



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION

The Epilepsy Association of Northern Alberta - Our 60th Year of Service

(This Newsletter can be viewed in full colour on our website: www.edmontonepilepsy.org)

Member Outings & Activities

February

**ANNUAL GENERAL MEETING and
Volunteer Recognition Event**

Thursday, February 27th @5:45

St. John Ambulance Building

12304-118th Avenue

Fun Bingo for Prizes

Friday, February 28th, 1:00 – 3:00 pm

(Pre-register by Noon, February 26th)

(Registration Limited to 12)



February 17th, 2020

2020 Diary & Seizure

We have recently received
our stock of
2020 Diary & Seizure
Record Books, which can be
picked
up at the EEA Office
or mailed to you on request.

The EEA is Sixty Years Old!

Edmonton Epilepsy celebrates sixty years
of service in 2020.

Numerous events are planned
throughout the year.

Our actual birthday is June 7th and
our Anniversary Gala (featured on Page 5)
follows on June 11th.

MEMBER ACTIVITY

**2020 EEA ANNUAL GENERAL MEETING and
Volunteer Recognition Event**

When: Thursday, February 27th, 2020

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



Adult Support Group Schedule

(Group meets from 10:00 - 1200 p.m. in the EEA office.)

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

February 11th, 2020





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...Colleen Matvichuk
Vice President...Cameron Reid
Treasurer...Terry Mahon
Secretary...Katrina Breau
Past President...Cheryl Renzenbrink
Executive Director...Gary Sampley
Directors-at-Large:

Craig Heyland	Alex Law
Joe Scalzo	Anne Starreveld
Dr. Elout Starreveld	Irene Szkambara

STAFF

Gary Sampley... Executive Director & Chief Operating Officer
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
1-866-EPILEPSY



info@edmontonepilepsy.org
www.edmontonepilepsy.org

Canadian
epilepsy
Alliance

Alliance
canadienne de
l'épilepsie



Link to E-Action's On-line
Epilepsy Resource and
Community

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

Our 2019 allotment of Donate-A-Ride bus tickets is now depleted. However, Alberta Blue Cross has very kindly donated a number of adult ticket packs to us to hopefully get us through till next April. 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 qualify for an ETS low-cost bus pass.



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.





Dr. Sunny Kim is EEA's 2019 Volunteer Of The Year



EEA Counsellor, Dr. Sunny Kim is presented with her keeper plaque as the EEA 2019 Volunteer Of The Year Award by trophy donor Cameron (Cam) Reid and EEA Executive Director Gary Sampley.

Sunny has volunteered her time as Counsellor to the EEA for nine years.

Maxxam Johnson Is The First Brittany Hughes Youth Scholarship Winner

Max is presented with the sponsorship trophy by EEA President Colleen Matvichuk and his keeper plaque by Brittany's sister Lyndsay Kruger and EEA Executive Director Gary Sampley.

Max is using his scholarship to participate in an Advanced Dance Class.



Life Enhancement Scholarship Program For Youths



The **Brittany Hughes Memorial Life Enhancement Scholarships for Youth**, to a maximum of \$500 each, are available for Youths of any age, up to the age of 18, to assist them in participating in Arts, Music, Dance and/or Ethnic Identity Cultural Programs that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from www.edmontonepilepy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.





Our Newest Office Volunteer

Meet our newest Office Volunteer and our first Norquest Practicum Student.

Crystal Eggen will be with us for a 15-week learning stint as the first Norquest student in a 5-year agreement with Norquest that will see one of their students on a similar practicum with us twice a year.

Like Crystal, the students will work with us two days a week.

Welcome aboard, Crystal!

Wanted: Volunteer Casino Workers

The EEA is recruiting experienced Casino Worker Volunteers for our 2020 Casino whose dates were just drawn. Those dates are Friday, April 10 and Saturday, April 11th at the Century Casino on Fort Road in Edmonton.



If you have previous casino experience and are interested in helping us, please contact the EEA Office.

2020 EEA Continuing Education Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2020, 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, 2020



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.



Does Your Child or Teen Have Upcoming Sports or Recreational Activities Costs?



The **Garry Hannigan Memorial Life Enhancement Scholarships for Youth**, to a maximum of \$500 each, are available for Youths of any age, up to the age of 18, to assist them in participating in Sports or Recreational Activities that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from www.edmontonepilepsy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.



