

Epilepsy

{ *Breaking the Silence* }

**1 in 100 Canadians
live with epilepsy
and seizures**

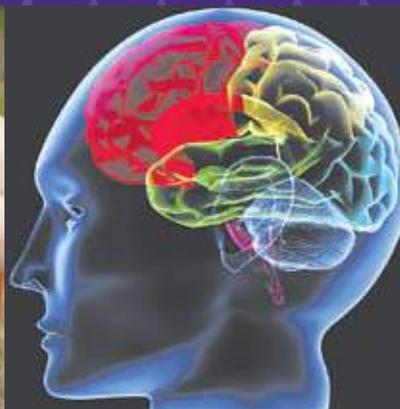
ep-i-lep-sy

any of various disorders marked by abnormal electrical discharges in the brain and typically manifested by sudden brief episodes of altered or diminished consciousness, involuntary movements, or convulsions

sei-zure

a) sudden attack (as of disease); especially the physical manifestations (as convulsions, sensory disturbances, or loss of consciousness) resulting from abnormal electrical discharges in the brain (as in epilepsy) b) an abnormal electrical discharge in the brain

inside



2 Faces of Epilepsy

4 Epilepsy Education
in our Schools

6 Canada's Hidden Gem:
35 Years of Excellence at LHSC



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the faces of epilepsy

When Tim was 38, his future was so uncertain, he could barely function and he did not know where to turn next.

For more than three years leading up to that point, he was having seizures – as many as 30 each day. He became disoriented for periods of time and was unable to recall his own actions.

Doctors thought perhaps it was due to anxiety attacks and Tim tried various treatments for that. But the truth came to light when his brother-in-law was doing a rotation in neurology, and he realized that Tim's problem actually looked more like complex partial seizures. He was right and it changed the course of Tim's treatment and his life.



TIM

Medication for epilepsy was the first line of treatment that he attempted, but nothing worked for Tim. He tried everything available, but received no relief. All he did seem to experience were side-effects from medication, heartache and overwhelming hopelessness.

"I was at the end of my rope," he remembers thinking. "I couldn't live anymore. I couldn't work. I hated myself. I hated life."

In July 1996, he was told by his neurologist that surgery was his only remaining option, and that he was being referred to the Epilepsy Unit at the London Health Sciences Centre in London, Ontario. Once admitted, he settled in at the Unit at LHSC and he immediately began undergoing EEG testing. Tim wasn't overwhelmed; instead he remembers feeling that the unit was homelike and serene. He even got a bed by the window. He played cards and made friends and for the first time in ages, he did not fear his seizures. In fact, seizures were the goal! That was the way neurologists could focus in on the location, cause and scope of his seizure activity.

The tests indicated a small benign tumour on his occipital lobe that was causing seizure activity in his temporal lobe. He qualified for surgery and when they removed the tumour, which Tim describes as being about the size of a sugar cube, he became seizure free.

Although things improved, Tim experienced a deep depression afterwards. It was a dark time, but he was not alone: he found help from both his doctors and the friends he had made on the Epilepsy Unit, some of whom also experienced debilitating depression and they knew exactly what he was going through.

Tim credits the Unit for not only helping him through the whole process but also giving him a wonderful support network – "The Epilepsy Unit for me – it saved my life." It was not long before Tim was back to driving and he returned to work. He went on to thoroughly enjoy his position as Executive Director of Epilepsy Kingston for many years, before accepting a challenging role change in 2008 and becoming Executive Director at the Saskatchewan College of Physical Therapists.

~ SIMONE GRAHAM

Diagnosed with intractable epilepsy at the age of sixteen,

Scott has bravely faced the challenge of living with seizures that cannot be controlled with medication. More than a decade later, an exciting new technological development might transform the nature of his fight. During his late teens, Scott persevered through the frustration of several unsuccessful attempts to manage his seizures. Realizing that they occurred mainly at night, he used his days to the fullest, pursuing an education in culinary management and finding work as a chef in various restaurants around Windsor and Essex County.

Scott's seizures progressed and became more frequent during his 20s, creating a major obstacle to full-time employment. With limited options and a strong desire to continue living independently, Scott applied for the Ontario Disability Support Program (ODSP). Making the decision to seek government support was not an easy one – and securing that aid proved something of a challenge as well. ODSP rejected his initial application on the grounds that he had been able to work in the past (and despite his neurologist's support for the claim that his situation had changed). Scott navigated the bureaucratic process for three years before finally qualifying for ODSP. Now thirty years old, Scott is about to embark on the next chapter of his life. He's scheduled for a Vagus Nerve Stimulator (VNS) - essentially a pacemaker for the brain. Scott hopes to see a significant decrease in the number of seizures he experiences after the device is implanted, allowing him to return to the work that he loves.

~ NIKKI PORTER



SCOTT

"To the doctors at the Epilepsy Unit in London, I would say: My mother gave me life but you gave me my life back."

