J loved me the best!"

Laughter filled the air and Mr.J said: "You got it partner!"

Ah thank goodness for family and friends...How we need them at this time. How we feel so lonely not even realize it till they come. Normalcy just for a few minutes...is what helps us to go forward at times like this. Just having people around...not talking about illness but talking about HOME!

Boys were here for the weekend and Mr.J was heading to some meeting so bid his farewell and told Justin to call him when he got back home and he would come over to visit at the House. Oh I forgot...Just before the boys left...in fact driving out of the driveway when a car stopped and Nelson jumped out of the car...where are you going? Toronto they all said...well I'm coming too. Nelson was a native boy that lived with us while he was going to school He was from way up North and called as usual just to talk and the boys told him about Justin. Well he gathered money from family and friend flew to Timmins then hitch hiked to our place. Arriving just in time to jump in the car for Toronto. Nelson is family so again when I talk about the boys...Nelson is very much so apart of the boys!

Nelson showed up the day of Justin's adoption too, so of course all the pictures and stuff has Nelson as part of our family. He just knows when to be there and when he is needed.

Ahh... think I will close on a good note today...Family and friends...helping me through...Just being there!

Hugs

Butterflymom

Well third day of chemo and all is well. Time for the boys to head back home, and after some discussion Hubby was leaving with them. Even though Hubby's company was covering the cost of a Hotel...there were meals, smokes and whatever else. If Justin didn't like the hospital food down we would go to pick up whatever we thought he might eat. So money certainly was not lying around.

Tears and goodbyes...I sat next to Justin realizing that now we fight this battle alone. Family and Friends gone back to carry on with their lives...and Justin and I in a strange city...not knowing too many people and now fighting the battle of our lives...After Justin's

nap...we started to really work with physio...no way was I going to let the Dr's be right about Justin never walking again. Placed sheets on the ground...sat there with Justin getting him to sit...pillows all around...so the tumbles would not hurt. Actually it became a game for us...one that Justin I must say enjoyed.

The day and nights were very much the same...tests, chemo, physio downstairs, stories, just trying to make the time pass.

One morning after washing up and cleaning room...a volunteer entered our room. Quietly she entered...picked up one of Justin's stuffed animals and said...HELLO? Are you Justin in a squeaky and friendly voice. Justin looked up and smiled...I looked up and just looked...now what? You get to the point that if anyone came into your room you actually cringed. I watched as she talked to Justin through his toy...and Justin smiled and laughed answering all her questions. Is this your Mommy? Yes...I bet she is special?...Yes and what is my name? I don't know...I'm Ernie...you know me...Yes...you are Ernie but who is talking? I'm volunteer Mary!

Well...volunteer Mary was a saviour...soon I felt very comfortable with her there and actually looked forward to the times she would come in. She asked me if I would like to go for a break downstairs to get some air...hesitating Justin saying...go Mom Me and Volunteer Mary are going to play. I went...first time for one smoke came back to the two of them playing and laughing. Next time a bit longer and eventually would go for 1/2 hour. It was so great, to go and just sit...not think...not worry about who was who and just do nothing.

Mary was our first Angel that came to help us through. Justin was going to Physio each day...one day the physio said why do you not take a break while Justin is here. You just watch...and the break would probably be very good for you. I thought about it...Justin claiming that I should not come to the GYM because it was his business...LOL He called Physio the 'GYM. See all his brothers would work out at a gym back home...so now he was excited that he had his own gym and trainers excuse me. LOL

Well why not...the break would do me good as well...the air although not the good old country air from home was better outside then in the hospital. So agreed to do that as well. They would send up a porter to pick Justin up and will return him in about 1/2 hour. O.K. agreed. Waiting for the porter to come that afternoon...Justin saw this Lady coming down the hall...Look MOM "La Bella Lady" she is here...I have to go to GYM. Well I wish you could have seen the ladies eyes...Here name was Isabella and Justin could not say that clearly so out came "La Bella Lady" needless to say...the lady was tickled pink...had the biggest smile...and I saw a few glistering tears in her eyes. Another friend..."La Bella Lady!"

Out I went...to my Pillar to just be...I wasn't there but 1 minute when at the corner of my eye I caught a glimpse of my Cigarette man. He was walking checking out ashtrays again...but he too noticed me. He slowed down looked...said nothing...I got out 2 cigarettes waited till he got close to me...handed them to him...this time he smiled...said thanks and went about his way.

Next day same as the above...the whole day...except maybe an extra pick or poke...but we were falling into the hospital routine. As long as things were well...we knew exactly what was up.

So out I would go during Physio...sit at the Pillar and eventually my friend...came and talked...gave him his two cigarettes each time...but that was a cheap payment for sanity. We talked about everything but hospital routine, Dr's, or Justin. We talked lye soap...how his mom would make and wash everything in lye soap. We talked planes and bombers...he said he flew in the 2nd world war. We just talked...about weather...how crazy some people are and just anything.

Each day at 4 to 4:30 I had my chat with my Friend. Monday to Friday. I was getting some breaks now...so seemed to be handling things a bit better. Volunteer Mary was great...came in each morning even on weekends...and spent time with Justin...mind you it was NOT just Justin she spent time with. She was there for everyone...but when she was with you...YOU WERE SPECIAL!

I'm getting through...meeting more parents, but watching as I still felt I had enough on my plate and just could not get into others problems as well. May sound selfish...but hey...have to survive here.

One evening ...Justin asleep another Mom came out to see me...at the usual Pillar. She too was on the floor and she introduced herself, Hi I'm Cheryl and we talked...actually checked on our boys and went for a walk at 2 in the morning to find a coffee shop that was open.

This too became a routine...while she was there. Although sleep was not part of this picture yet...more like cat naps...I was getting away while Justin was sleeping or having treatment or Volunteer Mary was there and Justin wanted time with just her. LOL Now we are hitting Dec. and I am wondering if we would ever get to go home. Justin was getting stronger with his sitting...in fact now he did not have to be tied into the wheel chair...his arms were much stronger...but the good old legs were taking there sweet old time. We had to get braces fitted as he was beginning to get contractors, so didn't need that as well to complicated things.

Spoke regularly with the Dr's and was going for a full day of tests to see what the chemo was doing...expecting no change...but at least no change was better than more growths. That day came and went...and our Primary came in and wanted to talk. Again...could tell by his way of walking...there is more trouble. Mrs. V. we will be doing more tests later...no point re-doing, but what we see is really no change...in fact there may be more growth...but it is so minimal right now...that we want to wait. Justin appears to be doing better so we will continue just like it is.

For the first time in a long time...I didn't fall apart. I asked...what does this all mean. Well...after many more words...I got out from the Dr. that things did not look good and that this Christmas will be a Miracle...Well Miracle I will have...and watch...time for a change.

The Dr. looked...said welcome back Mrs.V.

I will stop here for now...but may continue this one later today!

Hugs

Butterflymom

First time in a long time...I was dealing with just the moment. Had so much on my mind before that I had a mess in my head. Just plain too much, So could not figure anything out. Even though the news was terrible...I said to my self that it was time we really fought back. Did some very deep thinking that night and came to many conclusions.

1. Justin needed quality of life...how we are going to achieve this is work real hard with physio, try what ever to make it work...and this young boy needed to be up and running again.
2. There is something that happens in treatment...a very thin line between treatment and research...NOT going to the research part right now...no way...when the time comes...something will happen to let me know what to do.
3. If Justin is going to die...then it will be cancer...NOT the treatment. See Cancer treatment is a very harsh and hard on the body...some where again...there is a thin line. I will NEVER give up hope...but this is Justin's body...and he will let me know how...I'm not sure...and for right now...that is not a concern...but he will let me know when enough is enough.
4. There is something called quality of death...what the heck that is...don't know...but will find it when needed.

Now to talked to the whole family about these thoughts and have everyone agree. That night did just that...and after everyone had their own impute...all agreed. Making almost like a pack...that we are NOT swaying from these decisions not one inch. Told my

family that the next day I was going to talk to your Primary Dr. and let him know what we have all decided.

Did just that and then said...O.K. lets go...But know something...Justin will make most of his decisions I will just make sure that his wishes are carried out. Justin will say when to fight and he will also say when enough is enough. I also added that...now you are going to see a fight...like you never have before. We will celebrate this Christmas and more...watch.

The Dr. smiled...agreed and left our room.

We continued treatment and Justin worked so hard with Physio. My Angels on Earth were here helping each day. Volunteer Mary...putting smiles on Justin's face and hopes in my heart...something that I lost. La Bella Lady... coming each afternoon at 10 to 4 to hear the cry's of Justin calling out for everyone to hear..."Here comes La Bella Lady!" My 4 to 4:30 conversations with I tell you my Guardian Angel and then of course my night walks well really early morning walks between 1 and 3 with Cheryl to the coffee shop about 4 blocks away. Taking each thing that comes not one ounce more...just what was happening at the time. Besides it was enough!

Talking to one Dr who was on the floor...was asking if we could go home for Christmas. Gosh been here over a month now...really need to go home. Dr. said he would be talking to our Primary and would be doing more blood test tomorrow morning then will see. Another bout of chemo, coming up so maybe after that. Well the next day...Blood in preparations for our next chemo...NO...Have to hold off...Justin's blood levels were just on boarder line so No... Will have to wait till his levels are higher. Oh brother...Tears just came, I guess feeling that our chances of going home for Christmas were going to be a wish. That afternoon feeling pretty down...one of the daily supervisors came in and asked if Justin would like to go to a Hockey game tonight. WELL...Justin's eyes lit up??? HOCKEY?

Please yes...let's go mom...maybe the boys are playing. Justin never missed the boys hockey games, and to him this was medicine in itself. No Justin Toronto Maple Leafs...you get to sit in Cujo's Box with some other children and watch the game. Oh my...Justin nearly fell out of the bed. WHAT??? The M'Leafs??? Oh my...His eyes were popping out of his head!" Just as the floor Dr. came in...Oh not sure Justin your blood levels are too low...you really should not be among lots of people..."Oh come on...I just won't breath"...LOL that were his exact words...Everyone just laughed and with Justin's enthusiasm how could the poor man say NO! So there were 2 from the floor going and Saleem and his Dad would share a taxi ride with Justin and myself. The afternoon could not go fast enough...Finally the time came and we were to go down stairs for our taxi. Down stairs the volunteer was there with our tickets...and a voucher for the taxi. Saleem's Dad took them all and we climbed into the car. Wheelchair in trunk.

Justin could not stop talking...he was so excited. When we arrived he had his mask, but that didn't even hit his mouth and nose...it was off as soon as we got into the taxi. I can't wear this..."I cannot breath poperly". Got to the Arena, Air Canada Cup...and it was huge...we were shown to the elevators to take us up to Cujo's Box. We were being treated like Queens and Kings. It was just GREAT! Justin got to be right at the front with his wheel chair...and when the players came out well that was it. He yelled and screamed Hey

Guys...put your helmets on...oh guys come on...put those helmets on. He was so excited...yelling and cheering. Saleem and Justin had the time of their lives. Saleem was older...but from that day on they were hockey buddies...in fact that is what Justin called him...'My Hockey Buddy' The night was great and in between periods the mascot came up...Justin and the Mascot were on the big screen T.V. and again he just waved and waved to everyone. When the Zamboni's came out well everyone in the whole arena heard..."MOM... 2 ...they have 2 ...Boonies" LOL I am laughing my head off here...I tell you true...everyone heard him...in fact again the big screen T.V. caught all his actions and the delight and excitement in his eyes. The second intermission had Cujo's wife come up to visit (now Cujo was Toronto Maple Leafs Goalie and he rented this box for Sick kids to use and watch the game) Justin was talking to her, and said...who are you? She said Cujo's wife...don't think he really understood wife...but said..."Oh K...Cujo's lady...tell Cujo he let a soft goal in...tell him my Brent do's like this" and flings his arm around and up "and he catches the puck" Well again laughter filled the aired...Cujo's wife...said yes Justin

that was a soft goal and I will give him your message! Out of the mouths of babe's! I better explain Brent is number 4 son and he is a goalie.

The night was Great...I keep saying this...but I'm telling you NO Hospital could ever top this. Food all over the place...pizza, pop, hot dogs you name it...what ever we wanted Yes...we could have!

Third period saw a tied game...lots of fights...which again Justin yelling "come on Guys...Pay Hockey!" Then with a minute to go before over time...the other side scored...Justin just dropped..."that's it...you guys better smarten up...get out there and 'pay' hockey. " Well they must've heard him because it was drop the puck bing bang boom...He scores...Chris King!

Well this game is going into overtime...yeppppiiii

Only took about 3 minutes into the overtime game and you got it...as Justin would say..."WE WONNED!"

Now time to go home. The place is packed and getting into the elevator is going to take time. Really have to watch as Justin's Mask is nowhere to be found. The elevator door opens...the elevator man say...make room please for the wheel chair...I said it was O.K. not wanting to go into it with so many people...and Justin shouts..."Hey mister Elevator Man...I can't breath all these people!" well the next thing we know...everyone was ordered off...you heard him...he cannot breath all you people so I'm sorry get the next elevator. I nearly fainted...but in we went, Saleem and his Dad and Justin and I. Hey...the end of a great night...why not get the elevator to ourselves...Groan....

Back at the hospital Justin says...Mom have a smoke K...just want to wait one more minute before we go in. I agreed...beside Justin had not been outside for 1 1/2 months...Saleem and his Dad went in...Justin yelled "Bye Hockey Buddy see you upstairs."

I stood there having a cigarette realizing just how important this night was for both of us. Finished and went upstairs...Justin so excited...and telling everyone "We Wonned"...

HMMMM...In more ways than one!

Hugs

Butterflymom

The next few days were spent talking about the game. To everyone and anyone. Poor cleaning staff...I think they took their breaks and sat to listen to Justin explain every thing there was about the game. Tears started to change to some smiles. Worried eyes...but the face expressions were changing on me. I looked around at all the strangers...putting out their hand to Justin and I...waiting and wanting to help. Our choice!

Chemo came on the 3rd day after the game...believe me Justin was ready...I bet even the cancer was having a tough time surviving his excitement. Chemo was started and we had 5 full days. So we had to stay on the floor and depending which chemo...the good old mood change, the food cravings...and then... not being able to eat it...Justin was very fortunate he never got sick.

Oh I am wrong...Once he did but that really had nothing to do with the chemo. He had a craving for spaghetti and yoghurt mixed together...Ekkkk...everyone one he met...the cleaning staff, nurses Dr's and even visitors walking in the hall...he ask them to ask the desk for Spaghetti and Yoghurt. By the end of the day...you got it spaghetti and yoghurt all over the place. Ekkkk just the thought gave me the 'willies' but when you know that there will be times that he will not eat at all...believe me you give them what they ask for. LOL... He never did ask for that combination again.

I think it was about day 4 of this chemo when Justin wanted to go to the playroom. By this time he was much more stronger and could sit with no problems...in fact he was pushing himself all over in the wheel chair. No more head ties were needed and Justin's arms were really strong. The legs however...getting more spastic resistance when we exercised, he could at least now stand on them but that was it.

We were in the play room for only a few minutes...when we heard some drumming..."Do ya hear that MOM? Pow wow...I hear it..."Yes Justin but it is not a Pow Wow a little native boy is very sick...his family and friends are with him, and are playing some music and the hand drum. Justin loved Pow Wow's and we went all the time. He would dance and sing all day and all night. We

both sat there listening to the drum and I know we both were thinking about the Pow Wow's we would go to back home.

A Native, women elder came into the playroom, she was holding her hand drum. Justin looked up straight into her eyes...and the women said...would you like me to play for you? "Yes, Please..." was answered almost as fast as she had the words out. Do you want me to sing too? Yes, yes... Justin sat in his wheel chair just staring at this women...right into her eyes...I would glance from him to her...she in turn was staring right back...a very loving and concerned stare she would give back to Justin. Ahh... she began to drum...the feelings and sensation were just fantastic...my soul was singing...hadn't done that for a long time now. Justin in no time was singing along with her and before we knew it the whole playroom was full of people. They all came to hear the drum and songs. Justin and the women sang for about 1/2 hour. Even her family members came in to see and stand with all who had gathered. That was another wonderful day.

That evening Justin said that the lady was nice to sing for him...I said yes...then he said but now she is sad. I asked why because the little boy is gone now. I looked at him...said... I didn't think so and he said yes Mom go look. I went out to the hall just as the family was leaving the young boys room...yes...Justin was right he was now free...My heart sunk. Gosh...how did he know? We were in another hall not even near this child's room. When I came back to the room Justin just smiled at me and said..."I have to sleep now...Love you more"

Now emotions are raw again...fears and thoughts again coming into my head...all this for what? Believe me...this thought was always so close..."All This For What?" Sitting quietly beside Justin he was fast asleep in no time. I quietly got up to go to my Pillar to think...no to NOT think...but that is not what always happens.

Sitting I saw another lady came out...she was so worried and looking through her purse for smokes...I handed her one of mine and asked if she was O.K. NO, my daughter needs another heart transplant and right now it doesn't look too good. I have been sitting in her room all day and forgot to go and get smokes...do you know where I can go and buy some...Never mind here take mine...I have more upstairs. This was the beginning of a lifetime friendship. We talked for a while I told her I was on the 8th floor and she told me her daughter Kim was on the 6th floor. We talked and talked. It was about 5 when we went in to the hospital that night. I guess we both needed each other.

Next morning I saw Sheila again...hi how is Kim...stable she replied and then added I'm going to go and get smokes today so I'll get you another pack. Told it was O.K. but she was insisting. We made plans to go for lunch once both of the kids were napping, that afternoon.

A friendship through a medical crisis brought people together helping each other without even trying.

This lady was from out East in the Maritimes and had to leave her family behind. She was staying at the Ronald McDonald House. She asked if I was there and I told her NO, staying in the room with Justin. How long she asked Hmm 1 1/2 months now...Hoping to get home for Christmas...but do not know. Her and Kim would not be going home for Christmas that was for sure...and the social workers were trying to make arrangements for all the children to come to Toronto for the Christmas season. I sure hope that happens for you.

This friendship continued...mind you I must add...I still would NOT make any arrangements around the 4 to 4:30 time. Weekends O.K. during the week NO WAY...that was my time with the Cigarette Man.

As Christmas day was approaching and all the decorations and singing...hoho's and presentations for the kids came closer and closer...the Longing to get home was there for us both. Justin asked...am I going home soon? Don't know...well ask...I have to see Cool Dude...he misses me. Cool Dude was Justin's pony...he was now riding on his own and Justin and his Pony were inseparable. The pony was excellent with Justin... terrible to me...he would never let me catch him but Justin would yell..."Hey...Cool Dude time to ride!" Walk right up to him throw a lead line over his back...not attached or anything and walk back with Cool Dude walking right behind.

By the time he reached the gate the lead line was dragging on the ground with Cool Dude watching not to step on it. Justin had the pony out all the time...didn't matter where or what he was doing the pony just followed.

Justin had decided that next summer he wanted to enter a horse show with his pony...he had attended many a horse show that his older brother Jeremy entered, and he had decided it was

his turn. One night we were talking about home and he asked... "MOM now I can't do my show!" what show...my horse show...my legs don't work and how am I going to go to the show now? Tears in my eyes I said...Justin if Mommy has to hold you on the pony "YOU WILL GO TO YOUR HORSE SHOW...this I promise." I never promised things to my kids...just in case...I would say I will do my best...but never the word Promise...BUT...THIS ONE IS FOR SURE!

It was the 19th of Dec. hubby was coming down to T.O. on business so he was coming in to see us on the 20th. Another son's birthday...Yep cancer taking over again...missed hubby's birthday, Brent's son's birthday and now number 3 sons Michael's birthday. AND maybe Christmas...oh boy feel the emotions here...just have to be home for Christmas.

Now I was asking everyone...Nurses every Dr. that came in. Later that night one Dr. came in and said...sorry but they felt that it would be best for us to stay. Tears flowing...Justin who never really cry's cried..."don't listen to him mom...lets just go..." now he was so upset...the Dr. asked to speak to me out of the room. Out I go and he adds that Justin is really a sick boy...and that this could be his last Christmas...so they are trying everything to make sure he makes it there. I looked up at him...tears have gone dry...I looked back into the room and saw Justin sobbing...Justin you want to go home? I blurted without even thinking...Yes MOM...I need to go home. Then turned to the Dr. and said..."not asking... telling you...tomorrow we leave in the evening to go back home." We will spend Christmas at home and if you want us back on the 26th I will be here...But I'm telling you we are leaving tomorrow night...so get the stuff ready. Justin's tears stopped and all you could hear was "Whao...Whaooo I'm going home!"

Dr. just looked at me as I went back into the room. Started to pack our stuff...and looked back at him and repeated "NOT ASKING!"

Hubby called next day and said he would be over after supper for a short visit. Told him we were going home with him. Really...he was happy but then said...did the Dr's say yes...Said NO...Told them we were, that is it...so pick us up will be waiting. Or... we will take the bus home!

Primary Dr. came in early that morning...I knew that he was going to try and talk us out of it...but I said...get the blood work done...telling you I leave tonight with my son. He looked at me...I added If this is going to be our last Christmas...It Will Be With FAMILY! That is it...that is all.

Primary raised his eye brows smiled and said...O.K. I'll get the blood work done now. Justin pops up and says..."good cause if I need a 'pop-up' then you have time to give me it". LOL we both laughed...funny how kids even the very young ones know all the medical stuff. To Justin a Pop-up was a blood transfusion. So he was adding his too cents worth...that he has time to get some if needed. And of course yes...he needed it...so started that early enough that when Dad came in he was just finishing had to wait about an hour more then we could leave. Can you believe it...we are going home for the first time in a long time!!!!

Hugs Butterflymom

A few days before I made the decision that we were going home for Christmas. Volunteer Mary had come into the room. I could tell there was something up...but for the longest time she didn't say much of anything. Kept Justin company, with toys and Smoochy Man. Now Smoochy Man was a beaded man that was made for Volunteer Mary by another girl that also had cancer. Volunteer Mary would always come in with Smoochy Man in hand and give Justin kisses. Justin would always talk to Smoochy Man.

Volunteer Mary came back later in the day...and told us she was leaving to go back home. She lived in the States and was in Toronto for her husband's job. I just sunk...the first person I had ever trusted my son with...and she was leaving. Tears were filling my eyes...Justin asked when and she said soon. But that she would come to see him again before she left.

Volunteer Mary was one Special lady...she spent time with so many children...making them feel very important. She replaced a mom for one child. His mom was sick as well so she became his adopted mom during his time in the hospital. Staying all day with him...making sure he was O.K. just spending time. Now our first Angel was going to leave. Just, when we were beginning to feel comfortable.

Justin had asked that he make something for Volunteer Mary for her to remember him by...we did and the next time she came in Justin was anxious to give her his present. She in turn handed Smoochy Man to Justin. This was to keep Volunteer Mary close all the time. Justin was so

happy...but added that this is Volunteer Mary's Justin will take good care of him and when the time is right...Smoochy Man will go back to Volunteer Mary. Everyone agreed and from that day on...Justin did not go anywhere with out Smoochy Man.
The day came for Volunteer Mary to leave...tears...you better believe it...but promises of keeping in touch.

I think this is why we both needed to go home. The first lady we ever really felt safe and comfortable with was leaving us...and not knowing if we would ever see her again. Volunteer Mary has a very Special place in many children and their Mom's heart. I know Volunteer Mary was our Angel! Love you Volunteer Mary...Give Smoochy Man a Kiss!

Hugs
Butterflymom

WE ARE GOING HOME!

You know what the hospital building could have toppled over...I really would not have noticed...because we were going home. The Primary Dr. came in and gave a list of don'ts... top of the list was people and animals...had to say away from them. There really wasn't much of what we could do. I smiled...he looked and I said hey...we are going home...the first thing when we arrive is into the barn...and Justin is going to hug and roll all over his pony. Yes...these may be germs for many...but for us...this is life...so believe me I tell you true...that is what we are going to do.

Also got a list of groups that will be contacting us...Physio, VON, Home Care...ahhh I do not think so...we are busy and I can take care of my son. Not saying anything right now...when I get home though...the phone will not get answered. This is our turn...Justin's turn with family and FUN! We have 8 days before we have to be back...and we are going to make the best of our days!

The drive home was so long...not any longer than before coming or leaving Toronto, but just long...anticipating what will be. Justin snuggled right in and before we even got 3 blocks away was sound asleep. You know he was smart...just sleep then...bingo...home! I think I counted every building, every tree when we got closer and I remember like it was today...never mind yesterday...it was today. We turned onto our street...and the radio began playing..."Feels Like Home To Me!" The tears just came pouring out of my eyes...we are coming back home!

When we arrived the boys were all waiting at the door for us. Wasn't too sure what the house would look like...considering there were 8 men living there and no one to clean. Who cares...Got to the driveway and everyone was outside waiting. Family and Friends...Friends were there just to say hi...then left soon after our arrival. Like I had said...too the barn I carried Justin...his eyes wide and waiting to see his buddy. In through the barn doors right to the stall...Cool Dude was eating near the back of the stall and when he saw Justin...well there are NOT words with what happened. Justin crying...and yes tears and the works..."Cool Dude...I'm back." Cool Dude looked up booted the wall and ran...he ran right into the front gate...he neighed he cooed he swung his head all around. The 2 buddies were together again. Opened the door still holding Justin in my arms...and the pony just pushed with all his might and cuddled in close to Justin. Justin stroked his head rubbed his eyes and kissed and kissed and kissed. Finally I put Justin on the Pony's back and looked as the 2 Friends were together again.

Trying to get Justin out of the barn was trouble enough...he had come to the conclusion that he should stay there with Cool Dude. After some persuasion for both...Cool Dude had decide he was not going back in the stall either now, Finally we got everyone where they were suppose to be and got Justin to go inside the house. It is about 3 in the morning now and we were tired, but...too much excitement to notice.

Once in the House the boys carrying our stuff, Justin and I went to the living room. Justin was on my knee when he said, "K boys...I need my Hug, just stay there cause I'm coming for it" He instructed me to put him down on the carpet and pulled himself up with his arms. Dragging his legs behind...and telling everyone "Don't Touch ME!" he pulled himself to each person for hugs. Not a dry eye in the house. On top of the 5 boys and hubby we had 2 other people living with us. Graham we were helping out through his bad times and another Native student Caleb that was living with us and going to school. His 2 brothers lived with us as well before and now he was

going to graduate with our boys as well. So Justin went to each person...all of us pushing our arms out getting ready to catch him if he fell, With Justin Loudly reminding us..."Don't HELP!" but NOT once...his arms were shaking from taking all the weight...but Justin was doing what he wanted to do.

After something to drink, and realizing just how late or early it was we all headed to our rooms. Justin said...Mom I need to sleep with you K...No problem... Got Justin settled in bed... Hubby and I decided to have one more coffee before we hit the sack. Just sat and drank the coffee in silence...taking in all I could...WE WERE HOME!

The next morning came fast...considering it was already the next morning...LOL but wasn't even tired. Had a few things that had to be done for Justin and his treatment so got those things out of our way. Asked if hubby got anything for Christmas...No??? Was I suppose to? LOL nah...it is just 4 days away...we do not need a thing...LOL I laughed...just so glad to be home...I really didn't care...because our Christmas was already...we were home!

Talked to a neighbour that asked if he could come over on Christmas Eve as Santa to give Justin a present. Sam had not done this for a few years now...and felt that this is something he would like to do for us. This same Neighbour had been coming to make sure our driveway was cleaned of the snow each day with his truck and loader And told the boys if they had any trouble with the cars to see him.. Another neighbour, Mrs. Larrivier called and brought over food and Christmas cookies...and her famous soup. Corinne and her hubby Marcel came over, food in hand as well. The house looked really good when we got home, and this is when I found out that Corinne had got a few of the boys friends over and they all cleaned up. The boys came in with a tree that day...and once it thawed out we would be putting it up. The phone rang...this is VON...oh I have to get back to you...just popping out...Hello this is Physio we need to do an assessment of Justin O.K. what about after the New year...sure that sounds good...LOL we were going back on the 28th. Hey...like I said I can take care of my son...thank goodness for my medical background...Specialized in Peds...so this is where I am very comfortable. Mind you everyone else either never listened to me...or decided that I could not emotionally take care of Justin. Well They all LOSE!...Because I was...and outsiders right now were not coming in.

Did however have to take Justin the next day to the cancer clinic for blood work, so wanted to get that done early so we (Hubby and I) could get some Christmas stuff done.

Corinne called and asked if we were going to go there for Christmas Supper...I said NO you are all coming here like normal. We always had the Christmas Supper and everyone and anyone was invited. Are you sure??? Yes I am but this year you can help make some of the food. You do Desserts and I'll do the meal. Agreed. Called back for Justin's blood results and all was well. They asked if the other organizations had called said yes everything is under control... nothing more. LOL hey...got to do what you gotta do!

Justin had refused his leg braces ever since we got home... saying that his pants didn't fit right with them on, so we were doing tons of physio. Even the boys were helping out. Justin just enjoyed all the attention...but then this is what he was always used to...Justin would even get the boys friends to help out...especially their girlfriends...Justin would say...want to help me walk? Well what could they say??? So then he would say K...which ever brother "Go Now... we is busy!" LOL Some how Justin convinced each one that rubbing his back was really good for his legs...so Justin was just enjoying and taking advantage of all!

Christmas Eve came and knock, knock, knock. Oldest son Jeremy carried Justin to the front door. We knew who it was...But Justin didn't know. You see here at our house...no-one knocks...you just knock if you want too but better come right in...Because you will stay there forever. So this was strange and Justin knew it. When they opened the door...Justin's Eyes nearly fell out...he was startled at first...never said a word...just stared and stared...Santa came in had scratch tickets for everyone and then gave Justin a present. He said that he heard that Justin was in the hospital and thought maybe he would like to be a Dr. one day...Not sure if Justin even heard him...he was still just staring...then opened his present to the biggest Dr's kit there is. He was so happy...Gave Santa a HUGE hug...and kept staring. Santa had a natural beard...and to make it more realistic Santa's wife had dyed it white...so to Justin this was the real one. Santa said he could not stay but wanted to come and tell Justin how proud he was of him. He asked is there was anything special I can do for you? Justin without hesitation said..."Yes...I have lots of friends at the Hospital that cannot go home...you won't forget to go to Toronto eh?" Tears...all of

us...tears...Justin wanted to make sure Santa would not forget his friends. He even went as far as naming names. Kim, Wilson, Diana, Jennifer, Sheila, James, Kassandra, Beth, Jordon and, and, and. Santa had a twinkle in his eye for sure now...and tried like mad...to keep it right there!

Christmas morning was wonderful...all gathered receiving and giving...loving the family togetherness. Just being! Supper was great...and Justin had got a hockey game for Christmas so needless to say...he was busy playing everyone a game of hockey. Mind you he was a poor loser so better believe if you scored you cheated some way and Justin would yell... "MOM he is cheating!"

Ahhh...A great Christmas. The 26th had friends over again for supper...we had so much food that we were good for a few days. So why not share. The house was filled with people...and the boys friends were all coming over. Even Bruce Paris...remember the Hair cut...well we laughed again...because Justin now says..."Don't go to my hair cutter...because she cuts your hair so short it falls out!" I keep telling him that it is the treatment...he answers "I know MOM" but repeats the same thing..."She cuts it too short then it falls out!" Poor lady...she was so kind to come to the hospital to do it...never accepted a penny and now Justin would be terrible for her business. LOL
27th brought thoughts of going back. Neither Justin or I wanted to do that. BUT...we had too. Made arrangements to fly this time...as it was too long a drive to go there and back. Called the Ronald McDonald House...and yes we could have a room so we would get there on the 28th...go to clinic and wait for a bed!

Tears were now very close for both of us...having to leave again...not sure how long...but needed more testing and chemo so would be there till the New Year. Justin and I would spend New Years in Toronto. The Millennium New Year! Oh well not worrying about it right now...yeah sure...that's why I'm telling you all...but working on just taking in all the good right now.

27th at night had lots of the boys friends over...Justin again in his glory getting back rubs like no tomorrow. Me packing again...this time with my mind working so I will have more than one pair of socks and a few underwear this time. And Justin will not have as much as he is in hospital sweats when he is there.

Later that evening Justin and Brent were playing hockey in the living room...everyone else down stairs...I was in the dining room having a coffee. All of a sudden Brent started to scream. Oh my heart sunk...something happened... this has been all too good to be true...now what? I jumped up and ran...the boys from down stairs came running up and there we all were standing white as ghosts...watching Justin walk! He just stood and started to walk. Brent had tears falling from his eyes...everyone just stood there...Justin walking a bit crooked leaning forward and having to run to keep up to his body...but none the less walking. Again... not a dry eye except for Justin he was too busy running from person to person Telling them all "Don't Touch me!" until he threw his body into their arms. A HUGE Roar and cheers came out...this was the Millennium year coming up...and nothing would out do our night on the 27th...and the Millennium New Years even could not beat the cheers of our night!

Hugs
Butterflymom

The 28th came much too early for Justin and I. The goodbyes to our family was worse than the first trip. At least then I was in a cloud of smoke, and Justin was really sick, so our thoughts were not on family and missing them, it was on getting help for Justin, nothing else!

Off to the airport we went...said again our goodbyes...and I'm sure there were people crying because of Justin and I. We get to board early due to the wheelchair, so I must say...was glad because my throat was closing and my heart was broken so I needed time to put myself back together.

Arriving in Toronto...you seem to slip back into that 'hospital personality'. The Mask is put back on making sure it is on real tight. Arrived at the Ronald McDonald House...Got our key...went to our room. Just sat for a few minutes...then

went down stairs. Most people were at the hospital so very few families down in the kitchen. Got Justin ready to go to the hospital and off we went to clinic.

Waited for about 3 hours then finally got into a room. Had Blood work done first and now we wait here for another hour. Primary Dr. came in and nearly fainted. He comes in to see Justin walking around the room. He just stood there...I looked and smiled...waiting to hear what he had to say. Justin, come with me, I want to bring you to 8A. I want the nurses and Dr's there to see you..."O.K. Let's go". Justin eager to go and see some of his friends went running down the hall.

People ever where who had seen Justin before we left...just stood in ah... They could not believe what 8 days had done for this child. When we go to 8A all I heard was, Justin yelling..."I'm Back" and the cheers and clapping as he entered the floor.

Tears were in everyone's eyes, and then they looked to me. Hey...what can I say...Family was what was important at this time...and see what it did?

Our Primary Dr. was looking for other Dr's to see Justin and even the one that told us NO we could not go home came out to see Justin smiling, walking, and running.

