



Caitlin's Story

By Mom

May is Neurofibromatosis (NF) Awareness Month and though many have never even heard of it, it is the underlying cause for Caitlin's death and very common. Another child with NF just died yesterday and many more have also become angels since Caitlin. This disease takes lives. The Great Steps Walk 4NF raises money for research and all of the money goes directly to research, not in someone's

pocket! (Make a donation in memory of Caitlin [here](#).)

In honor of this month I am going to share a lot of Caitlin's Story for those who may not know it. This is soooooo hard for me to write but I promised her I would tell her story and let her live on through helping others. Please consider donating to help stop the suffering!

This is extremely long but doesn't even begin to cover all the details that was Caitlin's life. I hope to give you enough of a picture to show how this disease affected her and how despite it she still found ways to touch people, never gave up and wanted to give back! So here we go.....

Caitlin was born 2 weeks early because she was a very large baby. She ended up weighing in at 9 lbs 10 ounces which is very funny because anyone who knew her knows how little she was! Right from birth she had to fight. She got stuck and the doctors after 3 hours finally had to pull her out but she had no signs of life until they revived her through many efforts. It was so scary. They had damaged her arm and she couldn't move it. She wasn't doing well and they ran about every test under the sun, including a spinal tap that I happened to walk in on one evening. They transferred her on my request to another hospital (She was born in a military hospital in 29 Palms, CA, which is why California Girls is her song).

My mother, an ob/gyn nurse, had come to visit and noticed some symptoms the doctors hadn't looked at and was the reason they finally discovered she needed surgery to remove some small nodules in her windpipe near her vocal box, which is also why she couldn't cry but like a little kitten. She was a 10 lb baby in NICU next to 1 and 2 lb babies. She looked like a giant. Upon finding out she needed the surgery they transferred us again to Long Beach Memorial to complete it and she was finally released 2 weeks after she was born to come home. She didn't regain the use of her arm until she was 3 months and the dr's were watching her very closely. She had 2 more throat surgeries at Long Beach at 3 months and 6 months until it was all finally clear.

It was because she was being watched closely that we all noticed Caitlin's leg was an ever so slightly different in width and length and she had coffee colored spots (cafe au laits). After several more tests we learned she had NF. She had inherited it from her father who never even knew he had it because he had very mild symptoms. NF symptoms vary so widely from person to person that no two are ever alike and there is NO way to know what may happen or when.

Caitlin's leg length and width continued to grow as she did and soon she needed two different sized shoes and then a lift on her shoe to even her out. She had lisch nodules in her eyes (these are just a

symptom but do not cause problems). She began seeing orthopedic doctors at Shriners Hospital in Maryland and an NF specialist there as well. I learned that the reason for her leg width and length difference were tumors that grow along the nerves, in her case uncontrolled, called plexiform fibromas. Her entire right side was growing faster than her left and her leg and abdomen was filling with these tumors.

Her entire childhood from birth on was riddled with MRI's, blood tests, doctors and her always being stared at for her extreme leg width and length difference. We moved a few times and every new school came with an explanation of what was wrong with Caitlin so the kids would understand and not ask her endless questions. Going out into public was the same, stares and whispers and questions. Caitlin noticed all of them but quickly learned to try to ignore them. Even through all of this Caitlin was an active, fun, loving little girl who just wanted to be like every other kid and would even dance around with all the neighborhood children.

When she was about 8 the doctors at Shriners in Chicago operated to try to stop the growth in her right leg bone. After surgery she spent many months in a wheelchair and days into getting back on her feet with the use of braces, she fell at school and fractured her leg. Because of NF, bones do not heal like normal bones. Caitlin spent 6 months in a cast and many more in a brace and all these months in a wheelchair. We had already begun at the NF clinic at Children's Memorial Hospital in Chicago and she was monitored annually for any changes. It was at this time that we also started seeing the head of Orthopedics at Children's too.

Caitlin participated in many of the NF studies including natural history (many MRI's) and double blind clinical trials of medications to stop the growth of the tumors throughout her right leg and into her abdomen, among other studies. We developed a standing relationship with the oncology unit which is where the studies were conducted. Every few weeks we would go to Children's Memorial to receive medication, get blood taken and sometimes have an MRI. Caitlin spent a lot of time around the children in the clinic who were being treated for different cancers. She had so much empathy and was so caring.

