



*Connecting Family and Friends When
Health Matters Most*

Luke Remington's Journal

SUNDAY, NOVEMBER 15, 2009 9:09 AM, CST

Well, we have spent the last two nights at Carle Hospital fighting a fever. Luke and I went to the emergency room Friday night because of the fever and they admitted him and put him on antibiotics. He continued to have a fever Saturday morning, but has not had a fever now for a little over 24 hours. So far nothing is showing up from the blood cultures that were taken, so maybe he just caught a virus. He was very tired but seems to be getting better. His lab results are looking better. So we hope to go home later today. Yeah!

Thank you for all of your messages on the Caring Bridge page and your prayers. You don't know how much your support helps us to get through these days.

We will keep you updated as we learn more about what is ahead for Luke.

Erin

FRIDAY, NOVEMBER 13, 2009 6:05 AM, CST

Sorry it has been so long since I have updated Luke's webpage. Things were going well for Luke and I couldn't get the silly pictures to load on the site after hours of attempts so I kept putting it off until I had more time to figure out the problem. Of course time is something that is hard for all of us to come by some times.

Things took a wrong turn for Luke this week. We went for our monthly check-up and treatment on Tuesday and found out that his Leukemia has

relapsed. It was quite a shock. Luke has been so good lately, going to school, running around with friends, having a normal childhood. We were jolted back to earth though. So we went back on Thursday for a bone marrow procedure to see how extensive the relapse was. We were pleased to learn that his bone marrow wasn't packed with leukemia cells. This meant that we did not have to be admitted to the hospital and begin another 28-day reinduction therapy (similar to what we had to do when Luke was first diagnosed). Instead our doctor has switched us to a new medicine called dasatinib to see if we can get Luke back in remission. We will start the medicine today. The future plans are to look toward a Bone Marrow transplant. We will meet with Luke's doctors next Tuesday and learn more about that. Since Brendan is not a match for Luke, the transplant team will be looking at the National Registry of bone marrow donors for a match. Luke is being very strong throughout all of this. I am so proud of him. He is such a strong boy. I know all of your prayers have strengthened him. Please continue to pray for Luke and the other kids who live this terrible nightmare daily. I will update you as I learn more.

MONDAY, JULY 20, 2009 1:58 PM, CDT

Well, we made it back from our Make-A-Wish trip to Disney in one piece although I think Brian and I need a vacation to recover from our vacation. We had a wonderful time. Lots of roller coasters and water rides and characters to see. We were on the go the whole week. Luke was thrilled to get to ride the Rock - n - Roller coaster at Hollywood Studios. Although he did almost back out at the last minute, but he got a friendly nudge from his brother to get on. As soon as the ride was finished we had to head back to ride it again. Luke said that it was his favorite ride.

Another highlight was Sea World where we were able to pet sting rays and dolphins and even feed the dolphins. That was amazing. It was so hot in Florida though, I think we were all wishing we were dolphins about then and could spend the day jumping and diving and speeding through a crystal clear pool.

We also enjoyed dinner and entertainment at a show called Hoopty Doo at Disney. While you eat a group of six entertain you with music and skits in a down-home country style. It started out great when one of the girls in the show found Brian in the audience and plopped herself right down on his lap. She flirted with him, and teased him until he turned a bright shade of red. Brendan and Luke found it very amusing (as did I!) Then at the end of the show they pull people from the audience up on stage for their last skit.

This was Luke's turn to have all eyes on him. Luke isn't one for getting up in front of a lot of people on the stage, but they persuaded him and he was part of the final act. It was great fun, but Luke says that a career on stage is not for him!

We hustled and bustled all week from one park to another and one ride to another. When it got too hot or we started to wear down we headed back to the hotel for a break by the pool. Luke is so thrilled to be able to swim again, I think hanging out with Brendan at the pool was one of his best highlights.

We got home from our trip late Saturday night. Sunday was another day of fun as we went to a graduation party for some of our friends who are high school graduates. Congratulations Clark, Katie, Susie, Kaleb, Brendan, Betty and Jenna! It was a terrific party. Then we headed to a birthday party for our niece, Kelli. The kids had a great time playing in the back yard. And the weather was perfect! Luke and I had to take an early exit though and jump back in the car and head to St. Louis. We are here until late Wednesday as Luke receives his next round of treatments. He is having fun telling all of his nurses and child life specialists about his week.

We wanted to send out a Thank You to the Make-A-Wish organization for making such a week possible. We are humbled by the many people and organizations that help us along the way. Thank you too to all of you who volunteer and give generously to the many charities that help people in need. You make such a difference in so many lives.

When I get back home I will post new pictures on Luke's page. I'm not so good at doing that, but I am making it a **priority**. (We'll see if that "priority" designation has much power!)

God Bless You!

Erin

SATURDAY, JULY 11, 2009 9:38 PM, CDT

Well, there is excitement in the Remington house as we get ready for Luke's Make-A-Wish trip to Disney World tomorrow morning. We depart from Rantoul in the wee hours of the morning (3:30 a.m.) It will be interesting seeing how Luke handles that early wake-up time. He does not

like to be rushed into the day if you know what I mean! We will fly out of Bloomington and are scheduled to land in Orlando at 10:59 a.m. He and Brendan have been plotting and planning for the week. It looks to contain lots of roller coaster rides and a lot of eating! Yes, Luke is eating pretty well lately. In fact we went to his cousin Shelby's graduation party last night, and no sooner did we walk into the room, then Luke was in line at the food table getting the first taste of the great grub! Let's just hope he kept some of those calories on after a night of running all over the place with his cousins! He had a great time. It is quite a joy to see him having so much fun and running around like a normal kid, after such a stressful summer last year. What a difference a year makes. God has been good to us.

We will update you with lots of pictures from our trip when we get home.

As always I have to ask for prayers for our kids on the 9th floor at St. Louis fighting cancer. Even though we are so happy with Luke's progress, we are all to aware of the fact that so many kids are not able to have a chance to be a real kid right now and are really suffering and struggling along. Our hearts go out to them and are prayers continue. I also ask for special prayers for our new pastor, Father Bies, who we learned this weekend has cancer. He will be undergoing surgery soon and then working hard to recover. We pray that God will give him the strength to shoulder this cross that he has been given.

As always, thank you for the support you all give Luke and our family. God Bless You.

Erin

TUESDAY, JUNE 23, 2009 11:49 AM, CDT

Thank you so much to everyone for the nice messages you have left for Luke this week while he has been in the hospital for surgery. Luke was discharged on Saturday from the hospital. He was rather weak and not feeling quite up to speed yet, but he was definitely ready to get out of the hospital. Fresh air and sleeping in your own bed can do wonders. He is feeling better now but has to work on eating more and putting on some much needed weight. He lost 6 pounds while he was in the hospital, so gaining weight will be our major focus now. We went back to the hospital on Monday where Luke got his staples removed and saw his oncologist, Dr. Kanter for the last time. It was hard to say goodbye. Luke's new doctor was actually his first doctor when he was diagnosed in March 2008. Dr.

McDonald came in and saw Luke while we were at Children's Hospital Monday and gave Luke a pep talk about eating!

We will return for another treatment next Tuesday and then we have a few weeks off. Luke is happy about that because his Make-A-Wish trip to Disney World is just around the corner. We are heading to Florida on July 12th where we will spend a week at the Animal Kingdom and visit all of the parks. That brings a big smile to Luke's face as he begins to plan what rides he wants to ride first. He is looking forward the most to the Rock-n-Roller Coaster!

Thank you again for all of the prayers and encouragement you have given for Luke. We are so grateful for all of you as we continue to work toward getting Luke healthy again.

Erin

MONDAY, JUNE 15, 2009 5:19 PM, CDT

Just snuck out of Luke's room for a minute to let everybody know that Luke's surgery went well today. Dr. Warner was pleased with how everything looked and was able to connect Luke's small intestine back to his rectum. No more bag!!! But he is very sore, so now we are trying to manage the pain a bit and just rest. We are also watching closely to make sure that an infection doesn't develop. But so far, so good. Thank you for all of your supportive words and mostly for your prayers. They mean the world to us. I will keep you updated as to how the week goes. They expect Luke to be in the hospital recovering for a few more days.