~ Tim

Two years ago, a neurologist asked Jane a simple question that changed her life:

Are you interested in surgery? Jane was incredulous, "I thought I was hearing things because no doctor had ever offered me surgery." She had been living with seizures for most of her life. Jane saw a neurologist as a child, but his retirement left her, like many other people with epilepsy in Windsor, under the exclusive care of her family doctor.

In 2010, Jane finally made an appointment with neurologist Dr. Hiren Desai and he asked her that fateful question. Her answer was a resounding yes: "I wanted to get rid of these seizures. I didn't think I ever would in my life." Dr. Desai sent Jane to the Epilepsy Unit at University Hospital in London where she had her first EEG in over 20 years. The specialists found that Jane had a scar on her brain left over from a childhood illness - a combination of encephalitis and a 104°F fever when she was 2 years old.

The scar caused Jane's seizures. About a year after her first appointment with Dr. Desai, Jane had a surgery to remove that scar. She's been seizure-free ever since.

Now Jane sees a future she never thought possible: "I want to live my life with no handicaps, no illness, no nothing, so I know what it feels like." She's looking forward to getting her driver's license and she no longer has to worry about people staring at her when she has a seizure in public. "I feel so much more comfortable. It feels great." We can only imagine what her life would have been like if someone had asked that question earlier.

~ NIKKI PORTER



JANE


NATHAN GILLIS:

 November 20, 1983
 - September 13, 2003

Our son Nathan was an easy going kid with a broad network of friends. He had a personality that drew people in: he had an inclusive, caring, and loving spirit. He always had a smile for people and knew how to make people laugh. In his early teens Nathan started having seizures in his sleep. For him, the seizures were just an inconvenience. As he grew older, these seizures became increasingly frequent, but he tried not to let his condition slow him down. As always, he chased his dream. He was happy!

Nathan passed away while starting his second year at Sir Sanford Fleming College. None of us were fully aware of the need to get his seizures under control. We did not really understand the risks, and learned the hard way what the letters SUDEP stood for - Sudden Unexplained Death in Epilepsy. As a family, we did not focus on the importance of seizure control, rest, and stress reduction, with tragic results.

Since then, we have seen too many friends and acquaintances pass away from SUDEP...all of them loved, all of them missed. We were unaware that this condition could end in death. We now try to help raise awareness about the risks of epilepsy for people that have night seizures so that we can find ways to prevent this tragedy from happening to other families.

~ STEVE AND PEGGY GILLIS



CLOCKWISE FROM ABOVE:
 Chelsea from Chatham; Negassi, Epilepsy Support Centre volunteer; Betty, Barb, Stephen and Pat in London; Connor in Oxford County; twins Keanna and Kaylyn from Kettle Point, Lambton County.



You don't look like you have epilepsy.

FACT You can't tell someone has epilepsy just by looking at them.

FOR MORE INFORMATION VISIT WWW.EPILEPSYSUPPORT.CA

Can I be fired for having a seizure at work?



CÉZANNE CHARLEBOIS,
 B.A., M.A., LL.B
 ~
 Charlebois Associates
www.charleboislaw.com

Not legally. Employers who fire an employee for having a seizure at work are breaking the law. Not only that, they are contributing to the stigmatization, unemployment and poverty of persons with disabilities in Ontario. In Canada, both Federal and Provincial human rights laws require that employers recognize the dignity and worth of every person and provide for equal rights and opportunities without discrimination. The Human Rights Code in Ontario states that every person has a right to equal treatment with respect to employment without discrimination because of disability.

People with epilepsy still face insurmountable discrimination, unemployment rates much higher than the non-disabled population, underemployment and wrongful dismissals because of their epilepsy. Most employers are not so misinformed that they will openly admit or state that they are firing an employee because he or she has epilepsy. Instead, they will couch the termination or suspension as arising out of other performance reasons or "safety issues". If you think that your epilepsy has had any role in your termination, dismissal from employment, constructive

dismissal, temporary or permanent lay off or denied opportunity, you may want to speak with Michelle Franklin at the Epilepsy Support Centre (1-866-EPILEPSY) for free assistance in this area.

Unfortunately, upon discovering that an employee has epilepsy, many employers react with fear. They are concerned about potential liabilities, costs, absenteeism, safety issues, and the impression given to clients or members of the public should a seizure be witnessed. In responding this way, they contribute to profound discrimination against people with epilepsy. There are approximately 600 million persons worldwide suffering from disabilities and we are an aging population, so these numbers are growing. Progressive, socially conscious and visionary employers can play a critical role in reducing discrimination by offering an employee with epilepsy accommodation, support, inclusion and respect.

Cézanne Charlebois (Employer Representative in Workers' Compensation and Occupational Health and Safety Matters)

Why Epilepsy Services Matter:

AN INTERVIEW WITH MARY SECCO

BY ROCHELLE PORTER

Imagine if something switched in your brain causing you to experience a jerking arm or leg, a facial tic, or flashing lights, abnormal smells, maybe even loss of consciousness. Epilepsy is a neurological condition, meaning it stems from the brain, and the brain is the control centre of everything we do. When the brain is hurt or sick, it impacts the way we perceive ourselves and others perceive us. It impacts our self esteem, daily functioning and quality of life.

