



Who Is Garrett?

Garrett blessed us at 6:17 pm on June 16, 1995. At first he did not seem to want to come into our world and he took a lot of pushing, but once he was here, he stole our hearts. Being our first baby, we held him like a fragile piece of crystal, but Garrett was anything but fragile, through his nine years of being with us, he showed us more strength and determination than any of us could ever imagine. He truly lived up to the meaning of his name Garrett, "brave warrior."

Our first six months together were not easy, Garrett had colic and reflux. I remember having to put him on top of the dryer so that we could try to break up those nasty gas bubbles in his little tummy. His father would take him jogging in the stroller at 2:00 in the morning so that Garrett would go to sleep. Garrett's usual sleeping position was lying on my chest so that he would hear my heartbeat and I would hear his little toots of gas finally escaping, giving him some relief. Whenever you saw me, I would have a burp rag on my shoulder and the essence of formula as my perfume.

Things eventually got easier and Garrett was such a pleasure. He was always quick to smile and when he looked at you with those bright blue eyes with that little twinkle in them, you just had to go give him a kiss and a hug.

Garrett did all the things normal toddlers do, strip down and run around the house naked, take all the toilet paper off the roll and stuff it down the toilet, if you have children you know what I mean. He was so full of life and he was loving it. He was very smart (and that is not just a proud mom saying it). He was putting ABC puzzles together by himself and playing on the computer at 18 months. He would not allow me to help him on the computer so I had to buy one of those booster chairs to put on the chair in front of the computer so he could sit there by himself safely. Some things would drive me crazy, he loved doing a program that had farm animals on it and he would make the cow "MOO" over and over again.

Garrett became a big brother on June 30, 1997 and he was so proud to be one. He would watch out for Kyle all the time. Garrett knew that you were not allowed to go into the street and he would guard the end of the driveway so that our daring Kyle would not be able to go out there. Not to say that they did not fight like brothers should, but they always made up and loved each other so much. They were each other's best friend. They were still quick to blame the other one when someone did something wrong, "He did it. No, he did it." Sometimes both of them were so convincing that to this day I don't know who really did it.

Then the blessing of Caleigh came to us on May 6, 1999, a little sister. Garrett, being almost 4 years old now, was the wise and experienced big brother and helped me take care of his little sister. There were lots of kisses and hugs for her, because as Garrett would say, "She's a girl."

Our family now complete, when the three of them would go out with us and someone would come up and say, "What a lovely family," Garrett would proudly tell them, "I am Garrett and this is my little

brother Kyle and my little sister Caleigh." He was so proud that he was the big brother and he was proud of his family.

My husband, Darrell, instilled in Garrett that reading is the road to knowledge and taught Garrett to read at a very early age. Garrett would read Dr. Sues books at the age of three all by himself. From this gift of reading Garrett grew to be a straight "A" student and excelled in reading points at school.

We all have our "firsts" and of course it was hard to see Garrett go off to school. We lived in Pflugerville for his Kindergarten grade, Springhill Elementary. I was prepared to cry my eyes out the first day of school, but Garrett would not have any of that. He wanted to walk into school all by himself and find his own way. It was so hard to let him go and do that, but if that is what he wanted, then I let him do it. He knew what was best for him. There were no tears, just a look over the shoulder as he waved bye and off he was to start his school years.

We moved to Round Rock that summer because we needed a bigger house. We could not have found a better neighborhood. Garrett loved it because we had the park right behind our house and all he had to do was open the gate to get there. We live right across the street from the school so he was able to walk and never be late. Best of all there were lots of other boys right across the street to play with. He got involved in school, Boy Scouts, Tai Kwon Do (which he won two medals in his very first tournament) and many other things that kids do. He was happy.

We were getting ready to end our school year in 2003. Forest Creek Elementary has an end of the year day where you do activities outside. The typical races, tug of war and whatnot. I had been out shopping that day and the school called and talked to Darrell, one of the teachers, Ms. Ilgen, noticed that one side of Garrett's face looked slack while he was running. When I got home and Darrell had told me this I called the doctor right away. We went to the doctor and they told us that it was Bells Palsy and that it would clear up within three months. I had no idea that this was going to be the beginning of the end.

That weekend everything went as normal, just Garrett's face on the right side was paralyzed. There were no other signs, no other problems. Then on Monday when I called my mother and of course handed the phone to each child to say, "Hi" to grandma, Garrett put the phone up to his right ear and said that the phone was not working. I could hear my mother talking, but Garrett could not. I called the doctor again and we had a hearing test done. He was deaf in his right ear. The doctor told me that is not a symptom of Bells Palsy and scheduled an MRI the next day.

