

## Updates

December 24, 2002

My precious sister Margaret Creveling (sister #2) called last night to share the following poem with us. We know it was intended to lessen the burden of sorrow our whole family is feeling this Christmas season. I had never heard it before and thought it was so beautiful and comforting we felt moved to post it on the web site. We think it is especially comforting to all of those who have lost loved ones over this past year and we thank you Margaret for sharing it with us! God's blessings to all of our family and friends this Christmas and Holiday season!

### **MY FIRST CHRISTMAS IN HEAVEN**

I SEE THE COUNTLESS CHRISTMAS TREES  
AROUND THE WORLD BELOW  
WITH TINY LIGHTS LIKE HEAVEN STARS  
REFLECTING IN THE SNOW,  
THE SIGHT IS SO SPECTACULAR,  
PLEASE WIPE AWAY THE TEARS  
FOR I AM SPENDING CHRISTMAS WITH JESUS CHRIST  
THIS YEAR.

I HEAR THE MANY CHRISTMAS SONGS  
THAT PEOPLE HOLD SO DEAR,  
BUT THE SOUNDS OF MUSIC CAN'T COMPARE  
WITH THE CHRISTMAS CHOIR UP HERE.  
I HAVE NO WORDS TO TELL YOU  
THE JOY THEIR VOICES BRING  
FOR IT'S BEYOND DESCRIPTION TO HEAR THE ANGELS  
SING!

I KNOW HOW MUCH YOU MISS ME,  
I SEE THE PAIN INSIDE YOUR HEART,  
BUT, I AM NOT SO FAR AWAY  
WE REALLY AREN'T APART.

SO BE HAPPY FOR ME DEAR ONE,  
YOU KNOW I HOLD YOU NEAR,  
AND BE GLAD I AM SPENDING CHRISTMAS  
WITH JESUS CHRIST THIS YEAR.

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December 19, 2002

A belated Happy Thanksgiving and an "on-time" wish for a very Blessed and Merry Christmas and Happy Holidays!

Once again, we can not thank you enough for all of your prayers and for all of the wonderful acts of generosity exhibited to Joe and our family during both his illness

and since the time of his passing. It was six months ago today that Joe was called home to his "new life". As devastated and sorrow filled as we were on that day of June 19th, our God is so good that he has blessed us through many incredible and wonderful experiences thus showing us so well that our precious little angel has been at His side and in our hearts these last 6 months. For this we are extremely grateful this holiday season.

As we have told Mary and Ryan, Joe will have the most wonderful Christmas of all - he gets to spend this Christmas with the REAL baby Jesus, the holy family and with MANY wonderful family and friends who have gone before us, and yet, he will still be there to share this Christmas with us - how could you ask for more. We miss Joe's physical presence in our lives to the point that it hurts - but we are and will forever be grateful to have shared his short but incredible life and to know that he now has no pain, only love, happiness and peace in his new life and that his spirit will forever be in our hearts and minds.

Russ and I often talk about and reflect on how amazing Joe was in that, during his entire life, while both healthy and sick, he always exhibited happiness and JOY to others. This holiday season we have a new understanding of what JOY stands for and what it really meant then and now:

- Live for Jesus first.
- Live for Others second.
- Live for Yourself third.

We pray that this holiday season and always, that we are all filled with JOY like we've never known it before. Wishing you a Merry Christmas and Happy Holidays!

We love you like crazy and we pray for you always! God bless you.  
Mary, Ryan, Betsy, Russ and Our Precious Angel Joe

P.S. The new website has been designed and will be up within the next few weeks. We look forward to sharing with you all the wonderful things your donations have done to help children in many different ways!

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July 2, 2002

Blessings to those who have continued to follow Joe's website. We find ourselves getting on it everyday to reread the many messages of love, support and comfort we have received. We enjoy looking at the pictures and remembering all the fun and wonderful times we shared with our precious angel. It has proven to be very therapeutic for us as we miss Joe so very, very much.

Many of you have asked for a copy of the Homily and/or Eulogy. We also thought they were beautiful and are very happy to make them available to you. They are posted below. We can't thank Fr. Kalita and Joe's Aunt Pat Pat, for honoring our precious son in such beautiful ways. The warmth, compassion and the love felt (and shared) for Joe were evident in both. We were honored to have him recognized in such a moving way. We have also had several people ask what songs were played at

Joe's graveside services - they were "Angels Among Us" by Alabama and "You'll be in My Heart" by Phil Collins. The Tarzan song " You'll be in my Heart" was chosen for two reasons. The first being that during Joe's trip to Disney, among his very favorite shows was "Tarzan Rocks". The second reason is that it is so fitting, as he will forever be in our hearts. "Angels Among Us" was chosen because we know that forever more; we will have an angel among us. Joe will be with us forever and will watch over all of us always.

