

SEPTEMBER - OCTOBER 2015



FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION
The Epilepsy Association of Northern Alberta - Our 55th Year of Service

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

Member Outings & Activities

September

Visit to the Devonian Gardens
Sunday, September 20, 1:00 - 4:00 pm
Free transportation leaving EEA Office;
details available upon registration
(**preregistration deadline Sept. 15**)

Fun BINGO for Prizes
Friday, September 25, 1:00 – 3:00 pm
EEA Office

Back to School!



October

Computer Training Program
Wednesdays, October 7, 14, 21, 28
1:00 - 2:45 pm
EEA Office
(**program registration required**)

Fun BINGO for Prizes
Friday, October 23, 1:00 – 3:00 pm
EEA Office

Halloween Lunch
Saturday, October 31, 12:00 - 3:00 pm
Midnight Sun restaurant
11003 124 St
Meet inside restaurant
(**preregistration deadline October 27**)

Happy Thanksgiving



FREE MEMBER ACTIVITIES



Devonian Botanical Garden
Sunday, September 20
1:00 - 4:00 pm

Midnight Sun Restaurant
Saturday, October 31
12:00 - 3:00 pm



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.

be your own boss

THE CHRONIC CONDITION SELF-MANAGEMENT PROGRAM FOR YOUTH

A free six-week youth & young adult workshop series on planning for everyday living.

Series begins on September 17th.

See [page 4](#) for details

“Celebrate the Grape”

Tickets still available.

Thursday, September 10, 2015

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

See [page 5](#) for details



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.

Wednesday, September 9, 2015

Wednesday, October 14, 2015

Support for Parents of Children with Epilepsy

No formal sessions are planned. See “Free Member Activities” for EEA’s upcoming family-friendly activities. For individual questions or concerns, please contact the EEA office for support and information.





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 Wendy at our office or e-mail her at info@edmontonepilepsy.org

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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

Wendy Sauve... Asst. to the Executive Director
info@edmontonepilepsy.org

Edmonton Epilepsy Association



EEA Partners with TD Canada Trust in Employability Program

Through the initiative of EEA member Tim McCallen, a Branch Manager with TD Canada Trust, members who are potentially interested in part-time positions as a bank customer service representative (Teller) or full-time positions such as a Financial Service Representative have an opportunity to submit a resume directly through TD's Prairie Region Human Resources Counsellor

For Further information contact EEA Executive Director, Gary Sampley, 488-9600 or gary@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



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



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.





Save the Date!

Watch for upcoming information on our Free Epilepsy Educational Forum,
"Epilepsy Combined with Other Neurological Conditions"
November 12th 6:30-9:00 pm at the Glenrose Rehabilitation Hospital Auditorium.



A Wonderful Memorial for a Young Life Lost

Naomi Hope Larson (pictured left) of Lloydminster passed away on Wednesday, June 3rd at the age of 26. This young mother, who lived with epilepsy, touched many lives during her time on this earth.

In remembrance of Naomi, the Fred North Charitable Foundation gave Naomi's parents a \$25,000 donation cheque payable to the EEA.

In the picture to the right, Naomi's four-year-old son, Lucas, presents the cheque to EEA Executive Director Gary Sampley. Behind Lucas are his grandparents, Dianna and Lorne Larson, and to the right are Naomi's caregivers from the University of Alberta Adult Epilepsy Unit, her neurologist Dr. Don Gross and her R.N, Micheale Davies.



Celebrating 33 Twice

EEA Board member Cam Reid celebrated two milestones with "33" in them this year.

This is Cam's 33rd straight year of volunteering with the Association, making him by far the longest-serving EEA Volunteer.

For well over 20 of those years, Cam has been participating in annual fundraising runs to raise money for the Association. This year was his highest-ever achievement. He brought in

\$3765 for EEA Programs and Services from his run in the St. Albert Mayor's Walk for Charity.

In calculating Cam's year-by-year fundraising, we discovered that his cumulative total from his efforts amounts to \$33,273.

33 years and \$33,000 for the EEA. Cam, we should clone you!

Congratulations and thank you.



Purple Lemonade for Epilepsy!

The Grimoldby family of Spruce Grove, Alberta, held their annual "Purple Lemonade" sale in August. Ashley (9) lives with epilepsy. Along with big sister Katelyn (11), the girls sold lemonade at their parents' garage sale. At the end of the weekend the girls had raised an impressive \$476.10, which they have donated to the Edmonton Epilepsy Association to support our Programs and Services.

