

Zane's I.T.P. Journey

5/10/2007

Diagnosed:

4/6/2010





Almost three years went by with him being a normal healthy baby boy. Bringing a smile to just about anyone who met him!

Under one roof consisted of 8 people!! Brother Cody, 17; Cousin Ashley, 14, brother Wyatt, 5; sister Nadene, 3; Zane 2 years 11 months; Mimi (Grandma) and Mom and Dad, we had a house full!

Due to chronic ear infections it was finally decided to have tubes put in his ears on 8/25/2009. 12/1/2009, Zane had to have some dental surgery done, four caps on the top front and two cavities on the bottom.

Life was great! Until one day I had a concern. I was curious where all these bruises where coming from and they were not going away and also a weird rash, it was kind of like a rash but, not really. I was told by the P.A. that is was a strep rash at three different appointments and gave him antibiotics all three times.

4/5/2010 - Zane seen the other doctor in the practice. The Doctor asked me if there were concerns of him being abused. No, of course not. I did in home daycare and he was with me 24/7. The Doctor said she would do some blood work just to check a few things and would get back with me.



4/6/2010 at 8 a.m. while pulling into the Dillon's parking lot in Lawrence, I got the life changing call. I pulled into a parking spot, next to my Dad's truck (I did not know he was in town). I was in shock.....she said I needed to take Zane directly to Cotton O'Neil Cancer Center in Topeka immediately. He was to be seen by a specialist because his platelets were at a critical level of 12,000. I thought my son had CANCER!!!! I seen my Dad walking out of the store...I ran to him and we put Zane in his truck and headed to the Cancer Center.

Dr. Jakica Tancabelic, M.D. diagnosed Zane with Acute Idiopathic Thrombocytopenic Purpura (ITP). He was sent directly from the Cancer Center to Stormont Vail Hospital. This is where he received intravenous immunoglobulin (IVIG) treatment. That was the first of many 3-day stays at the hospital. The first day consisted of the IVIG treatment and the first shot of IV steroids. The second and third day in the hospital was to watch for dehydration, and the 2nd and 3rd shot of IV steroids.

This picture was the harsh reality that he would never be able to be a “normal boy”.

At this time Eric, Zane's dad was in Texas Pig hunting, he made the 12 hour trip home to be with us.



ITP, immune (idiopathic) thrombocytopenia is an autoimmune disease. In autoimmune diseases, the body mounts an immune attack toward one or more seemingly normal organ systems. In ITP, platelets are the target. They are marked as foreign by the immune system and eliminated in the spleen and sometimes, the liver. In addition to increased platelet destruction, some people with ITP also have impaired platelet production.

Platelets are relatively small, irregularly shaped components of our blood. They are required to maintain the integrity of our blood vessel walls and for blood to clot. Without a sufficient number of platelets, a person with ITP is subject to spontaneous bleeding or bruising. People with ITP often have bruises or small purple spots on their skin (petechiae) where their blood has escaped from their veins or capillaries. Spontaneous bleeding can also occur in the mucus membranes on the inside of the mouth or in the gastrointestinal tract. It is possible, with a decreased number of platelets, to have a spontaneous cerebral hemorrhage.

The specific cause of ITP is unknown. Some cases of ITP appear after a viral or bacterial infection, immunization, exposure to a toxin, or in association with another illness such as lupus or HIV. ITP is not a hereditary disorder. It is a rare disorder, with about 200,000 cases in the U.S. About half of the cases occur in children.

5/4/2010 - 3-day hospital stay, IVIG therapy and three days of IV steroids.

5/18/2010 - Zane's Platelets are 26,000 as of this morning, resorting to oral steroids

6/15/2010 - took Zane to Hospital last night, he was bleeding from the gums is not a good sign with ITP. Platelets are down to 16,000, double dosing his prednisone today.

6/16/2010 - Platelets are 66,000, Dr. T. said continue prednisone till Sunday, then blood work Monday.

6/21/2010 - Platelets are at 26,000. He has an upper respiratory infection, which means when an infection is present, his platelets are going to drop.

6/23/2010 - Platelets are at 13,000, another 3-day stay consisting of IVIG therapy and three days of IV Steroids.

6/29/2010 - Platelets are at 269,000!

7/3/2010 - the high platelet count was short lived, here comes the bruises and more bruises.