We also want to give a brief explanation of the Joseph Patrick Sanford Memorial Foundation. It is a non-profit (tax-deductible) organization set up to keep the memory of Joe alive. We know that Joe would want to do something to thank those that helped him over these past several years during his battle with cancer. So we will be using the donations received through the Foundation in multiple ways, all of which will be dedicated to keeping the legacy of Joe's love, courage, faith and compassion for his fellow man alive. We haven't yet had the opportunity to fully define specifics as to how we will be spreading this legacy, but over the next couple of weeks and months we will be praying hard for guidance. For the immediate future, we will continue to use this website as the primary method of communicating the status of the Foundation to our many friends.

We also want to especially thank Doug Arkin (Arkin and Company, Chartered) and Michael Flynn and Gerad Emig (Gleason, Flynn, Emig & Fogelman, Chartered) for providing their services, pro-bono, for the establishment and administration of the Foundation.

To read Joe's eulogy, [click here](#).

[Click here](#) to read Father Tom Kalita's homily.

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June 24, 2002

*"No Words - Just thoughts and feelings of love"*

Many individuals have asked Russ and I for copies of the Homily and Eulogy that were delivered at Joe's funeral Mass. We will be posting them on the website shortly. God Bless.

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June 20, 2002

As this is probably our last update, Russ and I would be remiss not to thank Paul Finkel and Kevin Wolf, owners of Podi.com for designing and allowing us to host Joe's website through their company. Also to our dear friend Mary Ellen Crichton, who is on their staff, for posting the updates for us. Their generosity allowed Joe to hear from his many friends and relatives and served to make him a very happy little boy. Thank you, thank you, thank you.

We also want to thank the staff at NIH, especially Dr. Kathy Warren, Dr. Balis, Alberta Aikin, Michelle O'Brien, Patty McGinley, and David Draper. We want to thank Dr. Packer, Dr. McDonald, Dr. Cogen and Debi LaFond and all the rest of the awesome staff at Children's Hospital. We will never forget all that you did for Joe and although your medical knowledge and treatment were superb - God wanted him more.

The visitation for our precious Joe will at St. Peter's Church, 2900 Sandy Spring Rd, Olney, MD on Friday, June 21, from 2-4 and 7-9. The Mass of Christian Burial will be on Sat, June 22 at 11 am. He will be interred at The Gate of Heaven Cemetery immediately following the Mass. We ask that, in lieu of flowers, memorial contributions be made to The Joseph Patrick Sanford Memorial Foundation, c/o Arkin and Company, 5 Choke Cherry Road, Suite 370, Rockville, MD 20850. Arrangements are being handled by Collins Funeral Home, Silver Spring, MD.

May the comfort that only our Lord can give be with each of you. God Bless you!

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Joe's Final Update - June 19, 2002

Our precious, precious son Joe "won his battle with cancer" and went home to our Lord's arms at 5:45 pm today. He is now finally in heaven, at peace with his beautiful new healthy body. No more illness, no more drugs, no more medical devices, no more hospitals and no more pain. He was surrounded by family who loved him so dearly and he was very peaceful in his passing.

Our hearts are completely torn apart and we cannot begin to imagine life without Joe. Parents usually think they should teach their children, and yet, our child Joe taught us so much about life, about love and most of all about faith. We thank you Joe and we pray we never forget a single lesson! We thank God for allowing us to have known Joe and although his time was brief we are so grateful for having been honored to share his short but incredible life.

Someone once asked Mother Theresa the purpose of life. She said the purpose is to live a holy life in order to attain eternal peace in heaven. Joe did just that.

We trust that, just as our Lord carried us through Joe's illness, He will continue to be there helping us through the most unimaginable grief a parent and siblings could ever feel. We ask for your continued prayers for our family and most especially for Joe's twin sister Mary and his little brother Ryan. Although we know that Joe is in a better place, it is hard for us to imagine our lives without Joe.

Joe will live forever - cherished in our hearts. When I told Mary that Joe would be her own personal "guardian angel" she said, "No, Mom, Joe will be a guardian angel to everyone who ever prayed for him." I believe she is right.

