FOCUS ON EPILEPSY

Magazine

> *"The people who are crazy enough to think they can change the world are the ones who do."*
>
> *Steve Jobs*

The Stories We Carry

JUL-SEP 2026

EPILEPSYALBERTANORTH.CA

IN THIS ISSUE

About this publication

The EAENA has been publishing an online and in-print version of our quarterly magazine 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 Magazine was made possible thanks to these individuals and their generosity, in sharing research and editing skills, ideas sharing and formatting and mailing support: Valeria P.; Sam H., Angie C.; Susan W.; Mai H.; Justine B. and Ramneek P.

MESSAGE FROM THE PRESIDENT

As summer arrives, perhaps due to my profession as a teacher, I always find it to be a season of reflection and renewal. As I read through this issue, one word keeps coming to mind: momentum.

Over the past several months, our community has continued moving forward in meaningful ways. An exciting milestone has been our official name change and the selection of our new visual identity and logo. I want to extend my sincere thanks to everyone who submitted ideas, shared feedback, and participated in the process. It was inspiring to see the creativity, thoughtfulness, and passion that members and the outside community brought forward. Our visual identity is much more than a logo—it represents our story, our growth, and our vision for the future. In this issue, you'll hear from the individual whose submission was selected and learn more about what this means as we continue moving forward together.

You will also read about many programs and initiatives that continue to thrive. Our mentorship opportunities and Hobscotch programming are creating meaningful connections and support for our members, and it has been wonderful to see volunteer involvement continue to grow. We are incredibly grateful for the many people who contribute their time, energy, and talents to strengthen our organization and our community. I have been lucky enough to be a part of the mentorship program this past month and it is a true reminder of the reason we exist - so nobody feels alone with a diagnosis.

This issue also highlights the many ways education and awareness continue to remain at the centre of our work. We have continued our Purple Lunch Hour sessions. I enjoyed sharing my story at April's lunch - you can read more about it in this issue. These lunch conversations are very casual and not only give you a chance to hear from a presenter but also ask questions. I'd highly encourage you to check them out.

We are also pleased to share updates on projects including our Kids with Epilepsy Mental Health initiative, our Seniors Project, and our growing French audiobook collection. It is exciting to see ideas move from conversations into meaningful action. These projects are all funded through grants and donations - which are getting more challenging to come by every year. I would encourage anyone who is able to do so to consider making a donation to the Rogers Birdies for Kids fundraising campaign as this initiative allows for donations to be matched up to 50%. If you're unable to donate, please share our social media posts about the fundraising campaign because the more we reach out into the general public, the more money we can raise.

One of the highlights of the season was our June 20 "Seize the Day!" Community Fun Fest. While I was unable to attend, it looked like a lovely event (despite the rain) with so many of you in attendance. Bringing people together through celebration, connection, and awareness reminds us that our organization is about more than programs and services—it is about community. Thank you to everyone who attended, volunteered, supported, and helped make the event such a success.

As you move through this issue, you will also notice some new ideas and opportunities beginning to take shape: Discover Our Books sessions, potential focus groups for adults with epilepsy, yoga initiatives, and future planning conversations as we prepare for our September board retreat.
We continue to evolve because our members continue to share ideas, identify needs, and imagine new possibilities.

Thank you for being part of this journey. Whether you participate through programs, volunteer opportunities, advocacy efforts, donations, or simply by staying connected, you help make our community stronger. I encourage you to continue sharing your ideas and your voice with us. Wishing you a wonderful summer filled with sunshine, connection, joy, and many reasons to seize the day.
Warm regards,

Warm regards,
President
EAENA

Susan Wilkie

FROM MY DESK

My reflections for this issue focus on three simple but powerful ideas: celebrate those who show up, never lose hope, and keep putting one foot in front of the other.

Let's see where those thoughts take us.

The biggest news of this past quarter for our community was the tremendous amount of work that went into planning and delivering our second annual awareness campaign, culminating in Seize the Day: A Community Fun Fest! on Saturday, June 20, 2026.

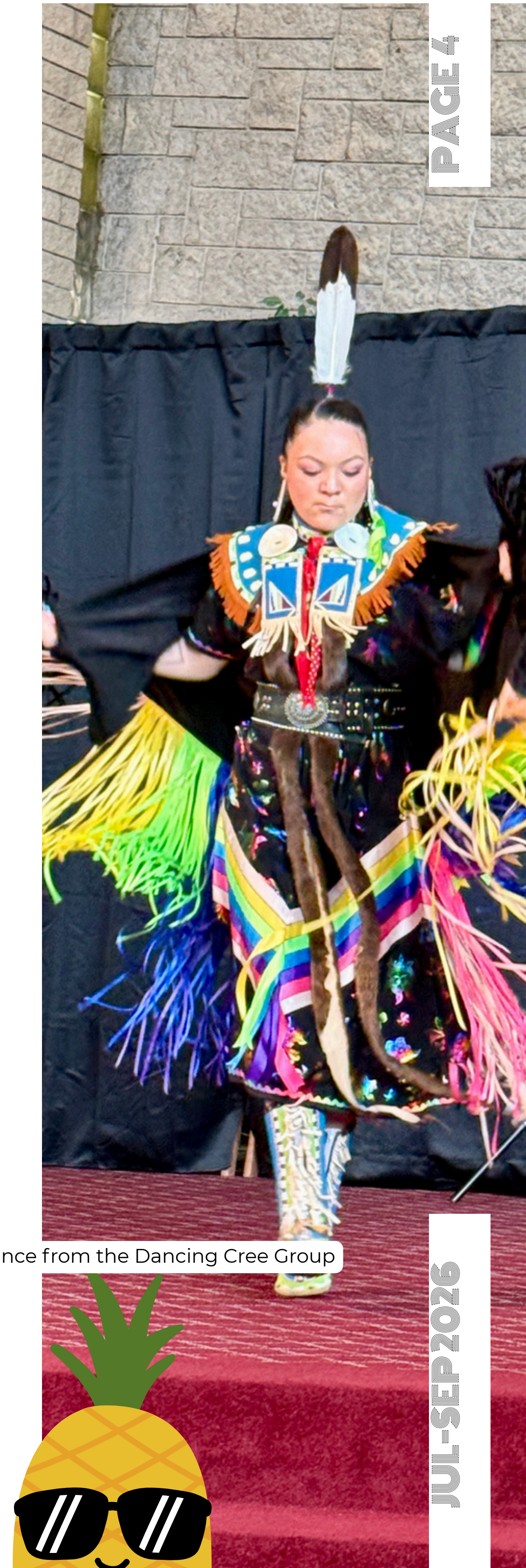
Having organized community events before, we knew what worked well, but we also wanted to introduce new ways to engage with our community, spread awareness about epilepsy, and create a welcoming space where everyone—regardless of their circumstances—felt they belonged. This has become one of our organization's central goals over the past few years: ensuring people know we are here, that we can share reliable information about epilepsy and seizures, offer practical strategies to reduce the impact seizures have on daily life, and foster a strong sense of community support.

This we year, a food truck joined the event and we even offered complimentary meal tickets to the first attendees. The food proved to be both delicious and greatly appreciated, adding another opportunity for people to gather, connect, and enjoy the afternoon together.

Another first in our association's history was welcoming an Indigenous dance group, the Dancing Cree, through a connection with one of our newer members whose seizures have recently returned after a period of stability. Dancing Cree contributed far more than an outstanding dance performance. We learned about the history behind the dances, the significance of the regalia, and the stories each dance carries. It was a meaningful cultural experience that left many of us feeling more connected and appreciative of Indigenous traditions. We hope this is only the beginning of future collaborations that strengthen relationships with Indigenous communities and deepen our understanding of their experiences of living with epilepsy.

Of course, the weather had other plans.

After months of preparation, we happened to choose what felt like the wettest weekend of the summer. As the rain continued, it became clear that attendance would be much smaller than we had hoped. Initially, that felt disappointing. So much work, planning, and resources invested for what seemed like a small crowd. But then perspective set in.



Dance from the Dancing Cree Group

FROM MY DESK

Approximately sixty people came through our doors during those few hours. Sixty people chose to spend part of their Saturday with us despite the weather. Some volunteered. Some came to show their support. Others were simply curious to learn more about epilepsy. They met one another, shared conversations, made new friends, celebrated scholarship recipients, applauded the unveiling of our new association name, enjoyed a meal together, and strengthened the sense of community that continues to grow around our organization.

