

?We never let his diagnosis create the people we are?



By Brock Weir

When Erik Ront had his first seizure, his mother, Laura Schaffer, wasn't sure just what it was.

It wasn't the kind of seizure you learn about in First Aid where the individual drops and falls. Erik just began to drool and stare off into space.

Knowledge of the complex world of epilepsy, however, soon became second nature to Erik, Laura and their family, and now they hope to help the wider York Region community tackle the stigma directly ? by hitting the ice to benefit Epilepsy York Region. Aurora businesses and community groups have jumped behind Epilepsy York Region's first large Region-wide fundraiser, Skate Away the Stigma, which will take place Saturday, March 23 at the Stouffville Arena to coincide with ?Purple Day?, a day dedicated to raising awareness of epilepsy.

?Epilepsy York Region has been a very small organization and we're really trying to flourish, especially after [the group moved] from Richmond Hill to Stouffville last year,? says Ms. Schaffer, noting their new location on Stouffville's Main Street area has brought increased visibility and foot traffic to the non-profit. ?We're now starting to realise how many people in York Region have epilepsy and are aware this organization actually exists.?

Now in its fourth decade, Epilepsy York Region is a volunteer-based organization dedicated to building awareness and helping families in need of support.

The Ront family has found their services invaluable and have never shied away from stepping up to underscore the work they do. Now, they are lacing up.

When they began their journey with epilepsy, Laura says they had a several misconceptions of just what epilepsy entailed. There is a prevailing misconception that people having a seizure can swallow their tongues, something that is just not possible.

?The seizures themselves won't typically hurt the person; it is their surroundings, what they are doing at the time when the seizure is happening,? she says, advising parents to make sure nothing is around their child's neck, that they have an open airway, and are turned on their sides in case they vomit. ?Just allow the seizure to take its course and allow it to finish. The only time we recommend you call 911 is if a seizure lasts longer than five minutes, then we request that you call in an ambulance.

?Seizures come in all different forms. When you see someone daydreaming and staring off into space, that can be a seizure. What people typically think of a seizure when you stiffen, fall and jerk is what is called a tonic-clonic. There are hundreds of different kinds of seizures. We want awareness for children not to be afraid of it, that there is nothing wrong with the person, that they are just like everyone else.?

That can sometimes be a struggle for a parent raising a child with epilepsy. While Laura was unsure what was happening the first

time Erik had a seizure, she caught on pretty quickly as they kept recurring.

?The hardest thing was taking him to a doctor,? she says. ?My son's seizures progressed in a month to tonic-clonics. He was always falling, hurting himself, and it was hard keeping him safe. The doctor told me: send him to school, give him a normal life, don't seclude him and don't let his epilepsy become him. Make sure he is always strong and aware of it, and proud of it.

?One of the hardest things in Senior Kindergarten was sending him to school in a helmet for an entire year. I didn't know how kids would react. I didn't know how he would feel, but we made it like it wasn't a big deal and he proudly wore it to school, the kids understood and it really educated a lot of the children in the classroom to help and advocate.

?It is a lot to learn in that sense and you have to change your lifestyle. There are things you're never prepared for, but you learn just to cope and ride with it. For us, we never let his diagnosis create the people that we are.?

Looking ahead to the March 23 skate, Laura says she and Epilepsy York Region are hoping to have over 200 people participate, learn, take what they learn out into the wider community and, of course, have some fun along the way.

After hitting the ice, food and refreshments will be available, along with live entertainment courtesy of Party With Steve, who has been a very active part in Erik's journey, raffles featuring items donated from various vendors throughout York Region ? and they are always looking for more donors, vendors, entertainers and supporters to come on board and make the day a rousing success.

?We see the same kids at our events every year, we never see it progress and we never see it get any bigger,? says Ms. Ront. ?I would really love to have people join our community, especially as a member, and be able to not isolate themselves from this illness, meet different families and talk about their experiences ? just feel like you belong somewhere. Epilepsy is extremely isolating because you don't understand the illness, why it happens and why it's here.?

For more on the Skate, how you can become involved, and learn more about Epilepsy York Region, visit epilepsyork.org, email info@epilepsyork.org, or call 905-640-8000.