MY TENTH GRADE YEAR WITH EWING'S SARCOMA

(NO RAINBOWS WITHOUT ANY STORMS)

By: Sydney Lister

August, 2011

As the summer came to an end, I became very excited to return to school for my sophomore year at St. Thomas Aquinas High School. I was anxious to see all of my teachers and friends. I was looking forward to having a great year, especially the football season, homecoming events, playing basketball and participating in Calini. Everything was going as planned and I truly love attending school at St. Thomas.

Early into the first quarter I developed some foot pain. I saw a podiatrist who recommended I wear softer footwear to school.

September, 2011

On Thursday, September 8, 2011, I telephoned my mom from school in tears. I had a pain in my lower back that radiated down my leg to my right foot. My mom picked me up and brought me home. My dad had called an orthopedic surgeon, Fernando Moya, and got me an immediate appointment that afternoon. Dr. Moya was in surgery, so I saw his physician's assistant. She took x-rays, told us it was muscle spasm and gave me a prescription for a muscle relaxer. My father insisted that an MRI be performed. An MRI was scheduled for Monday at DPI in Pembroke Pines.

I have never had an MRI done before. MRI stands for magnetic resonance imaging. It's a big machine with a hole that you go into and makes a banging noise. It takes a picture of the soft tissues in your body. They give you ear phones so you can listen to music while you're in there for about 45 minutes.

The following day, my parents were called into Dr. Moya's office to discuss the results of the MRI. He advised them that the films revealed a mass in my pelvic region and was more likely than not paraganglioma which usually are benign tumors. The mass measured 3cm x 3cm x 1cm. When my parents told me this, it was no big deal. Dr. Moya pulled some strings and got me an appointment on Wednesday morning at the oncology unit of Joe Dimaggio's Children Hospital in Miramar and another appointment in the afternoon with Dr. Mark Temple at the University of Miami, Sylvester Cancer Center.

On Wednesday morning I met with the doctor at Joe Dimaggio's, who again confirmed it was more likely than not paraganglioma. They told us that a CT guided biopsy would have to be performed. I learned that is when they put you in a machine similar to an MRI and they go in with a needle and take a piece of the tumor to be cultured. After telling my parents we would have to meet with the radiologist on Friday and then schedule the procedure the following week we left and proceeded to Dr. Temple's office at the University of Miami.

Dr. Temple is an oncological surgeon which means he operates on people to take out tumors. He examined me with a really cute intern. He told us that if he could pick up the mass on an ultra sound, he would perform the needle biopsy right now. After giving me a local anesthetic, he went in with the needle and did something that sounded like a clicking. The first time he couldn't get enough of the tissue so he had to do it again. He told us they wouldn't have the results until Monday.

That Saturday, I attended the Ft. Lauderdale Strikers game in memory of Kevin O'Connell. He was a good friend from St. Bonaventure who died in a car accident. I had fun. It was like any other Saturday. I was telling people I had a tumor.

On Monday September 19th, we returned to Dr. Temple's office. He told us that based on the biopsy there was a 90% chance I had Ewing's Sarcoma. I remember crying and saying "it's not true". Dr. Temple left us alone for about fifteen minutes so we could talk as a family. After returning, Dr. Temple notified that surgery is not an option because of the location of the tumor. It was wrapped around my sciatic nerve which was causing my pain down my leg. An appointment was set up for the following day so we could meet with Dr. John Goldberg, a pediatric oncologist at the University of Miami. On the way home I told my father that I was awesome and posted on my Facebook page, "Cancer, bring it on bitch".

Dr. Goldberg explained to my sister and I that this was not our fault and we did nothing wrong. I learned that they only treat Ewing's Sarcoma one way, with a protocol consisting of chemotherapy and radiation treatment. I learned Ewing's Sarcoma gets the harshest chemotherapy of any cancer. Apparently, I needed to get the following diagnostic procedures performed prior to beginning treatment, MRI of the chest, CT Scan of the pelvis, bone scan and a PET Scan. He told us these could take up to two weeks because The Sylvester Cancer Center uses Jackson Memorial Hospital. In the meantime, my father's law partner arranged for us to meet with Dr. Katie Janeway at The Dana Farber Cancer Institute in Boston.

He was advised that they roundtable every case on Tuesday mornings and need all diagnostic films in Boston before that time. My father contacted a family friend, the chief of staff of cardiology at the Cleveland Clinic who expedited all testing to be done within the next three days.

