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March is National Epilepsy Awareness Month

Epilepsy affects 50 million people worldwide.

The focus of Epilepsy Awareness Month is to make people aware of the disorder and promote tolerance and overall understanding for the condition.

2009 represents Epilepsy Durham Region's 22nd anniversary, a time to celebrate our milestones and to kick off Epilepsy Awareness month. On February 24th, 2009, The Golden Griddle, Oshawa, Denny's Restaurant Whitby, Wimpy's Diner, Simcoe Street Oshawa and Diamonds Grill Restaurant in Oshawa will all be hosting Pancake Day in support of Purple Day For Epilepsy, our international event to highlight epilepsy. Oshawa Fire Fighters Local 465 will be serving pancakes at Golden Griddle 8:30—1:30.

Be sure to check our website for updates for the many celebrations throughout the month.

Mark Your Calendar

2008 -2009 Community Events

- Feb 2nd, Epilepsy and Depression - Oshawa Public Library
• Feb 24th, Launch of Purple Day
• Mar 2nd, Living with Epilepsy from My Perspective - Pickering Public Library
• Mar 26th, Purple Day for Epilepsy
• Apr 7th, Epilepsy and Employment - Oshawa Public Library - Legends Centre Branch
• Apr 26th, Annual Walk of Courage
• May 5th, Economic Burden of Epilepsy - TBA
• June 11th, 10th Annual Charity Golf Tournament
• Aug 19th, Annual Gladioli Flower Campaign

Purple Day to Support Epilepsy ~March 26, 2009

Mark your calendar for Thursday, March 26th, 2009 as we celebrate Purple Day.

March 26th, promises to be a fun filled day. Schools and corporate offices are joining EDR as we promote Purple Day For Epilepsy.

It's easy to join in the fun, just wear something purple on March 26th and be sure to let your friends and family know why you are wearing purple. Perhaps your child's school or your office would like to join in. Our goal is to inspire everyone

everywhere to learn more about epilepsy and raise much needed awareness.

Consider hosting a fund raiser , 36,000 people are touched by epilepsy in Durham Region, just think if 36,000 people donated just \$5.00 we could raise \$180,000 during the month of March.

Let us know what you are planning to do, we'll be sure to add your pictures and stories to our website.

www.epilepsydurham.com/purpleday.html

Don't forget to join us for Pancakes on February 24th to kick start Purple Day for Epilepsy.

For more information contact Melissa McBride, our Chief Purple Day Captain, (905) 571-2099.



Annual Walk of Courage ~ Sunday, April 26, 2009

We are celebrating our 5th annual Walk of Courage. So, put on your walking shoes, bring epilepsy out in the open and help us make the 2009 walk for epilepsy the best yet !

In the past four years we have raised \$28,000. These funds support our community programmes such as our Thinking about Epilepsy Outreach Programme and enhances

our ability to advocate on your behalf.

Step out in style and wear our new Epilepsy Matters t-shirt. Please join us to raise awareness and funds.

Make a pledge online or send a contribution in honour of a loved one or register—Registration forms are now available on our website at www.epilepsydurham.com/walk.html

### *International Team Finds Gene Associated with Epilepsy*

**By sharing and analyzing data sets, we realized there was a common mutation in the PRICKLE1 gene in the family members with this form of epilepsy” Bassuk said.**

A University of Iowa-led international research team has found a new gene associated with the brain disorder epilepsy. While the PRICKLE 1 gene mutation was specific to a rare form of epilepsy, the study results could help lead to new ideas for overall epilepsy treatment. In epilepsy, nerve cells in the brain signal abnormally and cause repeated seizures that can include strange sensations, severe muscle spasms and loss of consciousness. The seizures may not have lasting effects but can affect activities, such as limiting a person’s ability to drive. Most seizures do not cause brain damage, but some types of epilepsy lead to physical disabilities and cognitive problems. Medications can control symptoms, but there is no cure.

“The study results were surprising not only because the PRICKLE 1 gene had never been associated with epilepsy, but also because the gene was not associated with any other human disease,” said the study’s lead author Alex Bassuk, M.D. Ph.D., assistant professor of pediatrics at the University of Iowa, Roy J and Lucille A. Carver College of Medicine and pediatric neurologist with University of Iowa Children’s Hospital.

