November – December 2017



FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION
The Epilepsy Association of Northern Alberta - Our 57th Year of Service

(This Newsletter can be viewed in full colour on our website.)

Member Outings & Activities

November

Fun Bingo for Prizes

Friday, November 24th, 1:00—3:00 p.m. (Pre-register by Noon, November 22nd) (Registration Limited to 12)



December

Christmas Lunch & Social

Saturday, Dec. 9th, 12:00 - 3:00 pm Central Lions Seniors Centre 11113 - 113 Street NW

(Pre-registration by Noon, Dec. 6th)

Fun BINGO for Prizes

Friday, December 22nd, 1:00 – 3:00 pm EEA Office

(Pre-register by Noon, Dec. 20th) (Registration Limited to 12)

Whichever Your Faith, We Wish Our Members and Friends Much Enjoyment During Your Holiday Celebrations!







CHRISTMAS

NEW YEAR'S



FREE MEMBER ACTIVITY

Free Epilepsy Education Forum:

"Sleep Problems and Epilepsy"

Thursday, November 16th, 2017 6:30-9:00 p.m.

Old Royal Alberta Museum Theatre Auditorium

For further details and to reserve your seat see page 5.



2018 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

When: Thursday, February 22nd Where: Room 113/115
St. John Ambulance Building 12304-118th Ave.



Timelines:
5:45 FREE Light Supper
6:15 Annual General Meeting
7:15 Volunteer recognition event
8:00 Wrap-up

"Help Seize The Day!"

Thursday, March 22nd, 2018, During

Epilepsy Awareness Month

In Support of Epilepsy Awareness, A Celebration of Greek-Themed Fine Food and Wine

Further Details on page 6!



Adult Support Group Schedule

(Group meets from 1:00 - 3:00 p.m. in the EEA office.)

Please call the Office to advise if you will be attending.

Tuesday, November 14th, 2017

Tuesday, December 12th, 2017





Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta



Focus on Epilepsy is published 6 times annually by the Edmonton Epilepsy Association.

Articles appearing in Focus on Epilepsy do not necessarily reflect the opinions of the Association.

We welcome your contributions:

Do you have a poem or maybe a short story (1/2 page) that you would like to share with others. Or maybe you have read a book from our library and want to share a review with others. If you would like to share your wisdom, please submit your items to Sharon at our office or e-mail her at info@edmontonepilepsy.org

BOARD OF DIRECTORS

President...Cheryl Renzenbrink Vice President...Cameron Reid Treasurer...Doug Griffiths Secretary...Erin Duke

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Colleen Matvichuk Tim McCallen

Anne Starreveld Katrina Van Den Berg

Brian Wilkie

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gary@edmontonepilepsy.org

Sharon Otto... Program Manager & Education Coordinator sharon@edmontonepilepsy.org

Dr. Sunny Kim...Counsellor sunny@edmontonepilepsy.org

Cam Reid...Volunteer Coordinator cam@edmontonepilepsy.org

Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta

11215 Groat Road NW Edmonton, AB T5M 3K2



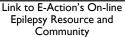
(780) 488-9600 (780) 447-5486 fax I-866-EPILEPSY



info@edmontonepilepsy.org www.edmontonepilepsy.org









Edmonton Epilepsy Association

EEA Employabilities Programs

- ⇒ Employment Counselling
- ⇒ Assistance with Resumes
- ⇒ In-office Skills Training
- ⇒ Referrals to Select EEA Partners In Employability

 For Further Information contact EEA Executive Director,

 Gary Sampley, 488-9600 or gary@edmontonepilepsy.org

Bus Tickets Available for Members in Reduced Circumstances

Please note that we now have our 2017 allotment of tickets available in the EEA Office. These can be accessed by MEMBERS with limited financial resources who need help getting to medical appointments, EEA events, food shopping, etc., and who do not have an AISH bus pass.

Call 780-488-9600 or drop by to pick them up.



