

Brady Simmer's Medical History

- May 30, 2005 Born at Bethesda Memorial Hospital Full Term
Wt. 7 lbs/3 oz. Pediatrician – Dr. Lee Edelstein
- June 16, 2005 2 Week Visit Wt. 8 lbs/4 oz.
- August 1, 2005 2 Month Well Check Wt. 12 lbs/3.5 oz
Concerns documented in his chart : Birthmark on left arm; and 2nd toe on right foot; **Lazy eye; not focusing**
Vaccines: DTP, Haemophilus Influenzae Type B (Hib), Pneumococcal Conjugate, Hepatitis B & Polio
- August 27, 2005 **What is wrong with Brady's eyes?** My husband and I saw the “white pupil”. Emergency visit to Dr. Edelstein @ 1:15 pm in his office. He didn't know what it was either....Hmmm.

Immediate visit to Dr. Lee Friedman, Pediatric Ophthalmologist in Boca Raton – dilation & diagnosis – Bilateral Retinoblastoma
- August 29, 2005 Palms West Hospital (Palm Beach) MRI of Brain w/ & w/o Contrast & Orbit, Face & Neck and CAT scan
- August 31, 2005 Initial visit with Dr. Timothy Murray, Bascom Palmer Eye Institute, University of Miami – Miami, Florida
Confirmed diagnosis of Bilateral Retinoblastoma and remarked “Worst case I've seen in the United States in a decade”
- September 6, 2005** First EUA – laser treatment – Dr. Murray stated that as long as there was a prognosis for vision albeit limited, poor or grave, that he would treat the tumors (as long as Brady responded well to the chemo rendering a positive result/progress)
- September 7, 2005 Surgical Insertion of Portocath in upper left quadrant of chest, Bone Marrow test and Lumbar puncture to rule out any other cancers
- Sept. 7-9, 2005 First round of chemotherapy – 2 hours Cyclosporine (gets injection of Benadryl to offset rash); “Push” of Vincristine (Onvovin) directly into port; 30 hour cycle of Cyclosporine with (1) 1 hour drip of Carboplatin and (2) 1 hour drips of Etoposide (VP-16) Additionally, 1.5 ml Zofran q8hrs to help prevent nausea & vomiting
First round tolerated well; no side effects
- Sept. 30, 2005** Second EUA – laser treatment – Dr. Murray stated Brady responded well to first treatment; tumors have shrunk; however, now there are complications due to retinal folding bilaterally and retinal detachment bilaterally. Expressed that a second opinion may be next course of action and that enucleation may be “thought about” as future course of treatment. Further complication was that Brady's port somehow “inverted”. The surgeon attempted to manually “flip” the port (and also

gave Brady a mild dose of morphine to help with the pain); however, he was unsuccessful. At 7:00 pm that evening, Brady had surgery again and the port had was inverted back to its position. The surgeon used the same area of original incision to gain access.

September 30
October 1, 2

Second round of chemotherapy – Drug levels administered increased. Increase is measured by kilo of weight. 2 hours Cyclosporine (gets injection of Benadryl to offset rash); “Push” of Vincristine (Onvovin) directly into port; 30 hour cycle of Cyclosporine with (1) 1 hour drip of Carboplatin and (2) 1 hour drips of Etoposide (VP-16) Additionally, 1.5 ml Zofran q8hrs to help prevent nausea & vomiting

Second round tolerated well, however, I requested prescription for Zofran and had to administer 1.5 ml po q8hrs for 3 days to offset side effects of vomiting. After 3 days, Brady bounced back and tolerated food and formula without any further complications.

November 2

Third EUA – laser treatment – Dr. Murray stated Brady tolerated the treatment very well. He said his progress was “remarkable”. There continue to be complications with the retinal folding; however, miraculously the retinas in BOTH eyes have reattached. The tumors continue to shrink and regress.

November 2-4

Third round of chemotherapy - 2 hours Cyclosporine (gets injection of Benadryl to offset rash); “Push” of Vincristine (Onvovin) directly into port; 30 hour cycle of Cyclosporine with (1) 1 hour drip of Carboplatin and (2) 1 hour drips of Etoposide (VP-16) Additionally, 1.5 ml Zofran q8hrs to help prevent nausea & vomiting

Third round of chemotherapy tolerated well. No side effects.

November 29th

Fourth EUA – Dr. Murray reiterates that Brady’s case of Bilateral Retinoblastoma is the “worst case he has seen in the United States in a decade”; however, his progress is both “remarkable & phenomenal”. There are still complications with the retinal folding but the retinas in both eyes remain attached and the tumors continue to shrink and regress. As Brady continues to respond well, we may be able to steer further away from the possibility of enucleation.

November 29, 30
December 1, 2005

Fourth round of chemotherapy – Levels of drugs increased due to the fact that Brady is now almost 20 pounds. 2 hours Cyclosporine (gets injection of Benadryl to offset rash); “Push” of Vincristine (Onvovin) directly into port; 30 hour cycle of Cyclosporine with (1) 1 hour drip of Carboplatin and (2) 1 hour drips of Etoposide (VP-16) Additionally, 1.5 ml Zofran q8hrs to help prevent nausea & vomiting .

Discharged and no side effects were apparent at that time.

December 2, 2005

At about 4:00 pm Brady wasn’t acting like himself. At approximately 7:00 pm he spiked a fever. We took his temperature with a digital thermometer under his arm – it was over 100.5. We called his

Pediatrician, Dr. Lee Edelstein and the Jackson Memorial Pediatric Oncologist on-call, Paul Gordon. We monitored him for approximately 1 hour. I administered the Lidocaine & Prilocaine cream (2.5%) topically on his port. We called both physicians and told them we were on our way to Bethesda Memorial ER. By the time we got there they took his rectal temp which now read 104. A chest X-Ray was done along with a thorough exam by Dr. Cuestas in the ER. His labs were done – CBC, differentials & neutrophils. His results were “okay”. He was given IV fluids and Rocephin via his port and we were discharged per Dr. Gordon and instructed to follow up with Dr. Edelstein the following day. We got home at 3:30 am & Brady & I were up all night and throughout the following day.

- December 3, 2005 Brady was seen by Dr. Edelstein for another shot of Rocephin and we returned to Bethesda Memorial Outpatient for another round of bloodwork. His levels remained “okay”; however, Brady was SUFFERING side effects from the Vincristine. I called Dr. Gordon and he phoned in a prescription of Codeine Elixir. I administered 2cc po q6 hrs. for pain. Brady was moaning and groaning in pain all day and most of the night.
- December 4, 2005 At approximately 8:40 am Brady’s fever finally broke. His appetite was fair however, he was very weak and his body was limp. We returned to Dr. Edelstein at 4:00 pm for another shot of Rocephin (per Dr. Gordon). I also ordered (and received) liquid Colace to administer prn to offset any constipation side effects from the Codeine. Thankfully, he had no constipation.
- December 5, 2005 Brady started feeling a little better today. I gave him one more dose of Codeine at 9:00 am. He slept almost 4 hours. At approximately 2:00 pm he had a ravenous appetite and appeared to be “getting back to normal”.
- December 9, 2005 Had labs done at Quest Diagnostic. Brady’s levels are VERY low. His CBC is 4,300. His platelets were not measurable as they were SO low and his neutrophils are in the 100’s. He is to be watched very closely and kept at home. His labs are to be repeated in one week for further assessment.
- December 12 Brady started running a low grade fever in the evening. I stayed up all night with him knowing if it spiked over 101 that it would be another trip to the ER.
- December 13 I called Dr. Edelstein and Dr. Fernandez (at Jackson Clinic) to advise them of Brady’s fever. Dr. Fernandez advised if the fever went over 101 – back to the ER for probable Admission. Previously discussed, Bethesda had no Ped’s floor nor Pediatric Oncology Department. St. Mary’s Hospital in West Palm Beach would be the place to go. At approximately 12:30 pm, Brady’s fever spiked to almost 102. I called Dr. Fernandez and she then called St. Mary’s ER to debrief their Pediatric Oncologists, Dr. Saxena & Dr. Gowda of Brady’s condition. I applied the EMLA cream, packed bags and rushed Brady to St. Mary’s. We were seen in the ER,

his port was accessed and labs were done – CBC, Platelets, UA and multiple cultures. He was immediately put on IV fluids and Fortaz. We were admitted to a private room on the 2nd Floor. Brady's admitting diagnosis was fever/Neutropenia. His platelets were so low that I now know to look for petechia and yellowish skin tone. We were advised that Brady needed blood transfusions. They typed and crossed his blood and Dr. Saxena ordered 180 cc of Radiated blood. They began the red blood cell transfusion; but Brady spiked another high fever and they had to discontinue the transfusion an hour into it due to the 104.9 fever. Brady has very little appetite.

- December 14 Brady was still spiking fevers over 104. Nurse Michelle suggested that Brady may have a sinus infection. A sinus X-Ray revealed opacity to the ethmoidal & maxillary sinuses indicating sinusitis with fluid. He was then put on IV Clindamycin to treat the Sinusitis. He was given Tylenol & Benadryl and the transfusion was able to be completed. He started to "pink up" a bit; however, at about 8:00 pm he was moaning in pain – AGAIN! Ironically, he kept pointing to his head. He was given 1 mg of morphine via IV over 1 hour. He was finally able to relax, slept through the night and broke his fever early the next morning. His labs were repeated at 4:00 am and he was still neutropenic and had very little appetite.
- December 15 Brady continued to receive IV fluids & Clindamycin but did not run a fever. I discussed with Dr. Saxena the side effects Brady had from the Vincristine and the terrible pain he was in. He suggested liquid Dilaudid; a stronger narcotic and better than codeine. I know that when I was administering the codeine every 6 hours, it was short-acting, there was a risk of constipation and that the Tylenol in the syrup would mask a fever. When Brady started moaning again, we gave him .5 mg Dilaudid and it made a world of difference. Brady was no longer in pain. Dr. Saxena wrote us a prescription for 20 ml Liquid Dilaudid to administer to Brady po q4-6 hrs. prn. IT WORKS! His labs were repeated and he started showing improvement; he has been tolerating formula very well but has little/no interest in any baby food.
- December 16 Brady was feeling better today. The transfusion made a big difference. He has gotten some of his color back and the petechia is beginning to go away. He was still in a great deal of pain due to the sinus headaches and was given .5 ml dilaudid every 4-6 hrs prn. His labs were repeated and continued to show improvement. He still wants only formula; no baby food.
- December 17 We were discharged from the hospital today. Brady had his final dose of Clindamycin over 1 hour at 12:30 pm. His cultures all came back negative. His labs continued to show marked improvement – enough to allow us to go home. He continues to tolerate formula but has no interest in his baby food. Brady is on Ceftin x 10 days (2.5 cc 2x/day) and we will be following up at St. Mary's clinic on Wednesday, December 21st for repeat labs and Pediatric Clearance for his 5th EUA/Chemotherapy treatment on December 23rd – December 25th.

December 18 Brady is feeling better today. He had 8 oz. of formula this morning and his Ceftin. He was very fussy and seemed to be in pain, so we gave him some dilaudid. Within 30 minutes he was laughing again. He had another 8 oz. of formula for lunch but remains uninterested in baby food. He has been sleeping on/off throughout the day.

December 21 Brady returned to Dr. Saxena's Clinic for follow up exam post hospitalization. Dr. Saxena did Pediatric Clearance after full examination and blood work was done. Brady's counts were GOOD!!!! He is ready for Treatment #5 on December 23, 2005

December 23rd Brady's Fifth EUA. Brady continues to respond "remarkably & phenomenally". Retinal folding remains; tumors are regressing. Dr. Murray never expected such positive results; but we're not out of the woods yet. At this stage of treatment, "we are now trying to save his eyes".