The last of the tests performed was the PET Scan, which was done on Saturday the 24th. PET stands for positron emission tomography. This test is important because it illuminates in your body where the cancerous cells are. The good news was that the only thing that lit up on my PET Scan was at the tumor site in my pelvic region. This was extremely important because it meant the Ewing's disease was localized as opposed to metastatic. Localized means it is one spot. Metastatic means it has spread to other parts of the body.

My films were overnighted to Boston and we flew up there on Tuesday to meet with Dr. Janeway on Wednesday. We stayed at the Marriott Long Wharf that had breathtaking views of Boston Harbor. We were right across the street from Faneuil Market Place that had a lot of neat shops and restaurants. I did a lot of shopping there. On our way to the hospital the following morning we drove by TD Banknorth Garden, where the Celtics play and Fenway Park, where the Red Sox play. Dr. Janeway spent two hours with us and confirmed the biopsy findings and explained the Ewing's Sarcoma treatment protocol to us. We flew back the following morning.

What is Ewing's Sarcoma

Ewing's Sarcoma is a cancerous tumor that grows in bones or soft tissues near bones and usually affects adolescents. Named after Dr. James Ewing, the American pathologist who identified the cancer in the 1920s, it can develop anywhere in the body, but most commonly affects the arms, legs, ribs, spinal column and pelvis. There are approximately 200 cases of Ewing's Sarcoma diagnosed annually in the United States. Ewing's Sarcoma often goes unnoticed or misdiagnosed as growing pains or a sports injury because symptoms often mimic those injuries. Regardless of a tumor's characteristics, every patient with Ewing's Sarcoma undergoes chemotherapy initially to shrink the tumor and prevent the spread of cancer cells to other parts of the body. Chemotherapy is also given after a tumor is removed to help ensure that the cancer cells do not come back. The chemotherapy is administered through a port, which is a thin catheter placed surgically into a large vein by the heart.

Ewing's Sarcoma chemotherapy protocol consists of 14 cycles. The drugs I was taking are:

Doxirubicin- This is also call adriamycin. It is used to slow and stop cell growth. It is administered for 48 straight hours. This was given the nickname of "red devil" or "red death" due to the severe side effects. The side effects I suffered from were nausea, vomiting, sores in my mouth and throat, loss of appetite, stomach pain, increased thirst, hair loss, eye pain, pain and tingling in my hands and feet and red discoloration of my urine. Doxirubicin may also cause heart problems for years after the treatment has ended and inhibit one's ability to bear children.

Vincristine- This drug is administered with doxirubicin and causes cell death by interfering with the way DNA in the cell multiplies. The side effects I suffered from were nausea, temporary taste changes, tingling in my hands and feet and hair loss.

Cyclophosomide- This drug is used to slow and stop cancer cell growth. It is administered over a two to five day period. The side effects I suffered from were hair loss, stomach aches, mouth sores and weight loss.

Etoposide- This drug seems to interfere with the growth of cancer cells. It is administered for one hour over five days. The side effects I suffered from were low blood pressure, hair loss and metallic food taste.

Ifosfamide- This drug is administered over a one hour period for five days along with a drug called mesna to protect your kidneys. The side effects I suffered from were hair loss, nausea and vomiting.

All of these drugs affected my white cell count, hemoglobin and platelet counts. After my treatment sessions I required daily neupogen injections for 7-10 days until my white cell count got back to normal. I also required several transfusions of hemoglobin and platelets during the course of my treatment.

October, 2011

I continued my studies at St. Thomas, but knew in the very new future that I was going to be forced to withdraw due to my compromised immune system. This made me very sad.

On Tuesday, October 4th, we went early in the morning to meet with Dr. Goldberg prior to checking in for my first cycle of chemotherapy. Dr. Goldberg kept wanting to tell me about Ewing's Sarcoma and the side effects of the chemotherapy, but I would ask him to leave because I didn't want to hear it. I don't like Dr. Goldberg and he has a terrible bed side manner. I painted a picture of Dr. Goldberg while I was in the hospital, it was a "red devil". After meeting with him, we walked across to the hospital where I was prepped for surgery so they could put in my port. I woke up in my room where my parents were waiting. The first cycle I received was the Doxirubicin and the Vincristine. I soon found out why the call it the "red devil". I have never felt so bad in all my life. I met a boy named Cody Meiers who was in treating for Ewing's Sarcoma. He was diagnosed in June. His father is a Broward Sheriff in Weston. We became friends and talked on Facebook. I was discharged on Thursday. I had to have neupogen injections into my thigh every day for approximately ten days until my white blood cell count got back to normal. I have to take a large pill called Bactrin three times a week. While at home, my temperature went over 101 degrees so I went to the ER at The Cleveland Clinic and was then taken to Jackson by ambulance. I was hospitalized for a couple days to make sure I didn't have an infection.