Still leaning forward...but let me tell you...who cares! Justin all of a sudden cries out..."Hey La Bella Lady...look at me...I'm back!" Poor Bella Lady...the tears just poured out of her eyes as she ran to Justin and gave him a BIG hug...oh Justin you are walking. The cleaning staff came out...all giving Justin a Hug...Justin lapping each moment. It was time now to go back for our check-up...Don't think they are going to find too much wrong here. Primary Dr. had made a call to the Ortho Dr's to get them to come up to see Justin. They were on their way. Even our Primary was getting into the excitement that Justin was walking...as we were heading back to the other side of the floor to clinic...the Ortho guys got off the elevator...They stopped dead in their tracks...WOW...Justin...they looked at me...and said...2

miracles...walking and you are here. Yes I said...and we are just beginning. The Dr's followed us to our clinic room...again we were meeting people that had seen Justin tied into the wheel chair...I saw Mom's with smiling tears...some came over and said...you guys give us HOPE! So important to find that little bit of HOPE...this keeps you going, doesn't matter if it is your child or someone's else...HOPE is HOPE!

Once in the room now the Ortho Dr's want to check out Justin...go for it...things will only get better I told them. Hard work...that is what it took and the Love of his Family! You guys did the necessary stuff...but...the rest was up to Justin and his family! I must say...there was lots of smiles on the floor that day...something that you really do not see much. Genuine smiles...ear to ear with tears...Smiles of HOPE for the future. But at the same time happy right in the moment.

Finally it was time for Primary Dr. and us to talk...They want to do more test...so he will make some appointments after that then we would do chemo. We agreed...Primary asked how the appointments went back home...and that Physio must've done some amazing work...I laughed oh that appointment is on the 4th haven't seen them yet...VON...well I forgot to call them back...you know how it is...Christmas and all...Yes we did go 2 times for blood work and that was O.K. he just looked and smiled...I see... he said...and I trust it will continue like that... Yep...Like I said we are quite capable of taking care of Justin...I think now the rest of you will see that! He just smiled...then added you won't be back home on the

4th...I know I laughed...so I guess that is one group we can mark off the list! He just looked and shook his head...told you I know what he need when he needs it...and no-one is going to interfere with that.

Also added that I wanted to talk to him after tests are done...My mind is working now and I have TONS of questions. So we made an appointment for when we are on the floor and getting Chemo that he will come in with our Primary Nurse as well and we would talk then.

Headed back to the Ronald McDonald House...stop for some groceries along the way, and got to see some of the people that we had met at the hospital previously.

One being Kim's Mom Sheila.

Kim was doing much better and Justin added he wanted to meet her. So tomorrow between tests we were going to go to the 6th floor and see her. Both of us had never met Kim so this was going to be our first time.

The Ronald McDonald House was amazing...kitchen to cook in, our own rooms with bathrooms, there was a playroom, games room and Alex the WoodMan. Every Wednesday Alex the WoodMan would come to the house and work with the kids doing woodcrafts. He would cut out patterns and bring them in for the kids and their parents to sit and paint, glue and whatever. He had been doing this for a long time...and everyone knew Alex the WoodMan. We all LOVE Alex the WoodMan because he gave us time NOT to THINK!

Justin was starting to know the days of the week and Monday was clinic...Tuesday was free at this time Wednesday was Alex the WoodMan Thursday was Tails...

Now Tails is a group of staff and volunteers from the hospital that perform a story called Tails. Tails was written by a Dr. at the hospital. Many of the staff and volunteers play the roles of all the characters. Justin loved Tails...and each Thursday we would go to watch the play. He knew exactly what was going on...probably could play each part, but each Thursday...off to Tails we would go.

Took about ½ hour for the play, and each time one lucky child won the book.

I remember once Chemo was to start on a Thursday...well Justin raised such a stink that Chemo started after Tails...No way was he going to miss his show! Sick or not...Thursday was Tails and that was it!

Lets' see Fridays were a 'fill in' day...just before the LONG and I mean LONG weekends at the hospital. Try to get this and that done because other than emergency stuff nothing is done on the weekend. Treatments continue...but tests etc...just do not happen. And you cringe when you are there for an actually long weekend because things now seem to stop for 3 days with Friday still being the fill in day...but when it is a long weekend Friday... that means very little on that day as well. So in all it means 4 days of nothing...just waiting and waiting...something us parents with sick kids just seem to do all the time.

Once all the tests were done we had to go back to clinic to see if we could get a bed for his chemo. So each day we would go to see Kim...Kimmy through Justin's words. The two would play for hours. Justin right in the same bed as Kim, sometimes they would read stories, watch T.V. and even nap together. Kim's Mom and I would go for a coffee and smoke breaks. Kimmy was still waiting for a heart...but at least she was off the critical list for now.

Monday came and Justin had his blood work done. Saw the Dr. that afternoon and he had a bed for us to go to the Hospital for Justin's chemo. So over we went. You see when you go to clinic you arrive before 8:30 to stand in line to register. Then go in another line for blood work then wait...wait and wait. By the afternoon you should get to see your Dr. at which time they will tell you if there is a bed so that we can get chemo. If the answer to the bed is NO then the next day you do the same thing until a bed is available.

Justin and I had spent New Years at the House...he fell asleep before the new Year rang in, but did get to see the fireworks through the window. I spent that New Years...looking through the window...wondering what lies ahead.

Because of the Christmas season all the appointments and tests days etc... will be different so we just had to wait. Finally got a bed and started the chemo. This time seemed different. One ... Justin was up and walking so it seemed to be a bit better.

Mind you he made sure he still had his gym every day, and like before this is the time I would go out to see my Cigarette Man... And yes he was there! Getting to know more and more families...taking in just enough but not letting their troubles over whelm me. My Friend came in as well, and Cheryl and I were talking and again going for our nightly coffees.

It was different somehow...maybe because I seem to have some control back...maybe that was it! Now knew what the routines were...knew that Waiting was part of the routine...and also realizing that today had enough on our plate so would only deal with that. Tomorrow unfortunately would bring more...but for right now...Today is what I had to deal with!

Had to go back to the Ronald McDonald House after chemo this time because the Dr. had now order a MRI and that was scheduled after Chemo.

I got to meet more people...volunteers and staff. These people were just great. Always there for you...asking how was your day...do you have food? There is a "house cupboard" in case you run out. Is there anything you need? We have workers available to talk to you. Families were great...all fighting for the health of their child. All with a common bond, all willing to help and be helped! A TRUE Family...and Extended Family willing and able to help if we wanted them too. The House Manager John knew just what everyone needed...he has that special trait...Polo the maintenance guy...was always there fixing strollers, wheelchairs, you name it he fixed it for us. Volunteers to read to your child, do crafts, Cher who took Justin on magic Carpet rides...became a regular routine for us on Friday nights and Sat afternoons. Justin and her spending time together talking about everything and sometimes not much of anything. There is the weekend Managers who kept the house running and making sure all the necessities were available for all the families.

All these people who gave of themselves...not for gain...but gave because they CARED! Here at the HOUSE you feel safe...protected, cared for...I remember coming in on a Tuesday and smelling cookies...wow what a great smell to see them lined up on the counter for everyone to have. Volunteer ladies came in every Tuesday and made cookies for everyone in the house. Just brings you back to when you were young. Just a second of yester years...and happy times...just enough to help you through regardless of what kind of day you had. All these people helping...caring...loving each of us...just because!

Ah...finally time for the MRI... which means pack up, clean your room for the next family to use, and leave for the airport to go home right after the test. Was a great day again because we could go back home.

Didn't really get to talk to Dr. about everything I wanted too, not because he didn't show up, but because I forgot half of what I wanted to talk about until after he left! Isn't that always the way? So saw him in the halls and told him I would fax him my questions for next visit...that way he knew what I wanted to talk about...get the answers I needed and that way each of us get to talk about what we need too. He agreed so that is the way we would do our things.

Went to MRI...now most of the children are sedated for MRI but not Justin...I sit with him keep him still and they do what they have too. It takes about 1 1/2 hours but we get through. Justin calls it the "Boomboom Test" because you hear boomboomboomboom for the whole time.

Done...headed upstairs to see Kimmy and Sheila and now were heading back to the airport. Home for 2 weeks then back again for one week.

Hugs
Butterflymom

For us 3 BIG Miracles Happened. And on the plane I just sat peacefully thanking GOD for where we were. For Justin he had his Christmas and at home. He also started to walk again and each day getting stronger. Not knowing what tomorrow brings...Today is good enough!

Got home to find house upside down, everyone back to their regular activities and family and friends going on with their lives. Although I'm glad that everyone is doing well...deep inside I had a yearning to be doing the same thing.

I cleaned the house, got Justin to his lab appointments, did his treatments daily worked on physio and took daily walks with Justin to strengthen his legs. We started skating again, and the boys had made a rink in our side yard. So Justin spent many hours out there playing hockey. Justin also did a lot of riding...we had someone come and clear the snow out of the riding ring, saddled up Cool Dude, but most of the time Justin went bare back and I sat for hours watching him play with his horse.

The two weeks seemed to fly by and it was time to head back. The usual call to the Ronald McDonald House found that the house was full, so when we arrived we would have to call to see if there was a room.

Had faxed all my questions for Primary Dr. So at clinic will have more questions answered. The day came all too fast to go back but ready we were. Got to the airport and back to the hospital we went. When we arrived I called the HOUSE to see if there was room NO. Oh well I'll stay in Justin rooms. Got to clinic, talked to Dr. and found out that there were NO beds on the floor. What are we suppose to do? Everything is full. Well call a nearby hotel. Well did, walked the 4 blocks with suitcases and wheelchair through the snow. Got a room and left our stuff there then headed back to the hospital. When there is NO room in the morning, you have to

stick around till about 5 to see if a room comes up...NONE so we went to eat then head back to the hotel. We were both very tired so gave Justin his bath and we both went to bed. Next morning we booked out, as we do not know till about noon if we have a bed and the hotel will charge for another night after 11. Doesn't matter that you are at the hospital...no excuse...they want their money. So back to the hospital we headed with everything in tow. Waited until 3 no beds...called the House a few times to see if anyone left NO LUCK. At 6 headed back to hotel hoping that they still had a room. Yes...and again hit the sack early. Next morning... the same thing. Lug everything back to the hospital to be told sorry doesn't look good. Well I was really upset now. Why did you tell us to come then? Well it is Justin's time. Yeah, but NO bed...so we wait! Sorry this is just how it goes. I called the House again...still no rooms, knew that we really could not afford another night in the hotel. We got a hospital rate of \$88.00 plus 15% tax each night. Then the food...can't do this. With really nothing left to do...I had to head back to the hotel. It was now 8 at night and I was really upset. Got a room, got Justin tucked in and I cried. I literally cried.

Gosh we have enough on our plate and now this. The next morning came very slow...I didn't sleep much just worrying about everything and so was not in great spirits in the morning. We headed to the Hospital to arrive for 8:30 waited in line then waited for blood again...and just sat there actually boiling I think. I went to 8A asked them if it looked like we could get a room today...they were not sure, but maybe later on in the evening. When we got our blood results back, I went back to the floor again asked, but added if there is NO room then we are going back home. I cannot afford to stay in the hotel. The Head Nurse looked at me and said. Mrs.V. you cannot leave, do you know how important Justin's chemo is? I replied; "Yes I do...but I think someone here has forgotten his protocol. So like I said NO room today...we will leave."

I took Justin down stairs to get him something to eat. Thank goodness I had the wheel chair, because this became his nap place. Gosh this was frustrating. Pulling suitcase and a wheelchair all over the place. Carrying our winter clothes, and waiting...just waiting.

Well we did get a room that night but it was at 10:30 p.m. Both of us were just exhausted and now Chemo will not be till tomorrow morning. Add a week to that now we just have 1 week back home. Gosh...what a mess.

The next day our Primary Dr. and Nurse came in I told them both that next time I will not come if we do not have a room at the Ronald McDonald House or in the hospital. Just will not come with out that reassurance. Primary Nurse said that their hands were tied...I said mine too. I cannot afford this. So that is it...NO

ROOM...Not coming till there is one! Talked about the questions I had...but now I'm really not in the mood to put my energies there. Told them we would have to do this another day. We chatted about adding GCFS to Justin's regular routine. This is to build up his blood after chemo. It is by injections each day, but a pick line will be put in. Use it for 7 days then the pick line is changed and placed in the other arm and we start again. This will be done at home. One thing that I decided that even though I am very capable of doing Justin's injections, I wanted to be his MOM...not his picker. So VON was going to becoming by to change his pick line when we got back home. I agreed to that because also the meds were like \$5,000.00 a month and

it was not covered by our medical insurance and if we had a nurse coming into our home then it is covered by our health coverage. I knew we could certainly not afford that kind of money so agreed to have the nurse come in, one time a week to change the pick line.

Did our chemo routine and saw my friends and then headed back home! Again the house a mess, everyone busy with their things, and Justin and I doing the medical stuff. Hubby was on a new project that sees him out of town. You guessed it the week we got to come home...Hubby gone. When we were to head back...hubby was coming home later that day. O.K. just Breath!

It came time for pick line to be changed and I received a call that they had to reschedule. But the pick line has to be changed, can't use it again tonight! Sorry we are short of nurses so it will not be changed till tomorrow. Just add to the all the other stuff. Feeling very much so alone now, I did what I had to do. What I really did not want to do. But changed the pick line. Justin was happy I did it...said it doesn't hurt when I do it. But I knew then...that this would be another treatment for me to continue. Justin was not going to let anyone else do it now. Next day the VON came in, here to change the line. Sorry did it yesterday when it was due to be changed. O.K. then I'll check how you give the needled. NO...it doesn't get done till 8 at night. Well it would be O.K. for today so I can see that you are doing it right.

Well I have done it for a week and changed the pick line so I think I know what I am doing. "Oh my, oh my someone got out of the wrong side of the bed today!" That was it...I never wanted to be his pick lady, you guys never came when you were suppose to, now you want to see what I can do, also want to change his meds times to be more convenient to you. Got up on the wrong side of bed??? No just have to deal with people who really do not know! She just looked at me...O.K. I'm going to take his blood pressure. Out comes an adult cuff...that is not going to get a proper reading...oh well that is all I have. He is 4 years old...you would have to wrap that thing twice around and then some. Oh it will be good enough. I laughed go for it...well of course some ridiculous reading and then finally she decided she had to go.

What a waste this was.

This trip home was very frustrating and very lonely. The boys tried to help out, but they were busy with their things. Friends and other family members were also busy after the Christmas season and now all back to regular routine. I started to feel sorry for myself. Justin and I went about our business. But I could feel a distance... that I was putting out now. Almost like a wall, protecting Justin and I from everyone else.

I received a call telling me that our Primary Dr has scheduled more test and if we could please be there tomorrow. NO I cannot...I live 5 hours away and you have our schedule so book while we are there. So when I get there on Monday we will talk then. They think we live across the street.

Sunday night before we headed to the plane, called the House and yes this time there was a room. So arrived and went right to bed. It was a tough time...sat with friends in the evening on the outside balcony where you can smoke and just listened to their stories. Justin and I headed upstairs early enough for tomorrow is another day at the hospital.

Got there early this time we also had to go for an Echo a heart test because of the chemo he was on this time. So after blood we headed there. Waited till 11:30 and still no echo. I went to the lady and asked when our appointment was? They looked and said soon. It was at 4:30 by the time we got in for the tests and now by the time we get admitted will not have chemo till tomorrow. Headed back to the floor and they said come back tomorrow. Thank goodness we were in the House this time, because again no bed today! Headed back, but not till I promised Justin we would come back to go to Tails. Which we did.

Next morning got the hospital regular early time and yes there was a bed. Went straight to our room and got ready. Once Chemo started I said to Justin Mommy needs to go outside for a smoke. He said sure as another volunteer was coming in to play with him.

Outside I saw my Friend Sheila I walked up and asked her what was wrong, was Kim alright. She got her heart last night! Oh my...are things good...Yes...I cannot believe it. I get to see her in 1/2 hour. It was long, but finally it is done. We both just stood there crying. What a wonderful thing...Yet so sad. For another one has lost their life and gave it back again... to Kim. Such a hard thing to think about! Told Sheila to come and get me when she saw Kimmy and we would go for coffee.

Well things continued as usual. But we added school to Justin's day as well. Each morning now a tutor would come in for 1/2 hour and do school work with him. He really looked forward to it and it kept our lives busy. Between the tests, Tails, crafts, stories, school and physio Justin had a full schedule!

Another test was scheduled for right after chemo so we had to wait another day before we could go home. I re-booked the plane and went for the I.P. Justin is put to sleep for this as they take spinal fluid out to test for cancer cells. Well here we go again...had booked out of the House, cleaned everything up, went for the test and was told we could not have it done till later in the day. Which meant could not go home today. PLUS...we booked out of the House! We have no ROOM...Again...We

could not fly that night for sure because of the test so I was going to be at the hospital for the night. We found a couch and that is where we slept...well Justin slept I sat next to him till the morning came. Now I just wanted to get home! Next morning we were off. Got home to the same stuff. Dishes all over, bathroom a mess, stuff everywhere. Had to take a taxi home from the airport as everyone was at school and hubby was away again. Got home...Justin was happy with everything, and I just cried...cried and cried...

Hugs
Butterflymom

That week at home now was spent, cleaning up, preparing meals for when I would be gone.

Hubby came home the day before we had to leave again. We could NOT go to the boys hockey games because Justin's counts (Blood) are low after Chemo, so cannot take any chances. Listened to every ones stories, and did the medical stuff that had to be done. Kept very much so to myself...feeling that way my downed spirit would not interfere with others. Justin was his happy self, and we continued our daily walks in the field.

We would walk to the back of the field, or should I say I would pull Justin on his sleigh, then we would lie in the snow make Angels and then pick pictures out of the clouds. The horses would come a running to be with us, and as we lay on our backs...they would keep watch. We went down trails collecting 'Treasures' as Justin would call them. We made SnowMen everywhere on our voyage, using branches and sticks for arms hair whatever. Usually in the evening Justin would skate with one of the boys and this would give me a break. Now, not sure if that was good. I would spend that time thinking and planning our next move. I was coming up with many ideas, contacting Dr.'s all over the world and just getting more and more information. Unfortunately the outcome was the same. Really NO CURE! Instead of falling apart...It made me realize the importance of here and now. So my energies went to the moment with Justin. Still searching never giving up hope but living life to the fullest as things presented themselves. Weighing things making sure that it would not put Justin back in treatment, but making sure he wasn't going to miss things too.

The night Hubby came home was a quiet one. I was feeling very much so deserted so really had NOT much to say. Listened to things going on at work...but really didn't care. The night before called the house to see if there was a room. Yes their would be but not till later in the day. So packed our stuff for another hopefully this time only our week of Chemo.

Got to the hospital and was excited to see our new family. Talked and caught up with what had happened to them over the week, and headed to the clinic. Justin was being admitted and Chemo would start that night. Next morning after getting Justin cleaned up for his day, we were heading to the playroom when all of a sudden I could feel Justin shaking. I looked down and he was crying so hard he could not speak. I stopped... bent down asked what was wrong? He kept crying "Kimmy...Kimmy Needs ME" between the sobs he would repeat this again. It didn't take to long before one of the nurses came over, as I said before...Justin NEVER cried, so the initial thought was he was having a reaction to the chemo this time. His body was shaking like a leaf...trembling all over and crying..."Kimmy Needs Me Kimmy Needs Me" The nurse returned back to our room and suggested that I go see Kimmy. Justin piped UP..."NO...I have to go!" You can 't Justin you have your chemo running and you cannot leave the floor. "Well Take It Off...Don't you know Kimmy Needs ME" Nurse sat with Justin and I ran down the stairs to see Kim. Just as I got to the floor Kim's Mom was walking through the doors..."What are you doing here?" she asked...I quickly explained what had happened up stairs with Justin and said I just came to see Kim. Just as I looked towards her door, people running all over the place...Dr's coming from every hall...I asked "What is going on?" Sheila answered Kim is having a 3A heart rejection. Simply this means Kim's body was rejecting her transplanted heart! Oh MY...I really couldn't even say anything. I hugged Sheila and told her I would be back. She just stood there watching, praying and not even really noticing anything else.

I ran back upstairs...to find Justin and the nurse reading a book. The nurse chirps...and says how is Kimmy? Not too good she is having a 3A heart reaction as we speak. Justin looked up...very sternly said..."SEE...I TOLD YOU KIMMY NEEDED ME!" and that was it. The nurse just stood up and said he had to leave...I could see the hairs on the back of his neck and arms standing. I sat next to Justin and said what do you want to do now? Go to the playroom, when the volunteers come you go to Kimmy's MOM, now she Needs you!

Just short, sweet and plain to the point. O.K. I will.

Didn't take too long for this to get around the hospital and we had Dr.'s nurses, workers volunteers even parents asking us how Justin KNEW? "Straight Line" is all I would say.

To tell you the truth, I was still trying to figure it out.

Last day of Chemo and all Justin could do was ask over and over again...when can I go??? I have to go see Kimmy? When he finally had his flush and we were ready to head out to the airport. Justin bid his farewells and said let's go right now to see Kimmy. I told him Kimmy was NOT doing well, that she was sleeping all the time and right now could not wake up. "Oh MOM just take me there."

Got down stairs...really worried as Kim was loaded with tubes, she had blown up... do to the steroid treatments and she really looked terrible. Justin was insistent, and put my

wheel chair next to her bed...so I can see her. Did what he asked, of course Sheila was there and she and I just looked at each other. Hearts breaking seeing this lovely little girl all hooked up to things. Kim had been in a coma since the rejection, and hope was dwindling away. But Justin once he got where he needed to be...grabbed Kim's hand said "Hi Kimmy it's me Justin...you are going to be O.K. now. I have to go home now, but when I get back we can play" Kim opened her eyes...pushed a "K" from the breathing tube and smiled. WOOOOOW...I just stood there tears flowing down my face...Kim's Mom was looking at me, again tears but the biggest smile and a nurse had come in as Justin was talking to her and she was now calling Dr's and nurses from all over the place again. I said we better go...Justin said O.K. Bye Kim see you in 2 weeks, and again through the tube..."YES"

Left...I was trying not to think because the tears would come. Had to get home that is all. Justin was his normal happy self but turned just as we got into the taxi and said..."See Mom, Kimmy Needed me, but she is O.K. now" Couldn't even respond.

Got home, hubby picked us up at the airport, to tell me he was leaving the next morning again...Said nothing...Boys were busy with school and hockey and other activities so it was Justin and I again. Family members were calling but you know...their lives were going on too. My Friend Corinne though...she was there every day. Just sat and talked, made lunch, did a craft with Justin. Funny thing about this is that my friend has Agoraphobia...but she was there...Drove herself too. She helped me clean the house, as it was a mess again. If she asked once she asked a million times...what can I do for you...my answer nothing!

Time to go back and this time...I'm looking forward to it. I had done tons of research so sent my questions in and knew this was going to be a big discussion. Main question... lets do something else. Why stay on a protocol that has 1% survival of Justin disease. We have nothing to lose...Also we get back all the tests that were done the last time and the time before. A big one this time...we will find out where we are in the treatment and Justin's progress, which remember is NOT suppose to be good!

Arrived put our stuff away and headed to the hospital. Justin wanted to see Kim so we went early. Kim was up in a wheel chair when we got there, she was more her proper size now and she smiled the biggest smile when she saw Justin...K, both said at the same time...you two go for coffee. So Sheila and I went for coffee. She was looking very tired and now tonight she was going to go back to the house to sleep. She had been in Kim's room since the episode and we laughed because other than washing she still had the same clothes. She assured me she had changed and that it was just a coincidence LOL
Sure sure...

Got back took Justin for his blood and clinic. Talked to the Dr. and like I said yes...long one. He also added that Justin would not be getting a bed today but probably tomorrow. So once he was in his room our Primary would come to talk some more. The short and sweet of everything...Once on a protocol cannot change unless there is a problem. My thought is...Kids with cancer sometimes their problems cannot be fixed...so why would we follow something like that? I had some ideas and wanted to share. Justin made some comments that maybe he could go in on Thursday night so he could see Alex the WoodMan and then go to Tails before Chemo starts. Told him when there is a bed...then that is when we have to go. Guess what...Told you he had a direct line...no bed the next day so Alex the WoodMan and Jenn his helper had Justin for the evening. Now Justin has girlfriends everywhere. He asked everyone want to be my girlfriend, and with his ice blue eyes and smile...no one has refused him YET! So now Jenn was his girlfriend and they would go and play games together. There were a few of his girlfriends that Justin just didn't like to share and Jenn was one. So off they would go to the quiet room, one day they went walking and another time he took her to the basement to play hockey.

Thursday got into hospital and yes...Justin got his wish right after Tails his chemo started.

I went outside to find a lady sitting at MY pillar. She was looking so lost. I introduced myself and she said her name was Judy. Her daughter was flown air ambulance and was up on the 5th floor. She has had many problems and believed she has Crones. She is in a lot of pain and tomorrow they start the test. She will probably have to have a colostomy.

She was staying at in her daughter's room but needed to get out. We talked over 2 cigarettes and then said once kids are sleeping I would come and get her to go for coffee. My other friend Cheryl was on opposite chemo times as me so we get one night together now. She is coming with her son and I'm leaving on the opposite.

Picked Judy up around 1:00 a.m. and off we went for coffee. We talked, both from the North and made plans to meet again the next day. Asked her if she knew about the Ronald McDonald House she said yes...but NO room. Told her to call each day. Eventually someone will leave and then you get the room.

Met a lot of new people this time...I guess just opening myself up to more people now. Justin well...he was making friends all over the place. He talked to everyone... People would drop by just to say hi. They would leave telling me he has such a great personality and Beautiful Blue eyes that light up his face with his smile!

This time there was a new diagnosis on the floor and the girl was also from the north. Although we did not know them...in we went...North is HOME now so when anyone from the North comes in you just go to see them. It is like our hidden family coming out! The girl was 13 and needed to go for a port. She was insisting NO WAY... So the staff had asked if I would go and talk to her. Sure and of course Justin came along. Well I didn't do much talking...Justin had his shirt off look see this is my Port...and you know what, you want one. All the BIG needles will really hurt if you don't have this. By the end of the conversation, though I only talked to Mom, the girl was buzzing front desk for her nurse to schedule the Port! LOL it was funny...I would have talked in circles first...NO NOT Justin...take the shirt off and this is what it is like! If you don't get one...watch out...you are going to be crying everyday. Then it will be too late. LOL straight to the point! We said our good nights and headed back to our room. As we were going there was another new lady...she was crying and crying...her husband was holding her and they were wheeling her daughter into a room. Ahhh...another new diagnosis. This girl was 16 and her Mom was a mess. I over heard they were from our hometown so went back to see if I knew who they were. She was standing outside the room crying her eyes out. The nurses were trying to comfort her but she kept backing away. I said Hi I'm Brenda and are you O.K? She fell into my arms...NO... My daughter has cancer. I just held her, convinced her to come to the quiet room where we talked. She calmed down for a bit, and I told her I KNEW what she was going through.

Told her where our room was and that she could come there anytime. Found out as well that her nephew and my 2nd son Spencer played hockey together.

The next morning the newest lady came to the room want a coffee sure...we went down stairs. She was saying that today her daughter was going to surgery for the port and biopsies. Told her to hang in there unfortunately this is a waiting game and you will see this real fast! She had her Husband so I kept my distance, but was there when the daughter came back and again she turned to me. Her hubby went with the daughter but she was so emotionally distraught that I think the hubby was glad I was there as well so he could be with daughter and knew his wife was not alone.

The other girl also went for her Port and Justin was waiting for her. It's hurts now...but you will be glad...

Another day...done...

Next day was much the same except this is when Primary Dr. comes back to talk shop. He is coming to listen to my ideas now and see if any can be implemented in to Justin's Protocol. Morning much the same. Except at 11 had the lady from our hometown come to the room. She just wanted to thank me and tell me her daughter was doing much better today. Funny how kids recover so fast from surgeries and we learn really fast that the surgery is the least of our worries. Too bad we didn't get that idea before the surgeries and it would save us so much worry and energy. We talked for a while and then she said that she had talked to her sister about me. Her sister and remembered our family and added that Justin was the adopted son. She looked right at me and said..."So you really do not know what it is like to have a child with cancer." Now you all have to realize and I did at the time...she did not mean it like she said. I looked at her and said...oh but I do...you see

Justin isn't just part of me...he was born in my heart and I had to wait longer than 9 months to get him. See Justin is very much my son and brother to his brothers. Justin IS MINE! Her response was...you know what I mean...it just cannot be the same. Obviously she was not getting it and I just dropped it by saying NO I do not understand what you mean and changed the subject.

Even though she was really describing how she felt about adopting, it hurt. It hurt to think someone would even think Justin wasn't mine. Even as I write this I get tears...yet understanding just why Justin came to us and not her family. This left a very bad taste in my mouth and although I still helped her out when she needed it, there were NO coffee's together anymore or long talks. When things were going upside down for her, she came looking for me and I was there, but that was it.

Dr. came in shortly after lunch and we sat in the quiet room. Justin was taking a nap so wanted to talk there instead of his room. Dr. started by saying "Once on a protocol we can not change it unless something happens" I looked and replied that this was defeating the purpose. Justin has 1% chance of surviving this protocol so why would I want to stay on this. What are the stats on children that survive? What do you mean? Well Justin WILL survive this protocol, but...what do we look forward to? Treatment can be just a deadly as the disease, so am I going to have a 5 year old on dialysis, bed ridden, brain defective???

What??? He looked at me...we do not know. Well if you do not know then really this protocol is a trial and once on a trial then we can try other things. NO...because he is on the Rhabdo Protocol which is the same for both types and until there is a problem we cannot by law try other things. Hmmmmm doesn't make sense to me. What are you thinking. Well told him that there was going to be Dr.'s calling or contacting him from all over the place. YES I already have got some calls. And believe me that is not the only ones you are going to get. I told them all YOU are the primary DR. but we were willing to hear anything that may help. He totally agreed. I added that my thoughts are...remove the primary tumour, get rid of it. Then lets deal with the end of that and the spreading of the disease. I also added that I felt that we should be injecting the chemo right into the tumour itself. Why do the whole body and the primary wait for it's meds. I also felt that the immune boosters that Justin has been on since the beginning has really helped and that this is something that should be introduced not only to my son but every child with cancer. At this point he said he had a friend in Washington that was working on immune boosters, they are synthetically made and he had discussed Justin's case with him and he was wondering if we would try this. Said NO...because Justin is on natural immune boosters that have been made just for him. So if that Dr. wants to talk to me about that sure, but no synthetic stuff, have enough now. Also what about the chemo injections. Well sounds good and they are doing studies on it but not something that is ready for people. BUT...our chances are nothing... Just at this point the nurse walked in and said Dr. you are wanted on the phone...he left came back with a HUGE smile and said...we got all the final results of Justin's tests. HMMM he is smiling and we are NOT in Justin's room so it must be good. I looked and said AND???? And all tumours have receded, bone marrow clear which we are really surprised of, and MRI, Bone scans and Cat scans show very little. The treatment is working right now. MY response was YES I knew it would, but we need to change something before we have a problem. Mrs.V you should be happy. I am but I am telling you we need to change something. We talked a bit more, talked about which Dr.'s had contacted him and one from St .Jude's has been calling regularly to see what is happening with Justin. He asked me how I got a hold of all these guys...told him not really sure just did, the problem is that I have to say everything I can because when I try to get back to them on the computer I can never find them...we laughed and I added I think they block me out. LOL

Our Primary Dr. is very open to Parents doing their own research and suggestions. We have a great rapport and I'm very fortunate to have him. Some of the other Dr's and I would have clashed well before now, with all my suggestions and thoughts. Oh yes...I also added that when we return back to our home after chemo I never go to the lab like they want me too, again remember I am a Registered Nurse so I can assess things quite well. BUT...as I told him what is the point going to the lab when I know his counts are low...and they take a

fit and want him admitted. I am not having him admitted and so I wait until the counts are on the rise. Really all the ones you need are the prior ones for chemo, so just to let you know that is why you may get only 2 counts before we come back. He just looked and smiled, and I thought they were slow in sending them...LOL well keep thinking that because that is all you are going to get. He assured me that he will be talking to a number of other Dr.'s and in fact has a conference in Boston about sarcomas one being Rhabdo. Hmmm asked if I could go and give impute and we both laughed. Finished by saying...I appreciate all your are doing and I understand only too well about all the red tape in medicine, BUT...My gut tells me regardless what the tests read...we are heading for trouble.

He replied that we have to continue as is, and to tell the truth he never believed that Justin would be where he is. You and your family are definitely doing something right. I better go and peek in at Justin, or he'll be mad at me. Yes that is very true...Justin now says to everyone this is my body I know...I guess his mothers thoughts are rubbing off. So if the Primary didn't go and ask how he was doing he would be looking all over the place for him and would say "HEY why you talking to my MOM...this is my body ask me!" Justin was awake so I graciously decide this was a quick minute I could go and smoke so I ran downstairs and left Justin and Primary alone to discuss the future. LOL

Rest of our stay was much the same but had to stay a bit longer than usual because primary decided to get the Echo done before we left this time so that when we got back we could just start chemo instead of waiting ahead of time for the test. Sounded good to me. Our 2 weeks home and 1 week at the hospital was getting to 2 weeks at the hospital and 1 week at home. We got in Tails again so Justin was happy to be there. He was part of the fixtures I believe, and everyone there looked forward to his intense and dedicated feelings about the play.

He would anticipate every move and next one, with so much enthusiasm that all the kids were excited not knowing what was going to happen with the exception of a few. So I think it really added to the play.

The day before our test and going home again, some wrestlers came to the hospital to see the kids. We were going to Marnies Lounge with is a play place for the kids in the hospital to go. Video games, air hockey which Justin loved, crafts and T.V's. Justin went in and saw the wrestlers, they really took a liking to him and his personality and just as it was time to go Justin said...this is boring do you want to play hockey. GOSH...I nearly fainted...but you know it was boring... the wrestlers signing autographs and shaking hands with tons of kids. So after the laughter and my face turning a red as all get out, Justin and 3 of the wrestlers decided to play a game of air hockey. Well it was a media frenzie. Justin took complete charge telling them how to play and the rules. 2 on each side, and ready go. First to reach 5 goals are the winner. The place went insane...Justin barely seeing over the edge, but has mastered that disadvantage very well, had the puck drop and he scores...LOL O.K. now we are ready... This went on for about 10 minutes...pictures snapping all over the place, video cameras for the T.V. and people asking me to sign off for Justin picture to appear with the wrestlers. Justin and his wrestler won...and it was time to go. Cheers and we are the Champions rang over the lounge and Justin and I headed back to the House.

Did the echo thing and headed to the airport...time to go home again for a week.

Hugs
Butterflymom
Will add more later.

Home we went too much the same. Everyone going about their own business. Hubby was leaving again in a couple of days. Justin was excited to show off his baseball cap and pictures of the wrestlers. Explaining when, why, and how he got them. Not once but 9 times...everyone had NO choice but to listen.

