

# Sophie

Our beautiful Sophie was born at 4:23 a.m. on July 4, 2003, in Cincinnati, OH. Labor was not easy...23 hours with 2 ½ hours of pushing, but Sophie was perfect in every way. She spent the first 30 minutes of life not crying, but looking around and taking everything in. We remember our first night in the hospital together, hearing fireworks outside, and thinking how neat it would be for Sophie to have fireworks on each of her birthdays for the rest of her life.

Sophie was the first for everyone. She was our first child and was the first grandchild. She brought so much joy to so many people. For us, our lives changed forever the day she was born. We knew we were going to dedicate every waking hour to ensure Sophie had the absolute best environment in which to grow, learn, and flourish.

For Sophie's grandparents, Sophie was someone they could spoil and love all over again. She loved playing and swimming at "Grandpa's cottage." She loved the countless care packages Grandma sent in the mail. She loved messing up Papa's hair and playing dishes with Nana.

Sophie was always a special kid. We know all parents think their child is special, but Sophie was different. She reached all the usual milestones before or on time. By ten months she was sitting still, listening to long stories and then was able to identify all the objects in the stories. By one year, she could identify all shapes, including pentagon, hexagon, and octagon. Once she learned how to walk and communicate, we learned how sweet, kind, and smart she really was. At 18 months, she knew all her letters and could say and spell her name.

The diagnosis and prognosis crushed us. We could not understand why our little girl had this mean and evil monster growing in her head. We kept asking ourselves, "How long has it been there?" and "Why us?" and "What did we do wrong?" We started to think about the signs which probably existed as far back as September of 2006. It started out with Sophie waking up three and four times a night, sometimes crying in her sleep, sometimes laughing, or talking and recalling past events. She would sometimes tell us her head felt "wobbly." We just thought she was overly tired. Then there was the anxiety. She was great for her first day of pre-school, not a single tear, but as the school year progressed, she was more and more anxious. We talked to friends and family, and our doctor who all convinced us that it was just a "phase." In January, we noticed her coordination was a little off. She had a gymnastics recital and Marc almost cried as she struggled through it. He remembers thinking that Sophie could do somersaults when she was 2 years old, but could not do a single one at the recital. We chalked this up to anxiety or a growth spurt.

In February, we noticed her coordination getting worse and then out of nowhere she started to vomit every other morning for about 10 days; again, we had a logical reason. This time we thought it was just sinus drainage because she had no other symptoms. Looking back we realized that she also started taking naps again in the fall, which she had not done since early spring. At the time, we figured this tiredness was due to the new routine of starting school and participating in more activities. She refused to race Marc up the stairs to take a tub. Instead of running (she was always running) she now wanted to be carried. On Saturday, February 17, we had family pictures taken and noticed that Sophie could not smile. The right side of her face was basically frozen. In hindsight we realized these were all symptoms, however, 99% of her days appeared normal and were filled with the day-to-day activities of a typical three-year-old. Life was good and happy for the four of us in Avon Lake, Ohio.

On Tuesday, February 20, Sophie vomited in the morning, but assured us that she felt well enough to go to preschool. After picking Sophie up from school and being told by Sophie's teacher that "Sophie seemed a little off today," we knew something was wrong. We called the doctor, and got an appointment for that afternoon. As Sophie slept, I searched the internet for a possible reason for her symptoms. Before the appointment, I was 99% sure that a brain tumor was the cause, and called Marc to tell him, and request that he come home from work to go to the appointment. We talked about what this might mean...how she would lose her hair, have brain surgery, and maybe lose some parts of her brain function. This scared us to death, but nothing prepared us for the words, "inoperable" or "terminal." We were sent from the pediatrician, who told us he was "very concerned," to the emergency room at Cleveland Rainbow Babies and Children's Hospital for a CT scan. That evening the scan showed an "ill- defined" mass and an MRI the next morning confirmed the diagnosis.

We cried and cried and hugged and hugged. Again, wondering what we did wrong and asking the question over and over, "How could we be so unlucky?" and most importantly, "What did Sophie ever do to deserve this?"

It's hard to accept that your three-and-a-half-year-old daughter may never get married, let alone graduate from high school, or even start kindergarten. We wallowed in our sorrow for a few days until we realized that we had to do something. We had to continue on, as we had her entire life, making sure she had the most love and best environment possible. We were committed to doing everything possible to prove the medical experts wrong. We explored every possible standard and alternative treatment option, and most importantly, we prayed and placed our faith in God.