Thank you all,

Erin

SATURDAY, JUNE 13, 2009 11:29 PM, CDT

Hello all,

I wanted to let you know how things are going with Luke right now. Luke completed his latest chemo round the week of May 25th. It was a rough week for Luke. He has been having rather severe reactions to some of his high-dose chemo treatments. It doesn't make him

nauseous as you might expect, but rather **very** angry and frustrated. For those of you who know Luke, you know that he is generally pretty even-tempered, but something happens and it makes him do a 180 degree personality change. It was pretty tough for his dad, who went with Luke for this treatment, and also for his nurses and doctors. Luke developed a fever, but thank God, there was no infection. I think it is just a side effect of the chemo and the negative reaction. But thank goodness for everyone's patience and care. By Sunday, May 31, Luke was back to his old self and he and Brian were able to come back home. He has been feeling great since being home. And the results from his bone marrow test came back negative again!!! Thank You God!

The next big event for Luke is rather exciting but also a little scary for him. Last June Luke had to have his colon removed while he was so sick. The surgeon who performed this procedure told me at the time that even though Luke would have an ileostomy he would be able to reverse it once Luke was healthier. Both Dr. Warner, and Luke's Oncologist, Dr. Kanter have decided now is the time! So, Luke and I are heading to the hospital tomorrow to check-in, for Luke's surgery on Monday. Luke is very excited to leave behind the bag that he has been wearing for the last year, and all of the inconvenience that it entails. He can't wait to go swimming again. But he has told me that he is nervous, so if you could please say a prayer for Luke to help him be strong and so that this procedure is successful we would very much appreciate it.

We were so lucky today to get a visit from Luke's doctor, Dr. Kanter, at our house! She and her husband, Todd and their baby, Sam, were in Central Illinois today visiting Ryan Coe's family. And since we are just a hop, skip and a jump, from the Coe family they were able to stop by and say hi on their way back home. What a treat. Sam is just an adorable baby and so good. We were tempted to keep him in Rantoul, but darn his mom and dad, they just wouldn't cooperate. We are sorry to say though, that Dr. Kanter and her husband will be moving back to New Orleans, where they are from, at the end of the month. We are happy that they will be back with family and friends from home, but we will miss them more than they can know. Brian and I as well as our family, are well aware of what Dr. Kanter has done for Luke because of her excellent care. But more than just being an excellent doctor, she has become a friend to us, and we will miss her greatly. But, hey, a reason for a road trip to New Orleans is always a good thing!!! Thank you Dr. Kanter for all that you have done for us! We can never thank you enough.

Well, I better get ready to sign off for the night and get to sleep. We have

to be on the road bright and early tomorrow morning headed for St. Louis. I think our car could make the trip on auto pilot by now!

Please keep all of the kids on 9W in your prayers. Our buddy Ryan is at home, but I read where he wasn't feeling too good today. I want so much for him to feel better and get to play with his trains and just enjoy summer time. Also, another little boy from 9W lost his battle with cancer this weekend. Ethan W. was from Quincy, IL and only 4 years old. I didn't know his family very well, but I remember seeing him in the clinic once while we were there, and he was in a cowboy hat and wearing boots, and you couldn't have seen a cuter little boy. May God be with his family during this time.

SUNDAY, MAY 17, 2009 11:01 PM, CDT

I apologize that it has been so long since we have updated Luke's web page. Luke has been doing well. He has been back to school with his classmates and was able to be in the Spring Program last week. He loved it.

We are heading down to St. Louis early tomorrow morning for a check-up with his Doctor. Since she had her baby in January we haven't gotten to see Dr. Kanter much, so we are very excited to see her and get an update on little Samuel. We are hoping that Luke will have put on an extra pound or two too. Dr. Kanter loves it when Luke gains weight. We are excited to see Luke's nurse Amy too! She hiked the Grand Canyon to raise money for Leukemia Research and we want to hear all about it. We are so proud of Amy and Tammy!

We should be just in for our morning appointment and then back on the road again to come home. Luke goes back next Monday then for another week of treatments.

Please continue to pray for the children and families that are battling cancer. This weekend we lost C.J. (<http://caringbridge.org/visit/cjsjourney>) He was such a wonderful young man. I have written about him before. C.J. learned about Luke from one of our favorite nurses at Children's, Nicole. He was so nice to come into Luke's room and visit him and ask how Luke was doing. He made quite an impression on Luke (as well as me). He did so many thoughtful things for the kids too. During one of our stays at the hospital, all of the kids who were admitted on the 9th floor got a balloon. When I asked where they came from the nurse told me they were from C.J. He got one for every kid on the floor. There is so little you can say, when

something so sad happens. But I want his parents and family to know that he made a difference to us and we were blessed to know him.

We also continue to pray for our good friend Ryan Patrick. I dare you to find a tougher kid. He struggles every day with painful side effects from his cancer treatments. But he perseveres. If you knew his mom and dad, you would know from where he gets his strength. Please keep both Ryan's family and CJ's family in your prayers, as they journey through such difficult days.

God Bless,

Erin

WEDNESDAY, APRIL 29, 2009 8:36 AM, CDT

We do not have a lot to report right now for Luke...which is a good thing. He has been well enough to attend school over the past few weeks, and is having a blast. He is very proud of the fact that he broke a bat the other day playing baseball - split it right up the middle. I asked him if he thought we should throw it away and he said, "No way...it's my first broken bat."

Luke is in St. Louis this week receiving Chemo and all is going well. He is looking forward to getting home, getting stronger, and getting back to school.

As always, thanks for your continued prayers and God Bless!

SUNDAY, MARCH 15, 2009 8:55 PM, CDT

Luke was able to come home from the hospital on Friday - Yeah! His fever had come down and his white count had come up - just the way we like it. He is on IV antibiotics to clear up the "bug" he caught. We are grateful it was caught very early and therefore easier to treat. He will complete the 10-day course of antibiotics at home. Our next trip to St. Louis is scheduled for March 30th. We probably will be staying for 5 days for that chemo treatment.

We were happy to see our friend, Brenden while we were in the hospital. Brenden was celebrating his last chemo treatment! He was even planning a party in the Parent Lounge for the kids, families, nurses and doctors for Saturday night. I have found from being at the hospital so much with so many families in similar situations, that when one child does well we all celebrate and thank God, and when others struggle we collectively hold our breath and pray that God be with us then too. Congratulations to Brenden. Our other buddy, CJ, had surgery for a tumor on his arm while we were there. It was a rough patch for him, but I just finished reading his caring bridge page, and today all is much better. He is not in the excruciating pain he was in and he is going to be able to go home. Good for you, C.J.

While in the hospital this week we were also surprised by a visit from one of the Washington University students, who was a part of Luke's care this past summer. Midori was such a dedicated student, and spent countless hours with Luke during some very difficult days. I can't begin to tell you how much I relied on her daily check-ups on Luke and her explanations about what was happening with Luke's care. She is going to be an outstanding doctor. It was funny, but Luke didn't have any memory of her at all. We both laughed, and Midori told him that she was glad he couldn't remember, but she certainly remembered him. She is graduating in May from Wash U., and is waiting to hear where she will be doing her residency. We wish her the best of luck as she pursues her career. We will be forever grateful for what she did for Luke and our family.

Finally, we want to wish a speedy recovery to one of Luke's most dedicated visitors, Mrs. Lankford. Guy and Barb Lankford, are transplanted St. Louisians, via Rantoul. They make it a point to visit Luke often when he is in the hospital. It is always nice to get a touch of home when you are far away. Barb had a hip replacement and is on the mend. We hope she is up and about soon!

And of course I would be remiss if I didn't wish everyone a Very Happy St. Patrick's Day!

Erin

THURSDAY, MARCH 12, 2009 9:40 AM, CDT

Well, we are back in St. Louis for what we hope will be a brief visit. Luke was running a temperature yesterday morning. We were scheduled to go to

Carle for a blood transfusion, but when I took his temperature in the morning it was creeping up to the area which sets off alarms for us. So I called the doctor at Children's and they arranged for Luke to be transported by ambulance to St. Louis. He ran a temperature throughout the day but has been much better overnight. He was put on antibiotics right away to fight off any bug he might have. We always get concerned with a fever when Luke's ANC is low, and on Monday it was a low 36. So that is why we don't take any chances. His ANC is coming up today and he feels good. They will keep an eye on everything today, and wait for the results from his blood cultures. Hopefully we will be heading back home soon. I will keep you updated.