Thank you for all your hard work!

Enhancing Accessibility at the EEA

The work to spruce up our new offices and yard continues.

One important step is enhancing the accessibility to our premises. We are looking forward to having an exterior wheelchair lift at our front door, scheduled to be installed within the next couple of weeks. This lift will provide wheelchair users and those with reduced mobility a safe and simple way to fully access our main floor.

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 13th from 9:30 am to 1:30 pm.

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





News from the EEA Office



be your own boss

THE CHRONIC CONDITION SELF-MANAGEMENT PROGRAM FOR YOUTH

If you are a youth or young adult aged 14-20 and live with one or more chronic conditions, you probably face many challenges. Alberta Health Services, in partnership with the EEA, is offering a free six-week workshop series on planning for everyday living.

September 17 & 24 and October 1, 15, 22 and 29 **Thursdays, 4:30-7:00 pm**
Edmonton Epilepsy Association, 11215 Groat Road NW

Supper Provided for All Participants

In a supportive environment with young people like you, you will learn:

- how to look after your condition and the various requirements associated with having a chronic condition
- how to carry on with school, homework, activities, social life, and relationships with friends and family
- how to handle the difficult emotions and stresses that come with living with a chronic condition

Contact 780-488-9600 or info@edmontonepilepsy.org to register. [Detailed flyer](#) available on EEA website.

Next EEA Computer Training Program Begins in October 2015

EEA members who wish to learn the basics of how to use a computer and have the opportunity to purchase a low-cost computer with a slim flat screen monitor, keyboard and mouse package are invited to register now.

- ♦ The training program will run for four consecutive Wednesdays, from 1:00-2:45 p.m., commencing October 1st;
- ♦ Registration is limited to 4 participants;
- ♦ EEA Assistant to the Executive Director, Wendy Sauve, will deliver the training;
- ♦ This program is a partnership of the EEA and the United Way InKind Exchange.



To register, call Wendy at 780-488-9600 or e-mail info@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.

Bus Tickets Available for Members in Reduced Circumstances

Please note that we now have our 2015 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. (Please note new EEA Office location.)



Transition Planning for Adulthood Workshop Series

Gateway Association is pleased to offer their popular transition planning workshop series twice this fall! Focused on parents/guardians of teens with intellectual disabilities, these workshops are designed to assist families as they undertake the process of transitioning their teen to adulthood. Parents/Guardians are lead through the process of visioning for the future and ensuring their teen has the opportunities and supports needed to succeed. [flyer](#)





Why We Moved and Why Our Offices Are In a House

Two years ago, the United Way of the Alberta Capital Region announced that they were going to be transitioning their funding impetus to "Creating Pathways Out of Poverty" over the following several months. The several months wound up being almost two years. In June 2014, all existing United Way funded Agencies were advised that, in November, we would have to reapply for funding as if we were brand new applicants. We did so apply.

In March this year, we were advised that we are going to be defunded by the United Way over a three year period of time, as we, and several other smaller Edmonton-area organizations do not fit neatly into UW's new funding direction of "Creating Pathways Out of Poverty". Several other Epilepsy Associations across the country have also lost their United Way funding. Most have now folded.

We are in disagreement with our United Way's decision, as about a third of people who have Epilepsy are unable to work and subsist on AISH or Income Support. However, we do not intend to let this setback end the good work of our Association. Luckily, our eleven consecutive years of financial surplus have left us in a very good cash flow situation.

We currently receive \$100,680 a year from the United Way, a little over 40% of our average annual \$250,000 budget.

This will reduce to approximately \$67,000 in 2016, to \$33,000 in 2017 and to zero in 2018.

Our Board of Directors decided to begin cutting costs this year to be in the full ability to absorb the impact of the first reduction in 2016 with no impact on the delivery of our Programs and Services.

Our first step in this process would be to move out of our leased premises into our own purchased building. As a Registered Charity, we are exempted from Property Taxes by the City of Edmonton.

At the time of receiving the bad news from United Way, we were renting 1801 square feet in a store front walk-in retail space on 124th Street at 110th Avenue. Our Lease was up on May 31st.

Our rent, including GST and common costs, was \$2285 a month (\$14.85 a square foot), or \$27,420 a year, 10.11% of our Expense Budget.