Now you can Donate to the EEA online!

If you would like to make either a lump sum Donation or a monthly donation contribution to the Association by credit card, please visit our website, www.edmontonepilepsy.org, and click on the Canada Helps Logo. This donation program gives you the ability to instantly print off a donation receipt.

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News from the EEA Office



Four Years And A Thousand Dollars

For the past 4 years, the Grimoldby sisters, Katelyn (left) and Ashley (right) from Spruce Grove have organized a Summer Weekend Purple Lemonade Stand with sales from the stand going towards EEA Programs and Services. Here they are presenting this year's proceeds to EEA Executive Director Gary Sampley. This year's stand took their overall 4-year total well over \$1000.





Annual Christmas Lunch and Social

Saturday, December 9th, 12 – 3 p.m. Central Lions Seniors Centre, 11113 113 Street, Edmonton

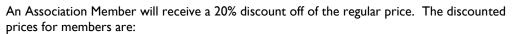
In keeping with our tradition of a different ethnic theme each year, this year will have a German theme, with entertainment by the German Male Choir "Liederkranz"

\$15.00 per person (remainder EEA subsidized).
Call the EEA office 780-488-9600 to book your seats
(Pre-registration by December 4th required).
Everyone in attendance will get to take home a special gift of their choosing.

Opportunity For Weekend First Aid Training For EEA Members At EEA Office

If any EEA Member is interested in First Aid Training Certification, here is an interesting opportunity at a 20% discount off the industry standard cost for this training. One of our Board members, Anne Starreveld, is a certified First Aid Instructor.

EEA is prepared to provide space in the EEA Office for putting on First Aid Courses that will benefit EEA Members.



Standard First Aid (2 day course) \$100.00
 Emergency First Aid (1 day course) \$79.00
 CPR with Defibrillator Training (1 day) \$64.00



Several courses are planned over the next four months. To book a space in one of these courses, or to obtain more information, call or email the EEA Office.





News from the EEA Office

2017 Garage Sales—A Success!

Our second one-day Garage Sale on September 15th of this year netted us \$2696. We also had \$527 in pre-sales, bringing the total to \$3223.

Combining that with the \$445 l.55 we made from our first sale on May 26th, our total Fundraising from garage sales this year amounted to \$7674.55.

Collective Kitchen Program Starting in January 2018

This is a combined support and training program to assist members living on a limited income who lack a knowledge of proper nutrition, as well of budgeting and cooking skills. Working collectively, course participants are guided into the world of nutrition and how it affects their seizures and overall health.

The course also covers issues such as low cost cooking, food preparation, budgeting skills and planning ahead. A hands-on course, it has components of active teaching. Each participant gets to take home what they have cooked, usually four to six individual portions, in freezable containers capable of fitting into a fridge freezer compartment.

The next Collective Kitchen Project runs from 12:30-3:00 pm on Friday January 12, February 9, March 9, April 13, May 11 and June 8. Interested members can phone Sharon at the EEA Office at 780-488-9600 to register. Registration is limited to **eight** participants.

2018 EEA Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2018, for the purpose of assisting students to advance to or continue with College or University studies. Application for these Scholarships is open to Greater-Edmonton area students aged 17-29 years of age who are currently under a Canadian physician's care for epilepsy and are Canadian Citizens or who have permanent resident status.



Visa students are not eligible for this award.

Deadline for applications is March 1st, 2018

To download an application, visit our website: www.edmontonepilepsy.org, or call our Office at 780-488-9600 if you wish to receive one by mail.



We're Looking for an Achiever!



Do you know someone living with Epilepsy who has accomplished significant success in life, inspiring others in the process?

If you would like to nominate someone for our 2018 "Achiever of the Year" Award, please do so, in writing, to the EEA office by **February 15th, 2018.**

If you have any questions about the criteria for the award, please contact EEA Executive Director Gary Sampley at 780-488-9600 or gary@edmontonepilepsy.org

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News From The EEA Office



Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta

Hosts a Free Educational Forum:

"Sleep Problems and Epilepsy"

Presented by:

Dr. Atul Khullar Medical Director Northern Alberta Sleep Clinic

There will be a post-presentation Question & Answer period.