FRIDAY, MARCH 6, 2009 8:53 PM, CST

I wanted to ask for your prayers tonight for the Gravez family, from Bloomington, IL. They lost their son, Emilio, yesterday after a heroic battle with cancer. He was a sweet little boy who lit up every room he was in. May God provide comfort to his family and friends.

I also wanted to tell you more about Luke's special nurse, Amy, at the Hemoc clinic at Children's Hospital in St. Louis. Amy understands all too well what the children at the clinic are facing because she is a Hodgkins survivor. She has undergone chemotherapy, radiation and a bone marrow transplant and her cancer has been in remission for eleven years. She is a wonderful example to all of us about the courage and strength needed to battle adversity.

Amy is not content though, to just be the wonderful nurse that she is. She has committed to doing more. So on May 9th, Amy is heading west, to hike the Grand Canyon to raise money for the Lymphoma and Leukemia Society. She is taking along another of our favorite nurses, Tammy, to hike along with her. They have been training all winter. We are so proud of them and we appreciate the dedication they are demonstrating to the kids at Children's.

Amy is walking in honor of three of her patients: Nathan, Andrew, and Luke! We would love to help her raise more money for the Lymphoma and Leukemia Society. You can join the cause. Please visit Amy's web page to learn how you can help.

<http://pages.teamintraining.org/gat/CanyonS109/atuckerl4h>

THURSDAY, MARCH 5, 2009 5:55 AM, CST

Luke completed another round of chemotherapy treatments this week and is now home. Everything went well. He has to start back on his dreaded neupogen shots to help his white count recover from the chemo. He never likes that. But we hope that it works well, and he doesn't have a low white count for very long. Thanks to the great nurses at the clinic who took such good care of Luke. I will be writing more about Amy, Luke's clinic nurse soon. She and another of Luke's nurses, Tammy, will be embarking on quite the adventure in May. They are hiking the Grand Canyon to raise money for the Lymphoma and Leukemia Society in their efforts to find a cure for these diseases. Amy is hiking in honor of Luke and two other boys she takes care of at the clinic. We really are treated by some of the most special people in the world. I will tell you more about Amy's efforts and include a picture of Amy and Luke. Thank you for your continued prayers for Luke. We love your messages; they help us get through these tough times.

Erin

THURSDAY, FEBRUARY 12, 2009 4:13 PM, CST

I just got off the phone with a doctor from Children's Hospital who gave me the results from Luke's bone marrow test last week. All tests were negative. There is still no sign of the Philadelphia Chromosome in Luke's bone marrow! What wonderful news. Truly a reason to celebrate. We will continue with his current treatment plan.

Luke's next round of chemo is scheduled for the first of March. He continues to take several medications at home too. We made a trip to Carle yesterday for a blood transfusion because Luke's hemoglobin had dropped significantly from his last round of chemo. So the nurses at Carle charged him up with another unit of blood and we came back home. Thanks Emily and Krista!

We cannot thank enough all of the people who so generously donate blood to the many blood banks in our area and in the country. Until Luke was sick, I never truly understood the impact these donors made. I am well aware now, and please know how very grateful we are for your help. You save lives with your generosity.

We also want to give a big welcome to Samuel David who was born on January 26th. He is Dr. Kanter's (Luke's doctor) first child. Of course a favorite thing to do when someone is having a baby is to guess whether it will be a girl or a boy. Dr. Kanter and I both thought it was a girl. But Luke would always say, "Get over it. It's going to be a boy!" Well, he was right and he is thoroughly basking in the knowledge of knowing he was right and we were wrong. We are so happy for Dr. Kanter and her husband. We know she will be a great mom. And I'm sure he is already a New Orleans Saints Fan!

Continue to pray for our buddies C.J. and Ryan. C.J. hasn't been feeling well since his last chemo treatment. We hope he bounces back soon. Ryan is in-patient now at Children's fighting off an infection he acquired. We know how that can be. On his latest entry on his caring bridge page his mom wrote that he was feeling better and starting to tease her a bit. Funny, how we look forward to that teasing spirit as a sign that our children are feeling better. Keep it up Ryan. We hope you can go home soon!

God Bless You All!

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God Bless You All!

Erin

WEDNESDAY, FEBRUARY 4, 2009 9:13 PM, CST

Luke and Brian are in St. Louis this week for another round of chemotherapy for Luke. We were supposed to start chemo a week ago, but after Luke's labs were drawn they realized his platelets were too low to begin chemo treatments. So Luke received a platelet transfusion instead and we headed home. Our next lab draw showed that his white count was too low. Luke really didn't like that because that meant he had to get a couple days of gcsf shots to help increase his white count. Surprisingly, Luke is not fond of getting shots! But they worked, so on Tuesday Brian and Luke checked in to the hospital for treatment.

It began with an LP and a blood marrow test. Luke is sedated for these but they make him pretty nauseous afterward. We will learn results from the bone marrow test later next week. We continue to pray that the Philadelphia chromosome will not be present in Luke's bone marrow. After these procedures Luke got started with his methatrexate chemo. This chemo runs

for 24 hours. Luke calls it his mountain dew chemo because that is what the chemo looks like in the big bag. Brian said that Luke had some bouts with nausea over the 24 hours but always seemed to bounce back.

When I talked to Brian tonight, Luke was on the computer playing Spider Solitaire (one of Brian's favorite pasttimes!) Luke also got to spend time with Julie, the art therapist. When Luke was last in for treatment he mentioned to Julie that the next time he came to the hospital he wanted to do an art project with her on crop circles. (I have no idea where he got this idea. Probabaly from the History Channel, his favorite channel!) So Julie asked him to do a little research on crop circles for her. So Luke went back to St. Louis armed with information about crop circles. And leave it to Julie, she has turned it in to an art project. Brian said they were going to invite some kids to the playroom to do a crop circle project with them on Thursday. I'm anxious to hear about it.

Luke has some buddies in the hospital this week too. His friend Ryan is in the hospital. He hasn't been feeling too well lately. Day in and day out he and his family battle this terrible disease. They inspire all they meet. Please keep Ryan in your prayers. Luke has also met two other boys while in the hospital: Brenden and C.J. Both are older boys and they are so kind to Luke and all of the kids on the floor. What fine examples they set. I hope their week goes well for them. Please keep them and all the children on the 9th floor in your prayers.

We hope everyone is well, and that the warm weather we are being promised by the weather men and women actually materializes!

God Bless!

Erin

SATURDAY, JANUARY 17, 2009 9:12 PM, CST

Sorry that we haven't written for a while. Things have been hectic in the Remington family. Luke has been back to St. Louis a few times since Christmas. He went back for the week of New Years, but the treatment was cut short. Luke periodically has to take high dose steroids with his treatment plan and they can have a lot of pretty bad side effects. In Luke's case they make him very agitated and not at all like himself. It got to be pretty bad so his doctor stopped them on just the second day. We were concerned that there might be something else that was causing Luke's

behavior to become so drastically different, but in the end the doctors were confident that it was a steroid reaction. So we ended up coming home on Friday, January 2nd.

Brian took Luke for his check-up with Doctor Kanter on January 5th and all was well. But Luke came down with a fever the next week (January 12th). Because Luke's white count was practically 0 and he was therefore at great risk of an infection, it was decided that he would be flown down to St. Louis. So Luke went off with the transport team, and Brendan and I drove down to St. Louis. Luckily that was before the weather took a turn for the worse and the frigid air blew in. Luke spent a night in the PICU so that his blood pressure and temperature could be monitored, and they started him on antibiotics. Thankfully he only had to spend one night in the PICU (where he received excellent care - thank you nurses and doctors) and then he was transferred back to the 9th floor (our home away from home). Dr. Kanter had him stay for the week so that they could keep a close eye on him and make sure that they got the bug that caused his fever under control with antibiotics. He was kept busy during the week with cool art projects with Julie from art therapy, and art project with the students from Washington University, board games with Elizabeth from the Child Life services and guitar hero with Christie from Music Therapy. Christie even learned a Kenny Chesney song on the guitar just for Luke. Pretty nice of her since he relentlessly teases her about being a Cub fan. Luke also was lucky to have the company of his big brother Brendan, who kept things more light and fun. I can't begin to tell you how much Brendan helps both Luke and Brian and I during these times.