Those sixty people mattered. They reminded us that success is not always measured by the size of a crowd but by the quality of the connections we create.

Celebrate those who show up. Always.

My second reflection centres on hope.
Many of the policy changes and funding decisions taking place today seem to be making life increasingly difficult for people living with disabilities. New programs are often introduced with promises of improving outcomes, yet too frequently they create greater uncertainty, additional stress, and more barriers for the very people they are intended to help.

At times, society seems to become increasingly selective about who deserves a good quality of life. Those living with the greatest challenges often have the least capacity to advocate for themselves because simply managing daily life already requires so much of their energy.
That is why organizations like ours matter.

Our role is to listen, support, educate, advocate, and offer practical assistance whenever we can. Sometimes that means providing information. Sometimes it means simply reminding someone they are not alone. Sometimes it means creating opportunities for people to connect with others who truly understand their journey.
Our charity remains small, and there are limits to what we can accomplish. Financial pressures continue to grow while funding opportunities become more limited and the cost of delivering services continues to rise.
But what we can do, we strive to do well. And we continue to believe that hope is worth holding onto.
Finally, hope only becomes meaningful when we keep moving forward.

For our organization, the past few years have required some significant steps. We have adapted our membership model, celebrated sixty-five years of serving the community, strengthened our regional focus, and recently adopted a new name that better reflects both who we are and whom we serve. Those are the larger milestones. But it is often the smaller steps that matter just as much.

Every day we open our office doors. We share information through social media. We build relationships with healthcare professionals, schools, and community organizations. We deliver educational presentations, offer free support programs, welcome new members, answer questions, help people navigate memory challenges, and continue working to reduce stigma and isolation. Each of those actions may seem small on its own.
Together, they move our community forward. One step at a time.

This issue carries us into the early days of fall. Whether you are enjoying a refreshing drink on your patio, spending time with family, or taking a well-earned vacation, I hope you find time to rest, recharge, and enjoy these pages.
Thank you for being part of our epilepsy community.

We are truly here for you.

Valeria

EEA UPDATES

- NEW LOGO AND NEW BEGINNINGS
- PURPLE LUNCH HOURS
- SEIZE THE DAY! COMMUNITY FUN FEST!
- KANANASKIS CONFERENCE
- AWARENESS TABLES
- KOB SHOWS
- SCHOLARSHIPS AND QUILTS
- EPILEPSY 101 SESSIONS
- BINGOS
- HOBSCOTCH AND MENTORSHIPS
- AGENCIES' UPDATES
- WEBINARS AND PODCASTS
- A SPECIAL GIFT

A NEW NAME. A NEW LOOK. THE SAME COMMITMENT

Following our 2026 Annual General Meeting, the Board of Directors and staff of the then Edmonton Epilepsy Association began implementing one of the most significant changes in our organization's 66-year history.

As of late April 2026, we officially became the Epilepsy Association of Edmonton and Northern Alberta (EAENA). Yes—we know it's a bit of a mouthful! But our new name better reflects the vast region we serve and the thousands of individuals and families across northern Alberta who are impacted by epilepsy.

With our new name in place, the Board turned its attention to creating a visual identity that could represent our organization for the next 65 years and beyond. Through Board motions and staff implementation, we launched an informal logo and tagline contest, inviting our members and the public to help shape the future of our charity.

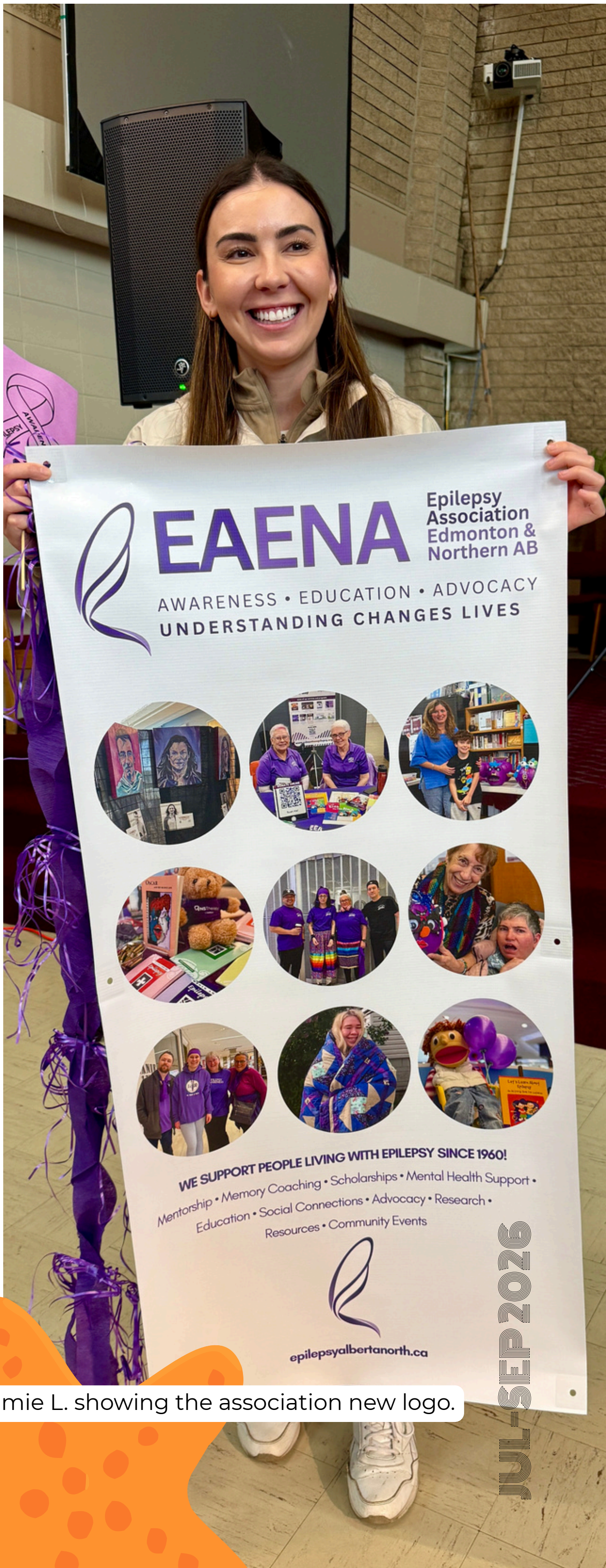
Over six weeks, six talented individuals submitted nine creative concepts for a new logo and tagline. Each submission reflected thought, creativity, and a genuine desire to strengthen our organization. We sincerely thank Tammy H., Patrina M., Mai H., and Mark M. for sharing their ideas and helping inspire this exciting new chapter. After careful review, however, one submission stood apart.

A Vision That Captured Our Future

The Board unanimously selected the design created by Jamie Libon.

Jamie's submission went beyond a logo. She presented a comprehensive mood board that documented her research, creative process, and the reasoning behind every design decision. She examined the visual identities of leading epilepsy organizations throughout North America and Europe, identifying common themes of hope, community, understanding, advocacy, and empowerment.

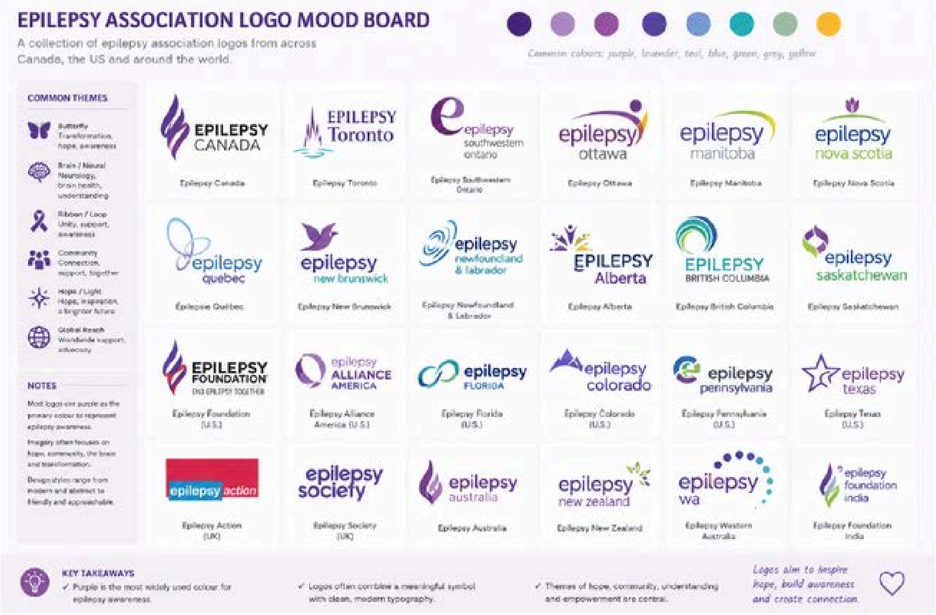
Her research revealed consistent use of epilepsy's signature purple colour, clean modern typography, and meaningful symbolism—elements that communicate trust, compassion, and optimism. Building on those observations, Jamie developed a logo that respectfully honours tradition while looking confidently toward the future.