After cleaning up again and making some meals for the next trip, our regular trips to the cancer clinic for blood and waiting for the missed visits by the VON (didn't really matter,

as there really wasn't much they could do). It was time to head back. Both of us are eagerly looking forward to going back...seeing our friends. Called the House and again NO room...called the floor...no doesn't look like there will be a room so called our Primary and said...NO not coming. When there is a room I will come. Right now NO place to stay. They were not too impressed but then...they do not pay for the hotel room. And when we are in the hotel room Justin is NOT receiving treatment so might as well stay home cheaper that way. 3 days went by no rooms. Then the Primary called and said that they would make arrangements for the treatment to be done here. How is that possible I asked? Justin has chemo for 5 days then flushes and all that stuff and here the clinic is day clinic. We cannot stop chemo and restart. Yes...they will make arrangements for Justin to have his chemo done in hospital. OH...then they are trained on the floor in chemo? Should be...WELL I knew differently. Just left it said O.K. you make arrangements and we will see what happens.

Received a call that afternoon asking if Justin could sit in a chair for chemo. I said yes, but he could NOT for 5 days. OH...was the response. Then said O.K. we will get back to you. Next morning received a call saying that Justin could come into the hospital. I replied and the nurse that will be administering chemo will show me her card? Oh just wait. Back...no cards on the floor but someone from clinic will check...NO...you need someone around 24 hours for 5 days. Well I'll have to get back to you. Nothing that day and then another call Mrs.V our staff is NOT trained but we could have nurses from the cancer clinic come in to check. NO...sorry... all or nothing. Again they said that it would take a while to rearrange the schedule in clinic to have a nurse available to do Justin's chemo then. Well I guess we wait.

Mean while our Primary called and asked when Justin was getting his chemo here. Told him probably never. Explained what was happening and that I refuse NOT to have a qualified nurse with Justin at all times. He thought we had already had the chemo so was very shocked. He said No you are right...I will get back to you. Not even 2 hour passed and I received a call from Toronto. Mrs.V could you have Justin here tonight. NO but I could tomorrow, have to make flying arrangements. Are you sure...yes I know the plane schedule and there is nothing till tomorrow. Could your hubby drive you then...NO he is out of town working. Oh...k make the arrangements.

Did just that, now a week past his scheduled time because there is NO beds available. Did the early morning flight arrive straight to the hospital...to find...no bed until later. Called the HOUSE No beds...I was really upset. Walked about for the whole day. Went to the floor many times to be told not yet.

Well 11:30 p.m. Justin and I standing out side the hospital and we get word that we would be getting a bed in about 1/2 hour. Just cleaning the room. Oh brother...needed to be here yesterday but by the time we get the room it will be 2 days later. Makes NO sense.

Finally arrived to our room at 12:30 in the morning. Poor Justin was exhausted. Just put things all over the place and wanted to get Justin ready for bed. About 1:00 a.m. a resident comes in and wants to check Justin for his Chemo. O.K. he asked..."what type of cancer does he have?" I looked at him and said do you have his chart it should be there. He looked at me saying..."Well this would be easier as I have not had time to read it all" All ...just look a the front page...oh brother...I'm tired frustrated and now 1:00 in the morning and someone wants to talk...I didn't even respond. He check Justin over then said..."He is always this lethargic" I looked saying..."no not when we are having a wild party and he is whopping it up...but usually he is in bed by this time sound asleep!" He looked up at me and left.

I just curled up and read a book...

Next moring was Chemo so got things ready for that. Had more questions and ideas about Justin's treatment and would talk to the Dr. some time that day. I was really tired, and wanted to just hide away.

All went well after this. Met my friends, talked, got Justin to Tails and just was. One day and we get to go home. Now it is a toss...I know that Hubby will be there this time, boys are doing O.K. and I'm just too tired to go home to clean. Decided to myself...that I would do toilets and that is it. They will have to take care of the rest.

Someone I never met came in and told me that she was from VON. She wanted to tell me I have been cut off back home. Oh O.K. no problem. But she said so is your card so the GCFS has to be paid by you. I looked at her...said not this time I already have it. She said how did you do that? I went down stairs and got it. Always get it the day before we leave so I have it and do not forget. She said well you are going to have to pay for it. You will get a bill...I said...Oh well...can't pay for it...so when they want they can come and get me and put me in jail...because I won't be returning it and I will not be paying for it. Besides...Jail time could be pretty restful for me. Tell them solitary confinement...I need the break! She just looked at me. Justin pops up "Mom you going to jail?" I just started laughing...couldn't be so lucky!

She stated that since VON has not been to our house in the last few weeks...and that is my fault. They called to cancel, I have to come back here, then there are NO beds so I am home the week I am suppose to be here, They call to find out we are not there and it is MY fault?? Don't think so. And Listen. I have the GCFS now, will get it the next time and the next so YOU better fix it. AND...I have an appointment...Justin laughs out "With her Pillar" LOL I looked at Justin just smiled and said see you later BUD! \$5,000.00 a month and they think we can pay for that. Change in my pocket...change in my pocket...no problem here.

I just had to leave...enough is enough. Saw one of my friends, she saw my look and followed me outside. Didn't say a word, lit our cigarettes and she left to get two coffees. Came back said I think you need this. Yes thanks I do...and then the tears fell. Gosh we have enough on our plates...why all this BULL...Said what I had to say...then laughed together when I told her what I had said. She looked at me and laughed but relied you are so lucky you can think so fast on your feet. I would just curl up in a ball and fall apart. It happens to me over and over again...now she is crying...gosh we make a great pair. By this time more friends we have met are coming over and by the time we were done there were about 12 of us all crying over something or other. It must have been some pretty funny site. Right next the PILLAR!

Mind you we came up with a great fundraising plan...all the parents of kids at the hospital will stand on street corners with our hats, collect money and give it to whoever needs it to pay for treatment. Laughing we all agreed the break would be nice and we probably could pull in big bucks! Our GOOD OLD PILLAR!

Our swearing post, our crying post, our thinking post, our smoking post, our do nothing post. I believe they made that Pillar just for that purpose too. It was frequent by every last person that ever walked into Sick Kids...and I'm not kidding. There is NOT a minute...that there is NOT someone there. On top of all it was...it also gave us strength. Left the baggage and garbage there, went back into the hospital to fill up again. That pillar should be bronzed or something LOL Maybe my next project!

That is it for today, actually was upset before writing this, but feeling better. Left the garbage at the Pillar.
Hugs Butterflymom

...Today 1999 got Justin home from first hospital admission, to dress for Halloween just to watch the kids...he was so sick and still they did not know what was wrong. Beginning of Sept to last day of October...LISTEN...

Didn't want to write today...Feeling emotions I try desperately to hide...But I'm here.

We went home again...now upset with the hospital and all there rules, upset because my family is going on with their lives and upset because ...WHY did this happen to us. Justin was fine mind you...he was enjoying every aspect and things that hurt he would block it out...deal with it in the moment and then it was gone. Gosh...so easy...just do it. Got home and was looking for things to be mad at...didn't take long to find it either. House a mess, no dishes in the cupboard and the floors looked like the horses had lived there

while I was gone. WHY???WHY???WHY??? Answers today I seek, but will never really find the answers I want.

Got a call from VON thinking that now I would listen to them complain...but no...telling me that if once a month seems to be enough for us that we would do that so we could get the meds covered. Thanked them...really couldn't get mad at that mind you I tried to think of something. LOL then accepted their offer saying I would call one day when I get back...schedule for that week and then we would be fine.

The week was O.K. Justin and I spent a lot of time outside. Just taking in what nature had to offer. Sometimes on our walks...Justin would say...lets scream MOM...he knew I was bottling up and needed to let out some of my frustrations...so scream we did...laughing our heads off as horses would come running our dogs and all. Laughter...yes...that is what was missing...the good old laughter.

One day after Justin was tucked in for the night, I was just sitting...tears rolling down my face and wondering "Now What?" "Where is this going?" tears were just streaming down my face...sitting in the dark my house full of family and friends and I feel so alone. Feeling like I have to deal with everything, and then explain to everyone...trying to get each to understand what is going on. Answering their questions but not having mine answered. It is JUST too Much. Can't do this anymore...then...a feeling or a warmth...I think both...give it to GOD...Yeah right...why did he let this happen? Give it to GOD...O.K. here... take it.

Nothing...nothing...nothing. Hmmmm thanks a lot. Sat a few more minutes...could have been an hour for all I knew...then the emotions explored...I sobbed and cried. I didn't want anyone to hear me so I went outside. Dogs came with me, walked to the back bush...dark as all get out...but needed to get away...wishing I could just run away...hide from this mess. Something inside said...regardless what the tests are showing which is all good right now...there is something wrong. Again who will listen? I'm a MOM...Just a MOM. Darn nation...someone is going to listen to me...Heard Justin's words...lets scream MOM and scream I did...in the middle of the night, by myself except for the dogs, and I screamed and screamed and screamed. Swore, told GOD that he left me...told myself this was my battle alone, told myself that it was O.K. to cry and be mad...yes it is...Not the way I planned...so it is O.K. to be where I was.

It was dawn when I went back in... Everyone was sleeping then I heard Justin ...Mom you O.K? Yes...just cannot sleep...that's O.K. MOM...Justin Loves you MORE! Tears again...I relied I Love you More and he said...But I loved you all my life...so I win... through the tears...laughter...yes Justin you win....

You know any disease that strikes a family is hard. It is not 'One' person that gets the disease but instead all the family and friends. Life IS different for everyone and each person deals with it differently. At the time, it really isn't something we think about, because our emotions are so raw...that we cannot think of others. It is 'ME'...so tell me why can we not think of ourselves in good times. When all is going well, why do we as Mothers feel we have to do everything? Why do we need that control? These are the thoughts that are running through my head for the next few days. Thinking to myself well this is a great time to get the great idea I have to take care of ME now...no time. LISTEN...NO TIME...heard that before??? Bet you said the same words...NO TIME...once I do this or that...then things will be O.K. Take it from me...life is never that easy. Take time for you NOW...when the chance is here, not tomorrow for the next day brings it's own stuff.

Stuff yeah, I was talking to Volunteer Mary about stuff...you know we need a room for all our stuff the stuff we cannot give away or throw away...maybe a room with a lock...place our stuff there, open it just to add more stuff but go on with our lives. Stuff is still there, but hey...no problems. BUT...there is a problem...the stuff will get too big for the room, and eventually we will open that door to place more stuff and the door will not close again. Then what??? Eh??? The stuff comes pouring out...now you deal with all the stuff instead of dealing with it one thing at a time. Hmmmm not a good idea me thinks' now...LOL This post is more like my feelings then and my feelings now. Combined together...making sense of this mess. Trying to at least.

The week home was good for Justin, I just had this uneasy feeling...deep inside...as though the axe was waiting to fall. Again don't care of what the test say...A Mother KNOWS!

My hubby and boys tried to ease my feelings telling me to remember what the tests show...look at Justin he is doing well. Running, playing, riding skating, doing all he wants to do. Yes...but...MOM no buts...please stop...each of the boys and hubby said the same thing. Then remember MOM...we are at the quality of Life stage of our decision...keep it as long as we can...we will deal with the rest when it comes...but for now...TODAY! Wow...I keep telling them that...but here I am into tomorrow, not being able to do anything about tomorrow so LISTEN...LOL I was frustrated with DR's not listening...and good OLD MOM is doing the same...LISTEN...deal with today! Although my fears were still there...I tried just to deal with today...hard to do...but I was at least trying.

Next visit was much the same, chemo did have rooms wanted to do more tests I think to ease my mind...so 2 weeks in T.O. again. Met more people...Makes you realize how this cancer enters so many lives. Met a wonderful woman from Thunder Bay. Her Mom was with her, because...her 2 daughters were diagnosed at the same time. Same day, and within 2 hours of each other. One had thyroid cancer and the other Leukemia. She was existing...Her Mom was with the older daughter that was too old for Sick Kids so was in Princess Margaret's and she was with the younger at Sick Kids...both went for their surgeries at the same time for ports, and MOM felt very much so pulled. So my energies went to trying to help her cope. I thought things were bad for me...then you see someone else!!!

That is it for today. I do feel better, didn't want to write today, but letting go...letting go those feelings that were so carefully put away with my stuff. Thanks...

Here it is April already. Justin is anxious to go home this time, because for once in this past year, we are going to be home for one of the boys' birthday. Justin had bought a few little things and made pictures to give to his 2nd brother. I had an inner sense...regardless what everyone said, saw, and felt...I knew something was up. Had to keep it to myself though, as I didn't want to dampen the spirits. But oh...so hard...MASK on tighter than ever in fact hard to breath at times.

Home we went, Primary Dr. is going to fax all the test results for me to read. He is very confident that all will be 'good' as it has been showing. Smile on my face...but heart thumping harder than ever. I waited.

Home was good...got there and things were clean...Ekkkkk. It felt so good. Anticipating the cleaning ahead. But no...my friend and a few of the boys and their friends cleaned up again. It was so nice this time. Ahhh...relax...things are O.K. Test results came back...and like the Dr. thought all was good. I kept reading and reading...trying to find something, because my heart was stills a thumping. BUT...in writing, all is well.

One more day till number two son's birthday and Justin was so excited making sure we had balloons and the works...don't tell k mom...it'll be a surprise. Next words...S, I'm making a surprise for you with balloons...you will never know till it is your birthday. Laugh...yes that is what helps us through...Justin and his comments that make us laugh.

It's the 19th, tomorrow is S's birthday and all is well. Justin was so excited for tomorrow he had trouble sleeping. He advised me that he would be waking early to get the house ready for the party.

Morning came as it usually does and I did some things for the birthday. Also got things packed as 3 more days and we were back in Toronto. It was 9:15 a.m. Justin called out...MOM???? I went to see him...he added..."Relax MOM...just sit here!" I did looked at him and asked what was wrong. He put his hands up in front of his face at arms length and repeated..."RELAX MOM JUST RELAX!" I looked at him said hey we got to get ready for the party..."NOT SURE...My Cancer is back!" My heart fell. What are you talking about??? He rolled over and a lump bigger than an over sized grapefruit was on his left buttock towards his hip. Can you walk...."NO...that is why I know that it is back. RELAX MOM!"

I ran to the phone called Sick Kids for our Primary Dr. to call me back...like yesterday. The Receptionist starts to ask questions, I was so upset I said..."Hey it is your job to answer phones not to ask personnel medical questions, tell Dr M to call me back NOW!" I hung up the phone. Waited not even 3 minutes...felt like hours. I looked at the time and it is 9:30. Picked up the phone hello??? Mrs.V, Dr.M what is up!!! Well...we got problems...big problems...so I guess we get to try something else.

Just like I wanted to do last month. Hey...what is happening??? I explained...he asked if we could get to Toronto right away...said yes called the airline and booked the 10:00 flight. Be there by noon. O.K. I am leaving for Boston at 12:30. Meet me in emergency. Hung up the phone...tearing streaming, grabbing things...almost like the first time. Grabbing but not knowing what to take. Had already packed some, so at least when my head was on straight I got some things I'm sure. Dressed Justin got ready asked one of the boys to drive us to the Hospital. Called Hubby at work...no answer left message that I had to leave with Justin call tonight. On our way out the door number 2 son comes up the stairs...Happy Birthday I say...he looks at me...where you going? To Toronto! You were right MOM...GOD You were right! Tears no words just tears. All I could think was he had a 1% chance...now a re-occurrence what does his chances mean now?

At the airport got our tickets...tears flowing down my face...I cannot even stop them. Trying not to look at people but having to get the ticket and get through the gates. GOD...this is hard...I'm going through it again. Heart racing...heart pumping like it is going to explode, eyes blurred through the tears, and Justin...sitting in his wheelchair smiling talking to everyone who looked in our direction. NOW WHAT...that phrase kept ringing in my mind. The phrase that so many times came through my head when I sat alone, walked in the back woods or just lied in bed.

NOW WHAT!

Got to Toronto went to get a taxi and realized I had NO money. Didn't think...had no time to go to the bank. OH NO...Through the tears I thought for a minute. Do I tell a taxi driver I have NO money and hope he takes us to the hospital? It costs a flat rate of \$40.00 Now...think... he will just look smile and take the next paying customer. So what do I do? Justin again just being his usual self.

I decided...to take the taxi once I got to the hospital then tell him I had NO money. So that is what I did. Never pay until you get there so...what else can I do. Be honest and I probably would still be there, so just take the DARN Taxi and what happens after... OH WELL...

Got to the hospital now it is 12:45. I missed our Primary. Now I have to deal with other Dr's. Never rains...always pours... Got to the hospital, got Justin into his

wheelchair and looked at the driver and said...I don't have money and no time to talk...call the Police if you want I'll be in Emerg and just left. He Said Nothing...Just watched us go into the hospital. I didn't even think to take the poor mans number of the cab so when I got money I could call him and give him the money. Least of my worries...just went to Emerg.

Now, the waiting. Cancer children cannot wait right in Emerg with all the other children who are sick, so we have to go to another room and wait. And yes...Wait we did. Told them to call to see if Dr.M was still here...don't think they ever did. Because I found out later that Dr. M waited till 1:20 for us to arrive. We had been in Emerg, but they did not call him.

It was about 2:45 when we saw the first Dr. He said they would access his port in Emerg. I asked if they do this regularly...he said he thought the nurses did. Waited again...3:25 Nurse comes in to access...I watched as she prepared the stuff and needle for the access. See accessing the port requires a 1 1/2 inch needle to be pushed through the skin into the port. It is not the pleasant and the child needs to apply Emla Cream to freeze the area. Justin having had this done so many times...really knew the procedure well. He also watched and told the Nurse..."hey you gots to put the needle here, where is the 3 cleaning stuff?" We use 2 here in Emerg.. Oh no...I use 3. I just sat back...Justin was doing a great job making sure all will be well. The Nurse in Emerg was NOT to impressed as Justin said..."You Gots to do it right!" I made the comment that maybe we could just wait and have the access done on the floor when we get there. Just a look...you know those looks? Well time to access...Justin watching and saying "hey...clean here...no way that is the wrong size needle." I didn't even catch that. I looked and said Yes...that is a 2" needle. She added that is what they use...I said NO, but Justin just repeated NO WAY! I should add that there are different sizes that are used for each port. Justin used a 1 1/2. She left again...came back with the right size...then Justin said..."you gots to change those gloves...you can't leave the room and come back with the same ones" I actually felt sorry at this time for the nurse. This is not common in Emerg so why do it now...knowing that we will be going upstairs and they do this all the time there. By the time everything was done, and by the way the access had to be re-done when we got upstairs...forget the reason right now...but told everyone on the floor that will be the last time that Emerg does an access on Justin. The nurses couldn't figure out why...they just didn't wait.

On the floor...waited in the room. In came the head Dr. on the floor that day Dr. G hello I said...how are you he asked...not good. We explained what had happened, he examined the lump and said he would be back. In he came alright with 8 Dr's the head Nurse on the floor (crabby) and they all came in to tell me that they have decided to do another biopsy, then if it is the cancer that has retuned then with Justin's diagnosis we would go Palliative Care. I said No Biopsy...has to be cancer. Only surgery I would let happen right now is to remove the tumour...what you do with it after is up to you...you can bounce it off of Toronto General for all I care. We need the tumour out! No Palliative Care...flew out of my mouth. They all looked.

Now...the stampede of reasons why... this was the way to go. Words flying everywhere...just words...because I really didn't take one of the words in.

My head was swirling...I came here for help and now they say it is done...NO WAY. We can't even say they talked for about 15 minutes, because when someone talks, someone has to listen...and I was NOT listening...Surgeons, Ortho, Pain Management (they wanted to start Morphine NOW) Chronic Pain Management, Radiation Therapy, Oncology Dr and resident's all telling me... It is over. I could feel myself falling to the wayside...then piped up and said...you have me all so upset that I have to go for a smoke. I will be right back. I just got up and left. Got outside heading to my Pillar and guess who is pacing...and I mean pacing...MY Cigarette man...Hey Lady...Don't let those B***** do anything you don't want them too. I just looked butt hanging from my mouth...I looked at him and said you are right. Headed back into the hospital, thought oh wait need to give him cigarettes turned around gave him 2, butt still hanging from my mouth headed in through the doors, some one said...lady you can't smoke here...oh yes opened the door through my cigarette out and headed back to the floor.

Got into the door of the room looked at everyone there...not knowing what I was going to say. Saw that look on everyone's face...she is going to comply. Voice shaking I asked..."Am I part of this team here?" All in unison said YES. I continued..."when this first happened and if you told me to run naked through the streets of Toronto and hit my son on the head with a hammer each morning because this would help...I would have done it. I know now, some of my brains back...and as part of this team."...and Dr.G piped in "Mrs.V you have the most important part." I looked at him said "Thank you...because we are going to be changing roles...I am now the team leader...you are all fired... none of you are my Dr's any. So BYE!"

Faces dropped...mouths open...Head Nurse said that is not nice...I looked at her...and said... "and do I look like I want to be nice? Get OUT...everyone. This meeting is over." Dr's slowly started to get up from their chairs; Dr.G. said he thought I would be calling him soon. I said No I won't, except I want Justin's Port Needle out NOW too. I will wait this out during this Easter Weekend until MY Dr. comes back. That may be too late...OH WELL THEN...my problem not yours! Asked again for the Port Needle to come out and added "If you do not take it out, I will and where it lands after I take it out is NOT my fault" Our regular Nurse was in the room as well and Dr. G said take it out. Head Nurse made some comment, I asked her to repeat it...then said...oh forget it...Just get the F**** out of this room.

Now faces really dropped because I swear only when I am really mad! This is the first time this floor has heard me. Just at this time...Justin pipes in..."Now you guys got my mom really really mad...you better all get out of here!" I started to laugh...through all this, Justin makes me laugh. I took on the whole floor and Justin says go and everyone goes LOL

Our regular Nurse stayed with us, she asked if I was O.K. I said no...Could you stay with Justin only after the needle is out so I can go for a cigarette? This Nurse I liked and trusted. She would NOT do anything I said NO too. She said sure...took the needle out again for the 3rd time today, gave me a hug and said take you time...I'll take my break now so I'll be here for 1/2 hour. She also added...GOOD FOR YOU MRS.V. Do what you feel is best!

Went outside...searching for my man...nowhere to be had...Sitting I started to wonder how did he even know we were back? We weren't supposed to be here for 3

more days. After the Easter weekend. Then S came by...asked what we were doing here? Told her and cried...she sat next to me on the pillar and we both smoked 2 more cigarettes. She asked if we were going to the House, said I didn't even call. No staying with Justin, in the Hospital. Told her talk to her later.

Went back upstairs...head Nurse followed me into Justin's room. Mrs.V since you are not going to follow Dr's orders then you and Justin have to give up the bed. I looked at her...said think so...well call the cops, because until YOU get me into the House this time...we are staying right here. So bye, and do not come into this room! She just looked said I've never seen you like this...well leave and you do not have to see me any further.

Shortly after another Dr. came into the room. I just looked up. She said she was looking at Justin's past tests and that they showed the tumour was growing so this should not be a surprise to me. I told her...NO the results were negative and I have all the written reports as well. She then got defensive and said...I looked just a few minutes ago and saw...so I know what I am talking about. I went to get my reports and said...sorry you are wrong...look. She didn't even want to see what I had...told her she must be looking at someone else's and she took a fit. Telling me the Dr's here are very good they do what is right for the children. It is the parents they always have to fight with. I broke in saying well...when you make a mistake with chart information, thank god some parents fight back. "You listen here..." That is all I heard... "You listen here...I'm fighting for my son's life here. I'm not ready to give up and either is Justin, so from now on I take the leader role" So BYE... She said something else and I added don't you have other people to bother. She was livid. Again our poor regular Nurse was here again and she just backs up to the wall. Looks at me again...and says...good for you...expect more to come in to convince you otherwise.

No way...I'm taking Justin for a walk.

Put Justin into his wheel chair and walked and walked and walked. Every once in a while Justin would say...Mom we going back yet...NO not yet. He sat in his Chair...I walked and walked. I found out later that I had gone really far. Ended up at the 'Hairy Krishna' place that is about 1/2 hour drive to the hospital. Really thought, when I realized what the building was, to maybe go and hide in there with Justin until our Primary Dr. came back from his holidays.

By the time we got back it was probably 11at night. Justin in his wheel chair, hospital garbs and blankets to keep him warm. Me...Looking like I went through World War III. Knowing that there is new staffs now for the night shift...I just wanted to be left alone!

Hugs
Butterflymom

Got through Friday night, with a call from our Primary Dr. He called from Boston. Asked what is going on? Told him the short version very short version and added waiting for you. Asked what he thought a MRI would do, and he replied that it

would determine if the edges are ragged and it is indeed cancer. It is a quick check, easier than biopsy. A quick reply came from me...well that is all I wanted and NO they wanted to do biopsy to determine if it was indeed Justin's cancer coming back. SO...I said NO they pushed and I fired. So Dr.M I am waiting for you. They are all ready to give up. Told you our plans...Quality of Life...Thin line between Treatment and Research, Justin will tell us when it is time to quit (and he says fight and no-one is listening to him) and Quality of Death whatever that is. Sticking to my guns...and No-one can change it. I caught him off guard when I asked the MRI question, I guess he thought the Dr.'s wanted to do it. So got my point across again...I'm in charge now. Then added...oh by the way...we will NEVER be on another protocol. Have our problem now...so we can change treatment to suit Justin NOT just treat the type of cancer he has. Besides his protocol SUCKS!

Dr. M asked if I was going to be O.K. told him yes...just tell those other ones to leave me alone. He added that he would be arriving on the Monday evening and would come to the hospital to see me. I said O.K. and we hung up. Then I cried again.

Thank GOD I have a Dr. that listens. Heaven knows where we would be if we didn't. He actually gave me his parents phone number if I needed to talk to him.

Stayed away from everyone on the floor. Justin and I were outside most of the time.

Very little ground and sand in the city, but we found a tree with a circle cut out of the cement. We would go there and Justin would feed the ants. Needed ground, dirt, and sand...NOT cement.

My Friend S knew how upset I was so we spent a lot of time together. Kimmy was excited because on Easter morning she was going to place Easter Eggs all over the playroom on her floor for Justin to find. She was planning our Easter.

Easter came and Justin found eggs in his bed in the hospital, slippers and then we went down to Kimmy. She was bubbling with excitement. We even decided that we would have dinner all together. Bring the food to Kim's room and all eat together.

Hey what is Easter for other than to be with FAMILY! Our new extended family...there when we needed them. Total strangers one day...and part of our beating heart the next.

Monday finely came. Dr.M came in about 6:30 straight from the plane like he said.

He came in and closed our room door and I cried...I just broke down and cried...blubbing and spitting everything I could in a single breath. I felt like I could let go, because I TRUSTED THIS MAN! He just sat and listened. Then I added about the second Dr. coming in and telling me that Justin's tumours have been growing for months. He looked at me. Asked WHO? Told him and added I never want her part of our team again. If she would not even look at my test results, which would be the same one's from the lab, then she really has a problem. He

agreed and also added let me handle her. Forget her O.K? Then got into the Morphine deal. Why are they so fast at starting Morphine? We both know that Justin's type of pain is really NOT controlled by it. WHY when a test result comes back or a tumour shows it's face is the next step Morphine? ASK the child if he is in pain...don't assume. Discussed this for a while and again told our Primary one day we will have to go there, BUT NOT NOW!

He was great, talked for about 1 hour non-stop then he checked Justin asked him if he can walk he said NO but it is coming. Asked him what he meant by that...he said

Mom knows...probably by tomorrow that is just how it goes. He looked at me and I said Justin and I do exercises each day and he rolls his hips trying to get the tumour to move over a bit. Once he can get it over enough then he can walk again and it doesn't hurt. He just looked and said that is strange. Yes...but watch if Justin says tomorrow he means tomorrow. Dr. reassured me we were working together and that he would have to think more on our next move. Tomorrow morning I will schedule the MRI and we will go from there.

Early the next morning we were off to MRI, and as suspected YES Justin's cancer had returned and with a vengeance. We knew this on Friday but now had to wait till

Tuesday because people would NOT listen again. Primary came in later that afternoon to talk about our plans. O.K. we are going to do Radiation. Yes the other Dr.'s were talking about that too called over at Princess Margaret's and wanted to start on Sat. But I said NO. Just to let you know it is all or nothing...Full radiation NOT Palliative Care. AND...We have chemo as well. Wow...have to think about that...it may just be too much, for Justin to take. Let's get the Radiation set up. Radiation is not done at Sick Kids so we have to go to the hospital behind us. So over we went...have pictures done, they were getting things ready for his actual radiation. He got a Lion to hold while he would be having radiation. One of the things this time is that I could not be with him. Told him that since his birthday is coming and that he would be getting older that he would go in for the radiation on his own. Mom would talk to him through the window and a loudspeaker. We tried it a few times without the radiation so that Justin would know what was happening and that he was on his own for this treatment. It would not take long but he had to lie perfectly still and NO I would not let them sedated. Said just explain try it and practice a bit more and all will be fine. Did all that then we were going to be talking to our new Radiation Dr. In we went, and he started to talk Palliative Care...NO we are going full swing here. No I have a sheet from Friday evening and it says...forget it ...it is OFF. I left took Justin and left. Didn't even get into our room and Dr.M our Primary was waiting...Mrs.V mistake...no we are going full. I said well I really do not have the energy to fight with Dr's anymore just the energy for my son...so when things aren't the way they are suppose to be then BYE! We both laughed and he said no he had the wrong sheet. Will you go back he his waiting for both of you. Yes we will. Back we went he was apologetic and we continued on what will happen for how long and when it all starts. Stuff to look for after treatment.

Tomorrow we start Radiation and for 3 months. I am here for 3 months. NO breaks no going home! Can't even think right now. Just have to do. 3 MONTHS! In the back of my mind I knew that, but...reality again...3 MONTHS! If, all goes well. Got back to Sick Kids, and Primary had left a message and said he would be back in the evening to discuss more. As we got to the floor the Head Nurse said we would have to do this as out patients and I added well then get me into the Ronald McDonald House and we will leave. Until then we are staying right here. She looked said you call...I said NO YOU! As we headed back to our room.

Justin was moving around in his wheelchair like he had to go to the bathroom. I asked him, he said O.K. put him on the toilet and went to sit on the chair. Next thing I knew Justin was walking out of the bathroom...Did it MOM...I looked up and YES you did it again...not #2 but was walking again. I knew that some of the Dr's

and Head Nurse that told me... all was done, and NO that Justin couldn't move the tumour around like we had explained were still on the floor, so I sent Justin out to ask a question. Well again the eyes said it all. I stood in the doorway, tears of course but so proud...and actually happy to be able to prove a point as well. LISTEN...Now the questions again...does it hurt? Let's see your tumour, when did you start walking again? Questions questions, I stood back watched my son repeat...I Just KNOW over and over again. 5 sh** days and one good. Not bad... But...This Part wipes the bad days all away.

Justin came back and wanted to go see Kim...so down we went, walking of course. Everyone we met was saying "good for you Justin" ...and he kept on walking to where we were going answering, "I know!" I just followed.

Primary came in and we talked again about chemo added as well. Asked whether we could think about removing the tumour but he had brought the actual MRI because he knew I would go there. He showed me how the tumour had wrapped itself right around the hip so to remove it we would have to take all the hip and part of the pelvic area on that side. Still with the fact that it had spread so it in all likely hood would return somewhere near the area again. This surgery would put Justin out of commission for about 1 year, and then he added for him probably 6 months...then added where is he? I said Playroom Camp Ooch is here, so he is having fun. We continued our talk, he said he was working on some kind of chemo treatment as well, just had to figure out what he can take physically to keep what he has now. Oh that is right he didn't know Justin was walking. Finished our talk then I said you better wave to him or something before you leave. Oh I will...I would never hear the end of it if I didn't. We laughed.

To the playroom we went, I stood back again, he looked in for the wheelchair and saw Justin jumping over some boxes. He looks at me...says what happened here? I laughed and said that is Justin. Justin saw him yelled hey Dr.M come and play. So in he went. He got on his hands and knees, and yes...I saw the tears building up in his eyes. Justin hugs his neck tells him he is having lots of fun and takes off again to jump over more boxes. Dr.M stood up, walked back to me standing in the hall looking through the window at them playing. He just looked at me, not blinking, and I said...SEE...Dr's Have to LISTEN!!! As the other Dr's that had given up hope for Justin stood by. He shook his head, asked what time is radiation tomorrow I said 10, he said see you after that before lunch. Said O.K. and decided it was time for a smoke again.

When I got back from my cigarette the head Nurse was waiting for me. She said we have a room at the House either tonight or tomorrow. I said we would go tonight. Went to the room packed all the stuff up and got Justin his supper and headed to the House. House Manager was there waiting for us, gave us our key and I added that we will be here for at least 3 months. Justin starts Radiation tomorrow. The rest not sure yet, but will let you know. He just looked at me asked if I was O.K. I said NO and started to cry. Our House Manager is fantastic. He just knows what to do and when. He just looked at me, said we are here when ever you need us, and asked if I wanted to go for coffee away from the House. I said I had to unpack, he said...it'll wait for you, and he is right. But...Justin...well Alex the WoodMan is coming in now or he is probably there already. Went to see yes he was and his

helper was there, so Justin was happy to have his 'Girlfriend to himself' So off for coffee I went. Just a block away...but at least it was away! Thanks J really needed that away. "You is a smart Man LOL"

Hugs
Butterflymom

Time to call home and let everyone know what is happening. Tears and fear took completely over at this time, but realizing there is really nothing we can do. I was in Toronto for the next 3 months and the rest of the family are home. That was our life right now anyway.

Justin's birthday was coming up soon and he wanted so badly to be home. We know that, that will not happen, so preparing for a party away. Justin just wanted to be OUT of the hospital...but we didn't know the schedule right now, so could promise anything.

Next day went to see the Dr. after our first Radiation. Things went well and Justin was a pro. He just lied there holding his Lion and a few minutes later it was all done. This is the first hospital that said 10 and meant 10. They were fantastic. Took all the time in the world with Justin and made the experience which he had to do himself a very positive one. I stood outside the window talking to Justin and watching his every 'NON Move'. LOL can't move!

Back to the house we went, time to get things settled in. I just had enough for about a week and this time everything is out patients except for chemo which this afternoon we go and talk about, so didn't have enough clothes even for Justin. Went to the corner bargain shop and pick up some joggers and shirts. It would be nice to change once in awhile. I also got the same thing. Lots of clothes at home, but then we are NOT there.

Got over to the Hospital early went to see Kim and she was doing good. We planned a walk after our meeting going through China town looking at all the things outside.

Finally time came for our meeting and yes...we had to wait. Waited till 4:30 and finally had our meeting.

Yes we are going to try the chemo as well. It may too much for Justin but we will try. So the schedule is now set. Radiation, Monday to Friday, Chemo every Wednesday by injection and every second weekend admission to hospital for 3 days of continuous chemo. Well that should take up some of our days.

