



Love and hope for MJ

When Michael John “MJ” O’Boyle was just 2-and-a-half years old, Grandma noticed his right foot slightly turned in as he walked. It was in December last year when she mentioned it to Michael, MJ’s father, who brushed away any concern. After all, what kid doesn’t walk a little pigeon-toed once in awhile? Maybe it was the new shoes or maybe he bumped his knee. But when he began to get ‘clumsy’ and started falling down more frequently, they immediately went to the doctor.

The pediatrician pointed them to an orthopedist, who recommended a pediatric neurologist. On Feb. 7, MJ was diagnosed with Krabbe Disease, a leukodystrophy, which is a degenerative condition of the central and peripheral nervous system.

A couple months ago, MJ underwent a breakthrough procedure involving chemotherapy, a bone marrow transplant and stem cell replacement therapy. The transplant was performed in mid-March and is followed by the “100 days,” a three-month period of uncertainty during which they will learn if the procedure was successful. It’s also during this time that MJ remains vulnerable to infection while his immune system regenerates.

MJ was diagnosed about two months after the date of his first symptoms. In that time he lost the use of his legs. Between diagnosis and engraftment, meanwhile, MJ had further degeneration of his hands and speech.

The bone marrow transplant/stem cell replacement treatment MJ received is relatively new and a risky procedure. Had MJ not received this treatment he would have certainly continued to digress rapidly. After losing the use of the feet, legs, hands and arms, a person affected with Krabbe loses the ability to speak, swallow and see before ultimately losing cognition. A patient then enters a vegetative state for several years before finally losing function

of vital organs resulting in death.

As advanced as the technology is, the best that medicine can do is stop further progression of the disease. MJ’s condition won’t improve. There’s no way to reverse the effects of the disease, only to prevent it from becoming more debilitating.

The tragedy is that a simple and inexpensive blood test at birth could have discovered the condition, and the condition could have been addressed before any of the symptoms appeared. If MJ had been born in a hospital in New York, he would have undergone this treatment before the symptoms appeared and possibly lived a completely normal life. No other states routinely test for the Krabbe disease, which occurs in 1 in 100,000 births. MJ’s parents urge everyone to contact his or her state legislators via Hunter’s Hope website (www.huntershope.org) to encourage them to explore infant testing.

MJ is being treated in Pittsburgh and was recently allowed to move from the hospital to the Ronald McDonald House, where his mother and grandmother have been since his treatment began. Medical insurance has covered the bulk of the expenses, which Michael expects to exceed \$1 million by the time the treatment is done. But the family recently had to move to costly COBRA insurance since Robyn is now using the Family Medical Leave Act (and work is not supplementing the cost of the coverage).

To offset some of the medical costs, family and friends, including LM National Sales Rep Craig MacGregor, have organized a fundraiser at Our Lady of Angels’ Linus Hall in Cleveland, OH, July 28 from 6 to 11 pm. There will be live music; an Irish dance performance by Patrick Campbell and Kevin O’Malley of “Michael Flatley’s Lord of the Dance”; silent and live auctions; and a raffle. For more information, visit the Facebook page at: www.facebook.com/BandTogetherforMJ. The benefit is currently accepting donations to “Band Together for MJ” at any KeyBank branch or via PayPal at the website above.



MJ Boyle needs your help as he continues to battle the effects of Krabbe Disease.