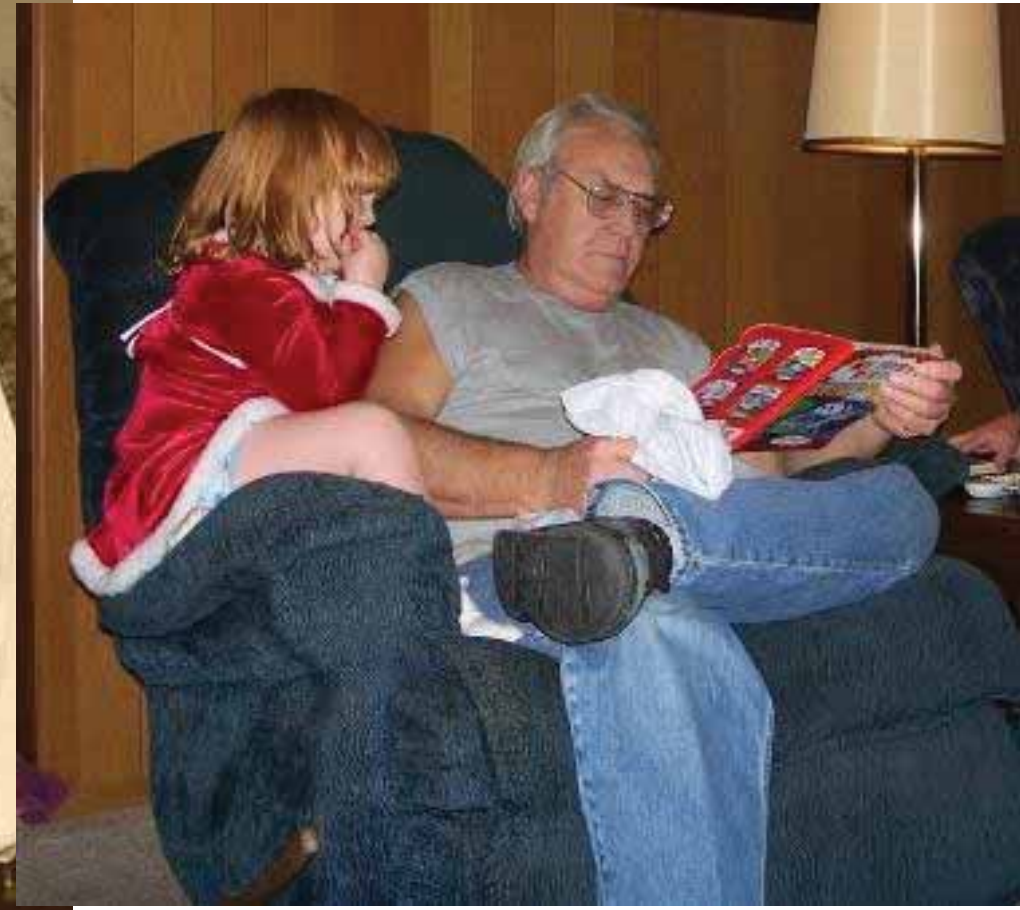
7/27/2010 - Platelets at 8,000 which is at a critical level. So, another 3-day stay filled with IVIG therapy and three days of IV Steroids.

7/31/2010 - had to take Zane back to the hospital overnight for IV fluids, he was dehydrated.



8/23/1946 – 8/20/2010

8/16/2010, our family learned that my Father aka Papa has colon cancer, and is suffering from kidney failure.



9/8/2010 - a virus has hit Zane, last week his platelets were at 75,000 and yesterday they are at 9,000. Back to the steroids and antibiotics.

9/16/2010 - well after a week of steroids and antibiotics Zane's platelets have come up to 37,000. A simple cold really takes a toll on my baby boy.

9/21/2010 - routine check up with Dr. T, Zane looks great no bruising, no peitchie, no “cold”, and then the news....Zane's platelets were at a all time low 2,000. This floored Dr. T and myself! We had to travel back to Topeka for 3-days of IV steroids. Yes, they had to put an IV in his arm 3 different times, but we did not have to stay in the hospital!

10/3/2010 - well Zane's Platelets are down to 5,000 as of today.....What to do?

10/5/2010 - Dr. T has determined it 5/be time to have his spleen removed. He cannot hold his platelets up on his own....only with the steroids.