Tickets \$125
Table of 8 \$875

Thursday, June 11th, 2020
6:00pm Reception | 7:00pm Dinner

Chateau Lacombe Hotel
10111 Bellamy Hill, Edmonton

Special guest room rates available at the Chateau Lacombe Hotel
Call 780.428.6611 to book

PROUDLY SPONSORED BY



CHATEAU
LACOMBE
HOTEL



For more information, contact:
Sharon Otto | Edmonton Epilepsy Association
780.488.9600 sharon@edmontonepilepsy.org

www.edmontonepilepsy.org



EEA Christmas Luncheon







High fat Foods Increase Absorption Of CBD Into The Body

A new study has shown how fatty foods help the absorption of CBD into the body.

While oral cannabidiol (CBD) capsules were approved by the US Food and Drug Administration (FDA) for use in patients with seizures in 2018, very little was known about the effect of food on CBD absorption.

A University of Minnesota study, published in *Epilepsia*, examined whether eating high-fat foods after taking CBD increased the body's absorption of CBD. The study tested whether fasting or a high fat meal has an effect when cannabidiol oral capsules were taken by patients.

The Impact Of Food On Absorption

To find out what effect a fatty meal would have on CBD absorption, the research group measured CBD concentrations in epilepsy patients at the MINCEP Epilepsy Care clinic who were taking 99% pure CBD capsules. Concentrations from patients who took CBD on an empty stomach and a standardised fatty breakfast – such as a breakfast burrito – were compared.

Angela Birnbaum, a professor in the College of Pharmacy and study co-author, said: “The type of food can make a large difference in the amount of CBD that gets absorbed into the body. Although fatty foods can increase the absorption of CBD, it can also increase the variability as not all meals contain the same amount of fat.”

“Increases in the amount of the CBD dose being absorbed into the body can also lead to lower medication costs,” said Ilo Leppik, study co-author, a professor in the College of Pharmacy and an adjunct professor at the Medical School.

The study found that:

- CBD exposure is vastly increased when CBD is taken with high fatty foods;
- When compared to fasting, taking CBD with food increased the amount of CBD in the body by four-times and the maximum amount recorded in the participants' blood by 14-times; and
- No cognitive differences were identified, which is consistent with previous studies.

Birnbaum added: “For epilepsy patients, a goal is to maintain consistent blood concentrations of drug. This study shows that CBD concentrations could vary significantly if patients take it differently, sometimes with or without food. Variations in blood concentrations could leave a patient more susceptible to seizures.”

January 27th, 2020

<https://www.healthueuropa.eu/high-fat-foods-increase-absorption-of-cbd-into-the-body/96910/>

Drug Interaction May Explain Cannabidiol's Effects On Severe Form Of Epilepsy

Findings from research on drop-seizure frequency in patients with Lennox-Gastaut syndrome have suggested an increase in N-desmethyclobazam exposure may explain the reduction in seizure frequency.

A drug-drug interaction between cannabidiol and anti-epileptic drug clobazam may explain why cannabidiol reduces the frequency of seizures in patients with a severe form of epilepsy, researchers have reported in the *British Journal of Clinical Pharmacology* (28 October 2019)^[1].

The research team used clinical trial simulations to investigate the effect of cannabidiol 20mg/kg/day on drop-seizure frequency in patients with Lennox-Gastaut syndrome.

Using population-pharmacokinetic models, the researchers simulated the GWPCARE3 trial — one of the trials that led the US Food and Drug Administration to approve the use of cannabidiol as an anti-epileptic drug.

In the simulation, patients taking 10mg or 20mg clobazam were assumed to have a two- to seven-fold increase in N-desmethyclobazam exposure.

Findings from the simulation suggest that the effect of cannabidiol on the reduction in seizure frequency observed in previous clinical trials may be explained by a six-fold increase in N-desmethyclobazam exposure, which occurs when patients are treated with both 20mg clobazam and cannabidiol.

Geert Jan Groeneveld, chief scientific and medical officer at the Centre for Human Drug Research in Leiden, the Netherlands, said: “The effects of cannabidiol on seizure frequency in Lennox-Gastaut patients could be explained entirely through estimated elevations of blood levels of clobazam, which might mean that cannabidiol in itself may not have any, or at best limited, anti-epileptic effects.”

References:

^[1] Bergmann K, Broekhuizen K & Groeneveld G. Clinical trial simulations of the interactions between cannabidiol and clobazam and effect on drop-seizure frequency. *Br J Clin Pharmacol* 2019. doi: 10.1111/bcp.14158

<https://www.pharmaceutical-journal.com/news-and-analysis/research-briefing/drug-interaction-may-explain-cannabidiols-effects-on-severe-form-of-epilepsy/20207605.article?firstPass=false>





What You Need To Know About Secondary Impotence (As Related To Epilepsy)

Erectile dysfunction or impotence is described as the inability of a male to achieve or maintain an erection sufficient for satisfactory sexual performance.

