



To support independence, quality of life, and community participation for people with, and affected by, epilepsy.

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Camp Fireworks Summer Camp especially for Kids & Teens with Epilepsy

Presented by Easter Seals Camp Horizon in partnership with the Epilepsy Association of Calgary presented on August 18-23, 2014 for Kids & Teens 7 to 17 years old.



EMPOWERING PEOPLE WITH DISABILITIES

Subsidies available for families in need!

An overnight camp filled with new adventures and new friends, all in a safe environment with nursing staff on call 24/7. Imagine not being “the kid with epilepsy” for an entire week!

A great place for kids to not let epilepsy hold them back from new experiences and memories. Camp staff are specially trained to support campers who live with epilepsy and give them the time of their lives.

Activities available for campers include: high ropes obstacle courses, giant swing, climbing wall, archery, river rafting, horseback riding, swimming pool, hiking, mountain biking, arts and crafts.

For more information, contact Michelle at 403-230-2764 / michelle@epilepsycalgary.com

To register for the camp or to inquire about subsidies, please call the Camp Registrar at 403-949-3818.



Calgary Marathon Join Team Epilepsy!

Walk or Run in the Calgary Marathon on June 1, 2014 on behalf of the Epilepsy Association of Calgary.

The Epilepsy Association of Calgary is proud to be an official charity for the Calgary Marathon - Charity Challenge in 2014. The Charity Challenge gives participants an opportunity to raise funds for EAC as a Calgary Marathon participant. There are a number of races you can sign up for including:

- Full Marathon (42.2 km)
- Half Marathon (21.1 km)
- 10 km walk/run
- 5 km walk/run
- Kids Marathon (5 km)

As an official charity, the Epilepsy Association can provide free registration to the first 15 participants (registration costs for the different events vary from \$30 to \$125). More information on how to register for the Calgary Marathon and join Team Epilepsy is available on our website: www.epilepsycalgary.com.

CALLING 1-866-EPILEPSY

If you live outside the Calgary and Red Deer local calling areas, you can reach us at no cost to yourself at our toll free number to ensure that support, information, and answers to your questions are just a telephone call away.

From within Calgary calling area please call: **403-230-2764**

From within Red Deer calling area, please call: **403-358-3358**

Medical Marijuana Use in Epilepsy

By Elizabeth Bertram, MS Psych
Education Coordinator

Epilepsy is an approved Category 1 Health Canada MMAR (Marijuana Medical Access Regulations) condition. However, under no circumstances should any person with epilepsy or a seizure disorder change or substitute any prescribed antiepileptic medication for another drug or alternative treatment without the specific approval (prescription) from their neurologist or attending physicians.

At the very least, some evidence suggests that marijuana can help in a wide range of epileptic conditions. Some users state that they can stay free of seizures while on a regular dosage of medical marijuana. At the same time, other reports show that high doses of THC (Tetra Hydro Cannabinol) can trigger seizures in some users as well. Clearly, there are large gaps in scientific knowledge showing the need for further and continued research and clinical trials into the issue of safety and effectiveness of medical marijuana and epilepsy. In the meantime, anyone interested in supplementing antiepileptic medication with cannabis to control seizures is advised to seek medical advice beforehand.

Most recreational users seek the highly potent strains of marijuana. This strain potency is attributed to one of the active components of marijuana, THC - the chemical responsible for the psychoactive high, and has moderate painkilling effects. To experience any noticeable psychoactive effects, about 10 micrograms of THC per kilogram of body weight must be ingested. THC is known for its most common short and long term effects such as:

- Sensory changes (e.g., loss of balance)
- Rapid heart beat
- Loss of inhibition
- Feeling relaxed or “high”
- A rise in blood pressure
- Sleepiness
- Poor coordination and judgement
- Confusion, hallucination, and paranoia
- Memory lapses and problems with concentration
- Anxiety
- Male sexual dysfunction
- Immune suppression
- Testicular cancer

Despite potential nasty side effects, many users claim that using marijuana helps them to relax and gives them a sense of well-being. The most common form of ingesting marijuana is smoking the dry leaves and flowers of the female Cannabis plant. However, there are many alternatives to smoking for example:

baking, steeping as tea, cooking and vaporizing. These forms of ingestion ensure a much slower release of marijuana into the blood stream and a prolonged “high”.

The increase of marijuana strains with high levels of THC is widespread however; research by the medical community is focusing on the non-psychoactive chemical called cannabidiol (CBD). CBD is a non-psychoactive component of marijuana that offers a wide range of medical benefits. Both CBD and THC are part of at least 85 other active chemical compounds found in cannabis.