If we were to stay there, our landlord wanted a three-year renewal at an additional dollar a square foot in each of the three years. This would make our annual rental costs \$29,249 starting June 1st, 2015, \$31,105 starting June 1st, 2016 and \$32,951 starting June 1st, 2017.

Most commercial properties are way out of our price range. We therefore started looking for a well-maintained residential property of about 1200 square feet upstairs and a finished basement in an RF3 zone (which zoning would allow us to operate an office), near public transportation and with good

on-site and on-street parking availability. Our goal was to find such a property in a price range not exceeding \$405,000. We determined that we could put a maximum of \$115,000 of our own funds into this property.

The Epilepsy Trust, which already sponsors our annual Continuing Education Scholarships and Collective Kitchen Programme, committed to donate \$100,00 to the EEA, specifically for the purpose of helping enable us to purchase our own building.

Also, The T.R. (Terry) Mahon Foundation, which sponsors our popular Kids on the Block educational Puppet Program in Schools, committed to donate another \$100,000 to us for the same specific purpose. Their donation was in memory of long-time EEA Member Terence Mahon, who passed away in 2005.

Our bank, Servus Credit Union, agreed to give us a mortgage up to \$150,000 at a small business rate of 3.15% on a 5-year term, 15-year amortization.

All told, we looked at 34 properties in our search. We actually found a very suitable property in Inglewood and were set to sign the purchase and mortgage documents for the transaction on May 27th and move into it on May 29th. However, around 2 a.m. on the morning of the 27th, the property under construction next door to our planned new home was set on fire by arsonists and burned to the ground, damaging our soon-to-be building beyond repair and badly damaging two other buildings.

We resumed our search. We finally found a suitable and affordable property for our needs at 11215 Groat Road, directly across from Westmount Shopping Centre and the Westmount ETS Bus Terminal.

We purchased this property for \$405,000. With the two \$100,00 donations and \$105,000 of our own funds, we only required a mortgage of \$100,000.

In the process, the net worth of the Association, what we call our Members Equity, has significantly increased

Our monthly payments on this mortgage will be \$700 or \$8400 a year. In practical terms, the \$8400 is 28.72% of what our 2015 rent would have been, and 27.01% of what our 2016 rent and 25.49% of what our 2017 rent would have been !!!





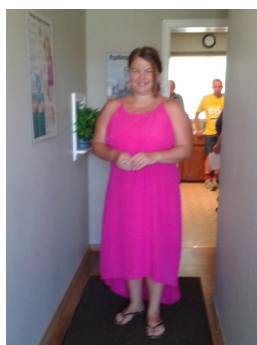
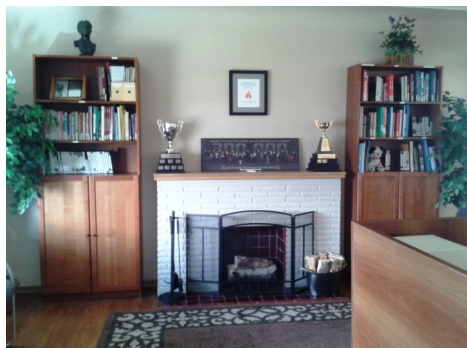
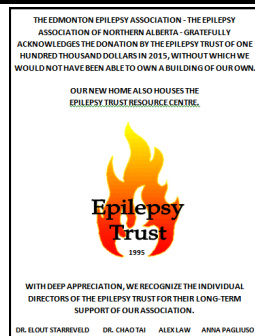
Open House & 55th Anniversary



**TERENCE MAHON
HOUSE**

HOME OF THE
**EDMONTON EPILEPSY
ASSOCIATION**

AND THE
**EPILEPSY TRUST
RESOURCE CENTRE**



Virginia, winner of \$55 Safe-way Gift Card door prize



Annual Member BBQ & Social





Celebrate the Grape

A Celebration of Fine Food and Wine
in support of
Epilepsy Awareness

Thursday, September 10, 6:30 p.m.
Yiannis Taverna 10444 - 82 Avenue NW

Tickets: \$125 No Minors

Up-scale entertainment, numerous and diverse
silent auction items, 50/50 draw, wine-tasting
contest (winner takes home a case of wine)
and other attractions.

Our M.C for the evening:



Rob Christie,
96.3 Capital FM

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

Edmonton Epilepsy Association,
780-488-9600
info@edmontonepilepsy.org





Generic Lamotrigine Equivalent to Branded Version, Study Shows

Epilepsy Society has welcomed the findings of a new study which shows that the performance of the generic version of lamotrigine is equivalent to the original branded version of the anti-epileptic medication.

