

## CAREPAGES for Genre Baker

Carepages was the hospital system for blogging during a child's illness. Family and friends were able to read about the child's progress and leave notes for the family. Daunette regularly wrote about Genre's treatment, bumps in the road, and the way God was with them throughout the entire journey. Thank you for taking a minute to read about this journey through childhood cancer

### Day 2

Posted May 27, 2009 9:29am

Today I picked the name of my web site to be FBI. It means Firm Believer in Jesus. My friend and future wife, Breanna, gave me a hat that says FBI. I will wear it a lot when I don't have any hair.

Bye,

Genre

Today is day two. A little harder today than yesterday. Genre didn't feel well for the first time last night. He was scheduled to have the mediport inserted this morning, along with a spinal tap. They originally cancelled the port procedure but they have since rescheduled....

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Today is day two. A little harder today than yesterday. Genre didn't feel well for the first time last night. He was scheduled to have the mediport inserted this morning, along with a spinal tap. They originally cancelled the port procedure but they have since rescheduled. We are just waiting to know exactly what time it will take place.

I know that you are worried about all of us. Please know that we are SURE that Jesus has his arms wrapped around our son's body and he is going to stay with him every step of the way! That doesn't make this any easier, I assure you. What it does is make this bearable. We can get through anything, for any length of time, just knowing that God will heal our son at the end of this journey.

I don't know what John, Genre and I would have done with out the help of my mother and Kaitlynn. I don't know what we would have done without the prayers, love, and support from each one of you reading this page. I don't know that I will ever get a chance to be able to explain what this all means to both of us. We sit and look at each other in amazement each time one of you helps us. We are surrounded by the most unbelievable circle of friends and church family. We are blessed beyond belief by all of you. Daunette

## Friday - day after chemo 1

Posted May 29, 2009 8:08pm

Genre was sick until about noon today. He hadn't eaten since Tuesday at 4 pm. Grammy B brought chicken noodle soup for lunch and he was able to drink some broth and keep it down. Yeah! The Child Life Group brought a beautiful dog in for Genre to pet. He was still feeling a little woozy so we didn't stay with Broday very long. He really enjoyed her tricks. Finally, around 2:00 the nausea subsided. He felt well this afternoon and his Deemer buddies, along with Mrs. Fitz, came for a visit. Jason, Ann, Lily and Kaitlynn brought James and Gionna for a visit later. While Jason was here, Genre got to play the guitar with him for a little while. They were working on Amazing Grace.

He was able to keep down a half of a grilled cheese sandwich for dinner and he drank some apple juice and some ginger ale. Hopefully he'll feel even better with something in his belly.

Some good things happened today! His white blood count dropped from 74,000 to 10,000. The docs said the medicine is working well. His elevated uric acid and phosphorus are under control. And the hematoma on his chest has not gotten any bigger.

I wanted to let you all know about my 3rd God Wink. They are amazing me and I hope you don't mind me sharing them. On Wednesday night after a long day of waiting for surgery and reviewing all the chemotherapy drugs with the oncologist for almost two hours, my brain was shot. It was 9 at night and I couldn't think. My brain just couldn't process one more thing. The Doctor had explained a study being conducted and asked if we would enroll Genre. It was no extra procedures or pokes, we just had to let them use some extra blood for a study. John and I want to help future patients...we are benefitting from all the children who have gone through this before Genre. He said we could think about it and let him know in the morning. After he left, he called my cell phone and said that he was mistaken. The paper work needed to be processed that night to prepare for the additional blood draws in the morning. The study was about 27 pages long. I almost cried. John took them and started to work through them. It was a lot. I thought 'I just can't do anymore tonight...I can't understand these papers!' Just then my cell phone rang and it was my dear friend, Stephanie. She also happens to be my pharmacist friend. She was in the lobby for a visit on her way to work. She took the papers and read through them. She explained to us what she was reading. She pointed out some issues she knew we would be concerned about. I was able to call the doctor back to ask him about certain parts of the study. She stayed until the issue was resolved. I'm sure she got to

work late that night and had to stay longer. I don't know what I would have done if she didn't come that night. I couldn't do it on my own. If God brings you to it, he will get you through it.

God Wink #4 - Genre's port was swelling yesterday. Someone mentioned a leaking port...panic set in. There were no answers for quite some time. My mom was here for the afternoon with James and Gionna. In the evening, when John arrived, my mother and I went to sit in the sun room for a few minutes to catch up after a very long afternoon. I was telling her that I didn't feel sure that the port wasn't leaking. I was questioning how they could know for sure that the lump was a hematoma and not drugs accidentally injected into the little guy's chest! I was still so concerned and I just couldn't shake some concerns that I had. Just then, I looked down the hall toward the room and a man in scrubs was walking toward us. I looked at him and I realized that it was my anesthesiologist angel! I walked down the hall way and he came right to me and gave me a big hug. I asked why he was in our wing. His son was suppose to be on 9A. He said they changed his room. We're next door neighbors. He asked how Genre was and I told him about the possible port problem. He said 'I saw it go in. I know it works. We tested it, watched it work and then saw it on an x ray. It works.' I was okay.

He's resting right now. He's had an eventful 24 hours. Thank you for all the love you are showing him. He read your messages this morning.

## Saturday May 30

Posted May 30, 2009 12:25pm

Genre had a great night!!!! He slept the whole way through! His white blood count is down to 1,100 and today the doctors used these words - great and nicely! One said he was responding great and the other said nicely!

He ate eggs and sausage for breakfast and then played Wii with Breanna and Sara for a while. He feels really well today. Praise God.

## Saturday May 30 #2

Posted May 30, 2009 1:03pm

Genre would like me to tell all of you a few things...

I now have a Wii in my room. Jaden, I brought my DS too so we can play. The food is good. Jason brought me a signed poster of Winters Halo. I still don't have any cheat sheets from Mrs. Fowler for MarioKart.

PS...Mrs. Deemer thinks she can beat me at MarioKart. How strange is that?

## Request from Genre

Posted May 30, 2009 2:54pm

Genre wants me to ask all of his friends in Kid's Kingdom to remember something for him when they are worried about him. He wants them to say Joshua 1:9...."Have I not commanded you? Be strong and very courageous. Do not be terrified; do not be discouraged, for the Lord your God will be with you wherever you go." He thought maybe they could sing the fun song that goes with this verse during praise time at Sunday school.

Want another God Wink? The social worker was here yesterday to tell me about all of the programs, meetings, support groups and camps available to Genre. I thought about her all night. I thought about whether we should let him be around leukemia patients regularly. I wondered if it would make him sad. I wondered if I needed to add more things to this crazy life. I wondered if I would be able to handle being at those functions.

Today when my little brother Dante called he was telling me about all the amazing support his employees were giving him. He said that one of his waitresses, Ashley, came to him to say she heard about Genre. She told Dante to have Genre hang in there. She said she had t cell all when she was a kid. She just celebrated her 23rd birthday. She told Dante to let me know that there are so many things available to Genre and that he should take advantage of all of them. She told Dante to tell me that support groups and camps really helped her. She was glad that her parents did that for her. Sometimes she needed to see that other kids were just like her and that some kids were way worse than her. It made her feel lucky! HE is amazing and he gives me everything I need.

## May 29

Posted May 30, 2009 10:35pm

Genre had an awesome day today! He wasn't sick once. He ate like a champ and his friends Alexis and Hannah came to visit him all the way from DuBois! Genre is making good friends with all the nurses. He's quite a hit when he's in his talkative mode. His dad is with him watching the Pens and he's staying for the night. Good night.

## May 31

Posted May 31, 2009 8:03am

John said it was another uneventful night filled with a lot of sleep!!!!Thank You! Thank You! Thank You! Thank You!

PS. I think I have my days confused. Today IS Sunday and the 31st, right? I wrote that yesterday was the 29th. Apparently, it was the 30th. Sorry.

## May 31

Posted May 31, 2009 10:30pm

Genre is on his way to bed. With as silly and active as he was today, he should be tired. I think we will have to replace the bed in this room when we leave. I'm not sure how many times it can go up and down for a ride?!

They said he is still responding well. His numbers are coming down and he is nearing what they call neutropenic. This is when we will have to ask you to refrain from visiting even if you feel well but there is someone at home who is sick. They've explained that his levels will bounce back and forth and when they are down he is very prone to infection. The docs said common sense hand washing, antibacterial lotions, sneezing/coughing into your shirt, and staying away when anyone is sick is the best line of defense. Good night.

June 1

Posted Jun 1, 2009 10:05am

congratulations kamryn for getting baptized!!!!!!!!!!!!!!!

June 1

Posted Jun 1, 2009 11:10am

Hi. Genre's sugar and sodium are getting a little high. This is totally expected! As much as he is enjoying all of the treats he is receiving (and eating) I have to ask that we hold off for a little while on the sugar and salt. Thanks for wanting to bring in all the goodies. They are just asking that we monitor his sugar and salt right now.

The docs are coming in to give him two shots in a few minutes. Please pray that there are no serious allergic reactions and that his body accepts the medication well.

He had a great night last night. He slept from 10pm - 8am! He's happy and nothing is hurting him so it is a beautiful day! Thanks for all the Happy Birthday wishes! I really appreciate them!

June 1

Posted Jun 1, 2009 7:31pm

Genre hasn't had any adverse reaction to the shots he was given today! (Thank You!) His oncologists were in and said that he is doing very well. They are very pleased with his progress and they can't believe how happy he is.

He's smiling and full of love. Last night when he said his prayers, first he thanked God for a beautiful day. He thanked God for all the people who love him and he asked God to take away his leukemia. Then he thanked God for giving him a mom and dad that 'don't mind spending all of the day and night at the hospital with me.' He amazes me every single day. I thoroughly enjoyed spending my birthday with him, James and Gionna today.

Thank you for all the birthday wishes!

## June 2

Posted Jun 2, 2009 12:13pm

Hi. We are doing something every day. Mrs. Murray brought me a whole bunch of Bible verses in a container she calls Victory Verses. I read one every day. I am going to start putting them on my web site. Today the verse is Isaiah 40:31 ...but those who hope in the Lord will renew their strength. They will soar on wings like eagles; they will run and not grow weary, they will walk and not be faint. I think that means if you trust in the Lord He will help you when you need him. Genre

Genre slept peacefully last night! The docs said the next two days should be pretty boring for him. We are praying for good results from his bone marrow aspiration on Thursday. Without anything unforeseen, they are confident that he will be home by Friday.

His play buddy, Mike, wants him to get up and play today. He told Genre he is going to develop buttitis if he doesn't get off of the bed! He is bribing him with a small pack of Cheezits. Mike is an amazing man. He makes these kids happy! Mike brought Genre in a fart machine (sorry - that's what it is called!) with a remote control! So now...Genre waits for the nurse (the PCT, the custodian, anyone!) to come in and then he pushes the button. I have never seen a child laugh so hard!

Another God Wink!...Last night Michele W. came with my cousin, Missy, for a visit. Genre's numbers were very low so we sat in the sun room. I was telling them how every single day God does something to let Genre and I know that we are not alone. Michele brought me Max Lucado's Grace For The Moment. It's a page of inspiration for every day of the year. I just opened up the book and this was the first page I turned to.....I cry out to the Lord and God listens...Your voice matters in heaven...He takes you very seriously.. You will not be ignored...It just jumped off of the page!!!

The other pages near by said things about being specially created, hate, repenting, etc...All very important topics, but I opened to the page that told me that God was listening! (As if we don't already know that!!!!!!!) It is amazing, and so are all of you who take the time to make Genre feel special every day when he looks at his messages. Thank you so much!

## June 3

Posted Jun 3, 2009 12:30pm

Today I picked the verse..."Your word is a lamp to my feet and light for my path" Psalm 119:105 I think this means that God will show you where to go.

Jason, I have been practicing my guitar and I know the Third Day song.

Mr. Murray, Have you bought Mario Kart yet?

Mrs. Deemer - No chance.

Another great night. Hopefully the docs were right - Tuesday and Wednesday will be pretty boring. Yesterday the hospital asked me to speak at the ribbon cutting ceremony for the Healing Garden. They asked me to tell a little bit about Genre's story and why I think it will be beneficial to have a place liket the Healing Garden. I told

everyone how strong Genre is and how his faith in Jesus is what has gotten him, and us, through all of this. I told them how he will be able to go out to the garden and read or play some games with his brother and sister. It will help him feel a little more normal. People were so touched by his story and they wanted to talk with me about him. I really just wanted to get back upstairs to be with him, so I excused myself. A woman followed me to the elevator to say that she was compelled to come and hear more about Genre. Her son also went through this - only he got it as a twenty year old which isn't the best time to get all. She couldn't hear enough about Genre's faith and she said that she felt inspired by him. Later that night (around 8:45) the nurse came in with a giant Spider Man balloon attached to a big stuffed dog. The nurse said that there was a woman out front who met me at the ceremony. She didn't want to bother us but she was out front. The nurse asked if she should send her back. Genre's ANC level was okay, so I said she could come back. It was Maggie from the ceremony. She just wanted to meet Genre and touch him. She said that she felt like she needed to come and offer anything she could to help him. She said she only lives five minutes away. If I ever needed someone to come and sit with him on short notice she would be happy to do it. She was just so moved by him. I felt awe and sadness at the same time. He clearly touched her. I was sad for her pain. I hope he helped her to feel some peace.

He is feeling great today. He is ambushing nurses with the Nerf Vulcan and making the docs who are rounding laugh with his fart machine. Nurses who have not been assigned to him come in the room and say "...so you are Genre...I've heard a lot about you, little guy!..." Because of his smile and cooperation, along with his wit, he has made so many friends here. We met Haley yesterday. She has been an all patient since 2006. She was giving Genre all sorts of tips about all. It was just amazing to hear two eight year olds chit chatting about what will happen to him in the near future.

When I look back at so many things that have happened to us in our lives - all through our marriage - I now am able to see (SO CLEARLY) that God was there every step of the way. It's like he was putting up bumper pads to keep us on the path to where we needed to be. Really, there was no good reason for us to homeschool. I liked school and so did John! One time at our Life Group we were talking about things that we felt we were called to do. I said that I really couldn't say that God led me to do anything but homeschool. I just knew in my heart that, no matter what anyone thought, it was what we were suppose to do. There was really no good reason for us to leave our Methodist church in Irwin. I really loved that church and I love Dr. Tom. We struggled with the decision to leave there. But, again, we were pulled to NCC. The day Kristie invited us to VBS was the day our lives changed and I know now God did that for a reason. Our family there has been like life support through this. Speaking of Kristie...there was really no good reason for us to meet. I approached her at the library out of the blue. We met at a 'getting started homeschooling' meeting and I kept looking at her. I knew the minute I saw her that I wasn't 'able' to let her leave that meeting without her phone number. There are so many things like this that have happened. We have tried SO HARD to move out of our house and it just has not worked. For fourteen years we have been saying that we want to move to Treasure Lake. We love AnnMarie and Dave and we have always wanted to be up North with them. We were meant to stay in North Huntingdon. I was meant to have the most unbelievable neighbor (friend) on the planet live across the street from me. There is no rhyme or reason to why her 16, 13, and 11 year old girls are best friends with my 10 & 8 year old boys. (gionna too!) We were suppose to have my mom, our family, all of our friends and NCC family around us to act as even more bumper pads. Really, why did Kaitlynn come into our lives out of the blue? Why did she want to move in with people she barely knew? Now, the support that she can give James and Gionna is invaluable. It is just too much to write to explain the path that God set us on a LONG time ago to prepare us for these circumstances. Of course, you can never be prepared. We do not want our son to have leukemia. If I could pull it out of his body and put it into mine I would do that right this moment. I would step in and take his place every single time they do a procedure to him. I know that is impossible. But, He prepared everything around us so that we were padded when we fell. I thank Him all day long for that. None of you can understand how much each and everyone of you means to us. Your loving words, prayers, hugs, the food,

the help, checking on my mom EVERY DAY...it all means SO MUCH TO US. I pray none of you is ever able to understand how deeply we are moved by this and how much we appreciate the love and support. Thank you from the bottom of our hearts.

The bone marrow aspiration and spinal tap will most probably be scheduled for the early morning tomorrow. I will let you know.

## June 4

Posted Jun 4, 2009 7:39am

Some people call these things a coincidence....Maureen gave Joanne a new curriculum to review for Kid's Kingdom this fall. They review many series each session. When Joanne took a look at this particular curriculum, guess what the first lesson is about? Yep!...Being courageous because God is with you. It has a nice verse to go with it too! "Have I not commanded you? Be strong. Be Courageous. Do not be terrified. Do not be discouraged; for the Lord your God will be with you wherever you go." That's a God Wink. I bet Genre will be able to be in Kid's Kingdom when that series starts - you watch! I have another one to write about later. I just have to make sure it's okay with the person I'll be writing about.

The little guy is still sleeping. They came in and put the numbing cream on his hip already. He slept right through it. He sleeps through them taking his blood pressure at night. He opens his mouth for the thermometer twice a night. He never really wakes up! Must be nice...

We should be in the procedure room by 9:15. John and I are able to be with him. We are praying continually for good results from the bone marrow aspiration and spinal fluid. Thank you for all the prayers and please continue to lift him up throughout the day asking for no serious reactions to the chemotherapy he will receive this morning.

## June 4 Victory Verse

Posted Jun 4, 2009 9:32am

Today I picked verse I Thessalonians 5:17 Pray Continually. I don't think I need to explain this one. Love, Genre

## June 4

Posted Jun 4, 2009 2:40pm

He made it through the spinal tap and bone marrow aspiration with no trouble at all. He has received three chemo treatments and now he is finishing up a hot dog (yes...he's eating a hot dog!!!), french fries (FRIED not baked!!!) and a bag of Cheezits! The Doc said he is leaving this afternoon! He is excited but a little tired. It was a big morning, but he did great. Prayerfully, the fluids will test in a positive way and Genre will be classified as a rapid responder.

## June 4th - bedtime

Posted Jun 4, 2009 9:45pm

The Doc called tonight to tell us that the hematologists, oncologists, and radiologists met this evening and discussed Genre with a Doc from St. Jude and a t cell expert from Cincinnati. They have decided that Genre does NOT need radiation at this time. There is no data to suggest that it would be of any benefit to him. (Praise God!!) As long as the leukemia stays out of his spine he should not need radiation. He also said that Genre's chromosome study came back perfectly normal. That means that there are no 'bad' indicators pertaining to how he will move through these treatments. Thank you, Thank you, Thank you!

I wanted to let you all know that Genre is tucked into his own bed and sound asleep. He had no side effects from the chemo at all. The Lord was with him before, during and after his procedures. Thank you for your prayers and please keep lifting him up to Jesus. Good night.

## June 5th Victory Verse

Posted Jun 5, 2009 9:34am

Today I chose James 1:2 It says 'Consider it pure joy, my brothers, whenever you face trials of many kinds, because you know that the testing of your faith develops perseverance.' It is long. I didn't know what trials and perseverance mean. My mom told me that I am going through a trial right now. It is a problem. I will believe in God even if I am sick. Love, Genre.

I explained to Genre that sometimes when we have big problems in our lives we wonder where God is. Our faith is tested. I told him that perseverance means staying strong and always believing. He said "that one doesn't make sense...I will always believe in God, even if I am sick."

He had a long, restful night and woke up asking for angel hair pasta with marinara sauce. That sounds good to me!

## June 5th

Posted Jun 5, 2009 2:38pm

GENRE IS A RAPID RESPONDER!!!! He is in remission!!!! Thank you, God!!!!!! The Doctor just called and said that his results were more than they could have asked for!! His body is responding to the treatments and he is being healed! He still has a long road of chemo ahead of him (3-5 years), but the treatment is on the right path! Thank you for all of your prayers...God has been listening!

June 6

Posted Jun 6, 2009 9:55am

Genre is feeling a little tired this morning so I am going to tell you what verse he picked instead of him. Today Genre picked "Be still, and know that I am God." Psalm 46:10 We have all had a lesson in slowing down and listening. Once we did - we heard (saw & felt) Him.

I'd like to share something with all of you. An amazing friend of mine, Jodi Fowler, contacted me with a private message recently. She said it was okay to paste it below.

Hi Daunette, I'm sending this as a private message, so hopefully it just can be seen by you as the website manager. I wanted to tell you about something and ask if it would be ok to do. About a year and a half ago, I kept thinking I'd like to run a marathon. It kept coming up in my thoughts. I got a book, "Marathoning for Mortals", which was a good training guide. It was written by a woman who runs and helps other train for "Team in Training". At that time, I thought it was great that this group raised money for the Leukemia and Lymphoma Society. I contacted the Western PA chapter to see about joining, only it was late in the season and I wouldn't have been able to meet the fundraising goal - so I just did some running on my own and sort of forgot about it. On May 4th, I got an email from the campaign director in Pgh, who asked if I'd be interested in joining their new team. I said, you can send me the information, and I'll look at it again. It came in the mail, and ended up in a stack of papers. The day you found out that Genre had ALL, the registration form fell out by the computer from my stack of papers. I felt that this was something I really wanted to do. I talked to Steve about it, and he had no hesitation. Team in Training is a sports training program that allows participants to raise money for The Leukemia & Lymphoma Society (LLS) which funds blood cancer research and provides education and patient services. As a runner, I would like to raise funds and run in honor of Genre. It would involve putting his name, his story, and maybe a picture of him on my website. Money would be donated to the LLS in his honor. His name would go on my running bracelet for the race day. I completely understand if you are concerned about privacy, and if you didn't want to be involved. I did register for my race, and they would then give me the name of another patient to run for. So, I would still be raising money for LLS no matter what. I am set to run the Nike Women's half marathon in San Francisco on Oct. 18th! I figured I'd better start with a half marathon before trying a full one! Anyway, I just wanted to let you know how it came about. I don't know if God is calling me to do it - as a way to share your winks with others, or if it's just something I want to do, because it's an important goal? But, think about it, and let me know what you'd like for me to do. Take care, and talk to you soon. Love, Jodi

Of course, we were touched, amazed and very supportive of Jodi's decision. We continue to be completely overwhelmed by the love and support we have been shown. Jodi has put her website together and I am including the address. This site will not let me make it a hyperlink.

<http://pages.teamintraining.org/wpa/nikesf09/jodifowler>

As I said, Genre is a little tired this morning. He went outside for a few minutes yesterday. Our neighbor Breanna was in our driveway and he went out to say hi. As my mom followed him out to make sure he was ok, (John hasn't found me the decontamination, padded, protective suit yet) he turned to my mom and said 'Nana, don't ruin my moment...' She cracked up and went back inside. She simply moved to the bedroom window and as she peered out, he caught her! Of course, he smiled and laughed at her. It's going to take a while to get comfortable with this, I think. Here's praying for an uneventful day!

June 7

Posted Jun 7, 2009 10:34am

Genre is up and moving - it's about 10am. He is NOT TOO HAPPY about me letting him sleep through Sunday school. He feels good today and he is sure he could have made it through. Boy, that's a tough one. It's his favorite place to be....but there are so many people there!!!! I know you all love him so much but right now this is what I see: bacteria, germs, viruses, mold....I'm kidding, but not so much! Maybe we will bring him next week if he is still feeling strong enough. The docs assure me that the bubble thing is not an option.

He's really irritated because our NCC Life Group picnic was cancelled. We were scheduled to have that picnic at our house today. Not only does that mean that Jaden, the Pop Princess and her sister, Sarah, and Bethany won't be here to play, but he also invited those four ER nurses... I think he really thought they were coming!

Please continue to pray that Genre responds well to his treatments. The Lord is listening, I know!

Hi this is Genre,

Today I picked Romans 8:26. "And the Holy Spirit helps us in our distress. For we don't even know what we should pray for, nor how we should pray. But the Holy Spirit prays for us with groanings that cannot be expressed in words."

I knew that distress meant bad times. I didn't know what groanings meant. I thought that meant sounds. I think this means that in our bad times the Holy Spirit can help us go to God.

Mommy said that in the ER she didn't know what to pray for so she just asked God for help. She said the Holy Spirit helped her find the words to tell me about my leukemia that night. Love, Genre

June 8th

Posted Jun 8, 2009 9:12pm

Just wanted to let you all know that Genre had a great day today! He's feeling well and is eating us out of house and home! (side effect of the steroids) He just gets tired very easily. His fourteen day wish came true today...he was able to play with Jaden for a little while. Genre informed us today that he HATES having leukemia. His reason? You have to wash your hands too much!

Genre was thinking that he might not lose his hair through this whole thing. He told me 'You know Mom, the doctors have been wrong about other things...' Tonight he started to notice some coming out when he ran his hand through his hair. He's okay with that, though. He has decided that he'll buzz his head once it gets to be more noticeable. All of you grown ups that were quick to join in on the bald talk best turn your cell phones off!!!! Have a good night.

## June 10th 1st clinic visit

Posted Jun 10, 2009 5:16pm

Genre's appointment was for 10:00 am. We met his new nurse; her name is Kristen. She will be Genre's nurse for the next 3-5 years. She has been an oncology nurse for ten years. When she accessed his port, he never flinched. She asked if he wanted to know what she was doing or if he wanted to be distracted. Nothing grosses out Genre and he said "I want to watch."

He received two chemo medicines today. Dr Shaw came in to examine him and to answer my eleven questions. He said that Genre's body has begun to regenerate (for lack of a better medical term) platelets on it's own. His platelets are even higher than he expected. His red blood cells are at a great number also and he doesn't expect Genre to need any type of transfusion any time this week. He told Genre that his hair should grow back AS SOON AS HE IS IN THE MAINTENENCE phase of this treatment. He was very positive that it would be in about nine months!!! He told Genre that he is responding as well and even better than they would have hoped.

He doesn't need another bone marrow aspiration or spinal until day twenty eight. That is June 24th. They start at day zero with your first day of chemo. So, today was his day number 14. The reason he does not need these things is because he responded so rapidly to the treatment and because there is no leukemia in his central nervous system.

Genre and Dr. Shaw joked the whole time. Genre has been so hungry for an Uno's pizza. The nurse was using Google to see if there was an Uno's closer than the Waterfront. Dr. Shaw saw what we were looking at and he said he is from New York, so he prefers a thinner crust. Genre told Dr. Shaw that 'New York is soooo five minutes ago.' Dr. Shaw said 'Oh yeah... what's the cool place to be now?' Of course, Genre told him Pittsburgh. So, when we were leaving, Genre said 'Hey, Doc, how about finding a cure for leukemia for next time?' Dr. Shaw replied "We ARE curing this Genre." Genre said "Then maybe we should find a vaccination for leukemia so nobody else gets it!" Dr. Shaw said "Genre, you are soooo five minutes ago...someone is already working on that." God really matched up two peas in a pod!

Genre's ANC is low but they expect it to stay low for quite some time. They are giving him chemo and it is doing it's job. Again, I questioned and questioned...looking for Dr. Shaw to say that I should keep him in that bubble. He won't say the words! He really feels that the child's mental state is directly related to the success of the treatment. When they asked Genre "On a scale of 1 to 10, how much do you want to go to Sunday school?" He said "10!!!!" Dr. Shaw said ' You need to let him go.' Ugghhhh!!!!

He is wiped out. He is really tired today - but not too tired to eat constantly! He's still happy and cuddly, and he's still Genre. I will keep you posted on how he feels.

PS Genre let me buzz his head because he's starting to see more and more hair on the inside of his hat! I'll post a picture of him later so his friends can all see how cute he looks with his new buzz!

## June 12

Posted Jun 12, 2009 9:24pm

I just wanted to let all of you know that Genre started to feel a little better late this afternoon. He was significantly more tired with this series of chemo. Thankfully, he wasn't sick at all - just so very weak and tired. Amy and

Aaron stopped this morning for a cup of coffee and Genre wasn't able to get up to play at all. (Gionna was happy to step in and play outside with Aaron.) He stayed on his bed most of the afternoon. Then, around 4:00 he started to feel much better. He even made the pizzas for dinner! They were delicious! His sense of humor came back during dinner and he's been laughing and teasing all of us (especially Kaitlynn) ever since. Thank you for keeping us in your prayers.

## June 13

Posted Jun 13, 2009 11:08am

As some of you may know, I have really been struggling with the idea of bringing Genre to VBS. I am okay with Sunday school - for the most part. Sometimes I still feel a little panic thinking about that one. But, I know most of those moms and each one would give me a head's up if there was some sort of illness I should know about. I KNOW I CAN'T KEEP HIM IN HIS ROOM! VBS, on the other hand, is just so many kids and I don't know so many of them. Even knowing that he will wear a mask doesn't ease my mind. I have just been sick thinking about Monday. Yesterday, before the children were up, I was sitting having a cup of coffee and I was asking God to please let me know if Genre should go to Bible school. I just prayed, 'Please don't let me do something that is going to make him sick.' I know God has been with us through all of this - in such obvious and extraordinary ways - and I guess I was feeling like He wasn't giving me any answers about what was best for Genre. (poor me, right?) I just kept asking all day long. "What do you want me to do about Monday?" My mom was here to stay with the kids so I went and did a few of those things that always pile up: banking, post office, etc... When I came home my mother handed me a blue Best Buy bag. There was a beautiful letter inside. It was a copy of what Kristie's sister Laura had sent to Best Buy. It explained to them that Genre was sick and would probably miss a lot of things with this illness. She asked them for two web cams - one for our house and one for a lap top at church - and they gave them to her. She sent two web cams here for Genre!

Now, I don't know what you think, but God was answering my prayer. I was tired yesterday and I wasn't thinking clearly. The God Wink didn't smack me in my face the way they have been. I feel a little sad about that - almost like I wasn't paying attention - I wasn't. I was so moved by Laura, but the God Wink didn't jump out at me. There were so many things to do on my list of TO DO's. (There is a lot of paper work to go with childhood cancer.) It wasn't until a few minutes later, while talking with Terry, that it occurred to me (like a light bulb turning on) that God was showing us the way. When I realized what had happened, I immediately thought that God was telling me to keep Genre home. John and Terry both feel that after this Sunday we'll know what these web cams were really for. Maybe Genre won't last through the entire service and God just cushioned the way for him to see everything at VBS. He loves Genre so much that he's not only giving him VBS, but he's also giving him his second wish - being able to talk and joke with Jaden and Travis!

If Genre can't come to VBS some of the days, I will stay home with him on our home computer, and Kaitlynn can take hers to church with a webcam on it. My mom and Breanna can take it with them from station to station. That should work. Don't you think? If there is anyone who knows how these things work, I'd appreciate a quick lesson!

I sat with Genre last night and I was honest with him. I told him how upset I have been about this. I explained that it is a big decision for us to decide if we should send him into a situation with so many kids. I explained that, although the doctors said he could go, he may get sick from being there. I told him that my heart would be so sad if I was the one who took him somewhere and it made him sick. I said that being sick might mean going back to the hospital and getting even more medicine than he already takes. I let him see the web cams and I asked him what he thought about them. He said he thought they would be really cool and that God was probably telling him

that he should stay home. 'But', he said, 'I still want to go to VBS at least a few times.' So, another angel friend, Maureen, arranged Genre's schedule so that the first two stations he will go to are the two that he wants to see - Terry's story and Chadder Theater. If he makes it through both, great! If not, we can watch from home with the web cams. Like I said before, we'll see how Sunday goes.

More than anything, I now know that whichever way this goes Genre will be able to enjoy VBS. That's all I wanted in the first place - for him to get to enjoy what he loves.

I am just amazed at the number of people who have emailed to tell me different stories about their God Winks!

Janet Allen told me that some of the kids in her Sunday school class are talking about God Winks. That is so awesome! I am so grateful that we are all paying more attention to God's presence in our lives. That's a blessing in itself.

I want you all to know that I can't take the credit for coining the term God Winks. (Here's a little PR for Norwin Christian Church.) God Winks are what you learn about in Kid's Kingdom at 8:45 am. Mrs. Fitz is Genre's (and James' and Gionna's) worship service teacher. She is an amazing lady and she taught all of us to look for God Winks when her son Matt was having some serious health problems. She told the kids that God Winks are those things God sends you to let you know he's watching and helping. We started looking for them a while ago but with Genre's illness - He just started firing them at us! They really got us through...Thank you Joanne.

And thank you to all of you for everything you have done to help us through these very difficult three weeks. I can't possibly name each one of you. So many of you have gone out of your way to make this transition time more manageable. Whether it was comfort, visits, listening, prayers, meals, groceries, helping with the kids, finishing up my school year, cleaning, emails, checking on my mom, gifts, a hospital thermometer, running a marathon, or writing on this care page, each one of you made every day a little easier on all of us. I'm not saying that this road isn't a difficult one or that it may not get even bumpier. What I am saying is that this road is the road leading toward full recovery. We will be able to get through anything that stands in our way with God and all of you by our side. Thank you, Thank you, Thank you!

**June 14th**

Posted Jun 14, 2009 8:17pm

Genre was a little nervous about going to church this morning. He was up and dressed and I could tell he really wanted to go. Once we were all ready to go, his belly started to hurt. He was laying on the couch and he said 'Maybe I shouldn't go.' Of course, I told him there was no problem - I'd stay home with him. He had tears in his eyes and it just didn't seem like his tummy really hurt. After John, James, and Gionna left for service, Genre and I sat on the couch and I asked him if he was afraid to go to church. He shook his head yes. I asked him if he was afraid that the kids would make fun of his mask. He shook his head no. At that point I just felt terrible. I knew what it was. Genre knew I was worried about him getting sick and I scared him. I asked him if he was afraid that he'd get sick going out when his ANC was low. He shook his head yes. He said 'Maybe I should wait until my numbers are higher.' I told him that Dr. Shaw said it was okay for him to go and he knows way more about cancer than Mommy does. I explained that every doctor and every nurse told us that he should go, as long as he wears a mask. I told him that Mommy is just a little more worried than I should be because he is my baby and I don't ever want to see him sick. I told him that I don't worry just about going to church - I worry about everything because I am crazy in love with him. I told him he'll understand that some day when he has a baby of his own. I promised

that I would try to stop worrying and told him that we will just pray instead of worry. He said he thought that would work better. (???!!!)

We went to church at 8:45 and he wore his mask the whole time. He asked me to wear one while we walked into church but once we were in there he said I could take it off. Just like we thought - he lasted until 9:45 and then he said 'I'm so tired. Can we go home?' He took a three hour nap when we came home and then he was up reading Treasure Island with me. He had a good afternoon and he keeps talking about VBS. I told him that VBS was early. He'd have to get up at 7:30 and he's been sleeping until 10:00. Being Genre he answered "Getting up to learn about Jesus is a good reason to get up." He told me how excited he is to start VBS tomorrow. I told him that I am excited too.

