

September 2005

Congratulations to Joshua Lusaile for winning our August Jelly Bean contest.

Kudos to the Coleman family for raising \$101.02 at their hotdog/garage sale in July and supporting EDR.



EDR Communiqué

FALL 2005



Now that those hazy, lazy days of summer are just about over, it's time to get back into the swing of things. Epilepsy Durham Region has had a very busy spring and summer and is excited to share the news with you. So here we go...

Living Well with Epilepsy... A Parent's Forum

Epilepsy Durham Region launches new Parents Forum. This new informal group entitled "Living Well with Epilepsy: A Parent's Form" will meet monthly to encourage one another and share successes. This initiative allows parents and caregivers to meet peers, make connections and learn from those who have gone through similar experiences.

Meetings will be held the first Tuesday of each month commencing October 4th, 2005 and will be held at the Village of Taunton Mills Oakwood Retirement Communities Inc. found at 3800 Brock Street North, Whitby between 1:15 and 3:00 p.m. This group will be facilitated by Volunteer Laura Armstrong, who brings a wealth of experience and compassion to our organization. If you would like to join this forum please contact our office. Registration is required.

Introducing Epilepsy Durham Region Silicone Wristbands



No doubt you have seen the latest trend of the very fashionable wristbands supporting various charities. This very hot summer has proven to be a very successful time for many who have made these charming bracelets available to their members. Not to be undone, EDR is pleased to announce that lavender wristbands are now available. Thank you to the many of you who have ordered wristbands, we had completely sold out of our first order and are currently on a second order. Each band carries the message which reads "Out of the Shadows" in reference to the World Health Organization's universal campaign for epilepsy and includes the website www.epilepsymatters.com information. This is an exciting opportunity to heighten the awareness of epilepsy in our community, they encourage conversation and meaning. If you would like to order these bracelets please contact our office. We would be happy to mail them to you; please add \$1.00 mailing fee to your order. Larger orders may be picked up at the EDR office.

Prices:

1 Bracelet for \$5

2 Bracelets for \$8

3 Bracelets for \$10

IMPORTANT DATES:

- **ANNUAL GENERAL MEETING—**
WEDNESDAY, NOVEMBER 16TH, 2005
7:00 P.M.
THE VILLAGE OF TAUNTON MILLS OAKWOOD
RETIREMENT COMMUNITIES INC.
3800 BROCK STREET NORTH, WHITBY
- **MEMBERSHIP RENEWAL —**
OCTOBER 31ST, 2005

SPECIAL POINTS OF INTEREST:

- EDR Lunches New Forum
- Lavender Wristbands Arrive in Durham Region
- New Epilepsy Questionnaire to Take to your Doctor
- EDR Launches New Website, Stay tuned for more details
- The Weekend Getaway for Young Adults

DID YOU KNOW?

THE GENE DISCOVERY PROJECT

The Epilepsy Foundation of America has launched a project focused on learning about epilepsy and genetics in order to further understand the role of genetics in the development and treatment of epilepsy. Participation is completely voluntary, however, you must be 18 years of age and have an e-mail address in order to participate. At least one member of your family must have epilepsy. If you would like more information you can visit the Epilepsy Foundation of America website: www.epilepsyfoundation.org/gene/.

New Book Available:

Complementary and Alternative Therapies for Epilepsy, edited by Orrin Devinsky, MD, Steven C. Shachter, MD, and Steven V. Pacia, MD.

This book is perfect for those physicians, knowledgeable laypersons, and other professionals looking to bridge the worlds of traditional medicine and CAM to foster better personal healthcare.

<http://www.demosmedpub.com/book183.html>

Golf Tournament A Tremendous Success.

Hats off to the many Volunteers and participants who supported EDR's 6th Annual Charity Golf Tournament. For a complete list of supporters, please turn to page 5. This event raised \$16,000.00 supporting outreach education programming for EDR.

