

NOVEMBER - DECEMBER 2016

FOCUS ON EPILEPSY

THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION
The Epilepsy Association of Northern Alberta - Our 56th Year of Service

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

Member Outings & Activities

November

Fun BINGO for Prizes

Friday, November 25th, 1:00 – 3:00 pm
EEA Office
(Pre-register by Noon, Nov. 24th)

The November
Member Outing
Is being held the
first weekend of
December—See
Below.



December

A Christmas Karol, Nativity Play

Saturday, December 3rd @2:00 p.m.
"Old" Royal Alberta Museum Theatre
12845—102 Avenue
Meet at Front Doors of the Museum @
1:45
(Pre-register by Noon, Nov. 30th)

Christmas Lunch & Social

Saturday, Dec. 10th, 12:00 - 3:00 pm
Central Lions Seniors Centre
11113 - 113 Street NW
(Pre-registration by Noon, Dec. 7th)

Fun BINGO for Prizes

Friday, December 23rd, 1:00 – 3:00 pm
EEA Office
(Pre-register by Noon, Dec. 22nd)

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

HANUKKAH



CHRISTMAS



NEW YEAR'S
EVE



FREE MEMBER ACTIVITY

A Christmas Karol: The Karol Wojtyla Annual Nativity Play

December 3rd @ 2:00 p.m.

"Old" Royal Alberta Museum Theatre
12845—102 Avenue

Pre-register by noon, Nov. 30th



Annual Christmas Lunch and Social

Saturday, December 10

For more details see [page 3.](#)

"Help Seize The Day!"

Thursday, March 23rd, 2017, During
Epilepsy Awareness Month

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

Further Details on [page 8!](#)



2017 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

When: Thursday, February 23rd

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 1:00 - 3:00 p.m. in the EEA office.)

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

(Support Group has been moved to Tuesdays.)

Tuesday, November 8th, 2016

Tuesday, December 13th, 2016



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...Ann Gillie
Treasurer...Anna Tymoszejko
Secretary...Cameron Reid
Executive Director...Gary Sampley
Directors-at-Large:

| | |
|----------------|-----------------|
| Tammy Anast | Szymon Bamburak |
| Guy Doucette | Erin Duke |
| Doug Griffiths | Craig Heyland |
| Tim McCallen | Anne Starreveld |
| Brian Wilkie | |

STAFF

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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

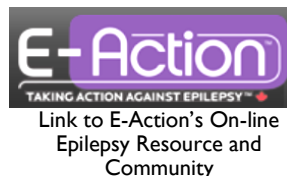
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Edmonton, AB T5M 3K2



(780) 488-9600
(780) 447-5486 fax
1-866-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

Our 2016 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 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.