While it is hard to put into words just what Joe's life on earth stood for and what his "new life" will be like, we think this poem comes the closest:

*IF YOU COULD SEE WHERE I HAVE GONE*

*If you could see where I have gone,  
The beauty of this place,  
And how it feels to know you're home,  
To see the Saviors' face.*

*To wake in peace and know no fear,  
Just joy beyond compare.  
While still on earth, you miss me yet,  
You wouldn't want me there.*

*If you could see where I have gone,  
Had made the trip with me.  
You'd know I didn't go alone,  
The Savior came with me.*

*When I awoke, He was by my side,  
And reached out his hand.  
Said, "Hurry Child you're coming home  
To a grand and glorious land.*

*Don't worry over those you love,  
For I'm not just with you.  
And don't you know, with you at home,  
They'll long to be here too."*

*If you could see where I have gone,  
And see what I've been shown.  
You'd never know another tear,  
Or ever feel alone.*

*You'd marvel at the care of God,  
His hand on every life,  
And realize he really cares,  
And bears with him each strife.*

*And that he weeps when one is lost,  
His heart is filled with pain.  
But oh! The joy when one comes home,  
A child is home again.*

*If you could see where I have gone,  
Could stay awhile with me.  
Could share the things that God has made, To grace eternity.*

*But no, you could never leave,  
Once Heavens' joy you'd known.  
You couldn't beat to walk earth's paths,  
Once Heaven was your home.*

*If you could see where I have gone,  
You'd know we'll meet someday.*

*And though I'm parted from you now,  
That I am just away.*

*So, thank you family, thank you friends,  
For living for the Lord.  
For teaching me to love Him,  
To trust Him and His Word.*

*And now, that I'm at home with Him,  
secure in every way,  
I'm waiting here at Heaven's door,  
To greet you some sweet day!*

Thank you from the bottom of our hearts for all your love, prayers and support. We will never forget how each one of you carried us through this suffering and we know that same support will help us face what the future now holds for us.

We will update the web site tomorrow with the funeral arrangements. God Bless each of you! Joe, Mary, Ryan, Betsy and Russ love you all very dearly.

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## **June 2**

Thank you so very much for your powerful prayers. I know we are all continuing to pray for a miracle and yet I believe we are living a miracle everyday - life with Joe.

We continue to do what is necessary to help keep Joe comfortable and happy. He is now in a hospital bed in the Family Room and it seems to help him rest more comfortably. I think he enjoys being downstairs where he gets to be included in the family day-to-day happenings. We continue to try to offset the increased discomfort by giving him ever increasing levels of his pain medicines. Thankfully, that seems to help him, and allows him to rest better. We have also obtained an oxygen unit to aid with his breathing. He is now sleeping a good portion of the day. We have been advised by his doctors that he could take a severe turn for the worse at any time so we spend most of our time at his bedside watching and being there for him.

When Joe is awake, he is still amazingly alert and coherent. We spend our time talking, sometimes coloring, praying and a lot of kissing. Last Thursday, as my parents and our family knelt around Joe's bedside, Joe proceeded to lead all of us in praying a decade of the rosary. Since then he has lead our family in a decade of the rosary every night. Last night our Pastor, Father Kalita came to our home and offered Mass with our whole family. It was a beautiful Mass and such a gift to all be together in such an incredible way. After Mass Joe again lead everyone in the rosary. Even though he struggles sometimes to form his words - he has maintained his ability to pray. It felt as though the presence of the suffering Christ was present in the room with us, a beautiful moment that none of us will ever forget.

There are no words that could possibly express our thanks to everyone who has prayed for our precious Joe. Russ and I are convinced your prayers are providing our whole family with God's peace, understanding and comfort. Please know that Joe and

all of us pray for each of you every night as well - when we ask God to bless all of you for your faith, love and support.

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## **May 6**

It has been a month since our last update and we are ever grateful to God for this time. He has continued to grace us with the gift of life for our precious son Joe. We cherish every moment of every day together. Joe's spirit, sense of humor and appreciation for life continue to be as positive as always. To help him with his battle, we rely on increasing stronger doses of the various pain medications that help to keep him comfortable.

Joe is counting down the days to his birthday next week. We have a very special day to celebrate on May 11th - it is Joe and Mary's 10th birthday as well as Ryan's First Holy Communion celebration. We think it is incredibly awesome that Ryan will be receiving such an important and wonderful sacrament on Joe and Mary's birthday. We are all looking forward to celebrating this VERY special day together.

Russ and I continue to try to balance our time taking care of Joe at home while trying to also stay focused and involved in Mary and Ryan's lives. They have both been so unselfish, thoughtful and considerate of Joe in every way. We know it has been very hard on them. They do whatever they can to make Joe happy. We are continuing to make as many wonderful family memories as we can together for as long as we can.

Last week my mother was hospitalized with heart problems. The doctors did surgery to implant a pacemaker and we are grateful that she is recovering but she is still experiencing some heart problems. She is the dearest and most faith-filled woman I know and we all love her so very, very much. I ask you to please keep her in your prayers at this time.

Thank you for your continued prayers and for all the various forms of support provided to Joe and our family. We couldn't do what we are doing to help all of our children without our family and friends. God Bless you!

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## **April 7**

I have sat in front of the computer several times over the past few weeks to try and find the "right words" to update Joe's website, this update has been the hardest.