He conditioned is now considered **Chronic ITP**. One of the spleen functions is to remove old red blood cells. In most patients with ITP, it is the main site of platelet destruction. In chronic ITP, surgery to remove the spleen is an option if the platelet count remains too low or doesn't respond to treatment. Only about 10 per cent of children with acute ITP have the operation. Zane also has to take a lifelong antibiotic to prevent infections and had to have pre-op vaccinations.

10/11/2010 - Pre-Op appointment set for next Tuesday.....NERVES ARE SHOT!

11/1/2010 - splenectomy day at KU Medical Center, after 3 hours the spleen and mini-spleens are out. We are waiting, he is in recovery, Doctor said he did awesome and procedure went perfect! ICU for 3 – days!

11/2/2010 - Zane is sore, but doing good. As of this morning his platelets are 230,000!

11/3/2010 - Platelets over 300,000! Now if the pain will go away!!

11/16/2010 - Zane's Post-Op appointment with Dr. T, platelets are 213,000!



February held a lot of changes for the Green household. After 5 years my Mom (Mimi) moved out on her own. She had been there for everything we needed, or wanted. How was I going to run a house, and take care of three kids without her! Oh No, we were truly on our own now. The Green family moved into my Father's Farm, aka "Silvers Farm", after months of court battles my dream of keeping my Father's dream is now reality.

2/15/2011 - bad news....Zane's platelets were falling again, 103,000, on to another week of steroids.

3/1/2011 - Platelets are up to 398,000! Great news! Steroids - on one week, off one week.

5/25/2011 - Platelets were at 103,000, continue on with the steroids this time every other day.

6/7/2011 - Platelets were at 93,000.



6/12/2011 - Zane's first crash and burn, face first off his bike into the gravel. First CAT scan done. Comes through with flying colors platelets at 126,000, so the risk of a brain bleed is rare.



6/20/2011 - Platelets are falling again, 38,000, continue steroids....

7/8/2011 - Platelets are at 84,000...

8/12/2011 - Platelets are at 114,000.

8/24/2011 - Platelets are at 132,000. Since infection is a risk now, next comes a tonsillectomy.

8/29/2011 - Zane's Tonsillectomy day! Dr. said he did great, tonsils were really bad and needed to come out.

Well he slept the whole day and when he did wake up, he could not breathe! Called Dr. T at 11 pm and she said take him to the ER.

Finally got him into a room. It seems the Doctor took out infected tonsils, which caused Zane's throat to close and could not breathe. After 4-days we finally get to go home.

9/19/2011 - Platelets are at 79,000.

9/26/2011 - After noticing petichie and bruising, CBC - platelets were at 20,000.

9/29/2011 - Platelets are at 36,000.

10/13/2011 - Platelets 36,000.

10/21/2011 - Platelets 24,000.

11/1/2011 - Platelets 68,000.

11/29/2011 - Platelets 19,000.

12/19/2011 - Platelets 18,000.

12/29/2011 - Platelets 54,000.



1/7/2012 - Mom's 6+ hour surgery to removed fluid from her lungs went well and Dr. was pleased. Mom is resting and vitals are good! Now recovery time.....Long wait. Learned that evening when the Doctor came out to talk to Eric and I, that she had cancer.

1/11/2012 - Platelets 25,000. Took Zane in to see Dr. T, he had been telling me that his bones hurt. I was kind of scared of Osteoporosis, due to the amount and prolonged exposure to steroids, but Dr. T. said that he had growing pains. Also, Dr. T has now determined that since Zane cannot stay out of the “critical range” that we should consider the treatment “Nplate” (<http://www.nplate.com/>).

Nplate® is a man-made protein medicine used to treat low blood platelet counts in adults with chronic immune thrombocytopenia (ITP), when certain other medicines, or surgery to remove your spleen, have not worked well enough. We have to wait 30-days to see what the insurance company is going to say about the Nplate treatment, because of the cost. The Nplate treatment requires weekly CBC and the Nplate injection for an unknown amount of time, it all depends on Zane and his reaction to it.

1/19/2012 - Platelets 20,000.

7/24/1954 – 1/20/2012

Connie Marie Feurt-Silver's aka MIMI, (My Mom) passed away.



2/3/2012 - Platelets 19,000.