Mary Secco is the Executive Director of the Epilepsy Support Centre, an organization mandated to improve the lives of people living with epilepsy through education and support. According to Mary, fear of the next seizure, of losing control, injury or dying and fear of being teased or embarrassed after a seizure can immobilize a person. "So many of our clients say they have difficulty with loss and this might include their driver's license, relationships or

employment. The biggest loss is feeling the loss of control. Will I have a seizure today? If so, how will people react? Will I be safe?"

The Epilepsy Support Centre provides service in six counties across Southwestern Ontario: London-Middlesex, Oxford, Elgin, Sarnia-Lambton, Chatham-Kent and Windsor-Essex. "Our programs provide families with information to help their loved ones to live a full and happy life, even if the seizures do not get under control. We help people to recognize what triggers their seizures and to know what medical options are available to them."

Seeing someone have a seizure and not knowing what is going on or what to do is frightening. Mary is dedicated to public education with the hope of dispelling the myths and mystery surrounding epilepsy. "Often what we have learned through movies and the media is not accurate. We need to provide the general community with accurate and authoritative knowledge to recognize different seizure types and the skills to know how to help. This knowledge will reduce fear and when we reduce the fear we will stop the discrimination."

An employer, teacher, friend or relative who is informed and knows what to do is a valuable advocate for people who live with seizures. In most instances, they can provide first aid or know if calling 911 is necessary. A person who is trained to provide seizure first aid can help others to remain calm during and after a seizure.

One in 100 Canadians and 1 in 14 seniors are diagnosed with epilepsy and up to 70% of those people successfully maintain control of their seizures, but the stigma they feel leads to living a secret life hiding the truth. Monday, March 26th is designated as Purple Day for Epilepsy. One of the objectives of Purple Day for Epilepsy includes encouraging individuals and families who live with epilepsy to disclose how seizure disorders have touched their lives. To begin a meaningful and informative conversation about epilepsy will lead to less discrimination and more opportunities for everyone living with seizures.



MARY SECCO
Executive Director
Epilepsy Support Centre

Fear of disclosure has negative consequences and impacts funding for community services and research. Community education leads to decreased health care costs, such as fewer emergency room visits, reduces public perception and misunderstanding about seizures and decreases the possibility of mishandling and

harming someone having a seizure.

Mary encourages anyone affected by the condition to call the Epilepsy Support Centre's office. "If they have epilepsy and are doing well, we want them to volunteer to help others live well and we also want them to donate so we can offer more programs to more people." All people whose lives have been touched by epilepsy are stakeholders in the Epilepsy Support Centre's services. Their ongoing support is crucial for Mary and everyone at the Epilepsy Support Centre to continue developing and expanding much needed education and support services.

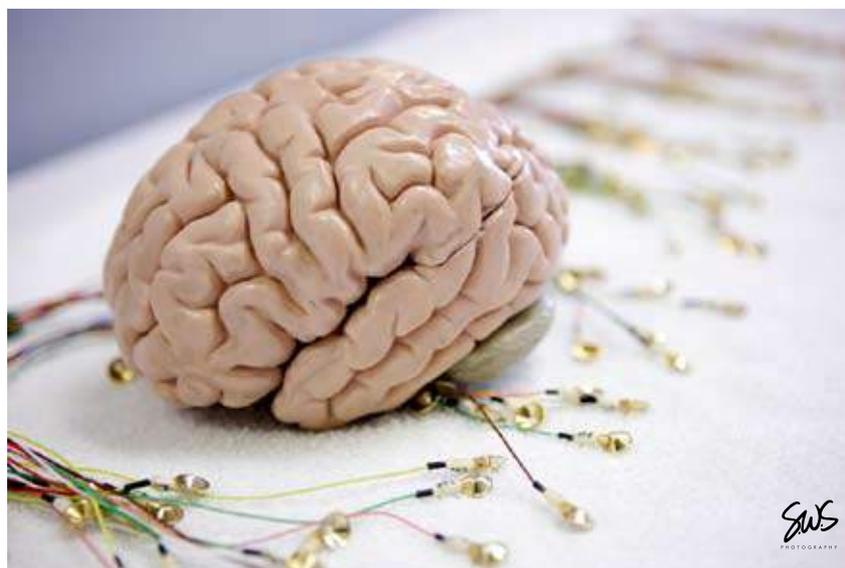
Epilepsy Education in our Schools

BY DAVID FIORE

One in ten people will have a single seizure in their lifetime. One in 100 will have a second seizure and be diagnosed with epilepsy. Unfortunately, due to stigma, ignorance and discrimination, they may not disclose their epilepsy to their classmates, teacher, friends, neighbours, relatives or employer.