Joe had an MRI of the spine done two weeks ago and it showed that many new cancer sites have now formed in both the spine as well as, new areas in the brain. We are now working with both NIH and a hospice care organization as we to try to keep Joe as comfortable as possible. Words cannot express the deep sorrow that we are feeling.

Just as Jesus did in His own life, Joe continues to quietly and courageously accept his suffering. Even now, Joe continues to lead and teach us. We've learned the unexplainable and awesome love that God has for each of us, in that He gave His ONLY child to suffer and die for us. That at any point in Jesus' suffering He could have changed things - but continued to endure so much because He loves us so much. Joe has never, in the 2 1/2 years that he has suffered with his cancer and associated limitations, asked the question why, or why me? Since Joe has never asked why, we will never ask why. Joe has been the ultimate example of Christ's love in our lives.

Our hearts are broken and every day brings more unbearable pain, still we are all (Joe included) holding on to our Lord's love and comfort. We continue to HOPE and pray for a miracle, knowing that our miracle may be that one day Joe will be eternally in the arms of Our Lord and that He will provide for Joe a love far beyond any that we could possibly give to him.

Please know that although Joe doesn't have the energy to see his friends, he still loves and misses them all. Thank you for your understanding in respecting Joe's privacy and comfort. E-mails and cards are most welcome and appreciated and we read them to Joe every day. We ask for your continued prayers for our precious son Joe and for the rest of our family. Your prayers are our only source of strength.

God bless you and we thank you for your love, support and friendship,

Joe, Mary, Ryan, Russ and Betsy

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**March 20**

***"Cast your care upon the Lord, who will give you support," Psalm 55:23***

We enjoyed our trip to Disney World. We had our good days and bad in regards to Joe's health, but overall it was wonderful to all be away together ([pictures on the web site](#)). Thanks to everyone who helped to make it so special.

We are especially grateful for all the prayers that were offered for Joe the evening of March 10th. We have been so touched by how many people prayed for our precious son. Thank you! There was a beautiful chapel on the complex where we were staying in Disney and Joe, Mary, Ryan, Russ and I went there to pray at 7:30. It was so wonderful to be together in "family prayer time" that we decided to continue to set Sunday evenings aside to pray for the intentions in our hearts, as well as, for your families and the intentions in your hearts. Your prayers have been carrying Joe and our family through these extremely difficult days. We continue to research other acceptable protocols. Unfortunately, so far we have found none. We go on praying for a miracle to occur, realizing we are all in God's hands, being loved and cared for by our precious Lord.

Joe's spirits, sense of humor and attitude continue to be positive. Just the other day Joe said to me "Mom, life is good - No Mom, life is really GREAT!" With all that he

has to deal with, Joe continues to teach us major life lessons - to cherish the "gift of life", each and every day, accepting and courageously doing God's will and most importantly, to keep the faith! Thank you for keeping Joe's spirit alive by your prayers! God Bless you!

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**March 5** - Dear family and friends,

First, we want to thank you for all the prayers that have been offered for our precious son Joe. Now, Russ and I have a very "special prayer request" for you. We would like to ask you, your families, and any friends you want to invite to unite in prayer for Joe next Sunday, March 10th at 7:30 p.m (E.S.T). This does not have to be formal and you do not have to go to your House of Worship, we ask only that you just take a few moments, wherever you are next Sunday and ask God's blessings for Joe.

***Mt:18:20: "For where two or three are gathered together in my name, there am I in the midst of them."***

God Bless you for your kindness in joining with our family next Sunday evening - we believe that our prayers will be heard and answered in God's own time and way.

All our love, Russ, Betsy, Joe, Mary and Ryan

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***February 26 - "Rejoice in the Lord always, I shall say it again: rejoice! Your kindness should be known to all. The Lord is near. Have no anxiety at all, but in everything by prayer and petition, with thanksgiving, make your requests known to God. Then the peace of God that surpasses all understanding will guard your hearts and minds in Christ Jesus." (Phillippians 4:1-7)***

Joe's MRI results were not very promising. The tumor has not shrunk, but the doctors at NIH are still looking for other options. Despite this setback, we will continue to be optimistic and recognize that the Good Lord's plan for our lives is His alone and ours to accept. As always, Joe's spirits are wonderful and he is handling this turn of events with the courage and faith he has always shown! What an awesome example we have in our lives.

Since we cannot start a new protocol until the previous one clears his system (usually a couple of weeks) we decided to use this time to make a return trip to Disney (which Joe really fell in love with on his visit a couple of years ago) and hope to go within the next week or so. Joe, Mary and Ryan are very excited.

Thank you for all of your prayers! God bless you!