A very special thank you extended to CIBC Imperial Service, Great Blue Heron Charity Casino, S. McWade and Associates Ltd., Menzies Chrysler, Canadian Premier Life Insurance, and Terry Johnson, CKDO 1350 AM Radio. These corporate sponsors truly deserve our applause and gratitude; it is only with their continued support and belief in our organization that we can continue to meet the growing needs of those living with epilepsy in our community.

The first place foursome of the tournament included Iain Adamson, Dave Gwyn, Jason Bailey and Steve Tuck. This is the third year in a row that Iain has won this event. Congratulations to Iain and his foursome and to all other winners.

Everything Coming Up Glads...

Once again this event has proven to be very successful for our organization. Through grants from HRDC and Immigration and Tourism we were in a position to hire two students to lead this project. More than 50 Volunteers stepped forward to support this very exciting project.

Special thanks are extended to Mike at Sobey's who donated all of the materials for our Volunteer appreciation luncheon on July 11th, along with Penny at Panago Pizza in Whitby. At great time was had by all. More than 100 corporate offices supported this event; new to the event this year was our point of purchase locations. Not only did this increase sales, but more importantly we were able to heighten the awareness of epilepsy at three major locations in Durham Region, the Pickering, Whitby and Oshawa Go Stations representing 41,000 Go Station riders who saw our signs and the word "Epilepsy" along with two medical clinics in Ajax and Oshawa. " The ultimate goal of these events is to provide education and awareness, often folks stop by just to talk and request information for a loved one.

As our Students return to school, we wish them every success and thank them for their commitment and passion which they brought to our organization. We look forward to hearing from them.

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.

EDR Members request information on the use of Marijuana to manage seizures.

New Rules Streamline Application Process for Marijuana for Medical Purposes

We have received many enquires from members with regards to the medical used of marijuana. Epilepsy Canada has provided the following information for those interested in this treatment.

“Changes to the Marijuana Medical Access Regulations will now make it easier for Canadians to apply to access marijuana for medical purposes, says Health Canada. Since 2001, the Federal regulations have provided a legal means to access and cultivate marijuana for medical purposes. Based on public input, important amendments to these regulations have recently been approved by the Federal government.

The new rules will be of interest to individuals with terminal or serious illness, as well as physicians, pharmacists and law enforcement officials. Applicants and their treating physicians will benefit from easier-to-follow, streamlined processes governing the use and production of marijuana for medial purposes.

The amended regulations have reduced the number of categories for those who apply for this course of treatment from three to two categories. Category 1 now refers to applicants with a terminal illness, as well as those suffering from specific symptoms associated with certain medical conditions including multiple sclerosis, spinal cord injury, spinal cord disease, cancer, AIDS/HIV infection, severe arthritis and epilepsy.

Applicants in the new Category 1 will no longer need to see a specialist for the sole purpose of having their application signed. The new Category 2 is now for applicants with symptoms associated with all other serious medical conditions, other than those described in Category 1. For those in Category 2, an assessment of their case by a specialist is still a requirement, but the treating physician, whether as specialist or not, can sign the application form.

The application and renewal process have also been streamlined, making it easier for patients and their treating physicians to complete the required forms. A short form renewal application has been introduced that can be used if there have been no changes in the applicant’s condition since the previous year. Also, to simplify the process, a new photo will be required every five years instead of every two.

Applicant declaration and medical declaration forms have been revised as well. Applicants are now required to acknowledge acceptance of risk and physicians are no longer required to make a definitive risk-versus-benefit statement about the medial use of marijuana.

In addition to the streamlined processes and simplified forms, Health Canada now has explicit authority to communicate specific non-medical information to Canadian Police about individuals, if asked, in connection with a law enforcement activity. This will help avoid unnecessary action by law enforcement. Moreover, the amended regulations now gives Health Canada authority to explore the feasibility of distributing the government-source of dried marijuana through pharmacies”.

To obtain more information about the amended regulations, visit Health Canada’s website (www.hc-sc.gc.ca/hecs-sesc/ocma) or call toll free: 1-866-337-7705.