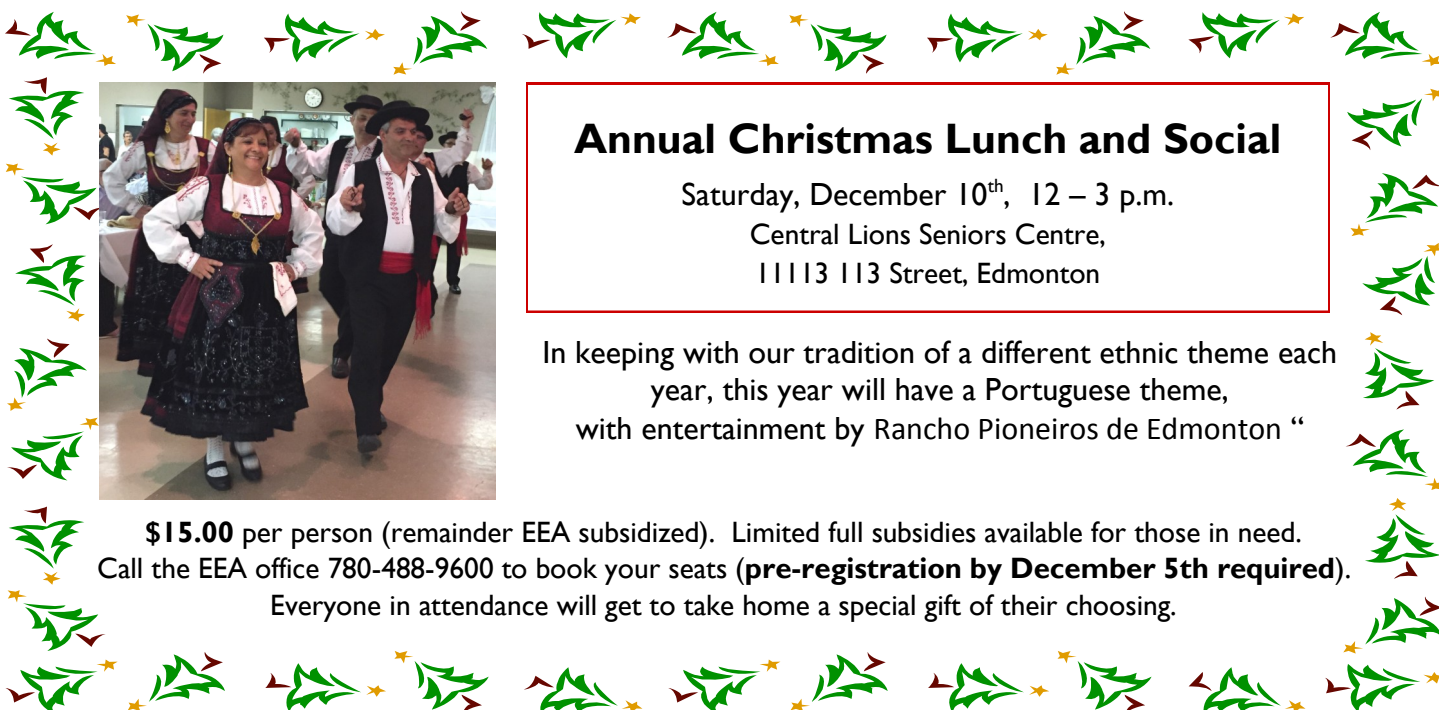
Forty years ago, Dr. Elout Starreveld co-founded the Adult Convulsive Seizure Clinic at the Glenrose Hospital in Edmonton. He recently retired as the Director of the ACDC. On November 3rd, Dr. Starreveld was honoured in front of a capacity crowd in the Glenrose Auditorium. The inscription on his presentation read:

**PRESENTED WITH DEEP APPRECIATION TO
DR. ELOUT STARREVELD
IN RECOGNITION OF YOUR MANY YEARS
OF EXCEPTIONAL SERVICE
TO THOSE WHO LIVE WITH EPILEPSY
BY YOUR COLLEAGUES, YOUR PATIENTS,
YOUR STAFF AND THE EPILEPSY
COMMUNITY.**

**WE ARE PROUD AND GRATEFUL TO HAVE
KNOWN YOU.**



L. to R. Dr. Starreveld, ACDC R.N. Kim Mahe, EEA Executive Director Gary Sampley, and ACDC Director Dr. Ken Makus



Annual Christmas Lunch and Social

Saturday, December 10th, 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 Portuguese theme, with entertainment by Rancho Pioneiros de Edmonton “

\$15.00 per person (remainder EEA subsidized). Limited full subsidies available for those in need.
Call the EEA office 780-488-9600 to book your seats (**pre-registration by December 5th required**).
Everyone in attendance will get to take home a special gift of their choosing.

2016 Garage Sales - A Success!

EEA held two fundraising garage sales - one in May and one in September. The total money raised from sales was \$5140.65. which will go to help fund EEA Programs and Services
Thank you to all our item donors and volunteers who worked the events!





News from the EEA Office



Collective Kitchen Program Starting in January 2017

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 13, February 10, March 17, April 14, May 12 and June 16. Interested members can phone Sharon at the EEA Office at 780-488-9600 to register. Registration is limited to **eight** participants.

2017 EEA Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2017, 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, 2017

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 2017 "Achiever of the Year" Award, please do so, in writing, to the EEA office by **March 1st, 2017**.

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

Does Your Child or Teen Have Upcoming Sports, Arts, 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, Cultural 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.





News From The EEA Office



Mirella Nardi of Alberta Blue Cross presents EEA Executive Director Gary Sampley with 420 ETS Bus Tickets for the use of our members in need who do not qualify for the AISH bus pass. The tickets are a god-send for us, as our annual allotment of ETS Bus Tickets received in April was totally depleted in October.

