

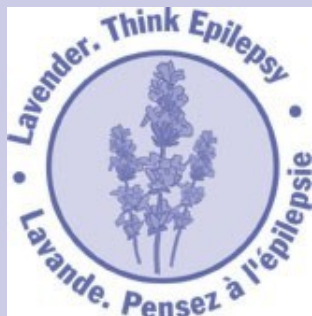
March 2005  
Epilepsy Durham Region  
Salutes National Volunteer  
Appreciation Week

We deeply appreciate the caring and generosity of our dedicated volunteers.

*Giving of your time begins the circle of understanding*

We dedicate this newsletter to you.

Thank You!



EDR Communiqué

## March is Epilepsy Awareness Month

Well, the days have finally begun to get longer once again, and that can only mean one thing—spring is just around the corner! Can you tell I'm not much of a snow person? Now don't get me wrong, I have nothing against those who love snow. I'm grateful for you. In fact, you can have all of my snow too!

With winter moving along, so to comes March and Epilepsy Awareness Month. Although we are busy all year round, it is in March that we go that extra mile to get the word out about epilepsy and seizure awareness. EDR Volunteers and staff have several events and activities planned ranging from health fairs at malls to bowling with Oshawa Generals, we are hoping to reach hundreds and hopefully thousands with our awareness campaign. Keep your radio tuned to 1350am at 7:52 March 8th, and a t.v. interview with Al Nichols on March 9th.

I am often asked about "how can I help," well, here is a perfect opportunity. Our members, supporters and anyone in Durham Region who has been touched by epilepsy—every single person can make a difference. It doesn't take that much time or effort. We live in such a large community that it is impossible for us to visit everywhere. But there are people in your community that want help, support and information.

So I want to issue you a challenge. Will you take just a half hour of your time to help people in your community with epilepsy? Just 30 minutes to help change your community for the better.

Don't think you can do much in 30 minutes? Yes you can! You can place pamphlets from us in waiting areas, put up epilepsy posters in public places, talk to a Brownie or Cub group about seizures, put a notice in your church bulletin for us, or anything else that you can think of. Just imagine how many more people we could reach, if we each gave just 30 minutes.

### Think Lavender Think Epilepsy

*The lavender flower is traditionally associated with solitude, symbolizing the feeling of isolation and seclusion that people with epilepsy and seizure disorders often experience.*

*The lavender ribbon has been adopted by the Epilepsy Foundation of America, Epilepsy Canada and Epilepsy Ontario as a symbol of support for people living with epilepsy.*

Epilepsy Durham encourages you to consider a new twist on an old favourite. How about adding a lavender ribbon to your Casual Friday attire? Many businesses and organizations run dress down days, where a dollar is donated to a non-profit organization for each employee who dresses down. We encourage you and your employees to wear a "lavender ribbon" on casual Fridays throughout the month of March and consider designating Epilepsy Durham Region as your non-profit beneficiary for March. We will happily supply the ribbons and in-service presentations.

For individuals, community groups or clubs wishing to assist us in our Epilepsy Awareness Campaign for the month of March, ribbons are available at a nominal donation. Perhaps your Bridge Club, Curling League or Civic Group would like to participate in our effort to dispel the many myths and misconceptions that continue to surround epilepsy. For more information please call 905-666-9926.

#### IMPORTANT DATES:

**March 12—Bowl with the Generals**



**Family fun afternoon, a silent auction and autograph session. Tickets are \$5 ea. or 4/\$15.00 call EPD @ 905-666-9926.**

**April 25th**



**Tie up those laces and get your sneakers ready for EDR Second Annual Walk-A-Thon. Your pledge form is enclosed.**

#### SPECIAL POINTS OF INTEREST:



Applications are now being accepted for SUMMERFEST 2005. This is a one to two week camp for children & youth ages 7 to 16, who have epilepsy. The camp will be held at Camp Couchiching throughout the summer months. Sponsorship may be available. Applications are accepted on a first come basis. For more information or to apply contact Epilepsy Ontario @ 1-800-463-1119 or access their web site <http://epilepsyontario.org>

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## Advances in Epilepsy—Could Stem Cell Research be the Key?

New solutions for learning and mood disorders caused by epilepsy may be a step closer to reality. Producing more brain cells might help, latest research shows.

Brain injury caused by an acute seizure can prompt the production of new cells, which researchers say is most likely the result of growth factors released from injured or dead brain cells. What remains unclear are the effects of long-term seizure disorder or epilepsy on brain cell development. Addressing these issues, says researchers, is important since both human and animal studies have shown that learning and memory function are affected by epilepsy.

