

# SEPTEMBER - OCTOBER 2016



## FOCUS ON EPILEPSY



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

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

### Member Outings & Activities

#### September

##### Soccer Game

##### FC Edmonton vs. Miami FC

Sunday, September 11th @2:00 p.m.

Clarke Stadium, 11000 Stadium Road

(next door to Commonwealth Stadium)

**Pre-register by September 7th)**

##### Fun BINGO for Prizes

Friday, September 30th, 1:00 – 3:00 pm

EEA Office

**Back to School!**



#### October

##### Fun BINGO for Prizes

Friday, October 21st, 1:00 – 3:00 pm

EEA Office

##### Halloween Potluck

Saturday, October 29th, 11:00 - 2:00 pm

EEA Office, 11215 Groat Road

**(Pre-registration deadline October 26th)**

**Happy Thanksgiving**



**Please Note:** Transportation to Member Activities is not provided when public transit is available. EEA Office staff would be happy to assist you with transit travel planning if needed.

### FREE MEMBER ACTIVITIES



##### Soccer Game, FC Edmonton vs. Miami FC

Sunday, September 11th @2:00 p.m.

Clarke Stadium, 11000 Stadium Road

FC Edmonton is currently the top team in the North American Soccer League.

Ticket will include a free hot dog, pop and on-field access for post game autographs. The Game will be followed by the Second Annual Woodall Cup Charity Game in honour of Constable Daniel Woodall (British Selects vs EPS Blues). Donation of Non-perishable Items for the Food Bank would be appreciated.

##### Halloween Potluck

Saturday, October 29th, 11 am – 2 pm

EEA Office, 11215 Groat Road

**(Pre-register by October 26th)**

Halloween costumes are optional but everyone who comes in costume will receive a prize.



**GARAGE SALE**

The EEA will be having a Garage Sale out of the garage behind the Office at 11215 Groat Road on Friday and Saturday, September 16th and 17th. Donations of clean, saleable goods for the sale will be much appreciated. If you wish to donate, please contact us. No clothing or books please.

##### Sale Hours are:

**Friday, September 16th,**

**10:00 a.m.—7:00 p.m.**

**Saturday, September 17th,**

**9:00 a.m.—5:00 p.m.**

### 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, September 13, 2016

Tuesday, October 11, 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](mailto:info@edmontonepilepsy.org)

## **BOARD OF DIRECTORS**

**President...**Cheryl Renzenbrink  
**Vice President...**Ann Gillie  
**Treasurer...**Anna Tymoszejko  
**Secretary...**Cameron Reid  
**Executive Director...**Gary Sampley  
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Guy Doucette	Erin Duke
Doug Griffiths	Craig Heyland
Tim McCallen	Anne Starreveld
Brian Wilkie	

## **STAFF**

**Gary Sampley...** Executive Director & Chief Operating Officer  
[gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

**Sharon Otto...** Program Manager & Education Coordinator  
[sharon@edmontonepilepsy.org](mailto:sharon@edmontonepilepsy.org)

**Dr. Sunny Kim...** Counsellor  
[sunny@edmontonepilepsy.org](mailto:sunny@edmontonepilepsy.org)

**Cam Reid...** Volunteer Coordinator  
[cam@edmontonepilepsy.org](mailto: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](mailto:info@edmontonepilepsy.org)  
[www.edmontonepilepsy.org](http://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](mailto:gary@edmontonepilepsy.org)

### **Bus Tickets Available for Members in Reduced Circumstances**

Please note that we now have our 2016 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 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](http://www.edmontonepilepsy.org), and click on the [Canada Helps](#) Logo. This donation program gives you the ability to instantly print off a donation receipt.





## Kellen Colthorp is EEA's 2016 Achiever of the Year!



Kellen receives her award as EEA's Achiever of the Year from EEA Executive Director Gary Sampley at the August 13th, EEA Annual BBQ.



Kellen celebrates after the presentation with Gary and Sharon Sampley and EEA President, Cheryl Renzenbrink.

The Achiever of the Year Award is presented annually to an individual living with epilepsy who has achieved significant success in life, inspiring others in the process.