That evening Justin had an accident. He was so upset...Called to me and said "LOOK...Poo in my pants, how did this happen?" Hmmm...Later again and again. Hmmm...Next morning made arrangements to see our Radiation Dr. Think that you have to move the radiation a bit...explained what was happening and he said lets wait another day. Same thing all day and night long. Gosh...convinced Justin to wear a pull up...not too happy with the fact, but we blamed it on the radiation. The 3rd day of Radiation found them changing the site slightly which helped the problem almost immediately. That fixed... on we went with treatment. Wednesday saw us there early to access Port get chemo then take the needle out again. Made

arrangements to go for our weekly blood tests so that added another day of running for us. The first weekend was going to be our 1st weekend for chemo, so got things ready for that. AND...YES...Justin's birthday will be spent in the hospital. Oh well getting use to the treatment and disease dictating what we do where why and when, so will make the best of it.

Everyone on the floor knew it was Justin's birthday so a cake was brought in, had a party right on the floor and he was happy for the whole day. Justin walked around with his I.V. pole like his best buddy, and smiled at everyone...because he is 5.

Kimmy was also waiting for Justin's party but it was bitter sweet. Our last party together, as Kim and Mom were finally going home. After 1 year and 2 months they are going home. 2 days...and they will be home. So tears of joy sadness and HOPE! All wrapped together. I was happy that she is going, but knowing that we may never see each other again. Helped S pack things and box more stuff up to mail ahead. She was going to be able to get on the plane with Kim. Kim was being transferred to her hospital back out East.

S and I really tried not to make eye contact with each other. We talked with our heads down. Just wanting NOT to burst into tears. We had become so close...helping each other through difficult time, just being there whenever. Oh life can be so cruel...yet so good, as Kim was going home!

Justin had received plastic golf clubs for his birthday so between the hockey stick, golf clubs and the best gift from his #3 brother a Toronto M'Leaf shirt...Justin was very happy. We found a hall on the floor that was not used very much and this became his hockey rink. I would sit on the window ledge and watch...he would play, then score I would cheer, every once in awhile people would walk by and Justin would say watch it is slippery because it is my arena. They would do the slippery thingy and then we would start all over again. At the end of the hall was a little bend...this was his change room. LOL he had everything all planned out. LOL when I think of it now...we spent many hours at that arena. Occasional he would bring someone to play there with him, but only if he had a hockey stick. Ended up many of the kids on the floor had sticks. LOL I think it was one of the volunteers that heard Justin one day saying too bad...you could come and play hockey with me in my arena...then the next thing we knew...plastic hockey sticks on the floor.

Hey Life goes on and we do what ever it takes to make it the best life we can. Even kids in wheelchairs would come, to Justin's arena. Had meeting with Dr's there too...LOL A few times they even got involved into the games...actually it was NICE!

Well I'm avoiding Monday Morning...Kim and S are leaving. I asked Justin if he want to say goodbye he said NO...Because he was going to see Kimmy again. I just let that one pass, too emotional to really deal with that. Went down stairs to see them off, tears could not contain themselves but we promised to keep in touch. Kim looked frail but good and S was excited but again tossed. Emotions were really high...and it was as though I just wanted them to leave now. GO...can't take this. Taxi came in they got to go to the airport and final HUGS and Goodbyes. Then I went to my Pillar. Again...just when I needed him...my Man...There he stood, waiting in silence for me to get there. It was morning so not the time we usually met.

This time when I saw him...I cried...you always KNOW when I need you. I said looking at him. He just smiled. Tears running down my face, I said..."YOU are my

Guardian Angel here on EARTH!" Again he smiled but this time it covered his face.
We sat next to each other...not talking but smoking ciggy butts and just existing.
Think I will stop here...Need to be with my Guardian Angel for a while.

Hugs

Oh so alone...with hundreds of people all over. Desperately putting my MASK on my slippery tear streaming face, trying to go on. Stopping my mind from going to far into the future...just wanting to get through today.

Found Justin sitting in his bed...talking to his 'Hockey Buddy'. Are you here for a check up? No was the answer my cancer is back...NO... My...Not another one. Just at that time Hockey Buddy's Dad came in...Yes...we are just waiting for a bed. Test came back and cancer is back. I just looked at him...said HOPE...never let go of the HOPE...Hugged him and we both just sat in silence and watched the two boys interact, catching glimpses of each other, and once again wondering...NOW WHAT?

Now what... We fight some more. That is all we can do. With each step forward it seems we get 2 feet back...but you know what...time to just be once again. Hockey Buddy's Mom was coming soon so when she arrived I went to talk to her. Tears streaming down her face now...talked about just doing what we can...and not letting the fear and confusion take over. Between the hugs and tears we decided to have supper together once the boys had theirs and we would put them in the same room for supper. Justin was going to be done his Chemo and flushes late that night so I packed things up to go back to the HOUSE. Had supper with Mom and we talked. Actually she was telling me about their religion. They were East Indian or something like that. She told me of alternative stuff they were doing and how when "Hockey Buddy" was out of the Hospital they were traveling to the States to find treatment as well. I told her I was at the HOUSE and that Justin's cancer had also returned so we were here for 3 months for treatment. Explained what we were doing and she said maybe tomorrow you could talk to Dad as he has a meeting in the afternoon with the Dr's to see what the next step for them was as well. Agreed to come back giving them my number in our room.

Justin finished everything about 11:30 p.m. We had the option of staying but with all that had gone on this day...I wanted to get back to the HOUSE. Just to be still in our room while Justin slept. So back we went. Justin was very tired so it didn't take much for him to be in dreamland. I just sat next to the window...now letting my mind wonder...again back to "NOW WHAT?" If only the answers would come...answers that to this day remain a mystery. Didn't sleep much that night, so when the morning came...I had my regular headache. Take another Tylenol and just get through.

Had our Radiation appointment and Justin talked Hockey stuff with everyone. He always was in a good mood regardless what was going on. He talked to everyone that looked in his direction, in fact...we were heading back from the hospital to the other hospital when he saw a man sleeping on the streets..."HEY...You having a snoozy?" Gosh...Justin don't talk to him I replied very quickly, as I rushed past.

Justin just looked back at me said nothing but had the look Oh O.K. Got to the hospital and talked with Dad. I explained all that we were doing, just as a guide. He was very thankful that I shared what we were doing. He added anything right now...we need to find something and soon. Tears were welling in his eyes and he was beginning to feel very uncomfortable so we ended the conversation at that point. Justin and I headed back to the House only after he went to GYM.

Next few days were much the same...talked to S on the phone she would call to let us know how Kimmy was doing. She was really glad to be home, but missed us all. Asked me if I met the other Kim form down there I said no, is she at the HOUSE? Yes but she is doing not too well so the parents are probably at the hospital. I told her I would be keeping an eye out for them. That night that family came in...Looking very tired and exhausted. Came in like we all did at the beginning. Lost confused and scared out of our wits. I introduced myself said S had told me you were here and we sat on the balcony for a talk. Mom was shaking...I asked if she was cold she said NO...Just my nerves. Dad was trying desperately to keep a stiff upper lip but it was shaking as bad as MOM. Then came another boy and grandma...they too had all come up to be with each other. I asked how Kim was doing...and MOM broke down. That was it for everyone...tears flying...I was crying because they were crying other families came out...they too started crying...we were a great group...sitting on the balcony crying.

Then came Justin...Hey...you guys are in my arena...do you want to see me play Hockey? We all started to laugh...Yes this was Justin's arena and he played hockey here every chance he got. He had his make believe dressing room and believe me you went through all the gestures like you were dressing or taking a shower...even washed your arm pits or he told you, you would stink. Kim's Dad said sure and so did Kim's brother. The rest of us laughed as they gently passed Justin the puck and he let it rip like no ones business. NAH hockey is tough...NO gentle shots here. Soon another father joined in used cardboard as his stick, one had a broom and another his foot. Justin told everyone that Alex the WoodMan was coming tomorrow so he was going to ask him to make mini sticks for the next week so everyone can have a stick. Everyone thought that it was a great idea...not knowing Justin to well.

The next day...Justin waited for Alex the WoodMan...Hey Alex can you make some mini sticks...the Dad's want to play hockey with me. O.K. Justin next week. He ran to everyone as they came in for the rest of the night and anyone he missed the night before he got the next day. Next week we can make our hockey sticks. They were thinking he was kidding...but the following week the playroom was packed...thank goodness Alex made lots of sticks because you had everyone and their parents there making hockey sticks to play on the balcony.

Now you all have to realize the balcony is NOT too big, and this is the only place you can smoke. So we re-arranged seating so 1/2 was for smokers and 1/2 was for hockey games. The amusing thing was watching all these people pretend to shower, change, intermissions pep talks and the works...I think this was a great therapy Session for everyone.

The lady I met who had 2 children with cancer came in with her MOM. She didn't smoke but her Mom did so out came Mom for a smoke. Justin was out there as usual playing hockey...he looks at the Mom and says what is your name? The lady

looked and said my grandchildren call me Gramma Vivian...Oh was Justin's response nothing more. We had a smoke together Justin took off to the playroom so I just sat longer outside. Tried talking to Gramma Vivian but little was being said. In came some more families...I introduced by saying this is so and so and this is Gramma Vivian...the Lady responded...I'm not Gramma Vivian, just as Justin came back in..."Oh yes you are...you told me that!" We all just laughed and from that day on Gramma Vivian WAS. Gramma Vivian was always cleaning up out on the balcony...when someone would come out she would complain that no one else was cleaning their messes outside. Justin popped our again like his usual self and said while Gramma Vivian was cleaning..."Hey Gramma Vivian Thanks for cleaning my arena." Well the look in her eyes...and that was it for her complaints...she wasn't cleaning after us anymore...she was busy keeping Justin's arena clean for all the games. LOL Poor Gramma Vivian. We became very close after that and spent many hours just talking.

Well time for Chemo in hospital again so we got ready to go to the Hospital. In we went, treatment went well and Monday morning Justin said early in the morning..."Kimmy Died!" I said What? He repeated...Kimmy died!" I just looked at him asked him what he was talking about, then he went back to sleep. It was only 3:30 in the morning, but now I could not sleep so went out to the Pillar. Putting Justin's comment in the back of my mind, I just sat. Should be able to go home about 9. Yes home...as the Ronald McDonald House was home now for us. 9 got here and we headed back to the house. Got in called home to tell them we were back at the house, oldest son said 2nd son wanted to talk to me...I said later after 6 when it was cheaper he said NO mom NOW! He came on the phone and said Kimberly died this morning...her Mom has been trying to get you. I stood there dumb founded...Said... hang up... I have to go. Chocking back my tears and numbness, Justin looked at me as we went to our room and said..."See I told you Kimmy died!" I asked him what that meant...he answered I was not going to see Kimmy again for a long time...but he was!" Couldn't go there. I just put things in the room, had to wait until after 6 to call S and headed for the kitchen. Couldn't think...didn't want to be alone...but didn't want to talk. The House Manger saw me and asked if S had got a hold of me...I said NO but I know. Tears welling but House Manager knowing I had to just go. Got in the kitchen...saw other friends who came to me right away...yes I know...Please don't talk...can't go there. Judy was there...She is such a great Friend. Justin came in and said "hey Judy...got's some Tea for Me?" Judy would make Justin Tea in the morning and Coffee at night. Now...it had 1/8 tea or coffee and full of warm milk. This was there thing...and MOM had No say. Right now that is just what I wanted...to say nothing. After some time...more people coming in that also knew Kimmy, some knowing others not. We just sat. Doing what we had to but looking for the chair to sit. Finally it got very quiet in the kitchen and Justin said to Judy..."Did you know that Kimmy Died?" Yes she said everyone is very sad..."WHY" he piped in "She is happy now, and you know what Judy...Justin is going to die too!" Wow Judy's face dropped and answered Oh NO Justin...that would make Judy really really sad" He looked at her with her BIG ICE BLUE EYES and waiting for awhile said..."OH you would miss Justin right?" Yes she said...I said nothing...just listening to their conversation. "Yeh...my MOM would cry

and cry!" then he took off. I just looked at Judy and started to cry...She cried as well and asked why is he saying that? Told her what had happened early in the morning just as the kitchen phone rang...It was for me...Sheila...oh my GOD how are you...I am heartsick. 2 weeks to the day of going home. We talked for awhile, told her I wish I was there for her...Both cried and then Justin came back in...as if he knew it was Sheila he said in his loud voice..."Hey let me talk to Kimmy's MOM!" I tried to shoo him away...not knowing what he might say. But as loud as he is...Sheila heard him and wanted to talk as well. I kind of held my breath...worrying about what he would say. BUT...he quickly said..."Sheila don't be sad...Kimmy is happy now, and she loves you still!" Handed me the phone and took off. Hmmm told Sheila I was back...she was sobbing on the other end...and said those two always had such a close bond. Didn't think it was the time to tell her about Justin in the early morning, but she added that Kim had passed very peacefully at 3:25 this morning. My heart thumped...Justin woke up at that time and at 3:30 told me Kimmy had died. Oh boy...need to go again and have another cigarette. I guess my face changed, Judy made me a coffee so when Sheila and I hung up I could have one. Explained to Judy what had happened as the second Kim's mother and father came in. Asked if they heard...they said yes...but they did not tell Kim as they didn't want to upset her. She just got out of the hospital now and was doing well. I told them that Justin might tell her so maybe they better talk to her before she heard it from someone else. Decided NO they felt it was best NOT to say anything. Their chose, so I just said a quick prayer asking that Justin NOT say anything to the people who do not know!

That night was glad to get to our room. I needed to let go...Justin fell asleep and I sat next to the window again. Crying, wondering what next...wondering why we were doing all this, wondering if I was heading in the same direction. All this for what??? Still playing on my mind. Is it really worth all this pain and suffering for everyone? Just as I thought my head was going to explode I heard Justin in his sleep laughing and giggling...Just what I needed to change my thoughts...then he said..."Kimmy you look so good now...no more boobos and no tubes. You are running, can you run fast like me? I just sat...even the tears didn't come.

Next few days were spent much in a blur...doing what we have to Justin enjoying life. Wednesday came and it was Radiation first then Chemo push. So on the way for Chemo...elevator packed...Justin yells in his BIG Voice..."Mom not going to died right now K!" I answered right away...because Justin is not the child you can put off. O.K. Justin that is good. People on the elevator just looked at me...then Justin. A little boy bald, blue eyes and he is telling his Mother he is not going to die right now...I was glad to get off the elevator, but then we were on the 8th floor and everyone else would get off before us except for those who were going to the same floor. I got a lot of weird looks, but hey...what can I say!

Justin was eager to see Judy and told her the same thing. She told him he made her very happy and thought maybe an extra tea would be good right now. Justin was all full eyed and added I like Pop Corn too. Justin would never ask for anything...but his hints were pretty subtle...LOL

That is it for today...my shoulders are aching from reliving this time...a time that I just wanted to keep still but know that it will be the last time my shoulders ache for this reason. Thank You!

Sore shoulders or not...it is a snowy day here, and not going to do much outside today, so write I will.

The next week was much the same, but at the end of the week Radiation Dr. said he was thinking of doing some tests. Not expecting too much right now, but just to see.

MRI is what he is going to ask for. We had a visit with our Primary Dr. today so I told him about the possible MRI. Then comes...who is going to pay for what? You...I said...no, it has to be Princess Margaret as they are requesting the test. Oh let me get this fixed up...I'll be back in 1 hour. Left with Justin went back to Princess

Margaret and looked for the Dr. there. Finally found him...told him just to get things straight...you are going to order the test at Sick Kids and then this hospital will pay. OH...just a minute...NO minutes...You ask for it you pay...Just getting it straight so we can get it done now...not another month from now. Wow...hmmm O.K. settled then, I'll go and tell our Primary No problem...Oh O.K. Well that was easy don't give them time to think...just do it.

Back we went Justin was laughing all the way...saying "Gee Mom you didn't even let the man talk!" Better that way Justin sometimes...just got to do what we need to do NOW! Saw our Primary and yes set up the test. These 'boomboom tests now last about 2 hours for us, so like them in the morning as early as possible or latest in the day. That way Justin falls asleep in the test and all is well. Primary gave me the request form and I went to book so I could get the time that is best for us. Getting good at this now...just suggesting good times.

We were getting right into the swing of things at the HOUSE. Feeling very comfortable with everything. This weekend the boys and Dad were coming for a visit. Since we cannot go home...then they come to us when they can. Justin was very excited and was of course telling everyone our business. LOL Another excuse for him to talk I guess...not that he needed any excuse. LOL

It was Wednesday and it was a double day as we called it. Radiation in the morning and Chemo Push at night. Justin was at the front entrance of the HOUSE with his plastic golf clubs playing when one of the fundraising staff came in. Well hello there Justin...where are you off to so early. Radiation...Oh...do you like golf? Yep...Would you like to golf? Yep I do...no would you like to come to a golf tournament today? Yes I do...hey Mom come on we are going golfing. Wait wait...Dan told me about a golf tournament that was raising funds for the House and was wondering if Justin and I could go with him. Brings reality to the fundraiser. What time...7 sounds good. Meet you right here at 7. Justin was so excited...he was taking his plastic clubs to the golf course. On the way to the radiation, I was thinking oh gosh this might be too much for him, forgot for that split second that he was also getting Chemo too. Justin said NO problem Run Mom don't want to miss my Golf. Well I'm not running but O.K. we would try it and see what happens.

Got to Radiation about 9:30 so had a 1/2 hour wait. Justin saw his nurse there and said..."hey could you let me go now...I have to golf today!" Nurse said let me see what I can do...Next thing I knew...in we were and heading to the Sick Kids for Chemo before 10. Hmmm maybe I should let Justin do the bookings from now on.

Got to clinic and Justin ran to the lab...right in the door Connie the Pick Lady...could you do me now I have to go golfing...Geesh...Justin wait your turn...I tried to say when he sat his butt on the chair and handed her his finger...tell them to hurry up. I just stood back...this may be the fastest Wednesday we have ever spent.

Had to wait 1 hour for the lab tests to come back and say whether his blood was high enough for Chemo. It came in after Justin asking the Ward Clerk about 50 times if it was back, then he ran into the room for his Port Access. "K, you got's to do me...I gots to golf...can't wait here!" I was laughing just watching him run from room to room, and believe me getting exactly what he wanted...One Nurse said that there were lots of other kids ahead of him... he just turned to another and said..."Well you do me...I can't stay here today!" Believe it or not, and anyone who has a child with cancer and has to go for Chemo pushes knows, that your day is spent at the hospital waiting your turn. Well we were back at the house by NOON! Justin saw Dan and said lets go...He looked at me and said is he done? I said yes... he pushed himself through everything. Going to let him take over, they seem to listen to him. Dan was going around 1 and then was coming back for us, so if we wanted to go then we could.

Got to the golf course and Justin was just beaming. He wanted a cart, he wanted to golf with HIS clubs and Mom had to stay behind at the Club House and wait. Besides I had no clubs so him and Dan would go and golf. I helped the ladies who were putting on the tournament for the house set up for dinner and awards that night. Justin was gone having a great time. I sat with one of the organizers and we chatted once everything was done. I was introduced to a number of people, can't really remember names now, but they were all part of this fundraiser.

A few hours went by and Dan and Justin came back in, Dan looked exhausted and Justin was beaming and FULL of energy. Mom I golfed...I'm good, ask Dan and I can drive the cart too. I won...I think I won. Dan looked at me and said I think he has to go to the bathroom. He told me that but now he is busy running around checking out all the awards. Justin do you need to go to the bathroom? Yep...lets go fast...maybe we can drive around some more Dan just wait for me. Off we went came back and Dan was having a coffee and checking out what was to happen tonight. He asked if Justin could give out some of the awards tonight, I said sure...and Justin said yep I can!

Some of the golfers were coming in and Justin was running up to each of them as though they were his long lost buddies. Dan explained that Justin met every golfer...They have some extra game thingies they do...like closest to the hole and some other ones. I won MOM is all I heard. Not sure what he was talking about but knowing too that he was too excited to explain anything anyway.

We all had a great supper, then the awards...Justin got to give the awards out and he was so excited...It was time for the first place trophies and awards. The captain or what ever you call them in golf, got up with his team but before leaving the stage said he would like to say a few words if he may. Justin was standing there. The

trophies were almost as big as him so Dan was helping giving out these. The captain said he has never been in a golf tournament where he has had so much fun. He looked at Justin and said..."you bring life to the game I love."

Now came the story. This team had won over all but this man hit the ball for the closest game, and just as it was going in for a hole in one and yes obviously the winner, Justin jumped from Dan's arms and saved the ball. LOL Yes...Justin decided to be a goalie in the middle of the competition...The placed roared with laughter...I turned beat Red...and Justin SHONE...with the biggest smile. Looked over to me and said "Yeah Mom I saved it...he didn't score!" IyIyI! He saved the golf ball...can you picture it. The man then said...I have to give My trophy to the best ball saver in the world...and handed Justin the trophy...the place went wide. Justin beamed trying to raise the trophy over his head like the Stanley cup winners. Like I said it was nearly his size, so poor Dan was trying to help and Justin saying "NO let me do it!" Gets it up there and walks around the whole place with the trophy over his head. I had tears running down my eyes. Poor Dan was trying to follow so the trophy didn't fall on his head. Justin was nearly running by now with his prize and everyone was standing and clapping. Oh what a night. By the end of the night it was 1 in the morning by the time we had packed everything up. Justin received small gifts from people, and he had this thing about business cards, so asked everyone for their business card. Mom's purse was full of cards. He was hugging everyone, and by the end of the night the house made \$35,000.00. The different groups joined together to meet the 15,000.00 raised at the golf tournament and another group put in \$5,000.00 to give to Justin's HOUSE! All in all, a great night. Justin was asleep in the car before we even got out of the parking lot. Dan and I talked and laughed. It was a great night. Told Dan if there were anymore fundraising events Just let us know...I'm sure Justin would love to help out. He looked totally exhausted...you see he was not married and no children, so he got first handed the joys of kids. I think Dan was going to have a good sleep too. Dan carried Justin into our room, even though he woke up just wanted Dan to carry him. I think it was his way of getting the brother and Dad carries that he was use to. The bond between Dan and Justin was so strong from that time on. Justin would see Dan and yell HEY DAN THE MAN...and he would yell back Who let the Dogs out...and Justin would respond...Justin Justin, and they both would laugh. A bond that was needed...Justin needed that guy thing again, and Dan was the MAN to deliver. This was the beginning of our Fundraising for the House!

The next day came all too soon. We had our Radiation treatment and came back to the house. We decided we would just have a quiet day. Yeah right...Justin was full of himself and wanted to take his Trophy everywhere he went. We took it to Radiation, but they had seen him on T.V. I guess the T.V. crews were there so while he was golfing with his plastic clubs...they took his picture. So when we arrived at our appointment even the older people there for their treatment were calling out to him. Telling him he was a star. He JUST SHONE...Looked at me...and said "You always say that eh Mom?" Yes I do...

We didn't stay long in our room, Justin was just so excited, so we decided to take a walk to the water front. It is a fair trek but...just the peace and quiet would be nice. It was a beautiful day, and when we got there Justin was treasure hunting. So came home with tons of Driftwood. Not sure what we were going to do with it, but had tons of small pieces. When we were returning again we saw someone sleeping on the side walk...In the loudest voice Justin had he Yells..."Hey Mom...Don't talk to him and don't look at him!" Oh brother...Yes Justin O.K. Hmm guess I better be careful what I say to him...he'll come back with it again. LOL

We got back to the House and as we were arriving we saw "Dan the Man" Hey guys how are you today. Just great and Justin showed him his treasures. Real nice Justin but I have a favour...you were such a Star last night, do you want to say Thanks to all the people that golfed yesterday? Sure...My Mom can do that! Lol You Justin NOT ME! The thought just flew through my mind...now I know why we had the driftwood. We would do thank yous with it and if we could add a picture to it.

Hmmm, good thing we picked up the treasures this morning.

Together we made a thank you, and brought it upstairs for Dan to send. Mind you he was going to have to bring it. When we got there, there was a man there that had seen Justin on the T.V. Dan said was going to call you, this gentleman is from ??? I forget, but anyway he has tickets for you to go to the Blue Jay game. Yeppiii...Justin shouted, my brother and Dad are coming do they have tickets for them too...how many do you need? Hmmm 4... Me, my Mom, Wade and Dad. DONE...the tickets will be at the game go to booth whatever and pick them up. Justin was just buzzing...then turned and said..."K Mom you better make another Thank You!"

LOL He keeps me busy. The game was Saturday and family were coming late Friday night. This will be great.

Friday night was a special story night, and Justin was so excited for Story Teller "Pat" to get there. Pat's daughter works at the house and of course Justin claimed her as one of his girlfriends too so Pat and Justin had already met. Justin loved Stories, so he was watching the time. Still had the little hand, big hand mixed up so every once in awhile would say look the hands are touching the numbers we need.

Nope...the other way around. LOL

Finally Story time...Justin was right in front sitting so patiently for the story. It was her first published story and it will be coming out in the New Year. Justin sat so wrapped up with the story...Every once in a while he would say "PUSH HERE TO START!" One of the boys from the house started to act up, Justin turned to him and sternly said..."Hey you quiet we are watching the story." Watching he was...Pat had come all dressed up and with all the whooshes and glooshes...you were watching the story. Justin jumped up at the end and cried..."Just Push Here to Start!" This was part of the story, and everyone was given a Button with

Just Push Here To Start!" We still have that Button!

Dad and Wade came in just at the end. Actually arrived earlier but waited not to disturb the story. Justin was now excited to tell the story to them that we were going to the baseball game and to tell them about golf. So much..."Come on Wade we got to go see my trophy I won!"

Saturday came and since it was an afternoon game we left the House early. Had to figure out the subway system. Got there and headed to the booth that we were

instructed to go to. When we got there they looked up said you must be Justin. Yes it me, I'm going to baseball. Yes one moment please. We waited and another lady came to get us. Come on, you are going to meet some players...BIG SMILE and #5 son had just a big of a smile. Down we went, and out came Darryl Fletcher and Carlos DeGrata. Justin looked at them both, hmmm O.K. in uniform and looking like baseball players. Each of them gave Justin a ball from practice and signed it, Justin said "give my brother one...we have to share", so off they went to get another ball. LOL Then Carlos asked Justin if there was anything he wanted...Ummmm get me a home run K? Well I'll do my best, but cannot promise that. As they were leaving Carlos looked around and asked Justin where are you sitting???? Justin said the chairs LOL and then he laughed and said where are your tickets? I gave the tickets to him he left and came back with tickets right behind catchers mound. He told Justin to wave to him during warm ups.

We got our seats...and Justin waved and yelled like a fool. People around were looking and smiling. Justin was saying there is my friend...hey friend!!!! They looked and thought to themselves yeah right, he is my friend too. Game went on, Blue Jays were losing badly and Justin fell asleep. Just in the last inning Justin woke up and it was time for Carlos to bat. He looked at me and said watch this...Just as he said it...Carlos hit the ball out of the park. Justin went wild...Carlos from third base to home...waved and waved to Justin as he yelled at the top of his lungs..."My Friend did it...he did it!" Now people all around are watching, Carlos touched home plate and yelled up...for you my Friend! Wow...now the tears again...it was great! Justin was just full of it now, and ready for another game. Unfortunately the next batter went out and the game ended 6-1 for the other team. Home we went with his treasures in hand. Everyone had a great time, and Justin was ready for the next adventure.

Sunday came and family had to leave to go back home. We bid our goodbyes and went for a walk. We had written some letters to people letting them know what was happening, so went to mail them. It was across the street so decided we would walk after that. I always take the wheel chair when we go for walks, just in case. We mailed our stuff and started walking up the street when Justin says, loud as ever..."Hey Mom look...all you have to do is put your hand in the cars and peoples gives you money." Oh no...Right in the middle of a drug transaction...I laughed...what could I do...No Justin that is NOT a good idea...But MOM...Hey...don't talk... as we walked by all the people involved watching us. It really was funny. Just forgot it and went our way.

Got by some Mall and some man was painting portraits. He asked if he could paint Justin. I said sure but I have NO money to give you. It is O.K. I just want to paint his picture. Justin sat there, the guy painted and he asked Justin what colour shirt do you want? I want TorontoM'Leaf Shirt. So after about 1/2 hour the portrait was done and the man gave it to us. For you Justin. He said thanks and then said you going to be here tomorrow? The man answered yes, he said OH and that was it.

That night Justin and I made another Thank you. The House had printed some pictures of Justin golfing so we were going to use that for the Portrait mans thank you. Justin had asked because he wanted to do something now for him. Talking to House Manager and he said give me the portrait and I'll shrink it, print it out and

you use that. Next afternoon after our appointments we headed back to look for the Man. Yes the man was there and Justin gave him the Thank you...He had tears in his eyes...thank you so much...I will put it on my table so every day I will see you. Got back to the House to find out that Travel Lodge had adopted a room. There was going to be press, and media coverage tomorrow morning at 7 could we attend? Sure, so we headed back to the room to make another driftwood Thank You. Told Justin we would have to go to bed early because we had to get up early. There are 28 rooms at the Ronald McDonald House, and people pay \$20.00 to stay there. You have your own bathroom in your room, much like a hotel. Laundry facilities free of charge, they even supply the soap. Have a kitchen, playroom quiet room and games room. They even have a house cupboard in case families need food. All you would ever need. BUT...\$20.00 a night for the rooms do not cover it, so they depend on fundraising to keep the cost low for all the families they service. I assumed that the Charity just covered the cost but NO...They help but it is up to the different houses to raise the money needed to keep the house open. This is one way they get money into the house, the room adoptions.

Next morning came and there was a knock on our door, Justin ran to open it and there was Kris King...OH hello Justin said, not really knowing who he was. He looked at him and said Mom the man is here. Introductions were done; Justin was walking around Kris looking at him. You see Justin caught the Toronto Maple Leaf emblem on his shirt, so was looking to see just who this guy was. Kris had adopted a room at the House for years, and it was called the TreeHouse. It was decorated just like a tree house, and Justin loved that room. Finally Justin asked...you play hockey? Yes I do...for the TorontoM'Leafs? Yes I do...well that was it...Kris King was his BUDDY! He was here helping with the media and stuff for the adoption this morning. Justin was in his glory. He was with a TorontoM'Leaf. The adoption went well until they asked him on live air...even though we said Mom made the Thank You...Did you make this for me? NO...My MOM did! LOL Oh well...everyone laughed, and Justin followed Kris around.

That afternoon was another publicity thing at the House. The Mayor had a fundraiser going on with a full size moose. Moose on the Loose in the city. The House got a Moose and the kids were going to paint it under the direction of an artist from the city. After some time the Moose will go to auction and the monies go to the charities that painted the Moose. Justin was going with the other kids to start to paint this moose. We had a long day. Got back from Radiation and Chemo just in time for the beginning of the painting. Justin was sitting in his wheelchair under the Moose and painting. He was covered in paint, more than the Moose but hey...he was having fun. Again, live T.V. The Mayor was talking to the media about the project and painting with his other hand. All of a sudden Justin yells out " Hey You...colour between the lines, you are going to wreck our MOOSE!" Oh brother...the mayors face turned red, I turned purple and hid behind another mother, and the T.V. zoomed into his face. Like I said he was covered in yellow paint, he looked up and said "Well you gots to be careful this is our MOOSE!" Oh what a day. They showed this clip about 5 times that day...with the caption..."Hey You...stay between the lines!"

And this is where I stop today...right between the lines where I am suppose to be!

Hugs Butterflymom

Make the Best of today...and believe me Justin knew exactly what this meant. I was just following along for the ride.

The next few days were much the same, treatment appointments and waiting time. We were meeting more and more people from the northern towns and all with their own stories to tell. Friends from the House were great and each day had our coffees and chats on the balcony. As I explained before this is the only place you can smoke in the House, so our balcony became our therapy room of sorts. People sharing, some crying, some mad as all get out...but when we left the balcony we left a little of our problems behind.

I remember one night sitting out there with lots of people and a lady coming in. She had been at the house for about a month. Then went home for a week and now was back. Her little daughter was to have a bone marrow transplant. Had a week to wait so she went home for that week. She was back with terrible news. The tests today showed the cancer was back and there was nothing more they could do. She was beside herself and sat in the corner in a ball. Shaking and shivering. I asked if she was O.K. She answered NO and explained. The next thing I know all of us were around her in a circle. Some crying and hugging some looking in silence. I was talking to her asking her what exactly was said...and she said "It's Over...my 18 month old daughter's life is over because they do not have anything more for her." I learned she had a brain tumour and they had exhausted all the chemo now and the bone marrow transplant was the last hope. BUT she had to be in remission before that could happen. Now they want me to decide what to do next? How do you decide that? Well what a question...Tears streaming down my face I held her hands and said..."There comes a time that your daughter will tell you what to do" She looked at me...and asked how..."Go tonight and hold your daughter...look at her deep inside...listen quietly to what your heart says...this is where the answer will come!" Listen to no one else...just you...not the Dr's, family, or friends...Listen to your heart while holding your child! She asked if I would come back to the hospital with her. I said yes after making arrangements for Judy to watch Justin. Justin was excited that he would sleep in Judy's room tonight. Over to the hospital we went...I sat silently in the room while my new friend held her baby. We were there for almost 3 hours. Her Hubby lived away from Toronto and he came in. I excused myself saying that I would see her tomorrow. That night was spent in tears...many of us sitting downstairs just wondering again WHY and Where Will this go? All letting our own fears surface...THIS COULD BE ME NEXT! All just wanting to find the right answers and yet knowing we were all in some sort of trouble here.

Was still down stairs when Justin and Judy came down. Justin cheerful as ever, singing coffee in the morning and tea at night! Hi Mom...Me and Judy had a sleep over...we had popcorn and pop. We had lots of fun! I took the next 1/2 hour to shower and get ready for radiation and then go to the hospital to see our new friend. Did our stuff and on the way to the hospital saw my man. I waved but he kept on walking. He sort of nodded his head but that was all...FUNNY!

At the hospital Justin wanted to go to 'Marnies Lounge' where he can play air hockey so brought him there told the volunteers where I was going and that I will be back shortly.

Got upstairs to see C signing papers...she saw me and hugged me said thank you so much, her husband came over and said you must be B thank you so much for what you did last night. We are taking our daughter home. She will spend the last days in her own bed with her family all around. Tears streaming down everyone's face now.

Even the nurses were crying...and C looked at me and said...you were right...Brianna has had enough...and yes...she told me last night with her eyes. So I know, what we have to do. Thank you for helping me to listen to my little girl. Bid our farewells and headed back to pick up Justin.

About a week later we got word that Brianna had passed, again the silence entered the HOUSE...another one. There have been too many...and we just seem to be adding to the list. Each of us fearing that our child's name will someday be on that list! Praying for the strength and courage to go on. Praying that we get through today! I received a call from Brianna's Mom at the HOUSE, we talked and again she thanked me for helping her understand. It wasn't me...you just listened to Brianna. Yes she had, and Brianna died in her arms, knowing how much she was loved and cherished. Knowing that Mom and Dad had given the greatest gift of all to a sick child...the Love gift for the "Right to Die"!