Erectile dysfunction is the most common sexual problem in men, affecting around 30 to 50% of men throughout life but commoner as the age increases. Erectile dysfunction strains the intimate relationships of affected men, reduces their quality of life and causes self-esteem problems.

Typically, erectile dysfunction is a complex condition involving many paths. As such, management may be difficult sometimes. It may also be a symptom of a more serious underlying condition. Secondary impotence describes erectile dysfunction in someone who had achieved and sustain an erection for a long time before recent events. Having an inability to achieve an erection or sustain it once in a while is no great concern. However, persistent problems should warrant a visit to your doctor.

How Does An Erection Occur?

In normal circumstances, an erection of the penis is caused by joint actions of the brain and spinal cord, nerves, hormones (chemical messengers in the body), and blood vessels. A problem in any of these processes can cause an inability to develop or sustain an erection. An erection may occur in response to touch, smell and visual signals. It may also be evoked by thought or memories.

What Causes Erectile Dysfunction?

The main causes of erectile dysfunction are

1. **Organic causes:** Diseases of blood and blood vessels (e.g. Smoking, diabetes, coronary artery disease), hormonal disorders, drug usage and nerve problems are a common cause of erectile dysfunction.
2. **Psychological causes:** People with anxiety disorders (including performance anxiety) or depression may have low libido or find it difficult to have or maintain an erection.

The following are important considerations in erectile dysfunction are:

1. **Partner factors:** Their sexual interests and overall health status.
2. **Relationship factors:** Communication problems, differences in desire for sexual activity or partner violence.
3. **Individual factors:** Prior sexual or emotional abuse, existing psychiatric conditions (anxiety and depression), prior surgery or accidents, especially in the groin area.
4. **Culture or religious factors:** Inhibitions or conflicted attitudes to sex.
5. **Medical factors:** Existing medical illness such as diabetes, hypertension, epilepsy, sickle cell anaemia or drugs such as anti-hypertensive, antipsychotics, and anti-ulcer medications. Ageing may also reduce one's ability to start or maintain an erection.

How Is A Diagnosis Of Erectile Dysfunction Made?

The first step is having a thorough consultation with a medical doctor who will enquire about the condition as well as prior sexual history. Questions will be asked about current medical illnesses (such as diabetes and hypertension), the use of medications (such as antihypertensive and antidepressants), and psychosocial issues. A physical examination will also be carried out to assess the blood pressure, heart rate, the genitals and surrounding structures as well as the body in general.

This clinical assessment is followed by blood tests, urine analysis, and hormonal tests. In some cases, ultrasound scans of the penis and tests to uncover the cause of the condition. Special tests may also be carried out to assess the functionality of the muscles of the penis.

How Is Secondary Impotence Managed?

If a cause of the condition is found, a management plan is started immediately. The following are ways by which treatment is proffered:

1. **Treatment of the cause of the condition:** This may be the cessation of a particular medication or the start of another medication.
2. **Sex counselling and lifestyle changes:** Usually, a referral to a sexual counsellor is made for assessment. Lifestyle changes are also suggested (cessation of smoking, weight loss, increased activity levels, and reduction of alcohol intake).
3. **Oral and Injected Medications:** Hormonal pills and special medications (e.g. Viagra, Cialis) for erectile dysfunction may be prescribed for use before the onset of sexual activity.
4. **Surgery:** Where indicated, surgery may be offered as a cure for erectile dysfunction or as a means to implant special devices within the penis that helps with the maintenance of erections during sexual activity, especially after the failure of medications and other therapies.

Special devices: These include vacuum pump devices and constrictors worn on the penis before sexual activity.

January 26th, 2020
Dr. Zubair Abduhlai

<https://guardian.ng/life/what-you-need-to-know-about-secondary-impotence/>





Hellested's Seizures

In ages past, people with seizures were considered "possessed" and ostracized or worse. Today we know seizures are a "mis-fire" in the neurons of the brain.

While some people suffer seizures after a head injury, others have them from birth. Stress, fatigue, alcohol or lack of sleep may increase the likelihood of seizures. However, in some cases flashings lights, a sudden noise, touch, motion, a specific song, music or even laughter may trigger a seizure.

Hellested's seizures are in the category known as reflex epilepsy. A reflex epilepsy seizure results from a specific trigger.

For instance, walking up steps would not trigger a seizure because it was a planned action. However, stepping on an uneven patch of sidewalk might trigger a seizure because the unevenness was unexpected.

Looking at twinkling Christmas lights would not be a problem because it was planned and expected. In contrast, having flashing emergency lights suddenly appear around a corner might well trigger a seizure.