I knew something was wrong when, after the regular MRI and we were going to do the contrast MRI, Garrett was not working with us to put the contrast in, he was deathly afraid of needles, and I asked if we really needed to do the contrast. The technician went to see the radiologist to see if we needed to do the contrast and the next thing I saw was the radiologist through the window, tucking in his shirt and straightening his tie. I knew that this could not be good. He walked in and told us that I needed to take Garrett to Children's Hospital right away. I started crying and Garrett, always worried about me and how I felt, asked, "Mom, why are you crying? What's the matter?" All I knew is that I was very scared and my heart just dropped to my stomach. I just told him that we had to go to a better place to take better pictures.

We did not find out that Garrett had cancer that day. It took a full week after that. We went to the hospital and was told that the doctor that was referred to us was not the person to be talking to and we were referred to an ENT. Well, if you ever have to get into a specialist it is always at least a week wait. We went to see Dr. Slater, he saw the films and told us that we should have never been released from the hospital. During all this time Garrett was as normal as you could be. He did not think of doctors appointments, all he wanted to do was have fun with his friends, it was summer break and time to play. We made an appointment to have surgery in three days.

June 2, 2003, the longest day in my life. Garrett went into surgery at 6:00 in the morning, the doctors telling us that it should only take 4 hours at the most. Six hours later Dr. Slater came into the waiting room. "It is not a cyst like I was hoping. Garrett has cancer. It is Rhabdomyosarcoma." My

first thought was that we had not even had Garrett baptized yet. What I was thinking next, I have no idea. It felt like I had hit a brick wall going 80 miles an hour. Then I just wanted to be with him. He was in recovery, they had already planted his port-a-cath in, knowing that he would have to have chemotherapy.

The next few days and even weeks are a blur. We met with Garrett's oncologist, Dr. Wells, and with the radiation doctor, Dr. Brown. Garrett throughout this was wonderful. I did not know how to tell him that he had cancer, but I tried my best to explain it to him and he took it in stride. We started chemo the very next day after his surgery, plus we started fitting him for his mask for radiation therapy. I think that might have helped that we were so busy doing all these things, we did not have much time to think about it.

Garrett's protocol was three different chemos, what I called the "chemo cocktail." The worse of which was the vincristine, which he had to have every week. One of side effects of this drug was losing your coordination. Garrett would be just standing there and all of the sudden he would fall down. He would just get up and say that he was all right and "That darned vincristine got me again." He lost the use of his hands, except for his thumbs so that he could still play Game boy. He was in a wheelchair for three months until we cut down on the dose. We would go to the doctor's office at least once a week, usually twice to have levels checked and treatments. Radiation took us to the doctor's office every day for 32 days, even weekends. He had Dr. Brown do a Yu-Gi-Oh mask for him and Dr. Brown did a great job. Since Garrett's tumor was in a fixed place, wrapped around his 7th and 8th nerve and the carotid artery, his radiation mask had to be bolted down to the table to keep his head still during treatments. Garrett never complained, he would just step up to the table and lay down while the technicians bolted his head to this table and laid still until his treatment was over. Sometimes he would even fall asleep. He always remembered to thank everyone while he was leaving the office.

Chemotherapy was 9 months, at least 4 hours every treatment, usually more. Thank goodness my mother was able to come up from Florida to stay with us and help us out. Because of the chemo and radiation, Garrett's white blood count dropped quickly and he was not allowed to go back to school at the beginning of the year. He had the most terrific homebound teacher, Cheri Dunham. Garrett's week was usually, Monday the doctor for treatment, Tuesday school, Wednesday have fun with Grandma, Thursday school and Friday doctors office. Of course there were variations to that schedule all the time, depending on fevers, white blood count and hospitalizations. Garrett would just go with the flow. He would only get upset if I had to tell him that he could not go out to play with his friends because his blood count was too low, which unfortunately was frequent. He would sit with me on the front steps or be looking out of his window saying to me, "Mom, I just want to be a normal kid again." And I would give him a hug and say, "You will be."

Garrett made friends while he was in treatment. He became an expert in Pokémon on the Game boy and shared all of his secrets with other children that were getting their treatments. They would play together or just sit in companionship while connected to their IVs. They did not need to talk to each other, just have each other's company.