Thursday, November 16th, 2017 6:30-9 p.m. Old Royal Alberta Museum Theatre Auditorium 12845—102nd Avenue, Edmonton

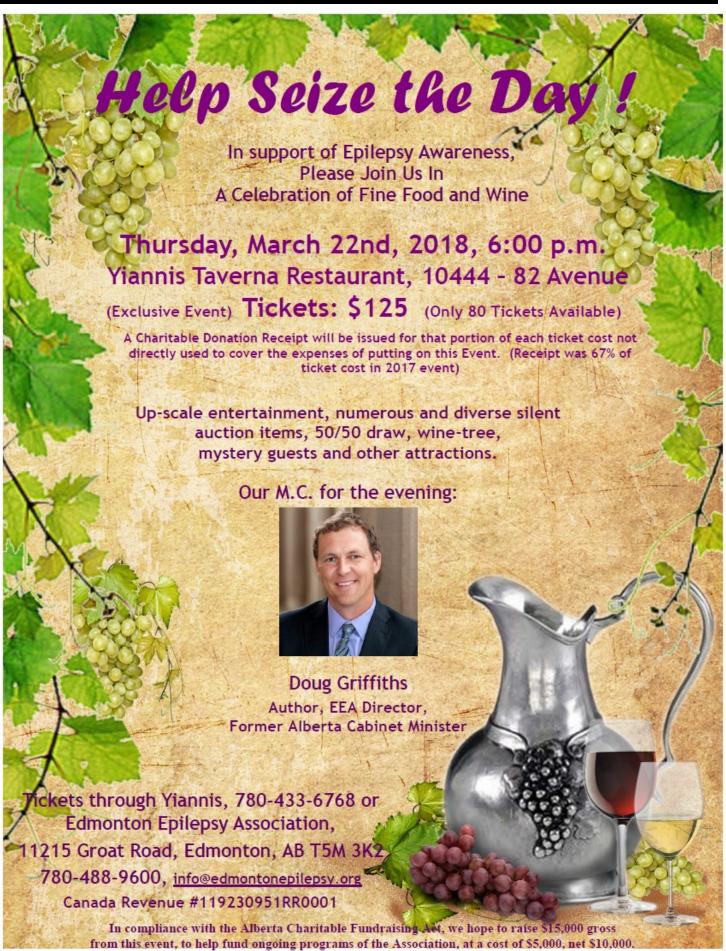
A FREE Light Supper will be provided

For more information or to reserve your seat, please call 780-488-9600 or toll free 1-866-374-5377 or by email at info@edmontonepilepsy.org

This forum will be of interest not only to individuals who live with epilepsy and their family members, but also to health care professionals, medical and nursing students and educators.

Help Seize The Day Fundraiser!







Halloween Luncheon



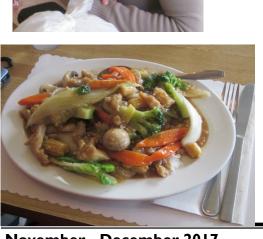
















November - December 2017

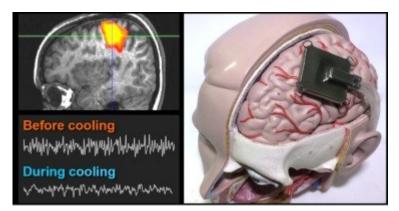


Epilepsy News From Around The World



How Can Brain Cooling Ease Epilepsy?

Epilepsy is one of the most common neurological diseases, affecting some 50 million people across the world. But treatment with medication or surgery does not work for all patients. As an alternative, scientists are investigating focal cooling, in which a device implanted in the brain suppresses the electrical discharges that underlie epileptic seizures.



