Billy Biviano's Story

In November 2012, "Brave" Billy Biviano was diagnosed with an inoperable brain tumor at the age of 14 months. Billy's tumor was described by doctors like a spider's web, wrapped around all the important parts of the brain. Billy completed 15 months of chemotherapy which is the limit for someone his age. MRIs indicated the tumor was no longer growing but that it was also no longer responding to the treatment or shrinking. Due to the secondary risks and treatment restrictions due to Billy's young age, chemotherapy was stopped and his port was removed in April of 2014. Our family began to live our lives in 3 month segments, MRI to MRI, and on absolute prayer.

Over the 16 months that followed, MRI results were showing both more enhancement and growth. Billy's tumor still could not biopsied due to the location which makes knowing the best way to treat it difficult. In February of 2015, doctors diagnosed the tumor with 95% certainty as a PMA (pilomyxoid astrocytoma) tumor, a type of brain cancer only first discovered 18 years ago. The number of cases where children have PMA are currently unknown.

Billy is too young for radiation therapy and did not qualify for any trials at that time. So after trips to Johns Hopkins & the National Institute of Health for further consultation, it was decided to move ahead with more chemotherapy. So in October of 2015, he began an oral regimen of chemotherapy that ran until August 2016. During this time, Billy was tested for Autism and registered as just shy of moderately autistic on the Autism Spectrum.

After completion of the chemo, further MRI's began to show some enhancement around the tumor again. Also, MRI's revealed that the tumor was creeping down Billy's left optic pathway. Once we confirmed that surgery and even the ability to get a biopsy was still out of the question, it was decided that Billy start on chemotherapy again. However this time, treatment would require reinsertion of the port into his chest (his new drug, "Vinblastine", cannot be administered otherwise).

In late June 2017, Billy had his port surgery and began a new chemo regimen. It calls for treatment once a week for 52 weeks at the Rutgers Cancer Institute of New Jersey. He is projected to be complete with chemo in late July 2018. With every visit, his Neutrophil white cell counts need to be high enough to allow him to take on the chemo, or he can become sick. Also having a port means that when he reaches a fever of 100.5 or greater, he has to be taken to the emergency room. He then needs to be admitted to the hospital until both his fever subsides and he shows no sign of infection in his blood stream from the port – this usually can last anywhere from two to five days. Such circumstances led to hospital stays for Billy in both July 2017 and December 2017. He continues to receive MRI's every three months to monitor his progress.

Billy has had a tough go with this regimen of chemo. He no longer wants to take the anti-nausea medication because of the taste, so his stomach sometimes bothers him. Also, he has pain in his legs at times (neuropathy). His eyebrows have fallen out and his hair has thinned. His tumor has also led to his poor vision and developmentally, he is approximately 2 years behind.

On a lighter note, Billy enjoys wearing his princess dresses, playing with his dolls, and dancing to music. He enjoys playing around with his twin brother Michael and his older brother Joey (age 12). He is an absolute joy to be around and can light up a room with his smile and personality.

We are extremely grateful and humbled that our family was chosen by the Shannon Daley Memorial Fund for such a wonderful event.