Following decades of animal clinical trials confirming the effectiveness of CBD in suppressing seizures, the U.S. Food and Drug Administration (FDA) approved clinical trials involving children with epilepsy. Charlotte’s Web is a new compound being tested and is obtained from CBD-rich (98%) non-psychoactive marijuana strains. This new drug, marketed under the name Epidiolex is a non-psychoactive liquid extract that can be administered with a syringe dropper, and it is THC free, making it ideal to examine its therapeutic effectiveness on epilepsy, specifically in young patients.

The safety of Epidiolex in pediatric epilepsy is currently being investigated in two separate clinical trials; one at the New York University School of Medicine, the second at the University of California, San Francisco. Each trial will involve 25 children. The success of these trials may not only bring relief to many children for whom traditional seizure control medication have failed, but also may lead to changing American federal laws pertaining to cannabis. Nevertheless, clinical trials will take years to complete thus, Epidiolex has to wait for the FDA’s approval as a safe and effective antiepileptic drug before it can be widely prescribed.

In Canada, the CBD-rich cannabis is currently not available as Canadian law only permits sale of dried marijuana. Therefore, Health Canada’s approval of a cannabis extract like Epidiolex may be years away. However, under the new regulation, licensed producers will grow at least 3 different strains of cannabis. For people with epilepsy and particularly those with intractable epilepsy this represents one more option towards attaining seizure control.

Health Canada estimates that 41,384 Canadians will be authorized to possess medical marijuana under 2014 regulations. In the next decade, this number will reach to approximately 309,000, and by 2024, the annual revenues from the medical marijuana industry will reach 1.3 billion.

New Canadian Regulation on Medical Marijuana in Canada

Marijuana is an illegal substance in Canada. In 2001, Canada is the first country to introduce the Marijuana Access Program (MMAP) to allow the “compassionate use” of medical marijuana to those in need. Thus, approximately 37,500 Canadians were approved by

Health Canada to possess cannabis for medical use. They were able to grow their own marijuana plant, or buy it from small-scale growers. Also, there are countless others who self-medicate without a license.

Effective April 1, 2014, Health Canada will no longer produce and distribute marijuana for medical purposes. Medical marijuana will be available only from producers licensed by Health Canada who will grow, process and package dried cannabis from secure facilities. Market prices are expected to be between \$6 and \$12 per gram. For a current list of authorized licensed producers please check the Health Canada website: <http://www.hc-sc.gc.ca>

Health Canada regulates and oversees every aspect of the medical marijuana program thus; Canadians can only obtain marijuana through the Medical Marijuana Access Division (MMAD) with an MMAR licence. After April 1, 2014 only dried cannabis will be offered by licensed producers and it will be mailed directly to the customer in child-proof bottles. Those who prefer to ingest marijuana orally will have to make their own extracts. The legal limit of possession is set to be a maximum of 150 grams of dried marijuana, or 30 times daily dose, whichever is less.

To register with a licensed producer, a medical marijuana user may require the following documents:

1. A medical document –completed in full and signed by a health practitioner
2. An Authorization to Possess – issued by Health Canada
3. A Form B “Medical Practitioner’s Form

The Epilepsy Association of Calgary encourages you to stay informed and to seek further updates on the CBD-rich marijuana research and its availability in Canada. Only then can you and your doctor make an informed decision if using cannabis in your particular form of epilepsy will be beneficial to you. If you have any questions regarding medical marijuana, please contact our office or speak with your doctor.

Melanie Grace Memorial Scholarship

Applications for the Melanie Grace Memorial Scholarship are now available on our website: www.epilepsycalgary.com, or by calling our office at (403) 230-2764. Donations to the Melanie Grace Scholarship are also welcome anytime - cheques can be made payable to the Epilepsy Association of Calgary with “Melanie Grace Scholarship” written in the memo.

Be Like Jelly on Purple Day

A HUGE thanks to everyone that helped us BE LIKE JELLY on Purple Day, March 26 and spread epilepsy awareness. To our volunteers and donors for our “Shades of Purple” in Calgary and Central Alberta we extend our sincere appreciation! To everyone that attended and supported our events - thank you!



Calgary volunteers, Pam, Mandy and Sydney

TeleCare Home Monitoring & Safety Support

Our homes are supposed to be our safe haven, our soft landing at the end of a long day - but for people with epilepsy who live independently, home can also be a scary place. What if I have a seizure and no one is around to help me? What if I leave something on the stove and start a fire? Good Samaritan TeleCare provides total home monitoring, safety and security support to individuals young and old, injured and in good health.

Two products in particular may be of great interest to those living with epilepsy - namely the “Cookstop” stove top monitoring device will sense inactivity and turn off the burners. This device can also be linked to a TeleCare base unit to signal an operator to check on you.