The one thing I have seen over and over again, is that children in there own ways... Ask for the right to leave. When the parents hold on, the child will hold on. I'm not talking HOPE here, I'm talking in our hearts we know...but NO WAY this cannot be happening to me. Regardless what is happening the child will not let go. I have watched in silence this happen over and over again, and I kept telling myself...I will not go there with Justin. There were times when things were going really well for Justin that I would go and hide to avoid other families. Especially the ones that have a child that was not doing well. You feel sorry and hurt for them, but you are having a positive time with the treatment yet...you feel wrong in being happy. Your emotions are just so mixed up...so I would go and hide. Every time you saw someone the first thing that is asked how is and the child's name...Great...and they tell you theirs is in big trouble.

Like when Brianna's Mom came to the House that night...I just found out that Justin's MRI showed NO tumour. The Dr's were just excited, as they expected a little change but nothing like this. How do you share this...when a friend is told her daughter is dying. You just don't. So mixed emotions lived with us as well. Knowing when, and who to tell, and when and when not to tell. Life is so abnormal...but somehow we get by.

Another thing that happens at the Hospital is that when you hear of one re-occurrence or death you hear of many. Spring and Christmas seem to be the worse times. Kids that had a clean bill in the hospital cancer back but another type. Starting over. You learn very quickly to read the eyes of everyone. Eyes tell the stories...regardless of age, gender, or profession. You learn to KNOW just where everyone is by their eyes. New diagnosis has that dazed fear look; regular treatment has the fear, but... look; re-occurrence has that desperate, Dear GOD help me look; and the end has that dazed now what look.

There was another family on the floor and her only son had received word there was nothing more left for them as well. Telling them they had to go home. Mother pleading that she could not cope with it. Dad saying O.K. Well the day they were to leave...Mom had a complete nervous breakdown, on the floor. She had to be brought to the hospital next door. Now the child had to stay as Dad ran back and forth to 2 hospitals. The sad thing was...Mom was NOT with her son when he passed. She had not left her son's side during all the treatment and now when she needed to be there for both of them, she was in the hospital because the system pushed her over. Again LISTEN...when they say they cannot cope...LISTEN. Often wonder what has happened to them. Many families split up after a medical crisis. Everyone is at their own level of grief and worry and they cannot cope with the stresses of others. I have seen this happen as well. Watched loving couples...fall apart and end with divorce papers. Now both, in more of a mess than before. So many lessons for me as I sit in silence watching.

One day after school Justin came running to me and said my friend is gone. Who I asked? You know that 'guy'. Well that 'Guy' was a boy that would play in the hospital playroom with Justin BUT whatever Justin wanted to play with the 'GUY' wanted it. Justin would get frustrated with him, but always gave him the toy. Many times Justin would just NOT go into the playroom when he was there. Both Mom and Dad were there for all of his treatments. The night before, I over heard the two of them arguing over a treatment change. Mom said No and Dad said Yes...as long as one parent says yes...treatment is a go. Well they did change the treatment, and the next afternoon the little boy passed away. Again...he was palliative and both parents knew this. Mom wanted to bring him home and Dad wanted to try something else. As Justin told me that, I looked to see them both walking off the floor. Yes...Tyler had passed and they now were going home to make the final arrangements. How Justin knew not sure...one thing though, on the floor they do not say...when someone has passed. Doors get closed, but that is it. Really didn't want to know how Justin knew...Just knew he was right!

On top of all the emotional stuff you have to fight sometimes families. Again watching in silence...we continue.

Hugs

Butterflymom

Hospital routine was our life now and when things came up to change the routine we grabbed it. Justin got another invitation to a golf tournament. It also went really well. After all was done and it was awards time, with a silent auction...the tears really began to flow. A group of men that were golfing together, got together and took a donation for Justin and I. They handed us a hat full of money. I really did not know what to say. The tears were falling the simple thank you just didn't seem enough, but that is all I could muster, and then Justin was presented with a HUGE picture of Curtis Joseph then goalie for the Toronto Maple Leafs. Justin any time he could talk about hockey and it didn't take too long for everyone to know who his favourite team was. This Man bought the picture at the silent auction and when it came time for him to pick up his picture he called up Justin. Gosh the eyes...Justin

again, carried a picture that was bigger than him, and so proud that it was his. The picture hangs for all to see today.

We also were invited to McHappy Day 2000. Ronald McDonald Restaurants do a McHappy day every two years now, and the proceeds for the event go to charity. The house had a few restaurants in the Toronto area that were giving their proceeds to the HOUSE. Families were going to go, but again an early morning deal. But Justin loving every minute of all these things wanted to go. We would be at the Restaurant by 7 and leave to go to his Radiation treatment for 10. The media stuff would be done by 9 so we had enough time.

At the restaurant that was close to both hospitals, had an area waiting for the families. We had breakfast and coffee...tons of coffee for me and Justin had his juice. Every person that came into the restaurant was greeted with cheers and applause just because. We were having the time of our life. Then the guest personality came in. It was Silken Laumann, the Olympic Canadian Rower. Just to cause trouble I started singing row row row your boat and everyone joined in we laughed and laughed. Justin looked up at Silken and Silken looked at Justin...don't ask me what happened, but a BOND like no other. The two were like one. Justin right beside, selling food at the restaurant. Silken holding and talking to media, with Justin in her arms. Justin even went outside to sit on the Police Motor Cycle and before we knew it he had the sirens a blaring. Silken asked if Justin could continue on with her to the other restaurant, but I told her that Justin had Radiation. She said O.K. then asked if she could come to the house to visit before she left. Said sure.

Justin was ripping he wanted to go with Silken and kept telling me to call the radiation place and say he was too busy. LOL

Headed for treatment and when we entered the floor applause and cheers for their celebrity. Justin had been on T.V. so many times that I think the other patients watched the television in the mornings just to see if he is on. Justin smiled at everyone, but told them that he was suppose to go some more...BUT OH NO...Had to come here. Some laughed and others said well Justin if you didn't come we would miss you. He added real quick..."well you could watch me on T.V." LOL always had a good answer. When he went for treatment he told all of them that he was very busy today...but had to come here. He was suppose to go with his friend Silken and now he couldn't go. He got over his madness quickly and got excited to tell everyone at the HOUSE about the event. Only problem was everyone else went back to the HOUSE and we went for treatment. He saw Judy and said...Judy you want to hear about this morning? She always wanted to hear what Justin had to say...so a HUGE smile and he sat next to Judy but not before she made coffee and both talked.

House manager saw us and came and asked if we wanted to go for supper tonight. The Olympic Rowing team is having a fundraising supper and a few families were invited. There was going to be about 6 people from the families at the house and 2 staff. Said sure, but what do we have to wear? Well dress up ...HMMMMM have no dress up clothes, what about all the families get Ronald McDonald Shirts to wear and the kids and then we will look O.K. he agreed and went to find shirts for everyone to wear. No money to spend on fancy clothes so why not wear the house shirts. Justin needed another one, because his was full of paint from painting the

Moose. Justin asked if Silken would be there and House manager said YES...she was the one that invited the people from the HOUSE.

Well off we all went, used the House Van and off to the fancy ball. Justin was excited as usual and when he saw Silken yelled his head off..."Hey Silken I'm here!" Well lost him again until the night was ready to begin. Silken brought Justin back to the table, as she got ready to act as Master of Ceremonies. There was a huge screen and it was showing different rowing events of the last Olympic races. Justin saw the Canadian flag and Yelled "LOOK CANADA! Mom Look CANADA!" Everyone laughed and then the ceremonies started. Silken introduced many people then added that she had special friends in the audience tonight...named each of the kids from the house and each stood to applauds. When Justin was named he stood right up and waved to everyone. Supper was great and when the intermission came Justin took off with Silken again...he was going to meet all the rowers for this Olympics. He was in his glory meeting all the people and of the course all the girls he asked if they wanted to be his girlfriend. Everyone agreed and he was delighted how many girlfriends he got that night. LOL All in all it was fun. I had time to breath... Justin spread his cheer everywhere he went. At one point he said to me I'm hot lets go outside. I said O.K. and let's go to the bathroom as well. Sure thing MOM...so off we went. Was standing outside when Justin met a man that was at the ceremonies, he asked the Man having a good time? The guy said yes I am, looks like you are too..."yeah, but... wanta race?"

Another older gentleman was there as well and laughed but the next thing you knew there were 4 older man and Justin racing in the lobby of a fancy hotel. People all over watching and cheering like it was the Olympics. Guess who won as usual...JUSTIN! Back to the ceremonies and soon it was time to leave. Justin bid his goodbyes and got lots of kisses I must say...people coming from every direction, Silken came over and asked if we were going to be busy tomorrow, told her treatment in the morning but afternoon or night is fine. Made arrangements for a night visit. I asked if we could have something at the House where people could get pictures of her and them she said of course then we would go to our room and talk. So arrangements were made.

Put a sign in the elevator that Silken would be at the House at 7 for pictures and autographs...the place was packed. I think families brought their friends from the hospital as well. The kids were all thrilled and Justin sat patiently waiting his turn with his new founded friend.

Something happened on that McHappy Day, for both Silken and Justin...a bond that just was...just happened when their eyes met...forevermore!

The following week there was another golf tournament...this time it was with the Hockey Hall of Fame. There was going to be 38 former NHL hockey players there plus other golfers as well. Another fundraiser for the House. Justin heard Hockey and that was it. YES...we will go! Made a really neat thank you. Got one of the mini sticks that Alex The WoodMan made and added Justin's picture to it. When we got there Justin's thank you was placed on top of all the autographed hockey sticks that would be given as prizes. Justin took off with Dan and after an hour or so came back to the clubhouse to check on me. I was fine, but he had to go to the bathroom. When we came out there was Kris King...Justin yelled "Kris King...I Missed you!"

Dan now was going to get a break because Justin was going to golf with his plastic clubs with Kris. Now the funny thing is we were at the Glenn Abby, where Tiger Woods golfs, and one of the pros came over to us shortly after we got there and had a full set of golf clubs Justin's size with a pull bag and all for Justin. He said thank you Please give them to my Mom. I knew by the way he was saying it...he would never use them...he had his plastic set which he was very proud of and was not going to change his clubs for anything. After Justin had gone out to golf again, I went to find the pro...thanked him so much but said Justin will not use these...they are very expensive and we really appreciate you thinking about him, but this is really not necessary. He understood laughed and said a true golfer will not change his clubs. He truly did understand, and I just felt that it would be awful not to use such a great set!

Back for dinner and awards and again, Justin would be giving them out. Now...pictures are not allowed, but because Justin was part of it...pictures were going everywhere. Autographs and the works. Everyone was really happy because usually you would not be able to do this. Justin talked with all 38 former players. When Carl Brewer came up to receive his award, he joked that Justin and him went to the same barber...LOL Both Bald. Apps that played for Philadelphia came and gave Justin an autographed authentic hockey shirt...I had to grab Justin and put it on and kept saying don't say anything...He looked at me...rolled his eyes and I rolled the shirts arms about 10 times for his hands to come back out. Justin came back to my table which was close to the awards area and said "BUT mom I like the M'Leafs" I know...but you will hurt his feelings if you say that...rolled his eyes again gave more awards and came back again. BUT...MOM!!! Justin don't say anything. Then Kris came over with a shirt for Justin...the eyes lit up off came the shirt, and on went the Toronto M'Leaf shirt...the biggest smile from ear to ear, and all was well again. At the end Justin gave the organizers his thank you mini stick and Justin received an autographed hockey stick by all 38 players. There was a group picture taken with Justin and them all and then when it was almost over he yells..."O.K. boys golf is over... lets play hockey..." Off a bunch of them went to play hockey on the Glenn Abby golf greens. Tons of people watching and laughing their heads off...then Justin throws his gloves off and yells FIGHT FIGHT and 3 players and Justin are rolling around on the greens. People were coming over and saying what a wonder boy he was, and also adding that he really shouldn't be playing with that stick...it is worth lots of money with all the signatures. The other sticks had about 5 names on that was it. Hey...it is his stick, and the worth is what you see...my son smiling and enjoying LIFE!

We met so many people at the house and hospital, some were success stories while others left in tears. All with their own stories to tell. We met another family who had been at the House for 7 months. Their middle child a boy Warren was in the hospital having a bone marrow transplant. His older brother I believe was the recipient. So Mom Dad, Brother Donald Sister and Aunt were all at the House tending to business. Justin and Donald hit it off great. Warren

was at the end of the treatment and doing very well. So these people were finally looking at going home. Donald loved basketball, and of course Justin his hockey. Although Donald was older than Justin he would come in find Justin and out they would go on the balcony to play hockey...Justin with a M'Leaf Shirt and Donald with a Raptors shirt. They would play for hours. And each time they would see each other at the House they would run upstairs to get their shirts on.

One weekend while Donald was away from the House a group from the Raptors club came into see the kids. Justin enjoyed all the games and treats to eat and was talking to everyone as usual. All the kids there got tickets to go to the game that Wednesday and one of the players that must have been 7 feet tall walked over to Justin and game him 2 tickets. "Hey buddy you going to come and see me play? I'm going to bring you right on the court for you to throw the basket ball...would that be nice?" Yeah that's nice, but I'm not going!" Why he asked..."Because I like the M'Leaf's but Donald likes you guys so I'm giving him my tickets so he can go, you can bring him out on the floor though he is good!" Everyone laughed, and the player offered to give us more tickets so Justin could go as well...No Thank You Donald will go with his Dad. The players left and Donald came in shortly after supper. Justin ran for his shirt but also picked up the tickets. He had made me promise NOT to say anything. When he returned Donald was sitting so of sad like. What's wrong Donald Justin asked Oh I missed the players today...I really like them and now I missed them...Don't worry because you are going to the game on What Day MOM??? And you are going to go on court with them and shoot the basket ball. Donald's eyes lit up and looked down at the tickets that Justin was pushing into his hands. Donald went NUTS!!! He was jumping and screaming, Justin jumped backed then smiled and jumped up and down yelling yahoo yahoo Donald is going to the game. It was so funny, and all happened so fast. Donald must've hugged Justin about 10 times. His Mom came over with the Aunt and asked how we got the tickets. Told them the whole story and said YES...they are going to get Donald to come on the court and throw the basketball. She was so happy for her son and both gave me a hug!

This weekend also saw us saying goodbye to the other Kim and her family. The second heart transplant went well and it was time for them to return back home out East. We had spent a lot of time together so the tears were just there. Every time we looked in each other's direction, the tears came. Gosh so hard...yet so excited that this is one of our success stories, but at the same time, knowing we may never see each other again. We had a final dinner together and the next morning they were leaving for the airport early. Up we were and Justin had Butterflies that we had bought at one of the stores and he gave them to Kim, her Mom and Dad. See Dad was the hockey coach on the balcony so Justin and him formed a strong bond. The taxi came they left and we all returned to the balcony for coffee cigarettes and some talk. Oh how hard...saying goodbye!

A notice went up on the elevator that the house was going to be getting a visit from the Princess of Nigeria. It also was asking that families that are available were invited to a get together in the kitchen. So we should be done treatment so yep we would attend. The day came and limousines by the 10's were in front of the house. Out stepped many women all dressed up guards and drivers opening doors. Oh

my...all the kids had Ronald McDonald Shirts on and all waved to the entrance. Gosh...Talks by Mayor and some other public figures and then some man from Nigeria spoke then we were going to the kitchen. Introductions of all the kids and their parents were made. A presentation was given by one of the other children there and we sat down for sandwiches and juice. Justin went up and asked the Princess where her crown was and she laughed. Pictures were being taken all over. Then the Princess came to Justin and asked if she could have a picture with him. Pictures were done again and she bent down and kissed him on his head. You could see the tears in her eyes as she looked down at him, Justin turned around and hugged her Neck, gave her a BIG kiss right in the cheek and other women in the group were wiping their eyes. Just at that moment in through the doors came 3 brothers and their Dad. A surprise visit. Now the Princess got to see what this house is all about. Justin yelled out "My Brodders, look Princess it is my Brodders!" He ran to them jumped up and hugged them all. Dad was wondering what was going on and soon found out that the Princess was here. They were wondering how they got in. There were guards in the front, but they just walked in. Mind you they were big guys right behind them too. Justin now went and introduced each of his brothers, he is always so happy to see them and likes to put on that this is HIS house and here he is the BOSS! So today was a great day to do it.

I was so glad to see the boys and Dad. We had talked but not seen each other for a few weeks now with all their activity. The House Manager knew they were coming but didn't tell. He had also got some tickets for the Hall of Fame and so later that is where we were going.

One minute saying goodbye to friends the next minute meeting a Princess and then FAMILY! It was a great day!

That night we went to the Hockey Hall of Fame. Justin was in his glory and there was a game that you get dressed up in goalie pads, gloves helmet and mask and stick. You go in this box and pucks come flying at you from different NHL players.

Well the boys all did it, and Justin wanted too. Gosh the pads were as big as him...the boys were telling him what to do and the pucks were flying. Then one came from Wayne Gretsky, Justin was just standing there, couldn't even see the pucks, but some how he moved his arm the puck hit his arm and he kicked it out. The place went wild. Justin was yelling I beat him I beat him...I won. Mean while about 10 others went out and in. LOL He told everyone he saw that he beat Wayne Gretsky. There were other games as well, and they all tried them. I just enjoyed not having to think and seeing the family together again. I stood back and watched as they all had a great day.

The next day we were going to go to the Zoo and then the Safari. This is going to be great. I packed some things, including small bananas so hubby didn't see, and off we went. Left early in the morning to hit the zoo and then went to the safari. Both were great. At the zoo #5 son threw some bananas into the Oran tangs place, one saw him and followed him right around the exhibit. He kept looking and reaching his hand towards my son. Finally when no one was watching #5 gave him a banana. Hubby knew it had to be us, even though we kept trying to keep ahead of him. We laughed all day.

The Safari was something lese. You go through with your car or on a bus. Taking your car is at your own risk. All the animals are right there and when we got to the baboons they jump all over the cars. We had a riot. Not suppose to open your window, but #1 son had to put bananas on the roof. Well the baboons came from all over. Our car was full. The car in front had its rubber from the windows pulled off and the strip of medal on the side. They pulled that like a roll of fruit roll ups. We all laughed. When we were going to leave this section the worker had to come and shoo the Baboons off our car. They KNEW where the food was. Hubby kept saying we were going to get kicked out...we all laughed.

The next part that was funny was going through the giraffes Justin started yelling take a picture take a picture...there was one licking the window of the car. Of what? "Giraffe boggers"...Oh gosh...we did and laughed all the way. And you know what we are probably one of the few families with a picture of Giraffe boogers! LOL

Hugs
Butterflymom

It was another great day with wonderful memories. This is what we needed, happy days with tons of memories that will keep us going. Like anything else the time comes to say goodbye. Family left about noon the next day. Again just Justin and I left. Justin was even sad this day...so we went for a walk down to the beach area. Just to take time for us two. To watch the waves roll in and to play on the play gym and riding toys that are available. Just to walk the beach, collect whatever treasures may have rolled in. It was a quiet, but re-connecting day.

Next few days were typical hospital scheduled days. We went for appointments and waited forever. Justin seemed to be quieter than usual and may times I asked if he was O.K. Yes he would always reply. But there was something up.

One day we were at the hospital waiting and Justin asked me..."what am I going to do without my Hockey Buddy?" I asked what he meant by that, he replied "I don't know" Saleem was still in the hospital and had gone through quite a bit. He had surgery, more chemo and now radiation as well. He was reacting badly to everything so the poor Saleem spend most days in bed. We went to see him Justin played a game then watched T.V. with him and Mom and I went outside for air. She told me things were not going well, but her hubby was looking for alternative treatment in the States. They are NOT giving up HOPE! Went back up Justin and I got ready to leave and said we would see them again tomorrow after radiation.

The moose on the loose in the city was in full swing, but unfortunately people were breaking the antlers off and damaging the Moose. One even had a huge whole kicked or pounded in the side. On the way home Justin saw some kids that would come for assistance in the house next to where we were. It is called the Covenant House and they help Street Kids. Sometimes you get a real variety of kids there. One things though, Justin seemed to even win them over. On the way passed Justin yells into the court yard..."Hey guys...come here!" Before I knew it there were about 6 guys and a couple of girls. "You see that Moose? that is My Moose and if you see someone trying to wreck it...Beat them up K?" Well...sure thing there buddy, hey Justin how are you anyway..."Good but watch my Moose!" well must've worked

because many of the Moose were damaged even in the area and ours was there Antlers in place and believe me I watched some of the kids from the House next door tell people hey Look... don't touch. Justin sure new how to pick his friends. Oh one more story about those kids. Well as you can imagine the dress was wild, the tattoos and earrings all over the place and every colour hair you can well imagine and some that I really do not think have a name as of yet. We were rushing to get to the radiation appointment and some guy was there with what looked like a giant coconut on his head. The guy was talking to some other kids form the House and saying "hey Man what do you think?" they were saying that it was really neat and where did he get it. Justin yells out..."That is the stupidest hat I ever saw!" Well I couldn't help it I started to laugh...because it was...the guys looked down at Justin and one of them said hey there Justin going to treatment? "Yep, and that hat is really funny looking!" Then they all agreed and we went on our way. The guy wearing the coconut was not too impressed with what went on...but it really was stupid looking.

Days went by, saw friends from before and said goodbye to friends. Coming and going and right now we were staying. Making the best out of each day. This weekend coming up was an in the hospital deal and also the gay parade. We were not going in until 4 that afternoon so I decided hey...why not go and see the parade. Well never saw it before and thought what harm....WELL here we were the streets packed and Justin and I are in the front. All of a sudden Justin yells "MOM look bare BUTTS!" Everyone around started to laugh and I looked up and sure enough just enough covered and that was it. I tried to turn around to leave but there were too many people in the area so could not do it. Justin was yelling and hooping it up and thought this was the greatest parade he ever saw. The next thing I knew I saw reporters and cameras, gosh...hope they didn't get us. Finally got out and headed to the hospital. Got our bed and Justin started his treatment. Later that evening the parade was being re-aired on the T.V. Justin saw it and called for the nurses to come and see. I looked up just before they came in and low and behold there we were on T.V. Justin yelling Bare Butts and me trying to get out. I had to laugh, but thank goodness the nurses came in right after that. Justin was just ripping it up...bare butts people went in the parade... bare butts and he would start laughing his heads off with all the nurses.

That night was a bad night, 2 children lost their battle to cancer. The doors were closed and when that happens you know something is up. I saw mothers weeping and fathers walking in a daze. Again reality sinks in..."Where is all this headed?" but as soon as that come sin you try desperately to change your thought.

Next morning was quite on the floor. All the nurses were also having a hard time with the deaths right now. It seems too many were losing their battles. We had more volunteers than normal so I had time to go out for awhile to sit and think. Met some of the other families outside and find out one of the kids that had passed last night was Kevins' son...Oh no...he was doing so well, I thought they were near end of treatment. Yes...but complications set in. Something about kidneys and liver. You see the treatment can cause just as much trouble as the cancer at times.

Saw Charlene out the side of my eye, she was sitting by herself...I went over and asked how thing swere going. He son was waiting for a heart. Not well...many

problems and now he is so unstable we are off the waiting list. Oh NO...It is just a matter of time. NOT another one! Yes it was and 2 days later we learned that her son also passed away. It comes in flocks... then it seems to quiet down, right now...news was NOT good for many people.

At the House Donald came in to tell Justin they were leaving on the weekend. They were finally going back home. Even Justin was sad at this one. Oh NO...who is going to play with me? Donald gave Justin hug and said everyone plays with you. We were happy for them, but again...more goodbyes.

The next few days saw people leaving and new people coming in. A family from Winnipeg came in. Their daughter was in for surgery. The Dad and son were there as well to keep the Mom and sister company. They were staying till after the surgery but then had to leave. The Mom seemed very shy, but before long Justin was talking to them all. Then he introduces everyone and then says there now you are friends. Justin had received some tickets to the Blue Jay game but decided he didn't want to go. I said we had to find people to take the tickets as it was not good to let them go unused. Justin asked the new family if Dad and brother wanted to go and you would have thought they recieved a lottery. That was one of the things they were hoping would happen, but the game tonight was sold out and the next one wouldn't be until after they were to leave. Justin gave them the tickets and added that maybe when they come back they could play hockey with him on his arena. Friends leave and New ones appear. Justin found them everywhere. Hugs Butterflymom

Trying very hard NOT to write today. Emotions are scattered today, with NO specific reason. So not sure where this will go today. BUT...the song Streets of Heaven come to mind.

Oh how crowded the streets of heaven must be. Why do you need them? One day they will be yours forevermore, but right now we need them more! Oh Please have Mercy...We need them more! They are our Angels, and they already have a home...Please Please have Mercy ... We need them more!

Life just is...and some of us have to let go...oh how hard it is to say goodbye to one who is loved and cherished so. We will never forget the way we felt that day. We still have friends going through a Living Hell...Those words...You have to carry on...Have you forgotten? We fought for our child's life...Some of us Lost MUCH!

Goodbyes stay forever, deep in our souls. The friends of yesterday remain in our hearts. These people that sat in silence, held our hand and hugged when it was time. Reliving the pain and frustration. Time for the masks again. Thinking that maybe it is best NOT to get close to people. BUT...that last only a second as new people come to the HOUSE!

We now have a new group of friends. Again many coming from the North, and Justin finding friends in each family that came in. Angie from Winnipeg, became Justin girlfriend for Life. There was another boy from Hearst there as well, and Angie and him hit it off very well. BUT...Justin would just wiggle is bum right in between them. Smile at G and snuggle in to Angie. We all laughed when he would do that. BUT...She was his girlfriend for life. Justin was talking to Dan one day and told him maybe he needed a girlfriend...Dan agreed and Justin said he KNEW just

where to find him one. We were all listening to see what he was about to say. Get the car Dan...and I'll show you. Dan had just bought a new sports car...two seater so there was NO room for anyone else. Just the way Justin liked it. So Dan made arrangements to come and pick up Justin the following day. Yep he would tell everyone going Girl Hunting with Dan.

Now listen to where the spot was..."Gots to go to McDonald's have chicken and fries then you will see some girls there. Then go to the beach...there are lots there too." In other words...Justin wanted Chicken and fries and then go to the beach to play on the toys. But not with MOM he wanted to go with Dan. We laughed as the two of them got ready for their adventure for the afternoon. Justin came back with stories like no other. Yes they went to McDonald's then the beach. They found lots of girls and when we asked where did they sit? He quickly answered we put them in the trunk...no room in the car. The place was in stitches laughing. Justin had an answer to everything. When Angie said she was upset that he went Girl hunting...I thought I was your girlfriend...he smiled and said..."Your my Girl friend for Life!" Oh well then ...all is well.

We made great new friends and together we all fought our battles. People came and went, but there were a few of us that were together longer. Angie had her surgery and things didn't go as they would have liked. Angie was now heading for a life of chronic pain, and would have to search for treatments for that as well now. Justin spent every minute of every day with the people. He would sit with them, talk, play games, snuggle and sometimes just rest in their arms. Like I said he was very much a people person so whenever he could snuggle he did.

We continued our daily radiation and Wednesday chemo and ever second weekend in hospital chemo. Justin actually did very well with all this treatment, and now we are seeing more and more children doing exactly the same routine. We were coming close to the end of this bout of treatment and going home finally. We had 4 months of the regular Protocol which I refused to be on really so that if something came up now, we could add or take something away. We were packing some thing sup sending them home with family that came to visit. Getting ready for our day...Our day that we finally get to go home.

More tests and stuff had to be done, just to see where we are. Radiation Dr. asked if we go the full treatment or if we wanted to hold some back...FULL we have nothing to lose right now. We were at the last radiation treatment when a trip on a Pirate Ship came about. It was in the morning and it would mean no radiation or NO ship. Justin was excited to go, he would get dressed up and along with other kids from the house they would go for the morning on a ship around the harbour and back around 3 or 4 in the afternoon. He was so excited. I told him we would have to reschedule his treatment then. That morning we mentioned to the nurses about the trip and then they told us to talk to the Dr. We made arrangements to talk to him, but he felt NO we could not re-schedule as it was important for us to stay on schedule. Well I added...hmmm when ever there was a long weekend we were re-scheduled and whenever something came up we were re-scheduled. Justin has a chance to go on a Pirate Ship and really wants to go...I know BUT....Well lets just say...tomorrow Justin will go on the ship, so you can believe two things...one he is sick and can not come to treatment or tow he is on the ship and having tons of fun.

Justin piped in..."What he say Mom?" I said he said NO and he replied..."Hey...don't you know I got Peiorities!" Well I laughed...looked at the Dr. and said...well you heard him...so sorry we will not be here tomorrow. That was it.

Looked at Justin and said...yes Justin we are going. Yeppiii was his reply!

Next morning saw us fixing up a costume from his own clothes. We had a bird so sewed it on his shoulder. We made a patch for his eye and bough a cheap sword that he was very impressed with. He was so excited and we met the rest of the group downstairs for our adventure. Some of the parents were also coming which was good for me as it gave me some company as well.

The day was great and the weather could not have been better. There were games, and dancing, singing and food...lots of food. Everyone had a great time. Back at the House all the kids that were able to go wore their outfits for the rest of the day. The House became the Pirate House. They played Pirates all night long.

Next day saw Justin wearing his pirate suit to treatment and was telling everyone how great it was. Even the Dr. saw him and Justin said too bad you could not come...it was fun!

Near time to leave...final packing, have a few more tests that have to be done then we go back to the 1 week here and 2 weeks home. Mind you never believe d that really ever happened except for the first 2 rotations. Oh well will not worry about that right now. It would just be great to get back home. 3 Months...the Boys were planning a party of sorts for Justin too so he was all excited about that. He had all these ideas of what they were doing.

Finally tests were done, and yes...we were going home. Had tons still to bring home, but hey...we would manage. Justin now had his Hockey stick all signed, and he was NOT letting anyone take that. We got to the airport to find out that due to renovations we were at the wrong terminal...How do I get to the other one. I was sitting and wondering now what...then the darn Bag broke. Oh brother now what. A man that worked there came over I guess he saw how frustrated I was. He ducked taped the suitcase then called someone to come and get us to bring us to the right terminal. It took about 15 minutes to get where we had to be but we made it. We boarded and yes...Justin had to give up his stick, but the man put it in a bag and sent it under the plane. Justin got to carry it right to the plane watch the guys put it under then we boarded. Gosh it felt funny...we were going home again.

Just sat wondering again...Now What...going home to start again...O.K. stop...at least we are going home. Justin was excited because the boys said they bought him something and that we were having a party tonight. He could hardly wait to get home. Finally landed this time seemed to take so long. Off the plane we got and everyone was there. Family and friends...waving and cheering as we came down the ramp. Justin was again start struck and just smiled. People in the airport were also clapping there hands...I guess contagious. LOL We arrived and all was well. Got our duck taped bag and of course Justin was waiting for his stick!

Got home to a clean house...and people waiting here as well. The boys had got the outside pool ready for Justin to use and there was a bike for him. His eyes opened so wide I thought he was going to burst. He was so excited. A beautiful two wheel bike with a HUGE bow, and there was the pool waiting for Justin. Mind you No money for a deck so the boys had taken a picnic table and fixed that up to get in and out of

the pool. They even had a board rigged up so you could not get into the pool unless it was taken away, and it was locked up. Justin was so excited. Then the boys said that tonight we are having a BIG bond fire...just for you! Justin was so happy...I was lost...I just didn't know where to turn. I was happy but sad...I left my support system, all the people that were there every minute of every day. Knew exactly how I felt without words...I was home with family and friends...but feeling so alone! Tried to shake it off, but tears were just there. I kept saying it was because I was glad to be home...but reality was...I was grieving my extended family. The day and party was great. Food, Family and Friends...but again...that longing...that missing of MY extended family!

It didn't take too much time before he got back to routine again. Going for Blood checks and then preparing for our trip back. We were back to the in hospital chemo so called to see if there was a room...thank goodness yes, but not available until later on the day we arrive. That is O.K. we will go to the Hospital and get set up first then I will go to the House.

I actually looked forward to going back. I knew one of the families were still there. Anna and Angie were still there and I looked forward to seeing them. When we arrived Justin was given a room, last test results were just coming in and then we realized he needed another echo before he could get his chemo. Over we went to wait for the test. Saw Anna and we hugged each other. Angie was waiting for her results but it looked like there had to be another surgery. Gosh...when Just waiting. Anna was glad to see us too, she really missed us being at the house. Seemed as though most of the people had left and now the House was full of new people again. Finally got Justin settled and called the House to see if they would leave my key at the front desk. I would go back with Anna so would get my key then. I had decided that instead of staying at the Hospital I would go to the house to sleep and return in the morning. Just a better sleep and Justin was O.K. with that.

Later that night Anna and I walked back to the House. Got my key put my stuff into the room and went downstairs to have a coffee and cigarette. Got down to the kitchen with all different faces. Saw a family that we had talked outside of the hospital so talked with them Nicholas was doing O.K. and was about ready to go home. So they thought. Nicholas was born with out an immune system, so had a bone marrow transplant. Both Mom and Dad have been through a lot. BUT...at least it seemed like things were going better.

Met them each night to walk back to the House together and usually met walking back in the morning. Justin treatment went well, and it was time to head home again. Made our plans for someone to pick us up at the airport and got home to much the same as before. Dishes piled, house looking like a storm had hit, and Hubby away. Oh brother...back to normal I guess you can say.

I was upset, but no use saying anything...I cleaned and called Anna to see how Angie made out. Unfortunately Angie was having surgery the day we left. She was alone and very upset. I called and things again did not go well. Angie was in lots of pain, and mom was crying. Gosh...again here is a friend and I cannot be there to help her out. Talked for a while then told her I would call again later that day. Did and Angie was heavily sedated due to the pain...Anna was not leaving her side and sounded so tired.

When it was time for us to return for treatment, Anna and Angie were going back home. So we would miss each other. Although we had a daily talk...she would not be there when I get back. We arrived and again were lucky enough to get a room. We arrived the day before because it was so long and tiring arriving the same day. Justin and I had a good sleep and headed to the hospital. Well back we were to the typical routine...NO beds...O.K. call when there is one. Headed back to the House. Met more people this time again...and had our daily talks with Nicholas's parents. Things were not going well now, and Nicholas's Mom's Parents had come to help out. I got a call one night still waiting for a bed, from Judy...she had gone back home, but things were not good and they were heading back by air ambulance to Toronto. She was so upset...but told her Justin and I would meet her in Emerg. Poor

Judy...

We got ready and headed over to the hospital about 1 hour after the call. We waited there for about 1/2 hour and Judy came in....She was so upset. But...glad to see us...

Judy had a relieved look on her face when she saw us there. Oh how I knew how that felt. Having someone there...not feeling that loneliness so many of us felt. Knowing that you have someone to lean on...someone to share your fears...someone who CARES.

We were in Emerg for about 3 hours until they finally got a bed. Judy was going to stay at the hospital, then call to see if there is a room at the house. I told her it was full, but call each day and eventually you will get in. That is exactly what happened. She was coming in the night before Justin and I were going to leave again. BUT...that is O.K. Not sure how long she was going to have to stay, but felt so much better in Toronto with the specialist than back home where locums come in every second week. We bid our goodbyes not sure if she would still be there when I got back. Which she wasn't.