Jamie L. showing the association new logo.

A NEW NAME. A NEW LOOK. THE SAME COMMITMENT (CONT.)

The Meaning Behind the Logo
The new EAENA logo combines three symbolic elements into one simple, memorable mark.
The familiar purple remains at its heart, representing epilepsy awareness worldwide.
The flowing shape also forms half of a butterfly wing, symbolizing transformation, resilience, growth, and hope—qualities that reflect the journeys of so many people living with epilepsy.
Finally, the design incorporates a lowercase "e" for epilepsy. While epilepsy remains central to our mission, the letter is intentionally integrated into a larger symbol of hope, reflecting our belief that epilepsy should never define or limit a person's quality of life.



Together, these elements create a visual identity that feels compassionate, modern, trustworthy, and empowering.

The Board and staff unanimously agreed that the new logo beautifully represents who we are today—and who we aspire to be in the years ahead.

Introducing Our New Identity
On June 20, 2026, during our Community Fun Fest, Vice-President Shandea P. officially unveiled our new logo and tagline as part of a special ribbon-cutting ceremony marking the beginning of this exciting new chapter.

While our website, publications, signage, and materials will continue transitioning over the coming months, this event symbolized much more than a new visual identity. It celebrated our renewed commitment to serving people impacted by epilepsy throughout Edmonton and Northern Alberta.
"Awareness. Education. Advocacy. Understanding Changes Lives."
Just as meaningful as our new logo is our new tagline:
Awareness. Education. Advocacy. Understanding Changes Lives.
Those six words capture the heart of our mission.

A NEW NAME. A NEW LOOK. THE SAME COMMITMENT (CONT.)

Much of our work focuses on building awareness and providing trusted education about epilepsy. We know that accurate information helps reduce stigma, dispel myths, and foster acceptance.

Advocacy completes that work by standing alongside individuals and families as they navigate challenges and seek meaningful support.

But it is the final phrase—Understanding Changes Lives—that truly brings our mission to life.

Awareness begins a conversation. Education deepens knowledge. Understanding inspires compassion, inclusion, and action.

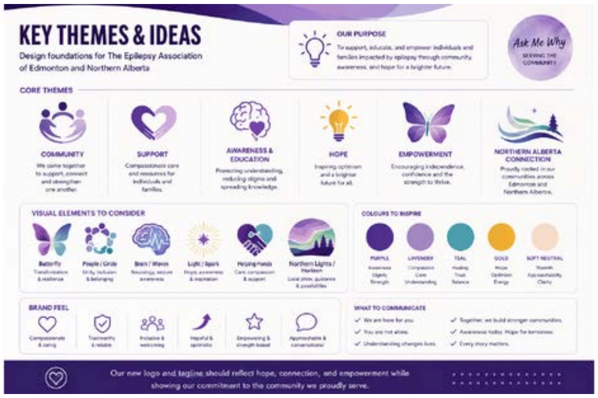
When people truly understand epilepsy, lives change—for those living with the condition, their families, their workplaces, their schools, and their communities.

We are proud to carry this message into the future.

Hear the Story Behind the Design

Jamie recently sat down with us to discuss the inspiration and creative journey behind EAENA's new identity. We invite you to watch her interview and hear, in her own words, how research, symbolism, and lived experience came together to create a logo that represents hope for generations to come.

Watch the interview here: (Insert website link)



KEY THEMES & IDEAS

Design foundations for The Epilepsy Association of Edmonton and Northern Alberta

OUR PURPOSE

To support, educate, and empower individuals and families impacted by epilepsy through community, awareness, and hope for a brighter future.

Ask Me Why

SERVING THE COMMUNITY

CORE THEMES

COMMUNITY
We come together to support, connect and strengthen one another.

SUPPORT
Compassionate care and resources for individuals and families.

AWARENESS & EDUCATION
Promoting understanding, reducing stigma and spreading knowledge.

HOPE
Inspiring optimism and a brighter future for all.

EMPOWERMENT
Encouraging independence, confidence and the strength to thrive.

NORTHERN ALBERTA CONNECTION
Proudly rooted in our communities across Edmonton and Northern Alberta.

VISUAL ELEMENTS TO CONSIDER

Butterfly
Transformation & resilience

People / Circle
Unity, inclusion & belonging

Brain / Waves
Neurology, seizure awareness

Light / Spark
Hope, awareness & inspiration

Helping Hands
Care, compassion & support

Northern Lights / Horizon
Local pride, guidance & possibilities

COLOURS TO INSPIRE

PURPLE
Awareness
Dignity
Strength

LAVENDER
Compassion
Care
Understanding

TEAL
Healing
Trust
Balance

GOLD
Hope
Optimism
Energy

SOFT NEUTRAL
Warmth
Approachability
Clarity

BRAND FEEL

Compassionate & caring

Trustworthy & reliable

Inclusive & welcoming

Hopeful & optimistic

Empowering & strength-based

Approachable & conversational

WHAT TO COMMUNICATE

- ✓ We are here for you.
- ✓ You are not alone.
- ✓ Understanding changes lives.
- ✓ Together, we build stronger communities.
- ✓ Awareness today. Hope for tomorrow.
- ✓ Every story matters.

Our new logo and tagline should reflect hope, connection, and empowerment while showing our commitment to the community we proudly serve.

EAENA

Epilepsy Association Edmonton & Northern AB

AWARENESS • EDUCATION • ADVOCACY

UNDERSTANDING CHANGES LIVES

PURPLE LUNCH HOUR SESSIONS — APRIL, MAY & JUNE 2026

Over the past several months, the Edmonton Epilepsy Association has been proud to host our new online initiative, the Purple Lunch Hour Chats — community conversations held on the last Tuesday of every month.
These sessions were created to provide a welcoming and supportive space where individuals living with epilepsy, caregivers, healthcare professionals, educators, and community members can come together to share experiences, ask questions, and learn from one another.

As the conversations continue to grow, Purple Lunch Hour is becoming an important way for our association to contribute in meaningful and practical ways to a broader understanding of epilepsy and its impact on everyday life, relationships, education, healthcare navigation, mental health, advocacy, and future planning.

The discussions featured in the following pages reflect the generosity, courage, and openness of everyone who participated. From personal family journeys to medical insights and advocacy experiences, each conversation highlights the strength and resilience within our epilepsy community.

We hope these summaries provide helpful information, encouragement, and connection for readers who may be navigating similar experiences.

Thank you to everyone who continues to join us, share their stories, and help strengthen community presence, understanding, and support for all those affected by epilepsy

PURPLE LUNCH HOUR CHATS

EAENA Epilepsy Association Edmonton & Northern AB

AWARENESS • EDUCATION • ADVOCACY
UNDERSTANDING CHANGES LIVES

Last Tuesday of the month - 12:00 - 1:00 pm. MST

Join us through the link! Let's talk epilepsy!

EDMONTONEPILEPSY.ORG

DONATE TODAY!

Every birdie builds a brighter future.

VISIT epilepsyalbertanorth.ca FOR THE LINK TO DONATE

donate today!
your dollars grow by 50%

April, 28, 2026 - A Parent’s Journey Through Epilepsy, Advocacy, and Hope

During the April Purple Lunch Hour session, members of the epilepsy community gathered for an honest and inspiring conversation with Susan Wilkie, President of the Edmonton Epilepsy Association, educator, and mother to a teen living with epilepsy.