The “Fall Detection” pendant is both a manual help call button and an automatic fall detector. Worn one of three ways, this water resistant intelligent pendant can send an automatic alarm if you fall to our operators.

For more information on these and other home safety products, contact:

Good Samaritan TeleCare

(780) 431-3630 / 1 (800) 676-8397

telecarehomonitoring.com

Upcoming Events

EPILEPSY ASSOCIATION OF CALGARY

All groups and information sessions are held at the Epilepsy Association of Calgary, 4112 - 4th Street NW.

Join us for:

The Celebrate Summer Picnic – (“Flood Free Edition”)

Saturday June 21st, 2014

11:30 am to 2:30 pm

At North Glenmore Park, Snowy Owl Picnic Site

Please RSVP by Wednesday June 18th 2014 to (403) 230-2764 or: michelle@epilepsycalgary.com
Please let us know of any special dietary requirements or allergies.

Announcing Our New Support Blog

Support Coordinator, Michelle has created the “Carpe Diem” blog to keep you updated on new information and research in the world of epilepsy, upcoming groups and workshops and articles related to issues many of you experience each day. This blog is available on EAC’s website under the “Support” tab. We hope this blog helps to keep you updated and better informed about issues related to living with epilepsy. Please send us your suggestions for future blog posts!

Taking Control of Your Wellness Skills Development Program

If you’d like to make some positive changes in your life, this could be the program for you! On-going registration is available for this program based on the work of Joel Reiter, MD., Donna Andrews, and Charlotte Janis, “Taking Control of Your Epilepsy”. Taking Control of Your Wellness Skills Development is a holistic health approach that considers all of you - the physical, emotional, intellectual, social and spiritual. The program provides a variety of skills and tools that help you learn to minimize the negative impact of epilepsy in your life, while enhancing your overall sense of wellness. The program consists of weekly individual sessions over 12 to 15 weeks.

Contact the Support Coordinator for more information.

No question is too big or small! If you would like more information on the programs above or any of our Support Program services, or if you would like to be added to our advance contact/reminder list, please contact **Michelle Kwan** at (403) 230-2764 or by e-mail at: michelle@epilepsycalgary.com

From the Support Program

The Parent Network provides a place where parents of children with epilepsy can come together to share their concerns with one another, learn from each other, and support each other.

If you are a parent, guardian, or care giver to a child with epilepsy, please join us!

Face to Face Support and Discussion Groups - a great way to meet with, and learn from others who understand your experiences. Primarily oriented to adults, but everyone is welcome. **Note that based on your feedback we have scheduled two Saturday morning sessions and two evening sessions.**

If these prove to be beneficial, we’ll consider scheduling additional sessions, so please join us if Saturday is your preferred day.

All groups and information sessions are held at the Epilepsy Association of Calgary - 4112 - 4th St. N.W. If you have any questions about our groups, don’t hesitate to contact Michelle.

The Parents Network 7:00 pm to 9:00 pm

Upcoming dates:

Thursday May 29, 2014

Wednesday September 10, 2014

Wednesday October 8, 2014

Wednesday November 12, 2014

Face to Face Groups

Upcoming dates:

EVENING

Thursday May 15, 2014

7:00 pm to 9:00 pm

Wednesday October 15, 2014

7:00 pm to 9:00 pm

SATURDAY

September 13, 2014

11:00 am to 1:00 pm

November 15, 2014

11:00 am to 1:00 pm



If you’d like to improve your health and wellness through healthy eating habits and nutrition, Alberta Health has created a website to assist you. Visit: HealthyEatingStartsHere.ca for information

Upcoming Events CENTRAL ALBERTA OFFICE

All groups and information sessions are held at the EAC - CENTRAL ALBERTA OFFICE, 4811 - 48th Street, Red Deer, Alberta.

From the Support Program

Face to Face Support and Discussion Groups are a great way to meet with, and learn from others who understand your experiences. **Groups are now being held on the third Wednesday of the month from 5:30 p.m. to 7:30 p.m.** at the Epilepsy Association of Calgary – CENTRAL ALBERTA OFFICE, 4811 - 48th Street, Red Deer Alberta. Please note the revised schedule.

Upcoming dates:

- May 21, 2014
 - September 17, 2014
 - October 15, 2014
 - November 19, 2014
- Calling All Parents! We've heard that there are parents in the Central Alberta Region who would be interested in attending a Parent Network Meeting. If there is enough interest we will schedule a session. Please let Norma know if this is of interest to you!*

Celebrate Summer Picnic Details will be available shortly.

Call us or check our website (www.epilepsycalgary.com) under the Central Alberta link for more information.