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## Epilepsy and Autism

It is estimated that nearly 33 percent of people with autism spectrum disorder also have epilepsy.



In recognition of this, Autism Speaks Canada have graciously given us the opportunity to share information on this situation by giving us an information booth at their annual walk in Rundle Park on Sunday, September 11th from 9:30 am to 1:30 pm.



Come visit us there to learn more about these shared conditions.



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## First Notice!

### Annual Christmas Lunch and Social

Saturday, December 10th, 12 – 3 p.m.  
Central Lions Senior Centre, 11113 113 Street, Edmonton

**DOOR PRIZES/GIFT EXCHANGE**

In keeping with our tradition of a different ethnic theme each year, this year will have a Portuguese theme.

**\$15.00** per person (remainder EEA subsidized). Subsidies available for those in need.

Call the EEA office, 780-488-9600, to book your seats (pre-registration required).





## Purple Lemonade for Epilepsy

The Grimoldby family of Spruce Grove, Alberta, held their annual "Purple Lemonade" sale in July. Ashley lives with epilepsy. Along with big sister Katelyn, the girls sold lemonade at their parents' garage sale. At the end of the weekend the girls had raised an impressive \$183.05, which they have donated to the Edmonton Epilepsy Association to support our Programs and Services.



## Nominate your Employer as the EEA Employer of the Year



## Do You Have Epilepsy???

Do you have a great and supportive Employer that recognizes and encourages the many contributions people with Epilepsy offer their fellow employees and workplace?

Nominate them for the 2016 Edmonton Epilepsy Association Employer of the Year Award. Contact us to find out how: 780-488-9600 or [gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

Nomination Deadline is October 1st, 2016

## Next EEA Computer Training Program Begins in October 2016

EEA members who wish to learn the basics of how to use a computer and have the opportunity to obtain a free laptop computer are invited to register now.

- ♦ The training program will run for four consecutive Mondays, from 1:00-2:45 p.m., commencing October 3rd;
- ♦ Registration is limited to 4 participants;
- ♦ Education Coordinator, Sharon Otto, will deliver the training;
- ♦ This program is a partnership of the EEA and the United Way InKind Exchange.



To register, call Sharon at 780-488-9600 or e-mail [info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)

## First Notice!

## "Celebrate the Grape"

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

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

Further Details To Come!







## A Donation With History!

Jo A. Steele of Smoky Lake, AB presents an Edmonton Eskimos Football Helmet worn by #42, Dan Kepley in the 1973, 1974 and 1975 CFL Seasons and Grey Cup Games.

Dan Kepley donated the helmet to ACT for a Silent Auction in 1976, but, in retrospect, decided he didn't really want to part with it. He came to the ACT fundraiser and bid on the helmet, but lost out to Lorne Hooper (Danny Hooper's uncle).

Lorne gave the helmet to family friend, Jo, then 12, who had epilepsy and who had been advised to wear a protective helmet. Jo already had another Eskimo helmet which she wore and kept Dan Kepley's helmet as a souvenir as he was her favourite player. Jo's Dad had Eskimo season tickets and they subsequently became good friends with Dan Kepley.

Don Carlson, President of the Eskimos and a family friend, arranged for Eskie's Equipment Manager Dwayne Mandrusiak to make periodic adjustments to the helmet Jo wore. Jo has donated the Kepley helmet to EEA so that we can use it as a fundraising item. We intend to sell it at our March 23rd, 2017 Silent Auction with the proceeds going to our Life Enhancement Scholarships for Children and Youth.



## 2017 Diary & Seizure Record Book

We have recently received our stock of 2017 Diary & Seizure Record Books, which can be picked up at the EEA Office or mailed to you on request.

Please note that, if needed, we have a limited number of the 2016 books, for recording seizures in the remainder of this year still available in stock.

## 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](http://www.edmontonepilepsy.org), or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.

## The Edmonton Epilepsy Association offers educational services that help to dispel assumptions and stereotypes as well as providing first aid and seizure-response information:

*Kids on the Block (KOB)* offers an entertaining, unforgettable educational puppet troupe that teaches children about epilepsy & seizures. Each performance consists of informative scripts followed by an interactive Q & A period with the puppets.