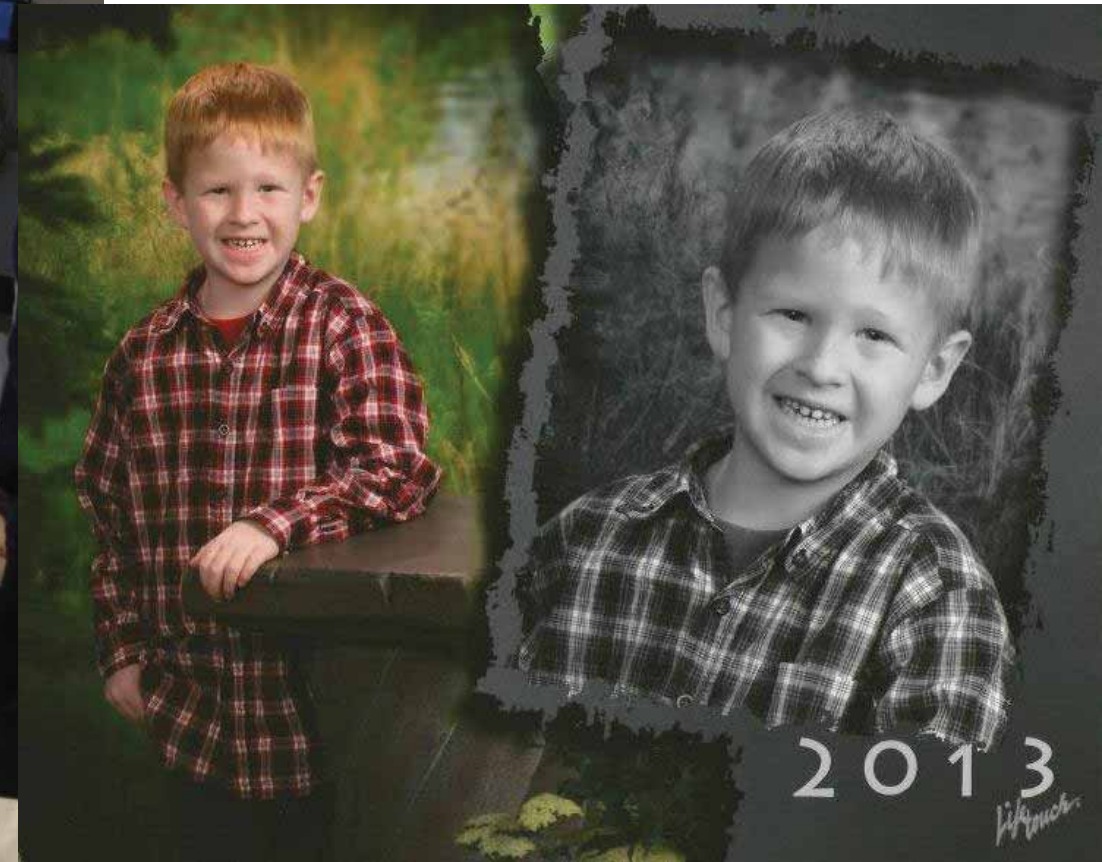
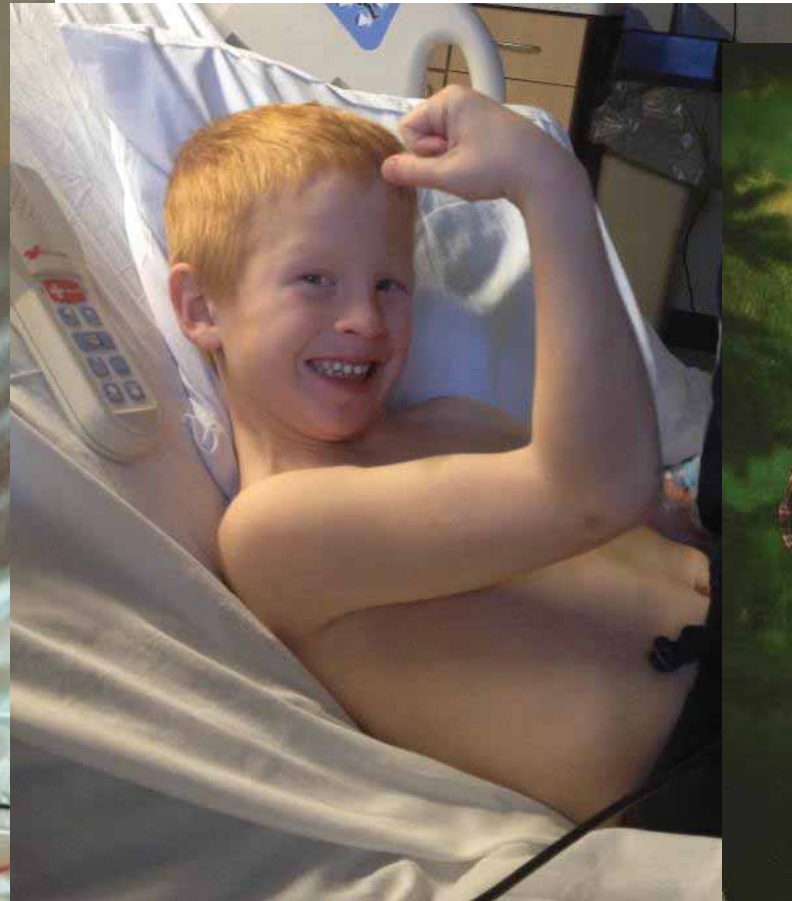
2/7/2012 - Zane gets his first Nplate injection! Platelets are at 17,000. Zane does not understand why he has to get a CBC and a shot in his leg every week, but he understands that he has to have good numbers to play baseball!

