

Autumn leaves don't fall, they fly. They take their time and wander on, this their only chance to soar – Delia Owens

SEP-0CT 2025

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ABOUT THIS PUBLICATION

The EEA has been publishing an online and in-print version of our bi-monthly newsletter since 2013. All archived copies can be found on our website at https://edmontonepilepsy.org/eea-newsletter/. We fund this project on our own, and always welcome sponsors to help us continue our mission to support the epilepsy community.

GENEROUS CONTRIBUTIONS

This issue of the Focus on Epilepsy Newsletter was made possible thanks to these individuals and their generosity, in sharing research and editing skills, ideas sharing and formatting and mailing support: Tammy T.; Valeria P.; Susan W.; Angie C.



President's Message

Dear members

As the summer days begin to shorten, it feels like fall will be upon us in no time. Here in Fort McMurray it sometimes feels like fall lasts only for a couple of weeks, so I'm hopeful for an extended period of warmth before the snow flies! I hope you had a summer of sunshine, rest, and connection. From handing over the keys to the former office location to reliving the 65th Anniversary celebrations in the photographer's work, summer has been an energizing time at the Edmonton Epilepsy Association.

We've settled into the new office space, and it's already becoming a place of community. If you haven't had a chance to visit yet, consider checking out the upcoming open house on September 6. I look forward to visiting the office space later in September when the board of directors meets for our annual retreat. The retreat is a wonderful opportunity to gather, plan, and set goals for our organization. We are so lucky to have a team of dedicated individuals who are always spreading the word about the EEA and epilepsy awareness in general.

This issue is full of updates that showcase the heart of what we do. Our summer social events - from bingo and Coffee with Katrina to the new walking group - aim to keep members engaged and supported. Valeria and a crew of volunteers have also enjoyed being out in the community, meeting new faces at display tables in St. Albert, Spruce Grove, and the Tri-Leisure Centre in Stony Plain. If you stopped by and said hello - thank you!

Speaking of events, we're thrilled to be hosting a special presentation on service dogs and how they can support those living with epilepsy. And while I'm unable to attend in person, I look forward to seeing the creativity shared through the creative connections art project for families and kids! The seniors' survey and project is underway - thank you to those who have participated so far! Your contribution makes a difference in the projects we can bring forward to the community.

As always, your involvement is what makes this community so vibrant. Whether you attend an event, volunteer your time, or simply drop by for a coffee, you are part of what makes the EEA special. If you ever have any questions or ideas to share, please don't hesitate to reach out to any of us as we truly appreciate the involvement and support of all the work done by the association.

Wishing you a warm and wonderful fall season,



From My Desk



As summer draws to a close, the crisp air and golden leaves remind us of the beauty of change and the promise of new beginnings. Fall is a time to reflect on the warmth and joy of the past months and to prepare for fresh starts, meaningful connections, and exciting opportunities ahead. We hope your summer was restful, peaceful, and full of rejuvenating moments. With the celebrations for our 65th anniversary behind us and our recent office move complete, we took a brief but meaningful pause to reflect, regroup, and begin preparing for a vibrant new season of programs and events.

Our recent move marks more than a change in location—it symbolizes a new chapter in our charity's journey. While we've downsized in square footage, we've gained a more versatile space, allowing us to host even larger gatherings and engage the community in new ways.

We're thrilled to invite you to our **Open House on Saturday, September 6, 2025, from 1:00 to 5:30 p.m. at our new location: 9915 148 Street.**Join us for light refreshments, community connections, and a special ceremony at 2:00 p.m. to unveil our new office sign.

On September 27, 2025, our Board of Directors will hold its annual Strategic Retreat, a vital part of our planning cycle. This full-day session will focus on shaping our vision for the next five years—including a bold roadmap toward 2030, when we celebrate our 70th anniversary.

A key goal of this year's retreat is finalizing a new Investment Policy to responsibly manage the proceeds from the sale of the Groat Road property. This policy will guide prudent, long-term investments, helping to create a sustainable revenue stream to support our mission into the future.

Summer Highlights and Fall Programming

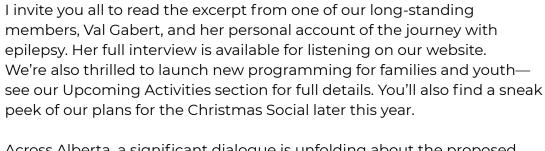
Throughout the summer, we continued serving our community by:

- Distributing free epilepsy resources across Canada
- Conducting the Seniors Horizons Survey
- Planning our upcoming French Audiobooks project
- Hosting information booths at summer markets
- Connecting with new agencies to expand awareness and support





From My Desk



Across Alberta, a significant dialogue is unfolding about the proposed Alberta Disability Assistance Program (ADAP). Many disability support agencies have raised concerns about how this new program may affect current and future AISH recipients.

We've dedicated a section of this newsletter to help you understand what's at stake, how to make your voice heard, and where to find updates. If you haven't yet participated in the survey or town halls, we encourage you to do so. Your voice matters—and together, we can advocate for a stronger, more inclusive support system.

Since the onset of COVID-19, our Focus on Epilepsy newsletter has grown significantly, now averaging 48–52 pages per issue. It's become a cornerstone of our mission—educating, informing, and inspiring those affected by epilepsy.

Beginning January 2026, we will shift to a quarterly publication schedule. While this change reduces the number of issues from six to four per year, it will help manage printing and mailing costs. Each edition will continue to be rich with valuable content—covering awareness, education, personal stories, and updates on services and advocacy.

As October approaches and we gather for Thanksgiving, we look forward to seeing you—whether in person, online, or at local library events. Let's welcome the fall season with gratitude, renewed energy, and a continued commitment to supporting one another. Wishing you a warm and inspiring start to fall,



EEA Activity Updates

Gala-Symposium Picture Gallery

Since early July, all attendees of the 65th Anniversary events—the Symposium on June 20, 2025, and the Gala on June 21, 2025—have received personal links to the photo galleries from the celebrations.

Here, we're pleased to share a selection of highlights as a tribute to the unforgettable memories we created together. Months of planning and preparation came to life in two extraordinary days, leaving lasting impressions on everyone who joined us in person.











Hands-on session





07

EEA Activity Updates





EEA Activity Updates

SYMPOSIUM VIDEO RESOURCES

We're excited to share another wonderful outcome of the Community Symposium held on June 20, 2025, in Edmonton: video recordings of the event's sessions are now available for viewing. You can access them here: https://edmontonepilepsy.org/edmonton-epilepsy-association-symposium-and-gala-resources/

We extend our sincere thanks to all presenters and contributors who generously shared their expertise on topics that impact people living with epilepsy. We're especially grateful for their willingness to make these sessions available online as a resource for the broader community.