Affecting the lives of hundreds of thousands of Canadians, epilepsy remains misunderstood by the public at large. This lack of familiarity with even the most basic facts about epilepsy has dire consequences – most notably and tragically, the people who deal with its effects every day and feel the stigma that comes with being perceived as different. In 2003, the Epilepsy Support Centre took the initiative in the struggle to promote greater awareness about this common neurological disorder by going directly into the classroom.

An unfortunate accident in a London, Ontario school served as the catalyst for this endeavour. A thirteen-year-old boy had one of his convulsive seizures at school when a well-meaning teacher panicked and placed an object in the boy's mouth, injuring him. This is not proper first aid for a seizure. The boy refused to return to school the next day because his epilepsy had been "exposed". Education about



the brain, seizures and proper seizure first aid help dismantle the damaging myths surrounding epilepsy. It also leads to greater empathy, opportunity and inclusion for people living with epilepsy. The program works, because it is proactive – it teaches what to do before a seizure happens and this alone reduces fear. This is the core of the Epilepsy Support Centre's education programs in the schools.

Developed as a supplement for Ontario Grade 5 health and science curricula,

the 45-minute "Thinking About Epilepsy" program has reached more than 35,000 students in Southwestern Ontario since its inception. The model proved so successful that it was quickly adapted for use in other parts of Ontario and Canada, as well as the United States, Israel and Australia. The program was evaluated by researchers at the University of Western Ontario in partnership with the Thames Valley District School Board and the London District Catholic School Board. Twenty-four schools

from the Thames Valley region participated in the research, and a total of 783 children were given the questionnaire to measure their pre and post presentation knowledge and attitudes. The research showed that the program increases epilepsy knowledge, teaches seizure recognition, reduces the fear people have of epilepsy and seizures, teaches seizure first aid, promotes tolerance and acceptance of those affected, reinforces that epilepsy should not stand in the way of achievement and encourages disclosure for those living with the condition.

In response to these findings, the Epilepsy Support Centre developed a second program – this time targeted to Grade 12 biology students. The unit, titled "Brain Matters: An Introduction to Neuroscience," meets the expectations of the Ontario Grade 12 biology curriculum, and includes a facilitator's manual, companion DVD, case studies, classroom demonstrations, videos and interviews.

Together, "Thinking About Epilepsy" and "Brain Matters" have greatly contributed to breaking down misconceptions about epilepsy and equipped a generation of Ontario youth with vital information about seizure first aid. The successful implementation of these programs represents a crucial step in the struggle to create a world in which everyone, whether they are currently living with epilepsy or not, can face the challenge posed by this disorder with dignity and in solidarity with others.



CLOCKWISE FROM TOP LEFT:
Kaylyn and Sydney; Amber and Maria;
Megan, Riannon and Nikki; Alex; Wes;
Amit and Keanna.

To register your child for summer or winter camp or to volunteer as a camp counsellor, please call Nicole Zwiers at 519-433-4073 or email her at youth@epilepsysupport.ca

Supporting the Next Generation

BY DAVID FIORE

Epilepsy doesn't discriminate. It is the most common neurological condition of childhood, with the highest rate of occurrence in children under ten. It's the time in a child's life when they begin and complete a critical part of their social, psychological and educational development. Living with epilepsy can be difficult, even under the best of circumstances. For children and youth, epilepsy can be particularly harsh. As they face the daily challenge of dealing with the threat of seizures, their situation is made infinitely worse by teasing, bullying and other forms of isolation that are often the side effects of having seizures at school. Parents report that when their child's seizures cannot be controlled, the school often imposes restrictions by not allowing the student to take the school bus, go on

field trips, participate in gym class or play in the schoolyard at lunch and recess.

The Epilepsy Support Centre's United Way funded Wacky Wednesdays Summer Camp provides programming to level the playing field and help kids living with seizure disorders feel included in their community. The 2011 camp was attended by dozens of campers who enjoyed themes like "Super Hero Training Camp" and "Medieval Knights and Princesses". The summer program also included field trips where kids were full participants at "All about Horses" in Lambton and Happy Hills Resort in Oxford. The camp matches youth volunteers one to one with a child who has epilepsy. It's a win-win situation. Youth volunteers receive a comprehensive training, they become role models, they complete their 40 hours of community service and get real life experience as camp counsellors for their resumes. The child with epilepsy learns new skills, makes

friends and has fun.

A survey of forty families whose children attended the Epilepsy Support Centre's summer program revealed that 95% of the campers had no other organized recreational outlet. Wacky Wednesdays Summer Camp was so popular that parents eagerly requested the Epilepsy Support Centre launch a Saturday morning recreation program during the school year.

Children with epilepsy face a disproportionately high risk of underachievement at school, learning disabilities, mental health problems, social isolation and poor self-esteem. Such risks can be avoided with early intervention programs, such as this one. It has become clear that targeted child and youth programs provide young people living with epilepsy with the support they need to feel confident and begin to realize their full potential.