2/13/2012 - Platelets 23,000.....rising slowly!!

2/20/2012 - Zane has Influenza Type A, because he has no spleen he is at high risk for everything.

2/29/2012 - platelets 23,000....steady.....

3/7/2012 - platelets 22,000....okay being patient.



3/21/2012 - Platelets 13,000.....darn cold.



4/2/2012 - Platelets 18,000.....cold finally going away.

4/11/2012 - Platelets 23,000.....rising again!!!



4/2/2012 – Zane decided to try to be superman and jump from the top bunk to his brother's twin bed, well, he missed hit his face on the wooden bed frame, first ambulance ride and second CAT Scan, Platelets 18,000



4/18/2012 - Platelets 37,000.....rising slowly – Zane get's to start Baseball Practice!!!

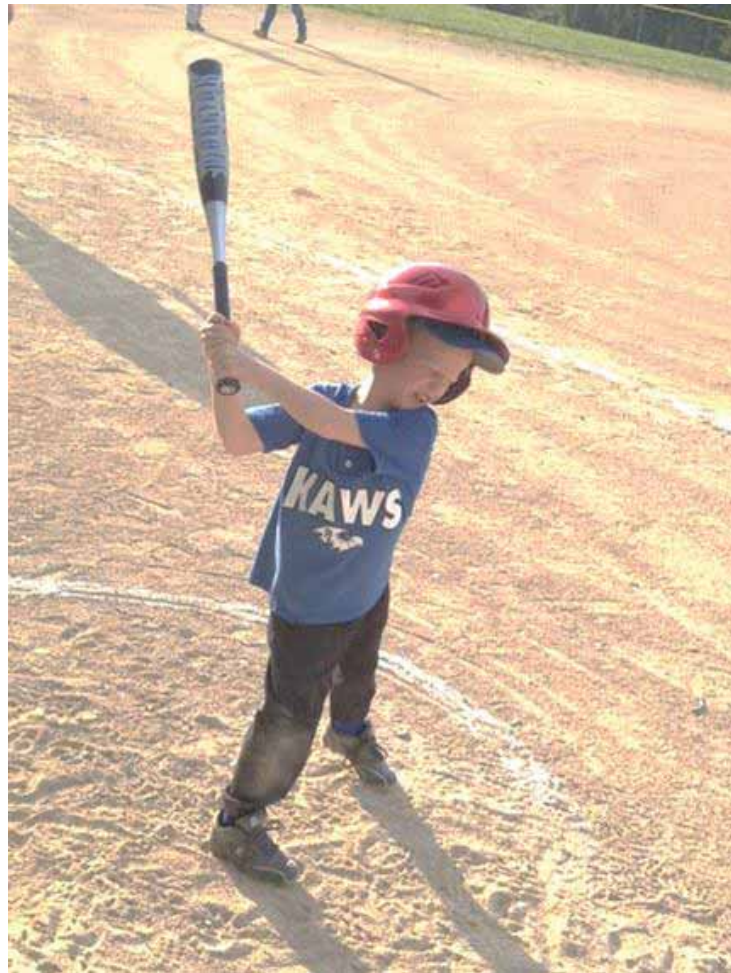
4/25/2012 - Platelets 134,000.....YES, YES, YES

5/2/2012 - Platelets 27,000.... I pray that his body accepts this treatment and does not reject it...