If you're an EEA member without easy access to digital resources, please reach out to us. We'd be happy to schedule a time for you to view any of these sessions — and all of our online videos — at our office. We'll make sure you're set up comfortably and will gladly answer any questions you may have.

We hope you find these and all our other resources insightful and valuable.

Cassidy Megan Keynote Address at the Epilepsy Community Symposium, held in Edmonton, on June 20, 2025.

Keynote address: "Surgical Treatments for Epilepsy—An Overview" by Dr. C. Elliott



Cassidy speaks of personal journey with epilepsy and reasons for creating awareness about the disease. She explains how Purple Day came to be. Watch a very personal, impactful presentation that will bring tears to your eyes.



Dr. Elliot takes us on a journey around decisions and procedures for brain surgery to treat epilepsy patients. A warning some graphic elements of the presentation may appear disturbing to some viewers.



SOCIAL EVENTS - BINGO, COFFEE WITH KATRINA, WALKING GROUP

Even during the quieter summer months, we continued to provide welcoming spaces for members who remained in the city — offering opportunities to gather, connect, and enjoy each other's company.

This summer, we launched a new initiative: the **Walking Group**. On selected Thursdays each month, we opened our office doors to any members interested in joining us for a casual walk through the new neighborhood surrounding our office. Participants were invited to grab a free refreshment, enjoy some friendly conversation, and then head out for a light stroll together. While attendance started off modestly, we're bringing the Walking Group back this September — weather permitting — and look forward to seeing more faces join in.

We also continued to offer our beloved **Coffee with Katrina** gatherings, even in August while Katrina was away on a well-deserved break. And on the last Thursday of the month, we hosted another fun round of **Bingo**, which remains a favorite among many of our members. Similar events are already in the works for the upcoming fall months, so be sure to check for updates and let us know if you'd like to attend!

Fostering community belonging remains a key priority for our charity. Whether five or fifty people show up, we know these small, informal gatherings make a meaningful difference to those who take part — and we're grateful to everyone who joins us.



SENIORS' PROJECT AND FRENCH AUDIOBOOKS

We're pleased to share a brief update on two of our ongoing initiatives: the Seniors' Project and the French Audiobooks Project.

Seniors' Project - The Seniors Online Survey has been completed, and the responses are providing valuable insight into the direction of our upcoming workshops. Final workshop materials and structure are currently being confirmed. Led by Katrina Breau, the project team includes several senior members of the EEA who live with epilepsy. A key goal of this federally funded initiative is to ensure that all programming is designed by seniors, for seniors, creating authentic and meaningful engagement.

We've identified 20 community centres across Edmonton and surrounding areas where we'll be hosting workshops. These sessions are designed to support seniors living with epilepsy and those who care for them. We'll also engage teaching staff and administrative personnel at each facility to raise awareness about epilepsy, its impact on seniors, and how communities can better support individuals to improve quality of life. The first session is scheduled for November 26, 2025, at the St. Albert Seniors Centre. All workshops are free of charge and will include social activities such as crafts and games, as well as light refreshments.

French Audiobooks Project

This project is progressing well. Several of our French-speaking members have reviewed and finalized the scripts we'll be using. We are now moving forward with selected voice actors to begin recording. Our goal is to publish two French audiobook titles by the end of March 2026.





NQ STUDENT PRACTICUM WITH EEA

While we usually receive requests from NorQuest College to host students for practicum experiences in their programs during the early winter months, this year we had the opportunity to welcome a student in August. Nicolas Moreno, who recently completed the Administrative Professional program at NorQuest College, joined us for a month-long work experience. During his time here, he supported Valeria with her duties, including assisting at market events where we shared information and resources about epilepsy and the EEA across locations such as Stony Plain, Spruce Grove, and St. Albert. Nicolas is a returning member of the EEA and lives with epilepsy himself. We asked him to share a bit about his journey in his own words. Read below for his personal story.

Hello, my name is Nicolas Moreno. I am volunteering with the EEA as part of a practicum requirement for my "Administrative Professional" program at NorQuest College.

I was born in Bogotá, Colombia, and have had epilepsy since birth. From the very first hours of my life, I was placed in an incubator. My parents were scared, but they have courageously cared for me ever since, and I am very grateful to them. Moving to Canada was a major step in my life. I faced challenges trying to fit in, as there were many people from different countries around the world—something I love learning about—but I initially felt distant from others. However, I managed to make friends during my high school years. I became a member of the EEA around 2020 and have volunteered with the organization by doing design work, which is one of my passions.

Mow that I'm back volunteering, I have learned a lot and helped organize the new office space. While I sometimes work remotely from home, I enjoy working in the office more because it feels like a real work environment. Even though I'm volunteering, I love having a dedicated space to contribute as if I were a regular employee. One thing I appreciate about the EEA is connecting with others who also live with epilepsy, like me. Through this volunteer experience, I hope to gain more office work experience so I can confidently operate in an office environment when I find a job.

My preference is to work in a school setting, as I hold a certification in Childcare. Caring for children has always been something I enjoy. I have volunteered at camps and worked as a babysitter. Connecting with kids always brings me happiness. As a message of hope to future generations, I want to say: live your life to the fullest, always have fun learning new things, and remember that your creativity and ideas are valid. Don't let anyone upset you—you are unique and loved by those who truly care about you.



DISPLAYING AT MARKETPLACES THIS SUMMER

Summer days bring many opportunities for the EEA to be visible in the community by attending farmers' markets and outdoor fairs. These events offer valuable chances to connect with the public in a relaxed, welcoming setting. Over the past month, we've had a presence at three such events:

- Spruce Grove Farmers' Market August 2, 2025
- Tri-Leisure Centre Night, Spruce Grove August 21, 2025
- St. Albert Farmers' Market August 23, 2025

Participating in these events is always a meaningful experience. While not everyone stops at our table, each passerby sees our name and our mission. Even a brief moment of recognition means that the word epilepsy enters their awareness—and it might resurface the next time they encounter someone living with the condition.

Those who do stop by always have a personal reason for engaging. It may be a family member or friend affected by epilepsy, their own experiences with seizures, or professional interest as educators or healthcare providers wanting to learn more. Every one of these reasons matters to us. Each short conversation helps raise awareness and sparks curiosity.

And now, after years of participating in these kinds of events, we're seeing the impact: people are beginning to say, "Yes, I've heard of you!" That recognition is a sign of progress—and we're grateful to everyone who makes it happen.

A big thank-you to all the volunteers who help make these outreach efforts possible. We have more dates planned for the fall and hope to connect with many more of you soon!

EEA ACTIVITY UPDATES 19915 148 St. Front entrance of EEA new office space.