Membership Renewal Due October, 2005

Epilepsy Durham Region membership renewal is due. For administrative ease all annual memberships are now due on October 31st, 2005. We are please to announce that our annual membership rate has not been increased and remains at \$10.00. Membership dues can be paid by cash or cheque made payable to Epilepsy Durham Region. So *what do you get for your \$10.00 membership?* Read on and you will soon realized that membership has its privileges.

An annual membership with Epilepsy Durham Region includes:

- Subscription to "Communique" the EDR newsletter delivered at your home on a quarterly basis
- Voting rights at the Annual General Meeting held each November
- Access to our many library resources, including books, research documents, videotapes and CDs
- Borrowing rights to our lending library
- Individual, corporate and in-school support, first aid for seizures
- Subscription to "Sharing" a magazine produced by Epilepsy Ontario

As a non-profit organization, we rely on external financial assistance to maintain the education and member services that we provide. As some of you may know EDR does not receive government assistance nor United Way funding. One source of funding that we rely on is the revenue generated through membership dues. The dues assist us in the delivery of this newsletter, and also in providing awareness and educational services throughout the community.

GOOD THINGS:

Thank you to the many members who have stepped forward to support one another. Often those living with epilepsy feel isolated and alone. Through our telephone support system, many members are meeting other folks, sharing experiences and successes. If you would like to be added to this amazing group of individuals, please feel free to contact our office. Only those who have given written permission to EDR will have their name released.

UNITED WAY:

If you plan to contribute to the United Way fall campaign and would like to donate your funds to support Epilepsy Durham Region, please indicate on your pledge form our full name as Epilepsy Durham Region, this ensures your donations remain in your local community.

Weekend Getaway for Young Adults: September 24-25th, 16-24 years of age.

This retreat is intended for young adults who are living with epilepsy; however siblings and friends may also attend. Please contact Epilepsy Ontario at 1-800-463-1119 for more information.

THANK YOU BANNER

JUST SOME OF THE FOLKS WHO HAVE BEEN SO KIND TO THOSE
LIVING WITH EPILEPSY

OFTEN GREAT GOOD IS BORN OF ONE ACT OF KINDNESS.

Scott Petrie at S & K Technologies, Panago Pizza Whitby, Mark's Work Wearhouse, Sobey's, Go Transit, The Village of Taunton Mills Retirement Communities Inc.



Epilepsy Durham Region

Sixth Annual Charity Golf Tournament

A very special thank you is extended to the following for their continued support for those living with Epilepsy.

*Often Great Good is born of one act of
Kindness*

CIBC Imperial Service

Great Blue Heron Charity Casino

The Municipality of Clarington

Baagwatting Community Association

S. McWade & Associates Ltd.

Menzies Chrysler

Canadian Premier Life Insurance

Quiznos Sub, Whitby, Oshawa
McDonald's Restaurants of Canada Limited
Salmers Stike & Furlong
Medwell Mowat & Fennell Insurance
Dr. Stan Fenwick
Patheon Whitby Inc.
Mark F. Seetner, Barrister & Solicitor
Window Bars Lock Inc.
Palm Beach Mega Tan
Oshawa Community Credit Union
Sleeman Breweries Ltd.
Sam's Club, Pickering
Golf Newcastle
Gus Brown Pontiac Buick GMC Ltd.
White Home Hardware
Canadian Tire, Oshawa & Whitby
Sun Life Financial
Staples Business Depot, Ajax & Oshawa
FNF Canada
A Division of Fidelity National Financial
Accuwrap Ltd.
Travelodge Hotel, Toronto Airport Location
Madgett, Roberts, Marlowe, Jackson & Associates

d'elegant el stavros
Hardiman Mount & Associates, Insurance
Brokers Limited
Can Save Realty Inc.
Purolator
Russett Auto Service
Mt. Kirby Skis & Boards
Oshawa Ski Club
Marigold Ford Lincoln Sales Limited, Whitby
PP Print & Digital Services, Port Perry
Shoppers Home Health Care
Hands in Motion
Oakridge Golf Club
Kirby Snow School
BWI Limousine
Golf Town
Mr. Walter Beach
Children's Technology Workshop
Molson Canada
Rogers Video
Tim Hortons
Ontario Science Centre
Diversified Ulbrich
Canadian National Exhibition
Armstrong Funeral Home Ltd.
Archibald Orchards & Estate Winery
Reid's Dairy
Winmar Durham Property Restoration
Specialists
The Durham Celtic Club
Assante Capital Management Ltd.
A Caring Volunteer
The Honest Mover
Abco Roofing and Sheet Metal
David Goodaire, Barrister & Solicitor
Deister Electronic Inc.
Mincom First Realty
Great Lake Beers
Via Rail