5/9/2012 - Platelets 66,000.... Increased Nplate trying to find the "magic" dosage!

5/16/2012 - Platelets 101,000.

5/23/2012 - Platelets 43,000 – Zane's 1st baseball game!



Well, Zane was at 43,000 yesterday and 101,000 last week. He has a virus going on ;(Up and down, down and up is the name of this game! He did awesome at his ball game last night, and he had a blast! Last day of school and Nadene has a game tonight! Let the summer begin!

5/24/2012 - Zane go to see Allergist Dr. Mante, no real answers just wait and see.

5/25/2012 - The City of Lawrence Solid Waste Division held a bake sale to raise money for Zane's doctor bills.

5/31/2012 - Platelets 88,000.

June was a trying month, my Sister in Law Candice was diagnosed with Leukemia. My niece and nephew came to stay the summer, so that she could get her treatments and not worry about them. (Kids on Skype With Candice).

6/6/2012 - Platelets 137,000.

6/13/2012 - Platelets 35,000.

6/20/2012 - Platelets 108,000.

6/27/2012 - Platelets 65,000.

7/5/2012 - Platelets 172,000.

7/11/2012 - Platelets 65,000.

7/18/2012 - Platelets 66,000.

7/25/2012 - Platelets 24,000.

8/1/2012 - Platelets 103,000.

8/8/2012 - Platelets 98,000.

8/15/2012 - Platelets 244,000, No Nplate!



8/16/2012 - First Day of School Kindergarten, 1st and 3rd Grades!

8/22/2012 - Platelets 13,000.

8/29/2012 - Platelets 114,000.

9/5/2012 - Platelets 370,000 No Nplate.

9/11/2012 - Platelets 24,000.

9/19/2012 - Platelets 62,000.

9/26/2012 - Platelets 351,000.

10/3/2012 - Platelets 12,000 -Eric and I picked up Zane from school Yesterday, had a bloody nose while waiting for Wyatt to get off the Bus. Headed to Topeka for Zane's weekly Wednesday, another bloody nose last night...then woke up this am with blood caked around his mouth.

10/6/2012 - Zane has blood blisters in both sides of his cheeks, petechie all around the inside of his lips. I DO NOT UNDERSTAND! Honestly I don't want to understand!!! I want him just to be better!!!



10/9/2012 - Platelets 133,000.
10/17/2012 - Platelets, 25,000.
10/24/2012 - Platelets, 97,000.
10/31/2012 - Platelets, 62,000.
11/7/2012 - Platelets, 96,000.
11/14/2012 - Platelets, 137,000.
11/21/2012 - Platelets, 55,000.
11/28/2012 - Platelets, 62,000
12/5/2012 - Platelets, 7,000, there was a problem with the Nplate Lot, there was more than one patient of Dr. T's that experienced a drop in platelets..Has to stay until his numbers come up :(
12/11/2012 - Platelets 471,000, No Nplate.
12/15/2012 - Upper Respiratory Infection .
12/17/2012 - Dr. T preformed a Bone Marrow Biopsy to Make sure everything still points to ITP and to check his Bone marrow for Fibroids. Also, this will allow Zane to receive a new treatment.
12/19/2012 - results of BMB came back with normal signs of ITP.



Zane will begin 4 rounds of Rituximab. Rituximab is a type of immunotherapy known as a **monoclonal antibody**. A monoclonal antibody is a man-made version of an immune system protein that fits like a lock and key with one certain protein. Rituximab is designed to seek out and lock onto the protein receptor (CD20) found on B lymphocytes (B cells) in the body. Some normal B cells carry this protein, as well as the cancerous ones found in non-Hodgkin lymphoma. Once the antibody attaches to the cells, it brings in other immune cells to help kill them.

12/28/2012 - Platelets 32,000, 1st round of Rituximab Treatment, Zane did very well, a little pale and tired.

1/2/2012 - Platelets 74,000, 2nd round of Rituximab Treatment, again he did amazingly well!

1/9/2013 - Platelets 24,000, 3rd round of Rituximab Treatment, numbers are going down.



1/18/2013 - Platelets 7,000, well Zane has the influenza He is doing pretty good, fever broke (for now), his received Nplate, hoping that will bring his platelets up to a safe place, he is getting Tamiflu to help him get over the flu type A, and get out of the "critical stage".