Thank you Blue Cross for your generosity and caring!



**EEA Member Tianna Lizotte, Age 14,
Fort Vermillion, AB
4th Princess, Miss Teen Canada Globe,
2016**

Read Tianna's Story Online in the March/April and May/June Editions of the EEA Newsletter



On her return from the 2016 Miss Teen Canada Globe Events, Tianna presents EEA Executive Director Gary Sampley with the proceeds of her fundraising for epilepsy.

Thank you Tianna and Congratulations!!





Halloween Potluck, EEA Office





Halloween Potluck, EEA Office





Help Seize the Day!

In support of Epilepsy Awareness,
Please Join Us In
A Celebration of Fine Food and Wine

Thursday, March 23rd, 2017, 6:00 p.m.
Yiannis Taverna Restaurant
10444 - 82 Avenue

Tickets: \$125

Up-scale entertainment, numerous and diverse silent
auction items, 50/50 draw, wine-tasting contest,
mystery guests and other attractions.

Our M.C. for the evening:



Doug Griffiths
Author, EEA Director,
Former Alberta Cabinet Minister

Tickets are available through Yiannis,
780-433-6768 or

Edmonton Epilepsy Association,
780-488-9600

info@edmontonepilepsy.org





This is What It Is Like To Be A Young Person With Epilepsy

It isn't easy, but you can't let it win.

Socialising, sleeping, relationships and anxiety These are just four of the things that have been affected since my diagnosis of epilepsy last year. Epilepsy isn't really something that people can notice about you. I can go months without any problems and then suddenly one day I'm coming to my senses with a paramedic leaning over me, muscles aching all over and a headache that can make a hangover look pleasant. Having this in general is the bane of my life, having this whilst being a student is much worse.

It is difficult to fully describe how epilepsy makes you feel while being a student. To start there's basically two positives—I have a reason to sleep longer and I won't spend money on events or alcohol as much. While this may sound like a blessing to many, when it's weighed against the negatives, there really are not blessings here.

You have to limit yourself on a night out

The whole idea of a drinking culture at university is massively shrunk. At first, I didn't fully take this seriously, if there was an opportunity to go out, I would take it. I presumed I would be fine and could take care of myself easily. But there's only so many times you can lie to yourself that the strobing in a club won't hurt your eyes. There's only so many times you can throw up and try everything to stop yourself from flinching. These moments may be few and far between, but when they do happen—they happen badly. It makes me scared to be put into these situations, I'm constantly thinking ahead and assessing everything in my life. Is it a pain? Of course it is. At the start of a night out I can tell if it's going to go one way or another. I may not necessarily have a seizure—I'll instead just think about how I might have one through the whole night, putting me in a disgusting state of paranoia. This then also affects the people around me, it amplifies onto their mood and their night—because I have to make sure they're made aware how I'm feeling for my own safety and piece of mind.

"If I don't go out, then no one has to worry about me"

Recently, especially for me, there's a constant fear which has escalated into pure anxiety in which I feel like me being around others on a night out is simply a nuisance. If I don't go, nobody has to "worry" in my mind. Everyone close to me knows what to do if I have a seizure, and I've been incredibly fortunate to have these people in my life. But the fact that every time I'll go out, the fact that these people will be focusing part of their attention on me almost makes me feel terrified. Almost as if there's pressure on me not to have one because of the consequences it will have upon others. Doctors, counsellors and those close to me will constantly reiterate that there's no need to worry and everything is all in my mind, the thing is I know they're right. Unfortunately, my brain works in peculiar ways, and can't believe it.

It doesn't have to limit you

Sure, if I have a seizure I can't drive for a certain time afterwards and I'll spend 50 per cent of a night out in fear of dropping in the middle of a club. But I won't let it win, and neither should you. In some cases then yes, chances are you won't be able to do everything you set out to. But so what? You can sit around and spend whatever time you have left crying and letting it control your life crying or you can find a way to embrace it, tell it to "fuck off" and live your life the best way you can even with certain limitations. I may never be an astronaut but I can happily say there hasn't been a night out in months in which I've forgotten something that happened, I have this pleasant collection of memories—which alternatively does wonder when holding friends accountable for money owed or trying to impress my girlfriend with obscure things we've done. The fact is, six days out of seven during the week I can wake up feeling like shit, as I have recently, I can have zero motivation to go into lectures and just want to spend the time locked up in my room listening to bleak music and wondering if Tumblr will solve all my problems. But I don't. Because if I do then I'm simply doing what my mind tells me to do every day, and I'll never achieve anything. You see people all the time who manage to live every day to the fullest who've got no limbs or struggle to survive on their own, and epilepsy is nothing near as bad.