December 23-25 Fifth round of chemotherapy – Vincristine levels of remain the same due to "no weight gain" however, Cyclosporine levels are increased. 2 hours Cyclosporine (gets injection of Benadryl to offset rash); "Push" of Vincristine (Onvovin) directly into port; 30 hour cycle of Cyclosporine with (1) 1 hour drip of Carboplatin and (2) 1 hour drips of Etoposide (VP-16) Additionally, 1.5 ml Zofran q8hrs to help prevent nausea & vomiting.

Upon discharge we began new regimen of treatment. Due to Brady's multiple illnesses in December we are going to try Neupogen (300 mgc/1 ml VL) shots to give him a "boost". Using a Ultra Fine 0.3 ML syringe, I will administer Brady 17 units Neupogen qd x 12; however, he will have CBC, platelets & differentials done on 1/2/06 or 1/3/06 with results faxed to Dr. Toledano stat. His results will determine whether or not we continue the full 12 day regimen.

December 29 I called Dr. Toledano today. Brady still hasn't had a taste for his baby food – and doesn't seem to have much of an appetite. Dr. Toledano suggested LABS be done tomorrow to check his ANC level....Maybe he doesn't need the Neupogen?

December 30 Labs were done today. Results rendered WBC is only 4.6, Platelets 120 and ANC is 552. Called Dr. Toledano and was told to continue the Neupogen until 1/5/06.

January 1, 2006 Brady ATE today. He appears to be bouncing back from this treatment far better than the past. I have been giving him Benadryl twice daily and that seems to be drying up the congestion. I can tell he is feeling better.

January 5, 2006 Brady's last shot of Neupogen. Continues to have great appetite and remains happy & healthy.

January 11, 2006 Brady had his labs done today and his Pediatric clearance. He weighs 20 lbs. 7 oz. and is 28 inches long. He has a little eczema on his lower back. I will be treating it with a moisturizing cream.

- January 13, 2006** Brady's Sixth EUA. Dr. Murray delivered us WONDERFUL news. He continues to remind us about the advanced nature of Brady's Retinoblastoma and the severity of his case; however, the complications mentioned in the beginning – being the “folding” of the retina in both eyes.....The retina in the right eye is no longer folded!!!! Now we have hope that if the right eye (being the worse of the two) can repair itself and respond to the treatment – so can the left....It is just a matter of time. Dr. Murray stated that he would have NEVER expected such phenomenal results from a case being as severe as Brady's. We are so proud of our little fighter.
- January 13-15th Brady's Sixth Round of Chemotherapy. His levels of Cyclosporine and Vincristine were increased. He reacted incredibly. He showed interest in eating the entire stay in the hospital. He tolerated his foods well with no vomiting. He slept through the night.
- We were discharged from the hospital at approximately 11:00 am. Discharge instructions were the same as always. No Neupogen needed for this round. Brady was behaving normally and showed no signs of any side effects.
- January 30th Another emergency for Brady. Brady started running a low grade fever this morning. He was irritable and restless. By lunch time his fever spiked over 100. I called Jackson to alert them of a possible emergency. They told me to give him Tylenol and they'd call me at 4:00 pm. Due to the nature of Brady's fevers, I decided to take him to St. Mary's Emergency Room. Rachel, my respite nurse accompanied me there. I packed bags for both of us knowing we'd be staying a while. By the time I got him there his temp was over 103 auxiliary. He was seen immediately in the ER. His port was accessed and blood was drawn. He was started immediately on Fortez and IV fluids. His ANC was 253. We were admitted. Brady needed another (red) blood transfusion. He was also given Morphine for the pain in his head. Our hypothesis was that he had another sinus infection.
- January 31st Brady had a sinus x-ray this morning. The x-ray confirmed the “sinusitis” diagnosis. He was put on Clindamycin together with the Fortez. I requested that an MRI of his brain be done due to the fact that he hadn't had one since September and based upon my observations of him grabbing his head frequently. I needed to see a negative result for peace of mind. He was scheduled for Thursday at 2:00 pm. I could tell he was improving today. His appetite was good and he was playful & active.
- February 1st Brady's condition continued to improve. His appetite was good; however, he showed signs of discomfort. He kept grabbing at his head. He was given Morphine to ease the pain and discomfort. His ANC was up to 300+.
- February 2nd Brady was up early this morning. He remained on the antibiotics until our scheduled MRI. His blood was drawn and his ANC was up to 484. We were discharged at approximately 4:30 pm with a prescription for

Clindamycin 75mg/5ml to be given orally 7.5 ml po 3qd for 10 days and also a prescription for dilaudid .5ml po prn.

February 8th Brady was seen by Dr. Gowda today for his follow up evaluation, pediatric clearance & blood work. His ANC was only 744; however, Dr. Toledano cleared him for chemo based on Brady's tolerance and notable progress. However, he will receive Neupogen again post chemo.

February 10th Brady's 7th EUA. Brady seems to be holding his own. Dr. Murray didn't have any "new" news to deliver. Only that Brady continues to respond phenomenally to the treatment.

February 10th Brady's Seventh Round of Chemotherapy. His levels of Cyclosporine and Vincristine were increased. He reacted incredibly. He showed interest in eating the entire stay in the hospital. He tolerated his foods well with no vomiting. He slept through the night.

We were discharged from the hospital at approximately 9:00 am. Discharge instructions were the same as always. With Brady's history of illness post chemo, it has been noted that months without Neupogen he winds up in the hospital; therefore, Neupogen x 14 days needed for this round. Brady was not himself upon discharge. On the way home, he vomited heavily x 2. I started him on Zofran immediately when we got home. He also had a small dose of Dilaudid.

February 11th-13th I kept Brady on the Zofran to control his nausea & vomiting. He ate reasonably and had normal urine & bowel movements. By Valentines Day (February 14th) he no longer needed the Zofran or the Dilaudid.

We had the healthiest month we've had in a long time. Next chemo scheduled for March 17th.

February 24th FUNDRAISER in Brady's Honor at Bootlegger, Fort Lauderdale to raise money for P.O.S.T. (Pediatric Oncology Support Team at St. Mary's Child Development Center, Palm Beach) and raise awareness to Retinoblastoma.

February 25th Just an update. It rained like a monsoon last night but that didn't stop over 400 people from walking through the doors to support our cause and our family. I'm proud to announce that we raised over \$40,000.00 in honor of Brady that will be used by the Pediatric Oncology Support Team to help other families in crisis, like ours, that have children with cancer. This money will be used to help these families pay their mortgage or pay their medical bills and remove some stress from their lives. I am so thankful for my family and for my friends that helped make this fundraiser possible and for their generous donations of time and items that were used for our raffle and silent auction.

March 15, 2006 Bloodwork today & Pediatric clearance. Brady weighs 24 pounds and is 29-1/2 inches. He is doing amazing. His ANC is 1201 – THE BEST ANC ever going into chemo.

- March 17th** Brady's Eighth EUA. Dr. Murray told us that surgery went well; however, Jeff & I were under the impression that after 9 treatments, Brady would be in remission. To our dismay, this is not the case; in fact, Brady is not even close. He is scheduled for his 9th and final chemo for April 7, 2006 (however, we are in no rush for this). Dr. Murray told us that he would continue the laser treatments and hopefully the tumors will continue to regress. However, if the laser does not continue to "do the job" and further control any "reactivation", then Jeff & I will be faced with terrifying decisions. We will then have to explore other treatment options – either radiation or enucleation. Jeff & I are prepared to travel to numerous other doctors (that are on the same research team as Dr. Murray) to have as many 2nd opinions as necessary if/when we are in a position to make life changing decisions on behalf of Brady. Jeff & I are very optimistic that advances in medical treatment of the retina will bring Brady future options with some vision prognosis; however, if the doctors have to remove one or both of Brady's eyes, they will also be removing his options. We are terrified.
- March 17-19th** Brady's Eighth Chemo. Brady got his butt kicked. We are at maximum dosage of chemo drugs. On Saturday morning Brady vomited. This is not typical for him. He usually tolerates the chemo well. This has me a little concerned.
- We got Brady home a little after noon. He drank approximately 6 oz. of formula. No more than 10 minutes later he vomited. I gave him Zofran and fed him again; only 2 oz. at a time. We gave him the Neupogen at approx. 5:00 pm; he vomited again. I slept with Brady to make sure he didn't vomit in his sleep and aspirate.
- March 20th** Brady was very sick – pain, vomiting, sheer discomfort. No appetite other than formula. All meds were given – Zofran q4, Dilaudid q 4-6, and Neupogen in the evening.
- March 21st** Brady is still sick. No appetite other than formula – constant moaning and groaning. The only time he doesn't moan is for approx. 1 hour after the Dilaudid. Brady did not have a good day.
- March 22nd** Brady is status quo. Still vomiting, nauseous, pain, discomfort. Called Dr. Podda at Jackson & expressed some concern about the vomiting. He advised: Water down formula, keep Brady on Zofran q 4 and decrease Dilaudid from .5 ml to .3 ml – if no change, call in 48 hrs.
- March 23rd** Brady seems to be feeling a little better. Still on Zofran, no Dilaudid, continuing Neupogen.
- March 24th** Brady is definitely better. He ate bananas for breakfast and two other jars of baby food. He appears to be getting back to his normal self.
- March 25th** Discontinued Neupogen today. Brady is eating, playing and laughing again.

March 31st CBC drawn today. We are waiting for the results. We are scheduled for chemo next Friday.

April 1st ANC is 1200 however, his platelets and hemoglobin are low. I called Kathryn and asked to have Brady rescheduled for April 21, 2006. No problem. Now we get to enjoy our son and watch him get stronger before his final chemo.

April 19th CBC drawn today.....6:30 am as always and then off to Dr. Edelstein at 7:45 am for his pediatric clearance. Brady now weighs 25 pounds and is 30-1/2 inches. It is truly amazing. Other than the cancer, Brady is a happy and healthy 10-1/2 month old. Over the past two weeks he has started to mimic Jeff & I, follow more verbal commands, pull himself up from a sitting position and plays for a longer period of time independently. We've really enjoyed him the past 2 weeks.

April 20th We received Brady's CBC – His ANC is 1007 and his other levels are within normal range. We will be going for chemo tomorrow.

April 21st Brady's 9th EUA. Today is a great day. Dr. Murray delivered us more good news. Brady has responded so well to the treatment. His left eye (where the retina has been folded and stuck to the lens) has now responded to the treatment and the retina has unfolded. Now both of his eyes are free of previous complications and now are anatomically corrected and the only thing we have to worry about is the cancer. Today we saw Rita & Chuck again. Their son, Reese has hereditary retinoblastoma (but only in one eye). Reese has had the laser surgery on his tumors and has not had to undergo chemo yet. Chuck had retinoblastoma as a child and had radiation. He explained to me that the reason for his facial disfigurement was due to the high beam radiation as an infant. That was the only treatment option back then and when radiation was done at such a young age (before the eyes and face had time to develop), that is what caused the disfigurement. He reminded me that he is at very high risk for secondary cancers but also reassured me that if Brady needed radiation the amount of disfigurement would be minimal if not unnoticeable. This is because the laser is so much less invasive and by the time Brady would need radiation, his eyes and face would have had much more time to develop and proportion. I feel so much better now about radiation treatment. Brady is scheduled for a tentative 10th chemo on May 19th.