## June 15th - 1st day of VBS

Posted Jun 15, 2009 7:59pm

We survived! I think I can actually say that I enjoyed being at VBS with Genre today. I can tell you for sure that he was on cloud nine just being back at church. As soon as we arrived his two buddies Jaden and Travis came out of the main room to meet him. Genre was going to watch the opening from the balcony so the boys decided to hang out in the balcony with him. They were all so excited to be together. Jaden and Travis can't possibly understand how they touched my heart today. I think the two of them will be a part of my heart forever. Just knowing that Genre wasn't going to be alone brought a tear to my eyes. Seeing how much these two little eight year olds wanted to be with their buddy - no matter what - was truly priceless. The boys put on masks and hung out with Genre the whole time we were there.

Genre made it through Terry's story and Chadder Theater. I think he must have been feeling really great in the story because he was talking about being able to stay the whole time. By the end of Chadder Theater he said "Okay, I think I need to go home." It was just great for him to be there. I'm so glad we went.

He's still eating CONSTANTLY and he's still smiling! I'll keep you posted as the week goes on.

## June 17th

Posted Jun 17, 2009 12:56pm

We visited the clinic this morning for Genre's day 21 of his first phase of treatment. One more week to go in this part of the plan. He was infused with two chemotherapy drugs and he is handling both of them very well - no nausea at all! The docs were so pleased with his blood work. His ANC (level of ability to fight infection) was 1100. An ANC of less than 1500 is considered abnormal. An ANC of 1000-1500 is considered mildly neutropenic (more susceptible). An ANC of 500-1000 is considered moderate, and 500 or fewer is considered severe. Last week Genre's ANC was 300 - so we were really happy with his number this week. (Especially since he has been at Bible School for the last two mornings!) His platelet count was 506 - which means we aren't too worried about additional bleeding either! His other numbers were great also. The docs took a look at him for about two minutes

and told him he was amazing! They keep asking - no nausea?, no vomiting?, no bowel problems? no bleeding? no dizziness? no rashes?..... They might be amazed, but Genre and I know the real story!

Genre will be having a bone marrow aspiration next Wednesday. That is how they test to make sure that no leukemia cells have returned. Genre asked 'If the leukemia cells are 0% after my next bone marrow procedure, then what are you trying to kill? The good cells? Why do you want to kill them?' Dr. Shaw took an extra few minutes and explained it as simply as he could. I have tried to do that also, but it is a difficult concept to get across to an eight year old. He also asked "If my leukemia cells are 0%, can you stop the chemotherapy in one month instead of five years?" Dr. Shaw explained that he thinks Genre's treatment is going to be closer to 3.5 years and that if they stop now, the leukemia will come back and be very angry at the treatments we have been giving it."

Genre said "How about three months of chemotherapy?" Dr. Shaw said 'I don't negotiate with terrorists like leukemia, or 8 year old boys!' They both had a good laugh.

Genre was wearing a silly t shirt that Nana bought him. It has a picture of what your insides would look like if you could see through your body. It's a rib cage/spine and there is a blue guitar stuck through the bones. Genre told Dr. Shaw "I don't think I need treated for leukemia - you have it wrong. What I need is a guitarectomy!" Both docs said they could arrange that, if necessary.

We were in and out in less than two hours! He had a great appointment and we are just so thankful to God that he has his hand on Genre's shoulder! Thank you for your prayers! Please pray continually - he is listening, for sure!!!!

## June 18th

Posted Jun 19, 2009 7:47am

Good morning! Just wanted to take a minute and let you all know that today is the final day of VBS. Genre stayed for 1.5 hours on Monday and then he made it the whole day on Tuesday. He even played the game - outside! None of us expected him to be able to go on Thursday, but he did. He went and he made it through the whole three hours! He even played freeze tag while WALKING LIKE A CRAB!!! (mask and all!) Last night he said 'Don't forget to get me up early for VBS! Do I get to go to the big party we have every year? The one with cookies?' I told him that I am definitely taking James and Gionna and that he is welcome to come if he feels up to it. He said "I will."

There's a lot of talk about Summer in the Son at our house because Kaitlynn is going this year as a chaperone. How about that? The child never had a chance to go as part of the youth group and now she is volunteering to go and help the youth! God has done amazing things for Kaitlynn also! She's looking forward to experiencing the amazing moments that happen at camp. Genre can't wait to be big enough to go to Summer in the Son. He talks about WHEN he goes to camp...and what he will do at Summer in the Son...and who will be the chaperones when he goes...(MOMMY!) I am so sure that God wants him to experience that week in Kentucky and so many more activities that help to grow your Faith. Look at the unbelievable and UNEXPLAINABLE energy he has this week so that he can be a part of VBS!!!!?? Genre doesn't think for one second that there will be ANYTHING he can't do!!! If he has that FAITH, why shouldn't I?

## June 20th

Posted Jun 20, 2009 7:15pm

I've had a lot of people asking why Genre wasn't at the VBS finale last night. There was concern that maybe he did too much over the course of the week. I know Terry was concerned because he took the children on that forty year journey around the property! (But Genre happily followed!) He was just fine! He actually wanted to go to the show. He'd just had enough of wearing a mask. No one can hear him when he talks and it's hot under the mask. He didn't want to put one on again. Thank you for caring about him and asking if he was okay.

Genre made it through the whole day on Friday. He has been playing Power Rangers all day today. The dad of one of James' friends came in to pick up James earlier today. There were moans and groans, bomb noises and crashes coming from the bedrooms! He looked a little concerned. I explained that the Power Rangers were back there saving the world and that's what it sounds like. He laughed. Those are good sounds!

Genre said he's going to Kid's Kingdom in the morning, as long as I will let him wear a hat to church. I told him that we would make an exception for him under these circumstances. James isn't real thrilled about that one!

Thanks again for the concern and thanks so much for the prayers.

## June 24th

Posted Jun 24, 2009 6:48am

Genre will be visiting the clinic today at 9:30. It is hard to believe that this is his last day of the induction phase. Tammy Pavsek told me that once Genre is better I will look back on this and wonder where the time went. I'm hoping she is right. I've been a mom for ten years and I've been so very careful NOT to wish away their lives or the time that I get to have them with me. I'm torn now. While I still want to enjoy them everyday and savor every moment, I would really like this part of the journey to be over. That's not fair to James and Gionna, I know. Even though Genre is tolerating the drugs very well, the psychological part of this is more challenging than I ever would have imagined. I'm not sure what it's like to be inside of Genre's head, but inside of this mom's head are many struggles and conflicts. Decisions that need to be made, worries of the side effects from all the drugs, and not knowing what is coming up next all make for a constantly uncomfortable (to say the least) place to hover. I say hover because that's what it feels like..it never feels as if we have fully landed or that we should take a deep breath and relax for a moment.

I know that someday we will look back at this and remember all of the love and support even more than all these personal struggles. I am looking forward to that day. For now though, would you please keep Genre in your prayers today? His bone marrow aspiration will be sometime this morning and I can expect the results sometime tomorrow. We are praying that the leukemia is gone - plain and simple. Please continue to pray for Genre to tolerate these drugs well and also that there is no damage to his little body from the chemotherapy regimen.

Thank you again!

July 25th

Posted Jun 25, 2009 3:45pm

Dr. Sidonio called us today when we were putt putt golfing with the Semans...NO LEUKEMIA AT ALL!!!!!! God is good! We will let you know how Genre enjoys his "maskless" week as we move through it. Thank you for your prayers! Please keep lifting him up.

June 29, 2009

Posted Jun 29, 2009 6:08pm

Just wanted to let you all know that Genre has been very busy this week! He is feeling great and has been anxious to get out! After he went golfing with his buddy Jaden, we spent all day Friday at the Museum of Natural History. History is Genre's favorite subject so this was an easy choice for him. He decided that he enjoyed everything in the museum except for the modern art. He didn't quite understand why stacking up computer paper was considered modern art. Frankly, neither did I. Our friends the Merritts joined us at the museum and we went to PF Chang's for dinner afterwards. We were happy to see Genre's friends Stephen, Alex, and David at PF Chang's. You don't usually run into your N. Huntingdon friends at the Waterfront! The next day Genre invited his friends the Semans (surprise, surprise - Jaden's family!) and the Fowlers (Flowers) over to swim. They had the best day ever! All the kids swam and played basketball. The dads even decided to get a little game of basketball going...ask John how his knee is! Later, Genre played some wiffel ball with all the kids and the dads. It was so great to see him pitching to the kids and even batting! His strength and energy has been amazing! On Sunday Genre went to Kid's Kingdom and then stayed for Sunday school. My mom took him to visit his great grandmother while the rest of us stayed for 11:00 service. He wanted to go to the zoo later in the day, so we did. We took my Nanny's wheelchair just in case he was tired. He never sat in it! We stayed through the rain and he got to see the tiger sharks, so he was very happy! Yesterday was the day that Cici's Pizza was donating 10% of the collected receipts to Team in Training (our friend Jodi is running a marathon and raising money for the Leukemia and Lymphoma Society in honor of Genre. Her web page is <http://pages.teamintraining.org/wpa/nikesf09/jodifowler>). We took Genre to Cici's and he got to see his buddy Stephen there! (Stephen's whole family was having dinner there!) As you can see, the little guy has been busy. Today he played with all of his homeschooling friends at the Deemer birthday party. He couldn't wait to see all of them. He was up at 8:00 and ready to go! The party didn't start until 1:00. Mr. Deemer took all of the boys down to the fishing pond - no touching the pond water, of course...for any of them! Genre is smart enough to know that he can't play football with the guys, so he played with his DS when they played football. When they played wiffle ball, he played. He had a great day and Mr. Deemer said he was never tired once while walking down to the pond. He really got a chance to hang out with the guys today. He had such a great time!

Dr. Shaw doesn't want Genre the monkey bars, or anything on which he can get hurt, but he has no problem with him being at the playground. He said the zoo was okay, but no monkey or bat house. That was sad for Genre because he loves the monkeys. But, seeing the tiger sharks made up for it!

We are just thanking God for this wonderful, healthy week. Genre has smiled all week long and that makes all of us smile! We are praying that the good health continues and that Genre's body stays protected and strong through this next phase of chemotherapy.

July 1, 2009

Posted Jul 1, 2009 8:12pm

We didn't get home from the clinic until about 5:30. It was a really long day for Genre. He had to have a thirty minute infusion of Humate P (which helps him clot better) and two bags of fluid before his spinal tap. That took about 2 hours. He didn't have his spinal tap until almost 2 pm. He was starving and quite thirsty!! Believe me...he told everyone how hungry he was! He made it through the spinal tap procedure just like each time before this. There is no other way to explain it - it's like he's laying on the table and Jesus is holding him in his arms. He is perfectly still; he never even flinches. The medicine relaxes him but doesn't put him to sleep. Throughout the procedure you can see him smiling. Sometimes he squeezes my hand or just opens his eyes to look at us. Our nurse, Kristen, looked at me today and said "He's smiling...he's an amazing boy." I said thank you. I think he is pretty amazing, but I also know that God is with him all the time and He is helping him through each round of this fight. I know why he is smiling!

Genre is up to 78 pounds. He was 68 pounds when he left the hospital. He's very happy about that because he's had this 'thing' this year where he wants to be 80 pounds while he is eight years old. So....maybe.

I was surprised to learn that Genre's ANC was only 800 when we got to the clinic today. It was 3900 last week and he didn't have any chemo at the last visit. When the docs say that the ANC drops 7 to 10 days after infusion - they are right on. His numbers dropped so low because of his treatment two weeks ago. It didn't matter that he didn't get an infusion last week. They expect him to be significantly lower next week. Please pray that there are no delays in his treatment because his numbers are too low to treat him. I am hoping that he can be in the maintenance phase before the full blown flu season arrives.

Today was a lot harder than any of the other clinic visits for some reason. It just seemed like they were doing so much to his body. They were putting so much into him. Each time we were done with one thing we moved on to something else being injected into him. Three of the drugs were new today and we don't know how he will react to them. I think it was easier when he took a new drug and we were staying at the hospital. The doctors were right there if anything happened. Having him here at home tonight and throughout this week is frightening. He can react in various ways at any time throughout the next week. The side effects are so much more serious and involved than just a headache or belly pain. The Augmentin insert I am usually reading seems like an old friend after I read the reaction possibilities on these meds. It takes my breath away. We'll get through it. I just keep praying for God to protect his body and to give me peace. I know he will.

July 2, 2009

Posted Jul 3, 2009 9:21am

Hi - this is a day late. I typed it last night and forgot to his post.

Genre had his first home chemo treatment today. His nurse is Connie. Guess where Connie works for her 'other' job....Children's Hospital on the 9th floor...the oncology/hematology floor. Can you guess who took care of Genre one of the days he was staying there? Yep...Connie. Oh, one more thing - she's a coworker and friend of Angie Sipple - Travis' mom! The way this has all been woven together to protect and care for Genre is nothing short of amazing and awesome. He has truly had his hand in this to help smooth the way for Genre.

Genre took the ARAC again today. He will have it tomorrow and Saturday also. He has had no reaction to the medicine at all. Thank God! He is feeling very well and has been playing and laughing all day. So far so good.

He received a new bike today from a group called Cody's Wheels of Hope. It is a memorial foundation that gives something on wheels to each child diagnosed with life threatening illnesses. (...can't believe I just typed those words~) The kids can pick a bike, scooter or skateboard. They also sent him a brand new helmet. He was excited and he can't wait until he is allowed back on his bike!

**July 5, 2009**

Posted Jul 5, 2009 10:19am

Genre finished his first week of consolidation yesterday (Saturday 7/4/09). That night his temperature crept up to 99.9. It stayed there for quite a while but through the night it dropped back down into the lower 99's. It is a temperature for him at 100.4. I'm not sure if I said this before, but his fever needs to be treated regardless of whether it is a side effect from one of the new chemos or not. They obviously can not take a chance with infection because of his ever decreasing ANC. He needs to be evaluated/treated/possibly admitted at 100.4.

He received fluids each day, along with his chemo. One of the drugs he received on Wednesday can cause problems with bladder bleeding. The docs don't want him to begin bleeding as that will become a problem for Genre because of his VW. In case you don't know, Genre has a condition (always has) called Von Willebrand disease. Let me first say that Genre refuses to refer to his VW as a disease. Each time Dr. Shaw refers to his bleeding 'disease', Genre corrects him. He very clearly explains, every time, that the Von Willebrand's is NOT a disease. He says "A disease is something that makes you NOT be able to do things like play baseball. A disease makes you have to wear a mask when you are with other people. I always have my Von Willebrands and it doesn't change my life." Dr. Shaw backs up and explains that he's sorry that VW was classified as a disease. The scientists MUST have been wrong when they named it. The reason Genre's reaction is so adorable to all of us is because Genre has no idea how much the VW has directed his life. All of our decisions about Genre over the last 8.5 years have been based on him having VW. We just have chosen not to make a big deal about it. It's part of who he is.

Genre has moderate Type I Von Willebrand's disease (sorry, Genre). Some studies show that approximately 1 in 10,000 people have VW. It is more common to have mild VW. The effect of this 'disease' is prolonged bleeding. Genre does not bleed MORE than I do, he bleeds LONGER. At the sight of an injury, the clot forms for a VW patient. However, the Von Willebrand's is the 'glue' that holds the clot together. Genre has about 60% of that glue, compared to one of us without the disorder. There is a synthetic drug available for this illness. It works on over 95% of the VW population. You guessed it...Genre is not responsive to the drug. So, when Genre needs help with a surgery, a spinal tap, or any other type of bleeding, he needs a blood products called Humate P. This contains the 'glue' he needs to help him hold a clot. Genre refers to the Humate P as homemade pee and the nurses crack up.

Prior to being diagnosed with ALL, Genre has never had a bleeding issues. He had never been given any blood products, including Humate P. So, this part of the journey is also new to us. Thankfully, Genre has one of the most respected docs as his hematologist - Dr. Ragni. She is not on staff at Children's, but her partner, Dr. Richie, is the head of the hem/onc department at CHP. Drs. Shaw and Sodonio are in touch with her regularly. They have great respect for her and they include her on much of the decision making regarding Genre's treatment. She is so wonderful. When she found out about Genre, she called me to tell me that she would stay as involved in his care

as she could. She gave me her personal phone numbers and told me that it would be alright to call her with anything I wanted to discuss!

That was a long explanation as to why Genre has been receiving fluids this week. It's to help prevent the bladder bleeding. He will get that same drug again in four weeks from now, so he will need the fluids the following week once again. Let me say that Genre has received even more attention than is normal for an ALL child because of his VW. The docs have never treated a child with ALL and mild/moderate VW. There is little to no data for them to refer to, so they consult with everyone they can. He has doctors checking in on him all the time, just because they are interested in the bleeding/ALL combination. I look at the VW as a blessing. It's a little more attention from a few more doctors. What could be bad about that? Maybe Genre will help the doctors with future bleeding patients.

This morning when Genre woke up he seemed extra tired. I asked him if he wanted to go to Sunday school and he said yes. A few minutes later, when I saw how slowly he was moving, I asked him again. He said "Mommy, whenever you ask me if I WANT to go to Sunday school I am always going to say yes. It's my favorite place to go." I asked him if he felt like he was ABLE to go. He didn't answer. I asked him again. He said "Well, if I don't go to Sunday school then you are going to miss church." He was thinking about me. I helped him get back in bed and I told him that he and I would read our Bibles when he woke up. I reminded him that God is always with us no matter where we are and that He will hear our prayers from home. We pulled his covers up and he shut his eyes again. He's been sleeping ever since.

I am thankful to God that Genre has felt so well throughout these last six weeks. I am SO thankful! I tell God all day, every day, "Thank you!" I am so grateful that our son has done so well through all of this. But, on the other hand, I realize that Genre still has cancer. He is still a very sick little boy with a very uncertain future ahead of him. Three to five years is a long time. None of us knows what will happen to us tomorrow - I know that. I know that it isn't good for any of us to be consumed with worry and fear. So, I pray everyday and ask God to take away the terror that goes along with all of this. He is helping us. Most times I am able to carry this burden and not feel like I will collapse under the weight of it. I have had SO MUCH guilt regarding my own worry and fear. I have felt like I was a misbehaving, complaining child telling God that I didn't want Genre to go through this. He has done so much for me!! Everything we have needed has been provided! How dare I feel overwhelmed with worry!?

During a low moment, Kristie said to me - Do you remember when Jesus was in the garden the night before He was crucified? As soon as she said those words, I knew where she was going. The proverbial light bulb went off in my head...like a lightning bolt!! Jesus asked the Father to "Take this cup." Although His pain would be the ultimate sacrifice of being separated from His Father, He was asking for God to take it away. It just hit me - I know that this path and ending will be God's will. I will accept His plan, no matter what it is. I understand that he sees the whole picture and I can not. But, I realized at that moment that it is okay to respectfully ask God to help with the burden, and even to ask that He take AWAY the burden. I don't know if Kristie realizes what that one sentence meant to me. It helped relieve so much pain. Funny how I wasn't able to think of that on my own.

Hopefully Genre will feel stronger when he gets up. Thank you for keeping Genre in your prayers. Please pray for his strength and that his numbers stay high enough to continue his treatments.

July 8, 2009

Posted Jul 8, 2009 8:29pm

Today was a really long day at the clinic for Genre. Tonight he is just wiped out, but in a good way. It's not from any medicine - he's just plain old tired. His appointment was at 10:00 and we didn't pull in to the driveway until about 5:30. You know how that is sitting at the hospital...it just makes you tired, and you don't know why. The docs had expected Genre's ANC to drop this week. It did not. He stayed at 800. When Dr. Sidonio saw Genre he said 'I am just amazed at how well he looks.' When I told the docs that Genre had been light sabre battling in the back yard and swimming all week, they both smiled and said "Wow! Great!" Genre lost four pounds this week, but that was to be expected because he is no longer on the steroids. This week Genre will be taking a drug which has a high rate of fever associated with it. He will take the drug Wed. through Sat. He took the drug last week and he did not have a fever one time! Thank you, God. So far he has not had a fever today. He also had a spinal tap and a chemo infusion into his spinal fluid. Another chemo was injected into his port. When Genre's blood work came back it showed that his red blood count was a little low. They expect his numbers to drop even more this week, so they transfused him with red blood cells. Dr. Shaw felt that he would need the transfusion this weekend anyway. We are hoping that by giving him the blood now, he won't get as tired in the coming days. The transfusion takes two hours -just for the actual infusion. The nurse told me that we got 'lucky' today because the hospital had the blood tht Genre needed. She told me that it can take hours for the blood to be delivered to the hospital if it needs to come from the Central Blood Bank. She said we could be there until 8 or 9 pm in those instances! Good thing I pack him a lot of snacks!

After his spinal tap we had a lot of tears again. During the time when he didn't really know what he was saying, Genre invited Dr. Shaw to come over to swim and to play light sabres with him. Poor Dr. Shaw; he didn't want to lie to Genre! Genre kept saying to me 'What day is he going to come?' Dr. Shaw would say, "I'll look at my schedule, Gen." Because of the drugs, Genre would cry and say, "He's not telling me a day...he's not coming...why won't he come over and play with me...doesn't he want to play with me?" Dr. Shaw felt terrible. This went on for a good 3-5 minutes! Finally, I said, "Just pick a day, he won't remember when the meds wear off!" Dr. Shaw said, "Next Tuesday, Genre." Genre said, "Okay, next Tuesday is good." That was it. He never said another word about it. Thirty minutes later when we asked him if he remembered any of it, he just laughed and thought we were making it up. It's giving us a lot of cute stories, but when he's coming off of that medicine he is so upset. He just sobs and he doesn't have any idea why he is crying.

The docs have never treated a child with ALL and mild/moderate VW. There is little to no data for them to refer to, so they consult with everyone they can. He has doctors checking in on him all the time, just because they are interested in the bleeding/ALL combination. I look at the VW as a blessing. It's a little more attention from a few more doctors. What could be bad about that? Maybe Genre will help the doctors with future bleeding patients.

July 9, 2009

Posted Jul 9, 2009 9:03am

Thank you for all your words of encouragement and love to go along with my post from yesterday. I just want to share one more thing with you. Even though we are home and now 45 days into this, God keeps smiling and winking at all of us. I have been feeling so much worry and terror (fear doesn't seem to cut it). One day this past week Joanne asked me if I had been keeping up with reading my Bible. When I thought about the time since we have been home, I was surprised to have to answer 'no.' I told her that I have been so busy praying, continually praying, that I hadn't picked up my Bible. Really, whatever I have read in recent weeks has been about cancer,

healing foods, research, sibling reactions, etc. Yesterday, I took my Bible to the clinic. I was okay when they did the spinal tap and I was okay when he was given the blood. It just really flips me out when they put the chemo into his port. I don't know why. So, I sat and I read Phillipians 4:4-7 over, and over, and over again. Those words just meant more to me yesterday than any other time I have read them! It's like they were different words, and they got me through. Then, this morning when I read Michele W's message, she was talking about the same verse! I fought back tears because it felt like God wanted me to know that it is okay to come to Him and to ask Him to take this away from Genre and from all of us. As long as I do it with the thanks and the praise that He deserves, it is okay. What a weight was lifted for me this morning. It is true. None of us ever knows how God will use us to help someone else. So, thank you Michele. Your words really were His.

**July 11, 2009**

Posted Jul 12, 2009 7:32am

Genre finished his first two weeks of consolidation therapy yesterday!!! How did those fourteen days go by so quickly? He didn't have any fevers at all over the last two weeks. We are so thankful and so full of awe about that. The nurse came in on Saturday (one that wasn't here all week) and asked Genre, "What days did you have fever?" He was able to answer 'none.'

The next two weeks do not include any home chemo so his port will not be accessed all week and he will be able to swim with his brother and sister. Genre will have a spinal tap/injection of chemo (into the spine) each of the next two Wednesdays. Those days he will also receive a chemo injection into his port. On the 15th he will get two injections of asparaginase. Normal cells are able to produce their own asparagine. ALL leukemic cells are unable to make the non-essential amino acid asparagine, but require high amount of it to survive. The leukemic cells depend on circulating asparagine. Asparaginase (the bacteria injected into the muscle of his thighs) basically eats the asparagine and deprives the leukemic cell of circulating asparagine. Hopefully this kills any of the cancerous cells that are lingering. The main side effect is allergic reaction any time you are given the asparaginase. It doesn't matter if you have received it once before, or ten times before. The chance is the same. Damage to the pancreas and clotting are two other risks. Please keep Genre in your prayers and ask that he will be able to take this medicine without any complications.

I'm off to wake him for Sunday school. He is excited to go today because he missed last week. Thank you for your continued prayers, love and support.

P.S. I thought that many of you would like to know that my cousin, Maria, came through her surgery well. All reports were good! Thank you for keeping her in your prayers!

**The docs have never treated a child with ALL and mild/moderate VW. There is little to no data for them to refer to, so they consult with everyone they can. He has doctors checking in on him all the time, just because they are interested in the bleeding/ALL combination. I look at the VW as a blessing. It's a little more attention from a few more doctors. What could**

## be bad about that? Maybe Genre will help the doctors with future bleeding patients.

Today Genre's ANC was 300. Yes, that is low. Below 500 is severely neutropenic. But, he feels great! His red blood and platelet counts were high enough that he did not need transfused. That means that he should have enough energy to continue doing the things he loves to do and that he is in no additional danger of bleeding. Obviously, large crowds are out. Dr. Shaw said that Genre can still have a buddy over to play as long as no one at their house is sick.

After the spinal tap, Genre spent a lot of time crying again this week. It wasn't as long as last week. His nurse, Kristen, gets so upset when he cries. He got the two shots of asparaginase in his thighs right after his spinal tap, so he doesn't remember getting them. Kristen put two camo bandages on his legs. Later, as the drug started to wear off a little, Genre looked at his camo bandages and he pulled the sheet up over his face. He was sobbing and he said, "I don't want camo bandages, I wanted pony bandages!" Kristen said 'No problem, Genre, I can find you pony bandages! Don't cry!' He pulled the sheet down and said "Got ya!" She laughed and 'scolded' him. To get him back, she put a Diego bandage on his chest when she took the needle out of his port. They are truly such wonderful people in the clinic. One person cares about the kids more than the next. Each person does everything in their power to keep the kids pain free and happy. They don't just work there...the place and the kids are part of their lives. It takes a special kind of angel to do what they do every day. The sights I see at the clinic let me know for sure that I am truly blessed and that things could be so much worse. My child WALKS into the clinic and WALKS out of the clinic. He is able to enjoy his time there because he is not so ill that he can not speak. My child is working toward recovery - some do not have that option. If there is one thing I have learned from all of this it is that whatever you are dealing with regarding your children - it could be so much worse. The things we think are so important just ARE NOT. Even when something really bad is going on, it could be worse. Never in my wildest dreams did I think that my child having cancer would NOT be my worst nightmare. But it isn't. He's here for me to hold and to love. So many other parents at Children's don't have that option. I feel blessed every time I get to hug and snuggle with him...with each of our kids. Not just Genre. We've learned that tomorrow can bring the unexpected and it can happen to anyone. I pray that we all learn a lesson from Genre's illness. I hope we all appreciate the time we have with the people we love just a little bit more, and that we do the things we want to do now, rather than later. Hug your kids and tell them that you love them!

Thank you for your love and prayers!

## Rock for Genre

Posted Jul 16, 2009 2:50pm

Jason just came for a visit to let us know about Rock for Genre! We were just amazed when he told us that NCC would be having a Christian rock concert in Genre's honor. The last concert we had at the church was on May 24, 2009. Genre was at that concert but wasn't able to enjoy it the way he normally would. We knew he wasn't feeling well half way into the show. His back and his hips were hurting, but he didn't want to leave because he was enjoying the music so much. We had no idea that his body had been taken over with leukemia. His blood was actually 86% leukemia cells and he was dying that night. He was diagnosed with acute lymphoblastic leukemia the next day.

Since the day Genre was diagnosed he has been a living example of faith, courage, and truly believing in what you say you believe in. Genre has never waived in his belief that Jesus has been with him from day one. He knows that God was with him in the hospital and Genre KNOWS that God has healed him. I have struggled with this. My eight year old says what he believes and believes what he says. Have I always done that? I would have to answer 'no.' As Genre's parents, our lives are forever changed because of Genre and his faith. For the rest of our days this house will praise God for all the good things he has given us. We will put him first and we will work every day to say what we believe and believe what we say...with all of our hearts and our souls. That's the promise we have made to God, because of Genre. I can only hope that we are able to help Genre spread The Word. If I can do that by letting all of you know that we are having an awesome event at our church, I'd like to do it. NCC has been our life blood through this ordeal. I'd like to invite you to come and enjoy an evening at our church. I'd like you to meet some of the people who are so important to Genre and to this family. And, I'd like for Genre to be able to see all of the people who love him so much in the place he loves so much. If this concert is one way that God intends to speak to our friends and family we will happily use Genre's illness to do so.

The concert is August 9th at 5:00. There will be four bands. The Apprentice, Havannah Drive, and Aaron Greer Band are three of the groups that will be performing. There will be snacks and sodas available. Jason has created a 'real' web page for Genre. It is [www.genrebaker.com](http://www.genrebaker.com). He has all of the concert information on that site. The site is up and running but not yet totally complete. We really hope to see you there.

## July 17th

Posted Jul 17, 2009 8:44pm

Genre is feeling a little tired today. I had to take him for blood work to check his counts earlier today. His ANC has dropped to 150 from 300. His platelets and RBC are close to needing transfused. He has developed a few sores in his mouth. (That's a side effect from one of the drugs.) Dr. Shaw called in a prescription for a mouth wash to numb and help heal the sore spots. He's also thrown up a few times over the last two days. He doesn't have any nausea. He feels okay. I can't complain about any of it because he isn't. He is happy and he doesn't feel sick. He's just tired. The doc told me that the second half of consolidation is harder than the first half.

Genre doesn't have any taste at this point in time, so his appetite is close to nothing. I am trying to keep him eating at regular intervals so that he doesn't lose weight. God bless him...he just opens his mouth and takes whatever I give him. He never fights me on any of it.

The docs have never treated a child with ALL and mild/moderate VW. There is little to no data for them to refer to, so they consult with everyone they can. He has doctors checking in on him all the time, just because they are interested in the bleeding/ALL combination. I look at the VW as a blessing. It's a little more attention from a few more doctors. What could be bad about that? Maybe Genre will help the doctors with future bleeding patients.

## July 17th 9pm

Posted Jul 17, 2009 9:02pm

Genre's temperature is 100.5. The docs want him to be seen at Children's ER so that they can culture his blood. My mom is coming over to stay with James and Gianna. I will let you know what they say as soon as we know anything. Please keep him in your prayers.

July 18th

Posted Jul 18, 2009 12:19pm

The docs allowed Genre to come home this morning after a long night in the ER and then on the 9th floor. They transfused him with platelets and red blood cells. Hopefully that will help him to regain his energy. He is having a difficult time eating and drinking. He is throwing up off and on so that makes him want to eat and drink even less than he already does. On a positive note, he doesn't feel sick. He is just throwing up. They gave him some medicine to stop the vomiting. We are praying that it stays down. (He started throwing up AFTER they deaccessed his port - right before we left!)

The docs are still pleased with his situation. They are not concerned at all. They say that they expected this. He is just stronger and complains less than a lot of kiddos. They told me today that a child like Genre makes care giving easier. Being that he never complains, we will know for sure when something is wrong. When you are very sick with a bacterial infection, you can't fight the shivering, the muscle aches, the stomach pain, etc. He will definitely complain when that is happening. They feel that this is probably something viral and/or a combination of the chemo side effects along with his low counts.

I think I had a wink to let me know that we'll get through this little set back. I don't know if I told you all about Halle. Halle was Genre's favorite nurse during our stay. Not just because she is such a skilled and loving nurse...he thinks she is so pretty. One day Halle told Genre that if he was twenty years older she would pick him for her boyfriend because she loves his sense of humor so much. John and I had never seen Genre blush before! He turned fire engine red and he couldn't even look her way. He talks about her here and there. Every Wednesday we tease him and we ask him if he wants to go visit Halle. He just smiles. Of all the nurses on the whole ninth floor, who do you think was Genre's nurse last night? She had been on vacation for two weeks and last night was her first night back!

I am so thankful for the doctors and nurses that spend so much heartfelt energy caring for these kids. I'm thankful that we live so close to a Children's Hospital. I am so thankful that God has helped to take away my worry and fear. Although I didn't want my neutropenic son to go to the germ infested hospital and have his skin broken with a needle last night, I wasn't panicked. I didn't feel the terror in my chest where I couldn't stop thinking 'what if?' There was peace...so much so that the doctor commented on how calm I was for our first fever set back. I just want to say "thank you" for that!

Please keep Genre in your prayers. He needs some strength and his appetite to return. He needs to avoid fevers and infection and he needs to get some rest today. Thank you!

July 21, 2009

Posted Jul 21, 2009 12:47pm

Genre is feeling well today. He is still tired, but smiling! This post isn't about Genre's health. It is about more kind and generous people that want to help him. Throughout these last weeks my eyes have been opened to the goodness that exists in this life. So often I have been overcome with feelings like 'What is happening to this world?' or 'What will my children have to deal with?' We watch the evening news and listen to talk radio and I feel like sometimes I don't hear anything that is good. I can tell you, first hand, that there is good left in this world. There is an abundance of it.

Grammy B called me to talk to me about a fund raiser that Prudential Preferred Realty will be hosting this Friday. Every year Prudential in Greensburg holds a Christmas is July and they donate the money to Make a Wish. Brenda (Grammy B) and Janice Smarto spoke with me about their benefit and the possibility of it paying for Genre's Make a Wish.

Well, it's happening. This Friday, July 24th, Prudential will be having a Christmas in July from 10:00-6:00. There will be vendors available with items such as Vera Bradley and Silpada (along with many others). They have also opened up the event to include flea market tables. All of their proceeds will be donated to Make a Wish and they will pay for Genre's wish. If you are wondering what Genre's wish is, we haven't gotten that far. A Make a Wish coordinator will be meeting with him soon so that they can decide what would make him happy. His first thought is to star in any upcoming Power Ranger movies??!!\*\* I told him that might not be an option!

Prudential is located below Westmoreland Mall, behind Boston Market. If you have any questions the number is 724-838-3660. You can ask for Jan. We are so grateful to Janice and all of the agents at Prudential Preferred Realty. Their kindness and generosity; their reaching out to this family; and their concern for sick kids is priceless. Priceless...that's a word I use a lot more now. I really understand the meaning of the word much better than I did before.

**July 22, 2009**

Posted Jul 22, 2009 5:02pm

We just got home from the clinic and Genre is in his room resting. It was another long day for him. His spinal tap went well and so did his exam and infusion. Today Genre completed the first one half of the consolidation phase. He has four more weeks to go in this phase. In order to continue with this phase, his ANC needs to be 750 and his platelets need to be 75 on their own - with no transfusions. His ANC was only 100 today. The nurse said that chances are he will not be able to begin the next phase one week from today. They don't usually see that big of a jump in ANC when taking all the factors of his blood work today into consideration. The PA gave us a prescription to have blood drawn on Tuesday here in N. Huntingdon. If his numbers are still very low, he won't go to clinic on Wed. These weeks off are totally expected. Some kids have more 'weeks off' than others do. I told our nurse, Kristen, not to count Genre out! He surprises us- all of the time!