Ontario Place Corporation
Rossland Chiropractic Associates
Bonded Cleaning Services
Dennis McIvor
Edward Jones Investments
Ballantrae Golf and Country Club
Clarica Sun Life Financial Company
Oshawa Kicks Soccer Club
Dave Sansom Insurance &
Annuities
Armoured Courier Express
Class Act Dinner Theatre
Paramount Canada's Wonderland
The BDO Dunwoody LLP
Collins Fluid Power Sales Ltd.
Baker Animal Clinic Professional
Corporation
Beckford Service Centre (Bays)
TD Waterhouse Canada Inc.
Munroe Auto Glass Inc.
Buffet Taylor & Associates Ltd.
Vickery Electric
William Saunders
Telecomp Systems Inc.
Fabutan
The Putting Edge
Royal LePage
Nascom
Hard Copy Solutions
The Best Western, Oshawa
Select Autoglass
The Nestle Group
Art Gallery of Ontario
The City of Ajax
Walmart Inc.

STUDENTS SAY THANKS TO EDR

Each spring thousands of grade five students from both the Durham District School Board and the Durham Catholic District School Board attend "Racing Against Drugs" a community-based drug and alcohol awareness program developed by the RCMP and presented annually since 1998. Racing Against Drugs is designed to promote healthy drug-free lifestyles through the implementation of a school curriculum and a visit by the students to the event. As we know one of the known causes of epilepsy is a brain injury, our presentation focuses on how we can prevent a head injury, first aid for someone experiencing a seizure and what epilepsy is. During the past two years we have educated more than 12,000 students, teachers, and parents on how they can support someone experiencing a seizure.

Our fun and interactive presentation enables students to feel confident that they could assist one of their classmates and addresses changing attitudes about epilepsy. This summer EDR received positive feedback from students; they include:

"Dear Epilepsy Durham

On Tuesday May 3rd our class from Pringle Creek P.S. attended RAD. One of our pit stops was Epilepsy Durham. We really liked it when we played the game where you made us do things really fast. We learned that if you have a seizure you should never put anything into the persons mouth. Thank you, Billy".

"Dear Epilepsy Durham

On Tuesday May 3 our class attended RAD. One of our pits stops was Epilepsy Durham. We really liked hearing about Epilepsy and learned that it is really important to wear a helmet for sports. We also learned about the effects of drugs, smoking and alcohol, but the most important thing was that we got to experience a seizure. Sincerely Christopher"

Epilepsy Durham Region Board of Directors, Volunteers and Staff are committed to education and heightening the awareness of epilepsy in Durham Region. We will continue to participate in Racing Against Drugs and other health promotion programming. We extend our appreciation to the Volunteers who assisted us at this week long event.

VOLUNTEER OPPORTUNITIES: Can you make a difference in your organization?

EDR is looking for Volunteers to assist with various up coming projects. Are you interested in assisting with our Bingo games? Bingo is the primary source of revenue for our organization. We really could use the help of three dedicated Volunteers. We promise to make it fun and just think of the new folks you will meet. Perhaps this could be a family Volunteer opportunity for you. **Please call if you can help.**

We are always open to suggestions and looking for newsletter ideas, if you have any ideas that you would like to share to improve this publication, please do not hesitate to contact us with your comments. Please send your ideas to info@epilepsydurham.com We thank the Victoria Epilepsy & Parkinson's Centre for the article on Epilepsy Questionnaire and your Doctor.

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