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**February 14** - Since our last update life has been filled with many mixed blessings. Joe had two good weeks after his chemotherapy treatment but took a downslide the end of last week. He has been suffering again from headaches, nausea and fatigue. Although the symptoms are sporadic during the day, at times they have been very worrisome. This past weekend the headaches and vomiting were enough to warrant a trip to NIH where, after a blood test showed a very low platelet count, he received a platelet transfusion on Saturday. Fortunately his neurological exam appeared to be normal, but they really won't know much more until he has his next MRI scheduled for February 25th. There are many possibilities for the headaches ranging from eye strain, sinus infection to tumor activity. We are praying for the best possibility. If the symptoms persist they may move the MRI to an earlier date. Today he had his physical and blood drawn and his counts were still very low so he was transfused with both platelets and whole blood. He wasn't able to go to school this week because of his counts but is looking very forward to opening his Valentine cards from his classmates and anxiously awaiting the doctors O.K. to go back to school.

On a more positive (and fun) note, our affiliation with NIH has introduced us to a support program called "Special Love" which has been set up for children with life threatening diseases and their families. This weekend, Special Love has planned a ski trip to Canaan Valley, West Virginia. Although we didn't think Joe would want to or feel up to going, he expressed his desire and excitement to try tubing (with a helmet of course) and enjoy the indoor pool facilities. We continue to take Joe's lead, enjoying and cherishing every minute of every day, facing life with courage and faith - just like he does! We didn't know until today if Joe would get a final O.K. from the doctors and when he got the O.K. this afternoon Joe was thrilled. Barring no other complications, the five of us are looking forward to some "family time" away.

Although the weekend trip to the hospital didn't exactly set the week off to a great start, it certainly improved on Sunday when Joe had some special visitors. Coach Ralph Friedgen, Mrs. Friedgen and Kristina came by to visit Joe (see pictures on the web site). The best part of the evening, aside from seeing Joe's excitement in receiving some really neat University of Maryland memorabilia, was seeing first hand what a warm, and caring family the Friedgen's are. Joe was very happy that Coach Friedgen took the time from his VERY busy schedule to come to his house and visit him and even more grateful that he turned down the Tampa Bay position. THANK YOU COACH!

A few weeks ago, the "Voice of the Terps", Johnny Holliday contacted us and arranged to have Joe come to a Maryland basketball game and meet Coach Gary Williams and some of the Maryland basketball players (pictures on the web site). Johnny, Coach Williams and the players could not have been more supportive and attentive to Joe, Mary and Ryan. Joe got some autographs on a basketball he brought and Coach Williams gave Joe a signed hat. We have been very touched by the support of the Maryland programs. GO TERPS!!!!!!!!!!

As a child, when you have to spend as much time in hospitals or at home, as Joe does, it is nice to focus on fun events such as these and forget about your illness for awhile. It is very humbling for Russ and I to experience the outpouring of kindness and support that has been shown to Joe and our family by everyone. We thank all of you for being so kind and doing so many special things for Joe and **we especially thank each one of you for giving us the greatest gift of all - your prayers!!!!** God Bless you.

**"The Lord is my light and my salvation:  
whom should I fear?  
"The Lord is my life's refuge:  
of whom should I be afraid?"  
Psalm 27:1**

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**January 31** - We are very happy to report that Joe's counts went up last Friday, so he was able to get his chemotherapy treatments on Friday and Saturday. This past chemotherapy treatment was harsher than the last, but Joe willingly did what he had to. He seemed a little more tired this weekend, but overall seems to be doing very well. With his counts back up he wanted very badly to go back to school. So he's been attending school for a few hours each day and is VERY, VERY happy to be back with his classmates and teachers. He wants to continue going back until his counts drop again. Hopefully, with no other problems he'll be able to do so. The fourth grade students, the teachers, staff and entire student body at Joe's school, have been an incredibly supportive and loving part of Joe's life. We are very grateful to them all.

Joe continues to have his blood drawn twice a week and a physical done weekly. We are very blessed to have a wonderful friend and neighbor, Michelle O'Brien, who is a nurse in the clinic Joe goes to and she comes by once a week to do his blood draws. It is so helpful to not have to go all the way to NIH, and it allows Joe to get to school that day. Thank you Michelle, you are a HUGE blessing in our lives.

Joe is scheduled for his next MRI on February 25th at 1:00. He will have had 2 cycles of chemotherapy treatment finished and at that point we will re-evaluate where we are at with things. We continue to pray for the tumor to shrink.

In our hearts, you are each a member of "Joe's Team." We couldn't have a more supportive, faith-filled and lovable team. God Bless you!

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**January 25** - A few weeks ago a very dear friend of ours, Steve Wright (also known as "Coach Wright") gave Joe an awesome gift - he wrote a poem for Joe. Steve has coached Joe in basketball since Joe was in Kindergarten and has helped and encouraged Joe to keep playing even during Joe's hardest times. Steve allowed Joe to play as much or as little as he wanted, without any regard to winning or losing. Since it is basketball season, with Joe and Steve's approval, I'd like to share his poem it with you.