How does cooling specific brain regions treat epileptic seizures?

Previous experiments in rats and epileptic brain regions in humans have shown that focal cooling consistently suppresses epileptic discharges without affecting the brain's normal neurological function. As such, this treatment shows potential for future development into an implantable cooling device.

The precise mechanisms by which focal cooling suppresses epileptic discharges, however, are still not clearly understood. In particular, focal cooling sometimes slightly increases the frequency of epileptic discharges in rats, even while suppressing their strength.

Now, a Japanese research team has used computer simulations to gain insight into how lowering the temperature of specific brain regions could potentially treat epileptic seizures. They employed a rat brain model that allowed them to simulate different mechanisms underlying the effects of a focal cooling device on epileptic discharges (PLoS Comput. Biol. 13 e1005736).

Based on data from laboratory and rat studies, Jaymar Soriano of Nara Institute of Science and Technology (NAIST) and colleagues used a neural mass model to reproduce epileptic discharge activity, simulating the effect of cooling by introducing temperature dependence into the model. They formulated two temperature-dependent mechanisms to reproduce the effect of cooling on epileptic discharge activity.

First, the researchers simulated a mechanism by which focal cooling reduces activity at connections between neurons, resulting in less frequent epileptic discharges. With this mechanism alone, however, the model could not accurately reproduce electrical activity patterns previously observed in brain cooling experiments on rats.

They then devised an intrinsic excitability mechanism that compensates for the reduction in frequency of discharges, resulting in discharges that were persistent during cooling but suppressed in magnitude. Incorporating both mechanisms into their model allowed the team to successfully reproduce results from the rat experiments.

"Focal brain cooling could be an alternative treatment for epileptic seizures with lower risk of irreversible functional loss compared to surgery," said co-author Takatomi Kubo from NAIST. "Our study attempts to start an initiative on thermal neuromodulation of brain activity using a computational approach that can elucidate its mechanism and complement animal experiments and clinical tests."

October 6th. 2017 http://medicalphysicsweb.org/cws/article/research/70113

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Epilepsy News From Around The World



STUDY SHOWS PROMISE FOR CHILDREN WITH SEVERE FORM OF EPILEPSY

A new formulation of a drug that was used to treat children with a rare neurological condition in the 1980s, and later became half of a widely used diet-drug combination, may offer promise for pediatric patients with a severe seizure disorder, following a large-scale trial led by UC San Francisco.

According to data released on Sept. 29, 2017, from a multicenter, phase III clinical trial, 70 percent of children with Dravet syndrome experienced at least 50 percent fewer seizures each month when they were treated with the investigational drug ZX008, or fenfluramine. "Dravet syndrome is a devastating condition that severely impacts the quality of life for both the children and their families," said Joseph Sullivan, MD, associate professor of neurology and pediatrics at UCSF, and the principal investigator of the study. "These results are very encouraging. Even reducing seizures for these children to once a month, instead of once or twice a week, makes a tremendous difference in their lives."

Dravet syndrome is a form of childhood-onset epilepsy that affects approximately one in 15,700 individuals in the United States. It is a lifelong condition, in which frequent seizures are accompanied by language and motor impairments, hyperactivity and difficulty relating to others, according to the National Institute of Neurological Disorders and Stroke. Approximately 10 to 15 percent of children with Dravet syndrome die by age 25, most commonly due to so-called sudden unexpected death, which is markedly more prevalent in people with epilepsy. In up to 80 percent of cases, Dravet syndrome is caused by defects in a gene required for the proper function of brain cells.

In the study, 119 children and teens under age 19 with Dravet syndrome were enrolled at hospitals in the United States, Canada, Europe and Australia, and randomly assigned to either 0.8 mg/kg/day or 0.2mg/kg/day of the investigational drug, with a maximum total dose of 30 mg per day, or a placebo.