April 22-23 Brady's 9th and FINAL (or maybe not) chemo. At least this time we know what to expect.
Brady is definitely sick. He vomited during treatment again – many times. He maintained a decent appetite but was definitely suffering a great deal of discomfort. They didn't keep him on Zofran around the clock (I don't know why) but there is definitely a difference – at least to control his nausea.

Brady vomited just before we were discharged – so we were able to leave the hospital and arrive at home before noon. I gave Brady Zofran as

soon as we got home and I plan to keep him on it around the clock for the first 3 days at least. Jeff and I will give him Neupogen in the evenings to minimize his pain and discomfort.

April 24th-May 5th

Brady's usual sickness following chemo. Because he weighs so much and the chemo drugs are administered "per kilo of weight", Brady really takes a hard hit these days. Fortunately now that we are more experienced in how to deal with the side effects from chemo, we know when and how often to give him medicines that offset some of the side effects. For the first 72 hours post chemo, I give him 1.5 ml of Zofran every 4-6 hours to control the vomiting. And if he shows signs of pain, I give him a lesser dosage (.3 ml) of Dilaudid. He gets his Neupogen shot in the evening to minimize the discomfort following the shot. These days he barely feels the needle (because his little legs are so chunky) and I'm able to give it to him pretty quickly. This week we were able to totally control the side effects with the medicines. He did not vomit and showed very minimal signs of pain and discomfort.

April 28th

Today is Friday and I placed a call to Dr. Toledano (Brady's pediatric oncologist) to express some behavioral concerns I had about Brady. Brady is very aggressive. He exhibits a very strange behavior with his hands (it's hard to describe on paper) and sometimes appears as if he's in his own world. In the evening when I try to comfort him, settle him down and attempt to get him to sleep (Brady is a little spoiled. I don't put him in his crib and tell him goodnight and let him scream & cry until he falls asleep). I put him on my chest and let him fall asleep and then transfer him into his crib. For about 30 minutes he turns his head from side to side and kicks his legs out repeatedly until finally he finds a comfortable position – and then falls asleep. I expressed all of these concerns to Dr. Toledano. He said that it was too early to diagnose him with any other "problems" (autism) and that *maybe* I was a little overprotective and a little paranoid (this is true). He said the kicking out could be because Brady's brain is still working and that he could be at the point where he's ready to crawl – but just not physically crawling yet. Dr. Toledano spent an hour on the phone with me – and he basically put a band-aid on my feelings. He told me not to worry. In summary, I have to remember that Brady will have some delays, particularly in motor skills. I have to crawl in the mind & body of an individual (and an infant) whom is visually impaired. I have to remember not to measure Brady's progress or lack of against another child his age. Brady will do things when he is ready. I did feel better after my conversation with Dr. Toledano and very thankful to him that he took an hour out of his day to comfort me.

April 29th

At 4:40 pm after a long day with grandma & grandpa – while playing on the floor with his father – BRADY STARTED CRAWLING. Jeff video taped as Brady just took off. This was a great way to end a day. My visually impaired little boy started crawling. We are so proud of him.

May

That was all it took. Brady started crawling and now he does something new every day. He can pull himself up into a standing position. He is

walking with his little walker. He started out with me holding his feet and telling him to “take a step” while I would move his feet forward. Now he holds on to the walker while I sit to the side and tell him to “take a step”. He falls down sometimes but he gets right back up and tries again.

He is into everything. He crawls all over the house and is particularly interested in the vertical blinds in the living room. He is doing remarkably well. Some of my concerns have fallen to the wayside and I feel more confident in Brady as each day comes and goes.

May 17th

CBC drawn today and Brady’s Pediatric clearance. Brady weighs 25 lbs. 5 oz. and is 30 inches. Now we just have to hope that all goes well in surgery on Friday and he doesn’t have to stay for chemo.

May 19th

Brady’s 10th EUA. Dr. Murray delivered us GREAT news today. As always, we’re reminded of the seriousness and advanced nature of Brady’s cancer. However, Dr. Murray feels that Brady is STABLE and does not need to stay for chemo. His next EUA is scheduled for June 16th. For now we can anticipate continuing with Brady’s surgeries every 3-4 weeks and returning to the clinic following surgery to maintain his port. We could have to stay for chemo at any time; however, for now – just more surgery. The port maintenance is important to avoid infections. The clinic will simply access his port, flush it with saline and push the heparin to clot the blood.

Brady was returned to us after awakening from anesthesia. He gulped down 6 oz of formula in record time – and then vomited. He has never done that before....But I think he just ate too fast.

We were discharged and went to the clinic to take care of Brady’s port. And at about 1:00 pm we were on our way home. WHAT A GREAT DAY in the Simmer family.

May 20th

Saturday afternoon – Brady & I were playing with his plastic rings. I have arranged his rings by color – red, yellow, blue, orange, green & purple – about 4-6 rings per strand. I now believe that Brady probably sees more than we think. I asked him today while holding up two different color strands, “Brady, where are your yellow rings?” - and he chose the yellow. It might have been a coincidence – but it sure made me feel good.

June 13th

Brady’s CBC today with Pediatric Clearance by Dr. Edelstein. All is well. Brady’s ANC is the best it has ever been.

June 16th

Brady’s 11th EUA. Not so good news today. As mentioned in the 9th EUA notes, the retina in the right eye (the more severe eye of the two) has unfolded. Upon the 10th EUA Brady was considered stable. Now, apparently the area that was underneath the fold has reactivated. Dr. Murray says he aggressively lasered that area. Now we wait. Due to Brady’s history of “remarkable & phenomenal” response to treatment, I am hopeful that he will continue to amaze the doctors; however, the fear factor has now heightened. Dr. Murray has said from the beginning that

we may have to enucleate one or both eyes due to the severity of Brady's RB. I cannot let this happen. If Brady doesn't respond well to the treatment, Jeff & I are preparing ourselves – and we're told that other treatment measures will be necessary. We are not sure what those "treatments" may entail. We won't know until July 14th. Right now Dr. Murray says additional chemo is not an option. He feels that the risks of more chemo outweigh the benefits. So, what we're left with is possible cryotherapy, radiation or enucleation. Jeff & I are prepared to seek second, third & many other opinions to be absolutely positive that we are making the right decision. Dr. Murray has encouraged second opinions and offered to coordinate care. We will be going to see Dr. David Abramson at Sloan Kettering in New York and Carol & Jerry Shields (The Shields Team) at Wills Eye Hospital in Philadelphia, PA. Hopefully this won't be necessary – but we're prepared. More updates on July 14th. I've sent out a mass email for Prayers. We need all the prayer and miracles we can get.

July 14th Brady's 12th EUA – Well, we're back on the roller coaster ride. Dr. Murray reports that Brady responded well to the laser and he is again, stable. The area that showed the reactivity has, for the moment, been managed by the laser. There was no mention of "other" treatment options today. Jeff & I are breathing sighs of relief. Dr. Murray has ordered a routine MRI and would like to have the report by the next visit.

August 5th Brady had his MRI today. The MRI is of the brain & orbits, with and without contrast. By this scan we should be able to see the degree of tumor regression/reduction since his first MRI which was done on August 30, 2005. We had the scan done at Palms West Hospital by the same team we used originally. He did well with the anesthesia.

We received the results of the MRI. The radiologist reports that there has been significant reduction of the tumors. There is no report of any cancer in the brain. The best news on the report was that Brady's optic nerves are of normal size and are receiving normal signal activity. So, whatever vision he does have, albeit minimal, the optic nerve seems to be in tact and functioning well.

August 11th Brady's 13th EUA – Here we go again....Dr. Murray reports that the area underneath the fold in the right eye has again re-activated. He says that this is a "small" area but he has aggressively lasered that area again. He reiterates the importance of these visits so that he can "catch" this activity in its early stages and continue to manage it without the use of other types of treatment. He was pleased with Brady's MRI results and wants us back in 2 weeks. This is the shortest amount of time we have had in between visits.

August 25th Brady's 14th EUA – We have now learned that praying for no activity isn't really realistic. Today we learned that the area in the right eye is still active; and that now there are about 5 small tumors in the left eye. We have now realized that this activity is more common than not and that what we should pray for is that the laser can manage/resolve whatever

activity pops up. Dr. Murray doesn't seem too worried. He said that he does not anticipate any additional chemo at this time; nor does he anticipate having to utilize any radiation. There was no mention of enucleation. He did say that if we kept going the way we've been going (with the activity being managed by the laser) that "we would be fine". He prescribed two eye drops for Brady – Cyclopentolate & Pred Forte to be given 4 times a day until the next EUA. I hope that means that eventually this cancer will give up and there will be no threat of Brady losing one or both of his eyes.

September 15th

Brady's 15th EUA – We just drove in from Brady's first trip to the Florida Keys – and today we got probably the worst news since the day of his diagnosis. Brady's retinoblastoma has come back with a vengeance. Dr. Murray reports that there are "too many tumors to count". He said he originally was considering new regimen of treatment in his left eye – using localized ocular chemo; however, after examining his right eye he said that our only option was radiation. I burst into tears. We were told we'd be in the hands of the best here at Jackson; however, that does not make me feel any better. We were sent home today to wait to hear from the Radiation Department with feelings of terror and told that we'd been seen STAT.

September 20th

We were seen today at Radiation Oncology. We met with several doctors and then with the Pediatric Radiation Specialist, Dr. Wen. We were informed of their goals as a department and also of the risks. This is exactly what I didn't want to hear – but what Jeff needed to know (I've done my homework!!) Several things could/may/likely happen. Due to the maximum tolerable dose of radiation that Brady will be receiving – the growth of the bones beneath his orbits may be stunted. When he reaches a growth spurt during puberty this is when we may see that Brady may appear to have that "sunken-in eye" look. That is the least of my worries. Additionally, radiation puts Brady at extremely high risk for secondary cancers (as if he wasn't already at risk). By the age of 15 and probably until he's 30+ he will be at high risk for cancer in the meninges (neurological lining of the brain) and bone cancer. Dr. Wen says these types of tumors are typically benign and may be resolved with 9 rounds of chemo.....More chemo? I can't even process this right now. However, we will try to focus on the positives right now and remember that radiation KILLS cancer.....

I was asked when we'd like to begin.....NOW, I said....They took Brady in for a simulation and to fit him with a mesh mask to protect the rest of his face and to help define the "field" they would be radiating daily – x 14 rounds. It's going to be a long month. We start TOMORROW.

September 21

Brady's port was accessed today at that clinic and we started our first round of radiation. Looks like the daily routine will be 9:00 am arrival – sedation cocktail of Saline, Versed, Ketomine, Zofran & then flush with Saline & Heparin. The total time of the process itself is less than 7 minutes....Then off to recovery and home. This will be done 14 times. We'll have his port accessed on Mondays and have a CBC to be sure he

is okay health wise. Then we'll de-access on Fridays to give him a break over the weekends. Jeff & I decided that I'll be staying with my parents in Pembroke Pines for this period of time to minimize the driving and too much time in the car for Brady. It is about 70 miles from our house in Lake Worth as opposed to less than 25 miles from mom & dads. We'll begin our stay with grandma & grandpa on Monday.

September 22nd Radiation #2 – All went well. No problems. Brady's port was de-accessed – BUT, we noticed a little white dot when they pulled the needle out. We were told not to worry. Hmmm – I've heard that before.

September 25th Radiation #3 – Brady's port was re-accessed today at the clinic. The little white dot is still on his chest where the last needle was. I don't have a good feeling about this.

No complications with radiation.

September 26th Radiation #4 – No problems...