*Epilepsy in-services* are tailored to fit the needs of staff meetings, meetings with staff and families, and/or individual classrooms, including Health, Biology, Science and C.A.L.M. classes. Presentations are interactive and include footage of seizures, resource materials and scenarios.

To book these no-cost services, contact [sharon@edmontonepilepsy.org](mailto:sharon@edmontonepilepsy.org) or call the EEA office 780-488-9600.









# EEA BBQ & Gary Sampley Tribute Day—August 13th, 2016





## Birthdays & Butterflies—The First Chapter Of My Son's Epilepsy Story

We didn't know it yet, but by Thursday 18th February 2016 my healthy and lively 6 year old son Luke had Epilepsy and was having quite frequent Partial Seizures. We were on our way to the Isle of Man to celebrate my sister in law's 40th birthday. I had observed some "odd" behaviour Luke had been displaying, namely 10 or 20 seconds long episodes of; his body stiffening, holding his breath, his face turning red, eyes flickering, a slight moaning noise and then a little giggle and a big wide smile. I was pretty sure that he was just kidding around and in blissful ignorance was not concerned about anything more sinister.

During the birthday dinner on the Friday night, Luke had one of these episodes at the table whilst I was speaking to another mum (a friend of his aunt), and I asked her opinion did she think he was "putting it on" or had she seen anything like it before. She mentioned something called Petit Mal, which I had never heard of before, but it was at this stage I did start to think, hold on maybe there is something more here that needs to be investigated.

Over the next week I observed a further 6 or 7 seizures. I spoke with his school teacher who said she had noticed a remarkable deterioration in his concentration and attention since the start of the school term and she had been planning to move him to the front of the class to be closer to her. Up to this point Luke had met all his developmental milestones and was above average in most areas—described by his previous teacher as a real sponge and everything came easy to him in school. The following day his teacher observed him having a seizure in class, I had made an appointment with our GP for the Friday but I rang up for an emergency appointment and took him that afternoon.

At this stage the GP referred Luke to see a Paediatric Neurologist and I got a Private appointment for Tuesday 8th March for a Consultant in Temple Street in Dublin. During the next 10 day period, Luke continued to have in the region of 4-5 seizures per day, each lasting in the region of 20 – 30 seconds. I had to travel on business to the US (a very tough decision to make, and one I will continue to question was the right thing to do, but as a small business owner I felt I had very little option but to go, as it was one of the biggest events in the business diary.) One of the most distressing times I have ever experienced as a mum was when I was in a hotel room in Phoenix AZ, on a video call with Luke when he had a seizure, I was screaming down the phone hoping his dad would hear me at the other end (which he did!) but being completely helpless and thousands of miles away, it was a 5 day trip, but felt like a lifetime away from my baby.

On Sunday 13th March, Mother's Day Luke had had a number of seizures, predominately in the evening time – although in great humour, I was becoming increasingly concerned. In preparation for the appointment with the Neurologist on the coming Tuesday I had managed to capture some videos of the seizures and also had been keeping a detailed diary of when they occurred, what he was doing prior, the nature of the seizure and how he was afterwards.

That night, after I had put Luke to bed, he came back down to the living room around 30 minutes later and said he had had a "butterfly" in his sleep. To explain, at this stage I did not want to alarm Luke or his sister by using the word seizure or in reality to admit to myself that this could actually be epilepsy, so I asked him to give the episodes a name, and he chose Butterflies. Coincidentally I later learned that some people who have epilepsy have an aura which includes a feeling of butterflies in your stomach.

I suddenly realised that I had not even considered that Luke could also be having seizures in his sleep, so that night I kept his door opened and listened. Around 11.30pm that night I could hear the thrashing of bed clothes (in his sleep Luke was scissoring his legs in and out) and the familiar moaning sound and yes Luke was having a seizure whilst fast asleep, although his eyes were open. I kept him in bed with me that night (the first of many to come!) and he had a further 4 seizures, all of similar nature; so although Luke had an appointment with the Neurologist the following day, I was too concerned to wait, and took him straight to the Accident & Emergency Department in Temple Street Hospital that Monday morning.