1/20/2013 - Platelets 5,000

1/23/2013 - Platelets 83,000.

1/25/2013 - Platelets, 325,000.

1/30/2013 - Platelets, 102,000.

2/5/2013 - Platelets, 56,000.

2/7/2013 - Platelets, 47,000.

2/13/2013 - Platelets, 251,000.

2/22/2013 - Platelets, 14,000.

2/27/2013 - Platelets, 65,000.

3/6/2013 - Platelets, 28,000.

3/13/2013 - Platelets, 204,000.

3/20/2013 - Platelets, 99,000.

3/27/2013 - Platelets, 101,000.

4/3/2013 - Platelets, 99,000.



4/6/2013 - Thought we had another ER run today, the Chicken Coop door fell on his neck. Thank goodness his numbers are okay so I will let him be a normal boy (aka watch him like a hawk!)....

4/10/2013 - Platelets 31,000

4/13/2013 - Zane received tickets for the Kansas Koyotes from the Cotton O'Neil Cancer Center. We had a wonderful time!

4/17/2013 - Platelets 23,000.

4/22, 2013 - Platelets 118,000.

4/24, 2013 - Platelets 275,000.



4/29/2013 – At dinner Zane asked me, Mom am I low? I said I don't know are you, he said Yep, I'm Sick.

5/1/2013 - Platelets 11,000, yes he was right....he was sick.

5/8/2013 - Platelets 129,000.

5/15/2013 - Platelets 97,000.

5/22/2013 - Platelets, 61,000.

5/29/2013 - Platelets 227,000.

6/5/2013 - Platelets 126,000.

6/10/2013 - Platelets 59,000.

6/13/2013 - Platelets 127,000



6/19/2013 - Platelets, 111,000, big brother carrying little brother after shot.

6/23/2013 - Platelets 34,000.

7/3/2013 - Platelets 67,000.

7/9.2013 - Platelets 139,000.

7/17/2013 - Platelets 117,000.

7/24/2013 - Platelets 136,000.

7/31/2013 - Platelets 60,000, It's Wednesday again....I pray for the day Zane does not have to make these weekly trips...But for me I get to see all the loving faces of the Cancer Center!

8/13/2013 - First day of 1st Grade, 2nd Grade and 4th Grade!



8/14/2013 – Platelets 199,000

8/21/2013 – Platelets 29,000

9/11/2013 – Zane tells the new Phlebotomist what needle (orange one) to use, and where to do it, right in the middle.



9/15/2013 – Jr. Kaws Football Coach Brian Damme made Zane the Official Water Boy! Zane will never be able to play football but, at least he can still be a team player!!



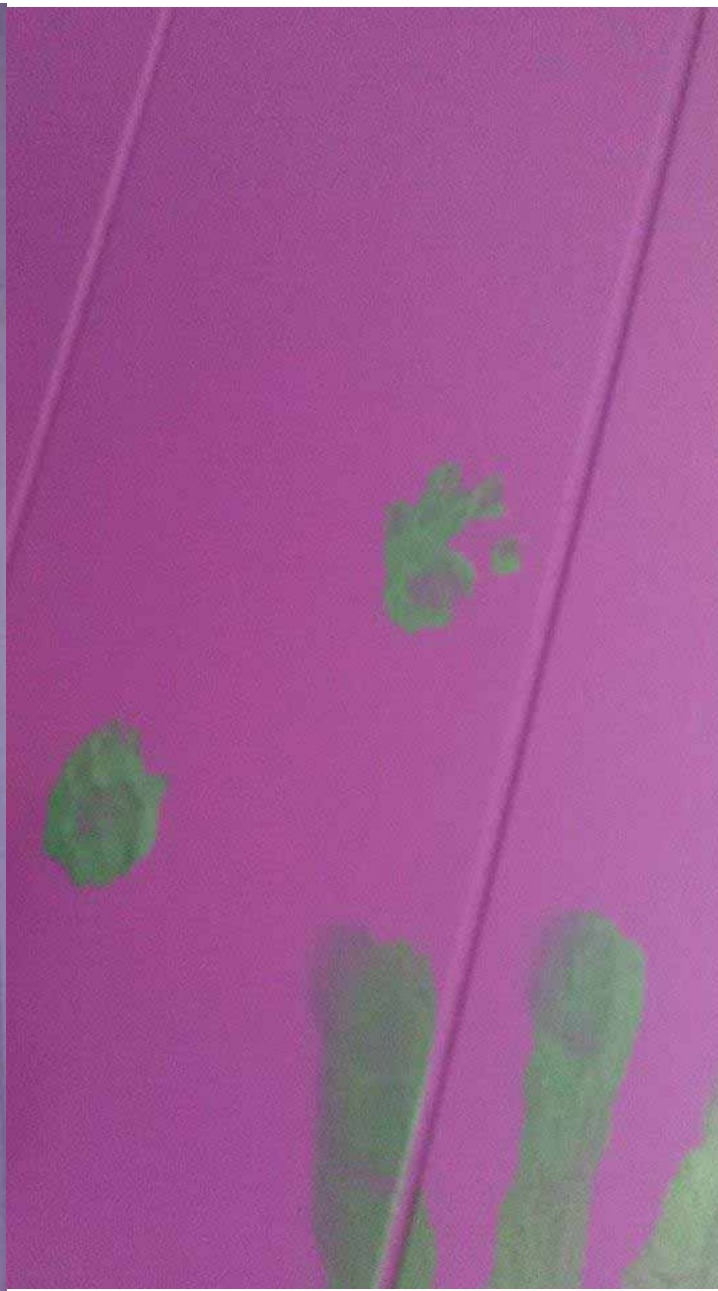
10/17/2013 - Platelets 25,000.