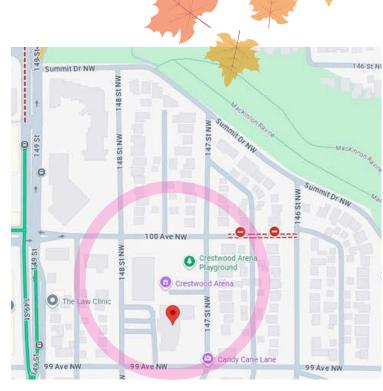
SETTLING INTO OUR NEW OFFICE – OPEN HOUSE INVITATION SATURDAY, SEPTEMBER 6, 2025 | 1:00 – 5:30 PM

We're thrilled to announce that our new office space is now officially open and fully operational! As shared in our earlier messages, the new location has become a welcoming and functional home for our team and programs. Our Executive Director's office is set up and ready, and the main room can now comfortably accommodate up to 20 participants for workshop-style, hands-on sessions (check out our upcoming Arts and Purple Pumpkin events!). We're also well-equipped to host larger information sessions, webinars, and community gatherings.

Technology from our previous space has been carefully transferred and securely stored in a locked closet, ready to support us for many more years to come.

Our New Location

Situated in the west end of the city, about 10 minutes southwest of our former site, the new office is fully accessible—no stairs required. We now have three accessible washrooms (men's, women's, and a fully accessible washroom). For larger events, we also have access to a basement hall that can accommodate up to 200 people, with a lift available for those using mobility devices.



Our new address 9915 148 street





SETTLING INTO OUR NEW OFFICE – OPEN HOUSE INVITATION SATURDAY, SEPTEMBER 6, 2025 | 1:00 – 5:30 PM

Getting There

While 149 Street is currently affected by roadwork due to LRT construction on Stony Plain Road, access via 142 Street and nearby residential roads remains easy and clear. And a fun bonus—our new location is on 148 Street, famously known as Candy Cane Lane during the holiday season! Expect festive lights and joy right outside our door come December.

You're Invited – Open House Details

We're excited to invite you to an Open House on Saturday, September 6, 2025, from 1:00 to 5:30 PM. Drop in to explore the space, connect with our team and community, and enjoy light snacks and refreshments. At 2:00 PM, we'll hold a brief ceremony to officially unveil our new office sign at the front entrance.

A new chapter is here—and we can't wait to share it with you. Come celebrate with us and see what's next!





UPDATES

Welcome to our regular Financial Updates section in the Focus on Epilepsy newsletter. Here, we share updates on our financial health and sustainability as a registered charity. Thanks to the unwavering support of our community, EEA continues to operate independently — a fact we're incredibly proud of. While recent years have brought financial challenges — rising costs and limited access to funding — we remain committed to making every dollar count. Visitors and new members are often amazed at the breadth of services we provide on such a modest budget. Every contribution is valued, used wisely, and directed toward lasting, meaningful impact.

Sale of Groat Road Property and New Hiring Plans

The recent sale of our Groat Road property has provided a small but important financial cushion, helping us cover the annual leasing costs of our new space. Our Board of Directors is finalizing a new Investment Policy to ensure these funds are managed prudently and safely for long-term stability. We wish to remind everyone that the property at Groat road became the EEA own asset, thanks to generous and significant donations by the Epilepsy Trust (Dr. Starreveld) and Terry Mahon.

The Board of Directors, in collaboration with our Executive Director, Valeria Palladino, are also reviewing the information necessary and the steps planned to hire a part-time fundraiser by the end of the year. We will share details about this plan in the near future and we count on our members to help us spread the word to select the perfect candidate for this contracted position.





We extend heartfelt thanks to everyone who donates — whether regularly or occasionally. In August, we were thrilled to receive a generous \$10,000 donation from Assif Law Office, which directly supports key programs such as:

- Epilepsy education books
- Kids on the Block performances
- One-on-one support for individuals and families facing epilepsy-related challenges

We also anticipate receiving proceeds from our spring casino fundraiser before the end of September and will provide an update in the next issue.

Fundraisers and Future Projects

The Birdies for Kids campaign closed on August 31, 2025. While we may not reach our \$10,000 goal for this year's youth project, we're excited to share that we're laying the groundwork for a new mental health initiative for children with epilepsy, thanks to early support from Walmart and Canada Post. Stay tuned for more details.

Looking ahead:

- October Fundraiser: Aligned with our Purple Pumpkin activities and daily educational posts throughout the ninth of October. This will be a fun and engaging campaign focused on children and epilepsy awareness.
- November 29, 2025 Holiday Party: This event will include a 50/50 raffle, door prizes, and other opportunities to give.

How You Can Help

Donations are welcome all year round — in any amount, and in many ways. Whether it's a one-time gift, monthly contribution, or participating in events and fundraisers, every bit makes a difference. Together, we make a powerful impact. Thank you for believing in our work.



EEA FINANCIAL UPDATES

YOU CAN SUPPORT US IN MANY DIFFERENT WAYS!





DIRECT DONATIONS

We continue to accept and rely on the generous donations of our members and supporters for most daily operational costs. We highlight here four key channels you can use today (if you read this online click on the logo you wish to to use as your way to donate).

Zeffy remains our preference, as it is the only platform through which we receive 100% of all your dollars. But we know many people like using **CanadaHelps** or **Paypal**, and we do thank you all for that. We will soon start a special campaign to fund all the initiatives we are planning for the EEA 65th Anniversary. In the meantime, if you know of a company or business who would love to sponsor any one of our many projects or initiatives, direct them to connect with our office.









THERAPEUTIC POTENTIAL OF GUT MICROBIOTA MODULATION IN EPILEPSY: A FOCUS ON SHORT-CHAIN FATTY ACIDS

Recently, a connection has been made between the gut and epilepsy. Since the gut is an important barrier in protecting our bodies from dangerous toxins and bacteria, problems in this barrier can cause issues such as inflammation or by allowing bacteria to enter the blood stream. When such issues occur, this can potentially trigger epilepsy in some individuals, which means it is vitally important to protect the gut barrier. One way the body maintains this barrier is through the gut microbiota, which is an extensive network of healthy bacteria in your gut which protects you from harmful bacteria. Scientists have recently found that there may be a way to utilize this gut microbiome to help strengthen this gut barrier and help control epilepsy. This research holds promise as this can open an entirely new avenue of treatment options for patients which works in a very different way than the usual epilepsy treatments. These new treatments might allow patients who have previously seen little success in the typical epilepsy therapies to try something new which might work.