Sophie began her treatments at St. Jude Children's Research Hospital. Although we weren't 100% convinced we wanted to put Sophie through radiation and chemotherapy, we heard such great things about St. Jude that

we decided to begin the 6-week journey as soon as possible. We packed up our things and left for Memphis five days after Sophie was diagnosed. While at St. Jude, Sophie had many appointments, from routine check-ups and blood draws, to physical therapy and occupational therapy, and of course six weeks of radiation. During this time she was also taking the chemotherapy drug, Zarnestra, as part of one of St. Jude's clinical trials. For 31 days of radiation, Sophie was sedated and strapped to a table with a mask placed over her face. Throughout her time at St. Jude and after, she continued to remain on steroids, in an attempt to control swelling which would hopefully minimize her symptoms. She gained about 15 pounds from the steroids, which was just over 1/3 of the weight she was before diagnosis.

We were told that upon completing radiation we would probably have "up to six good months" with Sophie before the tumor progressed, and that during this "good time" she might "be back to the normal, pre-diagnosis Sophie." Unfortunately at the end of the six weeks at St. Jude, we really never made it to that point. Although some symptoms had improved, it was really not the dramatic improvement for which we had hoped. Sophie never regained the use of her right side, never got her smile back, and never walked without a limp. At that time, there was really nothing else St. Jude had to offer, so we returned home to Avon Lake, hoping to make the best of the summer and have as much fun and create as many memories with Sophie as we could.

After Sophie's first follow-up MRI (2 weeks after completing radiation), we discontinued the clinical trial upon returning home because we did not see any benefit from it. Knowing that conventional medicine could not provide us with any options for a cure or any other treatments that might help Sophie, we spent endless hours reading books and scouring the internet for anything we could try. Anything that sounded reasonable and had any anecdotal evidence of success, we tried. We tried herbal supplements and tinctures, from Probiotics, iodine drops, wheat grass, oxygen drops, alkaline drops, krill oil to paw paw. We also contacted a doctor from India who had seen some success using Ruta-6 for brain tumors. We completed a phone consultation with one of the doctor's colleagues in the US, and ordered the recommended remedies. We gave this a shot; again, seeing no improvement. We met with a naturopath and used lasers and went through various phases of limiting certain foods in Sophie's diet. We cannot be certain of their effects, as some we continued until the end.

Sophie did have a couple of good months in May and June. She was able to get around by crawling. We continued her OT and PT here at our house, and although she didn't love it, she cooperated as best she could. We tried many times to reduce her steroid in an effort to get her off it completely. We longed to "see" the Sophie that we knew, as well as spend time with the Sophie we knew who wasn't as angry and irritable as the Sophie we knew on steroids. Throughout the course of Sophie's treatment and the use of steroids, she was always hungry and had a terrible time sleeping soundly. We tried to choose foods for Sophie that fit into the

“cancer diet,” but when your child is “starving” all the time, the guilt of not being able to feed her what she wants is excruciating.

The day before Sophie’s fourth birthday, she had her last MRI at St. Jude. At this time we were beginning to see signs of the tumor progressing. She was having a hard time standing with support. She was throwing up more often and was more tired. Although her MRI showed areas of enhancement, her doctor was still reluctant to say that it was progression because she still was only two months past radiation. He told us that if it was progression, we would see an increase in symptoms very quickly --- and we did. While at St. Jude for the MRI, we were given a wheelchair, and we realized that Sophie would probably never walk again. The second week in July, Sophie was granted her Make-A-Wish trip on a Disney cruise. We were a little nervous to go because we didn’t want to be away from home if things got worse. Sophie threw up at the airport, but said she still wanted to go. What a great decision! We made some very happy memories with Sophie on that trip. After we returned she told us repeatedly that she wanted to go on another Disney Cruise. We never got to go, but I know that every day is a Disney Cruise for Sophie in heaven.

We met with two different spiritual healers on two different occasions. In addition, we discovered DMSO/sodium bicarbonate as a treatment option. The plan of care was for 36 daily IV treatments, and from what we read, we decided to give it a chance. We headed to Tulsa, Oklahoma, and met with a doctor there who prescribed the treatment. He explained to us that he had seen DMSO work in about 30% of cancer patients. He told us that it works for some because it has the ability to change the cell’s mitochondria enough so that it becomes a foreign body, and the immune system will attack it. (The reason why our immune system doesn’t naturally fight the cancer cells is because they are a part of the body’s own cells.) DMSO also has the ability to cross the blood brain barrier – something traditional chemotherapy agents cannot do.