11/26/2013 - 2nd Bone Marrow Biopsy, he fought this one, he pulled his IV out 3 times during the biopsy.
BMB came back with normal signs of ITP!!

12/3/2013 – Platelets at 9,000 IV Steroids for 3 days.....
Fought the IV So much this is what happens :(



10/6/2013 - Cousin Kim came up to paint Zane's room Purple!!! Purple for Platelets!!



12/15/2013 - My bruised up baby . Going to see Dt T and Amy in the am!

1/7/2014 - Platelets 15,000 . Still on steroids until Promacta gets here!!! Needs to hurry up!

1/8/2014 - Promacta will be here tomorrow!!! I know this will be Prayers answered in a box in pill form!!!!

1/9/2014 - Zane took his first Promacta pill tonight!! 1.5 hours ago . So far so good, fingers crossed!

1/13/2014 - Well.....Zane started Promacta on Thursday, stopped Steroids Friday.....CBC today....9,000
Back on Steroids and another CBC Monday.....Trying to be patient!!

- PROMACTA is a prescription medicine used to treat low blood platelet counts in adults with chronic immune (idiopathic) thrombocytopenia (ITP), when either corticosteroids, immunoglobulins or surgery to remove the spleen have not worked well enough.

- PROMACTA should be used only in patients with chronic ITP whose low blood platelet counts and clinical condition increase their risk for bleeding.

PROMACTA is not used to make your platelet count normal. It is not known if PROMACTA is safe and effective in children.



2/11/2014 – 4 weeks and 5 days on Promacta 12.5 & Steroids platelets are only 27,000.....still being hopeful and patient

3/31/2014 – Platelets 12,000, About 3 weeks on 25 mg Promacta....bumped up from 12.5.....tapering off steroids only .5 ml once daily....only at 12,000 ;(.



3/31/2014 – Well seems like Promacta is not working...still hoping it will “kick in”. Dr. T. has determined that in 5 weeks if his numbers do not increase then we will be looking at more Chemo, in pill form. Dr. T. said in some patients a small amount of Chemo will help increase the platelets....

Since Zane's Journey began we have learned so much. We have learned how to lean on our family and friends, beg God for mercy, and pray that Zane can make it through another year. Though his Journey we have met some amazing people through The Cotton O'Neil Cancer Center, Dr. T jokes that she will be attending Zane's wedding. I have called her at all hours of the night and day, she is there for us 24/7! Amy has become a good friend to us, she is an amazing caring beautiful soul that would do anything in the world for her patients. Zane is well known at Stormont Vail Hospital, he would keep all of the nurses on their toes when he walked in the door! Through Facebook I have found people from all around the world, they are a wonderful support system. This group is a 24/7 support system We share stories, laughs, cry's, success and not so successful stories. There are members of all ages, races, and genders.

ITP is truly a rollercoaster....until the ride comes to a stop we have to endure the up's, downs, and plateaus.

One Day....One Day there will be a “cure”, until then....Ride On

Dr. Jakica Tancabelic



Amy Kline, R.N.