Among those on the higher dose, 45 percent experienced at least a 75 percent drop in monthly seizures, versus 20.5 percent of those on the lower dose and 2.5 percent on placebo. The longest seizure-free period was 20.5 days for participants on the higher dose, compared with 14 days for those on the lower dose and nine days for the placebo participants. "Since the degree of cognitive impairment may correlate with the frequency of seizures, our hope is that more effective treatments may also reduce these impairments," said Sullivan, who is also director of the Pediatric Epilepsy Center at UCSF Benioff Children's Hospital San Francisco.

The genesis for identifying Dravet syndrome as a condition that might respond to the drug occurred when it was prescribed for children with self-induction epilepsy, a disorder in which patients deliberately expose themselves to the triggers that cause seizures. While the drug was prescribed to suppress the need to provoke seizures, two doctors noted in 1985 that a "direct anti-epileptic mechanism cannot be excluded."

Since that time, researchers in Belgium have conducted open-label studies with fenfluramine, which suggested that it might be effective in children with Dravet. The UCSF-led clinical trial, which began in April 2016, was the first such study in the United States. Fenfluramine was one of two medications – with phentermine – that were known as Fen-Phen, a combination that was prescribed in the 1980s to treat adult obesity. Fenfluramine was withdrawn from the market in 1997, following reports of heart valve damage at the dosage of 60 mg to 120 mg per day.

Sullivan said the children in this study were followed very closely with echocardiograms and none experienced heart valve problems.

September 30th, 2017

https://scienceblog.com/496694/study-shows-promise-children-severe-form-epilepsy/

Study Finds Epilepsy Drug To Be Safe During Pregnancy

New research indicates that use of the epilepsy drug lamotrigine during pregnancy does not increase the risk of birth malformations or neurodevelopmental disorders. The *British Journal of Clinical Pharmacology* study provides the most extensive long-term report regarding children whose mothers took lamotrigine while pregnant.

The study included the children of 83 epileptic women treated with lamotrigine during pregnancy at a tertiary medical center between 2004 and 2014. All newborns were monitored and parents completed a questionnaire regarding their child's development and health up to the age of 12 years.

"The results of this study are good news for both pregnant epileptic women and their children, as well as their treating neurologists," said co-author Dr. Itai Berger, of the Hadassah-Hebrew University Medical Center, in Jerusalem.

October 18th. 2017

https://www.eurekalert.org/pub_releases/2017-10/w-sfe101617.php#.WejfwS4R2yk.email





Epilepsy News From Around North America



Melanie Griffith Has Revealed She Was Diagnosed With Epilepsy

Melanie Griffith has opened up about being diagnosed with epilepsy — and how stress from marriage and family life contributed to suffering from grand mal seizures. According to *The Hollywood Reporter*, Griffith revealed her diagnosis on a Women's Brain Health Initiative panel Wednesday night, where she sat alongside brain experts and Hollywood insiders like Sharon Stone.

She said she started having grand mal seizures, and they were always associated with stress. But she wasn't diagnosed with epilepsy until she received treatment in France. "[Doctors] said it was an anomaly — they didn't know what it was," she said. "The last two that I had I was on a boat outside of Cannes — on a big yacht — and I was extremely stressed out. Every seizure that I had was at a point when I was extremely stressed.

"She said she was taken off the boat to a hospital in Cannes after each seizure, but after the second one, doctors there performed tests. She was diagnosed with epilepsy once she came back to the United States. Now, she says she is taking the drug Lamictal and claims she hasn't had a seizure in four years. She's also got a clean bill of health from a medical testing facility. She says doctors now say her brain was purely reacting from stress.

"I'm not stressed anymore," Griffith said. "As women, we take on family, we get the husband, we have the life, we have the children, we take care of the house, we also go to work, we can't sleep at night because we are up with the kids. I don't think I've slept for 35 years.

"<u>The Hollywood Reporter</u> noted that though she didn't mention Antonio Banderas specifically, she did joke, "I got divorced, which is the real healer for me." She and Banderas divorced in 2014.