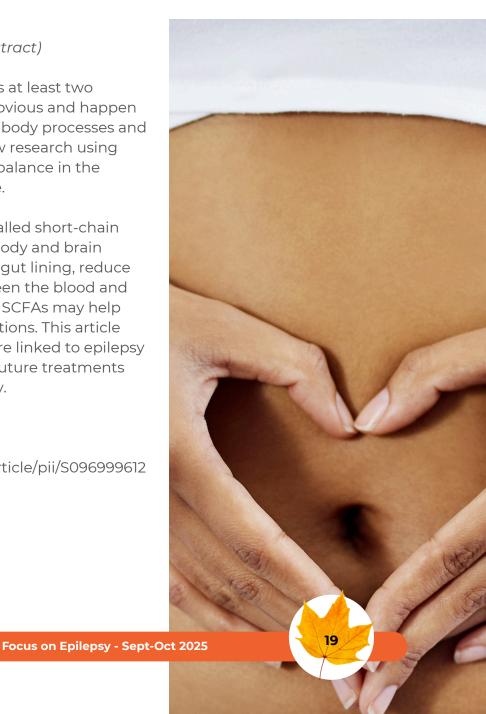
Abstract

(we simplified the language from the abstract)

Epilepsy is a condition where a person has at least two seizures that aren't caused by anything obvious and happen more than 24 hours apart. Many different body processes and health problems can lead to epilepsy. New research using advanced genetic tools shows that an imbalance in the bacteria living in our gut might play a role.

These gut bacteria produce substances called short-chain fatty acids (SCFAs), which help keep the body and brain working properly. SCFAs help protect the gut lining, reduce inflammation, and keep the barrier between the blood and brain strong. Recent studies suggest that SCFAs may help control seizures by supporting these functions. This article reviews current research on how SCFAs are linked to epilepsy and suggests that they could be used in future treatments that target gut health to manage epilepsy.

Find the full article at: https://www.sciencedirect.com/science/article/pii/S096999612 5000968



CHATGPT HELPS PINPOINT PRECISE LOCATION OF SEIZURES IN THE BRAIN, AIDING NEUROSURGEONS

ChatGPT and other AI programs have recently become a major resource in the world and doctors are using these programs to better treat patients. One way an epilepsy patient can be treated is through surgical removal of the epileptic region in the brain. Though this can be almost curative for some patients, there is a 50-60% chance that the region is not correctly removed and the epilepsy remains. The major cause for this high rate of epilepsy recurrence is due to the difficulties with determining the location of the epileptic region. Therefore, doctors at the Schaefer School of Engineering and Science at Stevens Institute of Technology decided to use ChatGPT to help them identify these regions. Using old patient data, they trained and then tested the program's ability to determine the epileptic region in comparison to actual doctors. What they found was that ChatGPT was able to better identify these epileptic regions in areas that have these epileptic regions more commonly. However, when epileptic regions were in more rare locations of the brain, doctors performed better. These results are hopeful in demonstrating how AI can greatly assist in the accuracy of epilepsy treatments which can hopefully help to improve the future success of these surgeries.



Epilepsy, one of the most common neurological disorders characterized by recurrent seizures, affects over 70 million people worldwide. In the United States, about 3.4 million people live with this challenging condition. Around one third of the epilepsy cases cannot be controlled by medications. For those patients, surgical resection of the epileptogenic zone (EZ), an area whose removal can lead to seizure freedom -- a period of time when a person with epilepsy experiences no seizures -- can be an effective option to reduce or eliminate seizures.

However, the current success rate for resective surgery --- in which the surgeon removes some of the brain tissues where seizures originate --- is around 50% to 60%. One of the reasons is that the EZs were not accurately identified. To identify the EZs, patients undergo a series of tests, including MRI, electroencephalography or EEG and intracranial EEG. Epileptologists use these data and images to describe the so-called seizure semiology -- the symptoms and behaviors during seizures. This information is used to predict the location of the EZs.



CHATGPT HELPS PINPOINT PRECISE LOCATION OF SEIZURES IN THE BRAIN, AIDING NEUROSURGEONS (CONT.)

However, the language epileptologists use to describe seizure semiology can differ from one epilepsy center to another. "Different epilepsy centers may use different terms describing the same seizure semiology," says Feng Liu, Assistant Professor at the Department of Systems and Enterprises, Schaefer School of Engineering and Science at Stevens Institute of Technology. "For example, terms 'asymmetric posturing' and 'asymmetric tonic activity' can be used to describe the same thing," he shares one example, referring to a posture where one arm or one leg is extended while the other is flexed. "There are a lot of terms that can refer to the same thing, but different centers may use different terminology to describe it."

That creates a certain inconsistency, presenting challenges to surgeons. Due to the descriptive nature of seizure semiology, Large Language Models or LLMs such as ChatGPT, which were trained on a vast cohort of public records, may be a valuable tool to help identify the EZs.

Liu and his team of collaborators evaluated the clinical value of using ChatGPT to interpret seizure semiology to predict the EZ location. "Large language models such as ChatGPT, could be valuable tools for analyzing complex textual information, helping interpret seizure semiology descriptions and assist in accurately localizing the epileptogenic zones," says Liu.

For the study, the team surveyed five board-certified epileptologists who completed an online survey comprising 100 questions about localization of EZs given the description of seizure semiology. Then, the team used ChatGPT to do the same task and compared the performance of ChatGPT with that of epileptologists.

It turned out that ChatGPT responses matched or outperformed epileptologists' responses related to the regions where epileptogenic zones are commonly located, such as the brain's frontal lobe and the temporal lobe. However, epileptologists provided more accurate responses in regions where EZs are rarely located, such as the insula and the cingulate cortex. Those findings are published in the Journal of Medical Internet Research on May 12.

To further improve the performance of LLM, the team built the first LLM specially for interpreting seizure semiology, called EpiSemoLLM, which is hosted on a Stevens GPU server. This platform can be a useful assistant in the decision-making during the presurgical workup phase for neurosurgeons and epileptologists.

"Our results demonstrate that LLM and fine-tuned LLM might serve as a valuable tool to assist in the preoperative assessment for epilepsy surgery," Liu says. "The best results would be for the humans and AI to work together."

Stevens Institute of Technology. "ChatGPT helps pinpoint precise locations of seizures in the brain, aiding neurosurgeons." ScienceDaily. ScienceDaily, 13 May 2025. www.sciencedaily.com/releases/2025/05/250512105207.htm.

EPILEPSY IN A NEWBORN?? CAN IT HAPPEN??

Some Newborns can experience some health difficulties after their birth that require their admission in the Neonatal Intensive care Unit. These may include problems in their Central Nervous System, whose only sign may be fits or seizures.

The majority of seizures in humans occur in the first months of life, owing to the less developed brains of babies that make them more vulnerable to them. The causes of these fits at this early life vary. While most of these convulsions happen due to a well-defined medical cause like delivery events that lower brain oxygenation, infections, abnormal body metabolism and others, 15% of these fits are caused by what we call epilepsy syndromes. These usually have a genetic basis and some are accompanied by abnormal brain development. Some of these syndromes have a benign course, whereas others may affect the child's development and require ongoing treatment.