The study, led by the University of Maryland, is the first to compare the performance of the branded and generic versions of an anti-epileptic drug, in adults with epilepsy who are taking medication on a long-term basis. Tests are usually carried out in healthy young volunteers after single dose administration.

The latest study looked at 34 patients who were already taking lamotrigine. All the patients were 'generic brittle' meaning they were sensitive to the smallest changes in the concentration of medication in their blood.

During the randomised, double-blind study, patients were repeatedly switched between the two versions of the drug Lamictal, the original brand version of the drug, and a generic lamotrigine. Results showed that few of the patients had worsened seizures or side effects.

Professor Philip- Patsalos comments

The study was praised by the head of Epilepsy Society's Therapeutic Drug Monitoring Unit, Professor Philip Patsalos. 'There have always been concerns about whether the equivalence of two different versions of one drug in healthy volunteers translates to therapeutic equivalence in patients with chronic epilepsy,' he said.

'This study shows that in lamotrigine, the generic and branded versions of the drug were bioequivalent, meaning the active ingredients were equally absorbed and distributed in blood.

'Previously we have had to presume that this would be so. Now, in the case of lamotrigine, we know.'

Risk of switching between generic drugs

However Professor Patsalos stressed that the greater issue around switching between two versions of a drug concerned switching from one generic to another generic, rather than from a branded to a generic drug.

'The difference in bioequivalence between a branded and generic drug is about six per cent which for most people is negligible but may be important for someone who is sensitive to small changes,' he continued. 'The difference between one generic and another generic can be much greater with the potential for greater consequences.

'Generic drugs are not inferior to branded drugs and it is not inappropriate to prescribe generic drugs for someone when they are first diagnosed with epilepsy. The most important thing is consistency of supply, meaning that you get the same version of a drug with every prescription.'

The Medicines and Health Regulatory Agency (MHRA) has issued guidelines about the prescribing of anti-epileptic drugs.

August 3, 2015

http://www.epilepsysociety.org.uk/Generic-lamotrigine-equivalent-branded-version-study-03-08-2015#.Vcoegd_bKM8

Music Therapy Might Help People with Epilepsy, New Study Suggests

By studying brain wave activity, researchers noticed differences in how patients reacted to tunes

About 80 percent of epilepsy patients have temporal lobe epilepsy, in which seizures originate in the temporal lobe of the brain. Music is processed in the auditory cortex, located in the same region of the brain, which is why researchers from Ohio State University's Wexner Medical Center wanted to study the connection.

The study authors said that the brains of epilepsy patients appear to react to music differently from the brains of people without the disorder.

"We believe that music could potentially be used as an intervention to help people with epilepsy," Christine Charyton, adjunct assistant professor and visiting assistant professor of neurology, said in an American Psychological Association (APA) news release. Charyton plans to present the research Sunday at the APA's annual meeting in Toronto.

The researchers looked at how different types of music and silence were processed in the brains of 21 people with epilepsy. Whether listening to classical music or jazz, all of the partici-

pants had much higher levels of brain wave activity when listening to music, the study found.

Brain wave activity in the epilepsy patients tended to synchronize more with the music, especially in the temporal lobe, the researchers said.

"We were surprised by the findings. We hypothesized that music would be processed in the brain differently than silence. We did not know if this would be the same or different for people with epilepsy," Charyton said.

Music therapy wouldn't replace current epilepsy treatments, but might offer a new method to use in conjunction with traditional approaches to help prevent seizures, she concluded.

Findings presented at meetings are generally considered preliminary until published in a peer-reviewed journal.

August 9, 2015

<http://consumer.healthday.com/cognitive-health-information-26/brain-health-news-80/music-therapy-might-one-day-help-people-with-epilepsy-701841.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





Exploring the Links Between Epilepsy Surgery and Academic Outcomes

A new study by a University of Toronto Mississauga researcher has taken the first-ever look at the academic outcomes of children with epilepsy who have had brain surgery, and found that they have a higher chance of struggling in class following their surgery.

Psychology professor Mary Lou Smith was co-leader of a team of researchers who studied the arithmetic, spelling, reading and reading comprehension abilities of children after having resective epilepsy surgery, a procedure that involves removing a part of the brain in order to halt seizures. The patients completed standardized tests both before their surgery and about 14 months afterwards, and all received lower scores on the second test in the first three academic areas. The results, Smith says, challenge a commonly-held but false assumption that stopping seizures can free up brain power for better academic performance.