Justin and I headed home again. Each time now...I was feeling more lonely. Looking forward to our trips back to T.O. not looking forward to all the nurses visit and blood check-up and running that comes to going home. Having the support connection continue via phone and e-mail, but not having that hands on stuff. Yes the family and friends were there, but time was spent explaining and answering questions...I was tired of that. In fact whenever we would have a Dr's meeting now, I would get the Dr. to call my hubby. Tell him what you said and answer his questions I just cannot do it anymore. I found that when I was answering hubby's questions I was adding tons of my own opinions in to it. He always had questions, and wanted to know exactly what the Dr. said. I understood that, but finally said then you come to the next meeting.

Justin was doing fine. He played with his pony daily and played with his imaginary friends. He had many, but so many of them were his friends that had passed. He would talk to them tell them to wait till he ate dinner and things like that. Hubby would ask him "who you talking to Justin?" He would answer..."Oh Dad you don't understand Mom does!"

There was always work to do around the house and one day we decided to cut wood. #4 son was home so we got the wood ready for chopping. Oh brother it is a hard job, so we decided instead of chopping lets make chairs. Justin was playing with his imaginary girlfriend Jenn and he was filthy. They were playing tag or something and he would always end up in a huge puddle...clean off his face so he could see and away he would go again. Both my older son and I laughed our heads off. Gosh if the Dr's saw him now they would have a fit. LOL

Son and I worked on our chairs, we laughed and finished them up just as Dad came from work. It had been a beautiful sunny day not a cloud in sight. Hubby came over to see our 'comfy' chairs we called them. Big, huge chairs for around the fire. the ones you sit in and push your legs back and forth as when you were a little kid. They were huge! But they took up the wood and that is what counted. LOL Justin was dirty and ran to see his Dad, he hugged him then looked up to the sky. In a loud voice as normal he says..."Hey GOD...keep my cancer awhile a little bit longer K Thanks!" We all stopped looked at each other but said nothing. We continued on to finish up, as Justin yelled..."Look he answered me Look!" We all looked up to the sky where Justin was pointing, and there was the most beautiful rainbow you could ever want to see. It actually had 2 rainbows one leading into the other at the top. We just froze. Even Dad just looked to the heavens. Brent, shivered and said I got to go, and Justin adds..."See yous got to say Thank you sometimes!" Again everyone stopped and said nothing. #4 son had gone into the house and hubby and I stood there looking at the rainbow. Hmmm, there is Justin a straight line straight to the heavens and they we are his family and he is trying to bring us all in. It was like a painting. Shortly after disappeared.

Justin just went on with his business doing what he had to do. That evening we went for a walk and brought Dad this time out in the fields. Justin told Dad to lie down on the ground and look up to the clouds...what do you see? They did this for a few minutes but by this time the horses were coming and Dad was a bit worried they would step on us. Justin and I laughed...Of course they would not step on us...We do this every day...they just come and herd around and wait till we move to the next place. Dad was not comfortable and Justin piped up..."Dad can't come next time MOM...he is too busy!" O.K. settled then...Dad you cannot come next time.

The rest of the time was spent much the same as usual. We received a call from a lady we meet and she asked if we would come over for coffee after one of our appointments. Made arrangements for the next day. We went for blood and all was well so made our arrangements to back for more treatment. Stopped in to visit. Justin had met this lady when he was very young, just an infant, so really does not know her. We entered the house and Justin immediately asked do you have a cat...yes I do 2 oh...where are they? Well one is here and the other is upstairs she is older and sleeps longer. She will probably come down soon though because she heard the door. Could you go and get that cat. I was really surprised, told Justin wait and wondered why he was so persistent. Actually held his arm gave him a motherly tug you know...stop tug, and the eye. BUT NO... He would not stop. We went to the kitchen, and made coffee but he kept asking and asking about the cat...go and get her...just go now. Finally the lady said O.K. Up the stairs she went. I told Justin that he was not being very nice...you should not keeping asking people

for something or asking them to do things they really do not want to. Justin just rolled his eyes and went to wait at the bottom of the stairs for the Lady to come back.

The lady did come back but with the cat wrapped up in a towel. Justin said ...give me the cat...she said Oh no dear...I think the cat is very sick...no give me the cat. M looked at me, I shrugged my shoulders and say if you want too. She added that the cat was losing control of her bowels and urine, BUT Justin insisted GIVE ME THE CAT! Justin sat on the chesterfield with the cat then lied down next to her. Stroking and talking to her all the way. We both just watched...I was getting uneasy now and just wanted to leave. Drank my coffee and then said that we had to go and get arrangements for us to leave tomorrow. Justin did not leave the cat...I said O.K.

Justin you have to give the M her cat now...we have to go. He sat up looked at M and said..." Cat is going to leave you now...just hold her like this, and does this, she likes it!" Added..."Cat doesn't want you to be sad...she is happy now...look just does these things!" As he stroked the cat, from head to the end of her tail. Oh brother I just wanted to go, the lady was crying and Justin was insisting that she hold the cat under her chin and stroke it the way he said. We were not leaving till he saw her doing it right. Finally we left. Gosh glad to go, but said nothing to Justin. Got home to the phone....The Cat had just died right in her arms... She wanted me to tell Justin... that although she is sad right now...she knows... that the cat is happy and thank you. Gosh wanted to get off. Justin pipes in "the cat is gone now eh?" Yes Justin she is..."that's O.K. mommy she is happy!"

Hugs

Butterflymom

Appointment was cancelled till tomorrow, and Hubby starting a new project that will see him away for a year with weekends home, so I decided to write more today.

Feeling like I am right back where I was...not that long ago.

Writing this, brings up the emptiness and loneliness that seems to be part of a mother fighting for the life of a child due to illness. The wanting to make things better, but knowing deep in her heart...what lies ahead. Seeing the signs, but no one else seeing the same thing. Seeing the lessons that are being presented but putting aside trying desperately not to go there. Feeling that lost feeling...feeling betrayed and wanting to run...knowing there is nowhere to go. Wanting to re write the chapters that lie ahead...knowing in your heart what it is, but also realizing the chapters are already written and the part I play is how I follow my path.

I talked to many people about the path I was on. The path I DID NOT choose but was thrashed to me...One September morning, back in 1999. The path that was going to bring great sorrow, yet now I know the great Love and Friendship that also came with the path. At the time...feeling many emotions...wondering how I would ever get through this ordeal.

Sitting in the evening is the tough part. When everyone else has gone to bed...you creep up and sit in the stillness of the night thinking. I would always say...hate when this happens, because the truth and reality always shows its face. I went over the

commitments that were made...Quality of Life, Thin Line between Treatment and research, Justin will know when enough is enough, and Quality of Death. NOT really knowing what any of these are going to be...but knowing somehow...we would not falter.

Death was showing its face to us over and over again. Making me think...is this what is coming? I watched as people would not let go of their children, and they linger...pain and fear around...the sadness and tears...NOT what I wanted for Justin. I watched as people lost pets...again the grief and pain so real...watching as people grieve. Talking to parents that are sitting at the side of their child's bed...waiting for death to come. Watching their eyes. The pain so real...yet lessons for me. Knowing that when the time comes...I had to listen to Justin. Leave my emotions alone and way back in my head...and do what is right for him. Knowing that this is NOT what I really wanted to do. Wishing and praying for that miracle that drug that will take all our pain and sorrow away.

The next little while I really had to fix my mask. It was getting really tight and at times again hard to breathe. I read the test results, I watched as everyone around was so happy with the results. Knew we were ever so close to be the success rate for Justin's Protocol. The one I refused to be on after the re-occurrence. One day talking to our Dr. I said to him...well we are near our end of treatment...things are looking good...I'm anxious to read your final report. Why he asked...Well we had 1% chance when we started. Had a re-occurrence and that left us in the hole. When he reaches the end of treatment he will be your success case and how do you write in the hole success story? He just looked at me...laughed and said only you would think of that. Well it is true. AND yes...Justin was the success story of this protocol. We finished treatment and he was cancer free.

When someone finishes treatment all the nurses and volunteers on the floor throw a big party on the last day...People were clapping and dancing all around. I stood in silence. Dr. was also there and he asked if we thought of a bone marrow transplant. Said I did my research and that the bone marrow has NO help with Justin's type of cancer. BUT he said...Justin is so different we just wouldn't know unless we try. Well like a hammer...NO WAY...this is the thin line between treatment and research I had said ...didn't know at the time what it may be ...but here it was. No not going there. Are you sure??? Yes I am...O.K. but maybe talk to one of the Dr's from bone marrow transplant. NO NEED! My answer is NO.

Justin had to come back in another week for final tests after treatment so we were going home then coming as out patient for a few days. We left the hospital with 3 months to look forward to. After the tests we would have three months of nothing then a check up...finally my son is going to be a boy again. NOT a boy with cancer, but a little boy who can love life!

Port was still in so we did have to go for flushes at the cancer clinic back home, but that was once a month. Blood test...H*** no forget it...I would know when something is not right then and only then would we go. I told the Dr. this...He raised his eyebrows and said this doesn't surprise me either. Home we went knowing that we had 1 more test visit and then 3 months off.

Felt GOOD...even though I would miss our new extended family from the HOUSE...we were going home for 3 months...could really handle this.

Got home and we had another party. Our parties comprise of BBQ's and Bond fires, dancing to music and singing. So it was just great. It is usually open house so there are lots of people who come. Just drop in say hi, and go when you want. Usually we have tons of people who stay over...where there is floor space you find people in our house. LOL that's the joy of a large family with all boys! Take us as we are...nothing more nothing less.

Was home a few days when my hubby called from work. He said he got a call from Sick Kids...He needs to be at an appointment with us for Bone Marrow Transplant.

I went ballistic...yes I was ranting and raving...here they go again...I said NO and now they try to get hubby to say yes. I was sick. I called the hospital and talked to people and let them know I was mad. I talked to Primary and he said it is just an appointment and he felt that Hubby should be there. Sure I said...when you don't like what I say...then bring the weak link in...Please don't get me wrong. Hubby wants nothing but the best for Justin, but he is very much so a paper man. Needs to see it on paper and believes that people go to school and gets their degree and they know what they are talking about. I was sick.

That night hubby and I talked about the bone marrow...I could see that he wanted to try anything that may save our son. I was trying to explain that Justin's cancer was NOT one that bone marrows helps. I explained about the bubble boy for a year after bone marrow transplant and told him his quality of life cannot be a given. I told him my feelings and that we were going against the promise we made, about Treatment versus research...but to him it wasn't research because bone marrow transplants are very common. He just couldn't understand.

One morning I was sitting crying. My 2nd son said MOM what is wrong? I explained what was happening and that I am NOT going to let Justin go through a bone marrow transplant. He looked at me and said..."MOM we have always all agreed on things for Justin, so why now are we not involved?" We will all go down for the meeting and decide from there. I looked up and thought...this is very true. So everyone made their arrangements to be there Monday morning after Justin's tests were done for the meeting. Told hubby that night he asked why??? Said all the boys have been part of decision making so why not now! I felt so much better. Not because I knew what they were going to decide but they knew what I was talking about.

Justin and I left for T.O. had a few days of tests, Meeting was Monday so had the weekend in T.O. Met with new friends and old ones at the HOUSE and went for lots of walks. Monday morning came and we went for our meeting. The Boys and hubby showed up about 1 hour before. Had breakfast and then went to the hospital. The floor was really surprised that everyone was there, and had to get more chairs. the Bone Marrow Dr. came in and said wow...we have a house full. Justin would you like to go to the play-room? I piped up NO he is part of this meeting. He jumped up on #1 son's lab and said NO this is my meeting so I'm here. Dr. began his talk about bone marrow stuff. Explaining how it is done, and since Justin would have to be 'self donor' how they would gather his marrow and treat for a few weeks then transplant it back into him after all the treatment is done. Explained the isolation stuff and that NO the boys would NOT be able to visit with their brother. Explained that even Mom and Dad could not stay over and each night would have to leave then

come back in the morning. Explained that it would take anywhere from 3 to 6 months before Justin would be able to go home then would be in reverse isolation for about a year after. I sat and listened...I researched so knew all this stuff. I watched as all the boys listened quietly and Dad was writing things to ask later. When the Dr. was done, he looked to me...You are awful quiet...never saw you like this...Listening I said...will make my comments at the end. It took the Dr. about 1/2 hour before he gave the floor for questions.

Well then the questions started. There was NOT one son that did not ask things...Dad had a list there and Justin sat and listened looked at me and smiled but didn't say a word. The 1hour meeting was now hitting 2/1/2 hours. Our Primary Dr. was outside waiting for us...and deep down I was laughing about that...Time someone waited for us for once. It felt good knowing he was pacing outside to see what the outcome would be. LOL Crazy thing to be happy about but I was.

Dr. asked again if there was any more questions, my 2nd son Mom your turn. Took my deep breath and began. As you know me I have done the research...Tell me what stats do you have for Justin's type of cancer with Bone Marrow transplants...Well... Just tell us...Well ...none...k and can you promise the quality that Justin has now? Well... no we cannot promise anything...k...and when we do the transplant if and only if...Some miracle drug comes up for Justin type of cancer can we use it? Well... NO...We will have used all possible chemo that his body can tolerate. K, so in other words...If that miracle that my hubby is waiting for with all the research comes around...We are totally out of luck? Yes... K ...Now the reverse Isolation at home...Just to simplify it...Justin becomes a bubble boy right...Everyone in the house wears masks we screen people coming in and Justin is isolated...I guess you can describe it like that. So the end result is that what we have we cannot keep, we do not know if this will help Justin and by doing it we make him a bubble boy and isolated for a year and 1/2? Well...that is really putting it simply...those numbers are not necessarily correct. But none the less...not too far off? Well...Yes. K... I already said what my answer is that is NO...Now everyone else say your peace now...Number 2 son pipes up ...Well my Mom has not been wrong so far...so NO, each boy said NO one right after the other...then Dad said BUT...well I said ...You are out ruled...So even if you said yes... We all have agreed NO so that is it...Justin piped up...Lets go home and have some fun.

The Dr. looked and really didn't know what to say. His nurse just sat there, wondering what had happened and a 1hour meeting turned into 3 hours. We all came out, the boys shaking the Dr's hand and thanking him for all the information...We walked out to find our Primary still there pacing and looking over at me and saying NO...right? Right I said...knew it when I saw all the kids here. WELL I said...You want to play games with numbers and stats then I come back with my numbers and these are the ones that count. He asked if we would consider more chemo right now... I said NO in fact we are going home so I will think about it and get back to you. Oh he said we have a bed for Justin so we can start more chemo now...Oh, sorry it will have to wait...Justin piped in again and said..."Yep going home to have some fun!"

Dad was still talking to Dr's and trying to get more information, but the rest of us left. We went to the car to go home. Our family is so large that we had to bring 2

cars so Justin was trying to figure out which car he was going home in...Such a big decision for such a SMART boy!

Late today, had appointments to meet.

The next 3 months were the best ever. We did what we had to do. Took time to enjoy life. Justin went everywhere. He followed his brothers, and even came home driving the cars...The expression on his face, steering the car home. Telling his brothers...

NO let me. Every time they would hit the country road Justin would yell...MY TURN!

We went for the flushes that were necessary, and was told each time we needed blood, but said O.K. because we are here, BUT no way are we coming back each week for tests, unless there was a problem. They even called our primary Dr. and he said Yes...We agreed that if there was a problem then she would bring Justin in. There was NO problem so why...get picks to tell you your levels are O.K. That is one thing with a child with cancer...a parent doesn't need the blood test to tell them that the levels are low.

Justin swam each day, we walked in the rain, getting totally soaked and laughing all the way back. We rode the horses and played good guys Bad Guys. Running with the Horses through the fields and into the bush out back, hiding behind some trees trying to hide from each other.

Justin so often said..."Ah Mom this is so much fun!" Yes Justin it was.

There was a horse show that came up in town, and that is one thing Justin wanted to do. He wanted to get to be in a show with Cool Dude. So we prepared and got Cool Dude all spiffed up and Justin too. The morning of the show it was pouring out. My Hubby said you are NOT going to go. Sure am...I said. This is something Justin wanted to do. So prepared we did and off we went. Arrived Justin in time for his event and it stopped raining then. He entered the ring to the Announcers: Now entering the ring riding Cool Dude is the Bald Headed Cowboy! Exactly what Justin wanted to hear. The crowd was small because of the rain, but everyone cheered and clapped for him. Flashes everywhere...most coming from us LOL. He did his stuff, Cool Dude was a gem...people had tears in their eyes watching this little boy so full of excitement and life putting his pony through all the paces. Justin won first place and got his ribbon. We got ready to re-load the pony when the heavens opened...and the show had to be cancelled. I looked at my Hubby and said...you thought he would not get the chance to ride. Hmmmm now was he or wasn't he suppose to be here? Before we knew it November had come and it was time to get ready for Christmas. Ahhh #2 miracle I guess because the Dr's thought we wouldn't be at the last season together. So take what we can...and make the best of it.

Justin was very happy with all the decorations and such. Each day we would put out more and more. The trees were lit, Santa and his Sleigh and reindeers were in the front, and the Elf was climbing the drain-pipe to help Santa out when he came. All the preparations... for a Great Season.

Then one morning nearing the end of Nov. Justin says..."Mom my cancer is back again!" Heart stops...didn't even get that extra thumping this time...just nothing. I looked at him and asked where...He said pointing to his primary...here and here. Oh brother. Got him dressed and went to cancer clinic. Said nothing to them just wanted blood done. Waited for the results and all was well. The Oncology Nurse came over and asked what was up??? I told her that Justin said his cancer is back. She looks at results and says that they are perfect. I said well results sometimes do not tell the truth. I'm making arrangements when I go back home to call Toronto. Think we need a check up. This was a Thursday and I new that Clinic for our Dr. is Monday so would be flying or driving down on the weekend.

Called Toronto and they asked if I would go back and get some tests done here. I told them to call the Dr. here and arrange it. Got a call shortly after that telling me the paediatrician wanted to see us at clinic now. Really didn't say much to the rest of the family. Justin and I just did what we had to do. Thank goodness we got all the decorations and such done...as NOW...my mind was well away from the season.

We drove back to clinic to wait for 4 hours. The Dr. was busy. Why did they book for this time if he is NOT even coming until 4 more hours? No one knew the answer. Just Breath...Just Breath....

Finally the Dr. came in and we chatter for a minute. I asked for an ultrasound just to look at primary and see what is happening to the edges. He said he wanted an MRI. I asked would you get it today? He said NO maybe by next week. I said NOT waiting that long so lets just do an Ultrasound. NO he wanted a MRI. I was upset now...because here we go again...not listening...WHY??? He answered so he can compare. Compare what? Well the other tests that we've done. Well now I was fuming. You never did any test here and you have absolutely nothing on Justin's chart since Feb. You do not know... that he had a re-occurrence in April and that he had full radiation and Chemo. You do not have any results. He looked at me and said Oh Yes I do! Well show me them. I was MAD!

You do not leave a mother who is a nurse in a room for 4 hours with her son's chart and think she is NOT going to read everything. I knew they had NOTHING on the chart. I picked up the chart and said here read...they really isn't much so it should take you 2 minutes. Well the nurse just stood there. I started to dress Justin back up and thought to myself that is it. I really do not need this right now.

The Dr. looked back at me after he glanced at the chart, and sheepishly said I feel that a MRI will give us more of an idea of what is happening. That is fine, but today then. Well I'll put him on the stat list but it will take until at least next Friday. Not acceptable is what I said. By this time I had Justin dressed. He said I wanted to check him...for what I asked? Listen here...His cancer didn't wait the first time you ditted around, and it certainly is NOT going to wait NOW! So there is NO need for you to check because you are NOT even sure what to check for. He looked at me...knowing I was really mad now, and said he wanted to check his primary site. I asked...tell me where you are going to look. He looked back at me...said nothing and I left. He didn't even know where to look.

What a DAM mess!

I got home...emotions right back where they were, and called Toronto. Primary Dr. called me back told him what Justin had said. Also gave the blood results but said...believe me we are in trouble again. He asked if I went to clinic said yes...but they never listen so I left. I have NO time for this right now. If they want to mess with me this time...then they will never forget me... He asked when we could get there. I said for clinic he asked if we could come sooner, I said Have to call House to see if there is room.

Called and yes...we were lucky a family was just leaving. So booked it. Call the airline and Justin and I were leaving that night. Called Dr. and said see him on the floor because I will not go to the Emerg again especially if they have to access, so might as well go straight to the floor and see you there. Agreed.

Well hubby came home from work and the kids from school and now was time to tell them Justin and I were leaving again for Toronto. Explained about the last two days, and that Primary was meeting us tomorrow morning on the floor. Hubby decided that he would come this time so we would drive down tonight.

Agreed...feeling like I really didn't know if I had the strength to go through this again.

Justin just was fine...he went about his business, got the kids to bring him to McDonald's for Chicken and fries and got back just in time to leave. It gave me a chance to cry my head off. To be angry and frustrated all over again. Bid our goodbyes once again and headed to Toronto. Got in got our room and Justin was starting to have trouble to walk again. The tumour was starting to show again, and once more his legs and hips were so sore. By the next morning he was wheelchair bound again.

Was at the hospital by 8 and waited for the Dr. to come and see us. Was really surprised because he was there by 8:30. Talked to Justin, asked him what was going on, he told him, but added "Dr, M I had such a good time!" Tears...tears in all our eyes...that is all he wanted was a good time, and he got almost 2 months of it. O.K. stop...have to decide what happens next.

In the back of my mind I know that radiation is OUT we used it all up. Knew that protocol Chemo is not working, and also that removing the tumour is again NOT an option...Now what? Today is Friday and know that weekends at the hospital is slow, so know that NOT much is going to happen for the next few days. Primary said he wanted to talk to us again about 5 he was going to check into some trials and see if there is one for Justin to try. Oh boy...do we go there?

Back to the HOUSE. Justin really was starting to feel not well and since he was not walking again stayed in the room. We all stayed there but finally I went downstairs to have a cigarette. I met a lady that said Hi you must be B yes I said and she introduced herself... Kathleen. Hello how did you know me? Well she said from some of the mothers here, they talk about you and Justin all the time. Oh ...yes and just by their description I knew it had to be you. We sat for a while. He son Alex had a re-occurrence in Oct and they were here now until this new protocol will be done. How long I asked 2 years! Wow...found out she was a mother of 7 and Alex was her youngest. We hit it off like we were born family.

The weekend was spent very quietly. Both Hubby and I would take time for a smoke but that was about it. Dr. M had given us a trial to look over and tell him Monday

morning if we wanted to try it. Justin was sore...very sore but at least the Tylenol was helping the pain right now, but in turn making him sleep.

Monday came and after talking to the boys and Justin said yes...we would try this trial. There would be test for the day to see if we could start tomorrow. It would be 3 days of out patient chemo then go home for 2 weeks then come back again. Because it was the close to the holidays we would try to get the last 3 down around the 20th and then wait until Jan 2nd for the next 3. Agreed. Lots of side affects on these. So lots to watch for. The main one to expect is diarrhea. Usually starts the same day as treatment, so there is stuff you have to take for that or he will dehydrate so fast.

K...lets do it.

This time my heart was heavy...the times before it was NO WAY...this is what is going to be done. This time...was... Listen, agree and do. Even Justin had the same mode! I watched him carefully at all that he was NOT saying. I asked him again one night what do you think? "Not sure!" k then we will go for it. "K Mom"

Next day started...had the treatment which took about 3 hours to go through then about 1/2 hour flush some blood test then home. Back the next day same thing. Third day same thing. Hmmm no diarrhea...are we going to luck out? Went home after 3rd treatment. Knew we were coming back so bid our farewells. Made arrangements for a room, but you cannot book the room so they knew when I would be coming back and they would keep our name on the list for the room.

Got home...feeling pretty PUNK...but doing what had to be done. Got the last minute stuff for Christmas...made sure the food and stuff were ready and headed back again just Justin and I this time for the next bout of Treatment. Still No bowel problems so we are lucking out. Had 3 more days, Justin was just starting to get back on his legs, but still in the chair. He could walk now holding on to things, so when we would go down stairs, I would watch him watch the kids playing. This broke my heart. He would smile and yeppii with them all but I could see the longing to be right in there like the rest. He couldn't even play hockey.

Thank GOD for Kathleen...she just seemed to know. Talked when she had to and kept still when that was needed. One evening just the two of us there she asked "what deep in my heart it was saying". I looked at her and cried..."We are Done!" I balled my eyes out. Kept this for this long and now it just came. She sat next to me...hugged me and said nothing.

Next morning was 3rd treatment and the 20th and we could go home for another Christmas. Dad had to be in Toronto on work so he was going to come and pick us up at the hospital and we would all drive back together.

Got home rather late that night, we were all tired so had a tea and went to bed.

Justin was just so quiet. Next day found everyone doing last minute stuff for Christmas and ME...well again the run and hide was presenting itself to me again. I wanted to curl up. Justin and I decided that we would go for a walk out back. Got as far as his pony and the pony took a fit. It was really funny. Cool Dude wanted to come too. Justin asked if we could bring Cool Dude and he would ride. I said yes. Put the winter blanket on the Pony and put Justin up...but he couldn't sit up there. He was sliding and falling. Poor Cool Dude was trying his best to keep Justin on but it was not working. Justin started to cry..."What is wrong with me MOM?" I couldn't hold back...Tears and sobs "Nothing is wrong with you Justin it your

cancer!" "DAM CANCER" came from his little mouth. I didn't even say a word! Then he looked at me and said..."Mom...I just want to have fun again O.K?" tell me what you are saying Justin, He looked up at me and said..."NO MORE!" I have to stop here...tears and sobs and hearing his voice again...Justin has made his decision and I had to LISTEN...even though my heart was breaking it was a promise!

**"Do what you feel in your heart to be right -
For you'll be criticized anyway."**

My heart exploded...my head felt like it was ready to blow up. NO MORE...mommy NO MORE! Tears and hugs, looking at Justin knowing exactly what he was saying. Wanting so badly to renege on my promise. Wanting to convince him, knowing that I could do that. BUT...remembering my lessons through the other children. Knowing in my heart...Justin had spoken...he told the truth...and we are now entering another phase of this journey now...one I knew was coming, but praying and pleading it would never arrive.

That day was spent in tears...not saying anything to anyone. Looking at my son... and watching... Thinking and remembering. The next day through the tears I asked again...Justin what do you want to do? He looked and said as clear as can be..."Just have fun...No More!" I hugged him and said...O.K. Justin it is your time.

Put my efforts back to Christmas...It was just a few days away now, and this time I KNEW it was our last Christmas together. Didn't mention anything to anyone...we needed a good Christmas. Put my feelings away when I could. Made sure Justin was pain free for as much of the time I could. He would come and say...Mom my legs hurt...I would give him Tylenol to take the edge off. Off he would go. Like usual the Christmas day was at our place. Food for everyone... Outside fun and hockey games. Friends came to spend the day with us and even my Friends Mom came to celebrate Christmas with us. It was glorious. Justin was out skating on his rink the boys had made, and believe me we do not do things small. It was HUGE. Horse and sleigh rides all day long while the women did the final preparations for our meal. Many times my Friend C would look out and say Look at Justin he is having so much fun. I would try NOT to look because in my heart I knew...this was the last time. Last time to go on a sleigh ride, last time to skate on his rink, last hockey game, last body check...Oh my ...My heart was aching...Just took peeks as I was afraid I would burst out in tears. My friend would come and hug me, her mother too. The tears just came and went, but everyone felt it was Tears of the season!

It was in a way...because Justin was doing what he wanted...finishing what he had to finish. Every year we do a CrisKringle with the family, but Justin decided he needed to buy everyone a present this year. I also knew he needed to do this. So out we had gone and you guessed it Justin found Butterflies. He bought each family member a Butterfly. Wrapped it himself and when the gift giving was complete he ran to get his present for everyone. The boys and Hubby said Hey Justin you are NOT suppose to buy for everyone...he said I know...BUT here! Tears are all I can say. My #4 son came close to me and asked what is up? I looked and smiled tears rolling down my face and said...He wanted to do it. Not the right time yet to say anything.

We needed this time as a whole family. I let my feelings stay in the back except for the wee mornings and dark nights. Occasional Justin would come and snuggle and just say "Thanks MOM!" Oh my when I think of it now...Not sure how I got through it...but we all did.

Each day Justin's pain was getting worse. I was hoping that we would be bale to hold off till Jan 2nd, but the 26th saw a lot of pain and the Tylenol was not doing the trick. That night was spent up rubbing and kneading his legs. That night I mentioned to Hubby what was going on. He just looked. Said nothing then the tears...He looked again and said what are we going to do? I said what Justin asked... "NO MORE!" He relied immediately...no call the Dr. we have to bring him back...maybe it is the trial and this is what is suppose to happen. I cried...No Hun...it is done! I said it...always had it in my mind...but said the words out loud. He just cried while we held each other feeling so lost and helpless.

Next morning found me calling Toronto. Talked to Primary and explained what was happening. Not that Justin said No More...just what is happening. Told him I would really like to wait it out till the 2nd, but need stronger meds. Talked again about what and that I would regulate the doses. I then said...you call the Dr. here and tell him exactly what we need, the dosage etc...O.K. He then called me back and said go to the clinic the Dr. will be waiting for you and will have the script ready. He added You know if you have to...Just come back. Oh you can rest assured that is what I would do.

Went to clinic to find the Dr. had left a script alright...Not the dosage we had agreed on and not enough to get us to the 2nd. I said to the nurse call him up...this is wrong. She said but that is what he ordered...NO I said this will bring me to New Years Eve...and if I need more we spend the whole night in Emerg with the drunks? I really should not have said that...but it was correct. No way...call him right now. She did and came back with her head hanging. He said if you need more then see him in Emerg. That's it...Never helped before WHY would I think he would listen now. She looked asked me what I was going to do...Go back to Toronto. Can you??? Who will stop me...of course I make all my arrangements in advance. Yes I can go there and we will go tomorrow.

Took the script, got it filled knowing now I would have to regulate it with half dosages and full. Why do they not even listen. I called Primary back he told me what he said to the Dr. here and then I told him what he gave me. WHAT??? See I told you and so many others have said the same thing!...When we come back home...the Dr's here do not follow what the Primary Dr has asked for. You people think we make these things up. That is why I wanted you to call...now you KNOW!

Made our arrangements to be in Toronto the next day. Justin was in so much pain and the Demerol was just making him sleep, the pain was still there. Called the airline to change the flight from the 2nd to the 28th and was told NO... It is the holiday season...well this is an Emergency...well sorry we will not re-book right now...I was so Mad I said well then "GO TO HE**!" Again not nice...but again another one who would not listen. I hung up the phone defeated...how do we drive down to Toronto 4 to 5 hours with Justin in so much pain. He cannot sit... it hurts too much. You just do what you have to...so in the back of the car he was placed, blankets and all...pillows for his legs and we headed back.

Back to the new start of our journey...the one we all knew would come one day...but never prepared...never prepared... never prepared. Emotions are high with everyone, so snapping and tears... little digs and snide remarks...we all did it. I think I was the worse. BUT...not with Justin present...we all had our MASKS on in front of Justin.

Got to Sick Kids and had another Dr. He was short, crude in my opinion, and started the conversation off with..."I really do not care how you feel or what you think, My concern is just Justin so here is what I am going to do!" Well my mouth dropped, I looked at him and said...excuse me...this is my son and I do things for him and only him...My hubby piped in "Don't mind my wife she is very upset!" Oh wow...here we go again...when I need support and backup again...like the other times..."Don't mind my wife...she is upset!" Upset was NOT the word...I was livid, and now my thoughts were clouded with anger. The Dr. just proceeded on with what he was going to do. Morphine...pump...and it will be started now. I couldn't think although I knew where we were on this path, my mind went numb...didn't work I was angry at the Dr. for how he spoke... my hubby for not backing me and now my most dreaded drug is being started.

The only way to express the next few hours was LOST, and AFRAID. Trying to find a way out, but there was none. My friend Kathleen had her son in Day Care, so when we went in with Justin there she was. Thank GOD...I looked at her and she said come on lets go for coffee. We went down stairs and I exploded...I cried and cried, I smoked and smoked...and said..."It's Done!" She cried with me, but said nothing. Finally we went back upstairs, not really knowing where I was walking but like a magnet attracted to another magnet...just got there. As I entered the nurses were getting ready to start Justin's morphine...I lost it again. I looked at my Hubby and said "This is wrong...This is wrong...and if you were not here...this would not happen!" Kathleen had to take me out again...I lost it...losing the control I had for

my son's treatment, having to somehow come back to terms that this is not treatment, but I had to find that Quality of Death...I knew had to be...but how do you find it...when you are losing your son? It didn't matter now...that my Hubby was losing a son too, or the boys were losing their brother...Right now Justin was MINE...and now I changed my mind...I don't want to give him UP!

K have to stop... Love to everyone! Hugs Butterflymom

Wow when I think of it now...if it was not for my newly found friend...I could have walked into the busy streets of Toronto. I could not even breath. The fear that had lingered deep in my heart...has come to pass. The knowledge...here...

I had to take about a full day. Couldn't talk to anyone, had to figure this out for myself. Realizing the next step is not close...but here. Trying to find that Quality of Death...Not knowing even what I meant by that. Said the words, but WHAT IS...Quality of Death?

Everyone stayed very far away from me. Dr's would come in...I would leave...Hubby would sit with Justin...I would go outside for my breaks. Nurses or Volunteers would come in...I would go for a walk around the hospital...Just needed to be with me...Just ME! No questions...no more thoughts...for my head was full.

I was again outside at the Pillar sitting and watching life continue on for so many people. I wanted to stand up and scream...hey all of you...why are you smiling and going to work? Why are you joking? Don't you know???? Don't you KNOW??? I sat angry that life continues on...I didn't even want to see people happy right now. I was in a pain that is indescribable, I hurt...so I wanted everyone else to hurt.

Then...my Man appeared again. I was watching...but never saw him approach, he just was there...standing right beside me...I turned and looked and for a split second, I wanted to hit him...Looked again...and he said..."Lady...Pray to Michael...Pray to the Arc-Angel Michael. I looked again at him...he was expressionless, he looked right into my eyes...and I cried. He never touched me...only stood next to me...I cried for a while, someone came over asked if I was alright. The Man said yes...Then I sat in silence. He stood next to me. I'm told now that some of my friends that I had met had come over to the Pillar but the Man shoosted them away. Finally after some time...I looked at him and said thank you. He smiled and said he had to go. Then turned to me and gave ME 2 cigarettes...Oh brother...now the tears were really coming. I always gave him 2 cigarettes...I knew this meant I would NEVER see him again. I stood up...hugged the MAN, he hugged me back and slowly left, turning after a few steps to see if I was still there. I stood watching him till he was no longer in view. Tears streaming down my face, with 2 cigarettes in my hand, and waving each time he turned to look at me.