In lab tests, rats with epilepsy produced 64%-81% fewer new cells in the brain's hippocampus region. The hippocampus region of the brain oversees learning, memory and mood.

Coaxing the brain into making up for the shortage could make a difference. "In the future, we could theoretically treat chronically epileptic patients with stem cell factors that induce new neuron production and see if it alleviates their learning and memory problems and depression," says Duke University's Dr. Shetty, PhD.

Shetty, a research professor of neurosurgery, worked on the study with Duke colleagues and experts from Durham VA Medical Centre in North Carolina. Their report appears in the December issue of the journal *Neurobiology of Disease*.

Exercise, enriched environments and antidepressants could also help. "All of these treatments are known to considerably increase adult brain cell production in the hippocampus, says Shetty.

Boosting brain cell production might even curb seizure activity. In Shetty's study, rats producing fewer new brain cells were more likely to have epilepsy. However, it's not just a matter of pumping out the brain cells. There appears to be a fine line between overdoing it and falling short. Sudden seizures can trigger a fast and furious spurt in brain cell production, the study shows. But that wasn't good news.

The rats with sudden seizures couldn't handle all those new brain cells at once. It was too much, too soon. As a result, the new brain cells weren't effectively used and the spurt made matters worse.

Finding the best solution will take more work. Meanwhile, there is promise in the process. "Understanding the brain's long-term response to epileptic injury will enhance our ability to treat the disease," he says. The decline in brain cells may be to blame for the decrease in memory and learning observed in epilepsy.

*Miranda Hitti, WebMD Medical News, January, 2005*

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## Highlights— Upcoming Events for 2005

### March - Epilepsy Awareness Month

Look for our new display booth materials at the Pickering Town Centre and the Oshawa Centre during the month of March. A Public Relations Co-op Student from Durham College will be joining EDR through the months of January to April 2005 supporting our Lavender Ribbon Campaign. Don't forget to wear your lavender and ribbons. Ribbons may be picked up in our office, or pop into a Scotiabank nearest you.

### April - Community Partnerships

Making A Difference One Step at a Time. Sunday, April 24, 2005. Please consider joining EDR and the Oshawa Kicks Soccer Association as we raise funds and awareness for epilepsy. You can register with our office. If you are unable to attend or complete the walk, why not support the many other volunteers by collecting pledges.

### May is Racing Against Drugs Month

EDR will once again be joining this fabulous group to educate students and staff about epilepsy, the appropriate response to a seizure and the importance of playing safe. Last spring EDR volunteers and staff had an opportunity to educate 6200 grade 5 students throughout Durham Region. It is a very exciting week.

### June - Polish up Those Clubs and Swing into Spring.

Our annual charity golf tournament will be held on Friday, June 17, 2005 at Oakridge Golf Club. Last year's event was a terrific success and fun was had by all. We are thrilled to announce that Mr. Joe Tilley of CTV has once again agreed to MC the event. We look forward to another successful and fun day. We have an early bird draw for those paid registered golfers who have registered by April 15th, 2005.

Lora the Lavender Laborador: Available in our office, she makes the perfect Easter gift.

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# A Ten Point Plan

## for Parents, Teachers & Caregivers of Children with Epilepsy

1. If a child has epilepsy there are two possibilities for the future: They may out grow it, or they may not. Ideally, we should act as if they will and make a provision for the eventuality that they do not.
2. Never make epilepsy an excuse for lowering our expectations of their performance!
3. Make sure that life does not revolve around their epilepsy and that we don't use it as an excuse, or a scapegoat.
4. Discuss it with your child, when necessary and make sure they know they have epilepsy and understands what it is. The older they are, the more facts they will be able to absorb.
5. Do not talk about them as if the weren't there, or talk about their epilepsy in whispers or behind closed doors.
6. Help them along the path between timidity and aggression, defeatism and over-ambition.
7. Encourage any activity that improves their self image. Concentrate on what they CAN DO, rather than on what they cannot and assist them to increase their interests.
8. From age 11 or 12, guide them to a choice of career or job that is realistic for them, but do it without stressing their limitations! Persons with epilepsy can and do work in a large variety of occupations.
9. There are 365 days in a year. If your child has an average of one seizure per week, that leaves them 313 days seizure free and capable of living life to the fullest. Encourage them to count the days that are seizure free, rather than those that may be interrupted by a seizure.
10. Their acceptance by the community will then depend on their ability to form relationships, take responsibility as a member of the community, and live a productive and independent life.