What causes epilepsy?

Epilepsy has many different causes. In any given individual, the cause is a combination of their genetically-determined seizure threshold, an underlying abnormality in the brain which predisposes them to epilepsy, and factors which bring on epilepsy at that time. Determining the specific cause for any one person's epilepsy is usually difficult. In about 60% of all cases, no specific cause is found, much to the frustration of the epilepsy patients involved.

Epilepsy of an unknown origin is called idiopathic epilepsy. In many cases it is presumed to be genetic.

When the cause of a person's epilepsy is identifiable, it is called symptomatic epilepsy. Basically, any lesion, scar, tangle of blood vessels or any other abnormality in the brain that can interfere with its delicate electrical workings can cause epilepsy. Common causes are head injury (e.g. from a car accident); brain

tumour, scar or lesion; brain injury during fetal development; birth trauma (e.g. lack of oxygen during labour); aftermath of infectious diseases (e.g. meningitis, encephalitis, measles); poisoning from substance abuse, like alcohol; and stroke.

If epilepsy is due to an acquired brain lesion which has not been identified, or the cause of which is unknown, its cause is termed cryptogenic (hidden).

Canada's Hidden Gem

BY SIMONE GRAHAM

The London Health Sciences Centre (LHSC) Epilepsy Unit celebrates 35 years of excellence as one of the preeminent centres in Canada for the treatment of epilepsy. It is the largest epilepsy

monitoring unit in English Canada with eight inpatient beds on the 10th floor at the University Hospital campus of LHSC. The Epilepsy Unit is world renowned for its highly qualified team of professionals. This team includes neurologists, neurosurgeons, nurses, psychologists, EEG technologists, neuropathologists, neuroradiologists, neuropsychologists, speech-language pathologists and neurophysiologists – all of whom are dedicated to the management of epilepsy, particularly epilepsy surgery.

The Epilepsy Program began in the early 1970s when Dr. Warren T. Blume, a neurologist and epileptologist, and Dr. John P. Girvin, a neurosurgeon and neurophysiologist, recognized the need for a specialized epilepsy unit in English Canada. The only other unit was the Montreal Neurological Institute and Hospital made famous by epilepsy pioneer Dr. Wilder Penfield. Drs. Blume and Girvin were concerned that when epilepsy cannot be controlled by medication, patients are not safe; they are often marginalized and find themselves facing a very uncertain future. Drs. Blume and Girvin knew that the complexities of treating epilepsy and performing epilepsy surgeries are best dealt with through a team approach and they set out with this goal in mind.

In 1977, they formally established the Epilepsy Program and a multidisciplinary team of health care professionals with expertise in epilepsy gradually took shape. By 1986, the program grew to include a four-bed inpatient epilepsy unit with a focus on the investigation and monitoring of seizures. Over the years, a growing need for inpatient evaluation led to an expansion of the Epilepsy Monitoring Unit, including an increase in the number of inpatient beds to the current eight.

Services further progressed with the opening of a dedicated paediatric epilepsy monitoring bed, using the same kind of equipment and team approach, at LHSC's Children's Hospital. This approach mirrored the team-based focus that was used for adult inpatients, which was a proven formula for looking at all segments of patient care, the medical realities, the surgical decision-making, and the quality of life.

The Epilepsy Unit is a safe haven for patients who experience debilitating epileptic seizures and who do not respond



to drug therapy. For most of the inpatients, the quality of their lives has become severely compromised due to their seizures and this Unit provides an incredible ray of hope for them.

The goal in the unit is to record seizure activity, which can help determine a path towards better long-term seizure management. When patients are admitted, their seizure medications are safely withdrawn under close supervision. Sometimes patients are admitted to help them to manage their drug therapy, but usually the collaborative team collects data to determine whether the patient could benefit from surgery.

When epilepsy is suspected, one

"I am pleased to be able to salute the men and women of the Epilepsy Program at London Health Sciences Centre. I congratulate them on 35 years of outstanding service to the community and wish them and their patients every success in the years ahead."

~ PAUL E. COOPER, MD, FRCPC, FAAN, INTERIM CHAIR/CHIEF,
DEPARTMENT OF CLINICAL NEUROLOGICAL SCIENCES, LONDON HEALTH SCIENCES CENTRE

of the more common diagnostic tests used is the electroencephalogram (EEG). While on the Unit, patients undergo continuous EEG monitoring to measure and record the electrical activity of the neurons in the brain. An EEG can tell the healthcare team if there is abnormal electrical activity in the brain and the types of seizures the patient might be experiencing. This test may help the team identify any other abnormalities existing in the brain. An EEG can also track the path of seizure activity in order to determine where the seizures begin in the patient's brain. That knowledge is key to determining if surgery is an option.