With Genre's ANC being so low, I have to ask that you use caution when visiting Genre. Of course, if you feel sick at all, we ask that you don't visit. If anyone in your home isn't feeling well, or if you've been around anyone who is sick, please wait to see him until we make sure that you aren't coming down with something. Obviously, he doesn't wear a mask when he is in our house so he will be able to pick up the germs that are brought in more easily.

Hopefull his numbers will bounce back up quickly. He is a strong little guy with a lot of spirit so I can't imagine this will hold him down very long!

We discussed for a long time today whether or not Genre should go out. Dr. Shaw is a big advocate of letting him go. The PA, Whitney, and our nurse, Kristen, not so much. They are on very different ends of the spectrum. John and I are to the point where we know that Genre is fragile, but we do not have the heart to keep him locked up in his room. (Although that is what my heart wants to do!) We are not going to take him out to Heinz Field or to some Jonas Brothers concert, but we are going to let him go to Sunday school and to events like the concert at church. As long as he will wear his mask, with in reason, we will let him go out. It's the best we can do. If he does

get sick, we will have to deal with. On the other hand, what if he doesn't get sick and we never let him do anything throughout the next three years? What will we look back and say? How can we rob him of three to five years? We've decided that we can't. Whatever is going to happen...God already knows. So, we'll just ask Him to watch over Genre ever day and we'll use our best judgment on a day by day basis. And we'll pray a lot!

July 26th

Posted Jul 26, 2009 9:58pm

Just wanted to let you know that Genre has been feeling great! He has been out back playing all weekend. His friends Alexis and Hannah came from DuBois to visit him today. He's eating and drinking a lot - getting stronger and stronger! Maybe he'll be able to get his treatment on Wednesday. Last Wednesday, Kristen told Genre, "Hey, maybe you'll get a week off next Wednesday!" Genre replied, "Every week that I don't have to come to clinic is one week longer that I have leukemia." He's right. He just wants to get it over with.

Over the weekend I heard a great phrase from my friend Tina. She sells Tastefully Simple and this weekend was a fund raiser for Jodi's marathon. Tina was telling a quick life summary of the owner of T.S. The woman had much tragedy in her life and when she had moved past all of it she said 'You can be bitter or you can get better.' WOW! I was so glad that I went to that T.S. party! You can be bitter or you can get better. We are choosing to get better! Genre, John and I have decided NOT to sit around and wait for Genre to get better before we give something back.

When we think about what got Genre through those twelve days in the hospital - the answer is easy...his Nintendo DS and the Wii. The DS gets him through every Wednesday and all the days when he doesn't feel so strong. We have talked openly with Genre about the money that our friends are raising for him/us. He knows that the money is for circumstances that could arise in the future where we might need that money. He doesn't know about any of the circumstances that would dictate our needing to use those funds. He doesn't need to know all the bad things that could happen just around the bend. Anyway, I am positive that we will never need any of that money! I just know it. So, together, we decided that we would turn around and give that money to the oncology clinic. We would ask them to use it to buy things to entertain the children.

Slowly but surely the idea has evolved. Genre thinks that it would be 'awesome' if every child who is newly diagnosed with ALL at Children's Hospital of Pittsburgh could receive some kind of hand held electronic game. The social worker can fax us a form and we can over night a game to the child. Better yet, Genre can deliver it!

Wouldn't it be great for the child's mom and dad to see a 'seasoned' ALL patient delivering a present to their newly diagnosed child!!!! What encouragement! Even if the child has a DS, he can pick something else. The fact that he was just diagnosed with blood cancer makes us think that he should receive a nice new game delivered right to him/her. No matter what - you get a game! We can do VSmiles for the littles kids, Leapsters, DS games, PSP's...maybe even laptops for the big kids. Who knows, maybe we do enough fundraising for this and we wind up giving out college scholarships to ALL survivors!!!! We are all so excited!!

So, everyone is always asking what they can do to help us. I need information, please. If you know anything about starting an organization that we want to call Genre's Operation Electronics, I would appreciate the input. Genre and Jaden came up with that name the other night! I've been looking into it little by little after the kids go to bed, but it would be a big help if someone already knew what to do. Please let me know.

At first I felt so awkward and afraid when my friends started selling Genre's bracelets...then they started with the t shirts! They have done one thing after another. Each one of them is an amazing, kind, and wonderful friend who I love. While I am so appreciative, we don't need the money right now. Genre is feeling well and we are fine. That

was the awkward part. The 'afraid' part came in to play because I knew WHY they were collecting that money. It's been hard to even talk with them about any of the fundraising issues because that money represented a future ordeal that I feared. However, because of Genre, I have been able to turn that fear around. Now, I am so excited about the money that is being collected from bracelet and t shirt sales! I know that when we DO NOT need it, we can use those funds for Genre's Operation Electronics!

Many of the foundations that have helped Genre have been started after a child was cured or they are memorial foundations. We want to put together some kind of organization now. We don't want to wait until Genre is cured. I think that helping other kids who are just starting down this path would be a great way for Genre (and the rest of us) to get through the next three to five years. It's something I can see us doing for the rest of our lives! We are planning (hopefully) on being set up before fall arrives.

Genre is dreaming BIG! Not only does he want to start Genre's Operation Electronics, he has other plans. He says that he wants every kid with cancer to be able to get free golf lessons somehow. Genre is thinking putt putt, driving range, par 3, and indoor lessons all winter long!!! I told him to write it all down and start planning. You never know what is possible!

I'll take him for his blood work on Tuesday and I will let all of you know about his ANC /treatment then. Friday night Jaden was here and we were all sitting around the kitchen table after dinner. We were taking bets as to whether or not Genre would have his treatment on Wednesday. I said that I think he will get to go to the clinic. Jaden said 'I think he will definitely get to go to the clinic and have his treatment.' I asked Genre what he thought. He said 'If God is on my side, of course I will have my treatment!' He turned to Jaden...Jaden said 'Yeah!'...and then they high fived! Believe like a child.

## July 27th

Posted Jul 27, 2009 9:51am

Just got some pictures from the Christmas in July fundraiser that Prudential Preferred Realty did for Make A Wish and Genre this past weekend!! What a wonderful day the event turned out to be. There was so much support for all the agents who put so much effort and hard work into the day. We went up in the morning and the place was really crowded. Santa and the Chick-Fil-A cow were waving people into the Prudential parking lot! They had food from one end of the office to the other - Gionna had a field day with the sweets tables! I enjoyed the purse section! There were jewelry sales, home furnishings, candles, and flea marketers. We didn't take Genre with us because his ANC was down so low, but Gionna didn't mind stepping in to represent him!! Prudential arranged with Chick Filet (on the highway) to do a Make A Wish/Genre fundraiser part II on September 29th. That is Genre's birthday and Chick Filet will be donating 20% of their profits from 4-7 pm when a special Make A Wish for Genre coupon is presented. ( I have them.) Thank you to Prudential and Chick Fil A for part II!

A special thanks to Grammy B, Helene, Jan, Janice, Sugar, Pam and all of the other agents that we might not have met that day. We also want to thank Bill for donating his time to HO HO HO people into the parking lot! When Genre's wish finally comes to life, I'm hoping that the wish will be one of his greatest ALL memories, not all of the needles and times that he felt so lousy. Thank you for making it happen! Thank you also to all of the people who donated towards the day. We appreciate your kindness and generosity more than you could ever imagine. We know that your office raises money for Make A Wish every year and we have always thought that was a wonderful thing to do. We have always known that Make A Wish is an important charity to support. But this year it is for our

son... Never in our wildest dreams did we think that an event like this could mean so much to all of us. Thank you again!

## July 27th

Posted Jul 27, 2009 5:09pm

I've had a lot of emails about Genre's FBI t shirts. Tracy (aka Jaden's mom) is coordinating the t shirt sales. If you would like more information please contact her at [tshirts4genre@comcast.net](mailto:tshirts4genre@comcast.net). Thank you!

## July 28th

Posted Jul 28, 2009 4:25pm

I just got Genre's blood work back. His ANC is 418 and his platelets are 350,000. His ANC needed to be 750 and his platelets needed to be 75,000 to get the next chemo treatment. No big deal...we'll go next week. I look at it this way - we have seven days of Genre feeling pretty great to enjoy ourselves! Have a good day!

## August 5th

Posted Aug 5, 2009 9:28pm

We went to the clinic today. Dr. Shaw wanted to see Genre even though his ANC was only 540 yesterday. When we got there today his ANC was 900! He had lots of baby white blood cells (called monocytes) floating around in his blood yesterday and Dr. Shaw predicted that his ANC would increase over night. When there are lots of monocytes in the blood the docs predict significant increases in ANC. Dr. Shaw was right. No spinal tap today, or for the next three weeks! Yeah! Genre was infused with Cytoxin and ARA-C today. It was a long day because he needs so much fluid along with the Cytoxin. The fluids should help prevent any bladder bleeding. We are now on the same four week schedule he just finished. He will have a home nurse give him chemo on Thursday, Friday, and Saturday. It's the same schedule next week. The third week will be an injection of the aspariginase bacteria and one chemo drug . The fourth week will be just one chemo infusion. "Just one chemo infusion"...we've come a long way, haven't we? After that, he will need to have an ANC of 750 to move into the INTERIM MAINTENANCE phase. From day one of the Interim Maintenance phase, Genre will receive chemotherapy for exactly three years. That's 1095 days. Then he is done.

We are so excited about so many things that are happening. Pieces of this puzzle have been falling into place in such an amazing way. I mentioned that Genre wanted the kids at the clinic to get some free golf lessons in my July 26th post. We have had a golf pro in Jefferson Boro offer to give golf lessons to these kids. Schenley Park's golf program has volunteered to participate in this charitable work also. Someone has volunteered to pay for a portion of the golf simulator cost at Schenley Park so that the kids can golf in the winter or in the rain. We may have a golf connection near the airport, too. When Genre began talking about this, John and I were a little worried. Although we didn't want to ever discourage Genre, we knew that building a golf facility would cost millions. How would WE raise that money? How would WE make this happen for Genre? Well, WE don't have to make it happen. God, and all of these people who want to help kids with cancer, will make it happen. He is putting it all in place and WE will just shuffle the paper and help Genre to see the good in his illness. We are now looking for any golf connections within a forty five minute to one hour circle around Children's Hospital. That way, most of the kids who come to the clinic will be able to get to a facility once in a while and play some golf.

Genre's baseball coach, Coach CJ, has made Westmoreland Fire Station available to us on August 23rd for an LLS/Genre's Operation Electronics event. Jodi will be doing a fund raiser there to support Team in Training and LLS. All of the proceeds from this vendor show will go to LLS. I will post more information about the event as I receive it. So far, I know that there will be vendor tables, baked goods, 'garage' sale tables, and a chinese auction. People have donated exceptional prizes for the event, including the new 2009 American Girl doll - Rebecca! (I know where Gionna will put her tickets!) The firemen have offered to do a BBQ that day, and to donate the money to Genre's new idea! The same day that Jodi and I received confirmation for this event, which will be called 'Heroes helping Heroes', the K Love Encouraging Word for the day was this - "For I am about to do something new. See, I have already begun! Do you not see it?... ~ Isaiah 43:19, NLT Wink?

We are moving as fast as we can to start the charitable organization Genre's Operation Electronics. Now, Genre has some concern about the name because he doesn't want to 'just give sick kids electronics.' I agree, but I think I will always favor that name because it was the first idea in this whole big chain of events. Our lives are changing so quickly. God is just putting everything and everyone into place. It's exciting, but a little frightening. Of course I want to make my child's dream come true. Of course I want to help kids with leukemia. I just want to make sure we are doing it the right way. There are so many options available and so many legalities. I am still open to opinions and help, if anyone has some to lend. So many good things are happening - I know that all of this isn't the result of some random act of cell mutation. There is a plan for the good that will come out of Genre's disease! With the good, God's word will be spread also. Genre's thought is to include a Bible, or a Bible story, with each game that he gives. We haven't hammered out all of the details yet. Somehow, some way, these kids are going to hear about Jesus. Did I mention that he wants Jason to go to each golf lesson and tell each child about Jesus? Yes, he asked Jason if he would make one of his very cool DVDs and show it to the kids before each lesson. Can you add that to your schedule, Jason?

Now that the Steelers are at St. Vincent's, James was excitedly telling Genre that Troy Polamalu is back in Pittsburgh. James knows that Polamalu, along with many other Pittsburgh athletes, visits the sick kids at Children's. James is just busting for one of the Steelers to be at the clinic when Genre is there. He thinks Genre should take his Steeler shirt in our back pack every time we go, just in case. This is how different our boys are. Genre said, "Troy is a Christian, do you think he would sign my Bible?" My point is that John and I didn't make Genre understand his relationship with Jesus the way he does. We have raised each of the kids the same way. I am able to get through my son's illness with a little bit of peace because I really think that God plans for Genre to spread His word. I know He has a plan for each of our children - all of our children. I just mean that I feel it in my heart that Genre is meant to spend his LIFE spreading God's word. Not just a few short years. It gets me through.

James asked today if he would be able to put up signs to make some extra money either dog sitting or doing some odd jobs for different people. When I asked him why he needed money, he said that he wanted to raise money for Genre's project. This type of giving is what makes this whole leukemia situation bearable. While I can't say to you that I'm glad our son has cancer - of course I don't want our son to be sick - the generous, selfless acts of love are overwhelming! People are moved to help these sick kids, and it is amazing. There is so much good.

Genre is looking forward to the concert at our church this Sunday. (Again, the people who have helped and the people who have donated prizes to the event have just gone beyond what anyone could have expected.) I was hoping that he'd be able to go without a mask, but that won't happen now that he has begun his second round of ARA-C. I just want him to be able to go, with or without a mask! The ARA-C is a drug that causes fevers. Genre only ran a fever once during the last cycle. Maybe he'll do even better this time!

We are so thankful to all of you for the prayers you have offered up and the love you have shown us. These next four weeks and then the ten days that follow the treatment will be difficult for our son. Please keep him in your prayers. We ask that his body is protected from the side effects of the medicine and that he is able to eat and keep his food down. We pray that he is able to feel well and that he will need few, if any, blood transfusions. Thank you again for your love and the support you have shown our family.

## August 9th Rock for Genre

Posted Aug 9, 2009 2:20pm

Tonight is the concert at Norwin Christian Church which was organized in honor of Genre. He is very excited to go and he can't wait to eat the cookies that he knows are waiting for him! For those of you who won't be there with us, I thought you might like to see the video that Jason, our Youth Minister, put together. It means so much to me...I hope you love it too. You can view it at: [www.genrebaker.com](http://www.genrebaker.com)

Genre finished up his four days of chemo this week with just a little tiredness and nausea. Overall, he is feeling well and looking forward to playing outside tomorrow and Tuesday!

## Rock for Genre

Posted Aug 10, 2009 10:42am

What an amazing night last night!!! This whole family is just completely amazed by what so many people did for Genre!! I don't think I can list everyone for fear that I might forget someone! You know who you are and what you did for our son. No matter whether you are the guys that organized this, the women who organized bracelets & t shirts, the women who sold t shirts and bracelets, worked the door, baked cookies, donated snacks, helped clean up/set up, or even if you just came and enjoyed the evening - thank you for making it such a special night for Genre. He never stopped talking about how much fun he had until I finally shut out his bedroom light. Please know that he had more fun and enjoyed himself more last night, than he has since he has been diagnosed! He had so much energy, mostly from excitement, and it was overwhelming to see him rockin' out with his friends and the bands!!! From the time Genre arrived at the church he was a VIP! Each band that came to play made sure that they spent some time with him. He got shirts, CD's and posters. Each one of the guys wrote him a special note and he was so excited! All of the bands were so great, but I especially want to thank Aaron Gree for the time he took with Genre. I want to thank him for the amazing worship time he spent with all of us. We are looking forward to taking Genre to a Saturday night service when Aaron leads worship at his church! Thank you again if you helped or if you came to enjoy the great music and fellowship. Thank you. Thank you. Thank you. What an especially moving evening!

## Rock 4 Genre

Posted Aug 10, 2009 2:04pm

This is from Genre:

Dear Friends,

Thank you for putting together my rock concert and inviting all the bands to come. I had a really great time

yesterday. I especially liked meeting Aaron Greer and the food. Thank you for coming to my rock concert. I hope you enjoyed the music.

Love,  
Genre

## August 12th Clinic

Posted Aug 12, 2009 9:14pm

We went for a "quick" visit this morning at 9:00. Genre only needed one chemo treatment injected into his port. I didn't pack him a lunch or any snacks, and I didn't bring anything for me to do. Today was the first time I went to the clinic with only one bag! It was going to be an in/out visit so I thought it would be a good day for Gionna to see where her brother goes every Wednesday. Not so. He wound up needing a red blood transfusion and the day turned into six hours! That's a lesson well learned. I'll go prepared every week - from now on.

Dr. Shaw thought Genre looked great today. His ANC is down to 300. It will probably drop even lower because he started his ARA-C treatment again today. Same thing - four days of chemo, deaccessed on Saturday. In seven to ten days we will see another big drop in his counts. This is the cycle when he had a fever last time around. Prayerfully, this time he won't have any fevers. Today, Dr. Shaw told Genre that he is one 'resilient' little boy. He even took the time to explain to Genre what resilient means. I can't say it enough...Dr. Shaw, Dr. Sidonio, and Kristen were a gift. For them to be Genre's caregivers is nothing short of a blessing. When Kristen wasn't there last week (vacation) Genre questioned everything the new nurse did. She was very nice - she just wasn't Kristen. She used different tape; she gave the medicine at a different time; she didn't check on him as much...he noticed everything different. These people really become important to you. I have to say that I was even a little apprehensive when I realized that Kristen wasn't there last time. I don't really like anyone else accessing Genre's port, even though I know the other nurses are perfectly capable! We were glad she was back this week!

Genre is feeling great this evening. He's a little bored so that is a good thing! Mr. and Mrs. Murray were here last night for a heated Mario Kart battle. I'm a little sorry to say that Mr. Murray beat Genre two out of three times! Excited and psyched are the words that James used to describe Mr. Murray when he beat Genre. James stepped up to the plate to defend his little brother. James whooped Mr. Murray over and over again. When Mr. Murray finally had enough, he left. The boys are looking forward to their next encounter with their thirty-something friend!

Will you please pray that Genre doesn't have much nausea this week. Last week was a little more difficult on him. He did not lose any weight from last week which makes me very happy. As long as he can maintain his weight with healthy foods, I feel like he's better equipped to fight this fight. (Might just be me?) I'd also like to ask God to protect Genre's body as this medicine runs through him all week. I pray that He allows the medicine to do only what it was formulated to do. No unintended harm. Thank you for keeping him in your hearts and prayers.

## August 16th

Posted Aug 16, 2009 6:30am

The doctor called last evening to say that Genre's platelets had dropped significantly. He needs to go to the hospital this morning to be transfused. I am leading Kid's Kingdom this morning because Kristie is still (living it up) at the beach. As I was making some phone calls to ask someone else to step in Genre said, "I don't know why

you're doing that... I'm going to Sunday school and THEN I'm going to get a transfusion." (That's not one I ever planned on hearing??!!) So, we'll go to Sunday school and then he can go get his platelets. This was completely expected. The ARA-C drug knocks his counts down to almost nothing. His red count is on it's way down also. I'm thinking this might wind up being a really long day because they may say he needs reds also. The red infusion takes three hours. I'm thinking the platelets take the same amount of time. Thank goodness for Nintendo!!! Please keep him in your prayers.

## August 16th

Posted Aug 16, 2009 6:15pm

It's 6 pm and Genre is sound asleep on the 9th floor again. We came in around 11:00 am for platelets. That transfusion only takes one hour - I was wrong. The doc decided that Genre should have red blood cells also. (That one takes three hours.) During the red blood transfusion, Genre had some type of allergic reaction. He broke out in a rash from his waist up to his ears. They stopped the transfusion and gave him Benadryl. He is completely passed out now. Seven hours and not one complaint. He just goes from one thing to the next - from his DS, to a book, to the tv, to my lap. He never says a word. Today was our church picnic at Oak Hollow Park. The little guy was really looking forward to going. When we got here this morning, he and I assumed we would make it to the picnic later in the afternoon. When the doc said that Genre needed reds today or tomorrow, I could see that he was really disappointed. I told Genre that I would bring him back in the morning if he wanted to go to the picnic. Normally, I would not allow my eight year old to make decisions about blood transfusions. But, he never asks to do anything. He never complains. If he wanted to go home to make the picnic and then come back tomorrow morning, I would have done that. Genre said he would just get the blood now, since we were already here. He didn't want to come back two days in a row.

They just restarted the red blood transfusion. He has about 1.5 hours to go. Please keep him in prayer...he's had so much pumped into his little body.

## August 17th

Posted Aug 17, 2009 9:28am

Genre is home. They let him leave at 8:30 last night. After he had an allergic reaction to the red blood he received, they gave him Benadryl. He reacted to the Benadryl with vomiting, nausea, dizziness, increased blood pressure, and shaking legs and arms. Once he was able to get out of the bed by himself, they let me bring him home. He had a really hard evening. He was really frightened by the way he was feeling. He kept asking why he felt so terrible and how they could make it stop. But, at the end of the day, God was watching over Genre the whole time. I had no idea that his ANC was 0. I would have taken him to our church picnic that afternoon. Not that I would have thrown him into a crowd of a hundred people without a mask, but I definitely would have let him play around. He didn't belong going to the picnic and we didn't make it! There was nothing seriously wrong with the little guy...just enough real discomfort to keep us at the hospital. God is good.

August 21st

Posted Aug 21, 2009 11:33pm

Genre developed a fever of 102 this afternoon. The doc said to bring him into the ER. Because he has a fever and he is severely neutropenic, he was admitted. He will be here at least forty eight hours. They drew blood for a culture. If nothing grows in forty eight hours, he may be able to go home. Sometimes they make the kids stay until they see two consecutive days of an increase in counts. Tomorrow will be seven days after his last Ara-C treatment. As I have said, they expect his counts to be the lowest seven to ten days after that treatment. He still has to get through Tuesday or Wednesday when his counts can be their lowest.

Gen has really felt lousy the last few days. He never really got off of his bed yesterday and he was really too tired to come down the hallway today. He's been throwing up over the last two days and hasn't been able to eat much. True to Genre, there isn't any complaining. As a matter of fact, after one of the residents examined Genre, she called the attending doc to discuss his treatment. The attending doc told the resident to pay special attention to Genre's lungs and any reactions he may have because the child never complains.

He's sound asleep now after a dose of Benadryl to pre treat him for his platelet transfusion. He's always looked so beautiful to me when he's sleeping. I'm praying that he gets a good night rest tonight and that he is able to eat something tomorrow.

I'd like to tell you another way that we've seen God working on this journey. Another God Wink, if you will. A friend went to donate blood for Genre last week on Friday. The person at the blood bank told her that her blood wouldn't be compatible with Genre's. There was some element in the blood that wouldn't work with a child whose immune system was compromised. I frantically called another friend and asked him to go out the next morning and donate. He did. On Wednesday when we got to the clinic, Genre needed three units of platelets. The Blood Bank told Dr. Sidonio that both donors who gave were absolutely compatible with Genre. The woman who said that they weren't had made a "mistake." They got two units from each of the donors so four units were available! Dr. Sidonio said that it was fortunate that we were doing the directed donor program because there was a shortage of platelets and he wasn't sure when platelets would have been available for Genre. So, I worried on Friday (again) and there was no need. Once again, what I thought was a problem was really God taking good care of Genre. If the woman had not made a "mistake" in saying that the blood wouldn't have been compatible, we would have only had two units available, not four! Friend number two would never have donated that Saturday morning. When I think about what God did to make Genre's path smoother, I am truly moved beyond words. What can I say about that? It is truly a grand design and He is in control of every single aspect of our lives. Why do we so easily forget or ignore that!

Thank you so much for your prayers. I will keep you posted as we find out what is causing this fever.

(PS If you have some free time on Sunday, don't forget that Jodi is hosting a Leukemia and Lymphoma Society fundraiser at Westmoreland City fire hall from 12 -4!)

August 22, 2009

Posted Aug 22, 2009 11:44am

Genre had a high fever through out the night so he won't be able to go home tomorrow. As of now, he will definitely be here through Monday. He can't go home until the fever is gone for a certain period of time. That time is different with each child. He was able to eat some cereal this morning and he kept it down. (He even kept choc. milk down!) Dr. Sidonio is the doc on call this weekend. That makes Genre very happy! (Mom too!) Genre doesn't like change when it comes to his docs and nurses. The nurse in the ER yesterday afternoon was very sweet and kind. It didn't matter. Genre said, 'Can you call upstairs to the clinic to see if Kristen is there? I want her to access my port. She's the only one who knows how to do it so that it doesn't hurt.' Heather tried to persuade him that she would be as gentle as she could. It didn't matter. Genre was not rude but he was certainly firm in that he wanted Heather to call Kristen. Kristen wasn't in the clinic that day so Heather was the one to poke him. It was very funny - Genre told Heather that Kristen cleans the port site in circles, not back and forth. He told her that she uses gauze for pillows to put under the butterfly clamp - one on each side. He even told her that Kristen puts the tape in a big X, not in two straight lines. Heather was so sweet and she asked him how to do each part before she did it. He kept telling Heather that he didn't think the site was numb. When she poked him, he said "Owww!" (It's the same thing he did with a new nurse last time. ) Funny - the numbing medicine only works when Kristen puts it on????

One more time, thank you so much to everyone who keeps praying for Genre. Knowing that he is being lifted up all day long truly gives a certain peace through out the day. Much love to all of you who are checking on and taking care of James, Gionna and my mom. (The love you send my way means so much too!) I don't know how we would get through each of these battles without all of you. Please continue to ask God to lift from Genre's body whatever is causing this fever. I will update as soon as I know anything.

August 22, 2009 pm

Posted Aug 22, 2009 9:18pm

I just wanted to let you know that Genre still has a fever. He is feeling a little better and he was able to eat some cereal tonight. His temp is lingering around 101. Nothing grew in the first set of cultures that were drawn in the ER. For every twenty four hour cycle that he still has a fever, new cultures are drawn. When each culture is drawn, he will be in the hospital for about forty eight hours from that time. If nothing grows and his fever goes away, they will most likely let him come home. However, his ANC was zero today. His body has no monocytes, neutrophils, or bands at this time so, as long as he has a fever, there is no chance of them letting him go. That's okay, though. This is probably the best thing for him right now. Even though he's not too happy to be there ( and neither am I), we both know that he is there for a "good" reason. The chemotherapy is doing it's job. It is killing everything. That's what we want it to do. Genre is not in any type of critical situation - he just has a fever and he is tired. There are many children on the floor who are not so fortunate. Believe me, every day I look around and I know how blessed we are.

## August 23rd

Posted Aug 23, 2009 9:53pm

When I got to Genre's room this morning there was a completely different child sitting, not laying, on his bed!!! The color in his cheeks and the sparkle in his eyes were back. I was greeted with "Mommy!!!!!!!" He joked with me and teased me about having some good 'guy party time with a lot less sanitizing time.' I brought him some chinese food and some of Grammy B's home made buns. He ate three of them! He hasn't had a fever since last night and nothing has grown in any of his cultures. It's a good day.

Thank you to everyone who helped in some way to support Jodi's LLS fundraising today. Thank you for all the home made baked goods that were so lovingly prepared. Thank you to all the vendors. Thank you to everyone who came and donated an entire afternoon to help raise money for Jodi's race and Genre. I can't list all of you for fear that I will accidentally leave someone out. Thank you to Coachs CJ & Tom, Jamie and the other firemen who so willingly gave their time today. We truly appreciate everyone who came out to shop or just to take home a meal - your contribution matters very much. Thank you Jodi for putting so much time, effort, and love into raising money to fight this terrible disease. We will never forget the things that all of you have done to help. Finally, thank God for the peace of mind that comes from knowing that all of this is really in His hands. As we let Him lead this illness and everything that goes along with it, good things will flow from it. We are already witnessing that.

## August 23rd

Posted Aug 23, 2009 10:22pm

Gaylene was right...I got to Genre's room this evening, not this morning. Did I mess up anything else?

Genre was feeling terrific this evening at dinner time. He hasn't had a fever since last evening 8/22.

## August 24<sup>th</sup>

Posted Aug 24, 2009 4:46pm

Last night before we went to bed, Genre thanked God for feeling better and for Mrs. Flower and all the people who raise money to fight leukemia. He thanked God for his brother and sister and told Him that he was missing both of them.(!!!\*) After I silently wiped the tears from my eyes, we both had a peaceful night's sleep.

Genre hasn't had a fever at all today! He is feeling great! His buddy, Jaden, came down to play the Wii with him today. The kids will be starting back to school so the play days won't be so frequent.:~( Pappy Freddy surprised Genre for a quick visit too. It really broke up the day for him. When he was sick ,all he did was snuggle with me on the bed and watch movies. Today, he feels well and he wanted to do something! The visits helped the day to go by a little more quickly for him.

He also had a surprise visit from Kristen, his nurse from the clinic. How sweet was that?

The doc who saw Genre this morning (an attending we had not seen up to this point) said it's not likely that he will get to go home any time soon. Because Genre was admitted with a fever, they will need to see his ANC start to increase before he will be sent home. His ANC was still zero today. Kristen said she was in full agreement with that determination. I tend to think like Kristen does when it comes to neutropenia, so I was extra glad she stopped by today!!

For those of you who have been emailing to ask where you can see the video Jason made of Genre, or how to go to Jodi's Nike Team in Training web page, the best way to find those things is to go to [www.genrebaker.com](http://www.genrebaker.com) (which Jason also created).

Thank you for all your prayers and love!

## August 25th

Posted Aug 25, 2009 12:53pm

We have ANC!!!! Genre's ANC went from 0-8 today! Okay, I know that's no big deal, but he's excited. Actually, his red blood cells went from 7.3-7.7 without a transfusion so that is a REALLY good thing! He hasn't had any fever and the doc was just in. He said that an ANC of 8 is actually no different than 0. Apparently the new cells only last 6-8 hours. So, in 6 hours he could be back to 0. There were no monocytes or any other 'baby whites' in his blood. That's okay - I can see his body rebuilding day by day. He's definitely not leaving today or tomorrow.

Genre is back to cracking up the nurses and PCT's. Frank is one of the PCT's here. He is SO QUIET. He can sneak in through the night and take Genre's temp and check the urine and we don't even know he did it. Genre calls him 'the stealth'. (Let me warn you...if you don't want to hear bathroom humor, just stop now!) When Frank goes into the bathroom to sample/culture the urine he always has something in his hand, but it's in paper. Yesterday, Frank opened the paper in Genre's room where Gen could see what it was. It looks like a giant plastic eyedropper. Genre asked Frank what it was and asked what he did with it. Frank explained that he used the tool to sample the urine. Genre fell on his bed and laughed hysterically! He said, "So you get to use the new Giant Pee Sucker Upper 3000?" I can't explain to you how hard Frank laughed. He's a BIG guy and he was doubled over laughing. Of course, now everyone who comes in has to make a comment to Genre about the new pee sucker upper models that will be coming out some time soon - or something like that. It lightens up the day :~)

## August 27th

Posted Aug 27, 2009 3:33pm

This morning, the doctor was saying that Genre might be able to come home tomorrow because he hasn't had a fever since Saturday. We went down to the music room with Nicole who is the music Child Life Coordinator. Genre was playing the bongos and I noticed he had started to shiver. When I felt him...I knew. We came back up to the room and I asked the PCT to take his temperature. It's 102. They just took more cultures.

I was optimistic that he would be home for Gionna's birthday on Sunday, but there's no way that will happen now. It's okay, we can eat cake and sing Happy Birthday anywhere. (I enjoyed my birthday back in June - and we celebrated it here!) I can tell he's so disappointed, though.

We'll see what's going on as soon as the cultures come back. He had no recovery when his blood work came back this morning. ANC is still 0 and no baby anythings were on the report.:( This all sounds really bad to those of us who are not oncologists, but none of the docs are surprised by any of this. They keep saying, "His numbers will eventually go up." It's the eventually part that bugs me. You know, I need to know a time frame! Please keep Genre in your prayers. God willing, his numbers will start to increase SOON!!!!

## August 28th

Posted Aug 28, 2009 4:20am

As I'm sitting here typing, the ICU doctor is in the hallway talking to the 9th floor docs. I can't believe how quickly things can change...

They were unsuccessful at bringing Gen's fever down until about fifteen minutes ago. It just kept creeping back up all night. At about 1 am he said he felt like he needed to throw up. When he did, there was obviously blood in the vomit. The nurses are very good at not panicking, but you can tell when things move outside the realm of normal.

They've determined that Genre's platelets have slipped to a level (12)that is dangerous for spontaneous bleeding, especially with his Von Willebrands. They have the platelets ordered and will run them first. His red blood count has also dropped below his transfusion number, so he'll get that next. They are also giving him a clotting factor incase he is not managing that well himself. If there is a GI bleed, they're hoping that these things will help to alleviate it. If there are any more signs of a bleed, the GI docs will see him in the morning.

The ICU doc was here. He feels that Genre is fine where he is. He said they wouldn't be doing anything differently for him in the ICU. I asked if I should call Genre's Dad and they all assured me that this was not a life threatening situation and there was no need to wake him. Genre is easy to wake up and his heart rate is starting to come back down to where it should be. He is sleeping well now because his fever has finally broken.

It's hard for me to deal with the residents and the doctors that don't know Genre. I know they have to learn and I know they have to work, but I just want to scream, 'Call Dr. Shaw! Call Dr. Sidonio!' Our whole family feels so comfortable with 'Genre's doctors.' I just want Kristen to be the one taking care of him. She knows him.

As we all know, it's so hard to watch your child be sick. This has been such a stressful night, but we've gotten through it. I feel like it's a miracle every time God gives me the strength to handle one of these episodes. Each time I don't panic and I'm able to focus on the fact that God has a plan for Genre, I am truly amazed and I feel so blessed. He allows me to stay calm and ask the questions that need to be asked. He allows me to support and care for Genre in a way that doesn't upset or scare him. That is not my nature. I worry. When it comes to my children, I panic. God pushes that aside for me and lets me see things more clearly.

I'm asking God to heal whatever, if anything, is bleeding in Genre's body. I'm asking him to clear Genre's body of any infection and to allow his body to begin to rebuild itself quickly. Please lift Genre up in prayer today. The little guy may have a rough day ahead of him.