I must have sat for a few more minutes when one of my friend returned and asked if I was O.K. I looked and said I think so...Kathleen showed up with coffee, and sat

with us...before long there was many at the Pillar. NOT talking about Justin but sitting and smoking...saying very little.

I went back upstairs feeling...Questionable, but knowing that everyone was going to get through this mess, and that Quality of Death would present itself to me and when it did...no-one would shift it's path.

The next couple of days found the Dr's trying to regulate the Morphine. Justin was in extreme pain, even the nurses were in tears when they came to check on him.

Cleaning staff would peek in and cry. Justin was such a Happy and delightful boy...here was a child lying there...sedated, but crying out in pain. We had 2 teams of pain management...Pain Management and Chronic Pain Management. When I say team I mean team always at least 3 in each. I look back now...and sorta laugh...I think they figured they had to come to me in Teams...LOL

It was NOT fun...I would sit and cry next to Justin...I'm searching for quality of Death and this child is suffering. Our Primary Dr. came in and said they were going to start Palliative Chemo...I knew Justin's blood levels were not high enough for chemo...so not wanting to really discuss things said sure...let me know when you think you may start. Hubby had decided to go home for a few days, and would return with some of the boys. Of course to make matters worse for everyone it was exam weeks at the schools. Where we were going... I had NO clue. Well I knew where we were headings but how we would get there was the question.

I needed that time again just Justin and I. Throughout this whole ordeal it always was Justin and I with the occasional family visit or appointments to go to.

BUT...Justin and I.

It was what was needed again to get my head on straight. That night after Hubby had left...I was resting my head on Justin's bed. He took his hand and stroked my head...Justin are you feeling a bit better? "No Mommy it really hurts...and you know this pump thing? Well when they push it...It makes me NOT be able to tell you it hurts!" Wow...like a ton of bricks...we already knew that morphine did NOT ease the pain of muscle and bone pain. I already knew and refused it before. What was I doing? I had backed right away...and was letting the hospital take back over.

When I fired the 8 Dr's in our room when they gave up in April...I took an new position. I was the team leader...well this team leader was coming back.

The next nurse that came in I told her I wanted to talk to the Pain managements teams...both together. I asked that she let our Primary Dr. know that I wanted to talk to him too. Was informed and yes...he did tell me he was away this weekend and who would be replacing him...but just didn't listen. Not knowing exactly what I was going to say to these guys, but knowing I needed to talk to them. Justin began to cry in pain...and what did I do? Pushed the Morphine pump...He heard the whoosh...looked at me and SMILED...yes he smiled and raised his eyebrows...Oh

brother...I just leaned over...after all we had just talked about and pushed the button. I smiled back and said LAST time Justin LAST Time. I sat and stared at him...now thinking of the last 5 years...thinking of the time and how he came to our lives...thinking too this will all be gone very soon.

Hubby was coming back the next night and was bringing #4 son with him. The others had exams on Monday. They would stay till Sunday. The Teams came in and I asked...explain to me again what you guys are all doing? Explain the meds and

everything else...I think I can hear you now. They smiled and began to explain. I just listened. Then some lady came in and said she was there to take Justin down for a Kidney and Liver function test. Why I asked...I guess the Dr. ordered it...Well no one told me so NO. By this time a Registered Nurse Practitioner came in. They head these types of cases and she can order and stuff like that on the children. Well sorry NOT my son. She tried to explain why she had ordered this and just to let him go for it while I talked to the Dr's. I looked and said...sorry anything that goes on you speak to me first and then I will decide if...he will go. She looked at me and said...WELL Mrs.V You know that his kidneys and liver seem to be slowing down...we want to see how much? I looked at her and said..."GOD He is Dying...of course these things will slow down...guess what they are going to stop...with these test are you going to put him on treatment of some sort to keep them going?" Well NO..."Then why do we have to know now? Beside you have to pick and pick...looked at him his veins can't take picks...NO!" Then looked and said when did his kidneys start to slow down? She said Yesterday...when you came on? She just looked...then I looked over to the I.V. Gosh who put it so high? Well I did we are flushing him...O.K. here...listen carefully...the I.V will drip just to keep the vein open, Dr's the Morphine is coming down now...and if you guys can not come up with something that helps Justin's muscle and bone pain...then you know what you are all going to listen to him cry. If I want a 'lala child'...I could go on any corner and buy drugs...BUT I will NOT have Justin's last days...like this. They all just looked. At this time...the Lady who came to get Justin for the tests says...Well am I taking him...I said NO she looked at the Nurse, she shrugged her shoulders the Lady then added...well do they know downstairs, and I said..."They will when you go back down without Justin!" Oh...and she left.

I then turned to everyone there, and said...we will have another conversation shortly...because my head is starting to work again. They all just looked... some left except for one...he said there was a drug that tricks the mind to believe there is NO pain. Anti-convulsive drug...I said bring me a write up about it...I'll read it and then decide. BUT don't give me those Parent drug guide ones that say nothing. I want the ones that come with the drug from the pharmacy. He agreed and would have it sent up right away.

Now I never checked at this time if the Morphine was turned down, which it wasn't but right now that was O.K. we would just take the continuous no pushes... Wasn't a great day or night...Justin was in pain...but I knew the Morphine was just putting him in a state that he could not talk and express himself. I also knew we could not take him right off of it, and again thought back...But stopped myself...I cannot change yesterday but ...I can change today.

I sat next to Justin most of the time. One of the cleaning ladies would stop in regularly to see if I needed anything. She would even bring juice or a coffee for me. She was so special. She came in and asked if I wanted to go out for a smoke. She said you have not left this room. I looked at her and said Just one...would you sit with Justin? Yes...It was her break and she wanted to sit with Justin. I ran downstairs and just had one smoke. I think I just inhaled it...LOL Back on the floor I could hear Justin yelling something. I hurried to the room to find the Cleaning lady in tears... As soon as I left...Justin woke up and asked..."Leana could you help me???"

Get me out of here..." She said she couldn't get him out of bed but could call the nurse he said you Leana just you...but against policy...why won't you help me??

Leana was in tears...I hugged her, and told her it was the morphine talking and asked Justin what was wrong..."He looked at me and Said..."MOM I HAVE TO GO HOME!" Yes Justin Mom was going to bring you home as soon as we can manage your pain. He looked at me and said..."You don't even know what you are talking about...LISTEN...I Have To Go HOME!" Then fell back to sleep.

Poor Leana...she was crying and saying my heart is breaking...Tried to reassure her and said come back after again and he may be O.K. then. The new Dr. for the weekend came in introduced himself and said he was on the floor all weekend so if I needed anything have the nurse page him. Really didn't have much to say to him.

Next day Hubby and Brent were coming and Justin was excited about it, but in and out of 'lala land'. They arrived shortly after supper and came in...#4 son had a new mini stick so Justin and him could play hockey on the beside-side table. Justin heard them and opened his eyes...Where are you Brent I can hear you...where are you???

Come here...come here Brent why won't you come here. He was screaming it and Brent was right beside him... Again tears... Brent who is over 6 feet fell to his knees...crying..."oh my brother!" Hubby stood there and said nothing he was frozen. Then it hit me...Justin's words..."Mom you don't even know...you don't understand!" The morphine was still too high as a continuous drip. I looked and realized at that minute. I know now Justin...I pushed the call bell said I need to speak to the Dr. and since he was there on the floor he walked in behind the nurse. I looked at Brent, now sitting in a chair holding his head with his hands, Hubby still standing and staring and I started...O.K. listen here...I want this Morphine down to the lowest amount. Morphine is preventing Justin from even interacting with his family. That is it. I want it at this level IF I feel he needs more we can use the bolus or asked for an increase. There is NO discussing this. YOU KNOW...that morphine will not help his pain just put him in 'lala land'...and you know what...he needs whatever time he has to finish business. I nearly fell over...he agreed...I was actually stunned...he told the nurse to lower to exactly what I had said, which was done right then, and then they both left. My #4 son started to laugh..."Wow Mom you had your finger up his nose almost!" Justin piped up and said...what you laughing at Brent?

He said Mom know now and "NOW YOU UNDERSTAND!"

Yes Justin Mommy does and we are going to bring you home soon. Come on Brent sleep with me. They cuddled into the bed together, I left instruction...NOT to let them do anything while I was gone...and Hubby and I left. We went for coffee at a restaurant because we had some planning to do.

**"Enjoy the little things,
For one day you may look back
And realize they were the big things."**

Hmmm...Just take a few minutes today, and ask your kids, or spouse to tell you

their greatest memory. Anything...You will find that it was a little thing...that made a big difference in their lives!

Planning...that seems like such a stupid word right now. For the plan is already in motion. But the planning that is left for us to do right now was finding Quality of Death for a 5 year old child.

We went for coffee and if I remember correctly just sat. Drank at least 2 coffee before either of us said a word. Our whole lives were in totally chaos. Getting through the days was going to be very tough. We had to have something in place. Hubby cleared his throat...between the sips of coffee tears were just coming so we would wipe our eyes and sip again. He gently said well...what is next? I looked over and began. It is so important to find that Quality we all agreed too. Not even sure what that means, and especially now. I think we need to get some things in place. We need to make arrangements for his passing. I just need to get that out of my hair so I can continue. I cannot have that hanging over me each day. When Justin is strong enough to go home, then we will call the funeral home and make all the arrangements so one call is needed. Also I want Justin home...NOT in the hospital but at home. All of you have to realize what that all means. You will all have to agree, because once he is there...he will never ever go back to the hospital...not even to be pronounced. Hubby looked and said O.K. But I added NO we will have to have a family meeting. This is a family decision again. I know what I can handle...but there are 9 of us. Also... I have NO intentions of any more treatment...not even the palliative. No More...Justin said it...not crossing the line now. Hubby looked and said BUT Primary said when his levels rise we would be starting some chemo...you said O.K. to him. Well I had NO energy to start fighting then...but when his levels are up...we are taking him home. Hubby just looked...NO MORE I added. Could see the 'I do not agree here look' and the apprehension to say anything to me for fear of me blowing up. Right now that is exactly what I needed...Just listen to me...this is the way it is going to go. There are some choices, but this is NOT one. We chatted about our feelings for a while then decided we better get back to Justin and #4 son. As we walked through the halls...They now seemed longer than ever...darker than ever... and quieter than ever. People were looking at us...I could see the fear in their faces...Oh No This could be me! I could see the tears, and 'the what can I say look'. I saw the head nods with tears. I really could not deal with it all, so tried to the best of my ability to keep my eyes away from people. As we passed the Nursing Station, I heard the ward clerk Mary pipe up and say...your family amazes me...I turned to her and didn't say anything...but had that question look in my eyes...They are all here. I looked at her and smiled, tears streaming down my face...and looked towards Justin's room to see tons of people. Yes...boys made what ever arrangements they needed...well lets just say the boys have their Mom's personality in some things, they had gone to their schools told them that their brothers life was a bit more important than a darn exam if the school could not understand and needs to follow some rule that right now does not fit with our family and wanted Dr. reports before they left...then fail them all. Actually when the story was told...All the boys went together from school to school to give that message. There were 5 sons, 3 extended family members living at the house and one girlfriend who had been part of Justin's life

since the being, and she was very much apart of our family. She did not live with us, but in the same area. All left the same message with their schools, and together they all walked out. You know...I almost yelled yepiiii...I was so glad to see them, yet so proud that they did what they did. Some were in High School some in University and some in College. This was finals and could mean the whole semester lost. But in the back of my mind...When I got home...that would NOT happen. But the strength to do what they felt was right. My next thought was that there was another Dr's appointment tomorrow and again...when it really counts my numbers are higher...and they count. Wow what a great feeling...Together we were all going to make sure that Justin walks his finally path...HIS WAY! Not a Hospital Protocol...BUT HIS WAY!

We gathered in the room...many sitting on the floor and I told all what decisions were made and what had to be made. Our oldest son agreed that when they got back home, that Jeremy and Spencer would deal with the funeral home... and make the arrangements, come to us with the plan and we would make the final changes if necessary and then they would get that all done. They did not want either Mom or Dad to do that...just the final stuff was all. All agreed right away that Justin was coming home. I then explained what to expect and that right NOW was NOT the time to say yes. That each had to be comfortable with death in the house...for we would continue to live there after Justin had passed. So that would be made in a few days. We discussed some treatment that oldest son and girlfriend had found through professors and contacts. Some man who does herbal stuff in the dessert somewhere in the States. We all listened then they wanted to talk to me. I agreed with them and added they had to get certain information and stuff for me first. They were so glad to be able to look for more. Other son's and Hubby said ...You're not thinking about this? I said...I have many to worry about right now. I hope that this doesn't come to past, but right now this is both their needs in coping with the fact their brother is dying. So YES...I want them to keep trying. They need to feel like they tried to find something as well. All just looked, said nothing, but again said, but Justin cannot go and stay in a dessert. Well we will see. END not discussing it further right now!

During all the talk about what is to come and what the plans were Justin was there.

He added his two cents worth. At one point he said..."come on boys...I'm going home." We laughed as he had that way about getting his own way all the time, so I added Justin we have to wait and see... K Mom but you know I'm going home right? I looked and smiled...he smiled back and that was that. We cried together and talked about the good times as well. Justin was well into the conversation, and it seemed as though the Morphine again could not cope with family and its LOVE.

The next day Dr's came in... Not surprised this time when the room was packed. Came in asked if there was anyone who should be leaving...I said NO this IS Justin's family and the Dr's then said their stuff. Again boys asking their questions and sharing only what they want. I then talked to Primary outside of the room and I could hear Justin say to everyone..."Mom is the boss here and she is telling the Dr. about the dessert now...I know!" Funny thing was I was telling him, and explaining that I pray that it didn't come to pass as I really have NO energy, but the importance for the family members to feel they have added to the search. He looked

and said...I hope you don't go there either, and added but I know what you are saying. K... then he wanted to talk to Hubby and I in private...I said brothers as well, extended family will stay with Justin.

In to a room we went...I knew what was coming but everyone else needed to hear it themselves. I walked next to the Dr. and said to him...Please...be straight...tell them it is over...there is nothing else and the end in near. JUST be straight. He looked at me..I added No cushion stuff...they KNOW! But need to hear it. Not from me...but you!

The meeting was again longer...Primary started and was great...he told them all Justin is dying. We cannot put a date on it but in their opinion with in the next 2 weeks. His cancer is growing quickly and unfortunately a debilitating type. Boys asked what that meant he explained that he would lose control on all body functions...They asked about PAIN...and he said your mom is right, we can take the edge off, but until the cancer presses on nerves that stop feelings than he will be in pain. Oldest son cut in saying...but MY Mom will have control on his pain once we get home right? It will be regulated by her...not the Dr's back home. Hmmm raised eyebrows...Let me see what I can do. NO he added with others repeating the request...My Mom will take care of Justin. When everyone was finished asking their questions, I added...I have not talked to anyone about this...BUT...can any of Justin's organs be used for transplants...Silence...complete silence...for a minute...it was long...then the Dr. cleared his throat and said unfortunately NO...They could not take the chance with cancer, and transplants. He then looked at me and said...you caught me totally off guard here...never thought I'd hear this...we usually have to ask. Tears were falling from my eyes, but I added been here for almost 2 years now...and have seen many children lose their lives because a match could not be found. We are going to lose our brother and son, so maybe thought we could save someone else's child! Figured so though...but thought I would ask. Then the Dr. cleared his throat again...looked around and I piped in... Oh by the way...we do not want a code on Justin. If something happens...we want a Do Not Resuscitate Order on the chart now, and one for when we fly home for the plane. When we get back home will get it in our hometown. Again silence...I Dr. looked over at me...because this is what he was going to ask, but trying to find the right words. Everyone nodded but NO WORDS!

The Dr. left but we all stayed in the room together...everyone thought over what was said...and I caught a few of them checking their drivers license and checking off... in case...organ donation.

Hugs
Butterflymom

The boys could only stay that one full day and really needed to get back to school and stuff going on there. They all arrived when needed and now it was a waiting game for Justin's blood counts to come up. Boys left and Justin was telling them all to get things ready for him. He had decided that having his bed in the living room would be the greatest

that way more people could have sleepovers next to him. He had great plans for his return home.

Wednesday the Dr. came in early and said that Justin's levels were finally starting to rise so he felt with in a day or two we would be able to start chemo. I looked at him and said NO...Make the arrangements we are going home. He looked at me and said NO we are going to start Palliative Chemo first...I said NO. He looked again and said you knew this when we first spoke about it...Yes I said...why talk then when I knew what the answer was.

Hubby just sat there and looked said nothing. I then added that going back North is NEVER like here. So I believed it would be best that we transferred to the hospital there first to make sure everything is in place for when we go home. Dr. agreed and said he would get right on it and should have things in place by Friday.

Was sitting in the room and then I could hear Justin yell out JUDY...You came...I looked up and there was my friend Judy. I had forgotten her daughter had an appointment and I also did not tell her what had happened. So in they came...she asked what was going on I went outside with her and told her...She was in shock...No... Not My Justin...Please NOT MY JUSTIN...If anyone was going to make it, it was him. We went to the quiet room for a while.

I think at that time Hubby had explained to her husband what was happening and they went outside for a breather. Once Judy was feeling a bit better we went outside for coffee and a smoke where we found the two hubby's. Judy's Hubby asked if we could we go for lunch after, we agreed then went back upstairs. Justin had not been eating or drinking, but when Judy saw him she said Justin have your coffee yet...NO...Want some...He looked you could see he wanted to say no... but said O.K. Judy went to the floor kitchen and made his usual smidgen of coffee with full cup of warm milk. She came back sat next to Justin...I could see the pain in her eyes...as she looked at Her Justin...Her Buddy...Her friend! She would wipe her eyes every once in awhile but looked up and said if Hubby and I wanted to go for a smoke that she would sit with Justin...Her Hubby and Daughter had gone to register for their clinic. I knew that Judy needed her time with Justin...so off we went.

Now the word went around the hospital that Justin was going home. People came from all over. They wanted to say their goodbyes. Justin was fine with it...mind you when I would get upset...I could see him getting upset...so it was a very difficult time for me. Also there was one nurse that had stuck by me through all the ups and downs. Poor girl seemed to be there for all the downs, and never once...told me I was wrong. She encouraged and stood by each time. She wanted to take Justin home. I also had decided that I would drive back with Hubby have the boys meet Justin in at the Hospital and that way even the Nurse would have her turn with Justin. It is very difficult for the nurses...they are with these children all the way. They are the ones that do the treatment, they stand by both the child and family and they too have to say their goodbyes. We even had Nurses come in on their days off to see Justin.

Justin was given a new type camera, one that you take the picture and it comes out right away but like stickers. So he was taking pictures of everyone. At one point he even called to people in the hall and took their picture as well. The Pain was still there but more manageable. Justin and I would practice flying when it really got bad. Besides as Justin said "He needed to practice so when his time comes he will be good at flying" These practice fly's really seemed to help him with the pain and so Justin did it a lot. I even got word from someone about a Chinese Lady that does treatment to alleviate pain. Had her in one evening and she tried her best to get rid of some of the pain. At the end...she didn't charge for her treatment and had come from across the City to get there by bus, then did a treatment on me...cried...and left! It was very hard on everyone. You look at this child eyes so bright and full of expectations...yet stuck in bed...in pain...knowing the child is dying. Yet...He is the one with the smile...he is the one taking each day and believe me sometimes it was each minute to the fullest. Very HARD! Very Hard!

Dr. came in on the Thursday and said all was set...we would be leaving on Friday morning. Justin would fly out with his nurse by 6:45 a.m. He would leave the Hospital at this time, by the time they got on route it would be around 8 then arriving home airport by 9:15 arriving at the Hospital by 10. Had to call the boys to make sure they were waiting for Justin in his new room. Dr. said all was ready...He was back on the feeding tube so that is ready as

well. We would be at the Hospital until we have Home Care services in place. Also I felt that the boys still needed to understand that once I brought Justin HOME...he WAS NOT ever going back to the hospital. NEVER!

That night was really hard...Dr's and nurses coming in to see Justin, cleaning staff, friends we met Staff and volunteers from the House...all coming to have their last time with Justin.

Justin enjoying all the attention and taking Pictures galore. At one point our Primary Dr. and Primary Nurse came in to say good bye...I guess I realized at this time when we leave the two of us will never be coming back. It hit...I had to leave the room just got outside the door and Justin screamed out...everyone just stopped looked and I re-entered. They all

asked are you sore? He said NO I just need my Mom...I leaned over HUGGED him he patted my head and told me it was O.K. The Dr. added I can't believe the connection you too have...Justin looked up and said..."My Mom's is hurting, so she needs me!" Not a dry eye...I'm O.K. now Justin you know me...mommy needs to cry. He smiled and said BUT NOT too Much! We smiled and I said I was going for a cigarette. He smiled and was fine again. The Dr. walked out and said...YOU KNOW...You did everything right, with tears in his eyes he added it breaks my heart...but you and Justin have taught me a lot. Thank you and I am sorry. Tears were coming from both our eyes...I looked and thanked him...saying thank goodness he was our Dr. You allowed me to do what I had to do. You did what was

best for Justin and above all else you LISTENED...

I went outside...Kathleen followed me and like it has been for the pass week knew I needed a coffee and had it a waiting. I went outside but this time NOT to the Pillar...People were waiting for us there and I just couldn't talk right now. This was it...we are going home to

WHAT? We sat and cried...Again Kathleen standing beside me.

That night was Tails, and the nurses got it ready that Justin could go down to watch his favourite show in his bed. All the cast knew Justin was coming down and were waiting for him. I found this very hard...Last time for Tails too. Gosh...Last Last Last...Justin watched as if it was his first time. He always got right wrapped in to the show. He had his tail...always took the leopard spotted one, so they had that ready when we arrived. He was placed off to the side with no one in front of him...and his eyes widened as the show started. I could see the cast...people that had grown to love Justin as well...I think this was the hardest show they had ever done. You could see the sparkle in their eyes from the tears...more gestures to wipe the tears away...you heard the voice cracking...BUT...the show went on. Justin was the first to yell Yeeppiii...when all was done. We had to wait for everyone to get out so we could wheel his bed back at this time the casts came over to talk. Justin was in heaven...His show...Tails...But all of us knowing his last performance!

BREATH...BREATH!

I wrote yesterday, but lost everything in cyber space. Was really upset, I wrote the whole piece in tears and anger. Today, I realize that Justin didn't want Anger to take over so I guess pooooffffff it. Today we will try again.

We left our last performance of Tails and headed back to our room. There were many people waiting to see Justin and bid him farewell. It was such a trying time, but one that was needed for everyone. Justin needed to see his friends and say his final words to them all. They too needed to see him. Having to stand back and share him was very difficult for me. I wanted the time just for me. Even with my family. I was the one who was with him all the way, why now do I have to share, when I know his time is limited. Well life just is, and share I had to do. Justin had made a BIG impact on everyone he met.

That night found many people slipping in to talk, giving Justin small little tokens to remember them by. Sharing their Love and compassion for a child. I spent a lot of this night in the hall. I knew that Justin knew I was crying but it was O.K. tonight I guess. At one point the Primary Dr, and Primary Nurse had come in to talk to

Justin, and he cried out...MOM, MOM, MOM...I need you. I was standing outside the door and rushed in. The Primary Dr. asked if he was in pain, he replied "NO But my Mom is...she needs me!" Wow...so true so true. The Primary commented on how close Justin and I were and that when I walked in and Hugged him how he stopped right away stroked my head and said..."Don't cry too much K Mom?" I'm trying Justin but you know me. It's O.K. No it wasn't O.K. but I had to try and believe that it was right now.

I went back to the House to pick up our final stuff, Kathleen and Judy were going to clean the room for us and give the House Manager our key once all was done. I sat downstairs looking around and again feeling NOW WHAT? I was leaving my support and friends. The people that had seen me through this ordeal so far. NOW WHAT?

Gathered that last of our stuff and headed back to the Hospital. Kathleen helped me again and we picked up a coffee on the way. We didn't say much, what could you actually say? Got back put the final stuff in the car, and went upstairs. Sat down next to Justin and waited for the morning to come.

Next morning saw many of the staff arriving early. They wanted their final bye. The ambulance drivers came in and then Justin started to cry. "Why mommy do I have to leave MY hospital? Why?" We want to go home. Yes but I'm going to the other hospital, just for a few days so Mommy can get all the things you need to go home.

Oh...K...but there was that hesitation. Again I explained that I would be driving home with Dad so he wasn't alone and that Allison was going with Justin on the plane. I also told him not to worry because the boys are waiting for him right now at the new hospital. The final goodbyes were unbearable...knowing that the next time I see any of them will be in part. Knowing that the final journey was ahead, and again I was doing this myself. Each of our family members was on their own journey now, and we were alone.

The trip back home was very silent. Tears were just there and every once in awhile we would just wipe our eyes, but it seemed that there were so many that it really didn't matter if we did. When we arrived on the outskirts, heaviness was felt. Oh brother here we go! We arrived at the hospital to see Justin in the room with his brothers and happy as all get out. Allison had just left so we missed her, but the boys thanked her for bringing their brother home. I looked around and already the boys were decorating Justin's room. Putting things up here and there. The nurses were already getting their pictures done by Justin and that going on the bulletin board for all to see.

One of the Nurses came over introduced herself and said we had forms to fill out. So we got right to it. Answered all the questions and got that out of the way. I explained that I did most of Justin care, so other than a few things here and there we were fine on our own. The nurses were great. Mind you it was very hard on them as well.

They come in to see this 5 year old child sitting there with so much anticipation of life knowing that he is dying. One broke down and had to excuse herself. I walked out behind and she apologized over and over again. Told her it was O.K. Other nurses really tried to avoid us. Again bringing the fact that life is so brittle. You just never know.

The Dr. caring for Justin that weekend was the first Ped's Dr we had seen back in 1999. He came in and offered us anything we need to call him. We agreed but said we were fine. I also knew that our new Dr. would be in Monday. Mind you I didn't remember him but he just finished his residency and remembered us for Sick Kids back in 1999. Saw so many Dr's that I would have to wait to see him before I could remember who he was. I was pretty well set in what I wanted to do, but still waited for the family to make up their minds. I knew all I wanted was to get Justin home.

Of course coming from one hospital to another never finds things going the same way. Justin was on feedings as his appetite was NIL but when we arrived the feedings were not ready, we would have them in a few days. The Morphine was by I.V. now and had to wait until Monday for the pump. No use getting upset, I knew these things would happen like this. Mind you our Nurse that came from Sick Kids was not too happy and called that Dr. as soon as she got back to tell him. Primary called me at the Hospital and said Things O.K. there? As good as could be. Is Justin on Feedings NO not even the same stuff as he was getting back in Toronto. So I'm going to cancel it. No point putting his body through more changes. Just have to get him to eat that is all. Also the Morphine Pump? No I.V. but Pump coming on Monday. I thought they had all this...they told me they did. I guess now you know what the Parents mean...It is never done the way we are told. He added that if we needed to come back to Toronto for any reason that we could. I thanked him but said...NO we want to get home. That is it.

Not that it is wrong, but when you think you are coming home with things in place, and everything is so different it adds stress. Primary asked if I'm O.K. I tell him not really but will get through. Just want to get home that is all.

Next day saw more friends coming in to see Justin, he was thrilled with the company and each time someone came in it was my excuse to go outside for awhile. That evening the boys were all there and we had a family meeting. Justin called it because he wanted to go home. He talked to everyone saying..."can I come home now?" The boys all agreed that yes lets get him home. I explained that once he came home, he was never coming back to the hospital. They all agreed. They boys then ordered pizza and Justin and his brothers enjoyed their supper.

The next afternoon found a Lady come in and introduce herself. One of the Volunteers from Toronto Ronald McDonald House had contacted her and asked if she had time to drop in to see us. She had lost her daughter to cancer and the same type as Justin She came in and Hubby really had a great talk to her. I think she put things into perspective for him and he talked and asked so many questions. She left leaving us her number and telling us to contact her anytime. It was so very much needed. Hubby to this day considers her his guardian angel at the time.

Monday finally came and we met the New Dr. To tell you the truth I never saw him before, but he said we had met and told me a few things about our first meeting that did happen, but I guess that was when I was brain dead. LOL He was very helpful and was listening that really helped. I told him we had all agreed that we just wanted to go home. He said he would have Home Care come in and talk to us. Also added that feedings would resume that night. I explained I didn't want them, besides Home Care will not do home feedings so I'll make sure he eats. He hesitated and I added that I had talked to Primary so that is the way we want it. I also told

him Justin was swelling and I thought we needed a catheter. He checked and was going to make arrangements for a Specialist to come and see and make a decision. I reminded him we are not staying long, so hopefully he will be in soon.

The next morning saw Home Care coming in. They came in to talk about what they offer and how it will work. We listened for a while and then I said...well here is what I NEED to go home. The bed, the Morphine Pump and supplies...that is it. First she says that we cannot go home because of feedings, I knew that so cancelled them, she said I cannot do that...well I told the Dr. No...so I guess I did. Oh she said looking to see that the feedings were not there so I was right. Not going home with feedings.

Then she said they do not supply any bed let alone the airbed that Justin needs. I added Oh yes you do...maybe I should tell you I worked homecare so know that all that I am asking for is in place. Maybe a bit more work to get them but this is what I want, and this is what we will have. Really do not want to discuss anything else. She added that the dietician was coming in to talk to me. I added I really do not need to talk to her. She said oh yes you do...I said fine but Justin will eat whatever he can get in. Diet is not top of my priority list so it really is a waste of time. She just looked. Then she added that the Home Care would be coming into the House each Day. I added very quickly OH NO THEY WILL NOT! We are going home to be a family as much as we can. They can come once a month to flush. That is it, just like before. She looked up and said NO Mrs.V you are too close to the situation to handle Justin's care. I was mad now...Well sorry you feel that way, but if I need HELP I will ask. So right now it is once a month that is it. What about the Morphine cassettes...well that is easy I will change them myself. No we do that...well not this time I will. Hubby was getting a bit un-nerved and said...well lets just get home then we can figure the rest out. I felt it was time for me to leave. I was taking care of MY SON not someone else. That was it!

Next morning found Justin heading for a catheter insertion. It was agreed that we would have to go through his tummy. Justin was excited...believe it or not he was looking forward to watching the Dr's do this. The Dr. came back with Justin, which is very unusual and said he was GREAT. I had to explain everything and he asked enough questions that I think he could be my assistant. Justin added "Well just call me, I could help you next time!" We all laughed. Justin then proceeded to tell each of us what happened. How the freezing needle stung but really didn't hurt. How they cut his tummy and put the tube in. He was questionable about how pee was coming out this tube, but that is just what it does. He was totally amazed. And so were we that he explained each detail.

The following day found the Home Care coming in with more what we can and what we cannot do. I just said hey...I'm going home on Thursday so just have what we need O.K. Hubby spent time with her and I went for a smoke. When I returned Hubby said it looks like we are getting what you need to take Justin home. GOOD now hopefully the bed guy will get that ready in time. Hubby added that Home Care is just waiting for the call from him. Good looks like 1 more sleeps and we were home.

That evening a nurse came in and said the guy for the bed was on the phone. Wondered if I had any information on it. Told her sure did and that I would go and talk to him. No tell me and I will tell him, by this time I'm on my way to the phone.

Hello yes...you wanted information on the bed for Justin V? Yes...well it needs to be delivered tomorrow by 10 and bill Home Care Yes...that is it. Here is the address and thank you very much bye. The nurses just stood there. Is that what was arranged? Not sure, but that is what is now. If we waited for the Home Care to talk tomorrow that would put us off till Friday to go home. We are going tomorrow and now things are in place. So it is done. They just looked, one had a smile but the others were in shock I think is a good word for it.

Next morning saw us all packed and ready to go. The Homecare came in and said that she had NOT talked to the bed guy so we would NOT be able to leave yet. Told her no problem I talked to him and actually the bed is being put up as we speak.

Also she said well the Ambulance had not been advised as of yet...No problem we are driving Justin home. So we leave at 1. Well we need to talk about visits, well call me next week We can arrange that then. She then asked where is your hubby? Well he is getting things ready for us to go home. If you want to talk to him come back at 1 but we will not be here long, so I guess call him next week. She just looked. Justin was all excited and watching the clock hands to get to where they had to be.

Dad showed up about 12:15 and Justin was hooting and hollering "I'm goin home...I'm goin home. We packed the final stuff, and got ready. We had to take the bed downstairs to get Justin into the car. He knew it was going to hurt, but he said...Just Do it...Do it fast K. Just what we did. The Nurses on the floor all wished us good luck they hugged Justin and said that if he wanted to visit again he could.

He said No thank you...my hospital is in Toronto.

We finally got him ready and off we went. Nurses waving and Justin even though in pain now waving back with a HUGE smile. Justin was going HOME!

We arrived at our home to family and friends, waiting outside. No coats and even 2 of the boys in their socks. Hey Buddy you are HOME! Justin was so excited. Even the carrying him into the house didn't seem to cause any pain. In we went to his new bed in the living room, and the boys had everything set up. He even had his video stuff set up so he could play anytime he wanted to. One of Hubby's friends from work had collected tons and I mean tons of games for Justin so he had hours ahead to play with his family and any friends that came in.

We got Justin settled and I made coffee. Just sat back so relieved that I was home. My Friend had come over and HOUSE was sparkling clean and even supper was a cooking in the stove. Home...just where we needed to be.

It wasn't too long before the phone rang and it was Home Care. They wanted to set up an appointment tomorrow for us to fill in forms. Gosh these forms are enough to drive people to drink. The same questions over and over again...thought of buying a tape recorder and just say everything once and hand it to people when they came. It would have been much easier. On me anyway.

Agreed to the appointment and with the weekend coming new that we would not be bothered by anyone then. Justin was so glad to be home. He was making arrangements on who was going to sleep with him that night. He made the boys get a mattress which fit right under his hospital bed for night time. Justin loved the

story the Grinch that stole Christmas and ever since he received that video has watched each day sometime 2 and 3 times. I guess in his way it was replacing Tails. House manager had given it to Justin for the last Christmas. He was thrilled with it and so everyone was prepared to watch it over and over again.

The weekend was great...Friday with Home Care saw me answer all the questions once again and again telling them that once a month was enough. When we needed more then so be it. The nurse said they would have to come and supervise me changing the cassettes on the Morphine Pump, I said well it needs to be changed at 11 tonight so if they wanted to come then fine. No she thought we would change it now and then it would be done. I said no as we are responsible for the Morphine count. Oh it will be O.K. she will sign it as discarded. I said NO we are going to stick to schedule so if you cannot come tonight then sorry. Again that look ...hmmm...not be co-operative. Oh well makes no sense to discard 1/2 day of Morphine because of convenience. I also had been changing on the floor as I had already said this was not a usual practice on the floor so with me changing it they didn't have to call another nurse from another floor to come and do it. So if they wanted verification then call the hospital. I guess I was tired and fed up...Could do all this stuff, was doing all this stuff, so why now all the questions. We left it as that...quite sure they wrote a lovely note about Justin's Mom but I really didn't care.