On Friday Luke's white count finally rose to a number that was acceptable for him to be discharged. He still needs to complete the full antibiotics regiment but we can do that at home with the help of Home Health Care. (Thank you JoAnn). Luke is scheduled to go back to St. Louis on January 26th for another week of chemotherapy.

Thank you for your continued prayers and support. God Bless You!

Erin

Hi this is Luke. I've been learning about Franklin D. Roosevelt. Did you know that his dog Fala was barking like crazy when he died? Well got to get back to King Arthur.

Happy Martin Luther King's Day!

Luke

SUNDAY, DECEMBER 28, 2008 9:39 PM, CST

Merry Christmas and Happy New Year! We hope everyone is enjoying the holiday season. We sure are. Luke got to be home for Christmas and enjoy Christmas with grandparents and relatives galore! It was terrific. Santa even made his way to our house and brought Luke a remote control aircraft carrier that he has wanted for so long! It was a wonderful holiday with the Taylor and Remington clans!

We head back to St. Louis tomorrow (Monday) for four or five days of treatments. We have to spend New Years Eve and New Years Day in the hospital but that is a whole lot better than Christmas. We are planning to celebrate New Years Eve by ordering from our favorite Chinese Restaurant that delivers right to the hospital. And then we can watch football games all day on Thursday. Too bad the Illini aren't in the Rose Bowl this year. We also have some great Christmas books to read and some Christmas Lego gifts to build. And who knows what the hospital has in store. We will make the best of the week. Please say an extra prayer that Luke tolerates this chemo treatment well.

We also want to send out a special prayer request for a special friend of Luke's who has been so supportive of him during his illness. Mae Sage lost her granddaughter, Brittany in a terrible accident with a drunk driver. She was only 24 years old and making plans to get married in August. There are no words to express how truly sorry we are for Mae and her family during this very sad time. We are praying for you every day. God Bless.

THURSDAY, DECEMBER 4, 2008 6:21 PM, CST

Wanted to let you all know that Luke completed his chemotherapy treatment this week and all went well. We are still at the hospital waiting while Luke's white count drops and then recovers to a safe level. His doctor wants to keep a close eye on him in case he should develop a fever and need to be on antibiotics. She wants to get to it right away before it can develop into something harder to handle. We appreciate how closely she is watching and taking care of Luke.

While here we are spending time with all of the great support staff at Children's. Luke is enjoying time with the Art therapist, Julie and the

nurses and PCA's. He is being as ornery as ever. On Tuesday we had a special day here at the hospital. They celebrated something called First Lights. During the day they had special visitors visiting the kids rooms. Luke got his picture taken with Ronald McDonald, Santa Claus and Mrs. Claus and more. He also was thrilled to get a visit from Trent Green, St. Louis Rams quarter back, and Cardinal pitcher, Al Hrabowski, "The Mad Hungarian." They were both so very nice to stop and talk with Luke. I had to tell Luke about the "Mad Hungarian" and the crazy antics he used to do on the pitchers mound. It was hard to explain, I think you have to see it to believe it, so I'll have to look for some video of the "Mad Hungarian" to show Luke.

We also had some very sad news on Tuesday. Our friend, Ryan Coe, passed away at the hospital. He had battled long and hard against leukemia. He was very brave. He and his family were already coming down here to St. Louis when Luke was diagnosed and they have been very kind and supportive of us during Luke's illness. It has been lonely here without them. We continue to pray for them that they may have the strength to face this terribly sad time.

Thank you to all of you who continue to pray for Luke. Thank you too to Father Laible who visited us and brought Luke and I holy communion on Wednesday. Your prayers and support hold us up throughout this journey. God Bless You.

SUNDAY, NOVEMBER 30, 2008 4:35 PM, CST

We hope everyone enjoyed the Thanksgiving Holiday. We were very grateful to have Luke home and feeling better this week. We got to see grandparents, aunts, uncles and cousins. It was a real treat.

This Thanksgiving Brian and I want to thank each of you who have done so many things to help us this past year. There are so many of you and words cannot express our gratitude. But please know that we know we couldn't have come this far without all of your love, prayers and support. This Thanksgiving especially, we said a prayer of thanks to God that Luke is still with us and that we have been blessed with so many kindnesses from all of you.

We will be returning to St. Louis on Monday for another round of treatments. We should be there for most of the week. Please keep Luke in

your prayers, so that he can handle this round of chemo and get back home soon. Also please keep Ryan Coe, our friend from Paxton, in your prayers as he continues to fight off pneumonia and get stronger.

God Bless You!

Brian, Erin, Brendan and Luke

SATURDAY, NOVEMBER 22, 2008 6:39 AM, CST

Hello everyone,

We received good news this week from Luke's bone marrow test. It showed no Philadelphia Chromosome present! That means that the chemotherapy Luke is receiving and the medicine he takes specifically to fight this chromosome, Gleevec, is working for Luke. We are so grateful and relieved.

Luke has been feeling pretty punk this week. That is pretty typical the week following chemotherapy. We found out yesterday that he needed a blood transfusion, which helped explain why he was so tired. We were grateful to be able to get the transfusion at Carle Hospital. Luke was happy to see so many of the nurses that took care of him when he was at Carle in the Spring. And he loved getting to see and tease Diane, the child life specialist. She takes good care of Luke when he is in the hospital, and he gives her such a hard time! So we spent much of Friday in the hospital, but when we left Luke was feeling better. Thank you to everyone.

Luke has an extremely low ANC right now which means that he is very susceptible to infection, so we are staying indoors and away from any crowds. Luke is bummed to be missing his brother's basketball games, and sitting with his 3rd grade buddies and trying to get the other team to miss their free throws. We are giving him a daily shot of neupogen in hopes to help his marrow start producing white cells and get that ANC (Absolute Neutrophil Count) up. We go back to St. Louis on Monday for a clinic visit. They will check his blood work again and we hope it will show higher numbers.

Luke had a great time with his grandparents this week. They had a lot of fun activities for him to do at their house and they even managed to get him to do some homework. Thank you grandma and grandpa. Thank you also to everyone at Fisher Grade School and Kraft and our friends and family who have been so caring and supportive of Luke and our family. Thank you doesn't seem to say enough. You are in our prayers.

God Bless You.

MONDAY, NOVEMBER 17, 2008 5:52 AM, CST

I just wanted to let you know that Luke completed a week of chemotherapy last week and is back home again. We went to St. Louis last Monday and Luke received chemotherapy treatments for five days in a row. He also had a bone marrow procedure on Tuesday of last week. It was a pretty heavy week for him but he did very well. He had a few bouts with nausea, but not as bad as I thought it might be. He even got a chance to visit with his cousins, the Bradley's in O'Fallon. He had a lot of fun with Nolan. They both talked about their future plans of playing football in college and the NFL.

The initial tests on Luke's bone marrow came back negative which is what we want to hear. They are sent off to have more in-depth testing though, and we are still waiting for the results. With each bone marrow test we hope to see that the Philadelphia Chromosome which is very dangerous for Luke is not present in his bone marrow. Luke will be going back to St. Louis on November 24th for a check-up. He may check-in for another 2-3 days of chemotherapy, but it may be delayed until the following week. Dr. Kanter will decide based on his ANC.

Luke will not be able to go to school this week as his white cell count drops because of last week's chemo treatments. He is looking forward to spending time with his grandparents this week. We hope they are ready for him!

Thank you to all of you who continue to pray for Luke and do so many nice things for him. I cannot begin to tell you how thankful we are to all of you. We are very blessed. Please also pray for two boys from 9W that are fighting very hard against infections. Ryan Coe and Ryan Patrick are friends of Luke's and they are really struggling right now. Please pray that they can fight off these infections and feel better soon.

God Bless You!

MONDAY, NOVEMBER 10, 2008 10:37 PM, CST

I apologize that we haven't had an update over the past few weeks, but Luke has been doing very well and there hasn't much to report.

