

JUNE 2005

Congratulations to Leslie Dunlop in winning the jellybean contest at our bowling event.

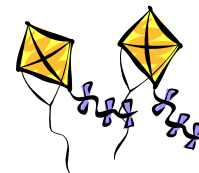
Congratulations are also extended to Arnold Clarke for winning the fabulous gift basket for raising \$566.00 for our 2nd annual walk-a-thon. Three Cheers for everyone who participated



# EDR Communiqué



## SPRING HAS SPRUNG



Now that Spring is here and summer is on its way, we can look forward to the green grass, to the smell of the lilacs and blooming flowers, to the warm sunshine and eating ice cream cones.

Epilepsy Durham Region extends a very warm welcome to our 26 new members who have joined our organization throughout March Awareness Month. Epilepsy Durham Region provides non-medical support services, education and awareness to people with epilepsy and their support network throughout the region.

We extend farewell and special thanks to Mr. Don Hand. Don has volunteered with EDR for several years facilitating the adult support group. We wish him well on the new chapter of his journey. Members will be contacted when group will resume.

### A few words of wisdom... The \$20 Bill

A well-known speaker started off his seminar by holding up a \$20 bill. In the room of 200, he asked, "I am going to give this \$20 to one of you, but first, let me do this. He proceeded to crumple up the \$20 dollar bill. He then asked, "who still wants it?" Still the hands were up in the air. Well, he replied, "what if I do this?" And he dropped it on the ground and started to grind it into the floor with his shoe. He picked it up, now crumpled and dirty. "Now who wants it?" Still the hands went into the air.

"My friends, we have all learned a valuable lesson. No matter what I did to the money, you still wanted it because it did not decrease in value. It was still worth \$20. Many times in our lives, we are dropped, crumpled, and ground into the dirt by the decisions we make and the circumstances that come our way. We feel as though we are worthless. But no matter what has happened or what will happen, you will never lose your value. Dirty or clean, crumpled or finely creased, you are still priceless to those who **DO LOVE** you.

The worth of our lives comes not in what we do or who we know, but by **WHO WE ARE**. You are special—Don't **EVER** forget it." Count your blessings, not your problems. And remember—amateurs built the ark...professionals built the Titanic!

**"He who is devoid of the power to forgive is devoid of the power to love."**

Dr. Martin Luther King, Jr.

#### IMPORTANT DATES:

Friday, June 17—Epilepsy Durham Region's Annual Charity Golf Tournament will be held at Oakridge Golf Club. If you wish to enter a foursome, please contact Epilepsy Durham Region at 905-666-9926 for more information.

Gladioli Flower Day—Stay tuned for Mother Natures' say so...(August, 2005)

#### SPECIAL POINTS OF INTEREST:

- Eastview Boys' & Girls' Club hosts 2005 Summer Camps this summer. If you happen to be an alumni member of the Club —please contact MaryJane at 905-728-5121 extension 301.
- **Seizure & Epilepsy Education Program.** June 11th & 12th, London, Ontario. Pre-registration is required. For more information contact Epilepsy Support Centre at 519-433-4073.

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# News from Epilepsy Canada

## WORK PLAN—Education and Support Services 2005

Epilepsy Canada has given top priority during the next twelve months to developing brochures/literature on the following topics to include:

- Women & Epilepsy
- Epilepsy, Employee, Employer
- First Nations and Epilepsy

Epilepsy Canada will be working on other projects that will include:

- Updating Epilepsy Canada's Web Site with the possibility of adding a map finder
- Tele/conference Web-Cast Nationwide
- Canadian Statistics Update
- Research Fellowships
- Scholarships for students with Epilepsy
- Advocacy for people with Epilepsy
- Support to Member Associations and Creation of Support Groups in Remote Areas
- LUMINA Publications

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### EPILEPSY AWARENESS MONTH—MARCH 2005

A very special thank you is extended to the many volunteers who supported our educational fairs throughout the Region. Only through education and working together will we eradicate the stigma of epilepsy.

### THE POWER OF KNOWLEDGE

ERD has been tirelessly working on educating the general population about epilepsy and seizures. Throughout 2004 7200 students learned the appropriate response to a seizure. As well, we continue to educate employers and their staff. We were very excited to present our educational materials to 160 school bus drivers, driving both in the Durham and Toronto Boards of Education this past fall.

### VOLUNTEERS MAKING THE DIFFERENCE AT EDR

During the week of April 12-17th we as a nation celebrated Volunteer Appreciation Week. EDR is supported by a team of dedicated volunteers and one staff person. I personally would like to thank each and everyone of the EDR volunteers for their kindness and support to this organization. You are an inspiration to many living with epilepsy and for that we thank you.

**Calling All Gardeners / Students needing your Community Hours and enjoy working outside. We are looking for volunteers who would like to cut the grass and rake the garden. Please give us a call if you would like to help.**



### SECOND ANNUAL WALK-A-THON

Through rain and blustery winds 20 members of EDR attended our Walk raising \$2,616.00. This event is sponsored and coordinated through a partnership with the Oshawa Kicks Soccer Club which benefits EDR. 100% of funds raised through EDR members is donated to EDR. This is an opportunity for members to meet and share an afternoon of family fun and support their organization. EDR does not receive United Way nor government funding, making events like our walk vital to meeting the needs of 12,000 individuals living with epilepsy in Durham Region.