"The surgery stops the seizures, but it's not like we put a new brain in there. These children still have a preexisting brain abnormality," says Smith, a UTM psychology professor, and a senior associate scientist in the Neurosciences and Mental Health Program in the Research Institute of the Hospital for Sick Children. The study published in the June 2015 edition of the journal *Epilepsy & Behavior*.

Brain surgery is performed on patients who don't respond to drugs, and whose source of seizures can be pinpointed in the brain. Smith says that of the approximately 25 per cent of people for whom drugs don't work, about 30 per cent meet the criteria to have epilepsy surgery. Working with three other researchers from SickKids and UTM -- including two UTM graduates -- Smith examined the academic achievement levels of 136 children ages 5 to 18, most of whom live in Ontario, and who had underwent pediatric epilepsy surgery between 1995 and 2013. All had completed academic testing as part of their pre-surgical and post-surgical neurological evaluations.

In the pre-surgery tests, most of the children displayed low or underachievement in at least one of the academic domains. This is because children with epilepsy are at higher risk of having cognitive problems in areas such as language, problem solving, learning and memory. The children's post-surgery test results, meanwhile, revealed drops in marks when it came to reading, spelling and numeral operations. Most students decreased about two to six points, but some declined by 10 points or more. This means that while brain surgery can help improve patients' quality of lives by stopping seizures, it doesn't necessarily stall or reverse the tendency toward lower-than-average academic performance.

"What I think is happening now is as they're getting older, they're not progressing at the same rate their peers are progressing, and so as a result of that, over time, you see these lower scores, because the difference between their performance and what's expected given their increasing age is widening," Smith says.

Smith cannot say whether the findings are due to the surgery, the epilepsy, or the children's development, but she is now conducting more research to figure out why. Meanwhile, she says, this new study may be useful to families weighing the pros and cons of surgery for their child with epilepsy.

"This is a tremendously challenging decision for parents, and they want to know the risks and benefits," Smith says. "I think this information is very important for health care providers if they're counseling patients, and for pursuing evidence-based practice."

June 2, 2015

<http://www.sciencedaily.com/releases/2015/06/150602130603.htm>

Information Source: University of Toronto

Breakthrough Seizures 'associated with substantial healthcare costs' - UK

A new study has shed light on the major clinical and economic costs associated with epileptic seizures that occur despite otherwise successful treatment.

This type of event is called a breakthrough seizure, and can be caused by a wide variety of factors, including infections, emotional stress, a lack of sleep, metabolic factors or non-adherence to the prescribed antiepileptic drug (AED) therapy.

For this study, a team from IMS Health and Sunovion Pharmaceuticals sought to measure healthcare resource utilisation and costs in treatment-adherent, previously seizure-free patients with epilepsy who were treated in the inpatient/emergency room setting for new-onset seizures, compared with matched controls.

Looking at data for 5,729 epilepsy cases and 14,437 controls, the team were able to collate a final sample of 5,279 matched case/control pairs, with results from the analysis appearing in the journal *Epilepsy & Behavior*.

It was shown that breakthrough seizure patients had significantly higher rates of all-cause hospitalisation and emergency room

visits compared to controls, and significantly higher total all-cause direct healthcare costs and total epilepsy-related costs, due to the greater amount of time they spent in hospital.

Among epilepsy cases, costs tended to increase with each subsequent seizure, again driven by inpatient costs, while these patients also had 2.3 times higher adjusted all-cause costs and 8.1 times higher adjusted epilepsy-related costs than controls.

The researchers concluded: "Inpatient/emergency room-treated breakthrough seizures occurred among 28.4 per cent of our treatment-adherent study sample and were associated with significant incremental healthcare utilisation and costs, primarily driven by hospitalisations.

"Our findings suggest the need for better seizure control via optimal patient management and the use of effective AED therapy, which can potentially lower healthcare costs."

Posted by Steve Long

August 17, 2015

<http://www.epilepsyresearch.org.uk/breakthrough-seizures-associated-with-substantial-healthcare-costs/>





Girls with Autism Prone to Severe Epilepsy

Girls with autism are nearly three times as likely as boys with the disorder to have severe epilepsy that responds poorly to medication.