## August 28th evening

Posted Aug 28, 2009 8:20pm

Genre didn't have a fever from 2:30-6:30, with no Tylenol. He's been feeling pretty well all day but just recently spiked a 102.2 temperature. Evenings are, of course, the worst. The doc put him on three antibiotics and one antifungal medicine. They aren't sure if he has either type of infection yet, but this is the standard line of treatment. Drs. Shaw and Sidonio were in. They thought Genre had greatly improved from last night's reports. I think Genre was as glad to see them as I was. Kristen was here three times today. Genre's access needed changed so she did it. That made Genre happy. Overall, he is feeling much better than he did yesterday and last night. He still has a fever and he doesn't feel that great, but it's so much better than last night.

## August 29th

Posted Aug 29, 2009 10:37pm

Genre is feeling somewhat better today. He has had fevers throughout the day but they have been easily managed with Tylenol. He's played on the computer and played with his action figures a little. That's more than I've seen him do in a few days. He ate a little today and kept it all down. His ANC is still zero, even with the drug to boost his white count. Dr. Shaw feels that may be indicative of a virus. He said that a virus frequently knocks down white counts. So far no cultures have shown anything. We are just so thankful that he is sitting up and making jokes. Thank God.

I want to clarify my comment about dealing with the residents. Several people have mentioned this and I don't want anyone to misunderstand what I meant. Each and every doctor, nurse, and PCT on this floor faithfully helps these children battle cancer. They unendingly care for and support each child. They have special gifts from God - gifts which I certainly do not possess. I in no way meant to imply that there was any lack of care. However, as a mom who has recently had to watch her child be severely ill while dealing with a life threatening illness, I can say that it's extremely hard to watch people make decisions about your child's treatment when the person has not finished all of their medical training. I, of course, want these doctors to learn medicine and go on to practice and do great things for children. But, if I'm honest, (and that's what I've tried to be on this page) it is much easier - especially in a stressful situation - to know that an experienced doctor is taking care of your child. It's difficult to watch your child's health steadily go down hill any time of the day. Two o'clock in the morning seems even harder. Patience and tolerance are qualities you have to concentrate on at that time. They do not come easily.

Genre obviously can not go home while he has fevers. Since he has been so sick they will not be able to budge on his discharge criteria. He will have to show them a steady increase in his ANC. One day up and one day down won't cut it.

Reggie is Gen's nurse tonight. She is such a sweetheart. She is kind and gentle. She treats each child as if they are her own. She is from India and she is difficult to understand. My mom said to Genre, "Honey, if you didn't understand something that Reggie said, would you say 'Excuse me' and ask her to repeat herself?" Genre said, "Of course not! I would just smile and nod a lot until she was done hooking up my medicine." We laughed!

Thanks one more time to all of you who have helped my mom so much. How will I ever tell all of you thank you enough? Thank you for lifting Genre and our whole family up in prayer. Thank you, Jesus, for keeping our baby in the palm of your hand.

## August 30th

Posted Aug 30, 2009 10:44pm

Genre was fever free last night! He slept so peacefully. After Dr. Graves ( a patient, understanding, and very insightful attending) spent more than a half hour with Genre and me this morning, I felt confident that it was perfectly sane to leave my child in the hospital and to spend the day with Gionna. He told me that the families who seem to do the best through out, and after, this disease are the ones who keep things as normal as is possible. He said that he would never tell me to leave if this was Wednesday, but Genre is getting fewer fevers and they are farther apart. He said the severity of the fevers is decreasing and they are being managed well with Tylenol. He said that today is Gionna's day and that she deserves to be with her mom. So, Genre and I spent the morning together. After church, my mom came down to spend the day with Genre. Gionna wanted to go to Kennywood, so John and I took Gionna, James, Kaitlynn and Kamryn to Kennywood. Our friends, the Merritts, met us there. Before I left the hospital, AnnMarie called to see what we were doing about Gionna's birthday. I told her we were going to Kennywood. Guess who got to Kennywood around 12:30???? They drove two hours to come spend Gionna's sixth birthday with her. Gionna was happy to be with Alexis and Hannah for the day too!! The kids had a blast and they were all so good. James hung out with Breanna, Sara, Alexis and Hannah. The dads joked saying that James' friends may think it's funny that he spent the day with four girls NOW...but they'll be thinking that's pretty cool in about five years! Yuck :(

It didn't feel right leaving Genre behind. I was so sad. I knew he was in loving hands with my mom, but he still wasn't coming with us. Thankfully, Anne was on top of that one! She brought Stephen to play Wii with Genre for a few hours. The nurses all knew the situation and they were so glad that Genre had a buddy for the afternoon!

When we were done at the park, we came back to the hospital so that Genre could have cake with his sister and brother. We did what Dr. Graves said to do...When Genre said, 'Hey, you went to Kennywood without me!', even though he was joking, John said, 'It's your sister's birthday and that's what she wanted to do today.' I told him that for the last eight years we've been celebrating his birthday however he wanted. I told him that he's had me here with him since last Friday - today was Gionna's day. He said, 'I know. I had fun with Stephen today. He treats me so kind because I have leukemia. He let me pick what game we would play all day.' It was easier than I thought.

## 8/31/09

Posted Aug 31, 2009 1:31pm

Genre had a 102.2 degree fever at 2 am. Of course, they drew more cultures. The docs are beginning to believe that no bacteria is going to show up. They are moving on to viruses and they've already begun the process to test him for several of the most common. We won't know those results for a few days. He is getting platelets again as I type. His nurse just told me that his temp is 101.3. He's sleeping from the Benadryl he gets with each transfusion. His red blood count is holding steady so they're not worried about a bleed at this time. He is FEELING better. He's eating, playing and teasing the nurses. In the middle of the night he asked his night nurse if Halle was working in the morning. He said, "I haven't got Halle for a nurse one time since I've been here!" Guess who his nurse is today? That made him smile. She was so nice to him when we were here back in May. Halle is the nurse that told Genre he was cute and it made him blush. She is a sweetheart. Well...we will keep praying and the doctors will keep treating...hopefully he'll be home soon.

9/1/09

Posted Sep 1, 2009 9:08pm

Genre's fever just stayed at 102-103 today, all day. Nothing has grown in any cultures. They've taken him off two of the antibiotics and the antifungal drug. At this time he's just on one antibiotic and protonix. His blood work showed 20% monocytes today! Monocytes will develop into white blood cells. His monocytes have been zero since we came in. I'm hoping that is a precursor to a little ANC tomorrow. Hopefully, he will start to make some whites and fight off whatever is causing these fevers. At this time the docs are still leaning toward a virus. This could also have something to do with the Ara-C drug he took. This Saturday will be three weeks since the drug. Most kids don't take that long to bump back up. That could be working along with a virus to cause this problem. There are many different variables and the docs have come up with a few ideas as to what is happening. Mostly, we just have to wait and see.

Dr. Shaw was in today. He could only stay a few minutes. When he was leaving he asked Genre if there was anything he could do for him. Genre said, "Let me do a Jedi mind trick on you..." He put his fingers up like Obi Wan Kenobi and waved them in front of Dr. Shaw. Dr. Shaw replied, "The force is strong with me - you can't make me do it!" Genre thought that was so funny!

No matter how long we are here, Genre teaches me something every day. I have to admit - I have been getting really frustrated with being here, away from James and Gionna. I'm not the one who is sick, so I can't imagine how Genre feels. This afternoon we turned off the tv and spent some time snuggling and praying. Before he prayed for himself, even with blood cancer, he prayed for other people in need. He prayed for Jaden's cold to go away. Okay...maybe that was for Genre too...But he prayed for the Sharps to not be too sad about their grandfather. The child has been here for twelve days and HE can still think about others. That wakes you up! I've been slipping into feeling sorry for him, but he doesn't feel sorry for himself.

I think God wanted to give me a little kick in my rear end today anyway. Mike had representatives from Gilda's (Radner) House here today. No parents were going into the room to talk to them, so he asked me if I would go for just a few minutes. I said I would since it was just down the hall. He had to make me a deal and stay with Gen. I went to the room to do Mike a favor, but I wound up meeting two moms that were probably intended to make me realize just how blessed we are. One of the moms has a twenty month old with an extremely rare tumor in his hip. There is a twenty eight percent chance that chemo will shrink the tumor. If not, they will remove his hip and leg. The other mom's nine year old daughter had a tumor in her knee. Her femur shattered in January and she hasn't walked since. She had a femur and knee replacement and she is just now starting to use a walker. I GOT IT!!! It's fever - so far that's all it is! What's twelve days in the grand scheme of life? Other than these fevers, he's well. I am going to remember that and praise God for it instead of concentrating on exactly what day we will get out of here.

I think it will do both of us a lot of good.

Please keep Genre in prayer. He needs marrow recovery and a renewed immune system along with an end to these fevers. Thank you for remembering him!

## 9/2/09 early morning

Posted Sep 2, 2009 9:13am

This is early - the doc hasn't even been in to see Genre yet, but HIS FEVER BROKE THIS MORNING!!!! Oh, I prayed all night. I just kept telling God that the docs can't fix this. They just really don't know what it is! He needs YOU to step in! Please step in! Even more than me crying out for help, I think God needed me to meet the two women I met yesterday. I think He needed to tell me, 'You asked me to handle this and I am. (Wow - "I AM") Now, let me do this MY way and on MY time line!!!! I have him.' I try so hard to pay attention...but I really found myself feeling so sorry for Genre. I know what all your messages will say - you're human; you're a mother, etc...But, if I am going to talk the talk about faith, I have to be willing to walk the walk of faith. That doesn't mean that just because we are stuck in the hospital for two weeks that it's okay to get frustrated and start to be discouraged. My son's favorite Bible verse says 'Do not be terrified. Do not be discouraged.' It's clear. It's not even a verse you need to interpret. 'DO NOT BE TERRIFIED. DO NOT BE DISCOURAGED.' God said it. do it. One more time, I'm going to set my sights on standing firm and not allowing myself to slip. Today, I feel renewed with hope.

Genre's counts increased slightly since yesterday. He actually is producing whites today. His white count is 700. A 'normal' person's white count could be anywhere from 5,000-10,000. He's behind but he had less than 300 yesterday. He has two neutrophils (attack/killer whites) and he actually has an ANC. It's 14. That really is not super significant, but it has been zero. Hopefully, it shows that his marrow is working.

After the docs come by, I will update with any news. Thank you for praying for our son! Thank you for your love.

## 9/2/09 evening

Posted Sep 2, 2009 7:51pm

Genre developed abdominal pain this afternoon. A CT scan showed that he has Typhlitis. It's not common, but Genre has it. He has a cluster of bacteria and/or fungus at the end of his colon. It can be very painful. As his white cells begin to 'come back' they are rushing to the sight of infection and that causes pain. It's a double edged sword.

We want him to produce white blood cells but as he does he will have more pain. This is not something that typically shows up in blood work. It seems to happen when the patient is neutropenic with fever for an extended time period. He will be fed intravenously for a few days to give his digestive system a rest. They've changed his medicine and the doc feels that he will probably continue with the fevers for a few more days. He said it will get worse, regarding fever and pain, before it gets better. But, once it begins to get better, we should see drastic improvement quickly. They have to rest his colon because they need to be careful about a bowel perforation. That would require surgery and they absolutely do not want him to go through any surgery with his counts so low.

Genre is very sick tonight. He needs prayers for strength and for the courage to make it through the pain. I'll let you all know how he feels in the morning. Thank you for your prayers.

## Blood Drive

Posted Sep 2, 2009 8:32pm

For those of you have been asking about the Replenishment Blood Drive that Norwin Christian Church is holding, here is the information:

Where: Norwin Christian Church

Date: September 9th

Time: 1 - 7 pm

Please consider donating. If you have any questions, or if you would like to help, you can call Joanne at 724-863-7163.

Thanks!

## 9/3/09

Posted Sep 3, 2009 1:01pm

It was a restful night for Genre. He had no fever and his belly pain was under control. He slept until 10:00 am. When we got his counts this morning his ANC had increased to 100!!! His body has begun to heal and take over cell production. Thank you!

The doc said nothing by mouth for two to three days. That will let them see if the pain subsides. Prayerfully, by just resting his gut and with the proper antibiotics this will all be behind him soon.

He is up and smiling, until he gets a belly pain. That's better than he's felt in several days. We'll take it!

## 9/4 Friday

Posted Sep 4, 2009 1:40pm

Genre had a rough night last night for pain. He had no fevers but his belly really hurt. The pain is still being managed with Tylenol. He is still allowed nothing by mouth, even though he is hungry now. They are feeding him through his port. I've been trying to get him to eat all week. Now he wants to eat....He's eight.

It must be time for Genre's body to recover...his ANC was 513 this morning! Hooray for a body that is healing!! He looks better today than he has in quite some time. Thank you for keeping him in your prayers.

Some of you have said that you are not receiving notification that a new message was posted. There were several posts since 9/1. I emailed care pages to let them know and they are checking into it. Thanks again!

9/5

Posted Sep 5, 2009 9:30pm

Genre's ANC increased to 1410 today!!! His belly pain and fever were gone all day. The docs allowed him to have clear liquids today and he did just fine with them! We are just thanking God today for a body that is healing, a boy who is so happy, and a circle of people who love Genre so much!

9/5/09

Posted Sep 5, 2009 9:49pm

Many of you have said that you do not receive email updates when I post to this site. I've also heard that many of you can't see some of the posts. The carepages help team said that many people have a problem with this site as several internet providers do not recognize it and either filter it or send it to spam. They suggested adding support@carepages.com and help@carepages.com to your address book. They also suggested checking your spam setting along with any filters you may have previously set. I'm sorry about any inconvenience this causes. They assure me that they are working on solving the problem. Good night!

9/6/09

Posted Sep 7, 2009 7:54pm

John stayed at the hospital with Genre last night. When he called me this morning, I just assumed he was going to tell me what Genre's counts were and let me know what the doc said. Instead...he said Genre could come home!!! Dr. Graves said it would be okay for us to keep him on a soft diet at home. Eighteen days was enough so he decided to let the little guy out! Gen can only eat soft food for the next two days. He still has to go to the clinic on Wednesday. I don't know if he will begin his next phase or if Dr. Shaw will just check him out. Either way, he can't upgrade to anything solid until we get the okay from Dr. Shaw. He is being so patient. He ate mac n cheese and mashed potatoes today and he was happy with that! He really wants Pizza Hut stuffed crust pizza with pepperoni and sausage, or a Subway Club. I'm thinking those dinners are in our near future.

As I was driving to the hospital to pick up my guys this afternoon, I was just overwhelmed with thankfulness and praise. This was a long stay and many days were unsure, but every step of the way things could have been so much worse. The doctors each told me that the children they see with typhlitis are really sick, not just sick like Genre was. I don't mean to trivialize what Genre just went through at all. But, the docs told me that some of the kids are terribly ill, need surgery, tubes up their noses, and much more. Genre didn't feel well at all, but it was just fever and it was just belly pain. In the grand scheme of leukemia and neutropenia, that's not so bad. He was bored. It was hard being away from the rest of our family, but we got through it. He's home. He's well. We will kiss him and love him and tuck him into his own bed tonight. That's a happy ending to a story that could have been much scarier.

We are just so glad to have him home! James and Gionna didn't miss a beat. They're right back into the routine of having Genre home. They were all building a Lego town this afternoon and now they're watching a movie together. Earlier, when I looked over on the couch and saw Genre sitting there, I just smiled and thought to myself, "Boy how I take just having my kids around for granted." I don't know about you but sometimes the little things become so unimportant. Sometimes I find myself hurrying the day along to get through things. Leukemia

has changed my perspective on all of that. I try to stop what I am doing to really look at my children. They change right before my eyes and if I'm not careful, I'll miss it. I try harder now to really listen to the words they are saying instead of just quickly answering them so that we can move on to another subject. They love it so much when you really pay attention. When James wants me to listen to a new song he wrote, I try to pay attention to the words and the tune. I try really hard to understand that when a button on Samantha's dress doesn't button, it ruins the whole look. Even though I can recite many of the scripts from Mighty Morphin Power Rangers to Power Rangers Ninja Storm, I still try to have the 'Which Red Ranger is your favorite?' conversation as many times as Genre wants to. I'm not perfect and I certainly don't always meet the standard to which I hold myself, but it's good to try. It's good to be aware. It does make a difference and it does change the way you see things. So many moms don't have the chance to try harder. I do, and I am so thankful for that.

Now that Genre is home, I want to say thank you for all the kindness that was again shown to our family. The outpour of love, prayers, babysitting, supplies, cards, and food is so appreciated and beyond any words that I can think of which would appropriately express my gratitude. Again, John, James, Gionna and my mom were so loved and well taken care of. Thank you for that from the bottom of my heart. It made staying at the hospital for such a long time so much easier.

Finally, I want to thank God for all the amazing people he has allowed to be a part of our lives. We have so much love and support and we are surrounded by so many people who love our son and care about this family. We are so truly blessed. He has allowed Genre know Him in a way that gets Genre through this battle every day. He has allowed John and I the peace and comfort of knowing that He is in control of everything that is happening, and it's all on His time. He has blessed us with a Nana who is willing and able to step in and care for and love James and Gionna in a way only a Nana can. He has given Genre a brother and sister who love him completely and are always willing to do what is needed to help their brother. He has allowed our son to recover and come home. Tonight, I feel so blessed.

9/14

Posted Sep 14, 2009 12:32pm

Care Pages is working on resolving the problem with the email alert. Many people have emailed to see if Genre is home yet because they haven't received an email update saying that he came home on the 6th. I don't know how to fix this other than to ask you to reply to this update.

If you are receiving this email and you have time, will you please shoot an email to my personal account at [jbaker9501@comcast.net](mailto:jbaker9501@comcast.net). I will check to see who is NOT receiving this and I can alert the help team. Thanks for your time.

Genre is doing great! He's back on a full diet and he's loving it. He lost seven pounds over the 18 day stay in the hospital. I'm thinking he's gained a few back!!

He starts his Consolidation phase this Wednesday. That means the three year countdown can begin! Chemo for three more years...

The docs expect his numbers to bottom out again approximately 14 days after he starts this next phase. That makes him neutropenic for his birthday which is on September 19th. No problem - he celebrated this past weekend. He took four of his buddies golfing and then to Pizza Hut. He ate his pepperoni and sausage pizza with stuffed crust,

so he was very happy. Later, he had a big camp fire with his friends! It was the most beautiful day - for all of us!  
All of our kids were well and happy, and we were all together!

9/22/09

Posted Sep 22, 2009 7:48am

Do you ever listen to KLOVE? It's a Christian worship station. We get it on 98.3. Kaitlynn was listening the other day and the DJ's were asking if you have any special Bible verses to help get you through the day. She emailed KLOVE to tell them about Genre and how he really uses Joshua 1:9. She added the link to the web site that Jason made for Genre's video. KLOVE sent Kaitlynn a beautiful email saying that they will all be praying for Genre every day and they added his link to their webpage! It is under newpage. This morning, it is possible that thousands of people will go to that website and they will hear about Joshua 1:9 and a little boy who has a strong enough faith to help him battle leukemia!! Wow! God just keeps making things happen. He just keeps using all of us to spread His Word! This is what I meant when I said that I KNOW this leukemia is NOT just some random act of cell mutation! God has a plan.

9/22

Posted Sep 22, 2009 8:19am

Sorry for two updates in one morning. It's 8 am and the Central Blood Bank just called me. Two bags of red blood which were donated directly for Genre will expire in three days. They called to see if I expect Genre to need the blood within the next three days. If not, they wanted to know if they can use it today because they are in such serious need of donated blood. I never knew how many times throughout the month the CBB is seriously short on blood and platelets. Several times I have been told that, had Genre not had directed donation blood, he would just have to wait for his transfusion!!! As responsible, loving human beings, how can we let that happen? Prior to this experience, neither John nor I have donated blood in years. That's all different now. I urge you to go to your nearest Central Blood Bank and get set up to donate. You can donate whole blood every 56 days. It only takes one hour, but each bag of donated blood can save three lives!!!

Volunteer blood donors are the only source for patients in need of blood and blood products. Here are a few facts about blood and blood products.

Only 5 percent of the national population donates blood

If all eligible blood donors donated blood at least twice a year, Central Blood Bank would be self-sufficient

4.5 million Americans would die each year without lifesaving blood transfusions

Every two seconds someone needs blood

About three gallons of blood supports the nation's blood needs for one minute.

the link to the Central Blood Bank is  
<https://www.cbbedonor.org>

Thanks for listening!!!!

## September 29th

Posted Sep 29, 2009 12:16pm

Genre wanted me to tell everyone thank you very much for all the birthday wishes you have sent!! The GIANT card from everyone on the Norwin Aqua Club swim team really made him smile! Thank you for remembering him. The cards, the gifts, the phone calls, the emails - they all make him laugh and feel really loved. Today is his birthday and he woke up clearly defining what he would eat all day. Sausage and eggs for breakfast, really healthy pizza bites and mini eclairs for lunch, Chick Fil A at 4:00 and then his favorite potato casserole and asparagus for dinner. He made his own white cake with white icing and did a beautiful job. He's quite the baker.

Chick Fil A is doing a birthday celebration for Genre today! From 4-7 pm Chick Fil A is donating 20% of each purchase to Genre's Make A Wish. There are coupon cards available, but the manager told me that they will make the donation for anyone who says they are there to celebrate Genre's birthday! If you don't have a coupon card they will still let you participate in the event. How nice is that? The manager told me that the whole Greensburg team prays for Genre every morning. She was really touched by him, but we are just as moved by her.

Genre starts his next phase of chemo tomorrow. That marks his three year countdown. We are very thankful for this day and we feel blessed to have gotten here so smoothly. I do have to say that the past few weeks with no treatments have been so wonderful. Being able to act like nothing is wrong has been a beautiful adventure. We spent a weekend in the mountains of West Virginia with the Deemers and we spent the next weekend in Treasure Lake with the Rays. I have to say that they were two of the best weekends of my life. Genre was so happy and so 'normal'. He's gained all of the weight back and he doesn't seem fragile at all. Our three kids and their friends laughed, ran, and played. All the things I just took for granted. They were just happy and healthy. What more will I ever ask for?

Genre will be taking a new drug. There are, of course, many side effects associated with the medicine. I am asking you to pray that Genre handles the medicine well. Ulceration of the mucous membrane is one of the most common problems. It can be extremely serious. Please keep him in your prayers and ask God to protect him.

Thank you so much.

## October 2, 2009

Posted Oct 2, 2009 10:12am

It was so hard to take Genre back to the clinic on Wednesday. Like I said, things have been so normal. He's been so well. On Wednesday morning I was up much earlier than the children. I was scheduled to drop the kids off to Kristie at 8:30. As I sat on the couch drinking my coffee I prayed, all the time begging God to let me know why we have to do these chemo treatments. It will be three more years! I believe with all that I am, with every single fiber in my body, that Genre is healed. The supernatural presence Genre and I experienced in the hospital during the first week he was diagnosed has assured me that my son is healed. He is cured. Now, whether or not God's hand did that directly, or he has used the doctors and the medicine- that is a debate that doesn't concern me. It is done.

What I know is that God allowed both Genre and I to feel His presence in Genre's hospital room the Tuesday before they did his final bone marrow aspiration. We both knew, without doubt, that the leukemia was gone days before the doctors actually told us. There are no human words that can explain to you what was clearly not human. I know that some of you are reading this and you are moved beyond words at the thought of our God

letting some of His people experience His love and assurance. Others are, right now, shaking their heads and wondering if they should continue reading these crazy updates. It is what it is. God has chosen this to be a struggle that Genre has to go through. Our God has guided Genre and I through this entire process. He has taken care of us every step of the way, and this is a post about how He continues to do so.

As I sat on the couch, sobbing and begging, I explained my pain clearly and repeatedly to the Lord. I told him that I didn't want to start back to the clinic. I didn't want to begin the treatments again. I asked why we had to do this when I know Genre is healed. I screamed in my head that Genre would be twelve when this was all done.

TWELVE!!! I just kept saying "I don't think I can do this until he is TWELVE! My baby will be gone by the time this ordeal is over. TWELVE is too long." I just asked over and over for God to tell me what to do. I begged Him to give me the strength to move forward with this - or let me know that we should be doing something else.

I had no choice. I had to get up from the couch. The kids needed to be up and moving so they would be ready to leave at 8:20. For some reason, I went to my computer and I turned it on to check the weather for the day. It would have been much easier to turn on the tv, but I went to the computer. My email screen popped up and the KLOVE Encouraging Word of the Day was highlighted. I clicked on it and this is what it said:

Encouraging Word  
Wednesday 9/30/2009

Rejoice in our confident hope. Be patient in trouble, and keep on praying.

~ Romans 12:12, NLT

You can interpret that however you'd like. It smacked me in my face and I lost my breath. There are thousands of verses in the Bible and most of them are not 12:12. TWELVE, TWELVE! "Rejoice in our confident hope. Be patient in trouble, and keep on praying." I can do that. I can continue on this path every day and I can be confident in His hope. I can be patient with His help, and I WILL keep on praying. In the future when I feel tired and alone, I will look back at these words and I will remember that God has given me hope, and He has commanded me to be patient and keep praying. I closed my computer and I woke up my kids. I smiled all morning and went about our day, assured, once again, that God is with us.

Genre was so positive and happy on the way to clinic and while we were there. He said many times that he didn't want to 'start up' again, but he never acted any way other than his happy self. His ANC was 1900! (no meds for three weeks) Genre had a lumbar puncture to test his spinal fluid for abnormal cells. They injected a chemo into his spine to help prevent any leukemia from existing/developing in the central nervous system. He was given a shot of asparaginase in the muscle of each leg. He was infused with two different chemos. He has dealt with the vincristine many times before. The new drug is methotrexate. That is the drug that can cause severe nausea and/or ulceration of the mucous membrane. He has been experiencing nausea since Wednesday evening. The nausea medicine helps for a while but it doesn't take it away completely. He's also very dizzy. If that continues today, I'm planning on calling the docs to see what can be done. He was having a hard time walking to the bathroom alone yesterday. He said everything is spinning.

Genre is now on a ten day clinic schedule. He goes again one week from today - October 9th. If the tenth day falls on a Friday, he goes Saturday. If the tenth day falls on a Sunday, he goes on Monday.

Thank you, again, for all your prayers and love. It really does matter to all of us. Thank you, also, for all the help and offers for babysitting. It is all SO appreciated!

## October 9, 2009

Posted Oct 9, 2009 4:28pm

Today is day ten of Genre's three year countdown! It was his second visit to the clinic on his new ten day cycle. And, it was his second dose of methotrexate. His numbers hung in there better than I expected. His ANC dropped from 1900 last week to 1100 this week. The Doc said it should take another large dip within the next seven days.

After his first dose of methotrexate, Genre had a rough few days. He was terribly dizzy from Wednesday to Saturday. The severe nausea continued through Monday. We are praying that he feels better this time. It's such a hard thing to explain to a nine year old...he asks, "Mommy, I'm praying and praying that I won't get sick, do you know why Jesus isn't answering my prayers?" Thank God he says, "Let's pray together right now and ask him again."

Nausea and dizziness are terrible. I wish Genre never had to feel that way again. But, as I have said before, in the grand scheme of cancer, we'll take the nausea and dizziness. (I know, easy for me to say when it's not me going through it.) When I look around at the other kids at the clinic, I feel blessed.

Kristen told me that she just feels like doing a dance when she sees kids that do as well as Genre is doing. She sees so many horrible situations. I am so thankful that she tells me things like that, because it helps me keep my perspective. By the way, we were so happy to hear that Kristen is expecting!

I will keep you posted as to Genre's treatments. Thank you for praying for him and thank you for always thinking of our family. I just need to keep telling all of you thank you - so much.

## October 10, 2009

Posted Oct 10, 2009 12:28pm

Just wanted to let you know that God HAS answered Genre's prayers. He is experiencing no nausea and very little dizziness. Once again, I am amazed at how He works. We have been praying and praying for Him to prevent Genre from feeling the terrible side effects of chemo. Honestly, I was asking that He just reach down and wipe it all away. I was asking for something so BIG! Instead, God had our nurse help me to get Genre on a good schedule for meds to prevent the nausea. She had me start all of this BEFORE he began experiencing the effects. Now, because of Kristen, I have Genre on one antinausea medicine every six hours, and another staggered in between that every eight hours. We are even waking him up through the night to prevent the nausea from setting in before he wakes. We are staying ahead of it this time. We will continue this for three days since that's how long the problem lasted the first time he had the methotrexate. He is just really tired, but we'll take that! God DID answer Genre's prayers, but He did it His way, not ours.

John and I just had a good talk with Genre about all of this. We were so concerned about his questioning "Hasn't Jesus heard my prayers?" We were having a difficult time explaining to him (in his nine year old way of understanding) why he feels so sick when he asks God to prevent it. Yes, I know the answer - God's time; God's will. That's a huge concept for a child to really, truly understand. Honestly, I'm just now REALLY getting it. At nine, patience and understanding are hard to hold on to, especially in a situation like this. Sometimes my kids want to know why God lets all of these children be so sick. It's a lot for them to comprehend and no matter what words I tell them, it's still a lot to understand. I don't like or understand it, so how can they? But, at 42, I'm willing

to let God guide and just quietly follow whether I understand or not. Hopefully we will be able to teach the children to do the same.

Thank you for your prayers and thank you for caring enough about our family to keep up with Genre's carepages. We appreciate you all very much.

**10/15/09**

Posted Oct 15, 2009 1:38pm

Genre is still feeling well. Thank you for all the emails and cards wishing him well.

Our friend, Jodi, will be leaving at 5:00 tomorrow morning to fly to California for the Nike Team in Training Marathon to benefit The Leukemia and Lymphoma Society. Her husband and two girls are traveling with her. They are all very excited. Jodi will be wearing a picture of Genre on her shirt. I posted a picture of it on this site. Please keep them in your prayers as Jodi travels across the country to complete a goal that I can only imagine accomplishing. Jodi rased \$4,900 for LLS. Amazing. Thank you so much to all who helped her meet this goal.

Genre goes to the clinic on Monday morning for his next chemo treatment. I will let you know how he is feeling!!!

**October 19, 2009**

Posted Oct 19, 2009 11:06pm

Genre's clinic appointment was today. I have a 'road map' of his treatment for this phase. I was so sure that I knew it inside and out. I told Genre that he was getting two infusions via his port today and we'd be out of there in a jiffy. Once we were in the room, Kristen mentioned that Genre would be getting the asparaginase shots in his thighs. I was confused. We looked at the treatment plan and he was definitely scheduled for this week, not in ten days from now like I thought. I felt terrible. I could see that Genre was starting to panic a little. We usually talk about what's going to happen to him many times before we actually get to the clinic. He was totally unprepared and it was all my fault. Kristen handled it like a champ. She numbed his legs and was as patient with him as she possibly could be, but he really gave her a hard time. He was physically upset and she had a lot to deal with today. It took a long time to get him settled enough so that she could actually inject the drugs. He wasn't cooperating at all. Once it was over he settled down and I could tell that Kristen was disturbed. She hugged him and told him that she was sorry. She said that she would never want to do anything to hurt him. We are so blessed that she is Genre's nurse. I just felt awful about the whole thing.

Genre's ANC was 660. That is too low to continue with the methotrexate for this week. He did get the vincristine infusion. There is no problem with missing a dose or two of the methotrexate in the interim maintenance phase. This phase is designed for the docs to discover the exact dose of methotrexate that Genre can tolerate. That will be the dose he gets throughout the rest of his treatment. They need to find an amount of methotrexate that does not knock his ANC below 750. Today was day twenty. He goes back on day thirty and day forty. That's it for interim maintenance. After day forty, when his counts are up to 750 again he will start the delayed intensification phase. With no delays, that phase lasts eight weeks. That should take Genre through January as long as there are no complications.

Our friend, Jodi, ran the LLS marathon yesterday. She said it was an amazing experience and one that she will never forget. She actually said that she would do it again!!! This past week was extremely difficult, though. I was completely unprepared for how emotional her running in the race would actually become for me. I have felt so appreciative, grateful and amazed that Jodi would do all of this training and fund raising to help wipe out the cancer that has rocked Genre's world. I feel so blessed to have a friend who would choose to run in honor of Genre and wear his picture on her shirt. But, at the same time, I can't believe my son's picture was on her shirt...Genre's picture was on her shirt! The polarity of emotions in my head and heart have been very hard for me to process. Joy and pride combined with pain and sorrow...they're not usually emotions I experience at the same time. I would look at the picture Jodi wore on her shirt and I felt like I couldn't get enough of that beautiful smile. I felt so much joy just seeing Genre looking the way he looked not so long ago. But, at the same time I just felt like my heart would break if I looked at it any longer. I was struggling and I felt like I was losing my footing. I prayed and prayed about my state of mind. I asked God to help me get back to the place where things didn't confuse me or seem so sad.

Once again, I was smacked back into reality. Today at the clinic Genre, my mother and I were sitting in the waiting room. A fifty something (?) woman with grayish hair walked into the clinic. Behind her was a pre teen girl who was holding onto the woman's backpack. The two of them sat near us and I noticed a beautiful pink blanket that the girl was holding. It was the kind of fleece blanket that a church would make for their missionaries to pass out. The fleece was cut around the edges and tied. It was bright pink on one side and pink polka dots on the other. It caught my eye because I knew Gionna would love it. I spoke to the girl and said, "Your blanket is beautiful. Did you make it?" She didn't turn to look at me, but answered, "No, it's a blanket that we made to take on a mission trip I just got back from." I said, "Wow, you went on a mission trip? How old are you?"

From there I found out that I was speaking with a twelve (12!)year old little girl. Her name is India and the woman who was with her is her adoptive mother. After I saw the scar that ran down the side of her head, her mother explained that India was diagnosed with a brain tumor when she was five and the tumor took her eye sight. She is now twelve and she comes to the clinic from Johnstown every two weeks for chemotherapy. India just came back from a mission trip to Mexico four days ago. She went with a group from her church. She is the youngest person in her town to ever go on a mission trip. Her older sister was the interpreter for the group. The group worked on a ranch for orphans and they raised enough money to buy them a refrigerator. They also were able to provide them with a significant amount of food to help them make tortillas. India plays the drums, cymbals and the piano. She sings and plays instruments in the praise band at her church. She is also in the band at her school. She marches in parades!

Now...what was that I was moping about? What was I feeling sorry for myself about? Oh, that's right, a picture was upsetting me...

If you would like to see India's story, you can find it here:  
<http://www.wjactv.com/news/21230484/detail.html>

Genre has felt well all day. He is always a little more tired on clinic days. He is looking forward to visiting with his buddy Jaden tomorrow. Jaden broke his femur last weekend and he is in a cast from his toes to his hip. On Sunday the kid in the mask was pushing the kid with the broken leg in his wheel chair. It was quite a picture.

Thank you for your continued prayers and well wishes!

10/20/09

Posted Oct 20, 2009 5:26pm

We're on our way to the ER. Genre has a 101.6 fever. Maybe they will just give him an antibiotic and send him home???? Probably not. I will let you know how he is doing when I can. By the way, cell phones do not work in the ER.