Rest of the weekend was great. Justin and I would have our time together, and the boys shared his time as well. Dad even got to sit and hold Justin for a few hours each day. He was getting much weaker and thin, but he never lost his smile.

Our house activities started to evolve around the living room. Justin, always being the centre of activity. He always had someone next to him, and each hockey game he played even with visitor knew if he lost the game then he would call out "MOM they are cheating again!" That was one game that Justin refused to lose in...HOCKEY! Justin received calls from Kris King regularly...he would call I would give the phone to Justin and if he really had nothing to say he would say Hi Kris King and hang up.

Poor Kris just got use to Justin's way. One evening when he called Justin was watching the M'Leafs on T.V. He said to Kris..."Good thing you quit...they is losing. "Kris laughed and said but maybe they will win..."NO Kris...they is going to lose!" totally disgusted. Silken would call and talk to Justin and he received calls and emails from his buddy "The Rat". The Rat was a Firemen from Toronto that Justin met. They hit it off and He would even come to the hospital to see Justin. Each day Justin would want me to carry him to the computer...he would send secret messages to his buddy. He could spell his name but the rest was in code. LOL Each day "The Rat" would write him back and Justin would tell everyone what it said. Sometimes it was a whole story on a fire in Toronto or a trip that he and the Rat took or whatever he decided to say. The priceless thing was each time he told the story that day it was always the same.

Justin's Story then ended up on a Butterfly Farm web site from Aruba and he started to receive e-mails each day. He was so thrilled to be getting the e-mails. I would print them off and he would tell his family and any friends that visited what each one said. He received poems written for him. Pictures of Butterflies from all over. He became the ButterflyMan. People shared their stories and wished Justin all

the best. I too ended up with e-mails from people sending their love and thoughts and prayers. Total strangers reaching out and helping. It was amazing.

Well we surpassed the time frame the Dr's had given us from Sick Kids and each week the Dr. would call to see how Justin was doing. Justin always had to talk and informed Him about everything that was going on. He told the Dr. that MOM does everything for him and that when the Nurses come in they just talk. He even told the Dr. that one day I had called and cancelled the visit because and he began to whisper... "She said I was too sick...he started to laugh and added it was a lie!" I heard him and really wanted to say hey...don't say that...but it was true. When I talked to the Dr. he was laughing...doesn't surprise me that you are cancelling but to say he is too sick and you get NO flack from that is amazing. Hey what ever works. One day when he was talking to the Dr. he told him about the catheter. He said "can you believe that I'm suppose to pee out of a tube crazy eh? But I'm not going to do it anymore." When I talked to the Dr. he asked me about that and I told him that, that morning Justin decided that you are not suppose to pee through a tube and since that time has used the urinal. He said it was impossible then added wait No it is Justin. I told him I had to flush the tube now to keep it opened but it really wasn't doing anything. To have it removed meant a trip to the hospital and we were not going to do that. But if it did block I would take it out myself.

Each week Justin also called the 8th floor of Sick Kids to talk to the Ward clerk. He also talked to the other nurses on the floor at the time. They looked forward to his calls and Justin in turn was letting everyone know how he was feeling. Every time the phone rang...he would say..."Oh no for me...I'm busy...or K give me the phone." He actually would get upset if he had the phone next to him and it was for someone else. He would say "well don't you want to talk to me?"

Life continued for us all. Knowing that Justin was getting weaker...but also knowing that in his time...No one else's but his time...he would fly.

FLY...yes we had many talks Justin and I about dying. He asked many questions. He knew many children that had died but now wanted to know what was going to happen to him. This is when I would really have to fight back the tears. How do you explain to a child that he is dying. That he will be going by himself and that his family and friends could not fly with him? How do you tell a 5 year old that even though he is gone from here. That he was in our hearts forevermore. Well answer the questions I did. Whenever Justin needed to talk we did. It always seemed to happen in the morning when everyone was gone to work or school and it was just the two of us. He would say..."Mom come and sleep with me...we have to talk!" And talk we did...what ever he asked I answered to the best of my ability. When he asked if I could see him when he leaves...I said no but I could feel him in my heart. When he asked if he would be alone...I said NO he will have friends and family that he didn't even meet yet because they flew before him. He asked if one day I would fly to him and I said OH for sure. He even would check out some of the things we talked about. One day he asked his Dad to pick him up and bring him to the window so he could see the birds. I had told him that day that it is like the birds when he fly's he will always have someone with him. He wanted to check out to see if the birds were together or if they were by themselves. I knew what he was doing, and I could see

the smile on his face when he saw so many birds at the feeder. He then turned to me and said...you going keep feeding my friends right? For sure I will.

One evening Justin said "MOM I want to sleep in your bed. Dad you can sleep in my bed in the living room but me and MOM have to sleep together." Justin's cancer had spread enough now that the pain wasn't constant but when you moved him he was in pain. So moving him was only at his request. I did however give him a bath each day and once in the tub he felt good, but getting there was really tough. Sometimes the anticipation of the pain had both of us in tears, but he felt so much better after a bath. It certainly wasn't an easy task as he had tubes everywhere. That night that we slept together in Mom's bed, as Justin would say. Justin talked about a trip that we were going to take. Both him and I got on our horses and rode to the Ronald McDonald House. I had to stay with the horses while he went to see the people he wanted to see. We even stopped by some of the golf tournaments that we had fundraised with and he saw and talked to people there as well. I just went for the ride. He talked and I closed my eyes and it felt like we were really on that trip. Justin telling me where to turn and when to get off the horse and hold on to his pony while he talked to whoever he wanted to. I knew in my heart he was saying his last good byes and that our time was coming close. It was also coming close to oldest son's birthday and even though we were planning his birthday celebration I could sense that Justin was just not part of it like he usually was. I started to fear that Justin was going to choose to FLY on that day. I watched and listened to his comments about things. His stories about flying and that he was getting ready. We continued our talks, and finally one day I could really see that he was getting really weak and I said..."Justin you cannot FLY on Jeremy's Birthday!" Why he asked..."Because when you fly we will be all very sad. This is Jeremy's Happy Day so he has to keep it just for him! Oh...he looked and said nothing. I shared my fear with my friends and hubby feeling like this is the day he is picking. The next day when alone again...Justin said..."MOM...I'm not going to fly now K!" I said I was glad to hear that and he added besides Jeremy needs his Happy Day and it is too cold right now to FLY! The tears came but I must add it was also tears of joy...as I knew that Justin would not FLY on our oldest son's birthday

February 23rd came and went without a hitch. Most of the decorations were in the living room where Justin had his bed. He gave directions to everyone where things had to be. He sang the loudest and YES...made sure his oldest brother had his day.

Although their were tears...thinking about how much time was left for our whole family, but thinking back, it was a GREAT day.

Our lives continued and many people came to visit with Justin. He seemed to attract many people and since he loved Business Cards, we had bristle board upon bristle boards full of cards. He would spend some of his time checking them all out and showing everyone his favourites. While Justin helped at the HOUSE he had a blank Business Card as well where we added his name. He was so proud of his card and of course this was his favourite. Always put in the middle of each display.

Justin would let us know who was going to sleep with him that night. We always had extended family with us so they too had their turns. The nights comprise of

watching "The Grinch Who Stole Christmas about 4 times, and playing hockey or just talking. Each of his brothers had several nights with Justin and got into some pretty heavy talks. He would talk to them about leaving alone. How they would have to help MOM because she will be very sad. He would tell them when he really hurts he flies just to see how it is, and when he does he can see everyone and who ever he wants too. When he looks down everyone is O.K. except for MOM she is always crying. He would say to them you have to help her...because she is going to be very SAD!

One evening it was my turn again. We went to bed, me on the mattress on the floor next to Justin. He asked if he could sleep with me on the mattress, I said sure and got things ready for our sleep out. Justin knew moving him was going to hurt but would tell me just to go fast then he would be O.K. Once down on the ground he curled up with me and fell fast asleep. I was surprised because NO movie. I lie beside him with tears...knowing that his time was very limited. Looking and realizing soon my youngest son will be leaving...on his own...without his MOM.

Gosh the feelings and emotions so fresh, so real so painful. Looking down at my child who should have many more years ahead, but knowing in my heart only days. Justin woke up around 3 in the morning and was so excited to tell me that he had a great dream. I asked him to tell me about it. He proceeded by saying that there was a Crystal Palace with many people, animals, birds and tons of Butterflies. He said the people were getting his party ready for when he flew. He told me they kept calling to him but he told them that it was NOT time yet. He also told me that there was a BIG rink, and people still had to clean more though. He told me he kept telling them that he wasn't ready yet but he would be coming to his party soon. I asked him why he was not ready, and he leaned into me and said..."They have NO pop at his party!" Though the tears, I had to laugh...Justin needed his party just RIGHT! Now that he was up he wanted to watch the Grinch so put the movie on and watched my son.

Next morning as soon as Dad got up we sent him off to buy some Pop to put under Justin's bed. We were making sure that Justin had all he needed to take when it was time to fly.

That weekend Silken was coming in to spend time with Justin. He was so excited and was waiting for his Friend to arrive. Of course when she arrived, Justin kept hiding his face. He had done this before and I had asked why he was hiding from certain people. His Buddy 'Pellow' would come to see him often and Justin started to hide his face. When I asked why...he said "Well Mom when I hide I do not see them so I do not have to say goodbye!" Deep breath...yes Justin I guess you are right. So when this was happening as soon as Silken arrived I explained to her what was going on. Didn't take too long though before Justin and Silken were just into the swing of things. Silken had brought to Justin 3 birds. One was him, one was his family, and one was his friends. Together we would all get by. Justin really took everything in and then wanted to get out of bed to see outside. I knew he was checking again to make sure that birds were together and NOT alone. Of course with our feeder we had tons of birds and Justin smiled as again he saw birds are never alone.

Justin and Silken had a great weekend and Silken had the mattress next to Justin for the whole weekend. She too watched the Grinch that Stole Christmas over and over again. When it was time to say goodbye...Justin had huge tears. He hugged her, told her he loved her, and that he would be in her heart forever. I had to go outside. Poor Silken had to find a quiet place to pull herself together before heading to the airport.

Final goodbyes...
Hugs Butterflymom

When I look back this was to be Justin's last week here on earth. Final good byes... everyday. The representatives from Local Service clubs, coming to visit and bringing more Business Cards. The boys' friends coming to see Justin and play a game of hockey with him. Final calls from the Hospital For Sick Kids. Mary, the ward clerk, talking to Justin for the last time. Nurses talking to him and asking how he was doing. Justin letting them all know, he was enjoying life to the fullest. Dr. M our primary calling to see how things were and Justin telling him that he was going to fly soon. Heard the crack in his voice as he said..."WELL Justin you always knew what was best!" The hiding of his face... But finally looking up and saying goodbye.

Not saying bye and see you again soon. Just plain Goodbye. I saw and felt these things ever so strong. And knew that his time was numbered.

Talking one day I asked Justin if he would let me know just before he flew. He told me yes...and soon Mom soon. Although the days were very emotional for me, I kept it as normal as I possibly could. Justin with his Morning HUG and Butterfly Kisses.

His enthusiasm of what e-mails he would receive today and cards or letters. He always had his smile.

The boys were all having a very rough time now. They could see their brother losing weight although he was still eating with them, and could see his frail body struggling even to play hockey. BUT...the jest for life was still there. He still knew he didn't want to lose in a game of Hockey and if he won he would ask them. Did you let me win? NO... Was always the word that came out...So he was happy thinking he had really won the game.

Won the game...for sure he had...he had won the game of life. At a time when all was ending in sorts...this child taught his family the meaning of Life and Fight! He was a true champion...and held us all to his goals.

March 4th in the evening Justin said Mom you have to sleep with me tonight. Sure no problem. When all was still, he asked me to hold him in the chair. It was very painful now to move him, but again..."Just go fast!" Got settled in the chair and he looked deep into my soul. "Mom I have to fly today!" I looked at him and the tears just came. "It's O.K. to cry today Mom...Tears are Love and You Love me Lots!" Yes Justin that was for sure. I held him for 4 hours in my arms. Just looking... and remembering... all the times together. Remembering this vibrant young baby who came into our lives needing us. Who now has blossomed into a young boy teaching his family the most important lesson in life...DEATH!

Justin finally asked to be put back into bed. Got him comfortable and waited till he fell asleep and went into the kitchen for a smoke and cried. Oh my what will life be
...with out my son!

Morning came and the boys were getting ready for their day. Dad was to go away for the day for work. They all asked how Justin was and I said Today is the day he will fly. They looked said nothing...then asked should we stay home? It is up to you. Even Dad asked the question... which actually made me mad at the time. They all felt that we could not pick our time like this. Oh but yes we can...if given the
chance...we certainly can!

Everyone finally decided to stay home, even our extended family. The morning went slowly and Justin and I did what we had to do. At one point Justin said "Mom I have to fly today...but I need a bath! Could you bath me after I fly?" Sure will
Justin.

Made a call to the VON visiting nurse to cancel her visit. I was NOT going have the port flushed today. Told them Justin was sick so we had to cancel, and to call me
back in a few days to reschedule.

It was about 2 when the mail came in. Justin you have mail...oh just read yours Mom I will read mine after. I opened the card I had got from Gramma Vivian a very Special Lady we had met in Toronto. I read the thinking of you card. Went about my business of the day, while Justin's brothers and extend brothers spent time with him. Finally at 3:30 Justin said Mom read my card now. BUT...Just to you. Don't read it out loud. I was having a coffee and Jeremy Justin's oldest brother was now sitting with him. I opened the card. Started to read...and the tears just came pouring out. Just a few words... "Keep your chins up...Love Gram!" Wow... The rest of the family that was at the table was asking what was wrong. I looked up to them and said that "G-G" my maternal grandmother that had passed many years ago was here for Justin. You see my gram would say those words. Gramma Vivian never said that so I knew...the only person I would trust with my son was now here...to let me know that the time was right and she was here for my son. I looked at everyone and said...It is time. Hubby called the boys downstairs, and we went into the room. Jeremy was sitting there next to Justin. I looked at Justin and he smiled. He then looked at each and everyone there and smiled to them alone...then took a deep breath and flew...He flew so strong and straight with the hugest smile you could ever believe. He is party was waiting for him and he was
flying there with Gram!

Tears and hugs... Mom, Dad, Jeremy, Spencer, Michael, Brent, Wade, Caleb, Chris and Graham...Then the words..."MOM my Bath". Hubby helped me strip Justin run the water in the tub and give him his last bath. Washed his hair and combed it just the way he liked. Got the clothes that he had chosen for his party and Jeremy helped me dress him. Since all the arrangements were already made. Jeremy called the Dr. to let him know but telling him to take his time as my Mom has things to do before Justin could leave our home. Called the funeral home to let them know that we were waiting for the Dr. to come and pronounce but to make them aware that when he comes we would call again for them to come for Justin. We placed Justin back on his bed...Dressed in his favourite clothes, Butterflies in his hand, and Kathleen's hair wrapped in its beautiful cloth to help him on his path.

The Dr. arrived and just stood and looked. Tears were flowing by all, but Justin was so at peace. His huge smile still on his face. Jeremy had made the call to the funeral home to say the Dr. had just arrived so it was not long that they too were at our door. Again...both men stood for just a moment and looked...An Angel soaring like the Eagle he was...Free!

As they took Justin the emotions were really wild. BUT...just like Justin...he would help us all get through this. The funeral Hearse left our yard, BUT...went to go by the second driveway. Oh know I heard form Michael our third son. Oh NO...Everyone went to look out the window. Even the Dr. was on his tippy toes trying to see what was happening. OH NO was heard from all the boys...I looked and couldn't help but to start to laugh. The hearse had gone and got stuck. We didn't clean the second driveway, and now they were stuck. Here are the boys all saying...Only us...oh yeah our brother dies and now he is stuck. Come on get dressed only our family would have to push him out of a snow bank. The Dr. was on his toes...saying surely they really are not stuck? Yes they are...The driver was going back and forth trying to get out. The boys were grabbing their boots and heading out the door when they finally got out.

In they came...looking lost...I just started to laugh out loud...Only Justin would make sure to take the edge off for us. At this point we all started to laugh even the Dr. Justin always letting us know who is control. One more STUCK...before his final flight!

In tears...but Laughing...Ahhh Precious memories!

Hugs

Butterflymom

A Child Lost

When you were born...

all I could do was cry...

Not tears of sadness...

but tears of knowing you are mine.

I have so many plans for you my precious child...

The happiness you have brought ...

is something I can never explain.

I will always protect you...

and always be near

In a heartbeat you were gone...

*This can't be real...
Wisked away from my arms.
How can this happen to MY child?*

*Why is this Happening?
I need you here precious child...
I will be lost without you
I feel anger...
I feel guilt...
I wasn't there to protect you...*

*This is not supposed to happen
Not to me...
Not to my family...
Not to my child
The pain I feel is too much...
I don't know if I can go on...
I don't know if I can face another day with you gone.*

*You were my life...
My child...
I just want to hear the words*

*"Mommy I love you"
one more time*

*All I can do now is cry...
All I can do now is pray...*

*"Please don't cry Mommy
I'm With You".
Butterflymom2001*

Watching the hearse take our brother and son away from the home he loved was very difficult. All of us stretched our eyes as far as well could see. Tears clouding our vision but feeling the emptiness and loneliness set in. The Dr. stayed for about 1/2 hour longer asking if there was anything he could do? I responded through the tears saying YES... Please listen to the parents. When they come in with their child who has been sick. Take the time to HEAR...They truly know when there is a problem. We all thanked him for being there with us, and asked if he would like to come to Justin's birthday party that was on the 28th of April. Justin wanted a bond fire with family and friends and this was still going to happen. We will call it our Celebration of Life Love and Friendship. The only catch is...That the Dr. could come ONLY IF he brought his family with him. He agreed asking us to remind him as the day approaches.

Well here we are...part of our family missing and forevermore. I just sat at the table in silence. Soon all the family was sitting around the table and then the stories and memories were shared. Do you remember when...Yes we all did, and through our tears...Smiles and laughs of how Justin enjoyed every minute of his life. How he lived for the moment and took the challenge before him. We all concluded that Justin truly was a WINNER as now the cancer was gone from his little body and he was FREE to soar the skies, just like the HUGE Eagle he chose to be. Reminding us that every time we saw a Butterfly it was him.

Sitting together we decided that we did not want the tradition funeral for Justin. No final goodbyes and mourning. We will have enough of our own to deal with. The boys, Brent, Wade and Caleb were to go to a hockey tournament the next day for their school. Brent was the only goalie and we knew the team could not attend if our boys did not go. So the decision was that we would celebrate Justin's life together and what better way than a hockey tournament with family!

Jeremy took Justin's bed apart and made the call for it to be picked up. We had the wheelchair ready to go as well. Wanted all that stuff out...that was the part that left BAD feelings and we needed them to leave. I had a few calls to make...very short but letting people know that Justin flew. Didn't talk long with anyone, just wanted to get the calls out. Called the paper and had the announcement placed in 3 papers.

Toronto, Timmins and Sudbury. Funny when you are doing these things, but you then realize that he shared equally, his life with these 3 towns. I had written the announcement earlier so it was just faxing as the payment was already done as well. We added that there was going to be a PRIVATE Family gathering and that April 28th was Justin's day for all his friends to attend. Called my friend to make sure she could come over the next day to make sure the bed and wheelchair were removed and then I called the VON to let them know that Justin no longer needed to be on their list of visits.

That night and for the next few days, you never found one of our family or extended family alone. There was always someone with them.

Going to the tournament the next day was very difficult for many other people. As we walked in...Eyes looked, some said they were sorry and others looked away. It is O.K. because it is very hard to realize that Death knows NO age. Brings reality to the surface and a scary one at that. For you never know!

Between games although usually the team eats together the coaches knew it would be different this time. Our family went to eat together. We toasted Justin with his favourite drink of Pepsi, again shared memories, and then the team started to come to our table. They too toasted Justin. I'm sure the people working were wondering what was going on, as BIG hockey guys were all around with tears in their eyes raising a glass of Pepsi after each memory shared. The guys also had memories to share as Justin never missed a hockey game until he got sick. Yelling and screaming telling the boys what they should do and never even flinching when he would say... "You played really bad tonight!" or "Great game guys...you finally listened!" What a wonderful feeling. I was visualizing Justin soaring and smiling his biggest smile knowing how much he was Loved.

The next day found reality creeping in. It was a teary day for everyone, but again together we got by. Many calls were coming in and this is what I found very hard. I didn't want to talk about it right now, so the boys just took over there. I gathered some of Justin's favourite things...his M'Leaf hockey shirt, his dream catcher with all the little things that people had given him and he chose to place ever so carefully on it. The boys had the living room back to a living room again. We had requested that donations be sent to the Toronto Ronald McDonald House. A Home away from Home. A Place that Justin loved.

My mind was racing, and I knew that I had to keep myself busy for the next little while. I decided that I would fundraise for the House. I wrote letters up and sent them out. I contacted my Husband's place of work asking them to adopt a room at the Ronald McDonald house, and YES...they did. One month later...A room was adopted by Falconbridge... In memory of Justin. We chose to have it called the 'Butterfly Room'. For people who knew Justin would know it was him, and others would love the Butterflies that would be on the windows and walls. They could bring them a sense of comfort and peace.

I wrote many letters and came up with many ideas to raise money for this house that so many people need. I never knew but the Houses are run on the donations that come in. So every bit helps.

I also got involved with NOFCC. Northern Ontario Families of Children with Cancer. This is a non-profit group that helps families in North Eastern Ontario with some of their programs. I wish I knew it was there when I was going through all we did. It was a very small group and they try to help as many families as they can. I came up with many ideas of how to get funds, and now have a weekly bingo that continues today, service groups that gave monies and also on a yearly basis. It was allot of letters and talks to do, tears yes... but the true feelings of how it was.

Now I also had to plan Justin's Celebration of Life Love and Friendship. A open invitation went to NOFCC and their families to attend, family and friends and of course the Toronto Ronald McDonald House. There could be NO party with out them there. My friend Corinne helped with the decorations in fact for a month we made butterflies till they came out of our ears. It really helped me get through and the bad days would get better when we started to make more for Justin's day. Calls were coming in Kris King could not come and he was very upset, but there was a toasting to him on this day. It is O.K. as Justin will be with you too. Silken was coming and so were people from the house, plus families that we had met at the

Hospital as well. Wow this is going to be great. Exactly what Justin would like...he loved PEOPLE!

Boys were getting nervous as here we can still have snow or slush! I kept saying that is the least of our worries...this is Justin's day and it will be great. I continued on with the plans as the family got even more worried especially when it snowed the week before the event. Again assured them not to worry. This didn't seem to help them though as they made plans with a neighbour to use a service groups place if we needed to. I knew it wasn't going to happen like that but hey...It seemed to ease their minds a bit.

The day was planned from 1 to 5 for the children. Clowns (friends that dressed up) with goodies butterfly stickers and stamps, everyone was stamped with a Butterfly when they came in. Food...wow tons of food, pony and horse rides, games and fun. Goody bags...hey what would a child's party be without the goody bags? Plus in the evening about 6 we would release 6 Butterfly Balloons, my cousin had written a song just for Justin and that would be played at this time...then we would have a HUGE bonfire, with adults. Go till we drop... music, song, sharing and food...again tons of food.

With the help of Corrine, her family and ours, we did it.

Tragedy Turned to LOVE...from everyone. Protecting... Yet... allowing the tears, and sharing. The loneliness still there, but again shared with those we loved.

Next will be Justin's DAY APRIL 28th 2001

Hugs

Butterflymom

One week to the day the snow flew...The family nearly had a fit. Saying MOM...We have to change locations. I just stood my ground...No 'guys' watch... I tell you Justin will make sure his day is Special. They really did not like the idea, but what are they going to do? Mom was busy making Butterflies and other decorations for the Celebration of Life Love and Friendship. Corinne and I had enough decorations to add in every tree in the front. I was off to the airport to pick up Angie and Anna.

They were coming a week early to get ready as well. We had met the two at the House and if you remember Angie was Justin's girlfriend for life! They were flying in from Winnipeg to share in this day.

At the airport...when they walked in from the plane...tears fell. Oh so good to see them again. All of us just held each other like a group hug that lasted for about 5 minutes. Tears and laughs...so excited to have them with me now. But feeling their grief and the loss of a Great little boy. Got home to Corinne with supper ready and all of us sat down for a talk. More hands to help out, just what we need. That was going to really help

Well time was fast approaching and calls of who were coming came in. We even had a hotel near by give Special rates for all that were attending the Celebration of Life Love and Friendship. A local grocery store was giving the event buns, juice, pop and some of the hot dogs for free. Oh what a great day it will be.

Night before and all is busy...Family were coming in trying to be the first so they could get a bed...LOL Then the friends...wow...flying in... Some came with their children that we had met in Toronto, others on their own. People from all over.

Silken was coming that night as well. Hmmm not sure but she may be on the mattress again. LOL

We had people from Toronto, Victoria, Winnipeg, St. Catherine's, Mississauga, Heron Bay, Hearst, Timmins and of course the area. The house was packed and we were going to have the best Celebration this town ever had. Neighbours had offered to put people up...but they all wanted to stay here.

Our Neighbour made sure we had enough tables and benches, bringing them over by the truckloads. Friends helping friends heal.

I wanted this to be a Celebration of Justin's Life but...at the same time not letting the people who were coming that did not know us... Know. It was time to sit back and have fun.

Jeremy was in charge of the horses and he had a lot of help from people who came. I had stayed away from the horses since Justin had passed and this morning was the time to go and see Cool Dude. There he was all tacked up looking as Cool as ever. I walked over to a 'well groomed' pony and just cried. Justin loved his pony so...and he was going to be the head horse today. Gosh the felling came rushing in, all the boys were close by as they knew Mom was staying away from Cool Dude. Again all around as I hugged his neck and stroked his head. Ahhhhh...Memories again... But happy and healing memories of a time when all was well. I don't think there was a dry eye at that time. Even Cool Dude had a tear! This was going to be the first time he was used since Justin had passed.

Time to move on to get things ready for the occasion. Balloons were tied on to the driveway fence and welcome signs put in place. The boys friends were all there to help out anyway they could. Their parents were coming that evening to share in the bond fire. Party was in 3 hours and still had a few more things to do. One of Wade's Friends had been helping to tie the Balloons up on the fence posts, when the sixth one flew away...he was so upset... Wade came to tell me and I laughed. It was Justin's 6th birthday so got 6 Balloons, but I guess he wanted one early to show his new friends. I told Eric it was fine, and with a huge relief on his face he smiled. We watched that one fly to where it was heading.

People all around helping and getting things just the way Justin would want them to be. Neighbours dropping by asking if there was anything they could do to help.

Now I must tell you...WEATHER...relax ...It was the greatest of days. All the snow had melted and the ground was dry. Should not have been, but... Like I said Justin's Day he had great contacts...so that was his job. People started to arrive...oh what a great day...everyone had to have hotdogs as they passed the food stand, we had so many that it became the rule LOL. Neighbours had also made Beans, and salads, plus munchies...lots of munchies. There was food all over with hot chocolate, tea and coffee. Clowns came dressed to the nines and children's voices began to ring in the wind.

Area Cancer families came in and rode the horses and some even took them in the side paddock for a try to see if they could do it themselves. Our Dr. from here came as well, and yes had his 2 little girls and his wife. The primary Oncology Nurse here

came with her 3 girls and a neighbour. Silken greeted everyone who came and people were snapping pictures left and right.

Corinne and her Mom were at the entrance greeting people and making sure everyone had their Butterfly stamp. Some on their cheeks while others had them on their hands. Now...as people gathered and the Toronto Ronald McDonald House gang arrived with the flag that had it's special place to fly free in the wind...the REAL Butterflies began to appear. People were stunned and amazed. They were not just flying by BUT...landing on people. Those who knew Justin knew it was his sign that all was well and he was having a great time at his party. He even brought many of his new founded friends with him. Never alone, with so much to do!!!

The day was GREAT. A huge success... With everyone who attended enjoying the day.

Five o'clock rolled around and people started to leave. The people who were going to stay for the bond fire of course were still here and food was again shared by all. Six bells and it was time for the serious part of the Event. Our family gathered, lighting candles to shine in the night. We gathered the 5 Butterfly Balloons that were left and walked the driveway to say a few words and release Justin's Balloons. Together... standing Strong and full of LOVE. Not a dry eye. As friends and family gathered around the fire, our family and extended family released the Balloons. Soaring oh so straight right to our loved one, who was giggling and singing. Donnie played his song while we all listened in silence, watching the Balloons reach their destination. I said a few words then asked everyone to join hands around the fire. A family that we had never met but heard our story from Mississauga had made us 1000 paper cranes, which we had strung and hung in one of the trees. These people had lost a daughter to cancer and wanted to share their custom with us. It is believed that a family who suffered the same loss would make 1000 cranes, (they made theirs out of the sears catalogue) and then gives them to the new family to help them on their healing journey. At one point the cranes would be placed in a fire helping the pain and loneliness to heal. We gathered the cranes and everyone held on to a part of the circle. I asked that everyone take just a few seconds to let go of his or her own pains and hurts. Then we added the cranes to our bond fire. The flames roared and colour sprung from the fire... Lighting the evening skies. People stood in silence and watched as our fears left us for that split second.

Families sharing, and coming together... Sharing the LOVE and Friendship that our Special Boy allowed to happen.

Justin brought us all together to heal...to laugh and smile and remember. A little boy who so needed our family... heals all who ever knew him!

A time NOT to MOURN but to CELEBRATE

Thanks you my Dear Son...for the Joys and Memories.

The Time and Love you gave so freely.

You will be in my heart forevermore.

As you continue your journey....

Love from the Pit of my Being

Until We Meet Again

**Love you my Son!
MOM**

Little Butterfly

Little Butterfly come rest your wings,
Come and sit with me awhile.
Let's spend this time remembering
The way it use to be.

Little Butterfly look at me,
For it is your face I want to see.
The glow the smile so bright
Flickering in the light.

Little Butterfly tell me true
IS your life anew?
I watch as you flutter on by
without a clue

Little Butterfly looked at his Mom
Smiled his biggest smile.
"I am free to soar the skies
I AM free again."

Little Butterfly leaned over so close
And gave his Mom a Butterflykiss
He smiled...
He turned...
He fluttered away
Turning to say...
MOM...I Love You So!

Butterflymom Jan 2004

Justin's Message:

KNOW That I am THERE

**When you lit that candle
To help you remember me.
And the tears begin to fall.
Just Remember...**

**Anytime...Everywhere,
Know that I am there.**

**Life goes on,
And Seasons come and go.
Nothing stays forever.
But my 'Love' for you
Is forevermore
Know that I am there.**

**And when you are lonely,
Call out my name.
The message is clear.
The whisper in the wind,
The breeze across your face.
Know that I am there.**

**And when the rain comes from the sky,
Know that I watch over you.
Look past the raindrops on the window
To the Rainbow in the sky.
Feel my presence so very near,
Know that I am there.**

**I'm there in the morning
And when you awake.
I'm there at noon.
And when the evening stars shine so bright
I'm there to tuck you in at night.
Know that I am there.**

**Look through my eyes
To the light in the skies
Look at the smile in your heart.
And feel the peace and KNOW
You are Never Alone.
For I am there.**

**When you feel like giving up,
Let that darkness turn to light.
And see all the Miracles so bright.
Keep the faith, hope and love
That we both shared with all our might.**

Know that I am there.

**Every now and then,
Feel me...
With all my heart I'm sure
I will make you see.
That there is more than one Angel watching over you.
Just believe. For I am there.**

**When I died,
I never really left you.
Just Believe.
For I am a part of you.
Feel my breath across your skin.
For I am there**

**You may not be able to see me.
My face but a memory.
But the Breeze across your face,
Is my Butterfly Kiss.
Know that I am there.
Know that I am there.**

**Reach...
For I am there!**

**Yes I am there
Forevermore!**

Written 2004-01-25 Butterflymom



**We are a Family You and I
Not by choice but by circumstances.
The first day we come to the House,
Our hearts are broken and our minds confused.
We smile as the tour is given,
Rules read,
And the keys to our rooms placed in our hand.
We go to our room
And Cry.
What do we do now?**

**We are a Family You and I
Not by choice, and certainly not by desire.
The gentle smile and friendly hellos
Ring through the kitchen and halls.
"Have a good day,"
Is heard as the door opens
For us to head back to the hospital.
The safe and secure feelings, as the door opens,
Makes us realize,
That this is our Home.
For how long?
We are not sure,
But...
We are Home!**

**We are a Family You and I,
Not by choice,
We all battle one of the biggest fights in our life.
As our child receives treatment
We wait - explain - research - cry - wonder - and pray.
Our prayers are heard - little do we know.**

**We head back to the House,
After another long and exhausting day.**

How is Justin?
Rings through the halls.
Concern and Unconditional Love is spread
Like the disease that threatens my child.
The walls begin to fall,
You greet people with a smile - or a tear - or a nod.
It really does not matter.
And the feelings that we are weak,
Because we cry - disappear.
We Are Who We Are!

We are a Family You and I,
Not by Choice,
But...
With the same questions and fears.
WHY MY CHILD??
We sit and talk,
Small stuff,
And life threatening decisions.
Everyone is concerned,
And we lean on each other.
In Silence and Laughter,
We get through another day.

We are a Family You and I
Not by choice,
But...
We share a bond
That we wish did not exist.
We gather strength from everyone in the House.
And share the Successes.
We accept the Tears and Fears,
We walk the road together,
Not knowing where it leads.
We are not alone.
We learn from each other.
We are a Family You and I,
At Home,
At the
Toronto Ronald McDonald House.

**To My SONS:
(Jeremy, Spencer, Michael, Brent, and Wade)**

All five of you were with us,
When the diagnosis came.
You stood tall and brave,
And had to Grieve on your own again.

You all found your place,
And did what had to be done.
For this my Sons I am grateful
And I thank you each and everyone.

You gave me the strength to carry on,
When life was upside down.
You all stood your ground so strong,
And helped your Mom go on.

There were times when I could not be there,
And Times I was but...
You never once turned away.
And stood beside me all the way.

For this My SONS...
I Thank You.

Then came the time for us all to know,
That Justin's time had come.
He would leave this world of ours
We would lose our brother and son.

Again you stood there,
Side by side Not even swaying in the wind.
With Courage and Strength,
You held on till the inevitable end.

If I could change our days before,
With a blink of an eye I would.
But my sons you showed the world,
What MEN you all have become.

Your Love is real and genuine,
And your future will be yours.
For going through what you all endured,
Shows you can open all the doors.

**So to you my sons,
Jeremy, Spencer, Michael, Brent, and Wade.
I Love You...
With all my heart.**

**AND...
I THANK YOU
ONCE AGAIN!**

Love MOM!

Written Jan 27th 2004 Butterflymom