Susan shared the deeply personal story of her son Owen’s epilepsy journey — one marked by uncertainty, resilience, advocacy, and hope. Owen experienced his first seizure at just four years old, shortly after the birth of his younger brother. What began as a frightening and unexpected medical emergency quickly evolved into years of hospital visits, medication trials, EEGs, and specialist appointments between Fort McMurray and Edmonton.

Eventually, Owen was diagnosed with Lennox-Gastaut syndrome (LGS), a rare and severe form of epilepsy often associated with developmental challenges and multiple seizure types. Susan recalled the overwhelming reality of hearing difficult prognoses and navigating life far from specialized medical care.
“We were told he might lose speech, mobility, and other functions,” Susan shared. “But Owen’s story became very different.”

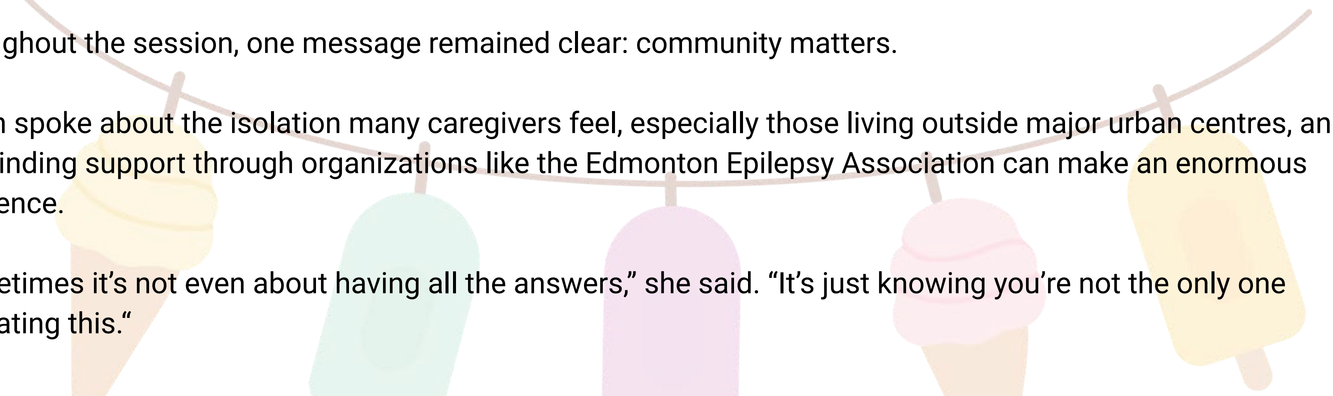
Following treatment at the Stollery Children’s Hospital, including steroid therapy and carefully managed medications, Owen gradually became seizure-free. Today, at almost 16 years old, he remains seizure-free and is no longer taking anti-seizure medication.

> *“Sometimes it’s not even about having all the answers,” she said.*
> *“It’s just knowing you’re not the only one navigating this.“*

Susan emphasized that while the medical side of epilepsy is significant, the educational and emotional journey can be equally complex.

As both a parent and educator, she described the constant advocacy required within school systems — from individualized education plans and classroom accommodations to navigating invisible disabilities, bullying, and the emotional impact epilepsy can have on a young person’s self-esteem.

“Advocacy becomes exhausting at times,” Susan explained. “You often have to retell your story over and over again. But it’s necessary to make sure your child receives the support they need.” The conversation also explored how epilepsy can intersect with other health concerns, including developmental and endocrine challenges. Participants discussed the importance of asking questions, seeking specialist referrals, and building strong partnerships with healthcare providers.



Throughout the session, one message remained clear: community matters.

Susan spoke about the isolation many caregivers feel, especially those living outside major urban centres, and how finding support through organizations like the Edmonton Epilepsy Association can make an enormous difference.

“Sometimes it’s not even about having all the answers,” she said. “It’s just knowing you’re not the only one navigating this.“

The conversation highlighted the importance of normalizing assistive tools and accommodations in schools, reducing stigma around invisible disabilities, and helping youth living with epilepsy feel understood and included.

We are deeply grateful to Susan for sharing her family's story with such honesty and compassion. Her experience reminds us that every epilepsy journey is unique — and that support, advocacy, and connection can profoundly change outcomes.

May 26, 2026 : Stollery & Kaye Clinic Conversations on Transitioning to Adult Epilepsy Care

On May 26, 2026, our Purple Lunch Hour session focused on the important topic of transitioning into adult health care for youth living with epilepsy. For many young people diagnosed during childhood, turning 18 often means they are expected to begin managing their own medical care, appointments, medications, and health decisions independently.

One of the key messages shared during the discussion was that successful transitions do not happen overnight. These conversations should ideally begin around age 16, giving youth, families, and medical teams enough time to prepare for the shift into adult care. Planning ahead allows young people to gradually build confidence, knowledge, and self-advocacy skills while still supported by their pediatric care teams and families.

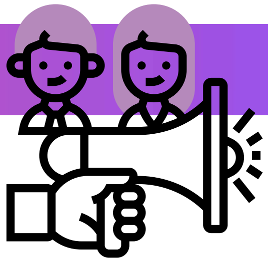
However, meaningful transition planning requires time, coordination, and access to appropriate resources — something that can be difficult to achieve within today's provincial health-care systems. Participants learned that most Canadian provinces continue to lag behind in developing strong transition supports and accessible resources for youth with epilepsy. This reality is especially challenging for epilepsy communities in northern Alberta.

The teams from the Stollery Children's Hospital and the Kaye Edmonton Clinic shared their expertise and guided an informative and thoughtful conversation about the challenges and opportunities surrounding transition care. Their insights highlighted the importance of collaboration between families, health-care providers, schools, and community organizations to help youth succeed as they move into adulthood.

We are grateful to both teams for sharing their knowledge and helping open the door to conversations that are urgently needed within our epilepsy community. We hope the key points and reflections from this session can continue serving as a helpful resource for families and individuals preparing for future steps in the transition journey.

> ***"Meaningful transition planning requires time, coordination, and access to appropriate resources — something that can be difficult to achieve within today's provincial health-care systems."***

What Patients and Families Need to Know



For many families living with epilepsy, the journey does not end in childhood. In fact, about half of children diagnosed with epilepsy will continue to need treatment and support into adulthood. As young people grow older, they eventually move from pediatric neurology services to adult epilepsy care — a process known as "transition."

Transition is much more than simply changing doctors. It is a gradual and important process that affects many areas of life, including medications, independence, mental health, school, work, driving, and relationships. A smooth and well-planned transition can significantly improve long-term health outcomes and quality of life.

What Is Transition?

Transition is a planned process that usually begins between the ages of 14 and 16 and may continue until age 18–25. The goal is to help young people gain the skills and confidence they need to manage epilepsy independently within the adult healthcare system.

Successful transition involves collaboration between the pediatric healthcare team, adult neurology providers, the young person, and their family.

Why Is Transition Important?

Without proper planning, young adults can sometimes "fall through the cracks" between pediatric and adult care systems. Poor transitions may lead to:

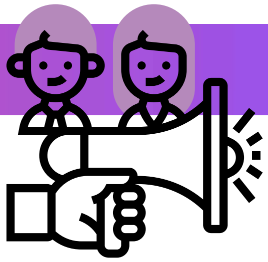
- Missed appointments and gaps in medical care
- Difficulty managing medications consistently
- Increased seizure activity
- Mental health challenges such as anxiety or depression
- Increased risk of serious complications, including SUDEP (Sudden Unexpected Death in Epilepsy)
-

A structured transition process helps reduce these risks and supports better long-term outcomes.

What Does a Good Transition Program Include?

A strong epilepsy transition program focuses on the whole person, not just seizure management. Areas often addressed include:

- Reviewing diagnoses and medications
- Updating testing when needed
- Mental health screening and support
- Education around driving, employment, and post-secondary studies
- Reproductive health and medication safety
- Access to community resources and financial supports



The Canadian Perspective

Canada is making progress in epilepsy transition care, but challenges remain. In 2017, Ontario introduced the first province-wide epilepsy transition recommendations through the Ontario Epilepsy Implementation Task Force. Canadian epilepsy specialists, including Dr. Danielle Andrade and Drs. Peter and Carol Camfield, are internationally recognized leaders in transition research.

However, structured transition programs are still limited across Canada, highlighting the need for continued advocacy and support.

