

## Living with Epilepsy

Dekson Thibert

Katelynn Thibert is a 30-year-old probation and parole officer in Leamington. She has been married to her husband, Jeff, for close to four years, and they are kept busy with their two young boys Duke, who is nine months old, and Dekson who is two.

When Dekson was born, the family had thought he was perfectly healthy. But the baby experienced his first seizure when he was only 19 months old, and their lives changed.

“At the end of July we switched Dekson from the crib to the toddler bed so that we could use the crib for the newborn,” explained Thibert. “We thought Dekson was going through behavioural tics just from stress with the new baby and the new bed.”

“But one day I noticed that his shoulders shrugged up his eyes actually rolled back into his head. So we took him to our family doctor, and we were given a referral to get bloodwork done and see a neurologist,” said Thibert.



When the results came back, the one-and-a-half-year-old was diagnosed with epilepsy. The parents had a hard time coming to terms with this news.

“We were kind of blindsided because we honestly thought it was a tic. We thought he was just going through a lot and he was acting out basically. We weren’t expecting that diagnosis at all - we thought the doctor was going to clear us and send us home.”

Dekson was started on medication right away, and was immediately sent to the hospital for EEGS. The new parents were utterly overwhelmed.

“We had to really struggle with quickly learning what epilepsy was. We basically had to become teachers, researchers, advocates, doctors and nurses. We had to take on all these roles as parents and we already didn’t really know what we were doing. Dekson was only a year-and-a-half old, so we were new at the parenting thing to begin with. I would just feel angry and hurt all the time; angry that Dekson was going through all this,” confessed Thibert.

That's when ESWO reached out to the family. By providing a PowerPoint presentation about epilepsy and connecting Thibert and her husband with epilepsy support groups, it helped to get the parents involved and educated about their son's condition.

"When I thought of epilepsy before the diagnosis, I assumed that anyone who had epilepsy was an adult and that they only had tonic-clonic seizures," admitted Thibert. "My lack of knowledge made me believe that there was one or two types of seizures and that babies don't get it."

At the support groups, Thibert was able to connect with other parents who experienced the same feelings of grief and loss. It helped to show the young mother that she's not alone. "It's not easy and you don't have to pretend that it's easy," she said.

"It's good to have people that know what's going on, and can understand the unique difficulties that come with kids. Toddlers are difficult creatures already," Thibert said laughing, "and to toss epilepsy on top of that is a lot to deal with!"