Over the following 9 days Luke was hospitalized, given a Video EEG and an MRI and was formally diagnosed with Frontal Lobe Epilepsy.

For more on Luke's diagnosis and his refractory epilepsy, please visit [www.mysonsepilepsy.com](http://www.mysonsepilepsy.com). Follow Roisin McArdle on Twitter: <https://twitter.com/mysonsepilepsy1>

August 24, 2016

Roisin McArdle, Huffington Post UK

[http://www.huffingtonpost.co.uk/roisin-mcardle/birthdays-butterflies-the\\_b\\_11661948.html](http://www.huffingtonpost.co.uk/roisin-mcardle/birthdays-butterflies-the_b_11661948.html)







## How to Prevent Bullying of Children With Epilepsy, Other Medical Conditions

It can be a serious problem for any child, but for children with a medical challenge such as epilepsy, the risk is increased. Knowing the facts about bullying is the first step toward preventing victimization of children and teens with epilepsy or other medical conditions, and keeping them safe.

What exactly is bullying, and how does it affect the children involved? Bullying consists of aggressive behaviors that are repeated over time and involve an abuse of power by the perpetrator. It may take the form of verbal or physical abuse, or, especially for girls, cyberbullying through social media. The child who bullies learns how to use power and aggression to control and distress another, and the child who is victimized learns about losing power and becoming trapped in an abusive relationship. The lessons for both parties are clearly destructive. Contrary to what some people may think, bullying is not a normal part of healthy adolescent development and the suffering it causes may start early and last a lifetime.

As all too many parents know, the negative consequences of bullying and peer rejection may be quite serious. Compared to their peers, bullied children more often avoid school, perform poorly in their academic work, abuse drugs or alcohol, and think about suicide. In fact, teenage victims of bullying are five times more likely to be depressed, and far more likely to be suicidal, than their non-bullied peers. Since suicide is the third leading cause of death among adolescents in the U.S., this is indeed a very serious concern.

Why is the risk for bullying increased for children and teens with epilepsy and other medical conditions? Various factors may be involved, including depression, anxiety, challenges with impulse control or social isolation. If the child is prone to having seizures at school, or has other physical or intellectual disabilities, then the risk for bullying may be even greater. Recognizing that bullying might be taking place and taking action immediately is critical to protecting a child's basic human right to be respected and safe.

If you know a child or teen who is at risk for bullying, then perhaps you are wondering how you can help. The first step is communication. Most experts in pediatric mental health encourage adults to open a conversation about bullying with the child as early as possible, and for children at risk, to bring it up even before it appears that anything has happened. They recommend asking children directly about bullying, mood and suicidal thoughts, to encourage open communication and foster trust.

Once the topic of bullying is out in the open, then the important adults in the child's life may work together to resolve the problem. Direct conversation with the teacher or principal is an important step, so that the bullying at school can be stopped immediately. And to keep the bullying at bay, some schools are employing innovative new tools such as StandUp, a three-session, online, computer-based bullying-prevention program designed to help high school students develop skills for relating to others in healthy, non-violent ways.

School-based programs like StandUp teach teens to treat themselves and others with respect, avoid being a bully, get help if they are a victim of bullying and stand up to stop bullying when they see it occurring. Initial research on such programs has shown significant improvement in students' healthy relationship skills, resulting in a safer, more respectful environment.

It is also wise to broach the topic during routine visits to the child's physician, so that he or she may suggest appropriate interventions at home and at school and help treat any coexisting depression, anxiety or post-traumatic stress disorder. The doctor may recommend consultation with a psychologist or psychiatrist to speed recovery and to help the child develop the skills and understanding to move forward with confidence.

Reaching out to a child at risk for bullying may prevent untold emotional pain and suffering, and perhaps even save a life. The good news is that with open communication and modern bullying-prevention techniques, we can work together to protect our children and teens from victimization.