10/22/09

Posted Oct 21, 2009 7:32pm

Genre is home from the hospital - just a long stay in the ER, no admission.

As you can imagine, the ER was completely swamped. Our nurse told us that they were seeing approximately three hundred kids each night. It was crazy. Thankfully, the oncologist calls the ER and they take the cancer kids back into a separate room right away. I was very appreciative of that. Now, don't get me wrong, just because we go back faster doesn't mean our stay is any shorter!

The docs did the regular routine - port access, culture, cbc, antibiotic, fluids...hours later when we got the blood work back Genre's ANC was 1800! It was 660 the day before. John and I questioned whether or not there could have been a mistake and they redid the reading by hand. It was correct. The little guy had a normal ANC!!! We were just amazed and full of questions as to how this could happen. His ANC tripled over night and he had been at the clinic the day before having two chemo treatments. The resident wasn't able to give us an answer but Genre spoke up and said, "Well, I did pray to God before we left the house. I asked him to take care of everything and for me to not have to stay in the hospital. So, He must have did this." We were all silent for a minute and then I smiled and said, "Well, Genre, you were part of a miracle tonight! How cool is that?" I could tell there was a huge smile behind that mask. I could see it in his eyes.

I spoke with the clinic nurse today and she said that the tripled ANC means simply that Genre's body is doing what it was inted to do...it is waging a war against whatever virus has invaded. His body is behaving normally!!! Genre's little body is responding normally...that's what I would love to hear every time!!

He slept most of the day today because we didn't get out of there until the middle of the night. He is feeling just 'okay' today. He's not eating much but we'll work on that over the next few days. The antibiotic they gave him works for twenty four hours so even if he has another fever tonight, we don't have to take him back to the hospital. If he has a fever tomorrow, we start all over again with cultures. I found out that the reason he has to go to the ER with a fever is not because of the leukemia. It is because of his port. Any time you have an implanted device you need to be treated with a fever. Infection in the port is not good. It could mean having a line replacement, so they see these kids immediately with fever.

I will keep you up to date on how Genre feels. Thanks for your concern and good night.

Thursday 10/22/09

Posted Oct 22, 2009 7:20pm

Genre is feeling really well today. He hasn't had a fever since Tuesday. It seems like he has a little cold, but that's it. He was outside this afternoon making paper airplanes with James and riding his bike. He ate well and has been smiling all day long. That's a good day!

10/29/09 Clinic Day 30 of Interim Maintenance

Posted Oct 29, 2009 11:34pm

We just came home from Genre's day 30 clinic visit. One more treatment and he is done with Interim Maintenance. Delayed Intensification is next. That is an eight week phase and is a difficult one to get through. Some of the medicines are quite severe. After that, Genre is into Maintenance and he only has to go to the clinic once a month! Treatment is mostly in pill form and administered at home.

Genre's ANC was only 500 today. Yes, Genre was at trunk or treat last night! At least he was wearing a mask! Dr. Shaw and I discussed this. He's a strong believer that Genre NEEDS to be with his friends and NOT locked up in his room. He keeps reminding me of that. He says that Genre should be with his buddies no matter what his ANC is. But, he stresses over and over that we (obviously) shouldn't have friends to the house who are sick or who have someone sick at home - that's the best we can do. That's what all the docs say. They were unable to give him the methotrexate chemo again because his ANC was not 750 or higher. The Physician Assistant ASSURED me that this has no long term effect on Genre's treatment. The phase schedules five methotrexate treatments. He's had two infused and was unable to receive two of them because of low counts. The docs say that this is perfectly normal. This phase is not designed to knock his counts down to nothing and then just keep hammering his marrow. It is not nearly as intense as each one of the phases he's been through since May. It's actually designed for a little count recovery.

Today Genre had a spinal tap and chemo injected into his spine. He also had another chemo infused through his port. He's tired, as usual, but he is not sick at all. The docs took him off of his antibiotic for the next ten days.

Genre takes an antibiotic three times per week to prevent a certain type of pneumonia that children with compromised immune systems are more susceptible to. Apparently antibiotics can suppress your counts a little and they want him to be able to have the methotrexate on day forty.

While Genre is sedated he has a really hard time speaking. I stay near his head in front of him during his procedures. He is laying on his left side. Once the narcotic started to kick in today, he was having difficulty speaking. It's like his lips are really big and he can't talk. (They aren't - he just sounds like they are.) He was trying so hard to tell me something. I was asking him what hurt. I was asking him if he wanted me to move him a certain way. He did his best to shake his head NO. He didn't know how else to tell me so he slowly moved his little hands together and he clasped them. He put them up to his chin. I said, "Do you want me to pray?" He tried to move his eyes to look toward me, and he shook his head yes a little. I began to whisper prayers into his ear and I prayed for a really long time. When I stopped he did it again. So, through the whole procedure I whispered prayers in his ear and he just laid there with his eyes shut and a smile on his beautiful face. I was so overcome with joy that this baby of our just automatically goes to God when he is in need that I wasn't really able to fight back my tears. There is nothing else that he will do in his life that will matter more than this. That IS what will get him through the rest of his life.

Our neighbor and friend Felicia came to the clinic with us today. She is a junior and she has decided to do her senior paper on the life of a child with leukemia. She was able to get some really great resources today. Mike was so helpful as were the nurses and the PA. Our amazing oncologist, Dr. Shaw, even gave her his email address and told her to contact him if she had any questions or needed any help at all. She said she learned a lot today and she told me that Genre has really made an impact on her in many different ways. That's another one of those times when I say to myself, "OK, I see the good things that are happening through all of this craziness."

So far so good...Genre hasn't felt sick today at all. No nausea. No dizziness. Thank God.

**10/30/2009**

Posted Oct 30, 2009 11:51am

Sorry for two posts in two days. I forgot to add this to my post yesterday. The oncology clinic has a 'treasure chest' for the kids who have a treatment. After a procedure they can pick something out of the treasure chest. There is everything in the treasure chest from crayons and paddle balls to Barbie dolls and Power Rangers. The clinic buys the toys when they can, but they also accept donations. I know I always have some puzzles and toys that were doubles or just were never opened. If that's the case for you, please feel free to pass them on to me and I will be happy to deliver them to the hospital. There is also a cart in the waiting room where the kids can choose a book to keep. Of course, they ask for 'like new' books. I'd be happy to deliver these also. Just let me know!

Thanks very much!

Daunette

**November 4, 2009 (Happy Birthday, John!)**

Posted Nov 4, 2009 11:12am

Genre asked me to share these lyrics with our friends through the care page. It's our new favorite song and it's sort of become a theme song for our house. These words mean a lot to all of us. Not one of us has been strong enough on our own to get through the last five months. Faith, hope, broken hearts, odds, silent prayers and miracles have all been a part of our daily life these past few months. We each realize how blessed we have been through this - especially in the fact that Jesus has been right there with us. Hope you enjoy the song as much as we do!

What Faith Can Do (Kutless)

Everybody falls sometimes  
You gotta find the strength to rise  
From the ashes and make a new beginning  
Anyone can feel the ache  
You think its more than you can take  
But you're stronger, stronger than you know

And don't you give up now  
The sun will soon be shining  
You gotta face the clouds

To find the silver lining

I've seen dreams that move the mountains  
Hope that doesn't ever end  
Even when the sky is falling  
I've seen miracles just happen  
Silent prayers get answered  
Broken hearts become brand new  
That's what faith can do

It doesn't matter what you've heard  
Impossible is not a word  
It's just a reason for someone not to try  
Everybody's scared to death  
You may decide to take that step  
Out on the water  
But it'll be all right

Life is so much more  
Than what your eyes are seeing  
You will find your way  
If you keep believing

Overcome the odds  
When you don't have a chance  
(That's what faith can do)  
When the world says you can't  
It will tell you that it can

<http://www.youtube.com/watch?v=7elxC8LXfzE>

PS Genre is feeling great!! Genre got to experience a living miracle! He met a new friend named John who is twenty three and who has been in remission from ALL for FIFTEEN years!! He's a beautiful young man with a beautiful smile! He is surrounded by an amazing family who totally understands when we say that we feel blessed through all of this. They don't think that sounds crazy at all!! Blessings were abundant through John's illness, as well. The similarities between the boys caused me to pause and when John's dad reminded me of Romans 12:12 I almost fell over. That was the verse that kept ME going one day when I didn't want to take Genre back to the clinic. He actually asked me if I knew it!!! When John's Dad told us that John asked for an RV for his Make a Wish, my John and I just stared at each other. Who asks to drive around in an RV? (That is part of Genre's request!!!) John told Genre that he even continued with his karate lessons while his port was in. Of course, Genre turned to us and said "Then why did I have to quit???" It was an inspiring day and I am sure that God was answering my prayers that day. He let me see my baby twenty four years from now - I'm sure of it!!! We so appreciate the Weisensee family inviting us in to their home so that Genre could meet John!!

Thanks one more time for all the love, cards, visits and prayers!! He goes to the clinic on Nov. 9th for his last treatment in this phase...yeahhh!! He'll have sixteen days off before he starts an eight week long, intense cycle of chemo. Have a wonderful day!!

**11/9/09**

Posted Nov 9, 2009 7:39pm

We went to clinic today for day forty of this cycle. It was the last day. Genre's ANC was only 520 again! We were so surprised. He wasn't able to receive the methotrexact again. That means he only got two out of the five doses. Of course, I was concerned. Whitney, the nurse practitioner, assured me that there are many children who only take two doses of the drug and they do just fine. The docs actually looked at Genre's blood on a slide and they saw no abnormal or leukemia cells. Everything is fine; it is just taking Genre's body a while to recover.

The first day of his next phase is November 25th. He starts the 'more serious' drugs twenty eight days later. (Can you believe that I'm to the point where I think some chemos are better than others?) That means he'll be right in the thick of things for Christmas. I was hoping that the docs would let him start this next phase AFTER Thanksgiving. That way he wouldn't be getting the ARA-C over Christmas. He would start it right after. (The ARA-C is the drug that wiped him out and put him in the hospital in August.) The docs fully intended on letting him start after Thanksgiving but that is not an option now since he didn't get the last dose of methotrexate. They won't let him go until December 2nd without any chemo.

Genre and I talked about it today. He wasn't very happy, but he understands. He is such an easy child. Even though he doesn't want to have a tube hanging out of his chest on Christmas day with home chemo in the morning, he sees that it could be worse. He sees that he could be in the hospital over Christmas. Lots of kids will be.

Now Genre gets sixteen days off! He is mostly looking forward to eating at Olive Garden and going somewhere to eat wings with Jason. This child should weigh one hundred pounds.

I will update soon. Thank you for keeping Genre in your prayers.

**11/11/09 fever**

Posted Nov 11, 2009 5:00pm

We are on our way to CHP. Genre's temp is 101. Please pray for no infection of his port. Will update later. Remember, cells do not work in the ER.

**11/12/09 Genre is home**

Posted Nov 12, 2009 10:39am

After evaluating Genre last night the ER Doc, along with the oncologist on call, decided to send Genre home even though his ANC had dropped to 480. Under 500 is usually an admission until the cultures come back. "Luckily" for us, the resident in the ER last night was Jackie. Jackie did her rotation on the oncology floor during the two weeks Genre was admitted after diagnosis in May. She also was in the ER when he was admitted during his 18 day stay in September. She assured the oncologist on call (who I did not know) that we would bring Genre back to the hospital if he developed another fever after twenty four hours. Apparently, some parents don't do that????! They gave him his mega dose of antibiotics which works for twenty four hours (until some cultures would start to grow) and we were home at midnight.

What I've learned...even when something seems to NOT be going your way, God is always at work. You might think that having an ANC too low to get your dose of methotrexate is a BAD thing. But look...if Genre would have gotten that methotrexate on Monday his ANC would be dropping down to nothing over the next week. He would not be able to fight this virus, or whatever it is, at all! Secondly, had he been infused with methotrexate on Monday, they automatically would NOT have let him come home last night. They would be preparing for his numbers to drop and they would have admitted him, expecting him to get sicker. If we really believe that this is in God's hands, and I do with all my heart, then God knows how much methotrexate Genre needs!!

Thank you for your prayers!

**11/14/09**

Posted Nov 14, 2009 10:05pm

Genre's been feeling great since his ER visit this past week. He spent most of the day outside playing. In the afternoon we met the Deemers at the park to go geocaching. What a beautiful day!

I wanted to share this poem with all of you. It was written by our neighbor and friend, Breanna Merritt. She is in eighth grade. We love her very much.

My Friend

Beauty is a fragile life, a boy, a friend, a disease.

A body treated to heal itself from a sickness made to kill.

Everyone looks and sighs and says "Awe, that's too bad."

They can't see the pain within the boy who is never sad.

Even though the head is bare right now he still has time to smile.

The courage he shows and the faith he holds makes me know God will keep him alive.

The doctors say that he will be ok in three to five years.

That seems like such a long, long time for his loved ones to shed tears.

Time seems to fly and you don't even know it for this time he must be treated.

I can't wait to see his beautiful eyes healthy once again, because all I know is the beauty of him as my friend.

**11/19 Genre is feeling well**

Posted Nov 19, 2009 8:23am

Good morning! Genre is feeling well, but his counts are not coming back up the way the doctors had hoped. He has been hanging around 500 now for thirty days, without any 'significant' chemo drug to suppress or drop his

counts. Dr. Shaw is giving him one more week to recover on his own. He'll have a blood draw on Monday to check his ANC again. If it has not come up on his own, his next phase of chemo will not start the day before Thanksgiving. We will still go to the clinic that day, but Genre will have a bone marrow aspiration and spinal tap to check for any leukemia cells that may have appeared. I am asking you keep our son in your prayers. Please pray that his marrow recovers on its own and that there are no returning leukemia cells.

That being said, I am also asking for your help. Over the last six months, so many of you have told me to ask if we needed something. Today, I am asking - because this is important to Genre. Our family has tickets to go to the Toby Mac concert on Sunday. He is a Christian vocalist and he is Genre's favorite singer. Anne contacted his people and they arranged for Genre to come to the concert ahead of time to meet Toby Mac and the other group, Relient K. Genre is just busting with excitement! Genre knew all along that this would depend on his counts. Last night, he broke down and just really complained about everything...which never has happened. He cried and told me how much it stinks that he either can't go to the concert, or he has to wear a mask and then he can't breathe. He cried as he told me that if his counts don't go up, he has to get stuck with another needle; but if they do go up, he will only get one day of high counts to be able to go anywhere and do anything because his new treatment will start in two days. He said that he really thought he'd be able to go to Sunday school without a mask while he had sixteen days off. He also wanted to go to the museum.:(

He seems like he's getting a little discouraged. I just don't want that to happen. Do any of you know anyone at Mellon Arena? I was thinking that maybe they would let us sit up one whole level away from everyone else. It's just the opposite of wanting really good seats...we don't want to be up front and in the crowd. I'd like him to be able to go as far away from everyone as he could. Then maybe Dr. Shaw would say he could take off his mask. I don't mean to be so bold as to ask for a favor like this, especially on such short notice. But, if you could help we would be so appreciative. Thank you!

11/19

Posted Nov 19, 2009 4:15pm

Thank you so much to everyone who has tried to help Genre enjoy the Toby Mac concert. A friend from church was able to arrange for Genre to sit off by himself, away from everyone else. He asked me not to mention his name, but I just want him to know that his concern for Genre is so very much appreciated. Each of you is so very much appreciated. So many people offered to help Genre. Each time you all go out of your way for my son, I realize even more how truly blessed we are to call you friends. Thank you from the bottom of my heart.

11/21/09

Posted Nov 21, 2009 9:10pm

I received an email from Dr. Sidonio assuring me that Genre should enjoy his days off from chemo. He said that he and Dr. Shaw really feel that Genre should go to the Toby Mac concert. He said that most likely Genre has already had H1N1 (when he had influenza type A) and that it shouldn't be too much of a concern. More than that, he took the time to tell me that I should breathe. He said that he and Dr. Shaw really do not feel that Genre is relapsing. Most likely, Genre's numbers are slowly creeping up and he is just ultra sensitive to the methotrexate. He said that some kids can only handle a certain amount of methotrexate, even in maintenance. They can adjust for that. He actually went and looked at Genre's most recent blood smears and they all looked good - no sign of leukemia at all.

So, not only did he take the time to go and look at Genre's blood again, he took the time to write to me to calm me. How blessed are we to have a doctor like that caring for our son? I am forever grateful. He will have another blood draw on Monday and we will see if his numbers are coming up then.

Today, the Deemers invited us to go to Fort Ligonier. We've all been studying that part of history and Kristie thought it would be nice to take the kids to see the fort. We drove up there and it was CLOSED! It doesn't open again until April! (Yes, we checked the website before we went. ) Since Genre has been begging us to take him to Olive Garden we decided to go there. We figured that 2:30 would be an 'off' time. It's not. John went in to put our name on the list and he met up with a sweet woman named Raeanne. He asked her if there was anywhere that we could sit which would be out of the way. She found us an area where we were totally by ourselves. No one even had to pass our table! She was so nice to the kids and Genre told her that he couldn't wait to get to Olive Garden. He said that all he could think about was a 'grown up size pasta with red sauce.' She talked with him a lot and he asked her if she thought they could put shrimp on his pasta. She said she'd see what she could do. A few minutes later, two men came to our table. They introduced themselves. The man that did most of the talking said that his name was Mike and he was the Manager/Chef. He told Genre he was honored that Olive Garden was the place that Genre loved so much. He said that it made him happy to know that Olive Garden made Genre happy. The man bought all of the kids their meals and then he tossed a stack of coupons in front of Genre. They were coupons for free kids meals. He said 'There, now you can come here and eat as many times as you'd like.'

He gave Genre his card and he told him that he would do anything he could to help Genre. He said for Genre to call him if he wanted anything. I should have told the man how much we appreciated his generosity and how grateful we are for such random acts of kindness. I didn't. Instead I was sobbing. You know, one side of my brain is just so thankful for each person who reaches out to Genre. It touches my heart and shows us over and over again that there is so much good in the world. It lets us feel the compassion that God allows to touch our lives every day.

But, the other side of my brain is instantly reminded that there's a reason why people are so nice to Genre. He's sick. They see him and they feel sorry for him. Logically, I know that. It's just that sometimes it smacks me in my face. Again, it's so hard to have two such polar emotions filling my brain and heart at the same time - thankfulness and sorrow. I think I'm getting a little better at dealing with it, but it is still hard. I had a chance to redeem myself because Mike wasn't done. He brought two cakes out for dessert. I was able to appropriately thank both he and our waitress, Reanne. She was just so dear. She had tears in her eyes and she doesn't even know us.

You won't be surprised that I am giving a giant kudos to Olive Garden for allowing such a terrific guy to manage their restaurant. We will definitely patronize the Greensburg restaurant in the future...as if Genre would have it any other way!

I just wanted to let you all know that we had our first meeting for Genre's Kids With Cancer Fund. We got alot accomplished and we are all excited to get moving and help families dealing with childhood cancer. The first thing we will be doing is collecting the toys I wrote about earlier. We will have a giant box in the foyer at Norwin Christian Church the first two Sundays in December. Again, they ask that you don't wrap the gifts. We are also collecting gift bags of any size and color. The only items that we ask you do not donate are flowers, scented items, latex items, and stuffed animals. Some people have asked what they could get for the older kids. Some moms with older children have suggested ITune cards, fuzzy socks, earphone replacements, puzzles and books. If anyone else has any suggestions, we would appreciate it if you post them on message board.

We are in the process of creating a web site. Until then you can keep up to date with what we are doing at

<http://www.facebook.com/#!/pages/Genres-Kids-With-Cancer-Fund/208457455621?ref=ts>

or you can just search for Genre's Kids With Cancer Fund on Facebook.

We also talked about a 5K run and a golf outing to raise money for the organization. Lots of good ideas and lots of good people! We're going to need lots of help!!!!!!!!!!!!!!

Thank you for keeping Genre in your prayers! Have a wonderful night.

**11/22/09**

Posted Nov 22, 2009 11:34pm

Mission accomplished! Genre went to the Toby Mac concert tonight - his first concert - and he had a blast without having to wear his mask for one minute of the concert! He wore it in, and out, and that was it! We were able to sit in a box all by ourselves! When we got to the concert, Toby Mac's people had left Genre floor tickets, right up front. It was very sweet, but we sat up high and away from the other 6,000 people that were there! Thank you to all of our friends who helped Genre enjoy his night out. You are so appreciated by Genre, and by us.

FYI, the concert was really great. John and I went because the boys like the music. I didn't realize how many songs I knew, just from listening to the CDs in the car. They put on a great show with a terrific unity theme. I have to say that we adults were rockin' out just as much as the kiddos!

I am taking Genre to have his blood drawn in the morning to check his ANC. I will let you know how he is.  
Goodnight.

**11/23/09 Happy Day!!!**

Posted Nov 23, 2009 3:26pm

GENRE'S ANC IS 945!!!! THANK GOD! Bev just called from the clinic...his marrow is recovering on its own.. All other numbers look great - no bone marrow aspiration is necessary. He will start his new treatment on Wednesday. I am SO THANKFUL that his marrow is recovering!!!! SO THANKFUL!!!! I have been trying to focus on accepting whatever is handed to me. Really...I've been trying so hard...I CAN ACCEPT THIS ONE!!! Thank you, thank you, thank you!!!

I will let you know how he is feeling on Wednesday. Thank you for your prayers and please keep lifting him up!

**11/25/09**

Posted Nov 26, 2009 12:50am

Today is six months since we first heard, 'Your son has leukemia.' It's strange...it seems like we've been doing this a lot longer than six months. It seems like we've been living childhood cancer so much longer than half a year. On the other hand...sometimes it seems like they just smacked me in the face with those words this morning. Sometimes I still lose my breath when I think about those first moments...I just can't go back there.

Genre did just great at the clinic today! He made it through his spinal tap and chemo infusions in true Genre style...smiling and happy all the way. Kristen says that she can tell that Genre is just 'done' with the treatments and with chemo. You can tell that he just wants to get in and get out. He isn't rude or short with Kristen or the docs. There's just something different. He still jokes and plays with everyone there, but his attitude is more business like...almost like he's on a mission to get through this. He just wants it to be over, and so do I.

This was a very significant day today as it was day one of the last phase of Genre's treatment before maintenance therapy begins. He has come so far and he has done so well. It won't be too much longer and he'll only have to go to the clinic once a month! Most of his meds will be pills that he takes at home! We are so thankful that Genre has been as healthy as he is throughout the past six months. We truly have been blessed. However, he is heading into a very rough cycle with very hash drugs that have the potential for dreadful side effects. I would ask that you keep Genre in prayer over the next fifty six days as he finishes up this last 'big' part of his treatment. I am asking that you pray for the medicine to do what it is meant to do, and nothing else.

I will let you all know how Genre feels over the next few days. After his procedure today he was feeling very well with no nausea or dizziness at all. Thanks again for your support and prayers.

Daunette

12/14/09

Posted Dec 14, 2009 2:52pm

Hello All! Genre has finished the first part of his last big phase of chemo which is called delayed intensification. He is well. His numbers are low, but that was to be expected. The last part of this phase was scheduled to begin on 12/23 and run for three weeks.. During that phase, Genre's port will remain accessed for four days in a row, so that he can get chemo at home. That continues for two weeks. He would have been 'accessed' on Christmas Eve and Christmas day. Drs. Shaw and Sidonio were compassionate enough to move that treatment back one week for Genre. It will begin on December 30th and continue for three weeks thereafter. In order for that phase to begin on the scheduled day, his ANC will need to be 750. It is much lower than that right now, but, prayerfully, his body is rebuilding and he will be well enough to begin on the 30th.

Genre's Kids With Cancer Fund is up and running! We are working on many great projects and have an abundance of good work to do. Everything is in the planning stages, but I am surrounded with an inspired group of women who understand exactly what Genre and I had in mind when we first talked about this charity...to help families through childhood cancers by assisting spiritually, emotionally and financially. To help people see that you can walk any path - as long as you have Jesus with you. You may not WANT to walk the path...you may not LIKE the path...but you CAN walk it, and find blessings scattered abundantly along the way.

Jason and I are in the process of building the new website. [www.genreskidswithcancerfund.com](http://www.genreskidswithcancerfund.com) It's not completely finished yet. We need to work with the bank so that donations can be accepted on line. Many of you have asked how you can donate to the fund. We will happily accept donations made out to Genre's Kids With Cancer Fund. The address is PO Box 127 Irwin, PA 15642. Thank you to all of you who have been kind enough to donate already!!

The first project we are working on is the foundation of why this fund began. Genre wanted every child who is diagnosed with ALL at Children's Hospital of Pittsburgh to have a hand held game. MANY hours of chemo

infusions are made easier with these video games. We are now planning several fund raisers and working with various companies to make this happen. It is our hope that someday we will be able to give a handheld video game to all kids diagnosed with any cancer!! If any of you can help in any way, please feel free to call or email. We would greatly appreciate your input!! Our fund even has it's own email now - [genreskidswithcancerfund@comcast.net](mailto:genreskidswithcancerfund@comcast.net)!!

Next, we will be working to contact families in need at Children's Hospital. The social workers and Child Life Coordinators will be our eyes and ears at the hospital. There are many people in need and we intend on helping them in any way we can. There are many factors, spiritually, emotionally and financially, that come into play when you are dealing with childhood cancer. Many of them are not health insurance related. It is our intent to be able to help our first family in the spring of 2010.

Genre is still very excited about the idea of providing his 'cancer kids' (as he calls them) free golf lessons!! That's a project that our friend Dan has volunteered to help with. We plan on focusing on the lessons right after the holidays when Genre's treatment is complete. If you have expressed interest in that part of our organization, we'll be in touch in January.

GKWCF has been collecting toys for the children who will be hospitalized over Christmas. Thank you to all who have donated. Because of the icy weather this past Sunday, the collection box will remain in the Norwin Christian Church foyer for one more week. It will be there through 12/20. If you'd like to drop off a donation during the week, just press the buzzer and Janice will let you in. Thank you to our wonderful church family for all they have done to help!

I also would like to mention that my friend/neighbor Gaylene took this toy drive to her church, St. Nicholas Orthodox Church. They have collected boxes of toys and Father Robert has been beyond helpful. Thank you to all of the people at St. Nicholas who were so willing to help us.

Thank you, thank you, thank you to the amazing team of women who have volunteered to run this organization with me. Jodi, Gaylene, Anne, Tracy, Laura, and Joanne - we will do great things for great people, with the help of a great God.

Thank you to my mom. She is always there for us, unconditionally, without fail.

Thank you to the most wonderful group of friends that any woman could ever be blessed with. You are a part of my heart forever and I love you all so much.

Thank you to everyone of you has encouraged us, loved us, watched our kids, made it a point to seek us out and hug us, made a meal, sent a card or prayed for us. You are all a part of this and we are forever thankful. I suppose I am just a little more sentimental this Christmas season. I suppose I am just so thankful that my children are home and well - that they are all here with us and we get to love and hug them every day. I am so thankful that God allows me that privilege. A woman I came to know through the hospital isn't so fortunate this year, and I think of her every day. Her holiday won't be like mine ever again and she needs our prayers. Her name is Meg.

Please don't feel sad for us this Christmas - we are not sad. We are well and filled with love. Genre is happy and excited for Santa to come! He is busy teaching Gionna about baby Jesus every day. I hope that your holiday season is filled with love and blessings just as ours has been. My wish for you is that you enjoy each minute with your children, the way we intend to. Play with them and make little memories that will last your lifetime. Time goes by

so quickly, doesn't it?! If I don't get to update the care page before Christmas, Merry Christmas to each of you and a blessed New Year as well.

## Christmas Eve 09

Posted Dec 24, 2009 2:23pm

Merry Christmas from Genre and our whole family! Genre is feeling well and enjoying his time off from chemo. He's been playing with friends, visiting, and eating a lot. He's happy to be able to go to church tonight without a mask and he's very excited for his shrimp and scallops! He has a big week planned - something scheduled for every day now through his treatment on the 30th. Thank you for all the Christmas wishes and love. Merry, Merry Christmas!!

## January 2, 2010

Posted Jan 2, 2010 6:34pm

Happy New Year! Hope you all enjoyed a healthy and happy New Year celebration. We did. Even though Genre has been accessed and receiving chemo treatments since December 30th, our New Year was wonderful. Looking back on 2009 is truly a bittersweet experience for us. Even though we all lived through great sadness in that year, the blessings, joy and love that will always be the landmark of our 2009 clearly outshine any of the bad times. 2009 will always be the year that our entire family grew more than at any other time throughout our lives. We were able to draw closer to each other; closer to the people who truly love us; and, most importantly, closer to Christ. My mother almost died in December 08/January 09. She suffered and was so sick through April of 2009. But, during all those bad moments, God was at work and my mom, Kaitlynn and James were all baptized into the family of believers in Christ. One month later, Genre was diagnosed with leukemia and none of us knew how we would live through it. The diagnosis reached far beyond this house. I realize now that people everywhere were terrified and saddened from the news. It affected so many people in so many ways. The people who are most dear to us now had to explain cancer to their innocent, small children who loved Genre so much. How hard that must have been for all of them... Even the people who we don't know that well were terribly affected. Along with feeling sadness for Genre, they realized that, on any day, it could be them. Again, God was at work. This illness has drawn our family closer. It has made our friends family, and it has made our acquaintances friends. So many strangers have come into our lives and we now care about each one of them very much. Every step of our seven month journey has been blessed by Him and made possible only through Him. More than anything, as we move into 2010, we are thankful.

Genre has already begun the last four weeks of his Delayed Intensification phase. If you remember, it is the last phase before he moves into Maintenance, which should be a little easier on him. Last Wednesday he was accessed at the clinic and he was infused with Cytoxan and Ara-C. Those are two of the most powerful chemos he takes. They are the drugs that have made him the sickest. He has remained accessed (with a needle in his port) since Wednesday and he has been infused with chemo each day at home. The nurse will come again today to give him his last infusion for this week and she will deaccess him. He goes to the clinic on Wednesday for three more weeks. Next week is the same treatment plan. He will get chemo four days in a row. This phase is difficult because he is also taking chemo in the pill form every day. Between December 30th and January 20th, Genre will have 29 chemo treatments! This is a hard phase for sure, but soon it will just be a memory.

Genre really didn't want to start back to the clinic after such a nice vacation from treatment. As hard as it was for him (and me), he said he'd come this far and he could get through this four week period. He said that he wished Dr. Shaw would just give him everything at once and get it over with. He said the sooner we start, the sooner it is over, and he is right about that! He told me that he knows he will be able to do anything for the rest of his life after living through this. He said that he has learned that God doesn't make it easy, but He does help you through hard times. I cried. But then, I cry a lot now.

Things change so much when you are living through pediatric cancer. Genre's friend Jaden was with us the other day and we went to Red Robin for dinner. Genre had a bump on his head. It was obviously a bug bite. (Even though it wasn't, it looked like a mosquito bite that was swollen a little.) The kids were joking and having a good time, except Genre. He wasn't joining in the fun and he looked like something was on his mind. I asked him what was wrong and he acted like he didn't want to tell me at first. I pressed him a little for an answer. He looked at me very seriously and he said, "Momma, do you think that the bump on my head is like the bump they found on Selena?" Selena is A friend from the hospital and she found her type of cancer with a lump on her chest. Fighting back the flood of tears raging behind my eyeballs, I assured him that the bump on his head was not a tumor. I promised him that it was a bug bite. He looked at me and smiled with so much relief in his eyes. THOSE are some of the hardest moments. Realizing how much of Genre's childhood has changed is the really hard part. Knowing that, instead of my son being irritated because his bug bite itches, he is worried that it is a tumor, weighs so heavy on my heart. When Genre says the dinner prayer on Christmas day and he thanks God for being well enough to go downstairs to open his presents just takes your breath away, but at the same time...it makes me so thankful for what we have. Our son was well enough to walk down the steps and open his gifts. Thank God. Our son wasn't in the hospital. Thank God. We have our son. Thank God. Those are the things I want to remember and hold true in 2010. Those are the most important things we have and I pray that I always remember this... even after Genre's cancer is long gone.

Happy New Year!

**January 7, 2010**

Posted Jan 7, 2010 8:24pm

Genre had his clinic appointment yesterday. Dr. Sidonio did the spinal tap and said that the fluid was clear - which is what we want. Actually, he said the words 'perfectly normal.' He had chemo injected into his spine and into his port. His red blood count was low so he was given one unit of blood. By the time they get the blood and actually put it into Genre, it can be four or five hours! Kristen does her best to move things along as quickly as she can. Needless to say, it was a very long day at the hospital...especially for Genre.

After Genre's spinal tap, he was a little loopy from the sedation. Kristen was ordering his blood and she told him that she is also A+. She told Genre that she would give him her blood, if she wasn't pregnant. Genre said, "Why? If you gave me your blood would I be pregnant?" I really thought Kristen was going to fall onto the bed laughing. She looked at me and gave me the thumbs up as she mouthed 'Way to keep him innocent!' Okay...my son DOES know that boys don't have babies!! In defense of Genre, a little girl we are praying for recently went through a bone marrow transplant. Her little brother was the donor match. Once the whole transplant is through, she will have her little brother's peanut allergy. I'm SURE that's what he was thinking about. Maybe an anatomy lesson wouldn't hurt? :)

The nurse was here today to give Genre his chemo treatment. She comes again tomorrow and Saturday. After Saturday, God willing, Genre will NEVER have Ara-C, Cytosin, Daunomycin or Daunorubicin injected into him EVER AGAIN!!!! He will be totally done with those awful (but, I understand, necessary) drugs!!! We go to clinic this coming Wednesday and next Wednesday. Again, God willing, Genre will never have to go to the clinic every week EVER AGAIN! He will be on a once per month maintenance schedule until September 30, 2012!!!

He has been feeling well with NO nausea or vomiting this time!!! Thank God. This cycle was hard on him back in August. He felt sick frequently and then wound up in the hospital for almost three weeks. The drugs take about a week to ten days to reach the peak of their strength. I wouldn't dare assume that he will breeze through the next few days or weeks, but he's been well so far and we are just so happy about that.

I will update again this weekend when the treatment is over. Thank you for keeping Genre, and our whole family, in your prayers.

**January 9, 2010**

Posted Jan 9, 2010 10:52pm

Genre finished his last Ara-C treatment today!! It was quite an amazing feeling to know that this difficult drug is BEHIND him now. Even with the next seven to ten days facing him...he is DONE with that drug! What a happy day!

The medicine is meant to drop his counts, and it is. Dr. Sidonio called tonight to say that Genre's platelets are low and that he needs to come in tomorrow for a transfusion. Genre said, "I'll be there after Sunday school!" So, it looks like we will be goin' to the hospital AFTER church, again.

I asked the nurse to leave him 'accessed' today since there was a very strong possibility that he'd be needing blood/platelets in the next day or so. There was no sense in needlessly sticking him. Every time you access the port you risk an infection, so one less puncture is a good thing. He just wants that needle out so that he can go out and play in the snow!

