

# ***Mya's Story***

Mya was diagnosed with brain cancer when she was 18 months old. Her tumor is specifically called a pilocytic astrocytoma of the brain stem. She underwent 2 brain surgeries after her initial diagnosis in October 2007. The first was to debulk and biopsy the tumor and the second to place a VP shunt. After she recovered and became stronger she had a port placed and began chemotherapy in November 2007 and completed 74 weeks of multi-drug chemotherapy. Her tumor responded to chemotherapy and decreased in size and malignancy. One of the chemotherapy drugs caused moderate permanent hearing loss, memory and comprehension problems, and several permanent dental issues. She was then off treatment and doing well until she relapsed at the age of 5. She again underwent multi-drug chemotherapy, but with different medications for 72 weeks. She continued to attend Kindergarten and 1st grade through these treatments and again her tumor responded and decreased in size and malignancy.

Since November of 2012, Mya has done very well. She has been very active in many sports and activities including softball, archery, piano, band, and most of all gymnastics. She has continued to do well in school, working extra hard to overcome some of the permanent long term effects of the therapies she has gone through. She had checkups every 3 months for the first 3 years post treatment and for the last 3 years she has been going every 6 months. She was able to celebrate 5 years off treatment in November of 2017. She then graduated at a Dance Marathon celebration in February of 2018 with a lot of family and friends there to celebrate.

January 10, 2019 Mya went in for a routine check. She had no symptoms and we had no concerns as she was our normal active girl. We were there for a MRI at 0700, saw hematology at 0830, had her shunt reprogrammed shortly after at Neurosurgery, and then we had to wait until 1300 for her appointment with the neurosurgeon to discuss her MRI results. We decided to hang out together on the 12th floor over-looking the Hawkeye football field where we ate, worked on some of my work and her homework together. When it was time we headed to the Neurosurgery Clinic. We were taken back to a room where we waited to see the doctor. He assessed Mya thoroughly while I observed. He left the room and when he headed back to our room I heard him say in the hall, "they are going to be devastated." I assumed he was referring to another patient/case. He then asked Mya to go to the lobby to play games on her phone while he talked to me about the scans. Mya did and he started to bring up images of her tumor on the screen. I immediately saw the tumor on the scan, but assumed it was her tumor from when she was younger, as he compares them all. I looked at the top of the scan image and noticed it said 1/10/2019. I started crying because I knew it was back. He saw me crying and said, "This is not good news." He then talked to me about possible treatment options, next steps and scheduled some follow up appointments with radiation therapy and chemotherapy specialists. I had Mya come back to the room and broke her heart, telling her that her cancer had returned. She was devastated, as we all were. This was even harder than the past as she is older and understands so much more than she did with her past treatments.

January 25, 2019, Mya started her regimen of chemotherapy treatments. The chemo is making Mya tired and nauseous at times, but she seems to keep a great attitude. Mya has been doing well overall, but is missing a lot more school and is much more tired and achy. She has really good moments where she can go to softball or gymnastics and give it her all for a couple hours or

maybe go to school for a half day. Then, she has other moments/days where climbing the stairs is her biggest task of the day with shortness of breath and exhaustion.

Over the summer of 2019, Mya's condition began to deteriorate as the chemo was taking a toll and her tumor was not responding. In September 2019, Mya's team and new physician changed her chemotherapy to something more aggressive and in hopes to allow the other side effects from the previous chemotherapies to subside. Between September and December Mya's balance was improving, she was able to return to gymnastics again and feel more confident in her skills. In December her MRI showed EXCITING news. Her tumor had decreased in size by 42%!!! We were all so excited the new treatment was working. Mya has continued on this treatment since, receiving chemo every other week for approximately 6 hours. In March 2020 her MRI showed that her tumor was still decreasing in size and her most recent MRI has shown that her tumor is starting to stabilize. Mya completed her chemotherapy on December 10, 2021. She is nearing 1 year of being off chemotherapy and we continue to closely monitor her tumor every 3 months.

While this diagnosis is not new for us, we found out that Mya's diagnosis and journey was new to many in our community. Immediately the support for Mya and our entire family poured out. People were bringing meals, sending cards, prayers, gift cards, and money. David and I have continued to work full time through all of this, making adjustments as needed to ensure financial stability through all of Mya's current and anticipated medical needs. Many families are not as blessed as we are with the ability to have good jobs, financial stability, and an amazing community that surrounds them with unwavering support. Mya sees this all of the time when receiving treatments, when she is at camp, and just talking with other friends with cancer. As the support continued to pour Mya asked if we could use that money to help others that are not as lucky as we are. She said, "wouldn't it be cool if we could just write a check to someone that just received bad news that they have cancer. They could use it for anything they need/want. A day of fun as a family, help pay bills so it isn't as stressful, or help get them to treatment." This is true typical Mya. Always thinking of others and worrying about what everyone else is going through. She always says, "I am fine I am more worried about \_\_\_\_\_." Feel free to fill that blank in with any name because she sees everyone else and worries about them more than herself. This is how Mya Strong was born into an organization to help others.

Over the past 4 years Mya Strong has accomplished a lot already:

- Helped 16 local cancer families with a financial gift of \$500-\$1000
- Sponsored 5 Camp Heart Connection Oncology Cabins \$24,000
- Donated \$1200 to Stead Family Children's Hospital
- Donated \$11,500 to UIHC Dance Marathon
- Given eleven \$500 Mya Strong Character Scholarships to local seniors.

Thank you for your generosity and support for Mya and for being part of our Mya Strong family. Thank you for supporting Mya's cause in giving back, thank you for your continued support and prayers, and thank you for helping Mya continue her mission of MYA STRONG.