August 10th, 2016

Elaine Wyllie, M.D., U.S. News & World Report

<http://health.usnews.com/health-news/patient-advice/articles/2016-08-10/new-ways-to-prevent-bullying-of-children-with-epilepsy-and-other-medical-conditions>





## Dog Saves His Little Girl's Life Every Single Day

We often hear stories about dogs that are heroes but Jerry, a springer spaniel, is a certified trained seizure detection dog. His boss is a 3-year-old girl named Keanna who lives with [intractable epilepsy](#). Jerry's mission? Cuddle the bejesus out of her. You could say being a seizure detection dog has its moments.

Like this one.



And this one!



And ... jeez.



And then — this is the part where Jerry truly shines — about half an hour before Keanna is going to have a seizure, Jerry alerts the rest of the family. He just *knows*.

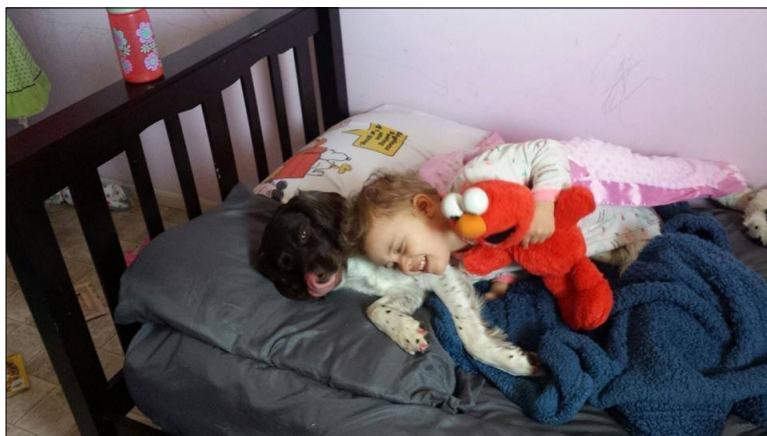
And he's always right. Keanna's family gets time to prepare for the attack, giving the girl medication that can even prevent the seizure from happening. It's a crucial alert that has saved the girl's life on countless occasions.

"When Keanna is having issues with her seizures or not feeling good, Jerry is stuck to her like glue," George Leonard, a master dog trainer with MSAR Service Dogs in Winnipeg, Canada.

It's good work if you can get it. Especially, when you literally worked your way up from the streets. Before he landed the job, Jerry was hauled into a shelter by animal control as a stray.

That's where a dog trainer from the Royal Canadian Mounted Police (RCMP) found him. He sent a message to Leonard: "I have found a dog that will be amazing. I am sending him to you. You will do great things with him, believe me."

At MSAR, Jerry's naturally friendly disposition and keen mind made him the perfect candidate for training to become someone's cuddle buddy lifesaving seizure dog. Someone like Keanna. Her condition means every seizure she has takes a physical toll on her brain. Leonard says if the attacks were not significantly reduced by the time she turned 3, Keanna would need surgery. But then, a year ago, Keanna met Jerry Springer.







After just two days in the family home, Jerry would let Keanna's mother know of an impending attack. At first, it was just a warning of a few minutes. Then 10 minutes. And, finally, half an hour. And soon, the dog who once needed rescuing so badly was rescuing his little girl every day.

Before Jerry moved into her life, Keanna was having 25 to 40 seizures per month. Now she's down to just one. "Jerry is a very special, one-of-a-kind dog," Leonard says. "The dog that no one wanted has found a place in the hearts of our organization and has changed and saved this little girl's life." Even Keanna's mother stopped sleeping in the girl's bed, watching over her throughout the night.

Jerry was more than happy to take her spot.



Keanna and Jerry live in rural Manitoba.

August 3, 2016

Ruby Brooks, Cutesy Stuff

<https://www.cutesystuff.com/2016/08/dog-saves-his-little-girls-life-every-single-day/>

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## Our Casino Proceeds



We have now received our Casino proceeds from the AGLC's second quarter Edmonton Casino Pool. Our share of the Pool was \$75,197.84. Thanks again to all the volunteers who worked on June 5th and 6th.

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## 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  
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*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...*