Genre is feeling strong and eating well. He is now on a Taco Bell kick. He NEEDS a chicken quesadilla with mild sauce all the time.

Please keep Genre in your prayers over the next week to ten days while his counts bottom out. We ask for prayers that his body will stay free from infection and that his bone marrow will start to rebuild healthy cells quickly. Thank you so much...

**1/10/10**

Posted Jan 10, 2010 4:28pm

We came in around 10:30 am for a platelet transfusion. After a CBC they determined that Genre needed red blood also. That was no big deal - once he's done with the transfusion we go home. But...as we have been sitting here, Genre's temperature has been creeping up. His ANC is down to 400. With a fever, that's an overnigher. Doctor Randy said he'll decide whether we stay or go home after the next temp reading. I'll let you know...

1/10

Posted Jan 10, 2010 6:49pm

We're staying...

Not sure if the fever is from the transfusion, the Ara-C or an infection...doesn't really matter - it's a sleepover when your ANC is only 400.

He feels just fine. After they do his cultures and hook up his IV antibiotics it looks like we're snuggling in to watch a movie. I will let you all know how he is in the morning.

1/11/10

Posted Jan 11, 2010 10:00am

Genre had a fever through the night, but it seems to be gone for now. He's eating/drinking well and he feels fine. No doctor has been in yet, so we are not sure what the game plan might be.

I will update as soon as we know something more. Thank you for your prayers.

PS...Mrs. Murray, this is Genre. I think that you should name your new baby Genre Anakin Murray. I think that one of my bffs should name their baby after me. Even though I might have Mr. Murray's platelets in me, I can still woop him on mariokart.

1/11/10 late morning

Posted Jan 11, 2010 11:31am

The doctors were just in and said that Genre will definitely be staying here again tonight. With no more fevers he will most likely be able to go home sometime tomorrow.

He needs more platelets today. Hopefully the transfusion won't give him a temperature...that might mean another forty eight hours. Even if we do have to stay - it will be fine. As long as Genre is feeling well, we can hang out here for a few days:) It's really the best place for him to be if there is any possibility of infection. I know that.

Kristen was in to visit and so was another nurse who Genre just loves. His name is Andy. They are all such special people and we are so blessed that they are here to care for Genre.

Genre has been having headaches off and on since Thursday. They happen mostly when he stands up. They are better when he lays down. Since he had a spinal tap this past Wednesday, the docs feel that the headaches are most likely related to the tap. His spinal fluid biopsy was perfect so there is no worry about that! The answer to spinal headaches is frequently caffeine. Genre doesn't like soda and won't cooperate to drink it. We offered him coffee too - he told me that 'coffee isn't good for a kid.' They are going to try some iv caffeine to see if that helps.

I'll let you know...

1/11/2010

Posted Jan 12, 2010 12:10am

Oh...it was a rough day! After Genre had iv caffeine, they gave him his antibiotic. After that he was pretreated with Benadryl for his platelet transfusion. They always do this so that he doesn't have any allergic reaction to the transfusion.

They still aren't sure what happened - around 3:00 Genre couldn't get up. He couldn't walk. He had a hard time speaking. When I helped him to the bathroom, his legs just wouldn't work. He tried to turn the light on and his hand couldn't hit the light. He couldn't turn it on. He couldn't touch his nose, or the dr's finger tip. His eyes were normal, but he said his vision was blurry. He had numbness in his arms and legs. He threw up and he couldn't remember his phone number or answer questions. He was really scared.

The docs were leaning toward some type of drug reaction with the caffeine and the Benadryl. They wanted to wait for one hour to see if these problems started to disappear. They didn't feel that an emergency scan was necessary because his pupils were working and he had the same amount of strength in each hand/foot. They do several neurological screening tests to determine if any damage has been done. After 1.5 hours, Genre was able to speak a little better and he was able to stand better on his own.

Each hour something seemed a little better, so the doctors didn't want to rush into a CT scan. Genre still had a headache. He said it was a 9. With Tylenol he said it went down to a 3. The doctor assured me that any pain associated with a bleed (or something like that) would not go away with tylenol. All the docs feel that it would be best to let him get some sleep and move forward with the headache issue in the morning. Right now he is feeling well and he is going to bed. Tonight, he and I are praying that these headaches go away!

11/12/10

Posted Jan 12, 2010 9:14am

This morning Genre is saying that his head doesn't hurt at all. He has not been vertical yet, but it hurt constantly yesterday. He is smiling and teasing with the nurse, which he didn't do at all yesterday. He has no appetite and he's not drinking so they hooked him up to the iv fluids again. Even though he is a smart child, he just doesn't put it together...no drinking/eating = more days here! Honestly, after what I saw his body go through yesterday, I completely understand that he doesn't feel like doing anything but laying on Lammy. But, he has to drink. ( By the way, Lammy is the stuffed lamb that Genre has been hugging since he was born. He was white and chubby at one time. Now, not so much. He's a mix of gray and brown with little to no stuffing. I explain to each new doc that Lammy is clean, he just doesn't look like it anymore. I gently dip him up and down in Oxyclean, rinse him, put him in a pillow case and spin him in the washer. Then, he lays in front of the dehumidifier until he is dry. Sometimes, if we really need him clean quickly, I will put him on air dry in the dryer. The dryer scares me when it comes to Lammy!)

His platelets are only 55,000. He is scheduled for PEG shots (asparaginase in his thighs) at the clinic tomorrow. It's the next to last treatment in this cycle. To do those shots his platelets need to be 75,000. I'm assuming they will transfuse him with platelets again today. That will mean more Benadryl.

The docs will be rounding soon so I will have the game plan after I speak with them. I'll update after that.

1/13/10

Posted Jan 13, 2010 9:56am

The same type of large motor skill problem happened last night. One minute Genre was fine, and the next he couldn't walk and couldn't use his right arm well. His speech was not affected but this time he couldn't keep his body upright when we sat him up??? The docs had no choice but to do a CT scan. :( They all agreed that it would 'probably' show nothing, but they were obligated to look for bleeding in his brain. His platelets have been so low and he does have Von Willebrands, so bleeding would be a possibility. He's already had one CT scan of his abdomen during the fight with typhlitis. There is so much more radiation in the CT.....

Anyway, they did it and the preliminary report showed no bleeding. Thank God. I am just holding on to the fact that God is GOD. If He decides that the CT scans won't affect Genre in any negative way, they won't. I believe the miracles that I read about in the Bible, and I believe that God can protect my son.

The symptoms appeared around 5:30 and lasted until about 10:00 pm. He didn't eat or drink for several hours before they appeared. Then, once they were gone, he devoured a bag of popcorn, a bag of chips and he drank two bottles of water. Weird! I know, not very nutritional. It's all we had at 10 pm!!!! This morning he is behaving perfectly normally.

The docs have not rounded yet so I don't have information as to what they are planning. Genre's ANC is only 60 now, so I don't expect them to be letting us go home any time soon. I'm okay with that. He needs to be here right now. Last night the docs discussed an accumulation of ARA-C in his cerebellum. That doesn't make a whole lot of sense because they said that they would expect ALL of his motor skills to be affected. He still was able to use his fingers normally. He was able to keep playing the wii. I questioned them about his spinal tap and about any type of reaction to the antibiotic he is getting. It's called Cefepine. They are looking into everything because they just don't know what this is!!

Genre has two new vocabulary words to learn today: enigma and anomaly. Those words were used frequently throughout the night. Seems like Genre is going to hear those words a lot throughout his life. He should probably know what they mean.

I will post again after rounds.

1/16/10 Saturday night

Posted Jan 17, 2010 12:21am

Genre is home from the hospital. He was discharged yesterday. I have not been able to update because Genre's 'paralysis' continued through Thursday and, at some points, he was unable to move from his neck down. After I updated on Wednesday morning, Genre's condition worsened quickly. He lost control of his legs first and then his arms. His back was so weak that he couldn't sit up or roll over by himself. He was no longer able to squeeze my finger or push with his feet. As he got worse, he developed severe panic attacks which came frequently throughout the days and nights. He was so scared and he said he couldn't breathe. He felt like he couldn't swallow or get any air, and his heart rate would race to 165 and beyond. It was terrifying for him. The CT scan showed no bleeding. Thank God. The MRI showed no signs of Methotrexate toxicity ( a build up of chemo on the brain) and the EEG

showed no seizures. By Thursday morning, Dr. Shaw suggested that Behavioral Health come in. Behavioral Health is just a new name for the team of psychiatrists and psychologists that help the kids at the hospital.

Dr. Newman was the Doc who visited with Genre. After the doc spent some time with him, he assured me that Genre would be able to walk again. He assured me that they frequently see these types of issues with children who deal with such traumatic illnesses. He said that, most often, they see this 'syndrome' in bright kids who really understand their diagnosis and the consequence of the disease. He said this shows up in the kids who fully understand their treatment and what is being done to their bodies. Intellectually, the child understands more than he is able to deal with emotionally. Genre's emotional capabilities haven't caught up to his intellectual abilities when it comes to cancer. The two clash and the child crashes. He said that they also see this in kids who deal well with their illness. The children who just accept what is being done to them; who never complain about the changes that have been made in their lives; who never get mad; who never get scared; who never complain...those are the kids who sometimes just crash. He said it's similar to post traumatic stress syndrome. Genre has dealt with so much for the past seven months. He's just a baby and it's all caught up with him at one time.

They are thinking that the first episode with 'paralysis' actually did result from the combination of caffeine and Benadryl. His legs and arms didn't work and it scared him so much that his brain somehow continued to make him believe that his body wasn't working...add that to the post traumatic stress syndrome and you have a child paralyzed for a week.

The panic attacks and partial paralysis continued through yesterday. They sent him home hoping that normalcy and routine would help him, but it didn't. His first night home was absolute torture for him. It was the first time John and my mother (not to mention James and Gionna) were able to see Genre in such a bad way. John had a cold all week long and wasn't able to be with his son at all. It just broke his heart, but Genre's ANC is only 60ish. James developed a cold next and my mother needed to stay away since she was the one taking care of James.

Jason came to pray with Genre late in the night when he just couldn't settle down. In the middle of a panic attack that lasted what seemed like hours, Genre said that he would try to tell Jason what was scaring him. The panic was just too severe and he couldn't talk any more. I am hoping that as he feels better he will open up to Jason and let go of whatever is eating at his insides. I worry about Genre's ability to share certain things with me. He tries to take care of me when we are in the hospital together. He was worried about me the first night he was diagnosed, not himself. He wouldn't touch me until he knew that I couldn't catch his cancer. Again, as we laid in the bed together this past week, he thanked me for staying with him every night. He said that he knew I wanted to be home with James and Gionna and he knew that I missed them. I worry that he won't want to upset John or me with what is bothering him. If he is afraid of dying (let's just be honest - that might be what this is about), I don't know if he will share that with me for fear that it would make me too sad. Maybe he will share that with one of his grown up best friends.

I am happy to say that Genre did much better today. Jaden came over for the afternoon and they played DS and Wii together. They watched a movie and then, later, I heard them chit chatting about Genre's cancer and how it feels when he can't use his legs. He was explaining maintenance to Jaden and I heard him say that he only had one more clinic visit until that point. Yes...I was eavesdropping...After Jaden left, we kept Genre busy playing board games and having snacks. He never had time to stop and think all day long. He is in bed with me now, sound asleep and able to use both arms and both legs. I am not saying that his problems are gone, just that today was a better day for him. As difficult as this past week was, we got through it. We may not have liked what we were doing and we may not have wanted to be doing what was laid before us, but God got us through it. Genre

obviously needed some help, mentally, and now he will get as much help as he needs. Dr. Newman even offered to meet with James and Gionna as much as we'd like.

As for me, I think this past week was a blessing in disguise. I now know that my son's MRI shows no signs of chemotherapy build up. The neurologist said if you put Genre's MRI next to one hundred other MRI's, his would never be picked out as the child undergoing chemotherapy treatment. For me that is the most remarkable blessing of all. Every time Genre puts a chemo pill in his mouth I pray, "Father God please wrap yourself around this pill and take it only where it's meant to go. Please don't let it hurt Genre's brain." Every time they put chemotherapy into Genre's port I pray, "Dear God, please line Genre's veins with your spirit and take the medicine only where it's meant to go. Please don't let it hurt our baby's brain." He didn't. And he let me know it. Had this not happened, I would have spent the next two years, eight months, two weeks and one day worrying about Genre's brain and any damage that may have been done by the first seven months of intense chemotherapy. Thank you... And thank you for the strength, focus, and courage He provided me while my son couldn't move and was being tested for bleeding in his brain. I was totally alone and totally calm. That is not my nature; it is only Him.

And thank you again to so many of you for the love and support shown to us through this difficult time. I don't know how we would manage without you.

PS I would ask that you keep a friend of mine in prayer. She is someone I know from church and she has been so kind to Genre through his leukemia journey. Her twenty one year old daughter was diagnosed with lymphoma this week. Her name is Shirley and she needs strength, wisdom, and peace.

1/22/10

Posted Jan 22, 2010 1:58pm

Genre saw the docs on Wednesday for his last appointment and treatment of Delayed Intensification. That means, simply, that all the really hard chemo treatments are now behind him! It's funny that I could ever think that any chemotherapy would be good...but the drugs he will be taking in Maintenance are approximately 1/20 of the amounts he has taken for the last eight months. His brain is healthy and well after eight months of intense treatment! Dr. Sidonio said that they would not expect build up/damage during this part of the treatment. I can so live with that! :)

I have to admit - going to the clinic only once each month is making me a little queasy...While I am so happy for Genre to get back to a more normal routine, once a month seems like a long time between appointments. Somehow, I have developed a comfort in hearing the doctor tell me that Genre's blood looks great each week. Every week, I hear that there are no leukemia cells in Genre's blood or spine. Even though I already feel that truth in my heart, it is comforting to hear the words spoken. Don't get me wrong, I'm going to lay all this fear and worry at God's feet and walk down the path...I'm still a little unsteady about it though. Selfishly.

Genre's ANC is only 100 right now and his platelets are way below where they need to be. He has been having platelet transfusions regularly. His nurse, Connie, was here today to check his platelets. We will know later today if he needs transfused tomorrow. Thank you to all of the people who have so selflessly donated blood and platelets so that Genre can feel well. Prayerfully, Genre will not be needing transfusions at all in a few weeks. He may never need one again!!! Once his ANC reaches 750 and his platelets are high enough, he will start Maintenance. Maintenance is a three month cycle and we go once each month. He has a spinal tap the first two months and 'just' a chemo injection the third month. He will take most of his chemo at home in pill form.

I am going to take this minute to get up on my soap box...Genre has never had to wait for platelets at the clinic because so many of you love him and have donated whole blood or apheresed platelets for him. As a matter of fact the people at the blood bank are just overwhelmed by the outpour of love and help that you have all shown to Genre. However, there are so many children who can not get platelets when they need them. There is always a shortage of platelets. Platelets only have a five day shelf life and they are used to clot your blood. They are the first blood product to die once a donation has been made. Red blood lasts 42 days. There have been times when Genre would not have received a platelet transfusion if we didn't have directed donations. Genre would have come home and waited for a call to say there were platelets available for him. We would have been sitting here praying that he didn't bleed while he was waiting...

So many of you ask all the time, "What can we do to help?" We have been so blessed and we have not needed any more than we have been given through this. But, I am asking each one of you to consider becoming a regular donor for whole blood or apheresed platelets. It is so important to these pediatric cancer patients (and adults as well). Please consider donating on a regular basis- it really is a matter of life and death. The website is [www.centralbloodbank.org](http://www.centralbloodbank.org) To find a donor center near you, go to 'donate blood' and then 'donor center'. Thank you from every mom of every kid with cancer.

Have a wonderfully blessed day!!!!

**1/22/10**

Posted Jan 23, 2010 12:11am

Genre developed a temp of 101.2 after dinner. With an ANC of 10 - that's an automatic admission. We are in the ER at Children's and on our way up to 9B for a while. He seems to be handling this pretty well. He's not upset at all. I will post to let you know how he is doing and when we expect to go home.

**1/24/10 Sunday morning**

Posted Jan 24, 2010 9:53am

Genre almost made it through the whole day yesterday without a temperature. We were hoping to go home today or tomorrow. Not so. He developed a temperature last night of 101.3. That means they needed to draw cultures from his port again and we wait for 48 more hours to see if anything grows. The significance of the temperature stems from his port. The worry is always infection of the implanted device. If not for the port, they would treat his fevers just like any other child's temperature (unless they lasted three weeks like last time, of course).

The PCT was just in to check his vitals. Everything is 'normal' this morning. Genre has been tired and a little crabby. Mr. Murray came to visit yesterday and Genre wasn't the best play mate. As a matter of fact, he was a little irritable and a bit rude. That's not normal behavior for Genre, especially when one of his two grown up bff's are here. It leads me to believe that there might be something more going on here. This is the best place for him to be until they determine exactly from where the fevers are coming. If they are 'just' neutropenic fevers, that's fine. They'll go away. But, if he's got something else going on inside that body that he can't fight, he needs to be here, not home. His body was designed to warn us when something isn't right, and I've learned, the hard way, to pay attention to it.

By the way, how about this "coincidence"? The Dr. who is on service this weekend is Dr. Jakacki. There are almost twenty oncologists here (including Fellows). Dr. Jakacki just happens to be the neuro-oncologist who studied Genre's MRI last week. I never had a chance to speak with her directly about his scan. I had the chance yesterday! She told me that Genre's brain could not look more normal. She said that it's probably the most normal looking brain of an ALL patient that she's ever seen. She said all vessels are a normal size. She said that there is a normal amount of space between his brain and his skull and that the white matter of his brain looks perfectly normal! Yes! She said to Genre, "It's working just fine...study." I like Dr. Jakacki.

No counts and no docs yet today. When I know something more, I will update. Have a good day!

**1/25/10**

Posted Jan 25, 2010 2:03pm

No fevers, but Genre's counts have all dropped. They won't break him out of here until the docs see some amount of count recovery. His bone marrow needs to start producing new cells on its own. Dr. Shaw was just here for a visit and said he is expecting Genre's ANC to increase, it's just a matter of when. In other words, we will get to go home when Genre's bone marrow says so...

Mike had Genre in the lounge playing with the Wii Fit today. They raced, did some yoga, and walked on the tight rope. He had a lot of fun. (Remind me about all that exercise when Genre says his legs are sore later in the week!)

He's eating and drinking a lot better today and he isn't crabby at all! :)

We had a nice visit with James and Gionna yesterday. They didn't get to see Genre at all during the last stay because John and James both had colds. Gionna stayed here all afternoon while James went to his basketball games. She didn't go home until bed time. We made up for all of our missed snuggle time. It was comforting to hear her and Genre complaining to each other about who did what wrong on the Wii Star Wars game!

Genre and I will be hanging out in 930 until further notice. No one will make any changes or decisions until they see his count report tomorrow morning. I will let you know how he is. Thanks for keeping Genre and his recovering bone marrow in your prayers.

**1/26/10**

Posted Jan 26, 2010 10:38pm

Genre's been doing great - but then he spiked a 101.6 fever at 4 am. That's at least another 48 hours of hangin' out at CHP. No other fevers all day long. He still has no ANC and his platelets are in the tank. He'll be getting a platelet transfusion later today. He got a giant bump from the platelets on Wednesday last week. He went from 19,000 up to 128,000 after his transfusion! As those platelets die off his platelet number drops, unless his marrow starts to kick in and make his own.

When Genre was here for 19 days back in September, I met a woman who has a baby boy and he was newly diagnosed with an extremely rare cancer. He was, at that time, the only baby in the world to have it. If you remember, I was busy feeling sorry for Genre and his fever, and then I met her... Her baby's tumor had invaded his hip socket and strangled all important vessels in his leg/hip. There was no chance of shrinking the tumor - no time to do that. They needed to remove his leg. He is here with us now, minus his little leg. He is absolutely

adorable and he is learning to walk with a tiny little walker. He is 26 months old now and he has mesenchymal chondro sarcoma. His name is Kristofer.

When I saw his mom last night, we began to talk about his treatment and what his 'plan' is. She's a young mom and she said these words to me: "His cancer will keep coming back. It always does. There hasn't been anyone with this cancer since 1959 who went into remission. There is no remission with this cancer." She wasn't crying nor was she bitter at all. She just gave me the facts. I know one thing FOR SURE from living through pediatric cancer...the doctors don't know all the answers and they can't account for God. The medicine and the doctors are so very important, I get that. There is so much more to this disease than just medicine and doctors though. I just couldn't accept listening to this young mom relay that prognosis and feel like there is no hope for her beautiful baby. . . No one can know that for sure! I asked her if she believed in Jesus. She said yes. I asked her if she really believed that he healed a blind man and if she believed that he rased a man from the dead. She said yes each time and I felt like she was listening for more. We talked for a long while and I got the chance to explain to her that I believe those stories too. For me, I felt like I needed to make the biggest decision of my life when Genre was diagnosed with cancer. I either TRULY believed what I always said I believed, or I did not. It couldn't be both and it was time to stand firm in my decision - whatever it was. I decided that I needed to give my son to God and let him lead me in all things from that point forward. For me, everything fell into place that day. My son is still fighting leukemia. He still gets sick and we still spend long weeks in the hospital. But, we get through it and we get through it with peace and a comfort that only Jesus could provide. My new friend will need to make a decision for herself. If she really believes that Jesus performed all those miracles then she'd have to believe that He can heal her son - if it is part of the plan God has for her child's life. Even if the path isn't smooth and even if the end of the story isn't what we want it to be, there is a point where you just know that you can handle anything as long as you have Jesus with you. At some point you look around and you realize that you've already handled all these things that have been thrown at you. There is only one answer because you didn't do it on your own! Suddenly, what you thought would be your worst nightmare wasn't. You look back and you realize that it was only your worst nightmare because God wasn't in your dream. You were alone through it. I am not alone. As the young mom wiped her tears, she shook her head "yes". I don't know that she will fully trust in Jesus just because we talked for a while, but she might think about it.

None of that really hit me last night because I didn't have much time to think about our conversation. Genre wanted popcorn and he wanted to watch a movie together. This morning, after a lot of thought, I realized just how blessed I was to experience that woman. For her to share her son's story with me touches my heart in a way I can not describe. Instead of feeling sorrow for her and Kristofer, God has allowed me to look at him and see an amazing little boy with such a story to share. He has the strength to learn to walk without a leg at two years old! Imagine what God could have in store for him throughout his life! I was truly blessed to have met the both of them.

I hope I allowed the words that God wanted to come out of my mouth to fall on this mom's ears. Although I want to shout from the roof tops about what God has done for us, I never feel like I should be the one telling the story. Me? How can that be? I just continually pray that I don't say something or type something that doesn't fall in line with what He wants me to be thinking or saying. I worry about disappointing Him. He does so much for my family and for me personally. Every day. We owe Him everything and I want to do my best to handle this disease with courage and grace. I want to let others know that they can get through this with Him, but I want to make sure that all the honor and all the glory goes to Him.

Thank you for keeping Genre in prayer. He is feeling well while he waits for his bone marrow to recover.

1/28/10

Posted Jan 28, 2010 10:31am

The doctors were just in and they are so pleased with the way Genre is looking/feeling/eating/drinking, etc...

Thankfully, he has not had a fever in over 48 hours. He still has no ANC but his blood report showed 12% monocytes today!!! That's indicative of an increased ANC SOON!!! With no fever and an ANC on the way up, Genre will be out of here by Saturday afternoon at the latest!!

Thank you for your prayers...please keep praying for a bone marrow that's healing!!! Please lift up all these 9B cancer kids and their families in your prayers. I will post tomorrow morning to let you know what his labs say. Have a wonderful day!! :)

1/29/10

Posted Jan 29, 2010 12:51pm

Genre is coming home this afternoon! His ANC is 60 and Dr. T feels like he is well on his way to bone marrow recovery. Thank God.

We will miss the nurses here very much, but not enough to stay. :) As I have said many times before, they truly are God's hands and feet here on the 9th floor. I have no words to explain the love and compassion they show these children. It is just something that you have to experience to understand, and I wish that experience on none of you. Thank you so much to all of the nurses who read this. Please relay our love and respect to our mutual friends, if you would.

No clinic this coming week. He returns two weeks from now. Maintenance treatment starts when his ANC is 750 and platelets are 75,000 without transfusion.

Thank you for keeping Genre in prayer. I would ask that you continue to pray for his well being through the rest of cold/flu season, and also for a healthy bone marrow recovery. We met a new friend last night who was just diagnosed with leukemia. Nick is 15 and scared, as are his mom and dad. They are faithful yet terrified, and they need our prayers.

Another happy note - Genre's Kids with Cancer Fund golf outing will be held on June 14th at Edgewood Country Club! We've already met lots of kids who could use our help and we've had so many people join in our cause. We have been blessed to have people volunteer to help both financially and through their service. We are looking for more photographers, golf facilities/pros for lessons, donations for a silent auction, printers, and donations for chinese raffle baskets. If you are interested in volunteering or donating in any way, please get in touch on our contact form at [www.genreskidswithcancerfund.com](http://www.genreskidswithcancerfund.com) or email Laura at [ljshook11@hotmail.com](mailto:ljshook11@hotmail.com). More information to come next month...

Feb. 2nd

Posted Feb 2, 2010 9:51am

I just got a call from Bev at the clinic. Genre's labs came back and his ANC was 280! He's got 24% monocytes, which is a really good thing! Neither his platelets nor his red blood cells have dropped so no transfusion!!! His bone marrow is working and recovering! Thanking God for a beautiful day and great labs!!

2/19/10

Posted Feb 19, 2010 10:44pm

I just wanted to let you all know that Genre began his maintenance therapy phase this past Wednesday (2/17). We were delayed last week because of the snow. It was okay - if you need to delay for any reason, it's best to do it in between phases. It's hard to believe that we have almost nine months behind us. Wow...in some ways it seems like it was just this morning that they told us he had leukemia. On the other hand, it seems like we've been dealing with cancer for so long. It's similar to how you feel as a mom. I can remember the birth of each of our babies as if it just happened. Yet, it seems like all three of the children have been with us always. I'm sure you moms all know what I mean :)

Genre was willing and happy to go to the clinic appointment because he knows that during maintenance he'll only be going to the hospital once each month. Maintenance will last for the next two years, eight months - until September 30, 2012. It is broken into three month cycles. Genre gets a spinal tap the first month and the second month. There is no tap during the third month, 'just' a chemo infusion. Then we start again for another three month cycle. This phase means so much less clinic time, but it is so much more chemo at home. Some days Genre has to take up to sixteen pills throughout the day!! The little guy is so cooperative about it. He even knows what each pill looks like and what he needs to do to prevent the side effects. (ie: drink a lot of water to prevent kidney stones) He has been so great throughout this whole illness. He really has done whatever he could to stay positive, for the most part.

Normally, during a spinal tap I stay in front of Genre and lean over him to whisper prayer in his ear. He is usually very heavily sedated and has a hard time talking. One time, he was able to pull my hands toward him so that I would come closer, and he motioned for me to pray. He always wants me to pray during his procedures. This time was different. This time he pulled my hands down and pulled me closer to him. I bent forward and whispered into his ear, "Are you ready for me to pray?" He shook his head no. He said "Me." Genre wanted to pray. As I listened to my son slowly and quietly pray, "Dear God please let my spinal tap go well and let my spinal fluid be good. Please let Whitney do a good job on my spinal tap and please make me not be afraid...", I was so overwhelmed. My son, during his weakest and most vulnerable moment, knew to go to God. I found myself chuckling ...smiling from ear to ear! This dear little thing is so sure, even when he is the most afraid. He has taught me so much throughout this cancer journey without even knowing it... and I am so thankful .

Thank you for always keeping Genre in your prayers. Will you please continue to pray for him as he moves through maintenance? Prayerfully, there will be only a few bumps in the road. Also, please keep all of the 9B kids at Children's Hospital in your prayers - there are so many of them

## Genre's Kids With Cancer Fund

Posted Feb 19, 2010 10:48pm

I apologize for two updates in one night. This update isn't about Genre's health, it's about Genre's Kids With Cancer Fund. Thanks to some very special people who were willing to step out in faith and make this charity a reality, we delivered our first round of electronics to the oncology floor yesterday!! Thank you to the families who have started this giant wheel in motion. Every day something happens to let us know that we are doing what we are meant to do. Things happen out of the blue, people help without being asked, or things just come together when they shouldn't ...every day. This is good.

We delivered Nintendo DS gaming systems, DS games, Leapster systems, Leapster games, and many different baby electronic games! It was so awesome, and I am so thankful that we could begin this very important outreach to help kids dealing with pediatric cancer. These children spend countless hours in treatments/transfusions and the games help them pass the time. I watch Genre escape reality for just a little while when we are at the hospital for five and six hours each week, not to mention those times when he is admitted for days at a time. The game help so much.

So many other good things have happened. We've been blessed to have several photographers join our team. Each one has volunteered their time to photograph these cancer kids and to assure that their parents have beautiful pictures to look at every day. So many people in the golf industry have stepped up to work with these children also. We have even had several families volunteer to mentor new families walking the cancer path. So many awesome things are happening. Please take a look at our website [www.genreskidswithcancerfund.com](http://www.genreskidswithcancerfund.com) frequently to see what's new. It's almost done and I try to update it as things change.

We can always use more people to help with photography, golf, and mentoring. Some of you have already volunteered to help us in one area or another . We thank you for that. Please don't think I've forgotten you if I haven't been in touch yet. You will be hearing from me soon. Things have just been a little crazy with the holidays and then Genre being in the hospital most of January.

Recently, we were contacted to provide financial assistance for the first time. There is a young family who is struggling and they have a long distance to drive for childcare of a younger sibling. Thank God we had a mutual acquaintance and we were put in contact with each other. That's how this is going to work. I am praying that people will just want to help others, and we will see people coming to us to let us know that someone is in need.

As you may already know, our first scheduled fund raising event is a golf outing at Edgewood Country Club on June 14th. I have received so many emails from people asking how they can help. I am going to try to give you all a few ideas about helping in this update because I don't have any other way to reach you all at one time.

There are several ways you could help us:

1. We need volunteers who are willing to do fundraising for the event. This means actually getting sponsors for the event and/or getting money or merchandise donations. We have lists of places that we'd like to go to ask for donations. We also have letters and everything you would need to do this. It would not be your responsibility to plan or organize. We just need help actually going to the businesses.

2. Maybe you know, or you are, a business owner who would like to sponsor the event, be a tee sponsor, or donate a gift certificate or some merchandise. This would all be very much appreciated! Just get in touch with Laura or me and we will give you all the details!!

3. We will need a lot of soda/water/Gatorade for the event. We will also need individually packaged snacks and/or protein bars. If you are willing to donate any of these items, we would appreciate it very much. Starting March 1st you can drop these items off at Norwin Christian Church if that is convenient for you. You can put them in the foyer under the sign marked Genre's Kids with Cancer Fund. You can also contact me to drop off at my house, if you know where we live and that works better for you. My email is jbaker9501@comcast.net. Laura Shuchert has also volunteered to be a drop off. She lives next to Kerber's on Guffey Road. Her email is ljshook11@hotmail.com.

4. We need to fill up the golf course! Flyers are being printed as I type. If you love to golf and you love a good cause – this is the event for you!! The day will include a continental breakfast, a boxed lunch and a delicious dinner! You will also have the chance to meet many of the amazing kids that this organization is trying to help.

5. We would like one of our larger auction items to be a backyard barbecue party for 20-30. We were hoping to include a grill, propane tank, grill accessories, cover, lawn chairs, backyard games, all the food and drinks to go with this, (like 20 lbs of ribs, 20 lbs of hamburger, etc..) and anything else you can come up with. Patio furniture would be great. How about a pool? Ok - I'm joking, but not really if you want to donate one!! If you, or anyone you know, can help with this, we'd appreciate it!

6. Finally, any other large auction items that you can help us with would be such a giant contribution! We are hoping for things like signed NFL/NHL items and/or tickets to auction off. College tickets and merchandise is always a big hit. Weekend get aways and/or trips would also bring in a lot of donations in an auction. Donated foursomes to various golf courses would be a big attraction. If you know anyone affiliated with the cultural district, that would be a big help too. Tickets to shows could be paired with dinners and/or hotel stays. Hotels, resorts, and restaurants are all such important fund raising items for this type of event.

Whatever you can do to help – we need it and APPRECIATE IT!!!

Thank you for taking the time to read this. We are really are on our way to beginning this mission ~ to assist families living through childhood cancer in any way we can, emotionally, financially and spiritually.

Thank you to all of you for continuing to read Genre's carepage and for caring about this family so much.

Daunette

**Wednesday 2/24/10**

Posted Feb 24, 2010 11:43pm

Today was Wednesday and we didn't have to go to the clinic!? I must say it felt a little strange letting the children sleep in as I sat on the sofa having coffee at 8 am. By 8 am on Wednesday, I'm dropping James and Gionna off to Kristie! Not today...or next week...or the week after that!!! Genre's next clinic visit is March 17th. Wow. That seems like a long time.

Genre is sure that he's 'already feeling better because he's in maintenance.' I know, very funny. He's been to his golf lesson two weeks in a row. He shot hoops with James' basketball team and he kept the scorebook at James' last game! He's been to Jaden's house for a whole afternoon and he went to Eat n Park with Jason. He wasn't 'too tired'

once! Even if this 'new' energy is all in his mind, I'll take it! The kiddo wakes up in the morning and exercises/stretches because he's 'in maintenance and he can.' He says he doesn't want to be 'out of shape for the summer.' I just smile and try not to laugh. It's so cute.

I want to tell you about this God wink...

A person contacted me via the Genre's Kids with Cancer Fund website and said she'd like to volunteer for the golf outing. I was a little surprised. It's not like this charity is well known or well publicized yet. Several people have contacted us on that page, but we've known all of them. I didn't know this girl and neither did any of the women who are helping me. I emailed her back and told her that we were working on organizing our volunteers right now and that I'd get back to her. I asked her if we'd ever met. She emailed me back quickly. She said that we had not met. She wrote that she is an AML patient at Children's Hospital. She has many of the nurses as Facebook friends and they told her to look at the Genre's Kids with Cancer Fund page. She found the website that way.

Next, she told me that she was visiting a boy named Nick who was newly diagnosed with AML. As she was visiting him, Mike, the Child Life Specialist, came into the room and asked Nick if he would like a Nintendo DS system. Mike told Nick that Genre's mom had specifically asked that he give Nick one of the games from Genre's Kids with Cancer Fund. It was our Nick... the Nick that we met before we left the hospital in January! The same Nick that we've all been praying for every day! I was just moved to tears. How humbling to see that God has this all under control. How humbling to know that this is all being orchestrated by Him. How awesome to know that

He cares about all these little details – even Nick getting a new game and his friend, Zoey, coming to our golf outing! I know he cares about Genre's leukemia. He has allowed me to feel the peace that passes understanding, and I am so very thankful for that.