Luke and Erin are back in St. Louis right now for another chemo treatment. I haven't heard from them today, but as long as his counts are good, he will be able to handle the chemo and will be home this weekend.

I saw Luke in church this weekend and he looked great! He had a nice head of hair and looked quite handsome..and boy was he talkative. It was good to see him that spunky. He was laughing at his cousin Kelli because she was freezing - but why was she freezing, because she didn't wear a coat to church. Luke thought that was pretty silly. He was super happy that he was getting to go to Red Lobster after church...I haven't heard yet - but my guess is that he probably tried for the ultimate feast again. That's o.k. Luke...you eat as much as you can - we love to see you with an appetite.

As soon as I hear anything about his stay in St. Louis, I will update the website and let you know.

As always, thank you for your continued prayers and support.

Thank you and God Bless.

TUESDAY, OCTOBER 21, 2008 8:35 AM, CDT

Luke made it through last week's chemo treatment very well. We were nervous about getting back on the treatment plan but everything went well. Luke checked in to the hospital on Monday the 13th and had a procedure where he is sedated and given methotrexate in his back (spinal column). Later that same day he was given methotrexate through an IV. This chemo runs for 24 hours. So Tuesday evening he finished this treatment. The next step is to wait for this drug to clear his body. When it gets to a low enough level then he can be discharged to go home. We were happy that he cleared the drug on Thursday and we headed home. We went back to the hospital yesterday, October 20, for a check-up and lab work. All looked great and Dr. Kanter told Luke he could head back to school for the rest of the week! We were glad to hear that. I have to tell you that before Luke and Dr. Kanter could get down to business though, they had to comfort each other over their football team's woes on Sunday. Luke, as many of you know is a Colt's fan and they took it on the chin on Sunday. Dr. Kanter, a native of New Orleans, is a Saints' fan and they had a bad

day too. I on the other hand reminded them that if they were Bears' fan their mood would be great! They didn't appreciate this.

Our next scheduled trip to St. Louis is next Monday for another chemo treatment. We will check in on Monday and Luke will receive IV methotrexate for 24 hours again. We will be discharged when it clears his body. We hope to be home for Halloween, but we'll take his costume to St. Louis just in case. The Children's Hospital always makes the Holidays for children in the hospital special. We have been in the hospital for Easter and the 4th of July and we witnessed the extra effort the staff made to make the day special for children who had to be away from home. There will be lots of Halloween activities planned and a nurse told me that the kids even get to trick or treat at the administrative offices in the hospital.

I also wanted to share with you that Luke had his first experience having a roommate (other than mom and dad) while in the hospital. Luke's roommate this past week was a young man named Ryan. Ryan and Luke have a lot in common. They both like to watch the History Channel and the Science Channel, they love dogs and their favorite restaurant is Red Lobster. Ryan felt pretty miserable while we were there and Luke I know understood. We have been praying for Ryan to feel better. We stopped by to see him while we were at the clinic on Monday and were so happy to hear that he is starting to feel better and even eating a bit. We look forward to seeing him when we are back next week. If you could please include Ryan in your prayers when you pray for Luke I would appreciate it. He is a strong young man who has been given quite a cross to bear. I know your prayers have strengthened Luke and helped him get through tough times.

Thank you again for everything you do to help Luke and our family during this illness. It means the world to us.

FRIDAY, OCTOBER 10, 2008 8:25 AM, CDT

Luke is having a good week at home. He has been back at school this week and is enjoying being around his classmates. All of the kids and teachers at St. Malachy have been so wonderful and supportive of Luke. Thank you so much. It means a lot to us. In addition to the St. Malachy community, Luke continues to be supported by so many wonderful people. Your prayers, cards and messages of support and generosity are overwhelming. We count our blessings every day and we are so thankful for all of your help.

Luke had a check- up in St. Louis on Monday. The good news is Luke is getting stronger and regaining his strength after such a long stay in the hospital fighting infection. The bad news is now he will have to get back on his chemotherapy regiment which is rather intense. But it is necessary to finish his treatment plan so that he can be free of his Leukemia. We will be heading to St. Louis on Monday and Luke will be admitted to the hospital for his next round of chemo. We will be there for several days and then back home. Please continue to pray for Luke and all of the children who are sick like Luke. We continue to thank God for each of you in our prayers. Have a wonderful weekend!

WEDNESDAY, SEPTEMBER 24, 2008 11:37 AM, CDT

Hi everyone. This is Luke. I am giving my Aunt Wendy a break from writing the journal because I wanted to write this time. Things are going good. I had my birthday, I caught Walter (a big catfish), I'm going to school part time, and I got to go to see the Cardinals play the D-backs on Monday night. They lost but it was still a great time. I want to thank all of you for the many nice things you have done for me. You made my day. Did you know that my cousins Jennie and Joe sent me an autographed jersey signed by Albert Pujols. It is awesome. They even framed it. Thanks Jennie and Joe and their good friend Danny who talked to Alberto about me. You are great. Thanks also to all my aunts, uncles, cousins, grandparents, sisters, brothers, nieces, friends, neighbors, classmates, nurses, doctors, therapists, everyone who has made me feel so special. Even though I am sick, I am very lucky to have all of you in my life.

I went to St. Louis for an appintment on Tuesday and got some more chemo treatments. I feel good. I will go back to St. Louis in 2 weeks for another appointment, but hopefully will come right back home. I am going to physical therapy at Carle in Rantoul. Omega is working hard with me on getting stronger. Things are going good. Thank you for everything. Bye!

WEDNESDAY, SEPTEMBER 17, 2008 10:04 AM, CDT

Below is an e-mail from Grandma Taylor. Take a look at the new pictures. Luke "reeled" in a big one.

Yesterday Luke stayed with Dick and I while Erin went to Brendan's game. Luke saw one of our neighbor's out fishing and wanted to go over and sit awhile and watch. We did and while we were there he said I am going to call my Dad and see if we can go fishing when he picks me up. Just as he was ready to dial him, around the corner came Brian. It didn't take that long for Luke and I to convince Brian that just a few minutes of fishing would be good for both of them. Brian had the fishing rods in the back of his truck. I had a couple of ears of corn on the cob that we cut off the cob to use for bait and down to the lake they went. The results were terrific and thought friends and relatives might enjoy seeing the results. First, we were excited when Luke reeled in a nice little bass, but the real excitement came later, I can honestly say I witnessed Luke bringing in the catfish he and Brendan calls "Walter" and as Luke describe the struggle bringing him in "Walter set me on my butt!" Needless to say it was a happy day---after the picture taking the little bass and "Walter" was sent back into the lake and all was happy!

Carolyn

SUNDAY, SEPTEMBER 7, 2008 7:11 PM, CDT

Hello everyone. Luke is now home and doing well. He has a minor infection and will remain on on antibiotics through Wednesday. He was not given any chemo treatments while in St. Louis, but if everything else goes as planned, he is scheduled to return to St. Louis a week from Monday for the first treatment in quite a while. Let's continue to pray that he is strong enough to take the chemo.

Daddy reports that Luke is still being fed through the feeding tube at night, and that he needs to start eating whole foods or his ears will fall off. (That made Luke laugh.) Daddy also thinks Luke needs a haircut; he didn't think that was as funny.

As always, thanks for your thoughts and prayers and God Bless!

THURSDAY, SEPTEMBER 4, 2008 12:19 PM, CDT

Good afternoon. I wanted to let you know that Luke is back in St. Louis. He developed a fever Tuesday evening, so Brian and Erin took him to the ER at

Carle. Taking no chances, they made the decision to fly him to Children's Hospital that evening. He was scheduled to take a trip to Children's yesterday for a chemo treatment, but obviously they did not plan for him to have to be flown there.

I spoke with Erin yesterday and she said his blood work came back negative and his counts were good. He still had a fever, but the paperwork was being drawn up to move him from PICU to the 9th floor, which is good...if he has to be at Children's for treatment, we want him on the 9th floor. I am not sure at this point if they will go ahead and give him the chemo treatment while he is there, or if the fever messed up the schedule. Erin did say he would be there for a few days for sure.

Once I hear an update, I will be sure to let you know.

FRIDAY, AUGUST 29, 2008 9:58 AM, CDT

Take a look at some of the pictures Grandpa took when Luke came home. He really does look amazing and is very, very happy to be home.