How Families Can Help Prepare

Families play a critical role in supporting a successful transition. Helpful steps include:

- Starting conversations about transition early
- Encouraging teens to participate actively in their healthcare
- Helping young people learn their medication names and doses
- Understanding seizure types and emergency plans
- Keeping a portable medical summary
- Connecting with community organizations and supports
- Asking about mental health resources when needed

What Young Adults Can Expect

Adult epilepsy care often feels different from pediatric care. Young adults are expected to take a more active role in decision-making and managing appointments. Adult neurologists may revisit diagnoses, order updated testing, and discuss topics such as driving, alcohol use, employment, contraception, and pregnancy planning.

Even during busy life transitions, it remains essential to continue medications consistently and attend follow-up appointments.

Community Resources

The Edmonton Epilepsy Association continues to support individuals and families through education, advocacy, and community programming. We encourage families to speak with their neurologist about transition planning and to reach out for support whenever needed.

Transitioning to adult care can feel overwhelming, but with preparation, support, and open communication, young people with epilepsy can successfully move into adulthood with confidence and independence.

Being Prepared: Understanding Status Epilepticus and Rescue Medications

This last article is a summary of the conversation held with Dr. Liu, Pediatric Neurologist, Epileptologist and Assistant Professor, Division of Pediatric Neurology at the Stollery Children's HOspital and University of Alberta, held on June 30, 2026 on Zoom.

Being Prepared: Understanding Status Epilepticus and Rescue Medications
For most people living with epilepsy, seizures end on their own within a few minutes. But when a seizure continues for longer than five minutes—or when seizures occur one after another without the person recovering in between—it becomes a medical emergency known as status epilepticus.

Although this can be frightening for families, caregivers, friends, and even bystanders, understanding what to do ahead of time can make all the difference.

One of the most important messages shared by pediatric neurologist and epileptologist Dr. Natari Lu during a recent educational webinar hosted by EAENA is simple: time matters.

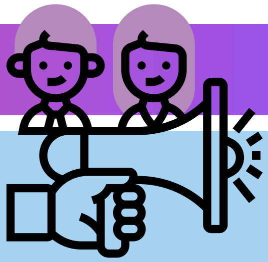
Healthcare professionals now recognize that a convulsive seizure lasting longer than five minutes is unlikely to stop on its own. This is the point when the brain's natural ability to end the seizure begins to fail, making prompt treatment essential. Acting early can help reduce the risk of injury, breathing difficulties, prolonged recovery, and other serious complications. Fortunately, there are effective tools available to help.

Knowing What to Do
When someone is having a seizure, the first priority is always to keep them safe.

Stay calm. Start timing the seizure if it is safe to do so. Move any objects that could cause injury, gently turn the person onto their side when possible, and stay with them until they have fully recovered. Never restrain them or place anything in their mouth.

If the seizure lasts longer than five minutes, follow the person's seizure action plan and call 911 if emergency assistance is needed.

These simple first aid measures, combined with timely treatment, can have a significant impact on outcomes.



Being Prepared: Understanding Status Epilepticus and Rescue Medications (cont.)

Rescue Medications Save Time

Rescue medications are fast-acting medications prescribed for people who are at risk of prolonged seizures or seizure clusters. They are designed to stop a seizure before it progresses into status epilepticus. Today, several options are available, including medications that are administered inside the cheek (buccal), through the nose (intranasal), or, in some situations, rectally. Newer formulations, such as pre-filled buccal midazolam syringes, have made rescue medications easier to carry and simpler for caregivers to administer during an emergency.

The right medication depends on many factors, including a person's age, seizure type, medical history, and lifestyle. Every treatment plan should be developed in partnership with the individual's healthcare team.

Every Person Should Have a Seizure Action Plan

One of the strongest messages from the webinar was the importance of having an individualized Seizure Action Plan.

A seizure action plan provides clear instructions about the types of seizures a person experiences, when rescue medication should be given, when emergency services should be called, and who should be contacted. It can be shared with family members, schools, workplaces, caregivers, and friends so that everyone understands how to respond with confidence.

A seizure emergency is never the time to guess what to do. Having a plan in place allows others to act quickly and appropriately.

Building Confidence Through Education

For many families, the greatest challenge is not simply the seizure itself—it is the uncertainty that comes with it. Education helps replace fear with confidence.

Just as people living with asthma carry inhalers and those at risk of severe allergies carry epinephrine, rescue medications are becoming an important part of emergency preparedness for many people living with epilepsy. Having access to these medications, understanding when to use them, and ensuring those around you know how to respond can improve safety and may even prevent a visit to the emergency department.

At EAENA, we believe that education empowers people to live well with epilepsy. By learning seizure first aid, creating a seizure action plan, and speaking with your healthcare provider about whether rescue medication is appropriate, individuals and families can be better prepared for the unexpected.

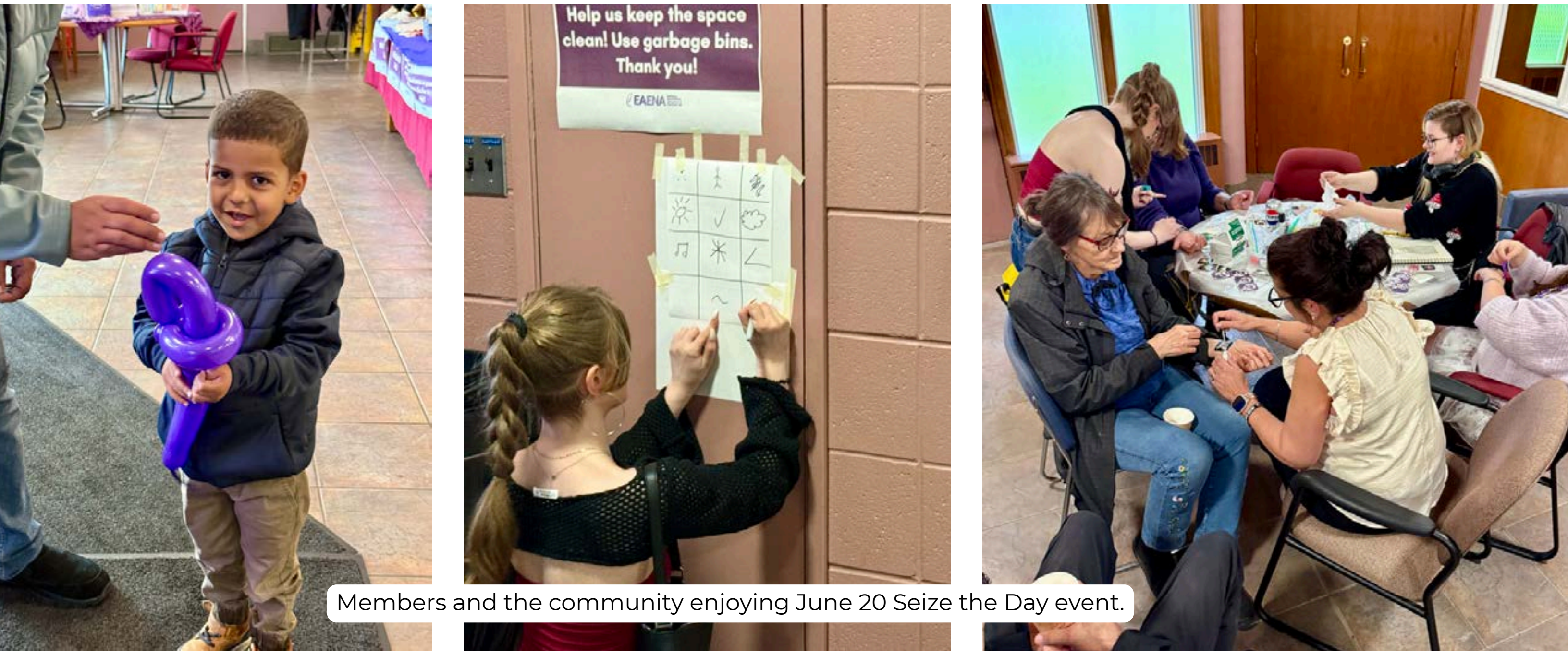
Because **when it comes to prolonged seizures, knowledge, preparation, and timely action truly have the power to save lives.**

RAIN COULD NOT DAMPEN OUR SPIRIT: EAENA'S 2026 COMMUNITY FUN FEST

Each summer, we look forward to bringing our community together to celebrate, learn, and raise awareness about epilepsy. This year was no exception.