Your friends do so much for you

To those who have been affected by me one way or another, and regardless of what you say you know who you are, I would just like to say this... I'm sorry. I'm sorry for having to be anti-social on a night out and not get as involved. I'm sorry for having to go to bed early or make it seem like I need to be attended to. I'm sorry for bringing up a concern in my mind when so many of you have more important things to focus on. I am one for making no excuses when I know I've done wrong, and there's probably many a time when you wanted to just leave me alone or feel the need to change what it is you're doing to make sure I'm okay when in reality it's irritable for you. And I hope that my kindness towards these people is acknowledged because they've done so much for me and the need to be kind to others outweighs that of being kind to myself, especially those that have been there for me. I'd like to have the self-belief that one day this will end, that these concerns will vanish, and I'll be able to live my life without fear. I battled with it, became terrified of it, and am now in the acceptance stage that is the grieving process. And whilst I may wake up constantly tired, bitter, anxious or a plethora of other negative objectives, I know that it won't win, because I won't let it.

October 25th, 2016, Tom Reynolds

<http://thetab.com/uk/falmouth/2016/10/25/like-epilepsy-student-struggles-young-person-543>





Epilepsy News From Around Canada



Cop With Epilepsy Says Edmonton Arrests Show Seizure Training Should Be Mandatory



A cop who has epilepsy says two high-profile arrests in Edmonton are further proof seizure training should be mandatory for police officers in Canada. Marcel Allen, a constable with the Ottawa police service, says he has woken up in handcuffs three times after having seizures on the job, and was Tasered in front of his children while off-duty near Parliament Hill in 2008.

'It's frustrating that they have access to it, but they don't use it. And they deny even having it.'

- Neil Ryley, epileptic arrested in Edmonton

Allen said when he read about two Edmonton men with epilepsy who were arrested and then charged for behaviour while displaying symptoms from epileptic seizures, he could relate. "It's very hard to explain," he said, as he tried to describe the feeling of coming back to consciousness from a seizure and finding himself in police custody. "There is that disorientation, the uneasiness, the fatigue. And then you're trying to figure out exactly what you're doing here."

Allen was never charged, but he said every time a seizure landed him in handcuffs, he was further inspired to develop a training program for Canadian police. Called "Recognition and Response to People Having Seizures," the program is accredited by the Canadian Epilepsy Alliance and published on the Canadian Police Knowledge Network website. Allen believes the module should be required training for officers across the country. "We don't want to have a contentious relationship here," he said. "But with all these things that are going on right now, we're on a powder keg just waiting to happen."

He said he was particularly shocked to hear about the case of Neil Ryley, whose family called an ambulance for help when Ryley displayed aggressive episodes during or after a seizure. Ryley claims that several officers arrived instead and beat him in his bedroom before the ambulance arrived.

Their thought in this case should be the well-being of that home and the well-being of that person," Allen said. "So how that results in that person being assaulted, I don't understand."

Ryley said he was surprised to learn that there is a seizure training resource available online for Canadian police officers. The Edmonton Epilepsy Association provided an older seizure training video to the local police service eight years ago, but spokesperson Cheryl Sheppard said officers have not been able to locate it.

"It's frustrating that they have access to it, but they don't use it and they deny even having it," Ryley said. "Because there's lots of people that have epilepsy. And I think they should be concerned about what can happen."

Ryley's most recent court appearance was delayed when he was in hospital for two weeks while doctors observed his seizures to see if he is eligible for surgery to alleviate them. (He is not eligible.)

The Crown recently [withdrew all charges](#) in a second, similar case in Edmonton from the summer. The man who was arrested did not want to be identified in the media.

There are roughly 300,000 people in Canada who have epilepsy. A 2011 national survey found only four per cent of respondents reported their medication allowed them to live seizure-free.