I took Brady home to my parents today and he seemed a little "off". I put him down for a nap at 2:00 pm. He awoke at 4:00 pm and was on fire. I took his temperature – 103.9 auxiliary which means almost 105! Calls to mom and dad....and off to Joe DiMaggio Childrens Hospital ER.

They took us right in. CBC, culture, UA and an infusion of Rocephin. His port was already accessed which made all of this pretty easy. After Tylenol he seemed a little better. After the 30 minute infusion we were discharged and told we'd hear back from them.

September 27th Radiation #5 – No problems.

NOW – BIG PROBLEM....As we were leaving the parking lot of Jackson I received a call from a doctor at Joe DiMaggio. "Your son Brady needs to be admitted immediately". WHY? She said he had a blood infection. What kind? We'd find out tomorrow. I ran home and packed our suitcases and ran back to Jackson.

Went through all of the admission processes and up to the 6th Floor. Home away from home. We got our private room as we requested – and next door to me....My friend Sandy and her daughter, Nadia. Nadia has bilateral retinoblastoma too. Nadia's port was accessed on the same day at the clinic where Brady's was. Nadia had already been there 6 days. Nadia had a Staph infection and was on Vancomycin. That is what they gave Brady at the clinic just an hour ago. Something was really wrong here!!!

September 28th I awoke this morning (in the hospital) to Dr. Toledano greeting me and telling me that – Brady has a Staph infection. I looked at him with FURY and said, "How is that Nadia & Brady had their ports accessed on the same day at the same place and now they BOTH have staph infections?" He had the nerve to tell me, "that is just a coincidence". Needless to say,

we'd be here a while. Brady had to have infusions by IV only of Vancomycin every 8 hours until the culture came back negative – and then he'd still have to finish a 14 day regimen of the Vancomycin. This all seems so surreal.

Thankfully, we were able to continue with radiation. Radiation #6.

September 29th

Another day in the hospital, of course.

Radiation #7. We're half way there.

September 30th

Resident at hospital. Today is Saturday. Hmm, there is nothing like spending your weekend in the hospital. No radiation today.

October 1st

Sunday at the hospital. Good news. Brady's cultures are negative. Good chance we get to go home tomorrow. But, there's a catch. I get to play nurse at home for an additional 7 days infusing Brady with the Vancomycin. I agreed to do anything just to get Brady out of this place.

October 2nd

Brady pulled the needle out of his port this morning – right before transport came to take us to Radiation. I told the nurse this would happen. She agreed to re-access him before we went. I specifically told her that we needed to have DuoDerm dressing because of Brady's sensitive skin. Not only did she try to access his port without wearing a mask – she told me "I don't have the Duo Derm on this floor". I got in a little bit of an argument with her and told her that "we are not dealing with a skinned knee or a paper cut – we are dealing with cancer AND THERE ARE NO SHORT CUTS!" I insisted that she DO HER JOB!!! Or that she was not touching my son. Well, she was mad – but she got the Duo Derm and we were off to Radiation. I've got to do something about these nurses here.

We were discharged this afternoon. A nurse came to my parents house this evening to educate me as to how to properly administer the Vancomycin through Brady's IV lines every 8 hours – and then to flush his port with Saline & Heparin. I found this experience to be very thought provoking.....Did I miss my calling? I think this has been a "Sign" from God. I am going back to school – to be a Pediatric Oncology Nurse....This is my new long term goal – in addition to Raising Awareness to Retinoblastoma.

October 3rd

Radiation # 8 – Same routine.

Vancomycin Schedule: 5:00 am, 1:00 pm, 9:00 pm – Until Sunday

October 4th

Radiation # 9 – cancelled due to Department computer problems.

October 5th

Radiation #9 – completed.

October 6th

Radiation #10 – completed; however, Department is closed on Monday to observe Columbus Day. Are you kidding me? This made me furious.

Brady has 4 more treatments and his EUA with Dr. Murray is on Friday, October 13th. Unfortunately, this has to be rescheduled.

- October 10th Radiation #11 – completed.
- October 11th Radiation #12 – completed.
- October 12th Radiation #13 – completed.
- October 13th Radiation #14 – FINAL treatment completed. Poor Brady's eyes and surrounding areas are so red. Looks like a bad sunburn. Dr. Wen says this is a deep tissue burn and will go away with time. I can apply alcohol free Aloe Vera lotion to sooth the skin....and just allow time to heal the wounds.
Kathryn called me from Dr. Murray's Office and said his schedule was booked until the 27th of October. I cried to her and explained "we couldn't wait until then for Brady to be seen". She called me back later and said that Dr. Murray had made an exception. He'd see Brady on Tuesday (adult day), October 17th at 6:00 am.
- October 17th Brady's 16th EUA – To try to put this feeling into words is very difficult....BUT, Dr. Murray reports that "There is NO cancerous activity in either one of Brady's eyes. This is the best Brady's eyes have looked yet". Jeff & I cried tears of joy. Dr. Murray wants to see us back on November 17th. He says if there is no activity at that time – we may use the word we've been waiting to use for almost a year and a half –
REMISSION
- October 31st Brady enjoyed his first Halloween (we were in the hospital last year doing chemo at this time). We took him over to our friends, Kami & Jeff's house and had a nice barbeque. Brady dressed up in his Piglet costume – and he was the cutest kid on the block. We put him in his car and went house to house with Brianna & Joe – but after about a block – Brady wanted out of the car....He wanted to walk around just like every other kid....He must have walked over a mile tonite!!! He was such a good sport about being dressed in pink. We are so proud of him
- November 7th I got a call from school today at about 11:30. Brady had a fever of 101 and climbing. I was about 5 minutes away visiting Sandy Erb (her 4 year old daughter, Ainsley has A.L.L. – Acute Lymphocytic Leukemia) so I was able to get to him quickly. I called Dr. Edelstein and let him know I was on my way – I really wanted to try to keep Brady out of the hospital ER. We arrived at Dr. Edelstein's Office – they did a CBC, blood culture, UA and what I thought was a thorough exam. We were sent home to wait for the results of the culture.
- November 8th Brady suffered all night with on/off fevers. I gave him 1 tbs. of Childrens Tylenol every 4 hours but the fever just wouldn't break completely. I called Dr. Edelstein at noon – so far the culture was negative for bacteria. However, I did not want to see my son suffering from ANY illness. I told him that he could either give Brady a shot of Rocephin or I would turn the

care over to St. Mary's Hospital. He opted to give Brady the shot and do another CBC.

- November 9th Brady's fever broke. The blood culture is still negative which is a good sign; however, Brady still isn't himself. Back to the doctor for another shot and some antibiotics. We're going to try Omnicef 3.5 ml po q10 days. I feel much better that he's on antibiotics. AND his CBC dropped which tells me that he has some kind of bug....maybe not bacterial – possibly viral.
- November 10th Brady is doing better; however, he has major diarrhea. This is either because of the Omnicef or a viral infection....He's active and playing – but getting a pretty bad diaper rash. I've been using Balmex and it is just getting worse. I wound up trying just plain cornstarch and baby powder.....and what do ya know? It actually helps!!
- November 15th Back to Dr. Edelstein's office for the routine Pediatric Clearance. Brady has been very congested and has a cough – hopefully this won't interfere with his clearance because his EUA is scheduled for Friday, November 17th. This is a big day for us – we're praying for "No Cancer Activity".
- November 16th Off to Quest for labs at 6:30 am. Lucille is always so wonderful with Brady. Optimistic for good results barring his cough and congestion – although Dr. Edelstein says, "his lungs are clear".... Hmm, I don't think so.
- November 17th Brady's 17th EUA and a day for celebration. Dr. Murray reports "NO CANCER ACTIVITY" Tears of joy!! Our little boy is such a fighter! Chris & Sandy were there with Nadia and Mitch & Michele were there with Emily. Nadia is responding well to the interocular chemo and her vitreous seeding is under control. Emily had her left eye enucleated on October 17th (the retinoblastoma tumor was attached to her optic nerve and Dr. Murray was afraid it would spread – they were left with no choice but to focus on saving Emily's life instead of her eye). At any rate, we all got good news!!! Our next appointment is scheduled for Friday, December 8th. We went over to Jackson Clinic to have Brady's port flushed and I asked Dr. Davis to please look at Brady. I explained his chronic symptoms of congestion/cough. She listened to his chest, again, "he's fine." Opinion # 2 and the same generic answer – "his lungs are clear".
- November 18th Brady was up half the night with that lingering cough. I've been giving him OTC PediaCare cough medicine but all it is doing is suppressing the cough. Jeff & I took Brady down to Robin's house (Jeff's eldest sister) where the family gathered to watch the University of Michigan lose to Ohio State. Laurel & Joel (Laurel is Jeff's cousin – and 5 months pregnant) are in town; so, Robin and I slaved in the kitchen preparing tons of food to feed the bunch. Brady was getting very cranky as he did not take his afternoon nap. I had to take a break from the kitchen and get Brady to sleep. My poor son cannot breathe through his nose and continues to have these coughing attacks. I told Jeff we'd have to cut the visit short and leave after dinner. I need to get Brady home and in the

bedroom with the vaporizer so he stands a chance of being able to breathe. I told Jeff I have had it....I'm tired of being patronized by these doctors. I understand that Brady's lungs are clear; but these symptoms are getting progressively worse and I can't stand to see him suffer any longer. I will call on Monday to make an appointment with Dr. Gowda (my go-to doctor at St. Mary's who is a Pediatric Oncologist) and insist upon a sinus or chest x-ray to rule out yet another sinus infection.

November 20th

Brady went to school today. He appears to be fine during the day (while he's vertical) and doesn't have a fever, but at night is when he suffers. I also noticed patekei in his groin area (patekei are little red dots on the skin – the blood vessels burst because they don't have enough oxygen and is the first sign to me that Brady's platelets are low). I was able to get an appointment with Dr. Gowda tomorrow at 2:00 pm. Uh oh, I'm not feeling too hot today. I think I might be coming down with the same bug Brady had/has. He has been coughing on me (he has a wet cough) for the past couple of weeks. I knew I couldn't get out of catching his germs.

November 21st

Okay, I've got it. I feel like death warmed over. I made an appointment with my primary physician at 1:00 pm and moved Brady's appointment to 2:45 pm. I'm thinking I have an Upper Respiratory Infection – congestion, sore throat, swollen glands and terrible cough. I took Brady to school and went home to kill some time. Went to the doctor at 1:00. Sure enough – URI. I'm now on Omnicef for the next 7 days. Our doctor is so wonderful; he wrote double the amount of antibiotics assuming Jeff would fall ill as well. So, we are prepared!!!

Brady went to Dr. Gowda. They pricked his finger for bloodwork. He screamed the entire time; but even worse, it took him almost 20 minutes for his blood to clot and for his finger to stop bleeding. Results are in – CBC looks good, ANC is over 3000 AND his platelets are low!!! I knew it. I explained to Dr. Gowda what has been going on with Brady while he examined him. And sure enough – Dr. Gowda said he would do a sinus x-ray but that he had all of the signs/symptoms of a sinus infection. Finally!!!! A doctor that listens!!! He prescribed another antibiotic – Cefzil 250 mg/5 ml – 2 ml po twice daily for 14 days. We have the Cefzil this time because we wanted to try something new that didn't have any GI affect (meaning, no diarrhea side effect). I also asked if there was a prescription cough medicine that would help Brady at night. YES!!! Rondec DM Syrup – ½ tsp. twice daily for 5-6 days. This cough medicine also has a decongestant and antihistamine that will work together with the antibiotic.