Convulsion in the neonates can take different forms and can be confused by other abnormal movements that are caused by other medical conditions or even normal baby movements or behaviors. Therefore, the diagnosis of neonatal seizures has to be established after close monitoring in neonatal intensive care units and confirmation by specific investigations and being witnessed by experienced professionals. This is the first step in efficient management, followed by treatment of the cause of the condition, together with prompt control of ongoing seizures clinically and with the EEG, to prevent further affection of the babies' brains. This is done by administration of specific antiseizure medications that are given in appropriate doses for age, according to established medical protocols.

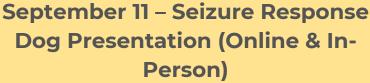
According to the cause and the baby's condition on discharge, the treating doctor may or may not decide to continue oral antiseizure treatment afterwards. In case of neonatal epilepsy syndromes, for instance, antiseizure medications have to be continued. Most of the babies who had fits after birth will require regular developmental follow ups and monitoring for their ongoing treatment.



UPDATES

Here's where we share upcoming programs and plans for the next few months—designed for both current members and those thinking about joining. Use these pages as your go-to guide for getting involved and staying connected with our community.





Join us for an informative session on Seizure Response Dog programs and how they support individuals living with epilepsy. This presentation, hosted by Diabetes Alert Dog Guides & Seizure Response Dog Guides – Lions Foundation of Canada Dog Guides, will cover program details, training, and how to access these life-changing services.

📅 Date: September 11, 2025

① Time: 6:00 p.m. (MST)

! Location: Online via Zoom (in-person option available)

Click here to register

This event is free and open to everyone. Whether you're living with epilepsy, supporting someone who is, or simply want to learn more, we welcome you to attend.



Join us for the official Open House of our new office at 9915 148 Street!

Our doors will be open to everyone—stop by to say hello, reconnect with friends, and meet some new ones. We'll have snacks, a short ceremony to unveil our new office sign, and a few relaxed hours to celebrate and settle into the new space together. We'd love to see you there!







Why a Seizure Response Dog Guide?

Seiture Response Dog Guides are trained to assist Canadians (14 years or older) diagnosed with intractable epilepsy through specific tasks. These Dog Guides are trained to bank in response to a seiture, go and get someone inside the home, fetch a medical kit or phone, and provide comfort during a recovery period.

We are excited to share that the Selanie Response program has opened its suits. Fleate state it will be the originate of updated Discovery Plackage document before you submit an expression of teres. If we receive more expressions of teres of the results, we will including selanies than available spots on the waiths, we will including selanies than available spots on the waiths, we will include the selanies of the results of the receiver of the property of the selanies of the receiver of the selanies was are not selected will include the selanies of the rest store the waitist reopers to reapply. Please note that we have intellige doors available for those who require hypoullegenic dogs, if you're usuable to complete the purposes of servers of other, please concepted the purposes of servers of other, please concepted the purposes of servers of other, please concept on the present of servers of other, please concept of the purposes of servers of other, please concept of the purposes of servers of other, please concept of the purposes of servers of other, please concept of the purpose of servers of other pleases.

September 11, 2025

6:00 p.m. (MST)

on zoom and in-person

edmontonepilepsy.org



UPDATES

September 11, 2025 – Special Presentation of the Kids on the Block (KOB) Show at New Humble Community School

We're thrilled to announce a special live performance of the Kids on the Block (KOB) show at New Humble Community School in Calmar, Alberta! This event marks an exciting milestone as we expand beyond the Edmonton region to connect with more young students.

During the show, elementary-aged children will engage in important conversations about epilepsy, seizure first aid, and how to be a kind and inclusive friend to everyone. We can't wait to share highlights from this event through photos and stories in our upcoming newsletter.

Interested in hosting a KOB show at your school?

It's easy—just contact our office to coordinate a date and time that works for you. Performances are always free of charge, though donations are gratefully accepted.

Let's continue spreading awareness, education, and compassion—one school at a time!



Saturday, September 16 – Community Booth at West Edmonton Mall

This event is quickly becoming a new tradition for the EEA! Join us at the Community 360 booth at West Edmonton Mall on select dates throughout the year, where we'll be showcasing our resources and programs while engaging directly with the public.

Come by to say hello to our volunteers and staff—we always welcome a good conversation and the opportunity to share ideas. Help us spread awareness about epilepsy and seizures, break down stigma, and promote accessibility. Let's normalize conversations around epilepsy and work together to build a more supportive community for everyone.

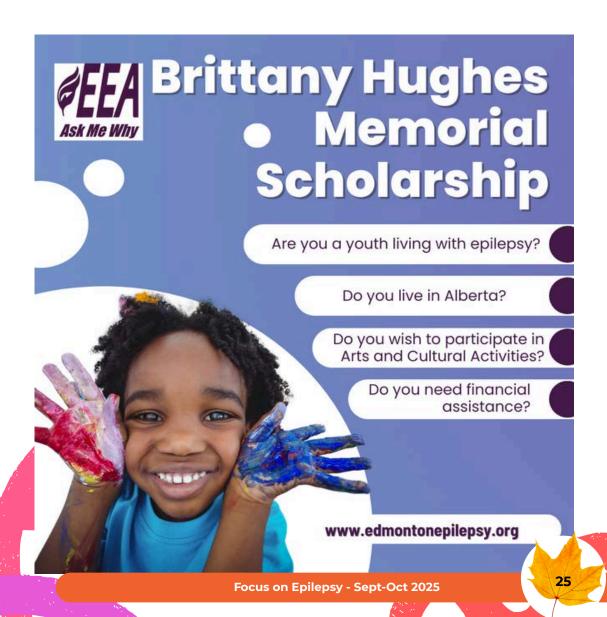
UPDATES

Display Tables – Stollery and Kaye Clinic

We are excited to introduce a new tradition of hosting display tables at two key locations: the Stollery Children's Hospital (near the cafeteria on the main floor of the University of Alberta Hospital) and the Kaye Clinic (on the fourth floor).

On the following dates, volunteers and EEA staff will be present to engage with both new and returning patients, as well as their caregivers, while they wait to see their specialists.

- September 9, 2025 10:00 to 2:30 (STOLLERY)
- September 16, 2025 10:00 to 2:30 (KAYE CLINIC)



UPDATES

September 20, 2025 – Arts Workshop for Kids & Families Living with Epilepsy!

Join us for a special, creative workshop designed specifically for families and youth affected by epilepsy. This inspiring event offers a chance to explore the art of creating beautiful silhouettes using acrylic paint — and much more! Beyond learning a new artistic skill, participants will enjoy a supportive and welcoming environment that promotes emotional wellbeing through creativity.

This workshop is open to all EEA members and their families — parents, children, grandparents, aunts, and uncles are all warmly invited, as long as someone in the family lives with epilepsy. Everyone will leave with their own unique masterpiece to be proud of!