In February 2004 Garrett's protocol was done. He had scans done and they showed that the cancer had not advanced in the last couple of months. Garrett was told that he was in remission. I cried. Garrett said, "Mom, why are you crying?" I just told him that it was a happy cry.

We went on our Make A Wish trip for his 9th birthday. Of course Garrett chose to go to Disney World. We were joined there by Grandma and Grandpa, we even had neighbors that scheduled their trip to be there during Garrett's birthday. My sister, Garrett's Aunt Christine, Uncle Shane and cousins came. We had a grand time. Garrett's hair was back and he was having fun. It was almost like he was normal again. He just got tired and had to have a wheel chair because it was just too much to walk around all the time. He even had one of his clinic friends, Mark, there at the same time. Garrett was so happy and loving and living life.

August 13th 2004, the day of the Lance Armstrong parade in Austin. We had been watching the Tour De France religiously and cheered when Lance won. We had a banner painted and were geared up to go to the parade. Garrett had gone to Jacob's house (a close friend from the clinic that also had rhabdo that lived not 3 miles from us) to play and I was on my way to pick him up and we all were going to the parade together. I got a call from Dr. Wells. Garrett's cancer was back, his tumor was growing again.

I tried to think of how and when I was going to tell him this news, he had been looking forward to going to the parade and seeing his hero, Lance. Of course I had been crying and Garrett could tell. He asked me, "Mom, why are you crying?" It was at this moment I decided that I would tell him everything. I told him that he would have to go back on chemo and have his port-a-cath put back in. He told me, "Mom, I beat cancer once, I can beat it again."

I asked him if he still wanted to go to the parade and of course he did. He wanted to see Lance. He was hoping to get right up there with him to see if Lance remembered him from when Garrett was in the Nike commercial. I told him not to expect too much, that there were going to be a lot of people out there in support of Lance, showing him how much Austin and the surrounding areas loved and looked up to him. He said, "It does not matter, I just want to go." So a terrible day was turned into a good day because Garrett wanted it that way.

I was fortunate enough to be able to have my Mom come back and help us, thank goodness for Moms. Garrett started his chemo again and was home schooled once again by Ms. Dunham. This round of chemo was more aggressive, more frequent. Thank goodness he was able to go swimming for just a little while over the summer, it was his most favorite thing to do, because with this round of chemo, his white blood count dropped and never came up.

On his first round of chemo, I would do all the fluids at home and became like an at-home nurse. This second round of chemo was exhausting. Not only did I do fluids, but there were shots everyday for a week every three weeks. I hated doing that, sticking him with one of his greatest fears, but again, he took it in stride. I remember one time I forgot to draw my "target" area on his tummy and completely missed the numbed area. Garrett did not even flinch. He just told me afterwards, "Mom, that kind of hurt, you missed your spot." Garrett learned what medication he had to take every day and started taking it himself without me having to tell him or grind it up and put it in chocolate milk. If you happen to know someone that is fighting cancer, you know that there are at least 18 pills that you have to take every day, sometimes more, and Garrett had it down pat.

On November 11, 2004 I got the call from Dr. Wells again. Garrett's scans showed that the chemo he had been on was not working, the tumor was still growing. Garrett was considered terminal. I could not tell Garrett this, even though it hurt me not to do so. I had told him that I would tell him the truth when it came to his cancer, no matter what. But I just could not tell my precious son that despite all of his hard work and determination, he was going to die. I asked him what he would like to do best, if he could do anything, what would it be. He told me, "I want to go to Disney World again."

So on November 13 we were on our way to Florida. I have to say that it would not have happened without help from Southwest Airlines and Picket Fences Realty. We were able to get free air fares for our family to and from Florida and a house that you would just dream of. It was wonderful and magical. We were able to have a house all to ourselves so that the kids could run and yell without worrying about people in the next room and it even had its own pool, and even being November, the kids swam in. The house was just minutes from Disney so we were able to have our "normal" breakfast and dinners and be able to play and explore at the park all day long. My sister was able to come up and stay with us overnight, which all the kids loved. Garrett was having such a great time and was bummed when we had to leave four days later.

When we got home I called Dr. Wells and told him that we needed to do something, anything, for Garrett. He was such a fighter and wanted to live so much. We started a different chemo and pushed the radiation limit. His chemo was everyday for five days every two weeks. His radiation was

everyday, this time he chose Spiderman as his mask. I think Garrett knew, without us telling him, that we were fighting for his life.