While March is recognized across Canada as Epilepsy Awareness Month, our commitment to awareness and education extends far beyond a single month. Over the past four years, we have intentionally created three annual touchpoints—March, June, and October—to connect with our community through education, celebration, and support.

As the seasons change, so do the challenges and opportunities experienced by people living with epilepsy. These gatherings provide an opportunity to pause, learn more about the brain and seizures, build meaningful connections, and remind everyone impacted by epilepsy that they are not alone.



Members and the community enjoying June 20 Seize the Day event.

RAIN COULD NOT DAMPEN OUR SPIRIT: EAENA'S 2026 COMMUNITY FUN FEST (CONT.)

This year's Community Fun Fest was especially exciting as it marked our first major outdoor event at our new home in the Crestwood neighbourhood.

Our beautiful new location offers a spacious private lawn, surrounded by schools, community organizations, and residential homes—the perfect setting for welcoming neighbours and families into our community. We envisioned a lively outdoor celebration featuring educational displays, interactive brain games, puppet shows, Indigenous dance performances, delicious food, and activities for all ages. Mother Nature, however, had other plans.

The weekend of June 20 turned out to be one of the rainiest of the summer. Thanks to the incredible generosity of the Saint Andrew's United Church community, we quickly moved the entire event indoors. Although the weather significantly reduced attendance, it certainly did not diminish the warmth, enthusiasm, or sense of community inside.

While we had prepared for well over 100 visitors, approximately 60 people joined us throughout the day—and together we created an event filled with learning, laughter, and connection.

A Day Filled with Community

Our formal program was expertly hosted by EAENA Vice-President **Shandea P.**, alongside her daughter, Keliah. Even with the rain falling outside, one of our speakers faced the parking lot and outdoor space, ensuring the neighbourhood could still hear and experience part of the celebration.

Throughout the building, volunteers welcomed visitors to educational displays, games, and activities. Smiles could be found everywhere as families explored the event, enjoyed balloon creations, and sampled delicious treats from the FireWheel Food Truck.

The day also featured several memorable milestones.

One of our members, **Shelly G.**, was announced as the winner of our 50/50 raffle, while many generous supporters contributed to our Birdies for Kids fundraising campaign.
We also celebrated the official purple ribbon-cutting ceremony, symbolizing our transition into a new era as the Epilepsy Association of Edmonton and Northern Alberta, complete with our new logo, visual identity, and tagline.

Members and the community enjoying June 20 Seize the Day event.

RAIN COULD NOT DAMPEN OUR SPIRIT: EAENA'S 2026 COMMUNITY FUN FEST (CONT.)

One of the highlights of the afternoon was a very special first for our organization.
For the first time in our history, we welcomed the Dancing Cree group to perform traditional Indigenous dances. The dancers shared not only beautiful performances but also explained the meaning behind their regalia, traditions, and dance movements, offering everyone an opportunity to learn and appreciate Cree culture.

The performance carried special meaning for our community, as one of the dancers is also an EAENA member living with epilepsy. It was a powerful reminder that our community is strengthened by the diversity of experiences, cultures, and stories that come together through our shared journey. We look forward to building an even stronger relationship with the Indigenous community in the years ahead.

Cutting of the purple ribbon to welcome our new name!

Looking Ahead
The weather may have made this year's event smaller than we had imagined, but it never diminished the spirit that brought everyone together.

Our commitment to promoting awareness, celebrating resilience, and creating a welcoming community for people impacted by epilepsy remains as strong as ever.

Sometimes the most meaningful gatherings are not the largest ones—they are the ones where every person feels seen, welcomed, and understood. We hope you enjoy the photographs featured in these pages, and we invite you to join us this October for our final awareness event of the year. Together, we will continue building understanding, fostering hope, and creating a community where no one faces epilepsy alone.

CONNECTING WITH ALBERTA'S EPILEPSY COMMUNITY AT THE WESTERN EPILEPSY WORKSHOP

On May 1–2, 2026, the Epilepsy Association of Edmonton and Northern Alberta (EAENA), alongside our Calgary-based sister organization, Epilepsy Southern Alberta, participated in the 29th Western Epilepsy Workshop in Kananaskis. This marked our third consecutive year attending this important annual gathering of epilepsy specialists, neurologists, EEG technologists, researchers, university students, and pharmaceutical representatives.

Hosted by the University of Alberta Hospital and led by Dr. Kassiri and Dr. Elliott, the workshop brings together many of Alberta's leading epilepsy professionals to explore advances in research, discuss challenging clinical cases, share emerging treatment options, and collaborate on improving care for people living with epilepsy.
For our association, the workshop is an important opportunity to remind the medical community that supporting someone with epilepsy extends far beyond diagnosis and treatment.

Each year, EAENA and Epilepsy Southern Alberta share an information booth that highlights the wide range of programs and services available through our organizations. While many physicians and specialists already refer patients to us for information and support, these face-to-face conversations reinforce the critical role community organizations play in improving quality of life.

Valeria P. and Laura D. at the Kananskis Conference.

CONNECTING WITH ALBERTA'S EPILEPSY COMMUNITY AT THE WESTERN EPILEPSY WORKSHOP (CONT.)

Our work includes connecting individuals and families with resources, providing trusted education about living with epilepsy, helping people navigate healthcare and community services, and offering specialized programs that simply are not available elsewhere. From mentorship, memory coaching, and support groups to youth, family, senior, and caregiver initiatives, we create opportunities for people to build confidence, reduce isolation, and live well with epilepsy.

Perhaps just as importantly, we provide welcoming spaces where people can gather, enjoy a cup of coffee, celebrate together, and participate in community events without fear of stigma or worrying whether those around them will know how to respond if a seizure occurs.

While our exhibit table serves as our primary presence at the workshop, we also make it a point each year to briefly address the audience and recognize the value of community-based epilepsy organizations.

This year, we unveiled a new video presentation showcasing the impact of our work throughout Northern Alberta. The response exceeded our expectations. Not only did the presentation receive enthusiastic feedback from attendees, but a pharmaceutical company also contacted us afterward to request permission to use the video to educate and inform its own staff about the vital role community epilepsy organizations play.
We were incredibly proud of this recognition and of the opportunity to further raise awareness of the importance of community support alongside medical care.

We wish to thank Terry Mahon for his generous donation of funds to allow the EAENA to attend this event on an annual basis.

If you would like to watch our short presentation, **visit our Vimeo channel using the link provided on our website.**

BRINGING EPILEPSY AWARENESS INTO THE COMMUNITY

As we've shared in previous issues of Focus on Epilepsy and during many of our public presentations, a significant part of the Epilepsy Association of Edmonton and Northern Alberta's work is dedicated to raising awareness about epilepsy, seizures, and what it means to live with this neurological condition.

One of the most effective ways we accomplish this is through our community awareness tables. Throughout the year, our staff and volunteers attend health fairs, community festivals, volunteer expos, seniors' events, hospital information days, and many other public gatherings. These events allow us to share trusted information, answer questions, distribute educational resources, and connect directly with members of the public.

Over the years, we have become a familiar presence at many community events, and organizations across Edmonton regularly invite us to participate because they recognize the value of providing epilepsy education to their audiences.

Every conversation at our table matters. Many people who stop by have a personal connection to epilepsy—they may live with the condition themselves, have a family member or friend affected by seizures, or simply want to better understand epilepsy.

Even those who only pause for a moment to pick up a brochure, accept a piece of candy, or glance at our colourful display leave with greater awareness. A simple interaction today may become the moment someone remembers us weeks or months later when they need information, support, or guidance for themselves or someone they love.

During the past several months, our awareness efforts were made possible thanks to the dedication of several outstanding volunteers. While our Executive Director was working off-site for several weeks, these individuals generously stepped forward to represent EAENA at community events with professionalism, compassion, and enthusiasm.

Val G. and NOella D. volunteering at awareness fair.