I started my meds and Brady got his...And for the first night in over two weeks, my little boy slept peacefully without the vaporizer – breathing clearly and through his nose. The moral of the story is: Mothers (parents) know their children best. From now on, I will be more proactive with Brady's illnesses. I'm switching pediatricians and when I know there is a problem with Brady's health, I will not take "no" for an answer. I've learned to ask more questions (in order to get what I need) and to be persistent when I know that more can be done to improve his health.

Brady is sick more often than normal kids – and his immune system is not as strong; so in order to give him the best quality of life I must be his strongest support and his best advocate. I will never watch him suffer again!!!!

November 23rd

Thanksgiving Day – No Thanksgiving for Brady & I. We have to sit this one out. With both of us on antibiotics and 4 young nieces and nephews, we can't risk exposing them to our germs. My mom & dad came over to bring us some food and Brady and I just lounged around....I'm feeling pretty rotten but Brady seems to be responding well to the medicine.

November 27th

Brady is well enough to return to school; but I'm worse!!! I put a call in to my physician and I'm on another antibiotic. At least with Brady in school I can take some time to rest.

December 6th

CBC and Pediatric Clearance for Brady today. He appears to have recovered from his month of sickness – still a little bit of a runny nose and residual cough; but nothing compared to what he had. Dr. says his throat is a little red but he's cleared for his EUA.

December 8th

Brady's 18th EUA. Dr. Murray reports that he lasered both eyes today and that he didn't see any cancer activity. That is the good news. The not so good news is:

Brady's retinoblastoma was so advanced and so severe from the start. Having been through 9 chemo and 14 aggressive radiation – and knowing how well Brady responded to these treatments AND still has both of his eyes.....Dr. Murray wants to leave no stone unturned. Dr. Murray has been utilizing a new treatment technique – localized ocular chemotherapy – and having great success. This technique is an injection of Carboplatin in the tissue surrounding the retinoblastoma tumor/affected areas. My understanding of this type of treatment is to manage any “microscopic” activity that if left untreated could spar the growth of new tumors. We have come so far to turn back now; however the thought of any more chemo makes me very sad. The side effects of this treatment will include increased discomfort for Brady, his eye(s) will swell and he will have to have 4 different eye drops 4 times a day after treatment. This chemo will also compromise his immune system. So basically, Dr. Murray told us to plan on Brady having this injection in his left eye on January 5th. January is going to be an extremely hectic month. It's a new year, I start school (my prerequisites for Nursing School), Brady is supposed to start additional therapy (to include OT, PT & Speech) at least 3 days a week and now he's going to have this chemo. All of that being said – it's going to be difficult, but as always, we'll get through it. And looking at the bigger picture, whatever is in the best interest of Brady's health and eyes.....We're committed!!! So, we're going to enjoy the holidays and deal with the other things as they come. We have come a long way this year and we have a lot to be thankful for.

December 22nd

Brady is still sick!!! He constantly has a runny nose and still has a chronic cough. This is getting ridiculous. I'm concerned that this problem might be secondary to the radiation treatment. Maybe the radiation beams hit a sinus cavity? I called Dr. Edelstein to ask him to refer us to a Pediatric ENT. Melissa said she'd work on it, but that with the holiday we'd probably not get in to see the ENT until Wednesday of next week. We've got to get to the bottom of this!

Today was also Brady's Evaluation/Assessment with the Early Steps Program. Our case manager Renee Williams and several other specialists observed Brady for over an hour and determined that he would be qualified to receive Speech Therapy and Occupational Therapy. Considering what he's been through he is doing very well for his age; however, he is still not eating table foods and I'm told at this age that he should have 15-20 words. Brady says ma ma & da da and mumbles some other words, but he definitely would benefit from speech therapy. He doesn't need physical therapy as his gross motor skills are pretty good. But fine motor skills need some work. He should be able to pick things up with his fingers & thumb (like a pincher grasp) and other similar tasks. I think that some of these developmental delays are obviously due to his vision impairment; but this is where the OT will be beneficial to him. I was given a list of providers and told to contact them to see which ones would come to our house to "home school" him. They feel that the children receiving the therapy benefit the most in their natural environment. I will be contacting these providers immediately!!

December 27th

We have an appointment today with Dr. David Kay, Pediatric ENT.

Dr. Kay did a more thorough exam of Brady (Brady screamed the whole time) and I gave him Brady's full medical history – and history of several sinus infections particularly during the months we were going through chemotherapy. I explained to Dr. Kay that Brady had been on Omnicef, Clindamycin, Amoxicillin, Ceftin, Cefzil, & Rocephin plus Rodec DM cough syrup. Dr. Kay pointed out that Brady had probably built up a resistance to these antibiotics and that he wasn't on a strong enough antibiotic for a long enough period of time. This made sense. So we decided to put him on a 21 day regimen of Augmentin (600 mg-42.9/5ml) 1 teaspoon twice daily and nasal spray (Nasonex). He advised that this may give him diarrhea but that it works. He said he'd see us back in three weeks.

January 3rd

Brady has responded very well to the Augmentin. His symptoms are almost completely resolved. He had a CBC today and his pediatric clearance so we are ready for our EUA on Friday.

January 5th

Brady's 19th EUA. There was absolutely no way we could have been prepared for this day. Jeff & I were assuming that Brady would be receiving the local ocular chemo in just his left eye today and that we would receive another good report from Dr. Murray. However, we were caught off guard.

Dr. Murray came out of the exam this morning and for the first time in over a year he looked worried. He explained that Brady had another relapse. Just 4 short weeks ago his eyes "have never looked better". Today he said that both of Brady's eyes are worse. Instead of just injecting the left eye, he injected the right eye too. I was not aware that both eyes could/should be done at the same time. Dr. Murray explained that we were about out of options. He advised that we should go over and speak with Dr. Toledano about additional cycles of systemic chemotherapy. Jeff & I were devastated. This day was worse than the day we found out that Brady had Bilateral retinoblastoma. At least at that time we knew that there were many options. We have exhausted almost every treatment option at this time. The only treatment we can do now is this ocular chemo together with systemic chemo – and if it doesn't work, then we have to discuss enucleation. This was the one thing that I was praying we'd never have to do; however, we have known from the beginning that this may be inevitable. We have been told too many times that Brady "has the worst case in the United States in a decade".

We went over to the clinic to discuss chemo with Dr. Toledano. After about an hour of debriefing Dr. Toledano said very matter-of-factly that "if this treatment works, it'll be a miracle". At that very moment, Dr. Toledano shot down the little bit of hope that we had. We were devastated to hear him say that. BUT that doesn't mean that we are going to stop fighting.

We took Brady home that afternoon. We were given two eye drops – Hyoscine (red cap) & Maxitrol. These drops are to be given 4 times a day to reduce inflammation & prevent infection. Brady was suffering from great discomfort not to mention both of his eyes were swollen shut. About an hour later, Brady started vomiting. Ironically, Rita Carpenter called me in a panic and said Reese was vomiting too. I immediately gave Brady 2 mls of Zofran (anti-nausea medicine) and that seemed to help him. I advised Rita to call the doctors and have them phone in the same medicine for Reese. I was not aware that vomiting was a side effect of this treatment; however, the doctors are saying it might be from the anesthesia. I kept Brady on the Zofran every 4 hours and that seemed to help him.

January 6th

We woke up today and Brady's eyes look like someone put golf balls under his eye lids and sewed them shut. We tried to put Brady down on the floor and guide him around but he just sat down on the floor and cried. This tore my heart out. How do you explain to a 20 month old that one day they can see (a little bit) and the next day he can't. I felt absolutely terrible. Brady slept most of the day but Jeff and I made sure we got the drops in. Brady screamed every time but the drops definitely helped with the inflammation. I kept him on the Zofran to offset the nausea and he appeared to be tolerating his food okay. He is supposed to be admitted for chemo on Monday. I just don't feel good about this.

January 7th

Brady looks a little better today. His eyes are still swollen shut but he just seems a depressed. He is still sleeping a lot and is very lethargic. He seems to enjoy the shower and taking walks but that is about it.

I put out an emergency email to my friend Abby White in London. I explained to her what was going on with Brady and that I needed her advice. Abby called me early Sunday evening. She told me that we shouldn't have Brady admitted for chemotherapy until we speak with Dr. Brenda Gallie in Toronto. I am very familiar with Brenda as I have read a great deal about her work and that she & her team specialize in recurrent retinoblastoma. Jeff & I had always considered seeing her for a second opinion. Abby said she'd ask Brenda to call me.

At about 7:00 pm I received a call from Brenda. At that moment I felt like the luckiest person in the world to be receiving an international call from a world renown ocular oncologist – on a SUNDAY!!! She advised that we should NOT have Brady admitted for chemo on Monday. She explained that the first chemo is the most important and that the Toronto Protocol may be very different. She also said that by using the Toronto Protocol that Brady MAY have a 60% chance of keeping EACH eye. So now we've gone from "it'll be a miracle" to "a 60% chance". We agreed that I would sign and fax medical releases from Bascom Palmer & Jackson Memorial up to her team in Toronto for her review and that she would follow up with me on Monday evening.

Jeff & I already feel a little better. We're not jumping into this decision. We realize that this treatment (however many cycles it may be) is our last chance of saving Brady's eyes. We need to know that we're making the right decision, the best decision, for Brady.

January 8th

Brady's eyes are showing signs of improvement. A great deal of the swelling has gone down and Brady is able to open his eyes a little bit. His mood seems to be better too.

I spent the morning signing and faxing and making numerous phone calls.

I received a call from Brenda that evening and we discussed the Toronto Protocol. She advised that the drugs are the same – Cyclosporine, Vincristine, Carboplatin & Etoposide (VP-16) but that the doses are higher and they are given over a shorter amount of time. She feels that this Protocol may give Brady a better chance. She was prepared to arrange her schedule to TREAT Brady in Toronto should we decide to go this route. She would be discussing this with Dr. Murray in the morning. Jeff and I were about to make the most critical decision of our lives.

January 9th

Dr. Murray called us this evening. We had a heart-to-heart talk.. He expressed his concern for not wanting me to leave the country with Brady to have chemotherapy. We would be leaving our country, our home & our family and support system for probably 4-6 months – as traveling back and forth was not a good idea for a child with a compromised immune system. I explained to Dr. Murray that Jeff & I realized this was our last

chance and that in order to be able to cope with whatever outcome – we had to know that we were doing EVERYTHING possible to save Brady's eyes. I told him that if we stayed here in Miami and did the treatment their way, and it failed, we'd always wonder what would have been had we gone to Toronto – and vice versa. I asked him if it was possible to ask Dr. Toledano to do the Toronto Protocol here. He said that what I was asking was not unreasonable. He said that he would discuss this with Dr. Toledano in the morning and that if he felt comfortable (and keeping Brenda in the loop) that we may be able to stay here. As we got ready to hang up the phone, Dr. Murray said, "I love you guys" and I responded, "we love you too". What doctor says that? What I do know is that we could not ever wish for a better doctor in this WORLD to be taking care of our son. I know Dr. Murray treats Brady (and every other child) like his own and I know that he truly has Brady's best interest at heart. Dr. Murray is our hero in his own right.

January 10th

GREAT NEWS!!! Dr. Toledano agreed to do the Toronto Protocol. We don't have to leave!!! I am so grateful to Brenda & Abby!! Timing is everything. Jeff & I now know that we are making the right decision. Brady will be admitted into the hospital on Friday and will begin chemo on Saturday. His chemo will be for a total of 6 hours on Saturday (including fluids) and the same on Sunday and if all goes well, we will be discharged on Sunday evening.