Hellested's seizures are very specific. Those who are triggered by one thing, such as their right foot hitting an uneven sidewalk are not triggered by the lights that would trigger another individual.

Since the seizures are quite brief, maybe only 20 seconds, and specific to only one trigger they often go undiagnosed. The seizure is thought to be a moment of inattention by those who see them. For the person having the seizure they may have a feeling they were startled. This is why many individuals with Hellested's seizures are not diagnosed until adulthood.

Dr. Elson L. So of the Mayo Clinic Alix College of Medicine in Rochester, Minnesota treated a woman who started having seizures in church when hearing highly emotional hymns. She would blank out and drop her hymnal. Electroencephalogram (EEG) studies of her brain found slow, emotional songs triggered her seizures while faster tunes had no effect. She was diagnosed with musicogenic epilepsy and successfully treated with anti-seizure medication.

In addition she wears earbuds connected to an iPod that plays classic rock and roll from her youth. She can talk to friends, watch TV and talk on the phone all without a problem. The music serves as a filter for her.

With musicogenic epilepsy it is unknown whether it is the emotion the music evokes that causes the seizure response or if it is the rhythm of the music itself that causes the response. Further studies are being done.

Interestingly it has been found that certain music helps prevent seizures in some people with epilepsy, while others have the exact opposite reaction. Further study of the phenomenon is ongoing.

In some cases the area of the brain causing the seizure can be pinpointed. Dr. Alan Ettinger, a neurologist at North Suffolk Neurology in Commack, New York, used an EEG and a PET scan to pinpoint an area in the right mesial temporal lobe of a patient's brain that was causing her musicogenic seizures. He surgically removed the problem area and she no longer has seizures.

Some seizures are triggered by laughter. A patient who was watching a comedy show would start having a seizure when he started laughing. He also responded to medication. Note that laughing followed by a seizure is not the same as gelastic seizures where uncontrollable laughter is the symptom of the seizure, not the cause of the seizure.

If you suspect your child is having Hellested's seizures consult your family doctor.

Mrs. Theil is a child advocate in Wayne and Holmes counties. She can be contacted at BeverlyVT@aol.com.

January 18, 2020

Beverly Thiel

<https://www.beaconjournal.com/news/20200118/hellesteds-seizures>





Epilepsy News From Around Alberta



Changes to Income Support and AISH Payment Schedule

The monthly Income Support (IS) and Assured Income for the Severely Handicapped (AISH) payment date is changing to the first of the month, effective March 2020. When the first of the month is a holiday or weekend, benefits will be paid on the last business day of the previous month. For example, March 1 falls on a Sunday, so the direct deposit and mailing date will occur on Friday, February 28.

Having a consistent and predictable payment date that aligns recipient's monthly income with monthly costs will help clients better plan and budget for expenses from one month to the next.

Month of Assistance	Benefit Payment Date	Days Between Payments	Month of Assistance	Benefit Payment Date	Days Between Payments
2020			September	09-01-2020 (Sept. 1/20)	32
March	*02-28-2020 (Feb. 28/20)	31	October	10-01-2020 (Oct. 1/20)	30
April	04-02-2020 (Apr. 1/20)	33	November	10-30-2020 (Oct. 30/20)	29
May	05-01-2020 (May 1/20)	30	December	12-01-2020 (Dec. 1/20)	32
June	06-01-2020 (June 1/20)	31	2021		
July	06-30-2020 (June 30/20)	29	January	12-31-2020 (Dec. 31/20)	30
August	07-31-2020 (July 31/20)	31	February	02-01-2021 (Feb. 1/21)	32

*Clients signed up for direct deposit will receive their benefits on the payment dates. Clients who receive benefits by cheque will receive their payment in the mail on, or within 3 business days of, the payment date.

How To Prepare:

- Plan ahead and adjust the timing of your monthly bill payments, if needed.
- Contact your caseworker to discuss your situation.
- Sign up for direct deposit to get your benefits faster than by mail, or talk to your caseworker for assistance.

More Information:

Call your caseworker of the Alberta Supports Contact Centre at 1-877-644-9992 (toll free in Alberta).

March Is Epilepsy Awareness Month

March is Epilepsy Awareness Month and March 26th is Purple Day.

The EEA will have a booth at the Farmer's Market on March 7th. Please come visit us!

The Province and City of Edmonton will be proclaiming March 26th
as Purple Day and the

High Level Bridge will be lit in purple.

If you are planning any Epilepsy Awareness events or Purple Day Events at your school or in your community, please let us know. We would love to post them on our Facebook Page.





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)
- ◆ Annual 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

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...*