Megan Friedman October 20th , 2017

http://www.goodhousekeeping.com/life/news/a46562/melanie-griffith-reveals-epilepsy-diagnosis/

Personal Trainer Turns To Exercise To Overcome Epilepsy

A personal trainer in Ottawa is hoping to use exercise to help people suffering seizures. Shaun Kehoe celebrated his ninth seizure-free year this summer, but that celebration didn't come without a long struggle. Kehoe found fitness to be an important lifeline while he went through surgeries and treatments for epilepsy.

'I felt like my fatherhood got taken away from me.'- Shaun Kehoe He's now starting a fitness group for people with epilepsy to help them overcome challenges related to the neurological disease.

Kehoe was diagnosed with epilepsy when he was 17 and the disease was debilitating. He couldn't drive or work because of his seizures and when he had a son, he wasn't allowed to be alone with him.

"I felt like my fatherhood got taken away from me," Kehoe said in an interview with CBC Radio's *Ottawa Morning*. Things were tough for a long time and Kehoe said he fell into a depression.

"I just couldn't figure out where my life was going to go at the time. That was the biggest battle."

Fitness was a motivator

But one thing he could do was work out. A friend of his, who was capable of taking care of him when he had a seizure, worked at a gym and fitness gave Kehoe a reason to get out of the house.

Kehoe said working out is what kept him going. He now hopes to give others who live with epilepsy the kinds of benefits he had from exercise.

"There's a lot more behind fitness than just physical benefits," Kehoe said. "It's very helpful mentally, emotionally. And a lot of people with epilepsy think they're not capable of doing things like this. I've put myself on a personal mission to bust that myth and show them what they can do."

Seizures could still return

While Kehoe's treatments have been successful, he said he knows epilepsy doesn't just disappear. There's always a fear the seizures could return.

"I will never, ever, ever put my guard down," he said. "The last thing I would do is sit back and relax and think my epilepsy is over. It's a part of who I am and it will be there forever."

But over the years Kehoe said he has become stronger.

"If [the seizures] happen again, I can't let [them] take over my life," he said. "I can't let it destroy me."

October 23rd, 2017

http://www.cbc.ca/news/canada/ottawa/shaun-kehoe-epilepsy-exercise-1.4364667



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Epilepsy News From Around Alberta



Lethbridge Researcher Makes A Scientific Breakthrough After His Son's Seizure

It was the middle of the night when Dr. Artur Luczak discovered that his infant son was suffering from a seizure.

"Such things are the worst moments in someone's life," he said. "I work in neuroscience, so I knew about seizures and have seen them happen, but when it's your own child who's unconscious and jerking...it's really something different." Fortunately, Luczak's son is a now healthy four-year-old who suffered his seizure as a result of a fever. But, even years later, the effects of the experience have lived on through his new scientific discovery. Luczak, a neuroscientist at the University of Lethbridge, was already studying the basic properties of the brain, but after witnessing his son's seizure he turned his eye toward understanding epilepsy.

"(My son) will probably be free of epilepsy," he said. "But, nevertheless, that was a big moment for me to decide that I should start doing some research in this area, because I can contribute to it." Luczak explained that the two types of neurons in the brain, excitatory and inhibitory, play a large part in seizures. Comparing it to a car, Luczak said the excitatory neurons are the accelerator and the inhibitory neurons are the brakes, and the two work to balance one another to keep the brain moving at the right speed.

It's been widely believed that in influx of excitatory neurons are at the root of the cause, but through a collaborative study with U of L's Dr. Bruce McNaughton and Stanford University, Luczak has found that this isn't the whole story.

"By looking more closely at the cells, we found that a surprisingly large contribution to the brain activity during a seizure is from the inhibitor (neurons)," he said. "This tells us that things are much more complicated than we thought." Although the research may not provide any quick answers on how to treat epilepsy, Luczak said it now opens new doors to understanding how seizures work. "We want to know how these seizures are hijacking regular brain activity," he said. "And I think this is putting us on a better path."