At the Epilepsy Unit, patients enjoy



CLOCKWISE FROM LEFT:

Dr. J. Girvin and Dr. W. Blume, founders of LHSC's Epilepsy Unit; Dr. D. Steven and Dr. J. Burneo, Co-Directors of the Epilepsy Program; Elise, an EEG tech in the Epilepsy Unit; Dr. C. Campbell, Dr. N. Prasad, Dr. S. Levin, and Nurse Practitioner Margo DeVries Rizzo, members of LHSC's Children's Hospital team.

spacious and comfortable accommodation, helpful to those who may be in the unit for several weeks during their evaluation period. The sophisticated bedside EEG monitoring equipment is designed to allow patients to move quite comfortably around the Unit, play cards, socialize or talk to visiting family members. Patients also read, rest and make new friends. These

has infrared capabilities to view patients sleeping at night, and can provide an opportunity to record and see physically what happens to a patient during a seizure.

The majority of patients who meet the criteria for epilepsy surgery experience improvements in seizure control after their operation. When seizures get under control, lives get under control, too.

relationships with other epilepsy patients reduce the isolation and anxiety that many patients state incapacitated them before they came to the Epilepsy Unit.

The experienced team of multidisciplinary professionals at LHSC has the knowledge, skill and technology to undertake a comprehensive evaluation. Each of the eight beds in the Unit is equipped with a colour video camera, microphone, and a state-of-the-art EEG, allowing physicians and nurses to monitor patients 24-hours a day.

Monitoring is all done without interruption, which is critical, so that the professionals can capture seizures and pinpoint their origin in the brain as they happen. The video equipment even

Many people credit the Epilepsy Unit for helping them to get a driver's license, to feel well enough to go back to school or to get a job. While the extensive evaluation upfront is onerous and takes time, it is essential to determining if a patient meets the criteria for surgery. Through the increasing sophistication of EEGs and the use of Magnetic Resonance Imaging (MRIs), the team is able to pinpoint the origin and causes of patient seizures much more accurately than ever before. With such a comprehensive approach to monitoring and treating epilepsy along with incredibly significant outcomes for the patients, the entire staff at the Epilepsy Unit, past and present, should be proud of their well-earned sterling reputation.

Scott's Family Couldn't Cope without the Epilepsy Support Centre

BY NIKKI PORTER

Seventeen-year-old Scott Ross has had thousands of seizures. After eighteen different medication combinations, two brain surgeries, one stroke, and three induced comas, Scott has finally achieved seizure control. The Ross family's journey has been tumultuous. Scott's mom Mary Ann credits the Epilepsy Support Centre with helping her family make it through the tough times. "Before Scott's seizures were under control, we'd call the Epilepsy Support Centre daily asking for help. They are the reason that we coped. We wouldn't know how to manage if we didn't have these services. They were an anchor to us in our times of deepest despair and hopelessness."

Mary Ann recalls a period when her son Scott was having 30 seizures a day. His elementary school was worried about both his physical safety and their liability. Mary Ann admits that he wasn't Mr Prince Charming either – he was constantly tired, irritable, whining, and after a seizure he was often aggressive. "The seizures and the drugs that people with epilepsy take to stop those seizures can cause extreme mood changes. Scott's day ranged from sleeping in class to hurting someone." His behaviour was aggressive and out of control, but Mary Ann understood his struggles and would defend him. "Children with brain conditions like epilepsy often have trouble regulating their behaviour. It's not wilful and it is not intentional." Unfortunately, the school and Scott's teachers didn't know how to handle him. The Ross family would receive daily calls from the school asking them to take Scott home.



Above: Scott Ross at Children's Hospital; **Above Right:** Scott at the Epilepsy Support Centre's summer camp

Mary Ann credits the team at the Epilepsy Support Centre for helping her family deal with Scott's school. She and her husband would call the Centre for assistance. "They would meet with our teachers and Principals and help them to understand how epilepsy impacted Scott. When he was suspended for his behaviour they would attend team meetings. They are the reason that Scott is still in school today."

Scott's seizures were a normal part of his life, but not a normal part of life in his community. The seizures would increase whenever Scott would go through a growth spurt or when his medications would stop working. During these times, he would experience spontaneous, dangerous drop attacks and would need to wear a protective helmet. Mary Ann recounts how this would impact the entire family, "We'd be out getting groceries, he would have a seizure, he would crack his head, start crying, people would stare and we'd pack up and go home. The stares can really get to you. People avoided us when they saw us in stores. We felt so isolated in our own community."

Scott bore the brunt of this isolation. He didn't have any friends and, after several

disastrous attempts, Mary Ann was very reluctant to enrol him in community programs. She registered Scott for one program designed for children with disabilities and was told that she needed to send her \$11-per-hour support worker to attend camp with him because of his seizures. "Scott went with his worker; he had a seizure and became aggressive. Pretty normal for Scott. They wrote up an incident report and told us that if it happened again we would need to withdraw him from the program. He was home for good by noon the next day!"