The nine families involved in the study all lived in the Middle East and came from one of three family lines. Of the 47 individuals in the three families lines, 23 had a form of progressive myoclonus epilepsy accompanied by ataxia — a condition that causes imbalance. One family line has been extensively described by Hatem El-Shanti-M.D. The two other family

lines had been researched by Dr. Berkovic, MD at the University of Melbourne in Australia.

“By sharing and analyzing data sets, we realized there was a common mutation in the PRICKLE1 gene in the family members with this form of epilepsy,” Bassuk said.

Bassuk and colleagues are now developing other animal models to investigate how PRINKLE1 gene is involved in epilepsy and are investigating whether PRICKLE1 mutations are involved in the general population of patients with epilepsy. With that information, there is potential to develop new drugs for people with different forms of epilepsy in the general population, as well as for the study participants with the disease.

For full article view *Medical News Today* November 19, 2008

**The overriding objective of epilepsy treatment is to achieve complete control of seizures, allowing the patient to maintain a normal life, with minimal or limited adverse drug effects.**

### *Experts Propose Minimum Standards of Care for Epilepsy*

Leading epilepsy specialists met recently at the American Epilepsy Society’s annual meeting in Seattle to unveil a recently published consensus report that proposes minimum standards of care for diagnosing, treating and monitoring epilepsy. Primary among these is the need for a detailed medical history, neurological examination, discussions with caregivers and diagnostic tests to make a diagnosis, as well as the need to weigh seizure

control, side effects and long-term safety when making treatment decisions.

The overriding objective of epilepsy treatment is to achieve complete control of seizures, allowing the patient to maintain a normal life, with minimal or limited adverse drug effects. The panel agreed that antiepileptic drug (AED) treatment should be initiated after two seizures. Currently, AED therapy is the initial treatment of choice for most patients and, in general,

long-term seizure freedom can be achieved by approximately fifty percent of patients with initial monotherapy. Several areas should be considered when selecting the appropriate AED therapy, including seizure type, co-existing conditions and drugs. Adverse events and tolerability should be carefully monitored and changes made when appropriate.

When a patient has not responded to treatment they are considered refractory (the failure of two or more AEDs);

## Introducing Nathalie Holroyd Youth Ambassador

Hi, my name is Nathalie Holroyd. I'm eighteen years old and I attend Trent University. I am majoring in English and minor in Sociology. I have epilepsy. I have three siblings, a boyfriend, and great friends. I enjoy reading, writing, traveling, photography, and trying new things. Out of everything I said, I can already guess what would stand out. But that's okay, because I have chosen to accept epilepsy as a part of my life, and include it in any introduction that I please.

Although it can be incredibly difficult at times living with epilepsy, I try to make it work for me. When I was first diagnosed, I became very depressed, because seizures took so much out of me and I hated going out to places, especially alone, for fear of having a seizure in public and being so vulnerable. But now, I try to spin it in a positive way. Believing that I am

strong enough to deal with it and that maybe I can use it as a strength and a way of empowering myself, as difficult as it can be. I believe I've always been an optimistic person and I tend to live on finding the light in the dark. I know for some people it seems as though things will never get better, especially when it comes to epilepsy, but I cannot impress enough that eventually it *will* get better. You will honestly find a way to make epilepsy not a huge part of your life, you won't *let it* become a huge part of your life. You have to keep telling yourself that **YOU** have epilepsy, epilepsy is **not** in control.

Sometimes I wonder what life would be like without it, and it would probably be a little less complicated. I do hope that someday there will be a way to conquer epilepsy, for myself and for others. But in the meantime,

I can live with it, because I know that I can remain in control over my seizures; and the people around me may not understand what I'm going through, but they care for me and can help me along the way. I recently found a quote which expresses the ideals that I try to impress upon myself, especially when it comes to epilepsy. I honestly hope that one day, everyone can try to conquer epilepsy for themselves, and so that they can live life the way they want to, and not let epilepsy get in the way.