The study was recently published in the neurology journal *Brain*, and Luczak is already looking at how to advance this new discovery. "It's not a 'eureka' moment," he said. "It was a lot of work, but in the end it paid off because we found something that other people didn't know before and that opens so many possibilities of testing different treatments."

Luczak said that epilepsy is a complicated disorder, and that there's plenty left to discover, but the next step is to manipulate activity on the inhibitory neurons (the brakes, if you will). He said he hopes a pharmacological treatment could be created to keep others from experiencing the same fear he had while he held his son's unconscious body in his arms four years ago. "It's something every father would like to avoid, having this inspiration, but it happened," he said. "And I started to do something about it."

Jennifer Friesen October 20th, 2017

http://www.metronews.ca/news/calgary/2017/10/20/lethbridge-researcher-makes-a-scientific-breakthrough-after-his-son-s-seizure.html

Need Prescriptions Filled?

We recommend the following Pharmacists, who support the programs of the EEA. For all your Pharmacy needs, visit their friendly, helpful staff today.

Southside G & E Pharmacy 7326-82nd Avenue 780-469-7667



Central
Royal Pharmacy
Ground Floor, 11010-101 Street
780-426-0872





Our Programs and Services



- ◆ Free "Kids on the Block" puppet presentations that educate children (and their teachers, administrators, caregivers, and group leaders) about kids with Epilepsy in an entertaining manner;
- ♦ Free specially-tailored In-services about Epilepsy to schools, businesses, group homes, Public Service bodies, Colleges, etc. (includes annual training for NAIT EMT students and ETS Supervisors and Security Personnel, and on-line information about Epilepsy on the EPS Training System)
- ♦ Twice-yearly no-cost Epilepsy Educational Forums, both of interest to Health Care Professionals as well as the General Public;
- ♦ Free provision of our series of 12 Epilepsy Education Information booklets to Members, Hospitals, Clinics, Neurologists' Offices and Pharmacies;
- ♦ Website, print and video information about Epilepsy, and a free lending library for members;
- ♦ Bi-monthly newsletter for Members that includes the latest current medical information available about Epilepsy, as well as current news about the Association and our services and events;
- ◆ Scholarship Program for Post-secondary Students with Epilepsy (minimum two scholarships a year);
- ♦ Garry Hannigan Memorial Life Enhancement Scholarships for Youth, to assist young people (up to the age of 18) to participate in sports, arts, cultural or recreational activities that will enhance their development as individuals;
- ♦ No-cost Counselling on Epilepsy-related problems for people with Epilepsy and families of people with Epilepsy, with referrals to other supporting Agencies as needed;
- ◆ Monthly group sessions geared toward Adults with Epilepsy and concerned family members;
- ♦ Information and support for Parents/Caregivers of Children with Epilepsy;
- ♦ No-cost provision of assistance/advice on diverse matters, including, but not limited to, finding employment, driving and Epilepsy, potential side-effects of medication, and dealing with the complexities of Government forms and applications (AISH, Disability, housing subsidy, etc);
- ◆ No-cost advocacy on behalf of people with Epilepsy experiencing discrimination or other problems;
- ♦ No-cost social and recreational activities for Members that help reduce social isolation, free ETS Bus Training, and free "Donate-a-Ride" Program bus tickets for Members in need;
- ♦ An annual no-cost in-house Collective Kitchen Cooking Training Program, An Annual Collective Gardening Program and an annual in-house Computer Training Program for Members;
- ♦ Ongoing recruitment and screening of quality Volunteers, annual recognition of all Volunteers, and annual award of Member-nominated Volunteer-, Achiever-, and Employer-of-the-Year Awards.



Edmonton Epilepsy Association 11215 Groat Road NW Edmonton, AB T5M 3K2

Place address label here

If you are planning to move in the near future please inform our office so that we can continue to ensure that you get your newsletter...