Details:

- **Date:** September 20, 2025
- **Time:** [Insert time if known]
- Location: [Insert location if known]
- Cost:
 - EEA Members: \$5 per participant
 - 0
 - Non-members: \$10 per participant

0

Reserve your spot online or call us at **780-488-9600**. Spaces are limited, so don't wait!

Bonus: Can't make it on the 20th? We're also offering this workshop on Saturday, October 18, 2025, from 12:00 to 3:00 p.m.

Come create, connect, and celebrate your creativity with us!



UPDATES

Coffee, Bingo & Walks — Join Us This September & October!

These coming months are packed with wonderful opportunities to connect with friends and the epilepsy community at the EEA office. Whether you're up for a relaxing walk, a cozy coffee chat, or some fun bingo games, there's something for everyone!

What to Expect:

- Enjoy peaceful walks with friends
- Sit down for coffee or tea and chat with Katrina about any topics related to living with epilepsy
- Play a free game of bingo and win some goodies!

Important: Some events require registration so we can prepare enough snacks and treats for everyone. Just give us a quick call or send an email to secure your spot!

Upcoming Events:

September 4, 2025 | 12:30 - 2:00 PM

Walking Together!
No registration needed — just show up and enjoy the stroll!

September 18, 2025 | 12:00 - 2:30 PM

Coffee with Katrina

Call to register and let us know if there's a specific topic you'd like to discuss.

September 25, 2025 | 12:00 - 2:30 PM

Bingo at the EEA Office Call to register!

October 23, 2025 | 12:00 - 2:30 PM

Coffee with Katrina
Call to register and share any topics you want to talk about.

October 30, 2025 | 12:00 – 2:30 PM

Bingo at the EEA Office Call to register!

We look forward to seeing you soon!

UPDATES

Epilepsy Presentation for Families of Children with Epilepsy

<u>Date: October 2, 2025</u> Time: 7:00 p.m.

Format: Online (Zoom) with potential in-person option

We're excited to resume our popular, free online sessions designed to support individuals, families, and caregivers new to an epilepsy diagnosis.

Our first session, on October 2, 2025, will focus on families living with children diagnosed with epilepsy. This session will be offered online via Zoom (link below).

If we receive at least 5 requests for in-person attendance, we will provide a hybrid format:

- Attend from home via Zoom
- Join us in person at the EEA office, where the session will be streamed live

Those attending in person will also enjoy free treats! Register today to reserve your spot!



Free online session Thursday, October 2, 2025 7:00 p.m

UPDATES



October 3- 4-5, 2025 at the Bountiful Market

We love the Bountiful Market on the south side of Edmonton! As an indoor venue open year-round on weekends, it offers a great space for community connection. Charities like ours are given the opportunity to host a display and awareness booth on select dates—and we're thrilled to be there October 3rd to 5th!

With the help of our amazing volunteers, we'll be engaging with the public, sharing resources, and offering encouragement and hope to those who share their personal stories about living with seizures.

Come by to say hello and enjoy the vibrant atmosphere filled with local farmers, artisans, and sellers offering fantastic products. Don't forget—the holiday season is just around the corner!

UPDATES

Paint It Purple: A Pumpkin Neighbourhood Party!
October 25 | 12:00–4:00 PM
Open to Everyone!

This October, we're excited to host a special Paint It Purple workshop as part of our ongoing epilepsy awareness and education campaign. Each year, we highlight important topics—such as epilepsy and safety or famous individuals living with epilepsy—through fun, engaging, and family-friendly initiatives. This year, we're adding extra sparkle to our campaign with daily social media posts and a vibrant inperson event you won't want to miss!

****** Event Details:

Join us for a festive afternoon of creativity and community! Between 12:00 and 4:00 PM, we'll host two workshop sessions (up to 50 participants per session) at our office, where each attendee will receive a purple pumpkin and access to a wide variety of decorating materials—no carving required or allowed! Bring your creativity and your family! This inclusive event is open to everyone, and we're especially excited to welcome our new neighbours from the St. Andrew's United community. Let's come together, raise epilepsy awareness, and have a spook-tacular time!

Registration is Required:

EEA Members: \$5.00

Non-Members: \$10.00

<u>F Register Online Here</u>

Spaces are limited — reserve your spot today!



JOIN THE FUN!



PANTIT PURPLE: A PUMPKIN NEIGHBOURHOOD PARTY

Celebrate creativity with your neighbours today



Don't miss out on this event!

EDMONTONEPILEPS

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UPDATES

Looking Ahead...

These important dates will also be included in our final issue of 2025—but it never hurts to share them early:

Save the Date: Saturday, November 29, 2025

Join us for our Annual Holiday Celebration!

We're excited to host this year's holiday party at our new office space! We've booked a room that accommodates up to 200 guests, so bring your holiday spirit and join the fun.

Time: 2:00 – 6:30 p.m.

Potluck Meal: We'll be sharing a festive potluck—details on how to sign up and contribute your favorite dish will be in our next issue.

Expect community cheer, holiday crafts, sing-alongs, games, and plenty of door prizes. And yes—Santa will be making a special appearance!

Mark your calendars now—you won't want to miss it!

§ Saturday, December 6, 2025

Catch Us at West Edmonton Mall!

We'll be hosting our final Community Display Booth of the year—come by, say hello, and see what we've been up to in 2025!



ADAP Engagement – Your Voice Matters

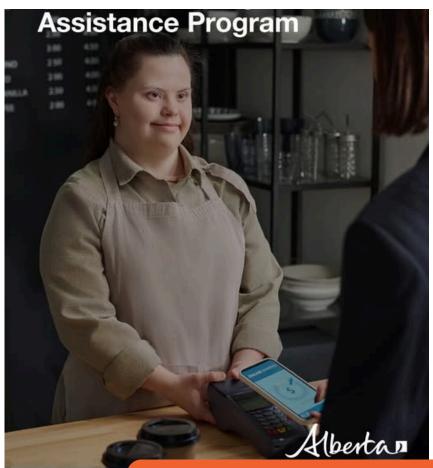
The disability community must take part in the ADAP (Alberta Disability Assistance Program) engagement process. Silence may be interpreted as agreement, so it's essential to make your voice heard. Participate in the consultations and share this information widely with your clients, families, and networks.

Learn more and get involved: Alberta Disability Assistance Program engagement | Alberta.ca

Need Help Understanding the Proposed Changes?

Our partners at Inclusion Alberta have created a clear and accessible resource that breaks down what's included in the Government of Alberta's Discussion Guide: Transforming Disability Income Assistance in Alberta. It's designed to help you understand what's being proposed and how it could affect people receiving AISH and other supports.