We had a great Holiday season. His Aunt Cathleen and cousin Nathan came right after Thanksgiving all the way from Germany to see him. His Aunt Christine and her family came right after Christmas to see him. Unfortunately he was in and out of the hospital all during this time. I remember him waking me up at 2:00 in the morning saying that he was not feeling well. I took his temperature and it was 101, calling the doctor and telling us that we needed to come on down to the hospital. He was saying, "Mom, can't we wait until the morning." I wished upon wishes that I could have told him, "Yes, we can wait."

New Year's Eve came and Garrett and his friends had a wonderful time. We had fireworks galore, not caring if the Police came and told us that we had to stop. This is the last picture we have of Garrett alive, with his sister Caleigh and his best friend Gisella. Garrett went into the hospital on January 3rd, 2005, never to come out again.

It started out a normal day. The kids getting ready for school, Kyle and Caleigh talking at the table and Garrett in his favorite chair listening to them talk. Caleigh had said something, I'm not sure what, but Garrett was disagreeing with her and he grabbed his throat saying, "Mom, my throat hurts real bad." His voice sounded weak and he seemed like he could not lift his head. So I called the doctor's office and told them that we were coming in even though it was before hours. He saw the doctor and took some tests, then they sent us to have an MRI. Garrett has never complained during an MRI, but this one, 20 minutes in to it, he said, "Mom, my throat hurts too much." I knew right then there was something terribly wrong. We went home that night for four hours, then he started running a fever and Darrell took him to the hospital.

They could not find what was causing the fever, but two days into his hospital stay, Garrett developed a redness under his right eye. I had come to see him and asked Darrell when this had started and Darrell said that it is the first that he saw it. I watched as the redness grew and called the nurse. She had asked if Garrett had rubbed his eye and I asked Garrett that, he said, "No." The redness continued to grow right before our eyes.

Eventually I convinced the oncologist on call that this was not radiation related and had his radiation doctor come down and see him. They finally got an ENT to look at him. During this time Garrett's eye swelled completely shut and he could hardly talk. They took him to MRI again, and told us that it might be a fungal infection, which being in his terminal condition, would not be treatable. I could not accept that this would be the end. Garrett went into PICU, being intubated and with fever. It was horrible watching him in that condition and not being able to help.

As it turns out, Garrett did not have a fungal infection. He was able to be extubated and was transferred to the Green Unit. He fought back. He was up and talking to us. He was strong. Until seizures started. He went back to PICU because of the seizures and we were told that it was because of either the medication he was getting or the tumor. So we decided to stop the medication. The seizures stopped and Garrett was able to go back up to the Green Unit.

We had a couple of good days with Garrett. He was talking with us and playing BINGO. I had talked to Dr. Wells about bringing him home on Hospice and we were making arrangements to do so. I talked to Garrett and was leaving to go home and told him that I loved him and that I would see him tomorrow and that maybe he would be able to come home the next day. He told me, "Mom, I love you."

Those were the last words that I heard from my precious son. He passed away in the early hours of February 1, 2005. Darrell called at 12:05 to tell me that Garrett was having trouble breathing. I told him that I was on my way down, I just needed to get together. He called again at 12:15 to say, "He is gone."

My son, my first born, and my "brave warrior" was gone. In all of his years we never told him that his name meant brave warrior, but he lived up to it to the fullest. He is still my strength and I look at his brother and sister and see him in them all the time.

This story, my son's story, is why we have started Garrett's KidStrong Program. He wanted to be a "normal kid" but it is very hard to do that when you are fighting cancer. It is hard on the child going through cancer, it is hard for the parents, and it is hard for the siblings. Garrett wanted to have fun, he couldn't. I want to make sure that if even for the shortest time a child can have fun with others that are going through the same thing they are and their siblings and parents can have someone to talk to about their experiences, we are there.

I have dreams about Garrett. That he is happy and having a grand time wherever he is at. I have never been a very religious person, but I want to believe that my son is in a better place and wherever he is, he is having the time of his life that he could not have here. If we can provide that for a child that is going through cancer treatment here where we are I think that would make Garrett proud.

We have carried on. Kyle and Caleigh are doing very well. Kyle is in football and Caleigh is a cheerleader, something that we could not have done while Garrett is on treatment. Darrell is working hard at APD and I am trying my hardest to get Garrett's KidStrong going. Life goes on, but Garrett's dream keep me going. His strength keeps us all going. We miss him and we still love him more than anything, I guess we always will.