January 12th

Here we go again. We began at the clinic on Friday morning. Brady's port was accessed and then we had a meeting with Dr. Toledano. He went over the details of the Toronto Protocol. I asked for a copy so I could follow along. He explained what "could happen" because of the way the drugs are administered and the side effects that follow. He pretty much gave us the worst case scenario. We were terrified. Nonetheless, we checked in the hospital, got a private room (thank goodness) and spent the rest of the day playing with Brady and preparing for the next day.

January 13th

We were up bright and early this morning. Chantel was our private nurse. They assigned us a private nurse because the amount of meds that are given and the timing is so critical. I couldn't see how a nurse could manage any other patients while following this Protocol.

We began at 10:00 am with the Pre-Meds, Vital signs & Labs.
30 minutes before Cyclosporine and then every 4 hours Brady got:
0.3 ml Simethicone po q1hr (not to exceed 6 doses) for gas pain
200 mg Tylenol po q4h not prn
2.6 mg Metoclopramide (Reglan) & 13 mg Diphenhydramine (benadryl) by IV (This would help with the GI system and insure bowel motility)
130 mg of hydrocortisone & 2 mg ondansetron

The first Cyclosporine infusion ran for 1 hour. Exactly 1 hour later the Carboplatin was given for 30 minutes. The remaining Cyclosporine was given over the next two hours. Brady then received 265 mls of fluid (this is 5x amount of fluid a child of this size gets in one day – given over 2

hours). Once all of this was completed – the evaluate whether the input (of fluids & chemo) is equal to the output (urine & bowel movements). If not, and in Brady's case at that time it wasn't) he was given 13 mg of Furosemide (Lasix) to make him urinate (lots of wet diapers) and also a fleet enema (to make him have a bowel movement).

At about 6:00 pm he was done....Input=output and he was pretty out of it from all of the benadryl. Chantel flushed his port with saline and heparin and Brady went to sleep for the night. The only difficult detail was that we could not feed him or give him milk during any of this treatment – but for the first time, Brady gulped down about 10 oz. of fruit flavored pedilyte – and he didn't throw up!!! YEAH!!!

January 14th

Brady woke up bright and early.....and it a pretty good mood. Since he wasn't hooked up to the IV we put him in the stroller and took him downstairs for a morning walk. When we got back upstairs he wanted to run around the hospital ward – and go visiting the other patients. He bobbed around with his bells in hand and looked like he was really having a good time. You'd never guess he had chemo the day before.

The doctors came and did their rounds this morning. They went over the discharge orders and all 9 prescriptions that Brady would be needing for the next couple of weeks. One of the meds, Suprax (antibiotic) they said that they did not have or know where to get. They said that it may be a problem discharging us if we were unable to get all of Brady's prescriptions filled. So, I called St. Mary's Hospital and spoke to an old nurse/friend on the Hem/Onc floor. She told me about Schaefer's Pharmacy in Wellington and that they typically had EVERY kind of medicine. I called and spoke to the pharmacist and went over all of the meds we'd need. Sure enough....he had them all. We faxed over all of the prescriptions and were told we could pick them up by 9:00 am in the morning...Talk about a great network!!! I am so fortunate to have such a great team!!

But the schedule for chemo today would be a little tougher on him. We followed the exact schedule from the day before as far as the meds were concerned but today we had the Cyclosporine for an hour, then the Vincristine IV *push* (this is when they literally push the dose from the syringe directly into the line connected to his port). This was followed by the Etoposide (VP-16) and then the remaining 2 hours of Cyclosporine.

No need for the enema today; but he did have the Furosemide (Lasix). We were doing pretty well.....It was about 5:30pm and they started preparing us for discharge. Brady was very lethargic and dazed. Jeff was holding him and he was groaning...and then he started vomiting this fluorescent yellow fluid. That is when I lost it. I started crying & sobbing. I just felt so terrible for him. Chantel gave him some Zofran and that seemed to help. Jeff held him the whole time. He really is the BEST father!! We packed up all of our things and I made rounds to the car while Jeff held onto Brady.

We were finally discharged at about 7:00pm. Chantel went ahead and drew the dose of Neulasta (similar to Neupogen – Neulasta is Pegfilgrastim and is a long-acting form of the drug, filgrastim. These drugs are called colony-stimulating factors and are used to help stimulate the bone marrow to make white blood cells – white blood cells help the body fight off infection).

Chantel gave us the best “stuff” for diaper rash. If your child ever has bad diaper rash, I highly recommend this combination. First apply Aquaphor Ointment (from Eucerin). This is for advanced healing for dry or irritated skin. Then apply Ilex skin protectant paste. This ilex is like glue but it seals the skin and totally protects it from the acidity & toxicity of chemo and/or from diarrhea! I swear by this stuff!!!

We said our thank yous & goodbyes and left the 6th floor....

We got home, unpacked and settled in. It's been a long week and a longer weekend. It's good to be home.

January 15th

Brady slept until 8:30 this morning. Jeff ran out bright and early to pick up Brady's meds. Most of these prescriptions are “just in case” medicines. Just in case he doesn't have a bowel movement, give this....Just in case he is nauseous, give that. So I'm hoping that we won't have to use all of these medicines – which include:

Metoclopramide & Benadryl (for bowel motility)

Lactulose & Simethicone (for gas & bowel motility)

Nystatin oral suspension (in the event that “thrush” develops”

Nystatin ointment (for diaper rash)

Zofran (for nausea & vomiting)

Suprax (antibiotic for common ear infections & upper respiratory infections)

Brady wasn't feeling good today. And we can't give him milk or yogurt for the first couple of days. We've got him on Zofran q4 hrs for the next couple of days so he won't vomit. And he's had his Suprax. So now it's just clear fluids and a lot of TLC!!!

We had to give him the Neulasta shot today at 4:00 pm. Within about 2 hours Brady was kicking his legs out and screaming in what I thought was pain. We started off by giving him his Zofran. Didn't work. Then Simethicone. Didn't work. Tylenol. Didn't work. Okay, we've done everything except – Dilaudid. Recommended dose is 0.75cc – we gave him 0.4 cc. Within 20 minutes Brady stopped screaming and fell asleep. My poor little guy was in pain – so we fixed it!!!

January 16th

Another day of a lot of TLC and rides in his car. He still doesn't feel good so Jeff & I are taking shifts. Every couple of hours we'll switch off. Brady will not do anything independently at this point and he needs to be held constantly – so that is what we do. By the end of the day he was starting to perk up a little bit....but so far other than the episode of pain, he has had very minimal side effects.

January 17th

Today is Wednesday and Brady is starting to act like his jovial old self. I am starting to wean him off the Zofran and he's hungry. I fed him a half of a jar of fruit medley and he kept it down. So for dinner I gave him some more.....and he kept that down too. I think he's on his way back up.

January 18th

Did this child just have chemo 4 days ago? Because today I am happy to say that my son is BACK!! He's running around the house, getting into everything, eating and drinking milk – NOT vomiting...no pain....plays independently....laughing BUT, symptoms of an upper respiratory infection. Runny nose and dry cough. We're not waiting until this goes full blown. He has an appointment with Dr. Kay, ENT on Monday. I put him back on the Augmentin but we're going to have him checked out anyway.

Brady is also putting his fingers in his ears quite often. We don't know if it's because it is soothing to him or if he's overwhelmed because maybe his sense of hearing is heightened or IF he might have a middle ear infection that the regular doctors are missing...So, we also have an appointment with an Audiologist on Tuesday. She is going to do a full work-up on him and also do a hearing test. This should rule out any questions marks in our heads about his hearing. We have also noticed that Brady has lost the vision in his right eye. I think it may be that his retina has detached again? I emailed Dr. Murray and phoned him as well. He basically said that it was possible....but that he couldn't tell for sure until his next EUA.

Also, today I finally made progress with Brady's therapists. We have Caren Helfman from Pediatric Therapy Associates for Speech Therapy on Fridays at 8:15 am and we also have Christine Sadecki from Therapy in Motion working with us on Tuesdays at 10:15 am for Occupational Therapy! And then there is Cindy Wolke from the Lighthouse for the Blind....she'll always be a member of our team!!!

So, today was a good day. And things are getting back to normal around here. We're looking forward to starting therapy to see how well Brady progresses from here.

January 20th

Brady still has the URI but Jeff took him to Uncle Scott's house and to the beach today. This gave me some nice peace and quiet to catch up on all of my loose ends. Wow! It sure is quiet with the two of them gone. I spent the day updating this medical history and cleaning the house. It feels good to have everything back in order!!

January 28th

Today is the day of the 2nd Annual Fundraiser for Brady. Scott Tinkler & Billy Ingersoll took it upon themselves to be responsible for this years donations. When Scott announced last year that he would be running the ING Miami Marathon again this year for Brady, I promised him that Brady would be waiting for him on the finish line. Fortunately Brady was healthy enough and we were able to honor that commitment. We met the Ingersoll family at Bayfront Park in Miami. Scott was pleasantly

surprised. As he turned the corner approaching the final ¼ mile, he caught a glimpse of Brady in his stroller. He asked Jeff if he could push him across the finish line. It was such a beautiful moment. Scott & Brady crossed the finish line and both received a medal. This is something that Brady can keep & treasure. We nicknamed Scott & Billy “Brady’s Angels” because that is what they have become. We had a great family day!!

February 2nd

Brady’s 20th EUA. I asked the anesthesiologist to give Brady some Zofran by IV because of the way he reacted to the Versed last time. Well, we still don’t know if or how well Brady is responding to this Toronto Protocol. Dr. Murray doesn’t want to be too encouraging because of Brady’s history with radical treatments. He says there has been some reduction/regression but we can’t get our hopes up. One bit of good news. The retina in the right eye has NOT detached. Dr. Murray says that the pressure is “up” in both of Brady’s eyes. This increased pressure caused a blood vessel to rupture and cause a hemorrhage. It was the residual blood that was obstructing his vision. Dr. Murray injected only the left eye with the Carboplatin. We were given three different eye drops (Maxitrol, Neomycin & Polymyxin & Cosopt) to administer to prevent infection and to control the pressure.

February 3-4

Toronto Protocol Chemotherapy #2. We had Chantel again – what a blessing. It was definitely comforting to have the same nurse, much less someone with more experience (and one of the more respected nurses). Brady tolerated the chemo pretty well. He did vomit a few times during the chemo; but more so when we gave him the simethicone (used to help with gas). Other than that little bit of drama, Brady did very well – and so did we. We had a very smooth and relaxed weekend with no complications. Same drugs, same routine. We were discharged by 6:00 pm on Sunday and came home and prepared for Brady’s recovery.

February 5th

Brady was up early today and appeared to be fine. You’d never suspect (other than his swollen eye) that he just went through a weekend of chemo. He is a warrior!! I have him on Zofran around the clock and we’re not supposed to feed him or give him milk for the first 72 hours. BUT this child is running around downstairs and tugging at his booster seat. Jeff & I decided to feed him anyway. What’s the worst that could happen? He’ll vomit? We’re use to that. The kid is hungry! Brady ate two jars of food – and continued to eat all day long. NO VOMITING!

February 6th

Brady is doing unbelievably well! He does not seem to be suffering any side effects from the chemo (other than hair loss and wanting to be constantly held). Children are so resilient! He does tire out a little easier than usual but he has fallen back into his typical routine.