We knew NF caused a lot of problems and when Caitlin was put up by her doctors for a "Make A Wish" trip, we really didn't understand how she could qualify, but after all she had been through, we did just that. She chose a trip to Disney with our stay at the Make a Wish resort. It was amazing and she got to even bring a friend with her. She was picked up in a limo, had a visit to the cockpit of the plane, received VIP service at all the parks and had all she could eat ice cream morning, noon or night at the resort. It was truly a trip to remember. We didn't understand the nature of this disease fully at that time!

When Caitlin started getting older, she battled internally with her body image and not being able to wear regular pants or shoes. She could only ever wear stretchy pants and tennis shoes that would fit around her leg as it grew larger. It was around junior high that she started having surgeries to remove the massive amounts of tumors that grew throughout her right leg and into her abdomen. As she reached into her growth spurts the tumors started also growing again along with the surge in hormones. It was finally in 2008 right before her freshman year of high school that the doctors suggested they couldn't do any more to equalize her growth and that a leg amputation below the knee was the only way she would walk straight and not hurt her back more. Her back had begun curving through all of this to accommodate her gait and how she sat. The picture the doctors painted sounded incredible. She could wear normal pants, normal shoes, walk straight and her quality of life would be so much greater. She

could “walk” into her freshman year wearing the cute jeans she imagined. Well things don’t always work out as planned.

Caitlin had the amputation in August of 2008 and they also removed massive amounts of tumors in a 10 hour surgery. She required 3 units of blood after and it was the first time I was scared for her life. It was the moment she was aware in the ICU after an incredible bout with pain where they had to infuse so much morphine that it suppressed her breathing, that she turned to the nurse and asked what it took to do what she did. It was at that moment that she decided she wanted to become a nurse, then later a pediatric oncology nurse to be able to take care of kids just like her.

The recovery was not easy. They had to re operate to repair part of the skin and it was endless months of recovering just to enter her freshman year in a wheelchair again. She then required another surgery in 2009 to revise the amputation and remove more massive amounts of tumors. Each time she hoped that this would be the time that ended the way she envisioned.

She spent part of her sophomore year in the Rehab Institute of Chicago learning to use her new prosthetic leg which again was much different than she expected. Caitlin was inpatient there so she spent a lot of time with other kids going through similar situations and even developed great friendships from her time there but refining her prosthetic leg over the years was a constant battle and never quite allowed her to be able to wear those cute jeans. She did however develop a passion for shoes and had quite the collection over the years though none could even have the slightest of heels.

Caitlin had another surgery to remove more tumors the following summer and entered her junior year fully caught up with a B average from everything she had gone through her previous years. The teachers and staff at Oswego East High School were amazing and worked very closely with her. She continued to seek honors classes and AP classes and though it was not easy for her she would spend entire weekends doing her assignments (instead of going out with friends) and studying to do well so she could get into college for nursing. She volunteered as much as she could through a club at school, was on the student council and started working for an in-home child care provider in our neighborhood. She battled with her feelings of not being able to do sports, or dance or run or be what she considered normal like all of her friends and usually only had a couple close friends at a time, but always had a smile on her face to everyone. Nobody knew her inner battle except the very few that were close to her. I knew! She still fought hard and got through her classes and was accepted into the Medical Topics program and took Anatomy and did everything she could to get into a good college, which she did in her senior year.

It was during her junior year that I found out I was pregnant and at first she was very upset as were the rest of her sisters. As the pregnancy wore on she became more and more excited and even changed her desire to be further from home to somewhere in the middle for college. When her brother Aiden was born she was immediately his second mother. She told me many times that she had never understood what I meant when I told her about a love so strong you could never imagine not having it. I said that is a Mother’s love. She said I get it now. She was so in love with him that she protected him just like a first time mother would.