While I was in the hospital, my parents were advised that I was selected as one of the sophomore representatives of the Homecoming Court. It really didn't hit me at that time because I was feeling so bad. When I got home I laid in bed for a couple days recuperating from the beating my body took. My parents told the doctors about the Homecoming and they agreed to extend my second treatment of chemotherapy a week so I could participate in the festivities at school. I remember lying in bed with my father a few days before the game crying because my hair was starting to fall out. The next morning my mother took me to Gilberto Hair Center in Miami where I had my head shaved and was fitted for a wig. I picked out a long blonde wig which gets glued to your scalp.

The next few days at school, the game and dance were the highlight of my year. The staff at St. Thomas and my fellow students made me feel so special. It is a week I will never forget. Sadly, Friday the 21st, my father filled out the necessary papers to withdraw me from St. Thomas. This made me sad but I knew it had to be done. He registered me at Western High School so I could enroll in The Florida Hospital Homebound program. I basically did not like this because I have had all of these classes already.

My second cycle of chemotherapy, the five day one, started on Monday, October 24th and I was discharged late Friday the 29th. Dr. Goldberg continues to want to talk about side effects and I continue to not want to hear them. Checking into the hospital is really a pain and takes a long time. The nursing staff is not the friendliest here either. By this time I was almost completely bald. I also had to undergo my first hemoglobin transfusion.

November, 2011

Monday, November 7th, I checked into Jackson for my second cycle with the "red devil". This time when I was discharged I was really sick and weak. I must have had about a dozen sores in my mouth that were so bad I could hardly swallow my own saliva. My wig came in and my mother and I went down to Miami so it could be fitted and glued. It looked pretty natural but was really uncomfortable. That Saturday, I went to the St. Bonaventure Family Festival. It was really good to see everyone, however, I didn't have any energy and just sat in a chair. The following week I made the decision to go with out the wig.

I was scheduled for a repeat CT Scan of the chest on November 21st and a repeat MRI with contrast on November 22nd. I hate getting the contrast because they have to run a line and I have difficult veins to stick. We went to Jackson Memorial Hospital for the CT and the process took forever. The following day was a nightmare. We waited almost three hours when my father said we were leaving and he made arrangements to have the MRI done that evening at DPI in Pembroke Pines. The following day we were advised that the tumor had been reduced by 70%.

The Monday after Thanksgiving, I had to check back into Jackson for round four of the protocol. This is really a pain, because I have to go to one building to have my blood work and port accessed and then we have to go over to register for my room on the pediatric oncology floor. My appetite has not been that great and probably have lost about 12-15 pounds at that this time. I was discharged on Friday, December, 2nd.

December, 2011

We met with the radiation oncologist at the Sylvester Cancer Center who discussed the radiation process. My parents were leaning on me getting Proton B therapy instead. Dr. Goldberg was pushing the standard radiation. Standard radiation is when there is an entrance point on your body, it hits the target and continues straight through and exits at the opposite side. The highest dosage of radiation occurs at the entrance site. It hits any and all organs that are in its path. Proton B therapy targets cancer more accurately. Unlike traditional radiation, protons can be directed to reach only the areas of the body affected by cancer. As a result, normal, healthy tissue receives less exposure to radiation treatment, reducing the risk of complications. The highest dosage with Proton B therapy occurs at the site of the tumor. There are only seven Proton B Centers in the United States, one being at The University of Florida, Shands Hospital in Jacksonville. You had to apply and be accepted into the Proton B therapy program.

I returned to Jackson Memorial Hospital for the last time on December 12th for my two day protocol with the “red devil”. We arrived at Jackson around 9:00 a.m. and after having my port accessed we went to register. We had to wait seven hours to get into our room. My father called Heather Miller, the head nurse in the oncology unit at Chris Evert Children’s Hospital to make arrangements to have my treatment transferred up there. My mother was notified that I was accepted as a patient for the Proton B therapy. We also met with Dr. Roskos at Broward General Hospital to arrange for my transfer there.

