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.

Once off treatment in November of 2012 . 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 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 2019 her MRI showed EXCITING news. Her tumor had decreased in size by 42%!!! We were all so excited the new treatment was working. Mya continued on this treatment for another 2 years, 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 tumor was starting to stabilize. Mya completed her chemotherapy on December 10, 2021.

Mya's tumor has remained stable over the last few years and we have been blessed to do many fun things together as a family with minimal hospital visits.

While in 2019, this diagnosis was 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 once again poured out. People were bringing meals, sending cards, prayers, gift cards, and money. David and I had 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 in Mya became more aware of friends she had with cancer that were not as lucky as us. One day in the waiting room at the University Stead Family Children's Hospital a family was discussing how they were going to afford treatment, and some of their other bills. Mya noticed how stressed they were about their situation. She knew that we had been saving the money people had donated for her to use someday if needed. She 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.

Mya has done an amazing job leading the Mya Strong Organization and spreading the message to "Choose Kindness" over the past years. Mya has experienced amazing individuals throughout her treatment, but she has also experienced some that have not been as nice. We have always reminded Mya that without bad we would never know good, but Mya wants people to know that even the littlest things matter and you never know what someone is going through. She chooses to be kind to everyone even through some of her own worst days. Before and during the Mya Strong Softball Tournament in August of 2023 Mya had been feeling extreme exhaustion. We had been in contact with her medical team and it was decided to perform a bone marrow biopsy to dig a little deeper into what could be causing her symptoms. The bone marrow biopsy results

showed that she had a blood/bone marrow disorder that was a direct result of all of the years of chemotherapy she had endured. She was diagnosed with MPN (Myeloproliferative neoplasm) with myelofibrosis. Mya's bone marrow was overproducing platelets and red blood cells and her blood was thickening due to the amount of cells it had. The first line of treatment was therapeutic phlebotomy. September 2023 - January 2025 Mya continued with therapeutic phlebotomy every 3-4 weeks where they would take off 350-450 ml of blood and throw it away and replace it with 500 ml of saline. This worked for a while, but in December 2024 Mya started having shortness of breath and extreme fatigue again. After an ER visit, lots of testing, and visits with her doctor it was decided to do another bone marrow biopsy. Mya's disease was found to be progressing and it was time for oral chemotherapy. Mya began oral chemotherapy January 2025 and just 3 weeks later her labs area already much improved and she is feeling better. Through it all, Mya has remained positive and has never given up. No matter how difficult the options are she always responds with, "at least there is an option." The positive mind can do so much and Mya is the best example of that.

Since the Mya Strong Foundation was established it has accomplished a lot already:

- **Helped 21 local cancer families with a financial gift of $500-$1000**
- **Sponsored 11 Camp Heart Connection Oncology Cabins $54,000**
- **Donated $1200 to Stead Family Children's Hospital**
- **Donated $19,100 to UIHC Dance Marathon**
- **Given nineteen $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.

<u>Mya's Accomplishments</u>

- **Got her CNA in 2024**
- **Works at Emery Place in Robins**
- **Morale Captain for Dance Marathon 30 in 2024**
- **Maintains a 4.17 GPA at Alburnett High School**
- **Received the Excellence in the Arts Award by the Gazette for students showing great stories behind their artwork/photography.**
- **Received the Troy Mills Legion Good Deed award for her work through the Mya Strong Foundation**
- **Had the opportunity to speak to the Troy Mills Legion members about her cancer journey and how to support pediatric cancer.**
- **Spoke to multiple Lions Clubs across the state of Iowa to raise awareness for childhood cancer. She met so many kind and amazingly generous people through this opportunity.**
- **Helped coach her sister's softball team.**
- **Gave four $500 scholarships to graduating seniors from the Mya Strong Foundation that show character and kindness within their community.**
- **Spoke at 3 different school senior awards ceremonies about character, kindness, and the mission of "choosing kindness" and educating about childhood cancer.**

- **Graduated from oncology camp as a camper**
- **Was a Leader in Training counselor for the 2nd year in a row at Sibling Oncology camp, helping with siblings of cancer patients for a week in June/July.**
- **Met Gary Dolphin and interviewed with him about her journey and pediatric cancer.**
- **2024 Kid Captain for the Iowa Hawkeyes vs Troy at Kinnick on September 14th.**
- **Met Dalles Jacobus and brought back the song “We Wave” to Kinnick stadium for the first time.**
- **Donated 8 inches of her hair to Children with Hairloss**
- **Was on the Alburnett 2024 Homecoming Court**
- **Hosted the 6th Annual Mya Strong Softball Tournament in October with 70 softball teams and raised over $34,000 for the Mya Strong Foundation to continue it’s mission.**
- **Sponsored 3 kids battling cancer with the amount of $1,000 each at the Mya Strong Softball Tournament**
- **Sponsored 4 cabins at Children’s Cancer Connection Camp Heart Connection in the amount of $20,000 through the Mya Strong Foundation which is DOUBLE the amount of last year and years past.**
- **Celebrated 3 years off brain cancer treatment on December 10th 2024.**
- **Donated to 7 childhood cancer families in 2024 in the amount of $500-$1000.**
- **Voted in her first ever election.**
- **Completed her final year of Alburnett Poms/Dance with the most incredible team and coaches where they placed 2nd in jazz and 5th in poms at state.**
- **Continue Kirkwood College classes while in high school to pursue a nursing degree.**

Updated: 2/10/2025