

Never Give Up

Couple fights for cure to save young daughter

By Diane Gale Andreassi

Thoughts of their 5-year-old daughter suffering from an early, painful death pushed Kelly and Kevin Kozole to start a nonprofit organization called Don't Forget Morgan, which raises awareness and money for research on BPAN.

The Troy couple never heard about the neurodegenerative disease before they started to notice delays in Morgan's development, setbacks in walking, talking and other missed milestones. They took Morgan to countless doctors, got bad diagnoses and continued to look for reasons Morgan wasn't thriving.



Looking for answers

Morgan was eventually diagnosed with Beta-propeller protein-associated neurodegeneration, which attacks the nervous system until it slowly depletes the body and mind. Morgan was 3 years old

when she was diagnosed. There are only 500 known cases, and there is very little research being done.

The Kozoles went on a quest to learn all they could about BPAN.

"This is worse than cancer I thought, how could this happen to our sweet daughter," wrote Kelly on their webpage, dontforgetmorgan.org.

As the information unfolded, one devastating blow followed another.

The lifespan of sufferers varies, but some can live to middle age. Deaths may result from complications of dementia or movement problems, causing falls or difficulties swallowing, leading to pneumonia. BPAN may ignite epileptic seizures that often begin in infancy.

Children with BPAN also have delayed development including significant problems with vocabulary, as well as difficulty coordinating movements that can affect the ability to walk and perform fine motor skills. Small things, like using a fork, can be insurmountable.

As the child gets older problems with movement may also occur, causing unusual slowness, rigidity, tremors and an inability to hold the body upright and balanced.

Overcoming obstacles

Their research into what BPAN was all about brought more bad news when they learned there was no cure, therapy or medicine Morgan could take to get better.

They were told to join the BPAN Facebook community, because not much is known about the disease. The pain and anguish in posts from other families with a child who has BPAN were almost too much for Kelly to read. But, despite the gloomy news, Kelly said, she has hope.



"I know that we will cure BPAN so we can save Morgan," said Kelly, who is the senior vice president of business development with the Detroit Lions.

She said the best advice she gives to parents with children who are diagnosed with a rare disease is to keep forging on.

"Never give up," Kelly said. "We just kept pushing ahead to be vigilant for Morgan. We had to be her voice. You have to look inside yourself for that inner energy."

The cost for medical researchers to study rare diseases is staggering, she added.

On the other hand, Kelly said, she is hopeful people will hear Morgan's story and will contribute whatever they can.

Raising funds for research

This isn't a short-term fight.

"For Morgan's entire life we will be dealing with her disease," Kelly said. "It's tough, different and wasn't the life I ever thought we'd have. It's a new normal for us. We're trying to enjoy being with her, trying to have a positive outlook every day."

So far, more than \$180,000 has been raised on the Don't Forget Morgan webpage that was launched at the end of February. The Kozoles also have a son, Connor, 8.

Some of that money will go toward a grant to The University of South Dakota Sanford School of Medicine, to study BPAN.

To donate go to dontforgetmorgan.org.