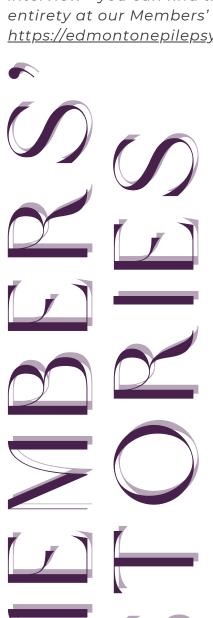
Download the printable guide here:
<u>Understanding the Proposed Changes to AISH – August 2025</u>



Click here to complete the online survey by September 12, 2025

VAL GABERT

We resume sharing special, personal and meaningful stories from our members in this issue. Earlier this summer, Val Gabert, a long-time and active EEA member, joined us for a recorded audio chat about her experience with epilepsy. She was very open and shared details on the bumpy ride, especially as a child and a young adult, and how her innate resilience and positive outlook on life, allowed her to make the best of all life decisions. We are grateful she agreed to share her story with us. We place here a section of the interview - you can find the audio recording in its entirety at our Members' Stories page here: https://edmontonepilepsy.org/memberstories/





Q.: Thanks so much Val for agreeing to share a bit of your story with us. So, to start, could you tell us a bit about yourself and which point in your story you find yourself - and by story I mean your life with epilepsy.

Val: My first seizure was in March of 1970 I had a grand mal seizure and at that time there were doctors who attended house calls, so he was called to the house as I had fallen on a knife, and I cut my eye. So, it was bleeding quite a lot.

So, he stitched it up. It wasn't on my eye; it was on top of my eye and it upset my parents because they had no idea what was going on and then in May I had a second grand mal seizure, but it was expected that I would outgrow it once I became an adult. My second seizure was at the top of a set of steep stairs which I fell down off and wrapped myself around the bed. So, I wrecked my back.

This time a doctor was called again to examine me. I didn't break any bones, but he asked us to come into the clinic the next day. And I started on Phenobarbital.

And at that time my parents kept me quite close to home and the only place I was pretty well allowed to go was my grandma's, and to attend school. So, I pretty well had only two places I couk' at this time.

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INTERVIEW SECTIONS (cont.)

It was believed you needed to stick something in someone's mouth at the time, so you did not swallow your tongue. It led to a lot of people almost having broken fingers. It was quite common. Around our house and eventually in my grandma's house to have, uh, padded tongue depressors all over the place.

[...] In spring of '73 in grade nine, the GP finally admitted defeat, but not before they admitted me to the U of A hospital numerous times, not just once for numerous tests, and one of them being the neuro-encephalography. I remember quite clearly, and I never recommend anyone go through it, which is nice because they don't even do it anymore.

[...] So other than that, I didn't show anything. But I did get to make friends with all the doctors and nurses because I was in the hospital for two weeks out for two weeks in, for two weeks, maybe one week out for two, back in for another week. Out for two.

So, it was fun. I had a lot of fun, a lot of adventures in the hospital, and visited other kids on other floors. It was a great time. It was almost like a holiday. I had more fun and I got to go out more in the hospital than I did at home, so that's why it was like a holiday.

[...] I've learned to just deal with things one day at a time and to continue to work on the bright side. Everything that you go through has a silver lining and people can't believe that I still have such an upbeat attitude. Um, that's just the way it is. For many years I could not do anything related to math, and slowly through the 30 years I have been able to learn things that I never could before.

It might be small to you, but to me they were like mountains. Then I suddenly could understand things about chemistry and biology that were totally beyond me. I know that every time I learn something, there is a chance that I could lose it all. If I have a seizure. I'll also not be able to remember it if I don't. I do it daily until it becomes routine, and it's built into me.

My best support was Dr. Starreveld. He had the EEA booklets in his office... [...] Q: Did you feel stigma when people learned that you had epilepsy? Val: I heard it very often from the kids I went to school with: "You're sick in the head. Sick in the head. We don't want you on our team, we don't want her on our team!" They said that to the teachers numerous times. It was different teachers that they'd say it to, but they still said it.

So really.... I didn't want to do anything either. [...] I became a person that loved my books. I didn't care for tv, nothing. I just loved reading because I didn't interact with anyone. Nothing bothered me, just with myself. So, yeah.

[...] Q.: So, what other things can you say that EEA has impacted your life with epilepsy?



INTERVIEW SECTIONS (cont.)

Val:

I have learned a lot about epilepsy. Mm-hmm. Um, I went on a lot of field trips that I never, never went on when I was a child. I never would've imagined that I would ever go on. So I did that. There was a lot of socializing with other people, other people that were like me. At the same time, it was like imagining how my life couldn't have been like that? Yeah, but you know, my life was what it was and it was like, okay, I wasn't born at the right time.

You know, I was born in, you know, your infancy basically.

Q: Is there any final word or message you want to leave our listeners and our members with? What would be something that you have an inner resilience and positivity, so I think that you have it regardless. You had epilepsy or something else. What would you say as a message of hope? Val: To live each day for itself and to be positive for, I always greet it with a smile and everybody else, because people might have a bad day, but smiling at them might be the only good thing they have that day. And to strive for whatever you want because you don't know what you might be able to achieve.





VOLUNTEER WITH US

At the Edmonton Epilepsy Association (EEA), we often say that 85% or more of what we accomplish is thanks to our dedicated volunteers. The truth is, that number hardly does justice to the impact they make—because without our volunteers and community supporters, none of our programs or events would be possible. Every person who contributes does so from the heart.

Each year, our cause directly touches the lives of over 5,000 individuals. And our reach extends even further—supporting more than 30,000 Albertans living with epilepsy and, through programs like our book initiative, making an impact beyond provincial borders.

Epilepsy doesn't discriminate—if you have a brain, you can have seizures. It's that simple. That's why our mission is twofold: to empower those living with epilepsy and to support the families, caregivers, and communities around them. Volunteers go one step further—they give back to the broader community because they truly believe in the difference they're making. We offer a variety of volunteer opportunities throughout the year. From fundraising events like Casinos to one-time community initiatives, we're always looking for passionate people with diverse skills and interests to join us. Whether you have a few hours or want to get more involved, we have a place for you.

To learn more about becoming an EEA volunteer, visit: https://edmontonepilepsy.org/volunteer/

Below, you'll find a list of upcoming events and the types of support we're looking for—this is your invitation to join our amazing volunteer team today!

Email: info@edmontonepilepsy.org

Call: 780-488-9600

If you've volunteered with us before, we'll have you up and running again in no time!

SEPTEMBER 6 - OPEN HOUSE

we need a couple of volunteers to help with set up and take down at the office (11:00 a.m. to 5:30 p.m.)

SEPTEMBER 13

WEST EDMONTON MALL COMMUNITY BOOTH - at WEM from 10:00 to 3:00 p.m.

We need two volunteers on a 4 hour shift each.

OCTOBER 3-4-5

BOUNTIFUL MARKET - volunteers at the booth for 4 hours shift - we need 2 for each day (10:00 to 3:00 p.m.)