I was scheduled to meet with Dr. Daniel Indelicato on Tuesday, December 20th. We drove up and stayed at the Marriott. The next morning we drove to Shands where I was registered. The facility was beautiful and much nicer than Jackson. After registering, we met with several of the nursing staff who were very nice, however, I was advised that I had to undergo a CT Scan with contrast and an MRI. The MRI was no problem, but I had to drink that pasty liquid for the CT Scan, which I can’t do. I was extremely angry with everyone. After the scans were done, they marked my body in several areas that were going to be the entrance point of the protons. They also had me lay down so they could make a cast of my body which I have to lie in when getting the Proton B treatment. Dr. Indelicato sat with us and started talking about all of the possible complications of the treatment and again I didn’t want to hear it. I left and went to wait in the lobby. The good news was that while I was undergoing the Proton B therapy I didn’t have to do the Doxirubicin because the combination of the two was too harsh.

Right around Christmas, my hemoglobin got extremely low and I became very anemic. I started noticing a vision problem and learned that capillaries in my eye had ruptured. I had to have an emergency transfusion. I checked in for my chemotherapy cycle at Broward General on December 26th. It was the two day nightmare with the “red devil”. The facility and the nursing staff here was so much better than at Jackson. As soon as my port was accessed I was taken up to the eighth floor where pediatric oncology is located. A lot of the nursing staff had attended St. Thomas Aquinas. I liked it here much better. After returning home it was time to pack for Jacksonville

<u>January, 2012</u>

I was extremely reluctant about staying at The Ronald McDonald House. An anonymous donor arranged for his private jet to fly my mother and me to Jacksonville while my dad drove my mom’s car up packed with all of our stuff for a 7-8 week stay. I got off the plane very angry and told my parents I wasn’t going there. When we arrived I told them I wasn’t getting out of the car. When I got inside I told them I wasn’t taking the tour or ever coming out of the room. Our room was on the third floor. After the first week they moved us down to a bigger room on the first floor. The rooms were nice but they were a little on the warm side. The following day, we went across the street to The Nemours Children’s Clinic where I met the oncologist and nursing staff. I would receive my chemotherapy at The Wolfson Children’s Hospital. I would be transported every day I was hospitalized to The Proton B Center and then taken back to continue my chemotherapy.

I went in for my five day cycle on January 9, 2012. The Proton B machine is like walking into a big space ship. I lie in the cast and it takes about three minutes. I typically went in the afternoon because the youngest children went early because they have to be anesthetized to keep them from moving.

When I got back to The Ronald McDonald House I began to warm up to the idea of staying there. Everyone there had cancer of some form and were in Jacksonville for Proton B treatment. I made a lot of good friends there. My best buddy, who I fell in love with, was little three year old Raegan Whaley. Raegan was suffering from a really rare brain cancer. They were in England when she was diagnosed. Her father was in the Air Force. I called my dad to tell him how excited I was that I met her. We did everything together.

I continued receiving my Proton B treatments everyday except Saturdays and Sundays. On January 23rd, I checked in for my cycle of vincristine. Thank God I didn’t have to the doxirubicin. I was really excited because I was going to fly home Friday after my Proton B session for the weekend to attend The Chili Cook Off. Luke Bryan and the Zac Brown Band were playing. I had a great time and got to see all of my friends. I flew back Monday morning with my mom to continue my Proton B therapy.

During the weeks that I wasn't doing my chemotherapy in Jacksonville, we had a lot of free time on our hand. After I finished my schooling we would go shopping or see the town. One day we went to the zoo with Raegan and her mom, Shelby. I loved Raegan so much. Over the weekends a lot of the people would leave The Ronald McDonald House. Sometimes we would stay out at Jacksonville Beach at a friend of my mother's.

February, 2003

I flew back home Friday, February 3rd, after finishing my Proton B treatment so I could work at and attend the That's Amore SIDES fund raising dinner. The food was prepared by celebrity chef, Mark Randazzo, who attended the event. I took a picture with him. The event ended up raising more than $65,000 for Ewing's Sarcoma research. I flew back Sunday because I was supposed to start my five day chemotherapy cycle. Monday morning I found out that my platelet count was low so it was put off. At Broward General they would have given me a platelet transfusion, however, in Jacksonville they wait for your body to produce the platelets on its own.