3/23/10

Posted Mar 23, 2010 10:59pm

Hello!

I can't believe that it's been over a month since I have posted about Genre. I'm sorry that I haven't updated. A friend said "I know Genre must be doing well...no carepage update!" You know, that really hit me hard. I got to thinking...I came to all of you in the darkest moments of my life. I have used this carepage as therapy to work through all the new words and procedures I learned about; to rehash the miraculous things that have happened; to think through all the decisions we made; and to pour out my heart when I just couldn't talk anymore. Now, Genre has moved into maintenance therapy and I have been so busy trying to 'get life back to normal' that I forgot to let you all know that Genre is well. I apologize. Thank you for being a support system through the toughest days. Thank you for allowing me to yell, cry or vent when I needed to. I realize that, although this cancer has become second nature to us, it does not feel that way to all of you. Genre is still in treatment for cancer. I realize that you would like to know how he is doing and I will pay more attention to posting on a regular basis.

As you know, Genre began maintenance therapy in February. He started therapy with a spinal tap/chemo infusion. He felt well and did not have a spinal headache after the procedure. They did give him caffeine, but at a much smaller dose and he was fine. The next week he was scheduled to take oral methotrexate. The methotrexate is the drug that Genre was only able to take two of the five treatments. It knocked his counts down too low. The oral methotrexate is at a much lower dose and they say it doesn't affect the kids the way the IV methotrexate does.

Not so with Genre. The oral dose knocked him down way below 500. The docs want his numbers to linger up around 1000. The docs stopped all of Genre's oral medicine until his numbers come back up. He hasn't had any medicine since about March 3rd. We went to the clinic this past Wednesday for his second spinal tap in this series.

His ANC was still only around 500. I'm taking him for a blood draw tomorrow to see where he is one week later. If his numbers are high enough, they'll cut the last dose of methotrexate in half and then test him again in 7-10 days. We will keep doing this until they find a dose that works. It's just a matter of figuring out what works for him.

Beyond all that medicine talk...Genre feels GREAT! He is up to 76 pounds and he grew one inch! His hair almost looks like a crew cut!! He is back on a regular school schedule and he complains when it's hot outside because he doesn't want to be stuck in the house. I'll take that type of complaining! He has been playing outside and taking golf lessons every week with James, Jake and Jordan! He loves it! His coach Kirk is so wonderful with him and he is very understanding of Genre's physical limitations. I have even more good news...Dr. Shaw said Genre can play baseball! Genre almost went through the roof when we told him! Genre's coach from last year (Coach CJ), is going to have Genre on his team again this year. CJ understands Genre's illness and knows that Genre may get tired and have to stop half way through a practice or an inning in a game. He's a wonderful person and so willing to help Genre. He really cares about him. I should also mention that the PAL organization has been beyond helpful in accommodating Genre's first step back from being 'a sick kid'. We are so very thankful for the support. As a matter of fact, the support that we have gotten from the Norwin Basketball Assoc., NCAA Girls Basketball, NCAA, and the Norwin Aqua Club has gone beyond anything a family living in this area could have hoped for. We live in a compassionate and conscientious community. It's not something you truly realize until you are faced with an obstacle such as childhood cancer.

Since I started talking about how thankful we are that we live in such a wonderful community, I have so many more thanks....Thank you to all who have helped Genre...not just in his return to playing sports, but also in Kid's Kingdom at church, in his Sunday school class, or at our homeschool coop. You have all been so careful through the winter, helping us to keep Genre well. Thank you for the emails and phone calls telling me that your kids were sneezing and I should keep Genre away. Thank you for teaching your kids to sneeze into their sleeves, and for all the giant bottles of hand sanitizer everywhere we go. Thank you so much to all the people who walk in our house and immediately take off their shoes and go to the sink to wash their hands....all of this has gotten us through the winter safely. I also need to say thank you to my mom and all my girls. You know who you are and you know that we couldn't have made it through the last ten months without you. Kristie and Gaylene, what would James and Gionna have done without you? There are so many more people to thank...especially those who have rolled up their sleeves and given a part of themselves to make Genre well. Thank you to all of Genre's special friends. Thank you for your prayers, and your well wishes. Cards continue to come for Genre regularly. People continue to write on the carepages and sometimes a package even shows up for Genre to open. Thankyou for all of that. You are all so very much appreciated.

Genre goes back to the clinic on April 14th. He'll have a big adjustment at that time because his friend and nurse, Kristen, will be gone on maternity leave. We have grown to love Kristen very much and we wish her and her family the best as they add another little blue bundle of joy to their home. We'll miss you, Kristen!

I promise to keep you updated. Please continue to keep Genre in your prayers, along with all of the other children on 9B who so desperately need our prayers.

September, 2012 doesn't seem that far away anymore...after coming this far, I know we'll get there!

4/21/10

Posted Apr 21, 2010 11:45pm

Hello! Genre went to the oncology clinic last Wednesday for his April visit. No spinal. He hadn't been taking any oral chemo since the end of February. The initial oral dose of methotrexate knocked his ANC down to around 100 – again! Dr. Shaw discontinued all of his chemo throughout March. When we went to the clinic last Wed., his ANC was still only 700 but Dr. Shaw felt he should start back on the oral methotrexate. The docs were a little concerned that it had been around six weeks since Genre had any drugs. They cut the dose of the methotrexate in half. Instead of taking eight pills once a week, he takes four. Today was one week since clinic. I took him for a blood draw. His ANC was up to 2,900. Yes, two thousand nine hundred! That's TOO high! LOL Dr. Shaw would like his number to stay around 1000. I'm sure he'll be adjusting the methotrexate again....

In a little more than one month, it will be one year since Genre was diagnosed with acute lymphoblastic leukemia. A whole year...on one hand the time has just flown by - I can remember Dr. Sidonio telling us about the leukemia like it happened this morning. But on the other hand, it feels like we've been dealing with cancer for so long! Some days are harder than others. When I let my brain AND my heart go back to the night when Dr. Sidonio first said 'leukemia', I can sometimes feel physically ill. Physically ill. Just for a moment, but physically ill. I think it's more the trauma of reliving that moment than it is the actual illness. That one, single, horrifying moment...it was worse than anything. It just seems unreal to me that Genre has been fighting the biggest battle of his life and he hasn't even turned ten.

All of that aside, it's almost one year later and we have come so far. We have moved from confused and terrified, helpless parents to a peaceful and empowered family. We are able to focus all of our energy on all the important things in life. We've been shown so much... By God's grace we have been able to do more than just move down some random pediatric cancer path. He has provided a specific path for us to follow, and He has enabled us to grow and to find ways to make this family work, regardless of what has been thrown at us. For that we are forever grateful.

Genre feels great! He looks great! He IS great! He is up to 78 pounds!!! When he was diagnosed last Memorial day he weighed 70 pounds. In September he was down to only 60 pounds. Now he is almost eighty!! Go Genre! He has also grown a little more than one inch since he was diagnosed! He's a whoppin' four feet, nine and one half inches! Those drugs are no match for Genre!

Genre just started his spring session of golfing lessons (along with James, Gionna, and the Deemer kids). He is back to playing baseball twice a week and he exercises/stretches every day. He is determined to be able to do push ups and sit ups the way he did prior to leukemia. Tonight he did six push ups and fifteen sit ups! He was lifting very light weights with his Dad and stretching with Gionna...I'd say he's off to a great start!

James and Gionna have been very helpful to Genre as he tries to regain his coordination and stamina. Sometimes Genre's ankles just don't want to work for him. He's got significant stiffness in his feet/ankle area. Sometimes he trips. Dr. Shaw feels that will go away when he is done with the Vincristine. James has been catching with him in the back yard and he even has him jogging around the back yard a few times a week. Gionna gets Genre to ride his scooter and his bicycle just about every day. She plays catch with him too. We are just so blessed.

We are thankful for and thrilled with Genre's progress. We are also thankful for all of the people who have cared for Genre since his diagnosis. Kristen is on maternity leave. She now has two boys- Dylan and Noah. She and the new baby are doing just great and we can't wait to see them! I am happy that it is 2010 and not the spring of 2009. This is a happy anniversary we have coming up – Genre is doing so well. I am painstakingly aware that this could have been much different and we would not be celebrating at all. I know too well that other families are not

spending their one year anniversaries celebrating and my heart breaks for them. Each of them is in my prayers every day. So, as happy as we are, I promise that I will never lose sight of what He has provided thus far. I will never forget how we have been guided, lifted up, and loved. For all our days, we will praise Him and be forever thankful.

Thank you for all your support and love. We would appreciate you keeping all the cancer kids in your prayers. We also ask that you keep Genre in your prayers as he continues with his treatments -only two years, five months and nine days to go! Remember when it was three to five years????

## Genre and Genre's Kids with Cancer Fund

Posted May 13, 2010 3:33pm

Hello! Genre had a clinic visit yesterday and I wanted to let you all know that he is doing well. You might remember me telling you that Genre's maintenance therapy is broken into three month cycles. For the first year he has two months of a spinal tap and a chemo infusion, and then one month without a spinal tap. Yesterday, he started his second quarter of treatment for this first year of maintenance. He had a spinal tap and a vincristine infusion. Although it's so much easier to go to the clinic appointments now that I know Genre's brain is 'normal', it is still so hard to watch them inject that huge yellow tube of methotrexate into his spinal column. It still bothers me so much. The docs treat the vincristine like it's not that 'harmful' of a chemo. It isn't, really. It doesn't drop his numbers like the other meds. It doesn't cause the REALLY harmful side effects...but knowing that the Vincristine is what stiffens his ankles and makes it hard for him to run – that makes it difficult to watch. Even though I know this is the 'easiest' part of treatment, it still stinks that he has to go through it!

It stinks...but we are getting through it. Staying focused on telling people how God has helped us along this journey makes a difference for each one of us. Staying focused on what we can do to help others know that they can live through this and not 'just survive' is truly what makes this even more than bearable. It fills this cancer experience with joy instead of sadness. Genre is well and we are so blessed.

I have so much to share with you since the last time I posted. Genre and James are heavy into their baseball season and they are both enjoying it very much. (Now if the weather would cooperate....) Genre is so fortunate to have a coach like CJ. He tries to understand Genre's illness and he is so patient. CJ had Genre's initials put on each boy's sleeve so that Genre would know that the team is playing for him when he doesn't feel well enough to be there. There have been a few times when Genre hasn't been able to go to a game or a practice. He has hurt his ankles several times over the last few months. As I said, Genre's ankles are very stiff from the Vincristine. Sometimes he has pain if he stretches his foot too far or if he turns his ankle the wrong way. The pain passes in a day or two, but nonetheless, he is in pain. I am so thankful that the only pain Genre has is ankle pain. I am mindful that there are so many other children who hurt so much more than our son.... I am just thankful that Genre can play baseball. If he doesn't make it to every game, that's ok.

We have been very busy with Genre's Kids with Cancer Fund...there is so much to tell! A new friend of ours is a blogger in Pittsburgh. She writes [www.thatschurch.com](http://www.thatschurch.com). Her name is Ginny. After hearing Genre's story at church, she decided to use her blog to raise money for gaming at Children's Hospital of Pittsburgh. Since the oncology floor had enough games for each room, she raised over \$14,000 for systems on the transplant floor! Microsoft stepped in and wound up donating all the systems!! The \$14,000 is being used to buy laptops and other electronics for the floor!! You can read about how this all happened on her site [www.thatschurch.com](http://www.thatschurch.com). On her site, you click on the Make Room For Kids tab and she explains why and how she did this (Genre is #3). Once the

Xbox's were ready to be delivered, Ginny invited Genre to deliver them with her! You can read about his day and watch a video of it at <http://thatschurch.com/2010/04/30/a-really-good-day/>. This next link is a picture of Genre from the Mario Lemieux Foundation website. The MLF acted as fiduciary agent for Make Room For Kids. <http://www.mariolemieux.org/headlines/mr4k.html> The whole thing was just amazing and we were honored to be a part of it!!!

Genre's Kids with Cancer Fund is now delivering Nintendo gaming systems to the oncology floor on a regular monthly basis. If a child does not have a system when he or she is diagnosed, we give the child a DS system with a new game. If the child has a system, he or she receives two new games from GKWCF. I need to thank Best Buy in Greensburg for their support. They stepped forward to help, when Nintendo would not. We are very thankful for Best Buy, and all of the managers and employees in the Greensburg store. We also have such wonderful support for GKWCF from the staff at the hospital and especially the 9th floor. The doctors, nurses, and Child Life staff have been overwhelmingly helpful and encouraging. I need to thank Mike Shulock because none of this would be possible without him. He is our hands and feet on the oncology floor. If you'd like to hear a little more about how these games are helping the cancer kids at CHP, please take a look at the video made by the CHP media department yesterday. <http://www.youtube.com/watch?v=eZWAK2mYv1k> This is the blog from the hospital: <http://begladyouhavechildrens.org/>.

I am posting these links for all of you to see not because I am feeling the need to brag about what we are doing, but because we are so honored to be able to help these families. The games truly make a difference for these kids. Our other services such as family photography, golf lessons, and spiritual/emotional support really do matter to people who are suffering. We are working on a way to provide 'to go' bags to each new mom on the oncology floor.

When you are hit with the cancer word, you are unprepared! You can't even think about what you might need someone to bring you from home...it takes every bit of energy and focus you have just to breathe!!!! My friend brought me a bag with everything I needed in it. Another cancer mom was able to tell her what I would need on this long journey. She included a few toothbrushes, pony tail holders, finger nail files, nail clippers, pens, notepad, Tums, Tylenol, tissues, quarters for laundry, and so much more. I have used the bag 47 days over the last year. Every time we had to go to the hospital in the middle of the night, I just grabbed my bag and we left...we are hoping to be able to do this for all new cancer moms.

Just in case any of you are interested in helping us in any way at all, I'd be happy to list some things we need....

The games, the marketing, and the bags do cost money. Sadly, the oncology floor sees 6-8 new cancer diagnoses each month. Some months the number is higher. We raise our money through corporate and private donations.

We would be happy to send our information to any individual or business who you think may be interested. Please let us know if you have anyone in mind. Email us at [genreskidswithcancerfund@comcast.net](mailto:genreskidswithcancerfund@comcast.net) We are now able to accept donations online through active.com. This is a secure site used by the Leukemia and Lymphoma Society and the Race for the Cure. You may have used it before if you have registered your children for sports online. A link to active.com can be found on our website on the donation page.

[www.genreskidswithcancerfund.com](http://www.genreskidswithcancerfund.com)

We still need some golfers for our golf outing on June 14th at Edgewood Country Club. If you would like to golf, please visit our website to register online, or to print a registration form. The registration is \$125 and it includes breakfast, lunch and a steak/salmon dinner. There are skill prizes for men and women, along with a hole in one prize of a new car! We have many auctions including a signed hockey puck, signed Lemieux shirt, Steeler tickets, Steeler autographed balls, Pirate tickets/dinner, dinner/hotel packages, and much more. We would appreciate any

sponsorship level given. We are able to accept cash, checks and credit cards at the event. Thank you to so many of you who have already contributed!!

We appreciate all of the donations of water/soda/Gatorade. If you would like to contribute in this way, please sit your donation in the foyer at NCC under the bulletin board with Genre's pictures on it. If you would rather drop your donation off at our house, please just email me. Thank you for the cases that have been donated already!!

We just started to collect used gaming systems of all types. A friend has offered to collect these systems (whether they work or not) and sell them on ebay to raise money for GKWCF! What a great idea!!! If any of the handheld games seem gently used, we will be cleaning them and delivering them to the oncology floor for the Child Life team to distribute to the siblings of the cancer patients. Siblings spend many hours at the hospital as well, and many families can not afford these games. Please tell your friends/churches/daycares/schools that GKWCF would be happy to take their used electronics!!

Another friend has volunteered to work with our community to organize fundraising. We have had several calls asking how people/businesses can help in ways other than a monetary donation. Organizing a drive to collect the used electronics, Coins for Kids with Cancer, and participating in our 5K/1 mile fun walk are all ways that the community can get involved. If your workplace, preschool or daycare might be interested, please let us know. We would be happy to talk with them about forming a team for the Footsteps in Faith 5K and collecting donations for GKWCF. We would love to share with them how a simple water bottle can raise almost \$100 for kids living through pediatric cancer!! Please get in touch with us for more information!

The golf outing and the Footsteps in Faith 5K information are explained on our website [www.genreskidswithcancerfund.com](http://www.genreskidswithcancerfund.com). They are both found under the Upcoming Events tab. As I am almost out of character space on this post, I'll write more about the Footsteps in Faith race on my next update. There are many areas where we need help regarding that fundraiser as well – volunteers, sponsorships, auctions, food, etc....Please keep this in mind.

As I close this post I just want to mention that Memorial Day is the one year anniversary of Genre's diagnosis. It has been a difficult year filled with much heart ache and much love. It has been a year of personal hardship and spiritual growth. It has been a journey on which I expected to never experience one moment of joy, and I was totally wrong. I enjoy each moment more now than ever before and I thank God for that. I want to say thank you to every one of you for your prayers and love. Thank you to every single one of you who is helping to build Genre's Kids with Cancer Fund. Whether you are directly involved or you make it possible for us to do what God lays before us, you are vitally important! We appreciate you very much! More than anything, "Thank you, God, for all that you do for us each and every day. Please help us stay focused on You. Amen."

## One year ago...

Posted May 25, 2010 9:53pm

On this anniversary of Genre's leukemia diagnosis, I find myself with an overload of mixed emotions. In my heart I am so humbled and so in awe of all the good things that have happened to my son and to my family over the last year – truly I am. I try to pray to say thank you, and I don't know where to begin...do I thank Him first for my son being alive? Do I thank Him first for my son being well? Do I thank Him for the amazing changes this has made in John and me? In what order do I thank Him for my mother and my priceless friends? Where do I thank Him for the doctors and angel nurses who care for Genre and all the other children living through this disease? Where

does Genre's Kids with Cancer Fund and the amazing people who make it happen rank? Before I fell asleep last night, I wanted so badly to thank God...but I didn't know where to begin....there is so much...

I wasn't ready for the flood of emotions that would start to creep into my head and my heart the minute I woke up today. Before I got up off of the bed, I fought off the panic I started to feel racing in my chest. I beat the pounding, racing heart and the fear that started to creep up my neck, but I couldn't get rid of the sick feeling in the pit of my stomach. It was haunting, for lack of a better word. Those first weeks of becoming the mother of a leukemia patient are so far behind me...they are locked away forever! I never expected to relive every moment in my head. I never again expected to hear the words that were spoken that day...but I did...today. I didn't expect to feel the pain again, but I did. So much pain and it's a whole year later... Before I was able to pull myself together, my heart hurt again. I just wasn't as ready for today as I thought. I really thought I had it beat. I didn't. After much thought and much prayer, I pulled myself off of the bed and began my day.

Beginning last night, Genre wanted to relive everything that happened last year. He would say things like "Right now I am at the concert at church and I started to get a fever." He said "Hey Momma, do you think my back hurt yet? What time did that happen?" We did this all night last night. When he woke up this morning, he started again. He reminded me that he was swimming in the morning and that he felt great early in the day. (He also wanted to know why the pool isn't opened yet this year!) By lunch time he moved toward remembering travelling to the hospital and he wanted to know who I called on the way to the hospital and when I told my Mom that he had leukemia. Honestly, I had to ask him to stop. I explained to Genre that we will definitely talk about it again, but that I just couldn't do it today. That may sound selfish – part of me feels like it was. I just KNOW that I can't let my mind and my heart go back to the two hours we waited for the oncologist (Dr. Sidonio) to come and tell us that Genre had leukemia. It is even difficult to type about that time. I just can't relive that moment now – maybe never. What came after that was unthinkable and I won't dwell there. I haven't done that for the last year and I refuse to start now.

I decided that the best thing to do would be to keep busy...keep moving and don't think. The three children and I went to a late breakfast and then we went mini golfing with my mom. My mom and Kaitlynn came with us to dinner to celebrate Genre being well . We went to the Outback because Genre loves to eat ribs there. It was wonderful to be with my family and feel so much happiness together. A few hours of laughing and a lot of love is always good for your heart!

It's almost 10 pm now...I'm glad the day is over, even though I am so thankful that today is May 25th 2010 and not May 25th 2009. I am so aware of all the blessings that we have been given over the last 365 days and we are so thankful for them. We are so grateful that our son is alive and that he is doing well. We get to love him and hold him every day. There is so much good....but it was still a really hard day.

**September 24, 2010**

Posted Sep 24, 2010 9:02pm

I haven't forgotten about Genre's care page...it's just that Genre and his brother/sister keep me so busy that I don't get a lot of time to sit and write about what he's been doing! It's all good stuff and it's wonderful to be able to keep busy with them! I'm thankful that we are able to be busy. This summer has been much different than last! We've concentrated very hard on keeping things simpler...we have spent more time together this summer as a family than we had in a long time...the kids seemed to enjoy it as much as John and I have. Some days, after we've done

nothing but swim and play run-down all evening, one of them will say 'This has been the best day ever!' You can't help but smile.

Genre is well. He is strong and he has really enjoyed his summer. I have added some pictures to his album so please take a look at all the hair!! Thick and curly is the way his hair grew back in. It's beautiful! Lots of times I laugh because I'm usually hollering at him to brush his hair now...just six short months ago, he didn't have any!

Genre was able to go to Kennywood this summer! It was on his 'to do' list and there was nothing that was keeping him from the park this year! It was so much fun for him - especially spending the day with Jaden and his other buddies! He hadn't been there for two years - last year he was just too sick to go. I suffered a lot of teasing during the days leading up to our Kennywood outing. There were jokes about portable pressure washers, giant wagons full of hand sanitizer, and bubble suits. We made it through and enjoyed a beautiful day with our friends. It was a beautiful day with beautiful people.

Genre played baseball for coach CJ on the Braves PAL team this summer. CJ and the other dads were so kind and understanding with Genre. They took such good care of him, without treating him too differently. They even let him play third and second base - He loved it. When Genre was too tired to finish a practice or game, they just let him sit out. CJ was so understanding every time Genre didn't feel well enough to go to a game. I don't think CJ realizes how much that meant to Johna and me. After Dr. Shaw said Genre could play, the PAL organization allowed Genre to register late and also put him on CJ's team. They were so helpful. Of course, early in the season our very large friend, Nick, pitched to Genre and nailed him directly in the hip. The ball smacked him dead on! Genre never even moved out of the way!!! Nick and his mom felt so terrible! Everyone at the game gasped and panicked!! John tried to explain that Genre's hip is just like every other kid's hip...it hurts, but it's ok! His hip has nothing to do with leukemia. Funny how far we have come!

In August we planned our Footsteps in Faith 5K and 1 mile Fun Walk. Jodi was the race director and she did such an amazing job at organizing the event! We had almost 600 runners and walkers! We were hoping for 300! The list of volunteers to thank stretches into the hundreds! Breanna's Girl Scout troop organized the concession stand for us - the NCC praise band donated their time and their talents - firemen and police officers blocked the roads and filled the dunk tank - Coldwell Bankers donated all the baked goods - the Norwin cheerleaders - all the volunteers who worked in the children's area - Terry who was a good sport and sat in the dunk tank - our balloon lady - our hair wrapper - the CHP nurses - our set up crew - our clean up crew - the Stoners - Gaylene, Kristie, Johna, Courtney, Anne (and all their husbands!), Tracy, Joanne, Tracy, Bonnie and Pete, Jeanne, my mom...the list goes on and on! So many groups stepped out to donate products or their time...the Irwin Council - the Irwin Public Safety Director - the Norwin Chamber - the Schubers - Bob Evans, Irwin - Kerbers - the ladies who put the race bags together for us - Calvary Assembly - Virginia Montanez and [www.thatschurch.com](http://www.thatschurch.com) - the Mario Lemieux Foundation - Microsoft - LWE - Pitt Rental - all the companies who donated products to make the auction a success.

I am sure that I have forgotten to mention someone who helped us in some way. This is not an exhaustive list. We appreciate the tents and tables you all allowed us to borrow. We appreciate the coupons and baskets you donated, and anything else that I might forget to mention. Thank you for walking and running. Thank you for coming to Irwin Park to eat or play games. Thank you from all of us who planned this event. Thank you for helping us make a difference in the lives of some really sick kids at CHP.

After the race and Gionna's 7th birthday, we headed to Hilton Head for a week. Dr. Shaw gave Genre the 'ok' to go to the beach...that was a tough one for me. Genre was so excited and he is positive that Hilton Head is 'the best

beach in the world.' I, on the other hand, wasn't so sure. The thought of him swimming in the ocean with all that 'stuff' in there practically gave me a panic attack. Honestly, I prayed and prayed that I'd be able to go and enjoy my family. I prayed that I'd be able to go to the beach and not feel a little sick every time I saw Genre digging in the sand. I prayed that I wouldn't want to yell and be miserable every time he put his face in the water... I'm so happy to report that we spent seven peaceful days together playing in the water and the sand! He was well the whole time – germs and all! There isn't much to tell because we really just enjoyed each other and played at the beach. We ate a lot...we golfed...and we rode bikes a lot. It was the most wonderful vacation we've ever taken. If I think back, there was a time not too long ago when I wasn't sure we'd ever take Genre to the beach with us again....and there we were – riding the waves, biking for miles, and eating crab legs until we couldn't eat another bite. Thank you.

During Genre's last clinic appointment, he struggled with the sad news that his nurse and friend, Kristen, would no longer be working on Wednesdays. She is staying home with Dylan and baby Noah more so that means less time at CHP. Genre could barely pick up his chin to look at Kristen. He was sobbing and she just felt so bad! It was awful for both of them, but true to Kristen, she promised that she would Skype with him and that she'd meet us to have some fun outside of the hospital! We are hoping that she and the boys will meet us at one of Genre's favorite places – the zoo. She already set up her Skype account and Genre can't wait to see her.

You may remember me writing about our opportunity to be a part of the Make Room For Kids/Mario Lemieux Foundation/Microsoft event to donate all of the Xbox's to the transplant floor at CHP. That happened back in April when Microsoft and their generous employees outfitted the entire transplant floor with gaming systems. As if that wasn't amazing enough...the goal now is to make sure that the Adolescent Medicine floor has a game in every room as well. That's the Make Room For Kids goal for 2011! Virginia says that Genre's ideas about sick kids needing games triggered her to do this. Sometimes it takes my breath away to know that so many good things, like this, came out of the worst moments of our life. Eventually, every inpatient room at the hospital will have a gaming system – pretty much, because Genre got leukemia....

Through Make Room for Kids, Genre's story touched the heart of our new friend, Luke, from Microsoft. Since we met him in April, he has kept in touch and has checked on Genre's progress regularly. As a matter of fact, he asked if Genre would come to the Microsoft regional sales meeting at Nemaquin Woodlands this week. He thought it would be nice to tell the Microsoft employees what happened at CHP and for them to meet the little guy whose idea triggered the event. Genre was able to tell his story about sick kids needing games to a room full of people who understand gaming! At one point, Luke asked Genre how the games helped him. Genre said that a blood transfusion would take three hours and a chemo treatment could take one hour. Some days he would get five to six hours of infusions....his DS really helped him through it. I leaned over and said "hand held gaming system." (Nintendo, not Microsoft, makes the DS.) The room laughed at my statement, but then Genre came off with this – "Well, if you and your people would make a hand held gaming system, then I wouldn't have to be careful about what I say..." The room exploded with laughter! It was a great experience and the Microsoft people were so compassionate and generous.

Not only did Luke want Genre to tell his story to a room of 150+ Microsoft employees, he asked if Genre would be willing to demonstrate the new Xbox Kinect system which debuts November 4th. Kinect is the newest addition to the Xbox 360. It is a remote free gaming experience. (Do I sound like I just sat through their sales meeting?) There are no remotes. Your body is the remote. After the presentation about the new system, Genre and James had the opportunity to demonstrate the game to the whole room! They were jumping, leaning, and bending to earn points in the Adventure game. It was so much fun for them! Everyone was cheering as their raft rode down the river. Luke let Gionna demonstrate the game after dinner. She jumped right in and did just as well as the boys. To the

kid's surprise, Luke told them that he'd be bringing them a new system early in November. They haven't stopped talking about it!

Genre continues with his treatments every month. He is still on a three month cycle where he has a spinal tap the first two months and they give him a break during the third month. He still takes oral chemotherapy every day. His tenth birthday is the last Wednesday of this month. That should be clinic day. Dr. Shaw doesn't want Genre to get chemotherapy on his birthday so he'll go another day that week. A good friend of mine asked me if I was bothered at all by the upcoming double digits. I have to admit, I didn't like it when James turned ten...but that was before leukemia. I don't even feel a twinge of sadness that my baby is ten. Now, every birthday is completely appreciated and enjoyed, double digits or not. At this point in my life, I know so many moms who aren't going to celebrate any more of their child's birthdays. Birthdays are good.

We just continue to thank God every single day for all of the blessings that have come out of leukemia. I thank Him all day long for getting us through this far. I thank Him for giving me air when I couldn't breathe and peace when I thought I would lose my mind. I am so thankful for the love and friendships that have grown out of cancer. I am eternally, not temporarily, grateful. I know I say this all the time, but so much more good has come out of leukemia than I could ever have imagined. I live it and it's hard to believe...it must seem a little strange to some of you...

Thank you for continuing to check on Genre's carepage.

Thank you for keeping him in your prayers. I'll try to update sooner next time.

## New Project and Genre

Posted Oct 22, 2010 4:38pm

The day after Genre was diagnosed with leukemia, a dear friend of mine gave me what she called a 'to go bag'. In that bag was everything that I would need during a hospitalization. She said that I should leave the bag packed and when Genre wasn't feeling well and we needed to get to the hospital I could just grab that bag and go. Little did I know on that day that we would use that bag more than 50 times in eight months. Sadly, Tracy knew another family who had lived through pediatric leukemia and that mom was able to tell Tracy everything I would need.

The bag had everything I needed from shampoo/conditioner and toothpaste to gum and notepad/pens.

At the moment when you first hear the words, "Your child has cancer", you can't think. There is no way you can possibly think of yourself and what you will need over the next two weeks to one month. You do not know that you will be sick in your stomach for the next two weeks...You don't know that you will have a continual headache for the next two weeks...You don't realize that you won't sleep for days and you will need something to do in the middle of the night so that you don't lose your mind. You just can't comprehend the severity of the pain and fear you are about to experience and then continue to live through.

The bag Tracy brought me helped me not only through those first two weeks, but every stay thereafter. Each time my son was ill and needed to go to the hospital, I was scared to death...but never once did I need to think about what I needed to take for myself. That burden was taken away for me by the "to go" bag my friend had prepared. I hope Genre's Kids with Cancer Fund can do that for every mom who deals with this nightmare. We are planning on giving these 'to go' bags to every newly diagnosed family at Children's Hospital of Pittsburgh.

So many of you have expressed an interest in helping with the 'to go' bags. I am going to provide a list here with the products and approximate sizes we plan to use. Please feel free to email if you have any questions or if you'd

like to be involved in any way. [genreskidswithcancerfund@comcast.net](mailto:genreskidswithcancerfund@comcast.net) You can drop the supplies off on my front porch or in front of my garage doors. I would be happy to meet you at your convenience.

Each bag will have the following items:

Shampoo and conditioner – approximately 8 – 12 oz size

Hair brush

Pony tail holders

Lotion – approximately 8 oz size

Disposable razors

Body wash – approx. 8- 12 oz size.

Deodorant for Dad

Deodorant for Mom

Toothpaste (brand name please ☺) – approx. 4 oz. size

Three toothbrushes per bag

Dental floss

Finger nail file

Nail clippers

tweezers

Small Tums

Small Tylenol

Lip balm

Small feminine products both tampons and pads

Steno sized notebooks

Post it notes

Pens

Highlighters

Gum and/or mints

Deck of cards

One gallon size baggies – to put the shampoo/conditioner in - incase the liquids would leak

One quart size baggies

Snack size baggies – for the smaller items

Misc. coupons as they are donated

We need 120 of each item per year. (Toothbrushes = 360). Would you consider committing to supply one item for one year? Would you ask your workplace, organization, or church group to provide some of these items?

Whatever you can supply, in any amount, is very much appreciated and needed.

The beautiful 9B nurses have agreed to distribute the bags since they really are the first point of contact for a newly diagnosed patient and family. The hospital tells us that there are normally 6 – 8 new diagnoses each month.

We are planning on providing ten bags per month. Thanks for all the emails and questions about the bags. As always, I am inspired and amazed by your eagerness to help these families.

Just a quick note - Genre went to the dentist yesterday. He needed to take 2000mg of Amoxicillin before they cleaned his teeth. In case you don't know, Gen isn't allowed to floss his teeth because it breaks free all of the bacteria between your teeth. With a compromised immune system, that bacteria is really harmful. Genre hasn't had his teeth cleaned in over a year and I have continually worried that he will have a real dental problem once he

moves beyond chemotherapy and childhood cancer. As Miss Tammy was cleaning his teeth yesterday, she mentioned that Genre only has two more baby teeth to lose. They are both very loose and will fall out soon. She said this is uncommon for a boy who just turned ten. He's really ahead of the game as far as losing teeth goes. He started losing his teeth when he was just four. Of course, I was worried about that way back then! LOL When I told Tammy my fears that stem from Genre not being able to floss, she said that I shouldn't be concerned. She told me that there isn't really anything to floss – he barely has any teeth! She said that he is brushing each side of his teeth because none of them touch! His teeth are perfect! I was concerned about giving him Fluoride. He has so many other drugs pumped into his body regularly...I just didn't want to add anymore. She said his teeth didn't even show one sign of wear and tear!! Do you realize how many days Genre was too sick to brush his teeth?? I wish I could count all of the days Genre was just too tired to get out of bed, much less walk to the bathroom to brush his teeth!! Do you realize how many times he has had sores in his mouth and he was unable to brush? It dawned on me that way back when Genre was a baby and he had ALL of his teeth before James, and began losing his teeth before James, God was already preparing him for this ordeal. He even had Genre's teeth in mind...that just boggles MY mind! He has protected Genre every step of the way and I just don't know how to say thank you.

Genre is well. He is feeling strong and he is full of energy! He is dressing as Polamalu for Halloween. He was too sick to Trick or Treat last year so he is very excited to get out this year.

Thank you for all your help and prayers. Genre goes to the clinic on Wednesday for a spinal tap and treatment. I will update to let you know how he is feeling.

**November 1, 2010**

Posted Nov 1, 2010 6:40pm

Hello! Genre was at the clinic for his treatment this past Wednesday. I am happy to report that there was no spinal headache! Having him rest for the 24 hours after his spinal tap seems to be helping in preventing the headaches.

Thank God, as the last one lasted six days. Genre will have another spinal tap/treatment the Wed. before Thanksgiving. No spinal tap in December.

