

TWO DECADES OF FOSTERING HOPE AND COURAGE

By Kile Blanchard

It's been 20 years since Epilepsy Durham Region (EDR) first sowed its seeds of hope—not just for those living with epilepsy, but their families, caregivers and employers as well.

What began as a passionate group of parents and volunteers seeking resources for their family members has evolved into a professional body dedicated to improving the lives of everyone affected by epilepsy. It's no easy task, but with Executive Director Dianne McKenzie and Community Outreach Education Coordinator Shelley Goodall at the helm, the organization's seeds of hope have taken root.

“The essence of what we do is to inspire hope and courage,” says McKenzie. “Hope that one day there will be a cure for epilepsy and courage to hold onto until there is.”

To say that hope and courage are essential is an understatement. Epilepsy knows no bounds and plays no favourites, affecting over 300,000 Canadians of all ages. Epilepsy Durham Region is a not-for-profit, non-governmental health organization dedicated to promoting independence and optimal quality of life for children and adults living with epilepsy and seizure disorders. This is achieved through education, awareness, support, and advocacy. However, none of these services could be provided without volunteer support from the community.

“Volunteers are the heartbeat and backbone of this organization,” says McKenzie. “Epilepsy Durham Region is what it is today due to the commitment and dedication of our volunteers. Without them, we would not be able to offer as much as we do.”

Currently, volunteers facilitate and lead seminars, assist with fundraising initiatives and help with in-house office assignments. They also help throughout the community by conducting parent forums. These sessions provide parents with the opportunity to celebrate successes and to discuss the many challenges of dealing with epilepsy.

The volunteers are not the only ones who are busy. McKenzie and Goodall’s days are full with an on-going barrage of events. Whether it’s the Walk of Courage, Epilepsy Awareness Month (March), individuals seeking help or one of their educational seminars for the Durham District School Board, McKenzie and Goodall never rest.

“My time at Epilepsy Durham Region has evolved from a job to a vocation,” says McKenzie. “Meeting so many families and learning of their struggles has inspired me. The one thing that makes it all worthwhile is when you come to the realization that you are making a difference. For instance, in 2006, the Durham District School Board recognized Epilepsy Durham Region as the leading authority of epilepsy education in our community. This was truly an honour.”

Despite being a not-for-profit, non-governmental agency, EDR has taken remarkable strides throughout its 20 years. It holds information forums, has an

Annual Golf Tournament and has even hosted a successful provincial conference. Epilepsy Durham Region's contributions aren't lost on Epilepsy Ontario's Executive Director, Dianna Findlay, who is thrilled about what EDR has accomplished within the community.

"Epilepsy Ontario is proud of what Epilepsy Durham Region accomplished amidst extreme financial restrictions," says Findlay. "We wish only the very best for all of the volunteers and members of the association. It is vital that community agencies continue to provide the programs and services needed by all people living with epilepsy either directly or indirectly. Only education about this leading neurological disorder will help communities understand how prevalent epilepsy is."

According to Findlay, it is imperative that people with epilepsy have access to medical professionals and community social services that are provided by a thriving epilepsy chapter. EDR has helped thousands of families coping with epilepsy in the Durham Region by providing support services, educating individuals about epilepsy and by putting individuals in touch with the appropriate medical professionals.

Epilepsy Durham Region's value to the community is apparent when speaking with one of its members, who prefers to remain anonymous. This individual had Complex Partial Seizures, which is a common form of epilepsy. After a considerable amount of research and soul searching with his family this member elected to undergo Front Temporal Lobe surgery, which removes the effected area of the brain.

Epilepsy Durham Region provided this same individual with pre and post surgery support, connecting him with community resources, providing links to research possibilities and educating him on the possible outcomes of the surgery. His surgery was a success. It provided him and his family with an improved quality of life.

“I would like to express my gratitude to everyone at Epilepsy Durham Region for what they have done for me and my family,” says the anonymous four-year member. “They have provided us with empathy and compassion over the years and truly have made a difference in our lives. Epilepsy is something that lurks in the shadows and is a topic that many choose to avoid. It’s wonderful to know that there are people who are passionate about shedding some light on this neurological disorder.”