OCTOBER 25

PURPLE PUMPKIN DECORATION EVENT - at our office - set up, welcome guests and help with decorations from 11:00 to 4:30 p.m.

NOVEMBER 29

HOLIDAY PARTY - help to set up and take down at the office (from 12:00 to 6:30 p.m.)

We provide detailed tracking records of all your contributions. For students preparing to enter the workforce or applying to post-secondary programs that require practicum hours—whether in an office setting or through community involvement—we can support those needs as well. Plus, you'll always have the personal satisfaction of knowing you've made a real difference.

EEA BOARD OF DIRECTORS 2025

The Board of Directors at the Edmonton Epilepsy Association (EEA) is gearing up for an impactful few months, focusing on key strategic initiatives that will help strengthen our organization and expand our reach across the region.

One significant discussion on the horizon is the possibility of a name change for our organization. This stems from a desire to better reflect the geographical area we serve — as the current name, Northern Alberta Association for Epilepsy, may not fully capture our community's identity. The board will be diving into research and consultation to explore the implications and opportunities such a change could bring. In parallel, the board is finalizing a robust Investment Policy to guide our future financial decisions and ensure sustainable long-term growth for the EEA.

Another top priority is the development of a thoughtful and effective hiring process to bring on a new contractor specializing in fundraising. This role will be vital in helping us grow our resources and enhance our programming.

We're also excited to be launching a brand-new volunteer program in collaboration with the Seizure Monitoring Unit at the University of Alberta Hospital. This initiative aims to create meaningful opportunities for community engagement and support for those affected by epilepsy.

In short, the Board of Directors will be hard at work laying the groundwork for a stronger, more resilient EEA. They continue to serve as the backbone of our association — guiding, planning, and leading with vision and care.

← We currently have two open positions on the Board. If you're passionate about epilepsy awareness and want to contribute your voice, experience, and ideas, we invite you to learn more about the role on our website: edmontonepilepsy.org/about-us/board-of-directors

You can join a wonderful team, learn about non-profit governance and learn to feel that personal satisfaction that your joint vision becomes a reality of our community. Or give us a call — Valeria is always happy to answer your questions.





EEA BOARD OF DIRECTORS 2025

If you believe you have great ideas and leadership to contribute to our association, learn all about who we look for in our

https://edmontonepilepsy.org/about-us/board-of-directors/

THE 2025 SLATE OF DIRECTORS



Susan Wilkie President



Shandea Patras Vice-President



Tammy Humphreys

Secretary



Tammy Tkachuk

Past President



Sherri-Lee Emiry Director



Noella Desaulniers



Treasurer



Angela Wilm





Anna Pagliuso

Director



Dr. Kassiri

Director



Brandon Brost

Director



Terry Mahon

Advisor



Valeria Palladino

Executive Director

EEA ONGOING PROGRAMS

WHAT WE HAVE TO OFFER

EPILEPSY BOOKS

We run a comprehensive 11-titles epilepsy information books. Learn more at this link.

KIDS ON THE BLOCK

Book your elementary-grades live puppet show today. More info at this link.

EPILEPSY EDUCATION WEBINARS

Regular online webinars offered on topics about epilepsy. https://albertaeweb.ca/

HOBSCOTCH MEMORY PROGRAM

Free memory-coaching program for people with epilepsy. <u>Click here for more info.</u>

SOCIAL GATHERINGS

We organize regular gatherings for children, families and adults living with epilepsy. Check our calendars for dates.

MENTORSHIP PROGRAM

Inquire with us about connecting with a trained EEA mentor, to get individualized support about life with epilepsy. More info here.

FAMILY PROGRAMS

We offer education sessions tailored to families with kids diagnosed with epilepsy.

KIDS AND YOUTH PROGRAMS

We run regular outings and kids-focused programs.

EPILEPSY 101 ON-DEMAND SESSIONS

We run online and in-person on demand educational sessions about epilepsy. Email us at : info@edmontonepilepsy.org.

SCHOLARSHIPS

Applications for these scholarships close March 31 every year. <u>Learn more at this link.</u>

AWARDS

We recognize special contributions by EEA members living with epilepsy. More info here.

AWARENESS CAMPAIGNS

We are all about epilepsy awareness. We run three official campaigns per year.



ADVOCACY

We advocate for people with epilepsy. Connect with us and see how we can help.

INDIVIDUAL SUPPORT

Every person impacted by epilepsy has different needs. Reach out to see how we can help you.



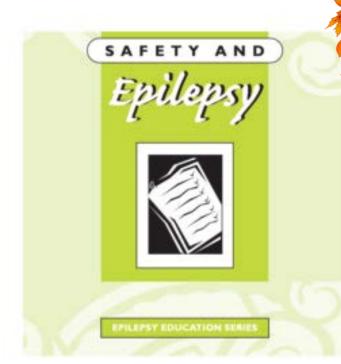
EEA EPILEPSY BOOKS

SAFETY AND EPILEPSY

There is an increased risk of injury in people with epilepsy. Seizures can present as a sudden fall, blank stare, confusion, uncontrolled movements, diminished awareness, odd sensations, a convulsion, or laboured breathing.

For some people with epilepsy, their seizures pose a minimal risk of injury. For others, their seizures may require extra precaution to avoid injury. For example, seizures that occur without warning, involve falls, loss of awareness, or confusion after the seizure could result in injury.

Precautions may be necessary depending on the activity. Assessing the risks associated with the type and frequency of the seizures may require implementing safety procedures.



Our books are now AUDIOBOOKS AUDIOBOOKS Taking Anti-Se

- Taking Anti-Seizure Medication
- Anti-seizure medication should always be taken as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus.
- The use of any other medications or vitamins should be discussed with the doctor or pharmacist. Decongestants, Aspirin, herbal medications, diet pills, and birth control pills can all interact with anti-seizure medication. Some drugs such as antidepressants and antibiotics may also interact with anti-seizure medication.
- Don't change from a brand name drug to a generic drug without first consulting your doctor or pharmacist. Don't even switch from one generic to another.
- Keep a 1-2 week supply of your anti-seizure medication to ensure that you don't run out
- 5 Always use a pill organizer or dosette even when the medication seems simple.

EEA SCHOLARSHIPS

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.





The Garry Hannigan **Memorial Life Enhancement Scholarships** for Youth, to a maximum of \$500 each, are available for Youth 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.

Edmonton Epilepsy Continuing Education Scholarship

EEA also manages the Edmonton Epilepsy Continuing Education Scholarship, funded by the Epilepsy Trust Fund.

9915 148 STREET T5N 3G1 EDMONTON ALBERTA

www.edmontonepilepsy.org CHARITABLE # 119230951RR001



Edmonton Epilepsy Association | The Epilepsy Association of Northern Alberta