We completed ten treatments there before Sophie’s condition worsened. The rapid decline we saw in Sophie made us decide to bring her home to continue the treatment. During this time we began to gradually decrease Sophie’s steroid dose to allow her body to have a normal response to the DMSO. (Steroids prevent the body from responding as it should.) She had a tough time coming off the steroids after having been on them for so long, and spent many days with a bowl in her lap because she was too weak to go to the bathroom to throw up as often as she had to. The DMSO was given intravenously through Sophie’s port. She hated having the port touched and accessed throughout this entire ordeal. We completed 45 treatments and having not seen any significant change, we discontinued the treatments, feeling Sophie and we had given this treatment option a fair chance. In hindsight, I still believe that the logic behind DMSO makes sense. Unfortunately for Sophie I think we started this too late. If I had to do it again, I would have started this treatment during radiation while the tumor was “stunted.” Upon returning home Sophie had many scary bouts of continuous

vomiting. Some of these may have been due to the steroid reduction, but also due to the pressure of her progressing tumor.

In the meantime, a doctor in Brazil who works in the "natural" health field informed us about a person in California who had had success in shrinking tumors using a PER machine. This is pulsed energy machine that focuses on normalizing the energy fields in the body. More specifically, the machine has been shown to put cancer cells into remission by normalizing the voltage of the unhealthy cells. We "rented" the machine from the owner/manufacturer in California and completed the treatments with Sophie 3-4 times a day. Again, although it is hard to say what the effects were, we do believe this is something that had we started earlier would've helped Sophie.

We considered traveling to Pennsylvania for a treatment during which Sophie's blood would be cleansed. This involved removing blood from her body, cleaning it with a laser, and then replacing it. Unfortunately we heard about this treatment rather late, and at the time, we did not think traveling with Sophie so far from home again was the best thing for her.

During the last two months of her life, Sophie had been completely weaned off of the steroids. However, despite continuing the alternative treatments, we just did not see the improvements for which we so desperately prayed. Sophie's symptoms gradually worsened, and in the last few weeks, she could no longer talk, walk, stand, eat, or sit. It was the most heartbreaking and gut-wrenching thing to have lived through; for as a parent, it was like watching your child being tortured. We always asked her if anything hurt, but she always said no. She went through a period of not wanting to read, watch TV, do stickers, or any of the things she had loved. But the week before she died, she wanted to do all of these favorites again, as though she knew she wouldn't have any more chances to do these here on Earth.

We were visited weekly by hospice throughout Sophie's last couple months. Sophie's vital signs were perfect up to the last time they were checked on the Monday before she died.

During the first week of October, Sophie actually had a few good days in which she seemed a little more attentive to the world around her and actually was able to eat a few bites of her favorites here and there. On October 6, we all went to Marc's work picnic. It was an absolutely beautiful day and Sophie seemed to be content being out of the house. She amazed us by eating bites of a hot dog, hamburger and potato chips. She was also able to swallow liquids without using the syringe that we had been using the week before. We were delighted to see these improvements, and we hoped and prayed that perhaps it was the miracle for which we had been praying. Even after the picnic, although she was tired, she had one of her best days. Upon

returning home, she threw up, as she had basically been doing daily for the last few months. Marc cleaned her up and took a long bath with her. (At the end of her illness, she could not support her weight, and the only way to give her a bath was to get in with her.) Looking back, those baths were wonderful times as we would hold her tight and repeatedly pour the warm water over her.

Never in a million years did we guess that would be our last day with Sophie. Although we knew from the beginning that the odds weren't in our favor, we weren't prepared to be holding our precious Sophie in our arms that night as she took her last breaths...but then again, what parent would ever be prepared for that day?

After having fought an amazing battle, our Sweet Sophie Girl left this earthly world at 11:55 p.m. on October 6, 2007. We miss her dearly...she left a very large void in our lives and in our hearts. Our prayers from the very first days of this horrible journey were that God would perform a miracle...the miracle of Sophie's survival. Although we were not granted that miracle, we also prayed that her name and legacy would make a difference in this world. As the days go on, we are continuing to ensure that this miracle lives on.

Many of us already know that Sophie's name and legacy did make a difference in our worlds, and although we only had her here for a short time, the world and we are much better for having known her.

Our hopes are that through awareness and fundraising, we will someday see the day when a cure for brainstem gliomas is found. We are dedicated to doing anything and everything we can so that not another child will face this fate...it is then that we will be sure that our miracle was granted.