#### **JUST A KID AND A COACH**

I am the coach,  
You are my teacher.  
I taught you to dribble,  
You taught me to be strong.  
I stressed teamwork,  
You brought togetherness.  
I taught you some skills,  
You taught me about life.

I am the coach,  
You are my teacher.  
When you shot and missed,  
I shot and missed.  
When you shot and scored,  
My heart jumped for joy.  
I cheered your every move,  
You rooted for everyone.

I am the coach,  
You are my teacher.  
I preached sportsmanship and character,  
You smiled and showed determination.  
I tried to inspire you,  
You are inspiration.  
I wanted to be a role model,  
You became one.

I am the coach,  
You are my teacher.  
I am big in your eyes,  
You are huge in my heart.  
We prayed with our team,  
You showed us the rewards.  
I coached you before,  
You teach me always.

Written for Joe Sanford  
By: Coach Wright  
January 11, 2002

Russ and I know that Steve wrote this as a tribute to our precious son, but after having read it we've realized it is not only a tribute to our son, but "in our eyes" a real tribute to Steve. The faith, caring heart, courage, and strength that he speaks about in this poem, could only be written by someone with the insight to recognize them and be able to so eloquently write about them. We have seen these characteristics in Steve time and time again. So to you Steve, we thank you from the bottom of our hearts. To all of our family and friends who read our web site, we ask you to remember our friend Steve Wright in your prayers. Steve was diagnosed this past December with non-hodgkin's lymphoma. Please pray for him, his lovely wife, Julie and his wonderful sons, Kevin and Sean. Through your prayers, God has, and will continue to bless all of us. This basketball season, we are ALL truly winners!

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**Jan. 14** - Just a quick update about the events over the last 2 weeks. As expected, Joe's blood counts are down pretty low as a result of the treatment received at the end of December and he had to receive platelets last week. If the rest of his counts don't start to go back up on their own he may require a transfusion this week. Although he was scheduled to start his next round of chemotherapy treatment this Thursday and Friday, if his blood counts don't get up to an acceptable range they will postpone the treatment for about a week or two.

Lately, Joe had been complaining occasionally about headaches and had a few episodes of nausea and vomiting. We informed the doctors at NIH about this and during his regularly scheduled physical last Thursday, they had an MRI done. We were very happy to learn that the tumor had not grown over the last month (which was the concern), but.... it had not regressed at all either. The doctors said that this wasn't unusual. We hope that the next cycles of chemotherapy will begin to shrink the tumor.

Joe's spirits continue to be good. He really misses school (I think he misses the social part of seeing his friends), but with his counts so low he really cannot attend school. He misses Mary and Ryan when they are at school and looks VERY forward to playing with them when they get home from school. We are looking forward to celebrating Ryan's birthday together today with a renewed realization of how extremely grateful we are to celebrate every birthday - no matter what the age - no matter what the circumstances!!!!!!!!!!!!

We will continue to keep you posted. Again, thank you for your concern, love, support and prayers! Joe's spirits are great and we truly believe it is due to the power of your prayers! God Bless you!

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**DEC 26** -. First and foremost, we hope that everyone reading this message had a most happy and joyous Christmas and we want to thank all of you who sent Christmas blessings to Joe and our family. Having Joe home with us made our Christmas the most special one possible.

We were successful in getting into the NIH study and Joe had his first two treatments last Thursday and Friday. As we said in the previous update, while the side effects for these drugs are not as severe as for some others, he does have significant discomfort during the administration of the drug. Without knowing exactly what to expect during the first treatment, he did well. But, we were especially proud when, on Friday, knowing what he was going to have to endure, Joe went right in and took the treatment without a single word of complaint. The staff at NIH has shown extreme compassion and has helped to make it as pleasant an experience as possible for Joe and the rest of our family. The protocol for this study is to have Joe receive the 2-day chemotherapy treatment every 28 days (if the treatment works). During that time, Joe will have to go to NIH twice a week for blood counts and a physical. They don't expect his blood counts to drop for about 2-3 weeks. An MRI will be done in approximately 4-6 weeks to determine if the treatment worked to shrink the tumor - we pray it will.

As we said earlier, we had a very Merry Christmas with our whole family together and supported by family and friends who helped, through words and/or deeds, to make our Christmas Day such a special one. Although we haven't had the opportunity to send a personal thank you, please know that you have our most sincere thanks and gratitude!

This year we found more meaning to the Christmas season than ever before. Among many things, we've realized what tremendous examples the Blessed Mother Mary and Joseph are for us, as they so willingly surrendered and accepted God's plan for them. Had they not done so, and without the birth of our Lord and Savior Jesus

Christ, His life, His death, and His resurrection, we would never had known His unending love and concern for each one of us. And so we learn from their example to accept God's plan for our lives and continue to trust that He and He alone knows what is best for us and will provide for us.

