Shannon Bain's Story

Life is filled with experiences—some small and some grand—which affect us in some way.

For us, one such experience was in 1998. Our 11-month-old daughter, Shannon, was diagnosed with Opscolonus Myoclonus Syndrome (OMS). A rare autoimmune disorder that impacts 1 in 10 million children a year, causes brain injury, and is usually accompanied with neuroblastoma (cancerous tumor).

When the doctors announced the cancer to us, we immediately asked if Shannon was going to die. The doctors replied they just don't know. We were lucky that we were able to remove the cancerous tumor and saved Shannon from near death. However, the doctors told us the OMS is going to be even more challenging.

The OMS caused such havoc on Shannon's central nervous system. She was unable to tell the difference between her feet and her head relative to the space around her, and this was only one of the many symptoms of OMS. The Opsoclonus is dancing eyes and Myoclonus is jerking muscles. Most importantly, Shannon's body was reprogrammed to attack itself. Specifically, her antibodies began attacking her brain.

Every day we had to inject our baby with life threatening drugs to save her life. Three years later after her initial diagnosis, Shannon was off her medications. Shannon had to learn how to manage the residual waxing and waning of recurring symptoms triggered by stress and infections. She was sick most days after starting school. The days she did make it to school were filled with frustration. Her brain injury weakened her ability to learn and caused severe anxiety.

Unfortunately, in 2008, Shannon came out of remission. There are still only about 2-3 doctors in the world researching OMS. They are doing research on young children in acute stages. There is no protocol for chronic OMS. Shannon was leading the way, again. We had to travel around to get a doctor that would even be willing to support a protocol and then find a doctor and hospital that would implement the protocol for Shannon's Chronic OMS. In 2010, we finally found a hospital but it was in Boston, which is out-of-network for us. We have to pay out-of-pocket for every visit.

Shannon is now 16 years old and still battling OMS. She has been in 3 different schools, countless therapies, 5 different hospitals for support of treatments and multiple counselors, psychologists and psychiatrists. Shannon has been through more than what most adults will see in their lifetime. However, when you meet Shannon, she is the happiest person. She loves life! The only times she is not smiling is if her anxiety is acting up.

Shannon will always have the threat of further brain injury unless she is able to "manage" how her body reacts to colds, virus and even stress. We still have to travel to Boston for check-ups and anytime Shannon shows a threat of OMS breaking through. Shannon is in need of Physical Therapy, Counseling and will be starting a special program at JFK Rehabilitation at age 18 y/o. We have had to sell our home to help cover medical bills and debt from managing OMS. Not being able to have a double income for years due to OMS requiring 24/7 care caused a strain on finances. We were very happy to become part of the Shannon Daley Fund. Any help at all will make a huge difference for us. Thank you very much!!