February 16th

Tonight Brady is sleeping at Robin’s (so are we) and we’re meeting Scott & Billy and their wives and also Jim Pizzutelli at Houston’s Restaurant for dinner. Tonight the guys are turning over the proceeds of the fundraiser to us. I am proud to announce that the grand total from this years fundraiser is \$24,858.00. That includes checks payable to Jeff & I, to POST, to Brady and to Brady’s Non Profit Organization. All of the money

will be utilized to enhance/enrich Brady's life – just as I stipulated in the Mission Statement for the Non Profit Organization. We also plan to “give back”. There are a couple of families that Jeff & I have become friends with that have children with cancer. We believe that we are very fortunate to have the support that we have and the financial resources are a blessing. But we believe in sharing some of that with other families that are going through similar situations.

March 2- 4th

Toronto Protocol Chemotherapy # 3 – Brady's EUA was pretty uneventful and Dr. Murray says he's stable. He injected the left eye for the third time with the periocular chemotherapy....and we went over to Jackson Memorial for another weekend of chemotherapy. The weekend was pretty standard. We had a private room and private nurse – Chantel, one of our favorites. Brady got sick a few times – but nothing we weren't already use to by now. Remarkably, his left eye was a little swollen on Saturday, but nothing compared to what we were use to seeing. We put in the eye drops as directed and the swelling went down by the time we left on Sunday evening. There really isn't too much to report this time other than we have ONE chemo left. We are scheduled to return on March 30th.

March 30th-
April 1st

Another EUA for Brady. This one didn't go so well. Dr. Murray said that the bleeding in his eyes has gotten a little worse. We don't know what is causing this bleed other than the fact that those little eyes have been through so much. We asked if this complication was any reason not to go forward with the 4th and FINAL cycle of chemo and he said “No”. He did not inject either eye with the periocular chemo as he wanted to let the eyes heal and allow the blood to resolve.

Jeff & I took Brady over to the clinic to have his Port accessed. Dr. Fernandez got word of the bleeding in Brady's eyes and did not want to continue the chemo. I explained to her that Dr. Murray didn't see a problem with it; but she continued to battle with us. She wanted to discuss this with Dr. Murray. I immediately got on the phone and called Brenda. I told her what was going on and asked her if there was any reason to not go forward with the chemo. I explained to her that IF there was no risk in continuing chemo, that Jeff and I wanted to finish what we started. Plus the thought of leaving that hospital without having the treatment and letting that cancer go without us having any defense was not an option. I explained to Brenda that Brady was already experiencing multiple developmental delays for which we have numerous therapists. We just wanted to get the chemo over with so that Brady could recover and start to catch up. We just want Brady to be healthy and start to enjoy his childhood. After much delay, discussion and a little bit of resentment, Dr. Fernandez spoke to both Dr. Murray and Brenda and reluctantly agreed to allow us to complete chemo at this time. She was not happy. I understand that she is doing her job; but I assured her that I, too, was doing my job.

Again we had our private room and Chantel for our nurse. I noticed on the doctors orders that Brady's chemo doses were a little higher than

those prior. Brady gained a kilo so his doses increased accordingly. He was a little sicker than he had been the past three cycles; but this was to be expected.

We got Brady home on Sunday evening. He was definitely sicker than usual. He vomited several times on the way home. He was starting to concern me. I gave him his Zofran immediately when we got home – and he vomited again. I knew I was in for a long evening.

April 2nd

Brady was up at the crack of dawn this morning; however, he still had his wits about him. He seemed to be in a pretty good mood considering he'd just been in the hospital. He was weak and very clingy, but he did have an appetite. As always, I kept him on the Zofran every 4 hours simply to help him with the nausea and vomiting. Ironically, he ate very well today and drank plenty of fluids. No vomiting. And I know he's going to get better each day.

April (continued)

While Brady has been in and out of the hospital for the past four (4) months, he has also been working very hard with all of his therapists. Christine has been doing such a great job with Brady on Occupational Therapy. At the beginning of the year, Brady was very hesitant in allowing others to guide his hands and he really didn't like to "hold hands" with even me. I purchased dozens of Touch, Feel & Hear books that have various textures and some that make sounds as well. He particularly likes what I call his "Duck book" that has a duck, sheep, rooster & pig – and each one of those pictures have a different texture and button to push to retrieve the sound that each animal makes. He now enjoys exploring different textures with his hands (not in his mouth YET) but we've got a little ways to go.

Caren has been diligently working with Brady on Speech. Brady says "ma ma", "da da", "ba ba", "na na", "pa pa" and combines some of those like "ma da da";. Jeff and I are also working with Brady every minute of every day trying to introduce new sounds, new words and trying to build words off of the sounds he already makes. Although we're not seeing the progress with speech that we are with Occupational Therapy, it is just a matter of time before he starts talking – and then it's all up-hill from there. One very interesting fact about Brady is that even though he does not actually "speak" to us, he understands EVERY word and every command. He knows how to remove his clothes before he takes his shower and he participates in dressing himself as well. If I ask him to go find his purple football and take it to daddy – he does it!! He also knows all of his body parts right down to each one of his fingers (for example, thumb, pointer, tall man, ring man, pinkie). He also really enjoys music. I have several CD's of nursery rhyme songs that we listen to in the car – HE LOVES IT!

April 20th

Wow, three weeks just flew by and here we are at another EUA. For the most part, it was an uneventful appointment today. Brady has only been 3 weeks out of chemotherapy so we weren't anticipating any bad news – but you never know. However, Dr. Murray reports today that Brady did not receive an injection in either eye. He still has the bleeding in his eyes

and apparently the right eye appears to be worse. I find that so strange because the right eye was supposedly the “worse” eye of the two – and the irony of it all is – Brady sees out of his right eye. We have observed him regularly tilting his head to the right to use whatever vision he has in that eye....It is so strange. Dr. Murray wants to see us back in a month and he also wants Brady to have an MRI of the brain & orbits with and without contrast material. Hopefully this MRI will give Dr. Murray a better idea of what is going on with the cancer. I plan on scheduling the MRI as soon as possible.

April (continued)

Now that Brady is finished – really finished with chemotherapy and any other treatments that would compromise his immune system, it is time for him to return to school. The challenge is going to be to find the **right** school for him. The Center for Child Enrichment was the school he was attending until December; however, Marta (the owner of the school and also became my friend) sold the school and I’m not particularly as comfortable with the new owners. So my mission is to find the right school for Brady.

I spent the week calling & touring schools in our neighborhood. Some had long waiting lists and some schools I was able to tour. I became a little frustrated when touring a few of these schools. I think that the fact that Brady is visually impaired maybe scared some of them. Of course they are all concerned for the children’s safety and some of the schools seemed to only meet the minimum requirements – meaning that there was only one teacher for (8) two year olds. For me, that wasn’t enough supervision – even IF Brady had better vision. So, I put a call into my contact at Easter Seals. Lydia was the woman whom originally guided me to Marta’s school. I would have loved to have been able to put Brady at Easter Seals but there was such a long waiting list. I left her a message about my recent experiences with schools and hoped that she could offer some suggestions.

April 24th

I received the greatest phone call today – AND the greatest news. Lydia returned my call from Easter Seals. She told me that “timing was everything” and that she had one spot available in the two year old classroom and that Brady could have it!! And even better, the school is only 15 minutes north of our house. This was just too good to be true. We set a meeting for Thursday so that Brady and I could tour the school and meet the staff. We are really looking forward to meeting everyone.

April 26th

Brady and I went to Easter Seals today. I must say that when we first walked in there I experienced so many different emotions. It was very overwhelming. I couldn’t fight the tears. My first thought was, “What am I doing here? This is a whole different world. I don’t belong here.” Then Brady and I met with Lydia, some of the staff and an Occupational & Speech therapist. We did what they call an *Intake* and then proceeded to tour the school. I learned that Brady would start school on Monday, May 7th and that he would start in the classroom of the Fabulous Friends. This is a classroom of eight children and three teachers – Miss Debbie (an older woman with tons of experience and a medical background), Miss

LaToya (a younger vivacious lady with lots of energy and full of smiles) and Miss Donna (you fall in love with her the moment you meet her). They have all been there for many years and truly LOVE what they do. This classroom is so warm and colorfully decorated with a small kitchen area, matted floors and tons of toys. There is a rocking chair in the corner where Grandma sits. Grandma is the ray of sunshine in the room. She is a grandma and also a volunteer. You can't help but to fall in love with her too. This class also has children with varying Special Needs where they receive more one-on-one attention. This will be a great place for Brady to get started and become use to being in school again. Then, when he is ready, he will transition into a regular two-year-old classroom. Brady will also be receiving his therapies here; and they have also committed to working with him at mealtime on his eating issues.

After a three hour visit it was time to go. But I must say that all of those mixed emotions I had when I walked in have been replaced with the fact this thought: This is my world, and it is Brady's world too. This is without a doubt in my mind THE BEST PLACE for Brady. The people here are not only teachers & staff and volunteers – They are people that truly love what they do and they love these children. You can feel the love when you enter the building. I cannot wait until May 7th when Brady can actually begin this new journey. And the best part is – he can stay here until he's FIVE!!!

May 7th-11th

Brady's first week of school. I must say, he did cry an awful lot the first couple of days. But, I only put him in school for half days so he didn't get overwhelmed. I stuck around the school and volunteered. There were various events taking place that week. It was "Teacher Appreciation Week". On Wednesday I helped the photographer take pictures of all of the kids and teachers and on Friday I spent the morning in the kitchen baking cookies for all of the teachers and staff. I had more fun helping out than I've had in a long time. And I got to stick around and watch Brady interact with the kids and the teachers. It was a great week for us.

May 14th

Brady stayed home from school today because we had his MRI at Palms West Hospital. Another pretty uneventful day other than spending about 4 hours at the hospital.

May 15th

MY BIRTHDAY!! Wow, I can't believe it. I took Brady to school this morning and I actually had the day to myself. This was a real treat. I haven't had a day to myself for over 6 months. I really didn't do anything too exciting. I went to Citiplace and went shopping in the morning, came home & rested for a couple hours – and then went back to pick Brady up at 3:30 pm. They told me I should have come later, but I missed my little guy. And we also had an early day on Wednesday.

May 16th

Brady's pediatric clearance and labs today. And then back to school for the day.

May 18th

Wow, we're six weeks out of chemo and this is Brady's second EUA post chemo. Today was a busy day. There were about five other families in

the room waiting to hear the news about their children from Dr. Murray. As Dr. Murray entered the room I felt a chill go down my spine. He delivered good news to the first two families. And then he came up to me. He said, "And you...." Well, it wasn't bad news but I certainly wouldn't consider it to be good news either. He said that Brady was stable but that things aren't looking good. Due to Brady's history of relapse, I think he's preparing us & himself for another relapse. I guess the Toronto Protocol wasn't as effective as we would have hoped, or was it? Dr. Murray received my email regarding the Intra-arterial chemotherapy being done by Dr. Abramson in New York. I assume he called Dr. Abramson because he was able to tell me what the treatment involved. He said that it would be reasonable to consider Brady a candidate for this treatment. BUT he wants Brenda's opinion first. He said one of the risks involved with this new treatment is dramatic vision loss; however, we don't feel that is enough of a risk since Brady doesn't have that much vision anyway. He wants to speak with Brenda – and wants to consider sending us up to New York. I was given instructions to phone Brenda immediately. If for some reason she does not feel comfortable just sending us to New York having not physically seen Brady, then I am to take Brady up to Toronto to have him examined by Brenda. Depending upon what she says/sees she may be able to offer some alternative suggestions. But, we're about at the end of our rope. We have exhausted every treatment for Brady –except for the intra-arterial chemo. The problem is, this new treatment has only been performed on 14 children and there is no data, statistics, risks or benefits published in any journal or recorded in any study. Apparently this treatment has been offered to children that are going to lose their eyes anyway – and there have been some successes and some failures.