May each of you be blessed abundantly during this special holiday season and in 2002! God Bless you and we wish you a very Happy New Year!!!

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**Dec 18** - Russ and I spent most of last week researching some of the available treatment protocols and talking with some different specialists in the Hem/Oncology and NeuroOncology fields and, after much discussion and prayer, we decided that we would transfer to NIH for treatment. Joe has to undergo several tests to ensure that he meets the criteria to be entered into the study but so far all have been within the necessary limits. We will complete the remaining tests tomorrow morning and, if all continues to go okay, he will be doing the treatments on Thursday and Friday. In this study, they will primarily be using a drug that has, in some other cases, shown some success in reducing the Medulloblastoma type tumors. They will be combining it with another drug that, we hope, will help to work to permit more of the active drug to reach the tumor and thus be more effective. The expected side effects are not supposed to be as harsh as Joe has experienced before but there will be some discomfort. One positive point is that, unless his counts drop or we have some other treatment related problem, much of this will be done on an outpatient basis. Meaning less time actually in the hospital for Joe. We discussed the options with Joe and talked about his leaving the "comfort blanket" that has come to know at Children's to go to NIH and he is ready to "get started". He said, "I won't complain, let's just do it!"

Knowing we are starting a new series of treatment, we decided it was a good time to take a pilgrimage to the Shrine of St. John Neumann who was canonized for (among other things) the miracles he performed in curing children with cancer. Our entire family went last Sunday and we were so touched to arrive and to see so many of our "Pennsylvania and New Jersey family" (aunts and cousins) who came to be with us and pray for Joe's healing. Thank you for your love and support!

We had an awesome visit this evening from a very special person, "Santa Claus". He arrived on the Sandy Spring fire truck and was accompanied by his helper elves that looked suspiciously like some of our dear friends from St. Peters. Joe and his siblings and cousins were surprised and "shocked" that Santa would actually stop at our house. They said it was "one of the best nights of their lives". Thank you to everyone who made it happen (pictures are on the web site).

Please continue to pray with us for our "Christmas Miracle".

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**Dec 11** - Unfortunately, we must tell you that the MRI results did not show the response we were all hoping for. The chemotherapy drugs that ordinarily show a positive response were not, in this case, effective in shrinking the tumor. What this means is that we now must look at some of the newer protocols that are being used. Joe's doctors are now putting together a new plan of action and Russ and I are

talking with other specialists to see if they have other treatment protocols that have shown even higher degrees of success in fighting this form of cancer.

Despite our best efforts in protecting Joe from exposure to any possible infection, we have spent the past few days back in the hospital because Joe broke out with a mild case of the chicken pox. Apparently, due to his immunosuppressed state brought on by the chemo treatments, he is susceptible even though he had the vaccine. Fortunately, it was a relatively mild form and he wasn't too uncomfortable. We were able to "spring" Joe last night and HOPEFULLY, will be home for the next few days while we decide what our next course of action will be.

Even during these last setbacks, Joe continues to be an example of positive and upbeat behavior. Joe has taught Russ and I many things. Right now, we are drawing upon two of his teachings. The first one is to LIVE IN THE MOMENT cherishing it and appreciating just what God has given us each and every day. The second is to face life's challenges with as much COURAGE AND FAITH as you have. Joe continues to show us the way in this regard. He takes each challenge and goes at it headfirst. He knows that he has had and will continue to have these battles but he chooses to fight rather than give up. So we will follow Joe's lead facing our next challenge with as much courage and faith as we can find while enjoying every moment until we get there.

We know and most sincerely appreciate that you have all offered many prayers for our precious Joe, and for the rest of our family. We thank you and we ask for your continued prayers. We love you! God Bless you!

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**Dec 4** - Joe's stem cell harvest went very well. The cell growth-stimulating hormone worked well enough that the doctors were able to obtain enough cells to use for several of his future chemotherapy treatments. The process itself required the insertion of a large bore catheter into a vein in Joe's leg which was then connected to a "blood filtering" machine which was used to separate the stem cells from the rest of the blood. Because of the size of the catheter Joe had to remain still in bed for approximately 8 hours. At the end of the procedure, the catheter was removed, and we were allowed to come home. Today, Joe only complained of a little soreness in his leg and when his sister and brother came home from school, he ran outside with them and played all afternoon.

Joe is scheduled for an MRI on Sunday afternoon and we are planning on a possible (probable) readmission to the hospital on Tuesday for his next chemotherapy treatment. For the next couple of days we plan to continue to enjoy this time away from the hospital, especially with Joe feeling good! Joe's ability to face each new medical procedure with courage while continuing to be optimistic and happy, gives us the strength to do the same. Thanks Joe!!!!