So with her need to not be too far from her new love, we toured a couple schools and she decided on the University of Missouri because she so loved the campus and that they had a fantastic “abled” program to help her. The nursing program was phenomenal and she knew she would be prepared to be the Pediatric

Oncology Nurse she had decided to be. I never understood why an oncology nurse and she said because they need good care to get through what they were going through and she knew what it was like to be in their shoes unlike most nurses might. She had been around so many children battling cancer in her youth she just felt that's what she wanted to do.

We were so proud, Caitlin graduated in June of 2012 and walked the path and accepted her diploma. She worked hard all summer and prepared for school. Her grandparents were so kind to help her pay for a good chunk of school, but she also received several of the hundreds of scholarships she applied for and also paid for some out of her own pocket. We had been hit hard by the economy several years prior and with the amount of medical bills we spent all of our savings to just get by and had nothing to give her. We were able to give her all the assistance to get done what she needed to get done though and she went to school paid in August of 2012. She had such a great time but so missed her brother, we talked every day. Caitlin would send videos to her friends back home on nights that she couldn't go out and even made a great friend at school. She was doing great. We decided to squeeze in what we thought was her last surgery during break in December.

The surgery in December went fairly well and after a nice break all together; she went back to school on the Megabus (which she hated). In January she started having increased pain and having been through many surgeries we just thought maybe the doc hit something which is always a fear with these plexiform fibromas as they are entirely on the nerves and so hard to remove. We knew she had these fibromas in her abdomen too, but were told there was nothing that could be done unless they became problematic which they never had. We also knew she had a fibroma in her brain, but again, unless symptoms appeared, we really didn't need to worry. So we always focused on her leg which was the most prominent issue for her.

In February she told me she was feeling tired all the time and was losing weight. So I had her go to the doctor on campus. They did some blood tests, but didn't seem to think anything was wrong. I sent her back to the counselor she had been seeing for anxiety and insomnia. Her meds were increased to try to help, but nothing did. When she returned for spring break we went to the girl doctor as more weird things were happening. Again blood work for thyroid etc but nobody seemed to think anything was wrong even though she had increased pain, major weight loss and lethargy.

She muddled through the last month but had made the decision that because she felt horrible and was having major issues just getting around there she would transfer to Aurora University so she could follow up on what was going on. She also wanted to save money and Aurora University had offered her a good deal of money to transfer. So we picked her up and she was so happy to be able to be home with her brother again and reveled in him.

In June, she was still not doing well and sleeping any time she could, not eating well, not sleeping well and in pain a great deal of the time. Her NF clinic's waiting list was so far out that I decided to take her to a family doctor. He listened to us and took blood and called us back in. He said, I think you have cancer which sent us into a tailspin. We immediately made an appointment with the oncologist he recommended. 3 days later in this physician's office after a weekend of fear and worry, he explained away her blood work and said he thinks it was the depression/anxiety she was feeling, low iron and leg pain that caused it all, not cancer. He took blood for an iron test, prescribed some Neurontin for the nerve pain and sent us home with directions to just schedule some mri's since she hadn't had them in a

while to check up on things.

PHEWWWWWW! No cancer, so happy, we talked about how scared we had both been but trying to put on the brave face etc. Iron came back lower but not under so she started taking the nerve pain medication and we tried to move on. She still had pain, still hadn't gained weight, still had no energy, but she worked and we went to help her buy her own car in August shortly after this appointment. She had a fabulous summer as the whole family was here for her Uncle and new Aunt's wedding, she enjoyed a week on the beach with her Dad's family and time with one of our oldest friend's family. We saw everyone last summer! She was so excited getting ready to start her second year of school. She was hired for a job at Old Navy and everything seemed to be looking up. She went to her first day at Aurora University.

The next morning she came to me and said she had no feeling in her groin region and could not feel to use the bathroom. She also said her pain was increasing to the point she couldn't sit. I called the doctor and after consulting with another doctor told us to go immediately to the emergency room. We had to keep pulling over for her to stand just to make it there. We did and our nightmare began!

They gave pain medication, started an IV and got her into an emergency MRI that showed a massive tumor in her pelvis. This tumor had eroded her pelvic bone and eaten into her spine area and was surrounding every major organ in that region. But she didn't have cancer we were told by an expert from this same hospital! She did. We were transferred to Northwestern where after weeks of being scanned, worked up and over they told us it was indeed a Malignant Peripheral Nerve Sheath Tumor (MPNST) and that it was inoperable without taking half of her with it.