My mother and I flew back to South Florida on the evening of the 10th so I could attend my sister's confirmation at St. Bonaventure. She has asked me to be her sponsor. I was so proud and thankful that she asked me. I feel so bad for my sister. I know I have been getting a lot of attention and it has to be hard for her. When we finish youth group on Sunday nights we each say a prayer and I pray for Casey.

That Sunday, my father drove up to stay with me. I checked into Wolfson Children's Hospital on Monday, the 13th for my five day chemotherapy cycle. Wednesday was the worst day I had from a nausea standpoint. I threw up about six times that day. After I did my Proton, we would go hangout at the house until I was scheduled back for the hospital. I continued to do my schoolwork with the hospital homebound program. After that, I would play on my Ipad or watch dvds.

I only had one week of Proton B therapy left. My mom drove back up to stay with me and brought my sister for the week. That was a pleasant surprise. She got to meet Raegan. We had a lot of fun this week. After my last visit, the staff at Shands Proton B Center had a little party for me and bought me a beautiful cake. We started packing the car so we could leave on Saturday. It was sad to say goodbye to all of these wonderful people I had met, especially Raegan and Shelby. Raegan was scheduled to leave the following week. My dad and Mr. Uhre flew up on the private jet and we met them at the airport with the car. I was excited to go home for good. I was not looking forward to starting the doxirubicin again.

I went to the St. Bonaventure Ball with my father. I had a good time and danced a lot.

March, 2012

I had a burn mark on my lower back about the size of a cantaloupe from where the Proton B beams hit me. It was not as bad as Dr. Indelicato said it would be. He told me that it would blister. I would have my mom and dad rub aloe and special creams on it. I went to a fund raiser with my father at the Hardrock for the Jason Taylor Foundation. I met Kevin Jonas and a lot of baseball and football players. I danced with Katina Taylor. I was tired so we didn't stay long.

I was supposed to check in on March 5th for my two day cycle with the doxirubicin. My counts were really low because of the combination of the chemotherapy and the Proton B treatment. I needed a transfusion. They told me that I would not get the doxirubicin due to the level of my blood counts. This was a pleasant surprise.

After completing my first chemotherapy cycle in March, I remember lying in my father's bed playing on my computer. It was all like a blur to me. I was following Raegan on her Caring Bridge site. The next thing I remember was calling my father crying. I told him Raegan was dying. They had moved her back home into hospice. He came home immediately and picked me up because he didn't want me to be alone. I loved Raegan so much. She was always smiling and laughing. I smiled every time I saw her.

I checked in for my five day session at Broward General on March 19th. When I'm in the hospital I sleep a lot. On Tuesday while I was sleeping, my mother learned from a post on the computer that Raegan had passed away on Sunday the 18th. My parents decided not to tell me until I was released from the hospital. I don't know if it was the drugs, but it made me kind of numb. God has the best little angel. I had told my parents that I wanted to put ceiling fans into all of the rooms up at The Ronald McDonald House in memory of my friend.

I was asked to do some modeling work with The Academy of Glam. I did several shoots. I hope fellow young cancer patients see these and realize they should not be ashamed of how they look. We are beautiful. Bald is beautiful.

April, 2012

On April 1st, a friend of my father's arranged for us to be a guest of the New York Yankees at Marlin Stadium. We got on the field for batting practice. There was a yellow rope keeping the fans on the field away from the players. There must have been over 100 people there. Some of the players came up, took pictures and signed autographs for the fans. Out of nowhere, Joe Girardi, the manager of the Yankees walked up to me and said, "hi Sydney" and gave me a kiss on the cheek. He asked me to come with him and he took me under the rope. We talked for about 45 minutes. He introduced me to all of the Yankees and had the team photographer take pictures of us. Mr. Girardi got me a bunch of baseballs for autographs. I made sure I got one signed by Derek Jeter for Mr. Zamarano.

I checked in on Monday, April 2nd. I learned that I wasn't going to have to do doxirubicin until my 13th cycle. This was great news. My hair was starting to come back in a little. I learned that my Make A Wish had been granted. I was going to meet and have lunch with Emma Stone in New York City. I was so excited.