### 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. Please contact our office if you would like to join us for the day.

### AUGUST - EDR ANNUAL GLADIOLI FLOWER DAY.

Mother Nature will let us know the exact date of the Glad Day. Be sure to order your bouquets, or let us know if you would like to volunteer for this event.

Volunteer to coordinate Glad Day at your office and be entered into a draw for a prize.

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# Marijuana Compound May Intensify Epileptic Seizures

Researchers with the University of Saskatchewan's Neural Systems and Plasticity Group have found that although a component of marijuana suppresses grand-mal type epileptic seizures in rats, it may intensify the severity of the most common seizures— those starting in the temporal lobes of the brain.

Epilepsy is conventionally treated with anticonvulsant drugs that can cause nausea, headaches, hair loss, swollen gums, impotence, depression, liver failure and in some cases, psychosis.

Some people with epilepsy who can't tolerate these medications use marijuana or cannabinoids (synthetic form of THC—the psychoactive ingredient of cannabis) to control seizures—with no previously identified side effects. Initial findings from a U of S study suggest that in some cases, cannabinoids may do more harm than good.

With funding from the Canadian Institute of Health Research and the Saskatchewan Health Research Foundation (SHRF), group leader Michael Corcoran is using rats to study the effects of a new generation of cannabinoid drugs on “kindling” - a small electrical stimulus in the brain that triggers a burst of epileptic—like activity that eventually generates seizures.

Discovered in Canada by Graham Goddard at McGill University in the 1960's, kindling works in a way similar to epilepsy and is one of the best models for studying temporal lobe seizures.

“The brain is caught in a constant tug of war maintaining a balance between factors that excite electrical activity and those that restrict it,” says Corcoran. “So to protect itself, it relies on built-in systems that act as firewalls, limiting the spread of electrical activity.”

During a seizure, the firewalls crash and electrical discharges spread in abnormal patterns to groups of neighboring cells, causing a storm of intense synchronized electrical activity that can manifest itself as convulsions. After two seizures, a person is diagnosed with epilepsy.

Kindling is a simulation of that same kind of electrical firestorm. To induce kindling, Corcoran's team applies a low current (about 20 microamperes of one one-millionth of an amp) to a specific site in a rat's brain for about 120 milliseconds. With repetition, the electrical discharge spreads from cell to cell and the brain is permanently changed in a way that resembles epilepsy's electrical activity.

In Corcoran's study, kindling gets worse when the rats are given compounds that act at the same cellular receptor as THC. He thinks that may mean the cannabinoid compounds increase epileptic seizures by reducing inhibition in the brain and drastically increasing excitatory electrical activity, but more research needs to be done before he can explain exactly what's happening when epileptic mechanisms affects brain function.

**For more information, contact:**

**Professor Michael Corcoran**

**Anatomy and Cell Biology**

**University of Saskatchewan (306) 966-4079**

**Kristina Bergen**

**Research Communication**

**University of Saskatchewan (306) 966-1425**

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# Canadian Statistics on Epilepsy

**Prevalence:** Epilepsy is much more frequent than commonly assumed, affecting approximately 0.6% of the Canadian population.

**Incidence:** The estimated incidence rate of epilepsy in Canada is estimated to be similar to that in other developed countries, that is, 50 new cases per 1000,000; the incidence is estimated at 15,500 new cases per year in Canada.

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## Health Canada

**“Safety Data Ordered on Seizure Drugs to Check for Suicide Link” April 22, 2005 The Globe and Mail**

By Andre Picard (Excerpt from article) For full article go to [www.theglobeandmail.com](http://www.theglobeandmail.com)

Health Canada has ordered more than a dozen pharmaceutical firms to provide more safety data on their anti-seizure medications amid growing fears that patients who use the drugs could be at increased risk for suicide.

Jirina Vlk, a spokesperson for Health Canada, said safety data on 23 different products—many of which have several manufacturers—are being analyzed.

The safety analysis is expected to take about six months and after the suicide risk is determined, “Health Canada will take appropriate action if deemed necessary”.

In the meantime, Ms. Vlk said, patients should continue to take their drugs as prescribed and discuss any concerns with their physician.

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## A Message from ACCESS

### **(Action Committee on College Education for Students with Special Needs)**

The Action Committee is looking to hear from parents with students entering their post secondary school year. In the near future, committee members will be presenting a proposal to administrators at Durham College for the establishment of a CICE program. It is their intent to convey the need for a program of this kind in Durham Region. They need to show that there is support for this type of program from families and young adults who would be interested in its development. The committee members are asking you to provide a letter of support for this initiative. It is their hope, that together, we can make this dream of post secondary educational opportunities for individuals with special needs in our community, a reality.

Letters can be sent or e-mailed to: Kathy Payne-Mercer, [mercerc@inerlinks.net](mailto:mercerc@inerlinks.net)

Alayne Korczynski, [alamoe73@idirect.com](mailto:alamoe73@idirect.com) or 43 Cawker’s Cove Road, Port Perry, ON L9L 1P6

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We are always open to suggestions, 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](mailto:info@epilepsydurham.com)

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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.**