Bright Light Foundation

Olivia LeMaire

2013 BLF Recipient

With all the daily difficulties Olivia Lemaire faces, she always has a big, beautiful smile.

While most people are very familiar with Muscular Dystrophy, many of us have never heard of Infantile Neuroaxonal Dystrophy (INAD). Mike and Leslie Lemaire, however, know first hand what INAD is. Their five- year old daughter, Olivia, was diagnosed with it in December of 2012.

This disease is so rare that there are only nine people in the United Stated who have been diagnosed with this. There were 10, but recently a 12 year old from Missouri passed away from complications of the disease.

"We have been searching for answers, and hopefully treatment, for Olivia for four years," said Leslie. "While we are relieved to finally find out what is affecting our daughter, Mike and I are devastated to find out there is no treatment or cure for INAD. And what is more heartbreaking, is the fact that the disease is progressive.

"While therapy may prolong the progression, it will not stop it."

INAD is a rare inherited neurological disorder. It affects the part of a nerve cell that carries messages from the brain to other parts of the body, and causes progressive loss of vision, muscular control, and mental skills.

While the causes are unknown, INAD is the result of an abnormal build-up of toxic substances in nerves that communicate with muscles, skin, and the conjunctive tissue around the eyes.

Symptoms usually begin within the first 2 years of life, with the loss of head control and the ability to sit, crawl, or walk, accompanied by deterioration in vision and speech.

Olivia was born in 2008 with no complications and was mentally and physically developing on time as time went by.

By the time she was 18 months old, however her parents noticed her walking was wobbly and had quit developing words. When they brought her to a neurologist who ran an MRI, the parents were relieved to see the results came back normal. But by the age of two, she began to fall often and would have bruises on her face. After being referred to a geneticist in New Orleans who did several tests, all of which came back normal, it was decided that a muscle biopsy would give all the answers as to why her muscles were getting weaker in her lower extremities.

And while waiting on the results of the muscle biopsy, Olivia had to have two eye surgeries because they started to cross.

Then, the Lemaires found out the results of the muscle biopsy test did not give any direct answers. Determined to find out answers, the Kaplan natives spent two years bringing her to New Orleans to continue genetic testing, only to get negative results on all the testing.

The geneticist told Leslie they may never find out what is wrong with Olivia's muscles and she may just have to settle for a diagnosis of cerebral palsy.

"I refused to believe that," said Leslie. "The symptoms just didn't fit the cerebral palsy pattern."

By 4 years old, she could no longer walk at all and started crawling. A decision was made to go to Texas Children's in Houston in July 2012. The doctors did a test called Exome Sequencing where they look at all the genes to see if there are any abnormalities and compare those genes to both of the parents genes.

After waiting four months, the results finally came in December 2012. The genetic counselor said they had found the gene that was causing all the problems.

"She explained that it is neurological and there is no cure because there are so few children diagnosed with the disease," said Leslie. "And the first thing I did when I got off the phone was to look up the disease on the internet and was devastated to learn about this dystrophy. The information gave us a bleak look in Olivia's future."

Next came a referral to a neurologist and PM&R in Houston for February of 2013. By this time Olivia's muscles were so tight that her ankles could not be bent to a 90 degree angle. The doctors put her on a medication which has helped to be able to get back into the braces for her ankles.

After attending a NBIA conference in San Antonio in March 2013 to learn more about INAD, the Lemaires learned of an 11 year old girl with INAD that lives in Lyons Point.

The two families met and have become great friends as they share similar experiences.

"They have become a big support for us," said Mike. "Because their daughter is a little older than Olivia, they

can help answer questions we have and prepare us for what to expect in the future."

Today, Olivia is able to walk very slowly with a walker, but no longer than 15 minutes with full assistance. She is able to say very few words, but her parents say she is the happiest little girl who loves music and to cuddle, and she absolutely adores her dog, Charlie.

While Mike is in from his 14/7 job off shore, he and Leslie are able to manage the daily routine of caring for their daughter. When he is offshore, Leslie's mother steps in to help with Olivia.

"We can mange now, but it will get harder,"said Leslie. "As the dystrophy progresses, we will also face astronomical medical care costs, medical equipment and 24 hour nursing care."

Family and friends are looking ahead and planning a benefit to help defray the costs. As more details are finalized, the benefit will be publicized at a later date.

"We know we cannot stop the progression of the dystrophy," said Leslie, "We are taking it one day at a time. All we can do is to love up on her daily, and make her life as happy and comfortable as possible."