The findings, published 26 June in *Autism Research*, add a twist to one of the biggest conundrums in autism: its 4-to-1 ratio of boys to girls. Research suggests that girls are somehow protected from autism-linked mutations. The new study hints that these mutations also lead to treatment-resistant epilepsy.

Roughly 25 percent of people with autism have epilepsy, compared with about 1 percent of the general population. In the new study, researchers found that women who have both autism and epilepsy tend to have milder autism symptoms, but more severe seizures, than do men with the disorder. The finding suggests that whatever protects women from autism does not shield them from epilepsy.

"It's really intriguing," says lead researcher Karen Blackmon, assistant professor of neurology at New York University.

Previous studies have shown that epilepsy affects more girls than boys with autism. The new findings serve as a warning to doctors that epilepsy in these girls may also be especially difficult to treat.

Doctors "should be prepared to try multiple medications and realize the medications might fail at the first try," says Shafali Jeste, assistant professor of psychiatry at the University of California, Los Angeles, who was not involved in the study.

Seizure skew:

Blackmon and her colleagues followed 125 individuals with autism who sought treatment for epilepsy. The participants ranged in age from 2 to 35 years.

Of the 97 boys and men, 24 percent showed no response to two epilepsy drugs. By contrast, 46 percent of the 28 girls and women did not respond. They also have milder autism symptoms than the males do, according to parent questionnaires.

The researchers excluded people with known genetic syndromes linked to epilepsy, such as tuberous sclerosis. But some participants may carry variants tied to both autism and treat-

ment-resistant epilepsy, such as a duplication of the chromosomal region 15q11.13 — which can lead to fatal seizures.

The study's findings may be a result of the girls and women in the study carrying a disproportionate number of these severe mutations, says Elliott Sherr, professor of neurology at the University of California, San Francisco, who was not involved with the study. That would skew the results to suggest that more girls than boys in general have treatment-resistant epilepsy, for example.

Still, the work sheds new light on the long-observed overlap between autism and epilepsy. "We know very little about the subgroup of individuals with [both] autism and epilepsy," says Christine Nordahl, assistant professor of psychiatry at the University of California, Davis, who was not involved in the study. "This study is a great first step in exploring sex differences in this subgroup."

The researchers also used magnetic resonance imaging to explore the possible neurological underpinnings of girls' susceptibility to intractable seizures.

They found that women who have both autism and epilepsy are more likely than men with both disorders to have mild abnormalities such as cortical dysplasias, in which some neurons in the top layer of the brain fail to migrate to the correct place. Roughly 42 percent of females in the study have unusual brain scans, compared with just 19 percent of males. These abnormalities track with treatment-resistant epilepsy in both genders.

Cortical dysplasias are linked to epilepsy, but some of the other abnormalities seen in the study are minor and may not be harmful. Blackmon and her colleagues are finding better ways to detect cortical dysplasias and plan to look for them across a large database of brain scans. The prevalence of these abnormalities may start to explain the connection between autism and severe epilepsy in girls, Blackmon says.

News and Opinion articles on SFARI.org are editorially independent of the Simons Foundation.

July 27, 2015

<http://sfari.org/news-and-opinion/news/2015/girls-with-mild-autism-prone-to-severe-epilepsy>

Study Highlights Traits Associated with Greater Stigma in Epilepsy Patients

New research from the US has shed light on the various demographic, clinical and psychosocial traits that can create a greater feeling of stigmatisation among epilepsy patients.

The University of Florida study involved a direct survey of 182 patients at an epilepsy centre, making use of the Epilepsy Stigma Scale as an assessment tool. Results were published in the medical journal *Seizure*.

Single individuals were shown to be more likely to have increased felt stigma, as were those with poorer health literacy, with higher levels of perceived stigma associated with a poorer quality of life.

It was also revealed that a greater use of coping reactions such

as denial, venting and particularly behavioural disengagement were associated with higher degrees of stigma.

The researchers concluded: "Programmes that increase the level of social support, improve health literacy and enhance quality of life may also help decrease the amount of felt stigma among people with epilepsy."

These findings underline the importance of ensuring that epilepsy patients receive social support and assistance with their mental wellbeing, in addition to treating physical symptoms.

Posted by Anne Brown
June 29, 2015

<http://www.epilepsyresearch.org.uk/study-highlights-traits-associated-with-greater-stigma-in-epilepsy-patients/>





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, and a bi-annual weekend specialized Educational Conference, all 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 and annual in-house Computer Training Programs 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...*