Marcel Allen manages his seizures with medication, exercise and healthy eating. As a constable, he does not drive or carry a gun. (Epilepsy Ontario)

October 19th, 2016

Marion Warnica, CBC News

<http://www.cbc.ca/news/canada/edmonton/cop-with-epilepsy-says-edmonton-arrests-show-seizure-training-should-be-mandatory-1.3811029>

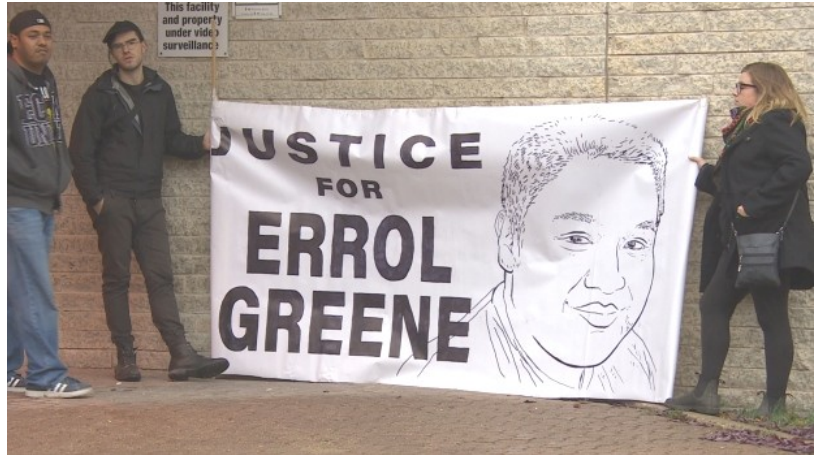




Denial of Medicine to Errol Greene May Have Had Deadly Consequences, Epilepsy Expert Says

When a person with epilepsy can't access their medication the consequences can be deadly, according to an epilepsy expert. Suzanne Nurse, director of information and client services with Epilepsy Ontario, says there are a lot of unanswered questions about the death of Errol Greene, a 26-year-old man who died at the Remand Centre in Winnipeg on May 1. CBC News obtained a copy of the detailed autopsy report proving that Greene was not administered his seizure-controlling medication while in custody and detailing how his epileptic seizure was handled by the corrections office.

"It really is difficult to find the words to describe how you feel about somebody being put in a situation where the medication that they need to control essentially a life threatening condition is not available to them," Nurse said. The autopsy report stated that Greene had two seizures, and after the first he was handcuffed, shackled and held face down. An ambulance was called after the second seizure which happened about 45 minutes later while Green was inside his cell. Nurse said people with epilepsy must monitor their medication carefully and if they don't have access to it the blood levels of the drug fall, putting the person at risk of having a seizure. "They may be at risk of having more severe seizures and more prolonged seizures than they would have had previously," she explained. Although seizures vary, Nurse said later phases of a prolonged seizure can reduce oxygen and blood supply to the brain, causing a brain injury. According to the autopsy report, the immediate cause of death was "acute hypoxic-ischemic encephalopathy," which simply stated means a sudden lack of oxygen to the brain. Greene was also restrained during his seizure, and according to his autopsy report that could have contributed to his death.



"You really wonder whether any of that response was required," Nurse said. "If the individual was having a seizure and was not aware of where they were and what was happening, they may have been confused. It would be very unlikely for somebody to have any type of directed aggression during a seizure." Greene's family is calling for an inquest into his death, but that remains in the hands of the Office of the Chief Medical Examiner. Andrew Swan, now NDP Justice critic and former Justice Minister, said that an inquest is warranted. "This is not about assigning fault or blame to anybody it's about trying to get to the bottom of it," he said. Roughly 40 people held a rally outside of the Remand Centre Wednesday night demanding justice for Greene and three other inmates who have died in custody this year. Cecil James' sister, Kinew, died at the Regional Psychiatric Centre in Saskatoon, Sask. in 2013. An inquest into her death has been postponed. "I know what they are going through and their quest for answers," James said. "It's absolutely shocking and you expect someone to be home soon to do their time and return home to you and they don't return home. It's absolutely heart breaking and I feel the need to come and support these families whenever I can."

October 26th, 2016
Kelly Malone, CBC News

<http://www.cbc.ca/news/canada/manitoba/errol-greene-epilepsy-medicine-denial-1.3823273>

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



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

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...*