Above Guidelines reprinted from The Epilepsy Association of Southern Australia. Even way off in "the land down under" the challenges and concerns of living with epilepsy are the same. We really are in this together!

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## Asked and Answered

**Q.** *Someone suggested I should be wearing a Medic Alert bracelet because of my seizures. Is that important?*

**A.** For people who have epilepsy, we know that when a seizure hits, it can be mighty hard to let anyone know what is going on at the time.

In the confusion and uncertainty, people around you may not understand what is happening, especially if it is a type of seizure that looks unusual, or not like a seizure at all. Seizures have been mistaken for all sorts of things from heart attacks to intoxication, affecting the reaction and response time that a person might get.

So, is it important? Absolutely. Any medical alert bracelet, or necklace or even a wallet card can be very useful in helping a passersby and emergency or health care services quickly identify and respond to your seizure. It can speak for you when you are unable to do so.

Should people wear them? Most definitely. Do people wear them? Sadly, not often. Sometimes people feel that the stigma of identifying one self as having epilepsy is enough to keep it in hiding. But this should not be the case. Perceptions on epilepsy are changing every day and often the stigma we think exists, isn't nearly as prevalent as we imagine. In any case, perceptions should never delay you in getting the help you need, when you need it, as quickly as possible. Please consult with your physician about your need for a bracelet. Forms to order bracelets are available in your local pharmacy and in our office.

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## Lyrice by Pfizer

Pfizer Pharmaceutical announced recently that their new AED Lyrice has been shown in studies to have “significantly reduces the incidences of partial seizures and is well tolerated in patients when used with other treatments for epilepsy.”

The medication, which has been fully approved by the U.S. and hopefully will be soon in Canada, is to be used as an add-on medication for people with seizures. Please discuss this new development with your physician.

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## Food— Substances & Seizures

Food Nutrition: Eating balanced meals with fewer processed foods is recommended. Skipping meals or eating a lot of junk food can affect seizure control.

Did you know ..... High fibre foods can help control fluctuations of blood sugar for people with epilepsy, preventing glucose highs and lows is important. Protein is important in the metabolism of certain brain chemicals and hormones.

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## Switching From a Brand Name Generic Medication? - Read This First!

A survey has revealed that people with epilepsy who are given a different version of their regular drugs can experience an increase in the number of seizures.

Epilepsy is the most common serious neurological condition. About three-quarters of people with epilepsy have their condition controlled with anti-epileptic drugs, or AEDs. These don't cure epilepsy, but they prevent seizures from happening.

However, the results of a recent survey highlight the importance of ensuring the consistency of supply of AEDs. Supply problems can arise with individual manufactures or because of the increasingly common practice of parallel importing, whereby drugs intended for use in other countries are imported into this country.

The survey of more than 1,800 people with epilepsy found that, during 2003, one-third of them were given a different brand of their usual AED. Of these, almost 25 percent said they suffered an increase in seizures as a result. According to Phillip Lee, chief executive of Epilepsy Action, Lack of consistency of supply in AEDs can have a huge impact on people with epilepsy.”

The effects caused by the change in medication on the lives of people who previously had their epilepsy under control can be significant, says the organization, and may result in their driving licence being revoked, adversely affect their school or jobs, as well as increase the risk of premature death.

The need for consistency of supply was highlighted in the National Institute for in the National Institute for Clinical Excellence's Guideline for the diagnosis and management of epilepsy. This stated that “changing brand of AED is not recommended “ and can lead to “increased potential for reduced effect or excessive side effects”.

Mr. Lee advises people with epilepsy who have concerns about different versions of their AEDs to talk to their GP and pharmacist, “as potential problems can be avoided by working together:

*Adapted from Epilepsy Action News, January, 2005*

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### DISCLAIMER

The materials and articles contained in the Epilepsy Durham Region newsletter are not intended to be a substitute for professional medical advice. Always consult your physician, neurologist or health care professional for individual diagnosis and treatment. Articles in our newsletter do not necessarily reflect the opinion or position of, or signify an endorsement by EDR. Epilepsy Durham Region, its employees, board members, medical advisors, volunteers, agents and sponsors do not assume responsibility for inaccuracies or omissions or for the consequences from the use of the information obtained in this newsletter. Epilepsy Durham Region is not liable for any outcome or damages resulting from information in either a direct or indirect form. We recognize that each individual's experience of epilepsy is different. Consult your physician and/or neurologist with any questions you have.

**People with epilepsy should never discontinue anti-epileptic medications or make changes in activities unless specifically advised to do so by an attending physician.**