I think I held it together pretty well when Dr. Murray was delivering these instructions; however, I could feel the trepidation running through my body. It was only a matter of time before the shock wore off and I had a meltdown.

I got Brady in the car and then I lost it!!! But I pulled it together and phoned Brenda immediately. She wasn't available at that time so I left her a message. Later on in the day I was able to reach her on her cell phone. We had a brief discussion and she expressed her hesitations in wanting to just say "yes, go to New York" because she doesn't know enough about the treatment. She said she would call Dr. Murray and they would discuss our circumstances and together make a decision. She said she would phone me when she & Dr. Murray had spoken.

May 19th – May 24th

I spent all of my time in the past couple of days carefully organizing and planning my trip to New York City to have Brady seen by Dr. David Abramson. I had a tremendous amount of help along the way. My dear friends at P.O.S.T. served as my Social Workers and helped me pave the way with the National Children's Cancer Society which took care of mine & Brady's flight up to New York. We were scheduled to leave on Saturday, May 26th. Kathryn & Jane from Bascom Palmer coordinated the care with Dr. Abramson's office for Brady's appointment for EUA on

Tuesday, May 29th. I was assigned a Social worker from Sloan Kettering, Ms. Juliana Yui, whom would be contacting the Ronald McDonald House for our accommodations for the duration of our stay in NYC – and so conveniently located only 5 blocks from Sloan Kettering. Now all I needed to do was get Jeff on the same flight out of Palm Beach on Saturday so that he could enjoy a couple of days with Brady and I before the appointment on Tuesday.

We got Jeff on our flight with no problem. However, he would have to leave New York early on Monday morning as he had to return to work on Tuesday. Fortunately for me, coming to our rescue (and to temporarily replace Jeff), Robin would be flying in Monday morning and staying until noon Tuesday – so she would accompany Brady & I at Dr. Abramson's office.

So, we're all set....Now we just wait for our departure on Saturday.

May 26th

Saturday – leaving Palm Beach airport was such a breeze. Brady awoke early that morning and we wouldn't allow him to nap at his usual time. We boarded the plane shortly after 3:00 pm – and our little guy was such a great traveler. He slept the entire time. And fortunately for us we had a direct flight right into LGA in NYC.

We arrived with no problems and took a taxi over to the Ronald McDonald House (405 E 73rd Street, Manhattan). I have to say, this RMH was like a 4 star hotel compared to others I've seen. We got a room on the 3rd Floor (Room 310) right across the hall from Belkis, Allan & Chloe Gorman, our friends from home....It truly felt like home away from home.

May 27th

Jeff, Brady & I spent an absolutely wonderful day in New York City. We began the day by walking from RMH to Central Park which was about a two mile walk. We spent a couple of hours in the park.....just enjoying the weather and people-watching. Then back to RMH for a quick lunch and nap. The afternoon consisted of a bus ride to 42nd Street and then subway to Canal Street where we did some shopping (mostly little souvenirs for Jeff's office and some cute little things for Brady's classmates at Easter Seals – T-shirts for all kids and teachers and finger puppets for the therapists). After a full afternoon – we decided to take a taxi back to RMH and order some dinner to be delivered.....and then just enjoy Jeff's final night in NYC. He would have to leave us at 6:00 am – bright & early.

May 28th

We saw Jeff (dad) off this morning and then took a walk (4 blocks) to a really neat little park for kids. Brady loved the swing sets and sprinkler park. We spent a couple of hours there just trying to kill some time before Aunt Robin would be coming in.

Robin arrived at about lunch time.....So we walked around until Brady dosed off and then enjoyed a quiet lunch at a neighborhood Sushi restaurant. From there we took another bus ride to Madison Avenue – where the whole street was closed off and a huge craft fair was going

on....More shopping and browsing – and then a stop at the restroom at Trump Towers. Back in a taxi and then to RMH to settle in for the evening. We ordered more Italian food – and then to our surprise, the staff at Ronald McDonald House threw a little Birthday Party for Brady down on the 2nd Floor. They had presents for him and a cake and decorated an entire area especially for him. They really go out of their way to make sure these kids have as much “normalness” to their stay there at the house. It was a nice and pleasant distraction.....

Then back to our room where Brady had just about had it for the day. Robin & I put him to bed and then she & I got on the phone with Abby in England to go over our long list of questions for Dr. Abramson in the morning. I think we finally settled down after midnight....and I set a wake-up call for 4:00 am – as if I was going to sleep?

May 29th

I really didn't sleep more than an hour. I was up pacing the floors half the night. I was up at 4:00 am showering and preparing myself for whatever was about to happen that morning. Was Brady going to be a candidate for this treatment? Would he begin treatment up here soon? When would we even get to go home? Am I really ready for this? I wish Jeff was here.

Needless to say, we all got ready and walked over to the hospital, checked in and filled out all of the paperwork. Dr. Abramson's office was definitely different from Dr. Murray's office – and packed full of patients. We were treated very nicely by his staff – and called back for the consultation fairly quickly.

Dr. Abramson spent a good amount of time with us discussing Brady's medical history, past treatments, responses & relapses and then he basically asked me why we were there. I told him that it was my mission to do everything possible to save Brady's eyes and the little bit of vision that he had. I told him that I knew we had exhausted every other treatment known to retinoblastoma and that he & his new treatment were probably our last stop. He briefed us on his standard EUA process and then took Brady back for anesthesia. I was able to go back to the OR with Brady and hold him until he fell asleep, kissing his forehead and telling him I loved him before he drifted off.....and then I returned to the waiting room – TO WAIT.

What I am about to share has taken me the past 6 weeks to actually digest and finally now be able to come forward and discuss in this journal:

After about 45 minutes, Dr. Abramson called us back into the “meeting room” where he was accompanied by 2 other doctors. I was introduced to both of them – one of which I had spoken to over a year ago, Dr. Ira Dinkel....what a pleasure to meet him in person. The other doctor, Dr. Brody, I was not familiar with. Dr. Abramson looked grim as he began to tell me how the EUA went. He discussed his observation of the blood in Brady's eyes (that we already knew about) and his difficulty in assessing whether or not Brady would, in fact, be a viable candidate for this new

treatment....Which lead us to Dr. Brody's assessment. I was about to be devastated. Dr. Brody explained to me that he was called upon by Dr. Abramson to assist with evaluation of Brady. Dr. Brody administered a test to Brady's eyes which was allegedly used to measure the signal from Brady's retinas to the brain. This test would measure any visual function in Brady's eyes. Dr. Brody very matter-of-factly told me that there was NO SIGNAL. A FLAT ERG. Dr. Brody told me that Brady was BLIND. I was stunned. I couldn't talk, I couldn't even move. I have been told a great deal of devastating news about Brady's condition before; but NEVER that Brady was blind – and I believe Dr. Brody's choice of words were "irreversibly blind" therefore Brady was not a candidate for this treatment because apparently there was nothing worth saving in Brady's eyes.

How could this be? I know Brady can see. Is this test 100% accurate, I asked? Yes, it is. Dr. Brody responded. "So you are telling me with all medical certainty that my son is irreversibly blind, is that correct, Dr. Brody?". Yes, Mrs. Simmer that is correct. I WAS DEVASTATED.

They brought Brady back to me from anesthesia and I got us out of there as soon as possible. All I remember is being so hysterical that I was having an anxiety attack just trying to make it those 5 quick blocks back to the RMH. Thank goodness Allan Gorman was downstairs when I arrived because at that moment of walking through those doors I felt like I was going to faint. Allan helped me up to my room and occupied Brady for almost 2 hours as I just screamed and cried and did not understand how in the world this was so....These doctors basically implied that I was to go home and consult with Dr. Murray and that maybe it was time to just allow Brady's eyes to be removed and move forward. This was just not happening...I think I was in complete denial and NOTHING OR NO ONE at that time was going to be able to do anything to take my pain away or make me feel any better.

I got through the rest of the day and just planned on using the following day to make plans to get home to my family.

May 31st

We arrived back home today, safely and soundly. I must say, though, that I am completely exhausted and emotionally drained....so much that I cannot type anymore for the day.

June 6th

I received a phone call today from Tim Murray. I think he was probably the only person that could have brought me out of the deep dark place I had been dormant in for the past week. He was very clear in saying that I should not pay attention to what the doctors said in New York. More importantly, HE thought that Brady still had visual function and definitely had something worth saving. He also mentioned that when Dr. Brody performed the "test" on Brady, that Brady's retinas were detached at that time.....SO OF COURSE they were getting a flat ERG. Had that been explained to me on the day of the test, I would have understood why the doctor was telling me that Brady was blind; however, he ABSOLUTELY used the WRONG word – he should have told me that perhaps Brady

was temporarily blind – as we all know that Brady's retinas have detached before AND they have also REATTACHED!!!! Tim also said that at this time I need to be planning my next trip – to Toronto...but that we'd discuss more about this after he saw Brady at his next EUA that was scheduled for Friday, June 15th.

June 15th

Brady's EUA was today. Jeff and I were going there prepared to hear that Brady had relapsed, again....But to our surprise AND relief, Brady is still stable. Tim reports no new tumor activity and that the bleeding in his eyes does not look any worse (as it did last month). We discussed his wishes for us to absolutely seek the opinion of Dr. Brenda Gallie in Toronto – and to try to do so before Brady's next EUA on July 20th. Tim is definitely very upset with what happened in New York and the delivery of inaccurate news. He felt that we were up there for one reason – to see if Brady was a candidate for the treatment – NOT to be told anything else....Anything other than that was Tim's place to tell us – NOT Dr. Brody – after all, he's only seen Brady once, will never see him again and has NO CLUE as to how TOUGH Brady is!!! So, we're off to Toronto. Here's the funny part: Tim and Brenda will both be at a conference in Sienna, Italy together in late June/early July. So we're going to have to move quickly to get this trip organized. Another advantage is that my dear friend, Abby White is coming into town next week and I know she knows her way around Toronto and some other helpful resources that we may be able to access when traveling up there. I am so looking forward to her visit.

June 22nd – Present

Abby White is here and we are having a wonderful time. Having her here is like breathing fresh air. Other than our planning the trip to Toronto – I have only one AMAZING thing to report – before I take a break from these updates – and until I get back from Toronto:

Last Sunday (today is Thursday, June 28th) Abby spent a great deal of time with Brady and some of her toys that she uses with visually impaired and blind children. She has a ball – a clear ball about the size of a tennis ball. This ball is covered by a sheer plastic coating to protect it (if thrown, particularly by Brady). It also has many different vibrant lights that shine from the inside. The one thing to remember is: IT DOES NOT MAKE NOISE. Abby called me upstairs after a while and asked me to "watch". As she moved the glowing ball around the circumference of Brady's head, when she got to the far RIGHT side (where we have always thought Brady had some peripheral vision) Brady grabbed the ball. When we put the ball on the floor and rolled it across the room and told him to go find it – he found it EVERY TIME. He did not scan for it with his hands – he tilted his head in his special way and found the ball. In short – **BRADY CAN SEE!!! BRADY CAN SEE!!!! THE DOCTORS IN NEW YORK WERE WRONG!!! BRADY CAN SEE!!!!** And a special thanks to Abby for spending that most precious time with Brady and giving me such a special moment.....watching my son do what I knew he could do all along – SEE!!!!