WEDNESDAY, AUGUST 27, 2008 11:35 PM, CDT

I am happy to report that Luke is home, safe and sound. WOW did he look good. He had a warm welcome from Dad and Brendan, Grandma and Grandpa Remington, Grandpa and Grandma Taylor, Aunt Wendy, Uncle Craig, Kelli, Lacey, Doug Quinlan, Debbie, Clark and Brooke Schmidt, Rick, Sue, Kati and Suzie Jean, and by the way - Suzie sure has that STM Cheerleading spirit (I hope it was Suzie..I still can't tell them apart) boy was he surprised. I must say he looked as good as I have seen him in many months. Close your eyes and imagine how happy he was to see Ozzy, his dog. It was a sight for many a sore eye.

Of course he will have to go back to STL for chemo treatments, but for now, he is happy to be home and we are happy to have him close.

If anyone has an extra prayer hanging around, we are happy to take it. Luke is living proof that your prayers do serve a purpose.

As long as I live, I will never forget each and every one of you that has

given your love, support, prayers and encouragement to this family. Luke has never looked better and I pray to God that he will continue on this path to recovery.

Thank you again and God Bless!

MONDAY, AUGUST 25, 2008 12:27 PM, CDT

At last, the moment we have all looked forward to is finally here. It looks like our favorite little patient will get to come home this week. I have been told that Luke will be released from Children's Hospital on Wednesday if his ANC counts are high enough. When I know for sure he is on the road headed for Rantoul, I will let you know.

I know many of you want to see him, but please remember that it is still very important that he not be around anyone that might be sick or not feeling well. If his counts are up, he will be fine; if not, and if he gets another virus, he will be back in St. Louis in no time. If you want to stop by to see him, just give Brian and Erin a call and they will certainly let you know a good time.

Your love and support has been amazing. As of now, his website has been hit 8,213 times which means there are a lot of people that continue to look in on him from time to time. This family has a network of tremendous support and it is overwhelming to say the least.

He is not out of the woods by far, but having him home makes me feel a little more at ease, that's for sure.

Take care and God Bless!

TUESDAY, AUGUST 19, 2008 10:04 AM, CDT

Just a quick note to let you know that I have loaded new pictures of Luke from St. Louis. He continues to work hard at therapy and improves each day.

Erin came home to get her classroom ready and Brian is in St. Louis with Luke.

I pray every morning that I can log on to report he is on his way home. I am hopeful to be able to do that soon.

Take care and God Bless!

MONDAY, AUGUST 11, 2008 9:56 PM, CDT

Great news for Luke! The bone marrow test came back with no sign of the harmful chromosome Luke is fighting so hard to keep out of his body. This is amazing news, especially since he has been without chemo treatments for almost two months while he was fighting this infection. Although he is still weak, he is working hard at all his therapy and he continues to grow stronger each day.

Keep the prayers coming. They are definitely working in Luke's favor.

WEDNESDAY, AUGUST 6, 2008 12:06 PM, CDT

Wow! What a day! St. Louis Cardinal pitcher Joel Pineiro stopped in to see Luke today. As soon as Erin forwards me a picture of Luke and Joel, I will post it on the website. He autographed a baseball and a picture for Luke - and boy was he thrilled. Tune in to tonight's game against the Dodgers because Joel is the starting pitcher.

Luke continues with therapy to help him get stronger. He was able to stand for about a minute today and take a few steps. It will take time, but he is working his way back. He gets a little nauseous with the chemo treatments, but they are trying different medicines to help with that.

Although I do not follow baseball that closely -- I wish the best to Joel and the St. Louis Cardinals tonight. His visit was very special and most appreciated.

MONDAY, AUGUST 4, 2008 9:04 AM, CDT

Luke is doing very well...continues to make a lot of little steps towards

improvement each day, but when we look back - we realize what huge strides he has actually made. He was able to visit the gardens this weekend and even walked on his own a little bit. He is still weak, but regaining strength each day.

Some exciting news for Luke - someone from the St. Louis Cardinals team is scheduled to visit him on Wednesday, August 6th. I'm not sure which player yet, but I know he will be so happy to see them. A very special thanks (and a great big hug) goes out to Erin's cousin, Cynthia Dunning, for helping to make this visit a reality.

I hope to be able to report real soon that Luke is on his way home. I think when this happens...we need a have ticker-tape parade to let him know how proud we are of him.

As always, God Bless and be safe.

TUESDAY, JULY 22, 2008 3:05 PM, CDT

Good news for Luke. He has been moved out of PICU and into a regular room in 9 West. As much as the nurses in PICU will miss having Luke around, I know they are so happy to see him well enough to go. My heartfelt thanks goes out to everyone who helped Luke get through this bump in the road...now let's just get him through the rest.

God bless and take care.

MONDAY, JULY 21, 2008 8:34 AM, CDT

Below is an e-mail that Luke's Grandpa Jim sent out to our family. It sums up Luke's progress quite nicely...hope you don't mind, Dad.

"A little update on Luke. He still has the chest drain tube in one side but it may come out in a couple days. His pain meds are cut way back, just some normal stuff for pain as needed. Breathing is much better. He is smiling and talking a little more. They put him on a BI-PAP breathing apparatus at night to sleep. He likes it. Really perked up when Brian got there Friday. He has a squeeze ball for therapy and he was throwing it to Brian and trying to say "slider - curve - changeup." Very well may be moved up to 9th floor in normal ped oncology area next week and out of ICU. Great step when that happens. Main thing is getting the chest tubes

out. Still running temp around 100 but not a great concern for the Dr.s He asked for a video of "Sand Lot 2" but the hospital didn't have it and the next day two different nurses came in with it. They had gone out and bought it for him. They said the smile went from ear to ear (the real Luke). They have started him back on half doses of chemo until he gets back to the 9th floor and his strength increases. Very little improvements each day but rays of increasing hope.

That's the part that makes me think of a brick salesman, the way some of us are feeling. A brick salesman sells bricks from door to door and starts out each month with 100 bricks on his rucksack. He gets a little disappointed when each stop along the way someone buys only one brick. But after each stop or day the load gets just a little lighter. He keeps going because the load gets a little lighter each day. There are also some that are carrying 2-3 hundred bricks compared to our seemingly heavy but relatively light load. Luke's small steps are so significant. Love ya all, Jim."

**update to e-mail - the chest tubes were removed on Sunday. Good chance Luke will be moved out of ICU today or tomorrow. I will let you know when I know for sure.

God bless you all.

MONDAY, JULY 7, 2008 8:56 PM, CDT

Hello everyone. I had the opportunity to spend a day last week with Erin and Luke in St. Louis and it was an amazing experience to say the least. I told you last week that Luke had to have his colon removed, but what I didn't know at that time was that his large intestine was also removed. The surgery went well and he is doing good, but he has a long way to go.

On Wednesday, Luke's breathing tube was removed. Great news! He was still laboring a bit with his breathing, so he had to use a bi-pap machine for a few hours at a time to help his lungs remember how to breathe. The bi-pap machine is a small, bedside respiratory machine connected to tubing and a facemask worn by Luke. It helps push air into his lungs and helps hold the lungs open to allow more oxygen to enter the lungs. He struggled with it the first night - but you know our Luke. When I was there on Thursday, he allowed the therapist to put it on and he tolerated it like a trooper.

While connected to the bi-pap machine, they wrapped him in a little chest belt thing (for lack of proper term - sorry). It was used to shake him in an attempt to loosen some build up in his chest/lungs. This was scary for me and Erin because we knew the shaking could not only hurt Luke's incision

and his chest tubes, but it could mess up his heart rate and blood pressure again, which wouldn't be good. But once again, he tolerated it for as long as he could and he seemed to understand that it was being done to help him get better.

He was able to communicate by moving his head and his arms and legs. He wasn't speaking yet, but I'm sure his little throat was still so sore from the breathing tube, which is to be expected.

Brian said that they removed Luke from dialysis on Saturday in hopes of "kick starting" his kidneys. He was producing a little urine on his own, but hopefully he will begin doing it all on his own from this point forward.