Her doctors from Children's came over through this process and were amazing in helping direct how to perform the tests with NF to get the best results. Upon learning we had no way but to try to shrink this tumor, we were transferred back to Lurie Childrens (the name had changed through the years) and her old oncology friend said he would do whatever he could to get rid of this monster.

A plan was made as fast as they could and Caitlin was released days before her 19th birthday from Northwestern. With the most amazing support from our friends and family, we were able to throw her the biggest birthday a girl could want. There were gifts and friends and lots of love. She tried to put on a brave happy face, but the pain she was experiencing was too much at points. She was so brave. Her best friend at the time organized a party too which she did also get to enjoy for a couple hours.

Caitlin started radiation and after battling with insurance had just started chemotherapy. Just moving, going to the bathroom and trying to go to the therapy was a huge battle. She tried so hard to stay as independent as possible but it got worse every day. The screaming out in pain getting clean, getting to the bathroom, getting dressed and undressed, getting in and out of the car every day was too much to bare even with the huge amount of medications she was continuously prescribed to keep everything under control. She was having such a hard time breathing so we went back to emergency and learned she had a blood clot in her lung. She also had a scan and we learned her cancer had spread. She couldn't continue with chemotherapy and had to have 2 shots every day for the clot control.

We went home after a week but she was never able to walk again no matter how hard she tried. The only way she was remotely pain free was in bed on her stomach. We were in and out of the hospital

several times and each time the story became more grim even with all the hope we tried to maintain. Blood counts wouldn't stay up, the cancer kept spreading and though I didn't tell her, the doctors did not give her long to live. She kept fighting though. I think she did it for all of us! She wanted kittens, we got her kittens and she loved those kittens for one week before going to the hospital just to get some more blood.

The docs took her count and saw just how low it was and decided to do more scans. They found a bleed in her abdomen and they couldn't do anything about it. We went in for blood on a Friday and on Tuesday I had to tell her she was going to die soon. She screamed out to the doctors in fury, "but I have to take care of my siblings and my mom", "It's not my time, I have so much still to do", "I need to be a nurse", it was the worst moment of my life to that point. She never took another bite of food from that day on.

We had everyone fly or drive in as quickly as possible and we surrounded her for days at her bedside never leaving her alone. Her entire family and her friends came and everyone was able to tell her how hard she had fought and how much they loved her. The hospital even let her kittens come stay with her and they laid on her for hours not moving! She was not able to say much in return and was deeply depressed. She did spit out a couple I love you's, but the worst was when she said to us, she was sorry. NOOOO baby you don't be sorry, you did everything right, it's not your fault. I told her how heaven was going to be amazing and she would be our angel and could laugh at us and dance and run and how much I loved her and PROMISED to tell her story and make her live on! We all told her she would be in the most amazing place where she would no longer have pain and it would be more beautiful than she could ever imagine and this suffering would be done, she would be with God.

On Thursday night she awoke in a massive pain episode completely awake unlike any other time, calling out my name. I ran to her and tried to help her. The hospital went right into gear and specialist came in the middle of the night from home to do whatever they could to help her. I asked her, do you want to be pain free even if it means you will know nothing around you and she said yes. After an hour or two and many kinds of pumps and medications they got her into a state of what seemed like rest.

She never awoke again as she died Friday after we all spent every minute with her. She was surrounded by her family and I believe that if we hadn't told her she could let go, she might have continued to try to fight. It was within hours of that talk with her that she let go and became an angel.

I won't tell you about how horrible that moment was but it is etched into my brain forever! I had to leave out many details, but I have been trying to be in a place that I could even tell this much for months and I finally did. I love her beyond any words, with A Mother's Love that I'm at least glad she understood in her short life. We miss her, but I pray that through her story can help others so maybe someday they won't have to go through this! To all moms of NF children, don't be complacent; get checked, even if you don't see symptoms!

So again if you made it this far, if you can donate any amount to help fight this disease as we walk in Caitlin's memory this year and not with her, we would be grateful!

Make a donation in memory of Caitlin [here](#).