*"There is no despair so absolute as that which comes with the first moments of our first great sorrow, when we have not yet known what it is to have suffered and healed, to have despaired and have recovered hope".*

**George Eliot**

To read Nathalie's full story, visit [www.epilepsydurham.com/volhigh.html](http://www.epilepsydurham.com/volhigh.html)



Nathalie Holroyd  
Youth Ambassador  
Epilepsy Durham Region

*"I encourage you to become involved, Purple Day is the perfect way to highlight this disorder.*

*Champion your cause like never before".*

***"You have to keep telling yourself that YOU have epilepsy, epilepsy is not in control".***



**What are you doing for Purple Day For Epilepsy, March 26?**

**Let us know and we'll post it on our website!**

[www.epilepsydurham.com](http://www.epilepsydurham.com)

## Experts Propose Minimum Standards of Care for Epilepsy cont'd

therefore physicians should refer patients to an epilepsy specialist. The ketogenic diet should be considered as a treatment option in pediatric patients after the failure of two to three or more medications or in cases of intractable seizures, but only if the family is committed to following the plan and other appropriate treatments have failed.

The panel also agreed that periodic evaluations to assess seizure frequency are necessary and monitoring for adverse events and tolerability

should occur at each visit. Common adverse events to look for include: cognitive slowing or difficulty concentrating, skin and hair changes, emotional or mood changes, involuntary muscle movements, double vision, drowsiness, fatigue and weight change.

While undergoing AED therapy, clinicians should be prepared to counsel patients regarding adverse events, co-existing conditions, driving, medication adherence, plan for seizure emergencies, bone

health, safety during recreational activities, seizure frequency, drug-drug interactions, cognition, sleep problems, occupational considerations, behavioral issues and effects and limits of physical activity.

The report was published in *Current Medical Research and Opinion Journal* in November, 2008.

To view the full report, visit [www.informapharmascience.com](http://www.informapharmascience.com)

## Epilepsy Durham Region — Building Healthy Communities

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### Important Change of Address Notice —

To reduce agency costs of newsletters returned due to incorrect addresses, please keep us informed of any change to your address.

Many thanks to the donors to the United Way for sending us donor choice contributions. If you would like to make a gift and support epilepsy, please indicate on your UW donation form and include our name in full, Epilepsy Durham Region and our charitable number: 89670-5399-RR0001

## Who is Epilepsy Durham Region?

Epilepsy Durham Region is a registered, not-for-profit health organization incorporated in 1987 and is solely dedicated to strengthening clients' and families' ability to manage the physical, psychological and social effects of epilepsy.

Seizure control is the first step in treatment but not the only step. Even when seizures are well controlled, individuals with epilepsy may still experience difficulties with self-esteem, learning, behaviour or social adjustment. The challenge therein lies for those whose seizures are not controlled by medication or who experience unacceptable side-effects, and invasive treatments.

Epilepsy Durham Region endeavours to work in partnership to ensure respect and improved quality of life for those living with epilepsy.



Epilepsy Durham Region

### Make Every Day Better

Your generosity can transform the lives of people with epilepsy.

We are working diligently to make a difference but only your financial support will enable us to provide advocacy and programming for those with epilepsy.

In 2008 Epilepsy Durham Region launched our appeal campaign to its 320 members.

Six percent renewed their membership and 3.5% made an additional donation beyond their \$10.00 renewal. This represented \$210.00 raised through our membership.

More than ever EDR needs your support. In 2008, we experienced a 97% increase for front line services.

Just think if 36,000 people donated just five dollars each that would mean we could raise \$180,000 in just one month. The possibilities are endless.

Your support makes all the difference. We can raise even more when you spread the word. Tell your friends. Wouldn't that make a fabulous Epilepsy Awareness Month supporting 36,000 people touched with epilepsy in Durham Region.

Cheques can be mailed to:  
850 King Street West  
Unit 20 Oshawa,  
ON L1J 8N5  
(905)571-2099

Attention:  
**Epilepsy Awareness Campaign**

A special Thank You to Hbc. If you would like to donate your Hbc points to EDR please visit ...



[www.hbc.com/HBCREWARDS/program/community](http://www.hbc.com/HBCREWARDS/program/community)

Thank You!

**EPILEPSY**  
*matters*

get the facts

[www.epilepsydurham.com](http://www.epilepsydurham.com)

**EDITOR'S NOTE:** Our newsletter and education meetings provide a range of information which does not necessarily reflect the views of our agency. Please use your discretion and consult your physician.