

Friends of Melana Story

It was the beginning of the school year, Sept. 2008. Everything seemed pretty normal for this high-spirited, energy filled, 8 year old little Garrettsville girl as she started the 3rd grade at Garfield Elementary. Melana was a good student. She liked school. She was very sociable. She knew no strangers. She had just completed her 2nd season of youth soccer, and if I should say so myself, she was quite athletic and a budding star. She also loved the outdoors. She loved to camp, hike, and go hunting and fishing with my son and me. She was an avid bird and star watcher too, and could identify most species and constellations. She was also an avid webkinz (stuffed animal) collector.

Around early November, we began to see some changes in her stature and her coordination. We thought it might be due to her doctor changing her medication. She had been losing weight and we were getting some reports from the school that she had fallen a few times in the hall and the classroom. Her Mom (my daughter Heather) and I made a pediatrician appointment. That appointment preceded an appointment to Akron Children's Hospital for a CAT scan when her condition began to worsen by January, 2009. There, a mass was discovered in her brain stem and she was immediately transported to the Cleveland Clinic for an MRI.

We were devastated when we got the results. A glioma tumor in the pons section of the brain. Diagnosis - Diffused Intrinsic Pontine Glioma (DIPG), an incurable and inoperable cancerous brain tumor. Prognosis - 9 to 12 month to live, if it is located in the pons.

Six weeks of radiation treatments along with an intense steroid treatment program kept Melana's condition stable for a few months, long enough for her to enjoy her Wish trip to Disney

World in June. By August she had lost a lot of her mobility, speech, and eye-sight in one eye. And by October, she was basically a human rag doll. She could no longer speak, had to be spoon fed, and had to be carried where ever she had to be moved. Heather resigned her position at work in order to stay home and care for Melana. Melana's wheelchair and her stair chair lift became common modes of transportation around the house. She passed away on Oct. 27th, almost 9 months after her diagnosis.

Through all of this, it was most disheartening to discover that research for this horrible childhood disease is grossly under funded. And it is the second leading cause of childhood cancer. Go figure!! There has been no significant development towards treatment or a cure for the last several decades. So kids diagnosed with this disease are basically given a death sentence.

We met many great people during Melana's treatment. Ed and Megan McNamara from Avon Lake reached out to us with moral support. They had lost their daughter, Maria, a few years earlier to the same horrible disease. They, like us, thought, "if no one else is going to do something to help kill this monster, then it might as well be us. They, with numerous friends in their church and community, formed the Prayers From Maria Children's Glioma Cancer Foundation, a 501c3 non-profit. Their objective is to provide public awareness and to provide funds for research so that someday, there may be better treatments and a cure for DIPG.

As Melana's first anniversary of her death approached, my wife and I thought, "so what now?" We looked back over that past year and saw what an impact that child had on our community, and the inspiration she gave to so many people. She left us very young, yet taught us lessons of inspiration and courage. We wanted to do something to carry on her legacy, give hope to others, and find a way to support research so that someday there might be a cure for this dreadful disease. We felt a calling to do something, yet felt

inadequate to do it alone and to see it through. So, with the help of about 25 concerned citizens in the northern Portage County area, and the help of the McNamara's, we - more than a year ago - formed a partnership with the Prayers From Maria Foundation called, Friends of Melana. Our goals are to raise awareness of children's glioma cancer, give hope to the afflicted and their families, and to raise monies to support the Children's Glioma Cancer Foundation, and hopefully someday - find a cure. No other kids and their families should have to go through this.

So, as I have stated, research on gliomas is grossly under funded and gets very little attention from the various cancer societies. Most people have never heard of glioma cancer. That is why the foundation was formed. Research takes money and people need to know about the most deadly childhood disease.

This past year, Friends of Melana, helped to organize a 5k run/one mile fun walk held during the Garrettsville Summerfest last June. We had over 180 people participate in the event. Proceeds from the race went towards research. We also had an awareness booth at the Summerfest and with the help of the Curtains Up Theater group and the Mantua Knights of Columbus, we held a murder mystery dinner at the K of C hall last Sept. It was very well attended and successful, and all proceeds again went toward research.

We hope to at least double the number of participants in this years 5k and are now actively seeking sponsorship from businesses and individuals to help defray race expenses and support the cause. We are also considering another mystery dinner for this fall.

Anyone wishing to sponsor the 2012 Friends of Melana 5k race can contact me for a sponsorship packet or receive one from me by way of email. Working together, we can kill this monster.

Norm Fashing, President - Friends of Melana, Children's Glioma
Cancer Foundation and
Melana's grandfather
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