The good news is that Luke is making a lot of little steps towards getting better every day...they might not be huge steps, but they are in the right direction. Although the updates might seem to be getting few and far between, please know that no news is good news at this point. It is difficult for Brian and Erin to share every little detail, because for now, there are many little improvements, which is hard for them to relay. I will do my best to let you know as I find out new details...and occasionally I will just pop in to say he is doing well.

I want you to know that Brian and Erin read your messages frequently and truly appreciate your support. They are continuously amazed at the generosity they have witnessed, as well all are.

I would be remiss if I didn't mention the doctors and nurses at Children's. They are incredible and it helps knowing that Luke is surrounded by these angels who want nothing more than to see him get better.

God bless you all and please be safe.

TUESDAY, JULY 1, 2008 10:22 PM, CDT

Hello friends and family.

As many of you know, Luke is still in St. Louis at Children's Hospital and continues to struggle a bit. As I wrote in the last journal entry, Luke underwent surgery about a week ago to help with the excess fluid retention as a result of a strep infection (Strep Viridans), and they had to keep the incision open in order to monitor the fluid retention and organ function. I am happy to report that the incision in his belly was closed yesterday. This is good news. The not so good news is that they had to remove Luke's

colon on Friday. As I learn more about the procedure, I will let you know. I do know that today, Luke is doing well. Erin said he had a good night and the doctors are pleased with his surgery to close the incision yesterday.

He continues to make a lot of little improvements or "baby steps" as Erin puts it...but, hey, we will take what we can get, right! I am traveling to St. Louis tomorrow to visit with them and will provide more updates when I can.

Luke has proven to be a very tough young man, but he cannot get through this alone. I know I have said this many times, but your thoughts and prayers are getting heard and are truly appreciated.

God Bless you!

SATURDAY, JUNE 21, 2008 7:05 PM, CDT

Good evening to everyone. Today is Saturday, June 21st and what a week it has been. I have read all of the recent guestbook entries and I must say that Brian and Erin and have the most amazing family and friends. Please know without a shadow of a doubt, that they absolutely could not go through this without your love and encouragement. Although Luke isn't able to read your messages right now - I know that he feels your prayers...there is no other explanation why he continues to amaze all of us with his strength.

Luke had to undergo emergency surgery on Friday on his abdomen to help rid his body of infection. They were unable to control his blood pressure and believed that the infection was limiting the blood flow to his organs which was causing the spike in blood pressure. Many of you know that the procedure was not without extreme risks, but the doctors were pleased with outcome. Although Luke is still in critical condition, he is stable and the doctors say that his internal organs look good. He is currently undergoing dialysis, but his kidneys are producing a little urine, which is a good sign. They have begun to wean him off of some of the blood pressure medicines, but will continue to keep him sedated to a certain point for his comfort.

In one of the guestbook entries, someone spoke of Luke's fight and how God is teaching us through him. Although I could certainly think of many more ways I would prefer God try to reach me, I am going to take the opportunity to listen and try to make this world a better place for Luke to

come home to. I encourage you to do the same. Don't forget to tell your family and friends that you love them everyday. Take the time to say hello to a stranger - who knows..it might be the only one they get that day. Whatever it is...just do something so that God knows Luke has made a difference in our lives and that he is ready to come home healthy and happy.

God bless everyone and once again, thank you very, very much for your continued prayers.

MONDAY, JUNE 16, 2008 10:26 AM, CDT

Hello Family and Friends -

Luke is currently in the ICU at Children's Hospital in St. Louis. He caught a virus towards the end of last week and the doctors are working very hard to determine what it is. We anticipate the results in the next few days. As a result of the virus, Luke's blood pressure dropped significantly and his heart rate increased...we were very fortunate that he and Erin were flown to St. Louis when they were. The doctors have him sedated now and are watching his liver and kidney function due to the drop in blood pressure. They are hopeful that they will kick back in soon. Although he does show small signs of improvement each day, he is still in serious critical condition.

Brian said that the nurses and doctors at Children's were (once again) wonderful. He mentioned at least one nurse that stayed past her shift just to help Luke when he arrived in St. Louis. This is truly an amazing hospital with a compassionate and knowledgeable staff. I sincerely thank them from the bottom of my heart for their attention to Luke.

Although Mom and Dad have been put through the ringer this past weekend, they are doing well. I know this goes without saying - but please keep them in your thoughts and prayers so we can bring Luke home soon.

I will do my best to keep you updated as I hear more information. Thank you once again for everything.

MONDAY, JUNE 2, 2008 7:04 PM, CDT

Hello friends and family. Today is Monday, June 2nd and the Remington family is doing well. Luke was in the hospital last week for his chemo treatments, which hit him pretty hard and made him quite sick. They did find one medicine that he was allergic to, which wasn't good, but he is home and feeling much better today.

As always, thanks to each and every one of you for your kind thoughts and prayers. Let's keep them coming.

FRIDAY, MAY 9, 2008 1:29 PM, CDT

Hello Friends and Family -

I apologize for not updating the website recently, but I guess the good news is that there hasn't been much to report. Luke continues to do well and is responding as hoped to his treatments. The last time I wrote, I told you about the Consolidation Block treatments. He was at Carle this week for the Consolidation Block II, which hit him a little harder because the medicine was pretty strong. He is home now and will proceed with the remaining treatments in this phase (full 21 days). After the initial week of chemo, his counts are very low, and he runs the risk of complications from infection and fever, but this is to be expected. After the first Block treatment, he was put in the hospital due to a fever, but everything turned out fine.

I visited him in the hospital last week, but the poor guy wasn't feeling too well...I didn't stay long. I brought him a Tony Larusa bobble head that a good friend of mine (Stephanie Elmer) had picked up for him at a Cardinals game. When Erin opened the bag...she just laughed. I didn't know what was so funny at first; after all...he is with the St. Louis Cardinals, right – was I missing something? But then she explained that when I originally told her what I was bringing, I was very excited and told her it was a Tommy Lasorda bobble head...Tony - Tommy...Cardinals - Dodgers...its all the same to me. :-)) For those of you that know Erin, you can appreciate the chuckle she got out of that one. Her laugh is definitely infectious.

If you didn't get the opportunity to see Luke on TV last week, Dick and Carolyn Taylor have a copy of the spot. I am going to try to get a copy of it to add to the links page of this website. I'm not very techno-savy at times,

so I will do my best.

For you mothers – have a wonderful Mother's Day. I hope you are pampered beyond belief. For you fathers, there's your reminder.

Thank you again for the love and support you have provided, and continue to provide, to Brian and Erin and their family. We all truly appreciate it.

MONDAY, APRIL 21, 2008 8:24 PM, CDT

Friends and family,

I am extremely happy to report that Luke continues to do very well with his treatments. He is currently undergoing what is called Consolidation Block I. This is a 21-day treatment phase consisting of five days of chemo (which he went through last week at Carle) and 16 days of an oral medicine called Glevec. During the ten days following the chemo treatments, he also has to have a shot of Neupogen to help stimulate the formation of white blood cells as his count gets low during the chemo treatments. Two weeks after the chemo treatment, Luke will go back in for tests. If the results of these tests show that Luke is responding well to the treatment, they will move to the next stage of treatments.

Erin did say that the doctors were very pleased with Luke's tolerance of this most recent series of chemo treatments, which is good news. But wait – I have even better news....the genetic tests showed no sign of the protein that causes the Philadelphia chromosome, so a bone marrow transplant will now be viewed as "option 2," and will not be needed as long as Luke continues to respond to treatments during the next stages. Erin also explained that Luke will have to go back to St. Louis at some point to undergo another series of treatments similar to that of his first stay.

My heart goes out to Brian and Erin right now, because as much as I try to comprehend the numerous steps and phases of Luke's future treatment, it seems impossible to get my arms around it all, yet they can recite it to you without missing a beat. They are truly an amazing couple that has been blessed with the grace of God for the strength to continue laughing, loving, and living life to the fullest. We could all learn something from their example.

Keep the prayers coming...they are definitely being heard. God Bless!