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**Nov 30** - Although Joe's counts are still low and they don't anticipate he will be ready for the stem cell rescue until Monday, we were able to get a 48-hour pass out of the hospital to come home for a few days. We are continuing his IV antibiotics from home, along with all the other medical care. We must return to the hospital on

Sunday in preparation for the procedure on Monday. If all goes well, we will be able to come home Tuesday or Wednesday for a day or two before they do the next MRI. The kids are very excited because we get to spend Russ' Birthday together today - another of our many gifts from God!

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**Nov 27** - Joe was readmitted to the hospital on Wed morning Nov 21. He was running a very high fever, was nauseous and very lethargic. When they drew his blood, his counts were very low. Over a course of several days he received different antibiotics, platelets and whole blood. He now seems to be "turning the corner" and feeling better, but there are still concerns about infections and other associated blood issues.

The plan at this point is to keep him in the hospital and monitor his counts. He is receiving daily injections that stimulate the growth of new white blood cells. When the white blood counts start to come up they will be able to "harvest" his "new" stem cells. At this point, we don't have any idea when this will be (but are hopeful within the next week). The harvesting of his stem cells must occur even though we still don't know just how effective the latest round of chemo has been. Since the cells must be harvested within a certain period of time, we must go ahead even though we are still unsure of the next steps. Shortly after the harvest, we will return for an MRI, this will be the test that gives a better idea of the success of the chemo treatment and whether the tumor has responded to the initial treatment. If so, we will proceed with the high dose chemo with a stem cell rescue. If not, we will look for other treatment options.

As always, although Joe is bored from reading, playing board games, and watching TV, he doesn't complain and keeps us all laughing with his antics and wit! The latest with Joe is that he is in the process of losing his hair once again. As usual, he is facing this latest issue with the same acceptance that he has displayed throughout this whole illness. The nurses suggested we give him a "fun" short Mohawk style. Although Joe is very conservative he agreed to try it. (Mom thought it looked pretty cute!) The next day, the hair started to drop out. For some reason, the longer hairs on top were the first to drop. He now has a very neat "racing stripe" down the middle of his head. When he saw this in the mirror today he said " Hey, first I had a Mohawk, now I have a "No-hawk". Gotta love it!!

We had a wonderful Thanksgiving! Traditionally, for Thanksgiving, the family has all come together at Mary Pat and Doug's (Betsy's sister and brother-in-law) home to celebrate the holiday with family and friends. This year, Doug brought Mary and Ryan to the hospital (along with a delicious dinner that Mary Pat made early for us), so we could all be together for awhile. Family members came by throughout the day and brought many "goodies" to Joe and our family. We were so grateful to all be together realizing how fragile and precious life is. It was a Thanksgiving we will never forget!

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**19 NOV** - As we had hoped, Joe was able to come home from the hospital last Friday. He is tolerating this first round of treatment VERY well. He has taken the side effects and home treatments in stride and never complains. In addition to being

home for the weekend Joe had other reasons to celebrate. Both the Terps and the Redskins won in exciting games!

The doctors have told us to expect that he will experience some very low blood counts due to the chemo he received which will require a readmission at some point to the hospital so he can receive whole blood, platelets and/or antibiotics. We are praying that we will all be home for Thanksgiving, but if not we'll be grateful to be together wherever we are. With Thanksgiving a few days away we have been reflecting on our many gifts. We are thankful for so MANY of God's blessings, especially our faith, family and friends!

God Bless and have a very Happy and Holy Thanksgiving!

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**13 Nov** - Joe was admitted to Children's for the initial 3 day high dose chemo treatment. He continues to respond well to the treatment with some (expected) discomfort. The idea at this time is to get a positive reaction to the chemo (shrinkage of the tumor). If all goes as planned, he will be discharged on the 16th and he is really looking forward to coming home. His courage and determination to fight and beat this cancer is remarkable and we know assisted by your many prayers! Thank you and God bless!

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**9 Nov** - Joe underwent "same day surgery" at Children's for insertion of his Broviac catheter which will be used for his chemo treatments and blood draws. Joe underwent this procedure with the same courage and acceptance that he has shown for so many of his trials. He was home with us Friday night.

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After much discussion and consultation, we have decided that, for the immediate future, we are going to proceed with the protocol recommended by Joe's primary physicians at Children's Hospital. We talked with several physicians who are recognized as "experts" in this field and all have said that Joe's doctors are among the best in the field. None had any significant differences in treatment plans for this specific condition. Basically this means that Joe will receive an initial chemo treatment to try to shrink the tumor. Next, he will be readmitted to "harvest" his stem cells. Then, we will undergo two admissions for an aggressive chemo course of treatment using high doses of extremely strong chemo agents in conjunction with his stem cells to stimulate new stem cell production.

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