Have questions? Need to talk to someone? Would you like to volunteer?

If you would like more information on the programs above or any of our CENTRAL ALBERTA services, or if you would like to be added to our advance contact/reminder list, please contact Norma Klassen at 403-358-3358 or by e-mail at: normak@epilepsycalgary.com.



Fund Development Manager, Mitch Ravvin, joins us at EAC!

We'd like to welcome Mitch Ravvin to EAC. Mitch will be working to enhance our fund-development skills and capacity at EAC for the next several months. The time has come for EAC to enlist some dedicated and professional support and we're delighted to welcome Mitch to our team!

CALLING 1-866-EPILEPSY

If you live outside the Calgary and Red Deer local calling areas, you can reach us at no cost to yourself at our toll free number to ensure that support, information, and answers to your questions are just a telephone call away.

From within Calgary calling area please call: **403-230-2764**

From within Red Deer calling area, please call: **403-358-3358**

Follow and "Like" Us on Facebook

The Epilepsy Association of Calgary is now on Facebook. For the latest news, check us out!

Calgary Office

www.facebook.com/EpilepsyCalgary

Central Alberta Office

www.facebook.com/pages/Epilepsy-Association-of-Calgary-Central-Alberta/405246279602341

We recognize our donors in our quarterly newsletter and our members and donors in our Annual Report. These documents are shared with members, funders, program participants, and others in the community who are interested in our work. In accordance with the Privacy Legislation: **if you do not wish to have your name published**, please call us at 403-230-2764 or indicate your wishes in the form below and send it to us by fax or mail to the Epilepsy Association of Calgary, 4112 – 4 Street NW, Calgary, AB T2K 1A2.

I do not wish to have my name published in the Annual Report or *Epigram* Newsletter.

Name (Please Print) _____

Signature _____

Date _____

The staff and Board of Directors of the Epilepsy Association of Calgary extend heartfelt thanks to all of our donors, members, and volunteers for their support of our Calgary and Central Alberta offices.

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Follow and “Like” Us on Facebook

The Epilepsy Association of Calgary is now on Facebook. For the latest news, check us out!

Calgary Office

www.facebook.com/EpilepsyCalgary

Central Alberta Office

www.facebook.com/pages/Epilepsy-Association-of-Calgary-Central-Alberta/405246279602341

VOLUNTEERS - Our Heart and Soul

To everyone who has volunteered during the past year, we want to extend our sincere thanks! Whether you helped out once or twice a week, a month, or as your time allowed, you have our deepest appreciation! We'll keep you posted on upcoming activities. We will be placing and monitoring coin cans in the Mac's stores during May and June 2014, and willing Macs-a-teers will be welcome.

Give us a call if you'd like to help or for more information (403) 230-2764

NEWSLETTER DISCLAIMER

Material contained in this newsletter concerning epilepsy, research, treatment, and patient experiences is solely for information purposes. Each individual's experiences of epilepsy are different. Please consult your physician for medical advice. Articles published in the Epigram newsletter do not necessarily represent the official policies or endorsements of the Association and its members.

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MEMBER/DONOR FORM

Name _____ Address _____
City _____ Province _____ Postal Code _____
Home Phone _____ Work Phone _____

- Annual Membership.....\$20.00
(January to December 2014)
- Life Membership.....\$200.00
- Donation amount\$ _____
Total\$ _____

Payment method:

- Cheque Money Order
- Credit card Visa MasterCard

Credit card number _____ Expiry Date _____
Cardholder signature _____

Pre-Authorized Credit Card Payment Program for Donations Only:

- Yes, I prefer to make a monthly donation that will help support the programs and services of the association year-round.
- \$ _____ per month, beginning on the 15th day of each month until otherwise notified.

A tax-deductible receipt will be issued for charitable registration number 11890 0778 RR001.

A WORD ABOUT PRIVACY

The Epilepsy Association of Calgary respects your privacy. As such, we do not share, sell, rent, or trade our membership lists, donor lists, volunteer lists, or participant lists with any outside organizations. Personal information provided in the context of program participation is never shared without your written consent, unless there is a legal or ethical obligation to do so. Information you provide us is used to deliver services, keep you informed about agency activities and opportunities, fund-raising initiatives and events, as well as volunteer opportunities.

If you no longer wish to receive some or all of the information we provide, you can contact us by telephone, fax, or e-mail, and we will remove your name from any or all of contact lists in accordance with your wishes.

Return undeliverable Canadian addresses to:

Epilepsy Association of Calgary
4112 - 4 Street NW
Calgary, Alberta T2K 1A2
Email: info@epilepsycalgary.com



To ensure your Epigram Newsletter always reaches you, please contact us with address changes as soon as possible.