The Ross family was relieved to discover a different camp experience for Scott at the Epilepsy Support Centre. "I didn't need to send a support worker to the Epilepsy Support Centre when Scott went to camp. All of the staff and volunteers were trained to recognize different seizures and to provide the right first aid, so I knew he was safe. They understood his aggressive behaviour and planned activities that reduce triggers that would otherwise escalate his behaviour." The biggest benefit is that camp provided Scott with a social outlet. To this day, his only friends are campers and youth

he has met at epilepsy camp. Mary Ann says that she, too, benefited from summer camp: "it's was a stress free day for me. When you have a child with so many seizures you are glued together 24 hours a day. Getting a break helped me to stay strong"

Mary Ann needed that strength two years ago when the Ross family faced their darkest days. Scott went into prolonged, repeated convulsions that did not stop. The seizures were life threatening, so the epilepsy team at Children's Hospital put him into an induced coma. It lasted for 59 agonizing days. Mary Ann recalls how she felt during this time, "We were told that he may die or become brain dead. Every time they would wean him off the drug that induced the coma, he would start seizing again. Until they could figure out the next step, it was safer to keep him in a coma to minimize the potential brain damage."

Mary Ann turned to a familiar source of support. "I'd go home at night and cry myself to sleep. The next morning, I would call the Epilepsy Support Centre to give them an update. It always made me feel better knowing that they were there to listen. They even came and sat with me in the ICU. They were there for us when the epilepsy team at Children's Hospital decided to do a second brain surgery." That second surgery marked a major turning point in Scott's seizure control. His seizure control is now excellent.

Mary Ann credits the Epilepsy Support Centre and the Epilepsy Program at Children's Hospital for giving Scott a chance to have a future. "We would never leave London. Our family has overcome adversity because of the support and care we have received from the Epilepsy Support Centre and Children's Hospital. We are grateful to live in a community that provides services to families living with epilepsy."

Anti-Epileptic Drug Shortage

During the past two years, we've seen an unprecedented short supply of a number of crucial anti-epileptic drugs (AEDs). Drug shortages have varied from region to region, and even from pharmacy to pharmacy. Some people taking these medications have had difficulty getting their prescriptions refilled, while others have not been affected at all. The shortages have not, by any means, been restricted to AEDs. Certain drugs used to treat infections, psychiatric disorders, cardiovascular disease, cancer and other conditions have also been affected. This is a problem that should concern every citizen, as Health Canada has no system in place to ensure that pharmaceutical companies will alert

medical practitioners and their patients about shortages in time to avoid serious consequences.

In the case of AEDs, these consequences can be particularly severe. A person with well-controlled epilepsy may experience breakthrough seizures if they suddenly stop taking their AED. There is a risk that people whose seizures were previously well-controlled may not achieve seizure control with a different medication or when they resume their regular AED. There are also other very important concerns for people with epilepsy if they experience breakthrough seizures, or a worsening of their seizure control, including injuries, accidents, loss of employment, loss of a

driver's licence, financial hardship and stress on their family and relationships.

Life-threatening seizures are the most serious concern, as any switch to a more readily available medication can trigger massive seizures or even lead to Sudden Unexplained Death in Epilepsy (SUDEP). As its name implies, the causes of SUDEP are not perfectly understood, but the effects of the phenomenon are clear and devastating. SUDEP is responsible for up to 18% of all deaths in patients with epilepsy. As yet, there is no proven method of preventing SUDEP, but neurologists do recommend certain precautionary measures, all aimed at optimizing seizure control. The most important of these is

maintaining steady compliance with the patient's prescribed medication regimen. Unfortunately, this vital and potentially life-saving step cannot be taken without the assurance of continued supplies from the major anti-epileptic drug manufacturers.

These drug shortages have had economic costs as well for the health care system including increased emergency department visits, increased visits to physicians and nurse practitioners, and hospitalizations. Fortunately, it appears that the most recent shortages have been resolved. However, it is not yet clear if this trend and the accompanying dangers are over for the long term.

Thumbs Up for Epilepsy

BY NIKKI PORTER

As Jaime Van Velzen and Jessica Wächter spent a Saturday afternoon devising creative and inventive ways to celebrate Purple Day for Epilepsy, their conversation took a goofy turn. They tried to convince Jaime's husband to wear purple makeup on March 26th to demonstrate his support for people with seizure disorders. As this friendly ribbing evolved from eye shadow to nail polish, Jaime and Jessica realized that purple nail polish applied to people's thumbs is a simple and fun way to raise epilepsy awareness. Thus, their Thumbs Up for Epilepsy campaign was born.



Jaime and Jessica

Anyone can participate and it's easy to buy purple nail polish, set up nail painting booths at schools or offices and encourage teachers, students or office staff to get involved. A person with a single thumbnail painted purple is unusual enough to invite others to ask questions. Participants can explain that it's in support of people with epilepsy, and take the opportunity to spread facts about seizures disorders. Thumbs Up for Epilepsy is more than a way to show support for people living with seizure disorders, it can

start conversations about epilepsy and provide a fun approach to raising awareness.