I had a bunch of tests that had to be done this month. On April 16th I was scheduled for a CT Scan of the chest and a pelvic MRI. I couldn't drink the contrast so they did it without it. On April 17th I had the PET Scan done. I ended with the bone scan on April 19th. All the scans came back normal and showed no signs of the tumor. I remember meeting with Dr. Rodriguez at the clinic later that week. He went over each scan and said perfect after reviewing each one.

On April 24th I attended Blu's Poetry Showcase at The Improv hosted by Omari Hardwick. The artist, Lebo, painted while the kids from The Jason Taylor Reading Room recited their poems. Afterwards, Katina Taylor took me to meet Omari. He was really nice and told me he was really proud of me.

I felt like I didn't have to get any more chemotherapy but my parents insisted on completing the protocol. I checked in on April 30th for my two day cycle.

May, 2012

I checked in on May, 5th for my five day cycle of chemotherapy. This was the first time I checked in on a Saturday. They allowed me to do that so I could have a few more days to recover and get my strength back before leaving for New York. My father took me in on Saturday the 12th to have my blood checked. They wanted to give me a transfusion because I was going to New York because they knew my counts would go down. I refused and had a big argument with my father. That evening I agreed and we went back and I had a platelet and hemoglobin transfusion.

On Friday, May 11th, I attended the Prom to Remember at the Ritz Carlton in Ft. Lauderdale. This event is put on for pediatric cancer patients from about a dozen hospitals from Dade, Broward and Palm Beach County. They buy gowns for you and do your hair and make up. I wore my own dress and did my own make up. We met at the hospital and were picked up by a party bus. When we arrived, the girls were escorted down a red carpet by a member of the Miami Dolphins. I danced the night away.

I was all packed and ready to go Sunday evening. On Monday morning the four of us were picked up at my mother's by a limousine. The Jet Blue staff had arranged for me to sit in the cockpit prior to takeoff. After landing at JFK, we were picked up by our limo and taken to the hotel. We stayed at the Hampton Inn on East 39th Street. After we checked in we took the subway to Chinatown to go shopping. When we got back to the hotel I was delivered a dozen cupcakes from Magnolia Bakery from Emma Stone. That night we went to dinner at The Palm with my uncle. I had developed a rash of some sort on my leg and my parents were concerned that it might be cellulitis. My father and I went to the NYU emergency room late that night. They wanted to start me on an IV antibiotic drip for 12 hours. My father got Dr. Rodgriguez from BGH on the phone and they agreed to oral antibiotics. The next day was rainy so I stayed in the room most of the time. We didn't get to do any of the sightseeing stuff Make A Wish planned for us. Emma had a beautiful bouquet of flowers sent to my room. The one thing I did do today that I wanted to was have a hotdog from a street vendor.

Susan McCann, the representative from Make A Wish, met us at the hotel at 11:00 on Wednesday. Ms. McCann is a cancer survivor. At 11:30, a Suburban pulled up in front of the hotel. When the driver opened the door, Emma leaned forward and said, "hi Sydney". We went to lunch at The Brooklyn Diner. It was great. We talked through the entire meal. After lunch, Emma had arranged for a private tour of the Saturday Night Live set. After leaving, Emma was on the phone and had her driver turn around after five minutes. We went back and she brought us up to meet Jimmy Fallon. He took us into his office and spent about a half hour with us. We went down and watched the rehearsal for his show. On the way back to the hotel, Emma got Taylor Swift on her phone and I spoke to her for about ten minutes. Emma gave me a locket from Tiffany & Co. at the end of the day. We exchanged phone numbers and e-mails and have been talking to each other since. It was a great day. That night we went to see How to Succeed in Business Without Really Trying starring Nick Jonas. Before flying back the next day we returned to Chinatown for some more shopping.

I was very upset. I had to check in on May 29th for my two day cycle. I was scheduled to get the doxirubicin this one last time and resisted. My hair was growing back. It made me really sick and my hair fell out again. It was very upsetting.

June, 2012

On June 18, 2012, I checked in for my last round of chemotherapy. The week seemed to last forever. As ususal, we watched a lot of dvds. The nursing staff was great and gave me a big banner signed by all of them. While in the hospital, I asked my father if I could get a miniature pig and get him certified as a therapeutic pet to visit the children during their hospital stay. I contacted Mr. Panagos and arranged for SIDES to purchase the pig and spoke to the woman that certifies animals. After completing my last session of the protocol I was declared "CANCER FREE". On Tuesday, the 26th, I picked Lily up at the airport.