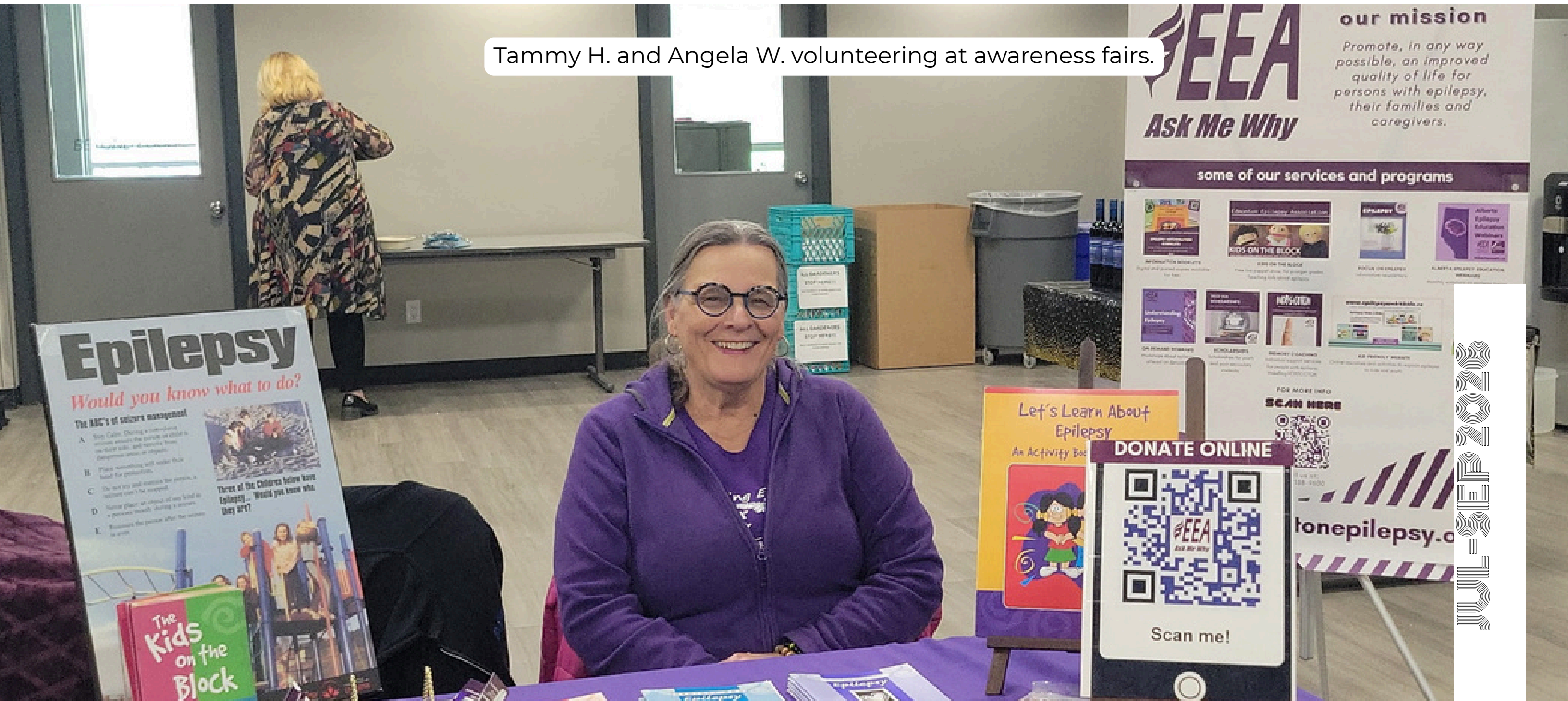
BRINGING EPILEPSY AWARENESS INTO THE COMMUNITY (CONT.)

We extend our sincere thanks to Noella D., Val G., Tammy H., Kim A., and Angela W. for donating their time and expertise to help us educate the community and represent our organization so well.

Recent Awareness Table Events

- April 15 – E360 Community Booth, West Edmonton Mall
- April 25 - WEM ECVO Volunteer Fair
- May 1–2 – 29th Western Epilepsy Workshop, Kananaskis Mountain Lodge
- May 12 – University of Alberta Hospital – Stollery Campus
- May 14 – Edmonton Community Ambassador Volunteer Fair
- June 2 – NESA Seniors Fair
- June 4 – West End Seniors Fair
- June 6 – Brain Injury Awareness Fair, Hawrelak Park

Every awareness table helps reduce stigma, increase understanding, and ensure that more people know where to turn for trusted epilepsy information and support. We are grateful to everyone who stops by to visit us and to the volunteers who make these opportunities possible.



Tammy H. and Angela W. volunteering at awareness fairs.

KIDS ON THE BLOCK CONTINUES TO MAKE A DIFFERENCE

It is always a joy to share news about our Kids on the Block (KOB) program. If you are a new reader or supporter of our association, you may not be familiar with this unique initiative.

We are proud to be one of the very few epilepsy organizations in Canada—and indeed North America—that continues to offer Kids on the Block, an engaging live puppet show designed for elementary school students. Through fun, memorable characters and interactive storytelling, the program teaches children about epilepsy, seizure first aid, inclusion, and the importance of being a good friend to everyone, regardless of their abilities or challenges.

For more than two decades, we have been offering this program free of charge to schools throughout our region. We are grateful that this important work continues to be made possible through the generous support of Terry Mahon and his charitable foundation.

The process is simple. Parents of children living with epilepsy, teachers, school administrators, or other school staff can contact EAENA to request a free performance for their elementary school. Our goal is to help build understanding, reduce stigma, and create safer, more inclusive classrooms for all students.

KOB show at Belvedere school.

On June 12, 2026, we presented our final school performance of the academic year at Belvedere Elementary School. More than 350 students, along with teachers, educational assistants, and school administrators, attended the presentation. We were truly impressed by how engaged and respectful every student was, from Kindergarten through Grade 6. Following the performance, dozens of hands shot into the air as students eagerly asked questions of our puppeteers and our main character, Brian, who lives with epilepsy.

One of our favourite moments is hearing comments such as, "My teacher has epilepsy!" These simple but powerful statements remind us that the show helps children connect what they have learned with people they already know and care about. Instead of seeing epilepsy as something unfamiliar or frightening, students begin to view it with understanding, acceptance, and even pride in supporting someone in their own lives.

Our KOB team will be performing next at Kids Fringe on August 19, 2026, and we look forward to sharing our message with even more young audiences.

If you know of an elementary school, community centre, or youth organization that serves younger children and would like to host a free Kids on the Block performance, we would love to hear from you. For communities located more than 50 kilometres from Edmonton, we also offer live-streamed performances, making it possible for rural schools and communities to benefit from this engaging and educational program.

Together, we can continue building a generation that understands epilepsy, knows how to respond to seizures, and welcomes everyone with kindness and inclusion.

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS

SCHOLARSHIP RECIPIENTS 2026

CONTINUING EDUCATION

Congratulations to:

Jack McGowan

www.edmontonepilepsy.org

SCHOLARSHIP RECIPIENTS 2026

CONTINUING EDUCATION

Congratulations to:

Ashley Grimoldby

www.edmontonepilepsy.org

SCHOLARSHIP RECIPIENTS 2026

GARRY HANNIGAN MEMORIAL SCHOLARSHIP

Congratulations to:

Hayden Witiuk

www.edmontonepilepsy.org

SCHOLARSHIP RECIPIENTS 2026

GARRY HANNIGAN MEMORIAL SCHOLARSHIP

Congratulations to:

Kayla Milan

www.edmontonepilepsy.org

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

The end of March marks the application deadline for two of our three annual scholarship programs. As in previous years, the Epilepsy Association of Edmonton and Northern Alberta (EAENA) was honoured to recognize several outstanding individuals whose determination, resilience, and accomplishments inspire our entire community.

This year, we awarded two Epilepsy Trust Post-Secondary Education Scholarships, funded through the Epilepsy Trust, along with the Garry Hannigan Leadership Scholarship for Sports and Physical Activity. These scholarships recognize individuals who are pursuing excellence in academics, leadership, and athletics while living with the daily challenges of epilepsy. Their achievements demonstrate that epilepsy does not define a person's potential or limit their ability to pursue meaningful goals and dreams.

By celebrating these remarkable individuals and sharing their personal stories, we hope to inspire others in our community—especially young people living with epilepsy—to believe in themselves and continue striving toward their own aspirations.

We are pleased to congratulate our 2026 scholarship recipients:

Epilepsy Trust Continuing Education Scholarships

- Jack McGowan
- Ashley Grimoldby

Garry Hannigan Leadership Scholarship for Sports and Physical Activity

- Kayla Milan
- Hayden Witiuk

Congratulations to each of these deserving recipients. Throughout this issue, we are pleased to share excerpts from the essays and personal reflections they submitted as part of their applications. Their stories are powerful reminders that perseverance, determination, and hope can overcome many obstacles.