Jaime and Jessica are both well aware of the need to spread epilepsy awareness, as they are all too familiar with the experience of marginalization that often comes with having epilepsy. Jessica explains that nobody understands it: "People don't know what to do when they see someone have a seizure.

That's why they freak out and call 911. There's too much stigma out there." Jaime also recalls the painful realities of that stigma: "In school, I didn't have friends. People treated me different. They looked down on me and bullied me."

Jaime is now a proud wife and full time mother, deeply involved in her community. Jessica is a veterinarian technologist in St. Thomas and volunteers at animal shelters. The two women's accomplishments have been achieved partly due to better seizure management after each had successful temporal lobectomy surgeries. Jessica had part of her right temporal lobe removed and Jaime's operation resulted in removal of part of her left temporal lobe. They like to joke that between the two of them, they share a whole brain. Perhaps it's this increased brain power that inspired their Thumbs Up for Epilepsy campaign.

3. Teach others that people living with epilepsy deserve to be treated with dignity and respect.
4. Help others realize that people with epilepsy are just like everyone else.
5. Let people who have epilepsy know they are not alone.
6. You will encourage others to self-disclose.
7. You may find out that other people you know also live with epilepsy.
8. Reduce stress. You'll no longer spend energy on protecting your secret.
9. Feel more comfortable with friends, colleagues and acquaintances by building open and honest relationships.
10. Honour how epilepsy has helped define your character.

Bonus Reason: Help your local epilepsy organization. People are more likely to contribute time and money to the Epilepsy Support Centre when they know that our services support someone they care about.

TOP 10 REASONS to Tell Others How Epilepsy Has Touched Your Life

When you tell someone how epilepsy has touched your life, you have the opportunity to challenge any misconceptions they may have about people living with seizure disorders, teach them proper seizure first aid techniques and inform them that epilepsy is a common diagnosis affecting 1 in 100 people. In other words, you are starting a conversation that can change the way they think about seizure disorders. These are just a handful of the many reasons that telling people you are living with epilepsy can benefit you and those around you.

1. Raise awareness.
2. Educate others and bust myths.

Seizure First Aid

1. STAY CALM

Most often, a seizure will run its course and end naturally within a few minutes.

2. TIME IT

If the seizure lasts more than 5 minutes or repeats without full recovery between seizures, call 911. Call 911 if the person is pregnant, has diabetes, is injured from the seizure or if the seizure occurs in water. Call 911 if you are not sure the person has epilepsy or a seizure disorder.

3. PROTECT FROM INJURY

Move sharp objects out of the way. If the person falls to the ground, roll them onto their side and place something soft under their head. If the person wanders about, stay by their side and gently steer them away from danger. When the seizure ends, provide reassurance and stay with the person if they are confused. If the person is still confused 1 hour afterwards, call 911.

**DO NOT RESTRAIN THE PERSON.
NEVER PUT ANYTHING IN THE PERSON'S MOUTH.**

Purple Day for Epilepsy



Tiffany and her family raised a whopping \$1,100 for Purple Day through a bake sale, raffle and partnerships with local schools and businesses.

Nine-year-old Nova Scotian Cassidy Megan told her friends about her epilepsy after a presentation in her class given by the Epilepsy Association of Nova Scotia. At first, Cassidy was afraid the other children would make fun of her, but then she came up with the idea of Purple Day for Epilepsy, where people would wear purple to show support for those living with seizure disorders. Purple Day for Epilepsy is named after the internationally recognized colour for epilepsy, lavender. The colour lavender represents isolation and solitude which is the feeling held by many people with epilepsy. Entering its fifth year in 2012, Purple Day for Epilepsy is celebrated in dozens of countries around the world.

The best way to celebrate Purple Day for Epilepsy is to honour its grass roots origins and organize events in your community. Whether it's simply telling people how epilepsy has touched your life, or organizing a major fundraising event, your efforts will raise awareness about epilepsy and show your support for others living with seizure disorders.

For more information about Purple Day for Epilepsy and activities in your region, visit www.epilepsysupport.ca/purpleday or www.purpleday.org.

We urgently need your support!

If you are receiving this newspaper supplement, you live in a community where the Epilepsy Support Centre provides education, seizure first aid training and support services. **The Epilepsy Support Centre does not receive government funding, nor do they receive funding from Epilepsy Ontario or Epilepsy Canada. Your generous donation will help us to sustain epilepsy education and support in your community.** Please fill out the form below and make your donation today!

NAME: _____

ADDRESS (TO RECEIVE TAX RECEIPT): _____

DONATION AMOUNT: _____

REGISTERED CHARITABLE NUMBER 11890-0802-RR0001

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690 Hale St., London ON N5W 1H4

Online donations: www.epilepsysupport.ca

Choice of three donation options:

Research Education Area of most need

Tax Receipts will be issued for donations over \$10 if full mailing address is provided.



Epilepsy Support Centre

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