When I returned to the hospital for my blood work the following week, the nurses in the clinic had a little party for me and gave me a beautiful cake. On a sad note, I learned that Cody's cancer had come back.

July, 2012

I was looking forward to my summer starting. I had plans to go to the Keys with my mom. Emma Stone called and asked me if I wanted to meet her and Andrew Garfield for lunch while they were down promoting their Spiderman movie. We met at the Mandarin on Brickell Key. She wants to bring me to New York this fall when she hosts Saturday Night Live. After lunch, I went home and finished packing for the Keys. When I got back the following week my blood counts were almost normal. I made contact with a distributor and got them to donate 30 Hunter ceiling fans for The Ronald McDonald House in Jacksonville. I spoke to a representative at Tri City Electric in Miami who is contacting an electrician in their union in Jacksonville to install them. When completed the fans will be dedicated in memory of my dear friend, Raegan Whaley. I started doing volunteer work with The Jason Taylor Foundation and worked at the Dwayne Wade/Camp Katina camp.

August, 2012

I went on a week long cruise on the Oasis. After coming back I was super anxious for school to start. I was contacted by a young boy in Hillsdale, Michigan, Tyler Bonsall, through the SIDES website. He was recently diagnosed with Ewing’s Sarcoma. His father asked my dad if I would talk to him. We have become friends on Facebook and talk weekly. I told him to stay strong and “no rainbows without any storms”. This will be over before he knows it.

I also learned that in late August, my friend, Cody Meiers, passed away. We all went to his viewing. This was very hard for me. I waited outside. I pray for his family everyday.

I was nominated by SIDES to be the Jr. Captain of The Winterfest Boat Parade. The winner is determined by a vote on Facebook that ends September 14th. If I win it will be good for SIDES and spreading awareness of Ewing’s Sarcoma and all pediatric cancers.

As for my future, I plan to have my port taken out in the next month. I will continue to work with SIDES, The Jason Taylor Foundation and plan to organize a group of fellow St. Thomas students and friends to do volunteer work at Broward County’s Ronald McDonald House and the pediatric oncology floor of The Chris

Evert Children's Hospital. I would also like to get involved with Make A Wish as well as a Prom to Remember. Myself and another cancer patient are collaborating on producing a music video featuring the patient's and staff at BGH. I was able to get a videographer to donate his services for this project.

This past year has been very difficult. I certainly questioned my faith in God. I would have never imagined that I would see some of the things I have seen at this age. I believe God has a plan for me and I will do great things with what I have learned and endured this past year. Staying busy, despite how I felt, helped me make it through every day. I am thankful that I was allowed to come to St. Thomas and hang out when I felt up to it, singing in the St. Bonaventure Church choir and assisting with the CCD classes. I looked forward to these every week. I have met and made friends with wonderful people this past year. I can say proudly, that kids of all ages who are fighting cancer are warriors and true inspirations.

WHAT IS SIDES

While we were in Boston at the end of September, several family friends and Weston business people created SIDES (Sydney's Incredible Defeat of Ewing's Sarcoma) and had it qualified as a 501(c)(3) charitable corporation. SIDES was originally created to help families who are suffering from Ewing's Sarcoma. The SIDES mission was expanded to find a cure for and a less toxic and more humane treatment for Ewing's Sarcoma. In less than a year, SIDES has raised in excess of $165,000.00 by hosting such fund raisers as The Ride For SIDES Spinathon, My Big Fat Greek Fundraiser dinner, That's Amore dinner, a golf tournament and teaming with The Jason Taylor Foundation for a poker tournament.

My initial involvement with SIDES was helping design the logo while I laid in my hospital bed at Jackson Memorial Hospital. After that I volunteered, worked and attended the different events. We are looking forward to another banner year in raising money for cancer research.

SIDES affiliated itself with Dr. Stephen Lessnick and his Ewing's Sarcoma lab at The Huntsman Cancer Institute in Salt Lake City, Utah. It is one of four Ewing's Sarcoma labs in the country. I had the opportunity to meet and speak with Dr. Lessnick at the That's Amore event. SIDES has funded a research scholar at the institute by the name of Tish Toomey.

The advantage with Ewing's research is that researchers are aware how this cancer originates. Huntsman has just concluded testing of a drug that kills multiple tumor types belonging to the Ewing's Sarcoma family of tumors. They have recommended further clinical development.

I have been invited to and hope to visit The Huntsman Cancer Institute in the near future.