This cycle, as I have probably repeated many times, was a three month cycle with two spinal tap months and one month 'off.' He still got a treatment infused into his port in the 'off' month, but no spinal tap. Beginning in January the new cycle will also be a three month cycle. However, this time the cycle is one month of a spinal tap/treatment, and two months with no spinal tap, just an infusion. Hooray!! This will be the treatment pattern until September of 2012! Like I have said, at that time they just stop the chemo altogether.

Trick or Treat was a lot of fun this year! Watching Genre run from house to house was such a happy time for me. Thinking back just one year...he wasn't even strong enough to walk down our steps to go outside on the back patio for a picture...and we only have two steps. Thank God it is this year and not last! Thank you for your prayers and love - I will post again after his next treatment.

**Doing great!**

Posted Nov 24, 2010 2:53pm

Genre's appointment at the clinic today was a late one. He was scheduled for 10 am and they never even began his procedure until 1 pm. It was a busy, busy day at the clinic. The little guy wasn't allowed to eat or drink and he never complained once. My mom and I don't eat/drink in front of him (except coffee as he does not want coffee) and I could hear her belly growling across the room!

All reports were great today - too great, as a matter of fact. They like to keep Genre's ANC around 1000 and today his was 2200! Because of his increased ANC, Whitney increased each of his medicines. Now momma needs to make sure I learn the new doses before I fill up the pill box! Genre's spinal fluid looked clear as did his blood...which is always the BEST news. Thank God for clean blood and clear spinal fluid.

I really don't have much to report in this update. Genre has been well and feeling very strong. He has been to the circus, out playing golf and looking forward to pumpkin pie tomorrow. Tomorrow...a day of thanks...a day to reflect upon all the blessings in our lives. At this time of year we love to ask each other, 'What are you thankful for?' If you asked me what I'm thankful for, you might be surprised at my answer. You might be appalled at my answer. I'd pick Jesus first. I'm thankful that He saved my life and that he gave us the breath and the strength to walk through pediatric cancer. Dare I say it? I'm thankful next for leukemia. The exact thing that I hate the most in the world is one of the things for which I am most thankful. This terrible time in our lives has brought so much positive energy and love into our lives. This nightmare has allowed us to love like we never loved before, and to appreciate like we would not have appreciated, had we not known these trials. Leukemia has, in a very strange way, been a funnel of peace for John and I. It's taught us patience and perseverance. It's shown us how to focus and prioritize. Leukemia has given us family and friendships that we will cherish forever. It's showed us hundreds of kind, generous, and loving people who we did not know before leukemia. Yes, in a crazy/ I can't believe this is real kind of way, I am thankful for leukemia.

All that being said, our child is in remission and we are blessed with two other healthy children. What else could we possibly ask for? Life is good. Love to all of you. Happy Thanksgiving

**January 20, 2011**

Posted Jan 20, 2011 10:50pm

Happy New Year just a few weeks late...I wanted to let you know that Genre had his January clinic visit yesterday. He is officially half way through his treatments. Twenty months done and twenty more to go!

Yesterday Genre had a spinal tap with a spinal chemo injection. He also had a chemo treatment through his port. I have to say, he handled the sedation and the pain medicine like a champ. He was barely tired or wobbly when it was all over! We are just thanking God for one more month of leukemia-free blood and leukemia-free spinal fluid. That is all we ever need to hear!

Things are so different one year later... this time last year, Genre was in the hospital for almost two weeks and couldn't use his legs. He couldn't walk! He was undergoing MRI's, EEG's, CT Scans, and more. Thankfully, this year, he is busy working on his first Pine Wood Derby car, which he will be racing this weekend. Without needing to think about it, Genre made his car inspirational. The car is purple with yellow words that say Be Strong Be Courageous. He is feeling so healthy and strong. When he's not enjoying Boy Scouts, he's at a basketball game or playing with his friends. We are so grateful that it's this year and not last.

Genre is now on a three month treatment cycle that will continue through September 2012. The first month is a spinal tap/chemo injection and a port chemo injection. The next two months are 'just' chemo injections into his port. No spinal! That cycle just repeats itself for the next twenty months. He won't have another spinal tap until April!! The various oral medications that he has been taking daily will continue through the next twenty months as well.

As we look forward into the new year, I realize that it's so important to never forget the past. Each day I purposefully remember Genre in the beginning of his treatment. ..not to be morbid or dramatic, but to remind myself to be thankful for what we have now. The further we move away from those first eight months of leukemia, the less terrifying they seem. I know it's like that with so many problems in life, and we so desperately TRY to forget the pain that we felt or the discomfort that we lived through. But, for me, I never want to forget how much I appreciated every single moment of every single day back then. I was in constant communication with God and I was so aware of His presence in our lives. I just don't want to 'get back to normal' and forget. That's my goal for 2011 – to keep appreciating, and to never forget.

Happy New Year to you all. I will update after Genre's next clinic visit. Thank you for your continued prayers, support, and love.

**January 21, 2011**

Posted Jan 21, 2011 11:27pm

Sorry for two posts back to back...

Remember Dr. Sidonio? He was Dr. Shaw's Fellow until this past summer and he treated Genre for fourteen months. We emailed with him tonight and he was happy to see a picture of Genre with hair - and a little too much of it, I must say.

Dr. Sidonio is working at a hemophilia clinic at Vanderbilt in Tennessee. He has 100 patients and many of them are Von Willebrand Disease patients, not just hemophilia patients. You might remember that Genre has VWD...nothing related to leukemia. His blood doesn't clot as well as it should. He doesn't bleed more; he bleeds longer. The drug that works on MOST VWD patients does not work on Genre. There was much uncertainty surrounding what to do with Genre's port surgery when he was first diagnosed with cancer. There was even MORE concern when they were going to puncture his spine...and then again...and again...and again! They were certainly HOPING that the blood products would help the puncture to seal properly!

Dr. Sidonio wrote that he regularly uses Genre as an example about how to treat Von Willebrand Disease patients for spinal taps and port placements. Genre went through so much after his port surgery! There was so much swelling/bleeding/uncertainty! It is so WONDERFUL to know that all the distress we felt (and everything that Genre endured) is helping other kids through their battles! What a perfect way to look back on that whole nightmare! As I've said before - I don't believe for one second that this leukemia was some "random act of cell mutation." SOMETHING GOOD will come out of it!

Good night!

## March 19, 2011

Posted Mar 19, 2011 8:13pm

Hello. I just wanted to let everyone know that Genre had his March clinic visit and we are thankful for one more month of clean, cancer-free blood. Genre has been enjoying his two month break from spinal taps. In April he will start his next three month cycle which begins with a spinal tap and chemo injection. Dr. Shaw thinks Genre looks great and he continues to tell us that every day in remission matters. He says that the longer a child stays in remission, even on chemotherapy drugs, the better the long term outcome is. We have been doing this for 22 months...18 more to go. We're more than half way there and I couldn't be happier about that. It seems much better to be 'more than half way there.'

Genre finished up his basketball season a few weeks ago. John and I are so proud of him. We weren't even sure if he would be able to last through a whole game. Not only did he LAST through the game, he worked very hard to be able to PLAY the whole game. Every day that was warm enough, Genre was in the driveway shooting baskets. If it was too cold to be outside, he dribbled in the garage. Genre worked harder than he has ever worked in his life, and it paid off for him. He even scored a few points in some of the games! He never seemed tired and he was a real part of his team! :)

Thank you for your continued prayers and love. The little guy still has a way to go so we very much appreciate you thinking about him and praying for him. Have a wonderful night. I will update again next month.

## April 13, 2011

Posted Apr 13, 2011 3:38pm

This morning Genre visited the clinic for the spinal tap which begins this next three month cycle of treatment. His blood work was perfect and completely free of leukemia cells! His ANC is hanging in there at numbers even better than they expect! Just like always, Genre was full of smiles and lots of love to show the nurses and doctors. There is never an ounce of fear or any hesitation in him as his port is accessed or as they prepare him for his spinal tap and Methotrexate injection. I am filled with pride every time I watch him go through these treatments. Even now, twenty three months later, he takes my hand and pulls me toward him. He pulls me close to his mouth and he whispers, "Pray." As I tell him that Jesus is with him and as I tell him over and over that Jesus loves him, he smiles the faintest little smile and says, "Thank you." It's beautiful and it continually reminds me of the courage and strength that, for Genre, comes solely from his faith. We are so blessed.

Genre is doing really well. He is strong and he's doing great with his school work. He is almost completely caught up from all the weeks of lessons that he missed. He works very hard to make sure that he is not behind in any subject. Genre is looking forward to Boyscout camp this summer. Once he found out that they will be shooting guns and arrows, he was in! He and his Dad are going to try the weekend camp first. John can go to that camp with him. We are not yet ready to send him off without one of us there. The people who run his pack are really great and we trust them very much. It's just hard for us... It will be easier, (I think), once his port is removed.

Speaking of ports being removed...God willing, we only have seventeen more clinic visits to go. Can you believe that? Seventeen. Goodness...do you remember when I was typing three to five years?

John and I recently volunteered to be a part of the CHP oncology auxiliary board to support the oncology floor. We were honored to attend the first meeting this past week. As we sat in the room with approximately fifty other people, we were just overwhelmed with thanks and an appreciation for what we have. Our story was the 'good' story in the room. It was an evening that is difficult to explain...we both went through a wide range of emotions. In a room full of people, we are usually different from everyone else...we are 'the parents whose child has cancer.' I'm not complaining about that classification – it's part of our life now. At the meeting, we were one of many in a sea of parents with really sick kids, and parents who no longer have their child with them. While we were happy NOT to be 'the only ones', it was emotionally sickening to be surrounded with so many parents who have lived through so much pain. So many. As I sat there, I kept thinking how there was no way to measure the unimaginable amount of pain that had been collectively lived through in that room. I had to concentrate on paying attention to the speakers so that I didn't allow myself to be overcome with grief. Sometimes it just sneaks up on me. Even though we have been living through this for some time now...there are moments when the thought of dealing with cancer for one more second is unbearable. Sometimes I just want to blink my eyes and never deal with cancer again. Thankfully, God gives me the strength to ask Him to help me through those moments. Then He centers me and reminds me of all the blessings and wonderful things that have come out of leukemia. He gives me the strength to keep putting one foot in front of the other and to continue doing what we know He would like us to do.

I want to let you know that I will be adding another Carepage entry later today to update about Genre's Kids with Cancer Fund. There are some wonderful things happening with our Fund and I would like to share them with you. I'll do that in a different update.

Thank you for your continued prayers and support. Thank you for the way you reach out to us and weave yourselves into our lives. Each and every one of you is forever in our hearts.

Have a beautiful day!

**April 14, 2011 GKWCF**

Posted Apr 14, 2011 9:22pm

Hello. Thank you for reading this update about Genre's Kids with Cancer Fund. We gave out our first gaming system to a child with cancer in March of 2010. Since that time, GKWCF has experienced much support and growth. We have been greatly blessed over the last twelve months and we are now able to include charitable giving to the electronic gaming that Genre knows is invaluable to a child living through a long treatment. The games will always be the beginning of this beautiful Foundation. However, only one year later, we have branched out in several different directions so as to help oncology families the best way we know. I am so proud and yet, at the same time, so humbled, to present Project H.E.L.P. (Hands Encouraging Loving & Providing)

Project H.E.L.P. – this is what we do now.

1. Genre's Kids with Cancer Fund provides a handheld electronic video system with two game cartridges to each new cancer diagnosis at CHP. If the child is too old or young for a Nintendo DS, they can choose from an mp3/iPod, or Leapster educational game. There are electronic baby toys as well. If the child already owns a gaming system, they receive two new game cartridges. There are 8-10 new cancer diagnoses at Children's Hospital of Pittsburgh each month. These games are distributed by the oncology Child Life Specialist.

2. Genre's Kids with Cancer Fund provides each family with a "go bag" filled with items and necessary toiletries to use during lengthy hospitalization stays. The bags are full of personal supplies for the very shocked and unprepared parent who has just heard the words, 'your child has cancer'. The bags have notebooks, pens, Tylenol, Tums, shampoo, soap, toothbrushes, etc..., and they are distributed by the oncology social workers or floor charge nurse.

3. Genre's Kids with Cancer Fund has closely partnered with the oncology social workers at Children's Hospital of Pittsburgh who selectively refer oncology families to our organization based on immediate need. We are committed to providing financial assistance on an individual basis because the disease is devastating. Its impact is challenging and the needs are great. Some families may need assistance with parking and travel costs while others may need help with child care for their other children. Often, parents take Family and Medical Leave and fall behind on their monthly bills. For the families who travel long distances to CHP, we supply the social workers with gas gift cards to be distributed at their discretion. We serve all Pennsylvania regions, Ohio and West Virginia – if a family is admitted onto the oncology floor of CHP, we will help them no matter where they live.

4. Genre's Kids with Cancer Fund provides financial support to the Adolescent and Young Adult Oncology Program at CHP for their teen weekend trip. This year Dr. Shaw took 23 cancer teens aged 15-21 to Seven Springs for a weekend trip. Teens who have lived through cancer join the teens who are actively receiving treatment. The 'experienced' teens provide support and encouragement for those kids who are just now living through the disease. Adolescents and young adults with cancer have the same needs as their peers. This program is designed to help them stand up as individuals without standing out because of their disease. They experience camaraderie and emotional support while spending time with other teens who have cancer.

5. Genre's Kids with Cancer Fund offers a multitude of services to families living through pediatric cancer. Emotional support and free family photography with color editing are among these services.

In such a short period of time, we are blessed to be able to help so many families...and there are SO many families...and SO many needs. Those five points are just the beginning of what needs to be done on the 9th floor.

This Carepage has two parts. It is a letter of thanks. Thank you for the support you have given us over the last year. It is because of you that hundreds of cancer kids are enjoying a handheld game as they sit through hours and hours of chemotherapy treatment and blood transfusions. It is because of you that over fifty families have received a bag from us, and they knew that someone was thinking about them and praying for them just as they began living through the darkest time of their life. It is because of you that a special single mom breathed a sigh of relief and knew that her water bill was paid once she and her child left the hospital after a very long stay. It is because of you that a widowed mom was unable to speak through her tears when she found out that her gas would not be shut off once her child was released to hospice care – after months in the hospital. We at Genre's Kids with Cancer Fund may be blessed to actually do this work...but the work is done because of the support you provide. Thank you so much for that.

Please know that we are dedicated to making the lives of these families a little easier in any way we can ~ emotionally, financially & spiritually. When a family asks why we help, our answer is simple. We are supposed to be God's hands and feet on Earth. We are supposed to show His love. This family was shown His love by all of you, and we will forever pass that on.

Part two of this Carepage is a request. Will you continue to help us? Your support and the support of anyone with whom you can share this story is vital to our mission. We have tried to make donating as simple as we can. You

can always mail a donation to PO Box 127 Irwin PA, 15642. You are now able to donate on our website as well. Go to the green tab/contact and then click on donate.

We are hosting two fundraising events again this year. The first one is our golf outing on June 13th at Edgewood Country Club. Last year we were honored to have 82 golfers attend our first event. We raised enough money at that outing to pay for the electronics for the whole year! Won't you join us this year? We are in need of golfers who would like to support a great cause. We would also appreciate any donations of products that could be used for our silent auctions. If you, or someone you know, would like to contribute an item for auction, please shoot me an email at [genreskidswithcancerfund@comcast.net](mailto:genreskidswithcancerfund@comcast.net). We would appreciate great restaurant gift certificates, show vouchers, unusual items, gift cards, foursomes, tools, getaway packages, auto care gift certificates, electronics and/or sport items....I list all of these because you never know what might remind you of someone you know. :) If you are interested in golfing or sponsoring the event, I'd be happy to send you the forms. They are also available on our website at [www.genreskidswithcancerfund.com](http://www.genreskidswithcancerfund.com). Click on the Events button and you will see a golf outing button.

Our second event this year will be our FOOTSTEPS IN FAITH 5K and FAMILY FUN DAY at Irwin Park. The event is set for August 20th. Last year we were just amazed when over 600 people showed up to run or walk! We were blessed by over one hundred volunteers plus all of the policemen, fire departments, sheriffs, and public safety people who joined us to make the event a success. I know it's early, but if you're like me, you need to put things on the calendar as soon as you know about them. We also do a basket auction and a silent auction at the race. I'm asking for your support of our race/walk and also to think about any way in which you or a friend might help us make the auction area a monetary success. Don't forget the live music, children's area and great food that are available after the race!

My dear friend, Jodi Fowler, is the race director. If you need to contact her for any reason please shoot her an email at [jodifowler2010@gmail.com](mailto:jodifowler2010@gmail.com). She is already busy planning for the event and this year we are hoping to need even more volunteers! Race registration and sponsorship information is available on the website under Events/5K. This year's confirmed sponsors (so far) are Dick's, Sheetz, Trib Total Media, and Children's Community Care. We anticipate many more!

Again, thank you for taking the time to learn more about Genre's Kids with Cancer Fund. Thank you for caring about Genre and each child living through this awful disease. We appreciate your prayers and support so much!

**5/13/2011**

Posted May 13, 2011 6:44pm

Hello!

I just wanted to let you know that Genre visited the clinic this past Wednesday. His report was cancer – free blood and a good ANC. His numbers were a little lower than they have been, but he could be fighting off a cold. That would mean that his body is acting the way it should. Genre is now 5 feet tall and 85 pounds! That means he has gained 25 pounds on chemotherapy, and he has grown five inches!!

May 25th will be two years since Genre's diagnosis. Two years ago I could not have imagined that my baby would leave to go to an over-night Boy Scout event tonight. Two years ago I wasn't sure that would ever happen. But, today he is strong and he is well... He is also with his Dad! Nevertheless, it was difficult for him to leave me today.

He hugged me over and over during the hour before they left. I got a bunch of kisses. He was trying his hardest to hold back his tears as he said, "I'm going to miss you, Mama." I told him that I felt just as sad as he did. I asked him if he realized that we really hadn't been apart for nearly two years. I explained that this is an important step that he needs to take because he is getting closer and closer to having his port removed. He said he knew all that but that it would still be hard for him to get to sleep tonight. Tell me about it.

I just want to quickly tell you about the Mother's Day card that Genre made me. It's really not one that you ever think you might get when you have a baby. Genre made me a card that said "Happy Mother's Day Mom. Since I had cancer, I know now that another mother would not have loved me as much as you and they would not have taken as good of care of me. Thank you for everything you did for me when I got cancer. Love, Genre" Yep...what do you do with that one with James and Gianna sitting there looking at me? They had just given me a Mom t-shirt and an I Love Mom statue. LOL! Don't get me wrong, I LOVE my t-shirt and I Love Mom statue. I know you moms get what I'm saying.

Never in a million years did I think I'd have these stories to tell, but it's ok. It's good to laugh. Genre goes to the clinic in another 28 days. I will update after his appointment. Thanks for always listening!

**2 years!**

Posted May 25, 2011 8:19am

Good morning!

Today is two years since Genre's leukemia diagnosis! Two years! I woke up feeling like I needed to share that this is still a hard time of year. I thought that I'd tell you all how the last few days have been difficult because I can't get it out of my head that during the last few weeks, just two years ago, cancer was eating away at my son's circulatory system....

I won't go in to that this morning. I got all of that negativity out of my head earlier today. (Thank you, Friend.) Instead I want to share all of the good things that have come out of cancer. Genre is well!

Our family, and anyone who has allowed Genre's strength and faith to touch their lives, has grown so much through his illness. We have gradually become better people while watching Genre handle cancer with such determination and a happy spirit. We all appreciate life more than we did before and I think we all have a new awareness about just how fragile life really is. Because Genre's journey through cancer is so long, we don't get to quickly forget what we've learned.

Our family has been abundantly blessed by the love and kindness of the people who constantly surrounded us through this journey and lifted us up daily. I have said many times before - through leukemia, friends became family. We will never forget what was done for us...how we were loved and cared for.

Through leukemia acquaintances became friends. People that we only knew casually stepped out to provide meals, offer babysitting, and to give their own blood and platelets. Strangers became a part of our life. People who didn't know Genre at all took an interest in his health and his ideas. Today we call them our friends. Each one of these very special circumstances is forever a part of our journey, and we will never forget.

Because of leukemia we are honored to know the entire oncology staff at CHP. I know each one of them was put on the earth for this very special purpose of caring for these sick children. The love and compassion shown by each one of them is unsurpassed and their dedication is unmatched. I thank God for them and for all He allows them to do for these children.

Through Genre's compassion and love for other people came, at first, Operation Electronics – a name he and Jaden coined one night while they were eating pizza. OE grew into Genre's Kids with Cancer Fund and all of the beautiful things we are able to do today. Because of Genre's cancer, over one hundred children at CHP have been given some type of electronic game or music device. Because of Genre's cancer, over 80 moms and dads have been given the supplies they need to get through those horrifying first few days. Families have received enough money to provide food for their other children, had their gas and electric paid, rent has been made current, Christmas gifts and meals were provided, and gas cards have been given regularly. On top of that, the entire transplant floor and the adolescent medicine wing have an Xbox in each room because of Genre's gaming idea. Are you hearing me smile through my words? All of this has come out of our son's CANCER. CANCER!

I write none of this to brag about my son or the hard work of GKWCF and every volunteer. I write this to say that there can be no doubt that God will use any bad situation in our lives for our good...I write this to say that our son was dying in the days leading up to Memorial Day 2009. In my human mind it was impossible for me to see, on my own, that any good could come out of cancer quickly destroying my son's body. On my own, I would have drowned in my fear and sadness...

As we are presented with awful things like sickness, loss, and struggles, we need to immediately and constantly remember that our focus can't stay on the bad thing that is put before us. If we lift the evil, the sickness, the worry, and the fear up to God, it's way easier to deal with. God's shoulders are definitely bigger than ours and He carries the burdens much more easily. I've learned that first hand and if this journey has helped anyone else know that peace, then it was well worth the walk.

Thank you for listening to me again. John, my mom, and I plan on loving and appreciating each other every single minute of the day today. To honor Genre today, please let somebody know that you are so thankful for their life. Have a beautiful day!

**August 7, 2011**

Posted 1 day ago

Hello! I just want to let you know that Genre had a clinic visit and treatment this past Wednesday. He is doing well. His numbers are lower than we would like, but Dr. Shaw is not concerned. He didn't even change any medicine. Genre's ANC is only 500 – which stinks because we will definitely be staying overnight at CHP if Genre would happen to get sick. So...back into leukemia mode we go for a while. I have to admit, we've been getting a little bit lazy in the germ prevention arena. He's not on lock-down or anything like that. I'm just going to go back to our old 'no one in our house if someone has a cold at your house' way of doing things for a while. It's ok. It's a good reminder of how blessed we are to have that part of our lives behind us.

Our family is well and enjoying the summer...lots of friends and fun. We are all busy preparing for our Footsteps in Faith event to benefit Genre's Kids with Cancer Fund. On August 20th we'll have a 5k run/walk and also a one mile fun walk. After the race we'll enjoy a family fun carnival-type morning. There are lots of new games and booths scheduled for the children's area this year, including a giant hamster wheel for the kids. Giant inflatables,

balloons, face painting, darts, and a fishing pond are among the many games for the kids to play. The NCC praise band and True Grace will both be playing during the morning. We have lots of great basket auctions and silent auctions as well. There are AirTran tickets, an Xbox, overnight stays, shows with a dinner, a Keurig, and an American girl doll to name a few items for auction. Come hungry because we'll have hamburgers, hotdogs, taco bowls, haluski, and a bake sale!

Thanks to our generous sponsors, the race costs have been met as of today. All money from registrations, games, ticket sales, auctions, food, and donations go directly to programs specifically designed for the families using the oncology floor at CHP. Genre's Kids is 100% volunteer driven. These beautiful friends work countless hours to make our golf outing and our Footsteps in Faith possible. Please come out and support us for the day! If you like to run or walk, please register and join us for the 9:00 start! If you like to eat and play with your kids, we would appreciate you coming out and supporting our family fun area. There is something for everyone that day!! We expect to be at the Park until 1:00 pm. We would appreciate your help in passing our event information along to your friends...the more people who hear about our event, the more lives we can touch.

You can register online at [www.genreskids.com](http://www.genreskids.com). We will be having a registration table at the Irwin Giant Eagle this Saturday from 11-1. We will be happy to register you at race bag pickup on Thursday (8/18) at Kerber's on Guffy Road from 6-8. You can register on Friday (8/19) from 6-7 pm at Irwin Park. Registration is also available the morning of the race beginning at 7 am. If you have any questions, please email our race director, Jodi Fowler, at [jodifowler2010@gmail.com](mailto:jodifowler2010@gmail.com). Thanks for always checking in on Genre and thanks for caring about Genre's Kids with Cancer Fund. There are so many needs on the oncology floor and we couldn't help with any of them if it wasn't for you.

Many Blessings and Much Love ~

**5/25/2014**

Five years ago was when we first learned that Genre's blood was filled with cancer. He was only eight years old. That night, when the doctors told us that Genre had acute lymphoblastic leukemia, I asked this question, "Is he going to live?" No one would answer my question....not for a really long time. They just didn't know, and they couldn't give us any answers. It was like we were in a dark pit and it felt like there was no way out.

Instantly, I was presented with life and death...not MY life or death...my son's. I remember writing in the journal I was keeping at that time, and the words went something like this: "Do I believe what I always said that I believe? Do I believe that there is really a Heaven? Do I really have faith in Jesus and believe that He will be there with my son if he dies?" None of that was how I wanted to spend my Memorial Day in 2009, and I never wanted to think about those words. As a matter of fact, I had spent the previous nine years of being a mom praying for the health and safety of my children.

What happened over the next five years has been a whirlwind of ups and downs, joy and sadness, love and pain. We have fought our way through three years and five months of chemotherapy treatments, blood transfusions, platelet transfusions, side effects from chemotherapy, spinal headaches from the drugs injected into our son's spine, hair loss, weight loss, friends dying and relapsing, critically low platelets, typhlitis, rashes, paralysis, post-

traumatic stress disorder and things that I am forgetting to list here. But through it all, one thing remained the same – God’s love and Divine Providence.

We have been blessed to see miracle after miracle along this journey and today, God revealed Himself to us powerfully. As most of you know, we have a charity called Genre’s Kids with Cancer Fund. God has allowed us to work in the lives of pediatric cancer families and to share His blessings with them. It takes many hours, love and hard work to make Genre’s Kids function. Each member of our team has played an integral and precious part in making this charity grow into the ministry it is today. But, seasons in our lives change and so do the commitments people are able to make. Change isn’t easy, and I have been praying and asking God to show me if He still wants us to do this work. I have been asking Him to allow me to feel His presence and to assure me that we are still following His will, His work. I don’t ever want this to be mine....

As I said, today is five years to the day when Genre was diagnosed with leukemia. Today, Genre and James both were scheduled to play on the student worship team for the middle/high school in the Warehouse at church. The adult leader of the team was Aaron Greer. Aaron didn’t know that today was an important day for us. We first met Aaron during the summer of 2009 when he played a benefit concert at Norwin Christian Church to raise money for our family. Genre had only been diagnosed a few months earlier. We didn’t know Aaron, but he sang his heart out that night and he gave a salvation message that really resonated with a lot of the kids and adults alike. After the concert, Aaron spent some time with Genre and he signed one of his Aaron Greer Band cds for Genre. On it he wrote Romans 8:28. In that Scripture, Paul says this: We know that God causes everything to work together for the good of those who love God and are called according to His purpose for them. We were thankful to Aaron and said our good byes. We had no idea how much that scripture would eventually mean to us. And we had no idea that Aaron would eventually lead the Cornerstone Ministries student worship team, mentoring James and Genre.

Like I said, Aaron was the leader of student worship today. Genre just made the high school team. Not knowing that today was five years since Genre’s diagnosis, Aaron scheduled Genre to play worship with Aaron for the first time. As a matter of fact, both of our boys played on stage with Aaron today.

When the boys play worship on Sunday, their rehearsal is the previous Thursday. This past Thursday, I didn’t sit at rehearsal like I do most weeks. Instead, I dropped off the boys and went to Sam’s club with Gionna and my mom. I had no idea what songs they were going to play today.

This morning, after the team finished Salvation Is Here – where the words say, “And I know my God saved the day and I know His Word never fails, and I know my God made a way for me.....” they proceeded to play Your Love Never Fails. Here is part of that song:

“You make all things work together for my good.....You make all things work together for my good...” A song right out of Romans 8:28. Aaron didn’t know what today was when he chose that song. I can’t explain what happened when I realized that they were singing that song. I felt like I was in a vacuum. Like there was no air, but I could breathe! I felt like there wasn’t anyone else in the room and it was just me hearing those words...

I don't call that a coincidence. I call it God revealing Himself just like a burning bush. I call it God shouting, "I am still here....just seek Me with all your heart and you will find Me. God answered me. He is still with us and He still has much work for us to do helping families living through childhood cancer.

Today, I am so thankful for each person who walked alongside of us through this journey. I am so thankful for each person who has played a part in making our Genre's Kids mission a reality – Helping Families Living Through Childhood Cancer Any Way We Can ~ Emotionally, Financially, & Spiritually. I am filled with thankfulness for all the growth and blessings we have all seen through this cancer journey. I am thankful for all of the new people God continues to bring into our lives and all that they add.

I am so proud of our son. He has handled his cancer with as much faithfulness, patience, and grace as is possible when you are eight and battling cancer. Now, he continues to give up his time to speak about our charity whenever we ask, and he never complains. He is helpful and loving to the other kids at the hospital when we visit them, and he shines a light for the parents during our visits. He has taught me so much about facing giants and faith.

But, more than anything, I am overwhelmed with thankfulness to the God who gave us Genre's life and allowed us to spend more time with him. I am humbled that He allows us to do His work and I pray that we are able to effectively live out His will and show His love.

Much love to all of you today. Thank you to all who serve our country and we are praying for those we have lost.

Daunette

**May 25, 2015**

Hope you are all enjoying a beautiful Memorial Day weekend and remembering all of those that gave their lives so that we can live in this amazing, free country. Our family appreciates the soldiers who never made it home and we are all blessed by the families that gave up so much for all of us.

Today is the sixth anniversary of Genre's leukemia diagnosis. It was Memorial Day in 2009 when Dr. Sidonio said, "Your son has leukemia." Many people reading this may think – it was six years ago. He is healthy. Quit writing about it. Move on.

If you are the mom of a cancer kid – or a kid with any serious illness or disability (and I pray that you are NOT) – then you understand how there are some times when God allows you to fly above the disease, but other times when He moves and makes you remember every detail. It's in those moments we get to remember in thankfulness, or look back in bitterness.

Most days I fly above childhood cancer. Most days it seems like another life time. But, the last ten days have been difficult. For whatever reason - God decided that I should relive every single moment of Genre's diagnosis.

Last week, my friend lived through the unspeakable torturing of her heart and mind when her son was admitted to Children's Hospital and tested, for five days, to determine if he had leukemia. We are thankful that he does not. So thankful. He does have another blood disorder called ITP and we are praying for him and his complete healing. For five days my friend was on her knees begging God to spare her son from the monster we know as cancer.

As she messaged me in fear, I was almost paralyzed. I walked her through what would be happening and explained much of what we went through. Each day, as I prayed for her son, I remembered what Genre went through like a movie was playing in my mind. I remembered telling him that he was sick and his tiny voice asking me, 'If the medicine is supposed to make me better, why does it make me feel so sick?' I remembered how his skin smelled so different when they were first rapidly killing many of the cancer cells. I smiled through tears as I remembered how bravely he went into his bone marrow biopsy and how he just kept saying Joshua 1:9 – "Be strong. Be Courageous. Do not be terrified. Do not be discouraged for the Lord your God will be with you wherever you go." I remembered how we both fit in the little hospital bed and how he wanted me next to him all the time. I thought about how he was afraid that I would "catch" his cancer and that I would get sick. It was so hard....at times, breathing was difficult and I couldn't focus on anything else. I wanted to be strong for my friend, but I was really struggling.

In 2009, we watched Genre wither away to nothing. We watched him fight for his life. As he fought for his life, I realized that John and I weren't enough for Genre anymore. We never were. I had cared for him the best I knew how for eight years. When it came down to the moment of realizing that Genre may live, or he may die, we didn't matter. All Genre needed was Jesus. At that moment, I told God that I wanted to give away my life. As I was curled up in the fetal position on the floor in my bedroom, I promised God that I would continually tell of the many miracles that He allowed us to see during Genre's illness. I promised Him that I would always share the stories of the many angels He sent to care for us - my mom, Kaitlynn, beautiful friends, a loving church family, amazing nurses, and wise, compassionate doctors with a sense of humor. I made a commitment that I would work to share our story – His story – as long as I was able. I made that promise and it killed me to include, "....no matter whether you take Genre home, or allow us to raise him."

God spared Genre's life. My heart aches for the many friends I have made who no longer have their children with them here on this earth. Many days, as I look at Genre, I would like to ask, "Why?" But I don't. I have to be ok with not understanding some of this, because none of it seems logical. I have no answers for them that will explain their pain, so I pray for them.

Today, Genre is 14.5 years old. He is healthy and strong. He just ran in his first 5K in the Pittsburgh Marathon. These are the words that he wrote on his fundraising page:

"This is the first time I have ever trained and run in a race. It's the first time that I have felt strong enough to do something like this. When I was really sick, I never thought I'd be able to do anything physical like this ever again. It seemed impossible. But, I have learned that God turns our weaknesses into our strengths. And my weakness became Genre's Kids with Cancer Fund."

What I have seen God do through this cancer journey has truly been miraculous. He took the worst day of our lives, May 25th 2009, and turned it into the beautiful blessing of Genre's Kids with Cancer Fund. He put together a beautiful group of people to work hard and build a ministry that would touch thousands of lives. He continues to show His sovereignty as he prunes, tweaks, and guides Genre's Kids along the path less travelled. But as we move forward, He clears the way.

As long as He chooses to allow us, we will raise money to help families living through childhood cancer. It is our deepest desire to show God's love to any family we can, in any way we can.....through games, bags, helping with utilities, rent, or travel....whatever need arises, we will meet it for as long as we are able. We will continue to share our story – the story of a little boy with a big heart. The story of God holding me up like a marionette on a set of strings as He built His ministry, Genre's Kids with Cancer Fund. The story of how he worked through a simple group of women to build an organization that can touch the life of every cancer family that moves through the hospital.

We all have the ability to cause a ripple effect. That's what a dear friend called Genre and his cancer – a ripple effect. I didn't quite understand what he meant when we were living through our darkest times. But today, I can see that, with goodness at the center, the ripples continue indefinitely.

As we move in to our sixth year, it is our hope that Genre's Kids will be able to provide funeral assistance to the neediest families. We are hoping to find corporate sponsorship for this program. If your company would be willing to help families living through the devastation of the loss of their child, please private message me.

God bless you and your family,

Daunette

Genre's Mom