THURSDAY, APRIL 17, 2008 11:27 AM, CDT

Hello everyone. Today is Thursday, April 17th and I wanted to take a minute to share with you a very special event happening today at the High School of St. Thomas More. St. Malachy Alum Rhea Michaels was given an assignment in her Economics to start a business. Of all the possible businesses Rhea's team could have developed, they decided to make cookies to sell. The name of their business....**Cookies For A Cure**. This very special group went one step further by deciding to donate the proceeds of their class project to Luke's Team. Listed below is an excerpt from the STM website (under Today's News) letting everyone know about the cookie sale.

Even though most of us will not be at STM during lunch today, I wanted to take a minute to share this with you. This is just one more example of the special people in this world.

Thanks to Rhea and her business partners!

"Cookies For a Cure will be selling TODAY at both lunches and after school, so make sure you come out and buy a cookie to get your free yellow ribbon to look fly and show that you helped support Luke Remington in his battle with Leukemia. Cookies for a cure, the little sweets that do big things!"

Please check out the STM website under "links" above.

MONDAY, APRIL 14, 2008 11:34 AM, CDT

Today is Monday, April 14th and we are all still amazed about the tremendous turn out and support at Luke's benefit yesterday. Although an exact count was difficult to obtain, we believe over 850 people were served yesterday and many more came out to support the cause without eating. I wish I could name each and every person that helped organize and run the benefit yesterday, but (fortunately) there are simply too many of them to mention. It is a true testament to the family and friends of Brian & Erin, but also to the residents of Rantoul and surrounding communities that came out in full force to help such a special family.

It is important to mention that all of the food was donated for the benefit and no businesses were solicited for raffle items. However, we ended up with several very nice raffle baskets because so many people wanted to participate and the items started to roll in. Those involved in putting on the event were truly humbled by the generosity of everyone that donated a raffle item, donated food, spent all day in the kitchen cooking and by those of you that stopped by for the delicious dinner and to provide support to such a special young man.

A special surprise was given to Luke on Saturday evening...an autographed baseball signed by none other than Albert Pujols. You should have seen the look on his face. An extra special thanks goes out to Joe Traficano for all of the autographed baseballs he sent in for the raffle - they were a huge hit. In fact, little Spencer Neitzel's name was drawn to win a baseball; he was so excited. As he was looking through the list of autographs, he focused in on former Cardinals third baseman, Scott Rolen. This came as a shock to many of his family and friends, because Spencer is a Cubs fan. Thinking that he was making a big mistake, they encouraged him to pick another baseball signed by a Cubs player, but Spencer insisted on Scott Rolen. When they questioned Spencer about his choice of baseballs, Spencer quietly said that he wanted to choose a ball that he knew Luke would like, because it was his plan all along to give it to his cousin. This is just one of many stories that surfaced throughout the day of the benefit. To tell them all would take days.

I encourage you to continue your prayers for Luke's healing as he enters another series of intense chemo treatments this week. He is a very strong and resilient young man who I know will fight this as best he can...but he still needs our help.

Again, thank you, thank you, thank you to everyone that worked so hard to make the benefit a success and to those of you who attended in support of this family. We sincerely appreciate it!

God Bless!

TUESDAY, APRIL 8, 2008 2:06 PM, CDT

The St. Malachy Children's mass on Friday, April 11th, will be for Luke. The mass will begin at 8:20 a.m. at St. Malachy Church, 311 E. Grove Street, Rantoul, IL (corner of Rte. 45 and Grove Street).

We can never underestimate the power of prayer for his healing.

MONDAY, APRIL 7, 2008 11:40 AM, CDT

Hello friends and family. Let me first say a huge *thank you* for the tremendous support and encouragement you have shared, and continue to share, with Luke and everyone in the Remington and Taylor families. Luke is a ray of sunshine and continues to do his part to get better, but he couldn't do it without your love and support.

On Friday, Luke made another trip to St. Louis for a chemo treatment and a bone marrow test. I am excited to report that the tests under the microscope at St. Louis Children's Hospital were good and there is a chance that Luke will not need a bone marrow transplant. The samples have been sent away for further genetic testing. If those tests find that the Philadelphia chromosome (and the protein that makes the Philadelphia chromosome) are no longer present, then the doctors would proceed with the remaining chemo treatment for a period of three years – but no transplant. If this chromosome is still present, a transplant would be needed. The additional genetic tests should be complete within one to two weeks, so we will hopefully know more by the end of next week.

Brian and Erin meet with the Carle medical staff on Friday to set up the treatment schedule for Luke in Champaign. If the results of the tests show that a transplant is still needed, Luke will need to return to St. Louis for treatment.

Luke was at the track meet on Saturday to cheer on his friends at St. Malachy. He looked very handsome with his new haircut. Even though he had to wear his mask, you could still see that he was smiling by the movement of his cheeks and the twinkle in his eyes.

You can tell he is very happy to be home.

TUESDAY, APRIL 1, 2008 3:30 PM, CDT

Today is Tuesday, April 1st and Luke gets to come home today. Nope...its not an April fools joke its true! Luke has been responding well to treatments and because his Absolute neutrophil count (ANC) has remained above 600 for a few days, the doctors say he can take a break and come home.

If you're like me, you have no idea what ANC's are...so here goes - Neutrophils are key components in the system of defense against infection. An absence or scarcity of neutrophils makes a person vulnerable to infection. After chemotherapy, radiation, or a blood or marrow transplant, the ANC is usually depressed and then slowly rises, reflecting the fact that the bone marrow is recovering and new blood cells are beginning to grow and mature. A normal ANC count (or "safe" count) is between 500-1500. A safe ANC means that the patient's activities do not need to be restricted (on the basis of the ANC).

We have to remember that even though Luke is home, his immune system is still weaker than ours, so we need to be careful about visiting him if we aren't feeling well.

Luke will have to return to the Children's Hospital on Friday for another bone marrow treatment, but he won't have to stay this time. YEAH!

SUNDAY, MARCH 23, 2008 8:47 PM, CDT

Hello all. News from St. Louis is good! Luke continues to respond well to treatments. Brian said that Luke had tests today and the doctors and nurses are happy because everything is where they want it to be. He does still have leukemia cells in his bone marrow, but considering he started at levels of 299,800, and is now down to 300, things are looking good.

Brian explained that the nurses were previously doing tests on Luke every four hours, but because they are happy with his response to the treatment, the tests are not as frequent. One test is done every twelve hours and the other is only three times per week.

His appetite is back and he is eating everything in site...which the nurses say is a very good thing.

Luke has to continue the treatments for the full 29 days, and can come home at that point if in clinical remission - and might even be able to come back to school. If not, he will have to undergo another two weeks of intensified chemo.

We should know within the next week if Brendan is a bone marrow match. If so, they will begin the process of preparing both Brendan and Luke for the transplant, which takes a few weeks.

At this point, Luke cannot get to the room with the computer to read your

notes, but please know that Brian and Erin are sharing each and every one with him. Once his counts get to a safe level, he will be able to get on the computer and might even make an entry on the journal himself. He gets pretty tired and sometimes does not feel up to talking on the phone, so please do not be upset if he isn't very talkative. You know him...he will talk your ear off when the time comes.

A benefit for Luke is being planned for mid-April. As soon as the details are final, we will put the information on this website.

Thank you all very much for your kind notes and your prayers. Please pray very hard that a transplant match is found very soon so that we can bring our little guy home.

WEDNESDAY, MARCH 19, 2008 12:49 PM, CDT

Luke is responding to treatment and his white blood cell count is down to almost nothing...which is what they are wanting. Of course, the result is that he has no immune system, but he is being pumped full of antibiotics and steroids, and again, seems to be responding to treatment. Last week, they found an abnormal chromosome called the Philadelphia chromosome. This particular chromosome is responsible for rapidly generating more abnormal cells.

Luke will need a bone marrow transplant which will hopefully take care of this chromosome. Brendan, Brian and Erin have been tested as possible donors and they should have the results by the end of this week or the beginning of next week. Brendan has a 1 in 3 chance of matching and Brian and Erin have a 1 in 100 chance matching.

Through all of this, Luke remains smiley and fun to be around. He has received many sets of Bionicals and Lego's and is very focused when putting them together.

Thank you for all your thoughts and prayers. Keep them coming.

WEDNESDAY, MARCH 19, 2008 12:00 PM, CDT

This CaringBridge site was created just recently. Please visit again soon for a journal update.

www.CaringBridge.org | 651.452.7940