Hayden's Reflection

Hi my name is Hayden. I am 10 years old and have epilepsy. I love to play hockey. Sometimes I can't play hockey because of seizures and being in the hospital but it is my favorite thing to do and I want to be in the NHL. I want to be able to play like my friends. Thank you for helping me be able to play my favorite sport and feel like a normal 10 year old.

Hayden

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

Kayla's Reflection

Hi,

My name is Kayla Milan and I am applying for the Garry Hannigan memorial scholarship. I am in grade six and found out about this when I was on The EEA website looking up information for my school project.

I was diagnosed with Epilepsy in grade 3 but it hasn't stopped me living my life like I want to. I love animals and have bought myself a budgie named Joy and a bunny named Comet. I also love school, math, playing the piano, going to the farm, and hanging out with my friends and family. I also love sports! Sports is what takes up most of my time from September to June. I play ringette, lacrosse and school volleyball. I also love swimming and am hoping to go to summer camp this year.

I am applying to help pay for ringette because that is my favourite sport and one I've played for 7 years. It is an ice sport played mostly by girls and is a great team sport because you have to pass over both blue lines. I really love ringette :) It was during ringette that my parents really noticed my absence seizures which was a scary and confusing time but my teammates and coaches were really supportive.

I would really like this scholarship because me and my siblings play sports year round and I know it is really expensive. This would help my family. I also think that I am good at teaching people about epilepsy and I am someone who shows others that you can have epilepsy and still be a great athlete.

This scholarship would allow me to continue to play sports. Playing ringette is a place where it never matters that I have epilepsy. When I am playing I am just like everyone else. I am strong, confident and fast. I am just me.

Thank you for taking the time to consider me for this memorial scholarship.

Sincerely,

Kayla #23

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

Essay by Jack McGowan

Epilepsy education serves as a required part of improving the lives all people touched by the neurological disorder. When I was younger I felt very in the dark about epilepsy and struggled significantly with the impacts it had on my life. As a result of my early personal experiences I came to understand the importance of education within the epilepsy community. In the years that followed I started to focus on more personal involvement in the epilepsy community with the hope of answering questions and providing support to other people who find themselves in the dark much as I had so many years ago. Over the past couple years I have worked to increase epilepsy education through a few channels, most notably my participation in the Edmonton Epilepsy Association (EEA) Portrait project and by getting training in mentoring and HOBSCOTCH coaching; two notable streams of the EEA's support and education services.

The EEA Epilepsy Portrait Project was the first significant community education project that I participated in. As a means to celebrate the 65th anniversary of the organization, myself and several other individuals who had been living with epilepsy shared our stories and excellent portraits painted and displayed both in the epilepsy wing of the University of Alberta Hospital and at the EEA Gala that year. I really appreciated the display of the portraits and stories in the hospital because I remember when I spent time in the hospital years ago and felt like because of epilepsy I would not be able to pursue my dreams. I think that if I had heard some of the stories presented in the Portrait project I would have both been somewhat reassured of my decision and learned that there are so many paths forward and that epilepsy, and brain surgery does not have to define who I am or what I hope to pursue.

Scholarship recipients and EAENA Vice-President, Shandea P.

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

More recently I have gotten involved with more direct services of education withthe EEA. Firstly I got the training to become a mentor, to provide supportive listening and education to people who are looking for some support around their epilepsy diagnosis. As of writing this I am yet to be formally matched with a mentee, however I look forward to being able to provide support. The second area of community education that I am currently involved in is being a Coach for the HOBSCOTCH program that aims to provide support with memory and attention for adults with epilepsy. I recently completed the HOBSCOTCH training program and am set to begin my first set of sessions shortly.

This opportunity means a lot as I can personally understand how seizures, medications and surgeries can result in various memory difficulties and I am encouraged to see that the HOBSCOTCH program can serve as good supplementary support for people with epilepsy. In both cases, with mentoring and HOBSCOTCH coaching, I hope to be able to further expand my understanding of epilepsy and to provide more support and education to the epilepsy community.

For much of my life I was somewhat removed from the epilepsy community in general. But a few years ago I came across the EEA and became a member. Since that time I have been involved in multiple projects that are designed to provide education and support for the epilepsy community of northern Alberta. The opportunity to be a part of the Portrait Project was an introduction to educating the community and I was able to see the significant impact such projects can have on individuals who are struggling with disorder.

The positive effects have encouraged me to become more involved and provide direct education and support with mentoring and HOBSCOTCH coaching. At the moment I see myself at the beginning of an epilepsy education journey and anticipate my involvement with the EEA and the epilepsy community in general to only increase in the future

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

Essay by Ashley Grimoldby

My Journey Through Diagnosis

My journey with epilepsy has had its ups and downs but has always been central to my self-advocacy. It started when I was 7 with my first known tonic-clonic seizure. We went to the hospital, had some tests and scans and a referral for my first EEG. At my EEG, my mom saw a Purple Day poster, and that's where the advocacy and awareness began.

At age nine I had my follow-up and was removed from meds because nothing showed up on the EEG. At the time, we were unaware that seizures can change and present differently. So, for about a year, we didn't notice anything except my increase in forgetfulness and my apparent "daydreaming" ac;cording to my Grade 4 teacher. She told my mom, "I just needed to pull up my socks."

Fast forward to Grade5, my mom discovered my absence seizures while she was making a video of me for an assignment. There it was, plain as day, not once but twice, an absence seizure. My mom watched me closely when she was with me. I would gaze for a few seconds and not recall anything during that time. It was like I forgot whatever it was that happened. Mom said the seizures were happening all the time.

One evening we went for dinner, and my mom noticed about seven seizures in twenty minutes. My mom phoned the neurologist who saw me right away, complete with another EEG. They didn't see anything on the test so they had scheduled me for testing in the hospital. Testingwas cancelled. My mom was frustrated and upset. She kept seeing the seizures and the impact it was having. Shehad asked tospeak to the neurologist directly. They put me back on meds and I was back to my self-advocacy and advocacy for others.As I made my way through junior high, with the help of my mom, myepilepsy diagnosis came first as I metteachers, wenton school trips,and attended school events which alwaysinvolved talking about epilepsy.In grade ten, I was finally put on an Individualized EducationPlan or IEP for short.Sadly, it wasn't for my epilepsy or the impacts it had on my learning. I was diagnosed with Attention Deficit Hyperactivity Disorder, Learning Disability, and Auditory Processing disorder in addition to my epilepsy making it even more difficult for teachers to understand that I may miss stuff that I don'teven know I missed. However, with perseverance, help from my family and educators who understood... ! graduated from high school!I'm in university now, still advocating and educating others about epilepsy.

The Changes I Have Made

When I was diagnosed,it was a lot for my family. We didn't have the knowledge and with school startingin a matter of days, we had to educate ourselves beforehand, this iswhen my Mom got in touch with the Edmonton Epilepsy Association.They provided us with guidance and literature for my school and us.The more we learned andtalked about it with my teachers, the more we realized that therewas so much misinformation surrounding epilepsy. My grade one teacher from the year before asked me after telling her of my diagnosis,"...and has it changed you?". I hadr eplied as any 7-year-old would," No, but I can't go swimming by myself."

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

In the first school year aftermy diagnosis, with the help of the EEA,we had The Kids on the Block come into my elementary schoolto teach others and even myself about what to do duringa seizure. Originally it was just my class thatwas going to attend but it turned into the entire grade, and then the whole school. With the help of a teacher, we also managed to make Purple Day an annualevent with classes putting aside time to talk about epilepsy and how to help someone having a seizure. During the summer monthsup until I was about 15,we had purple lemonade stands, and during garage sales a "pay what you can" table, to help fundraise and spread awareness. With continued support from the EEA, weprovided many resourcesduring our front yard events, including pamphlets and first aid cards that people can keep in their wallets.

When my seizures changed, so did the protocol. I went from having tonic-clonic seizures which required a first aid response and were more noticeable, to absence seizures which didn't require medical attention but an explanation as to why it looked like I was daydreaming and needed support "remembering" what I had missed, not an easy task if you don't know what you missed. We always supplied my schools with information booklets and resources on how to help me. Many times, we usually get the "oh I didn't know about that, now I do" statement.

What I Still Do

Epilepsy has become a part of me and who I am. It is usually the second or third thing I mention about myself when I meet new people and it is definitely the first thing I mention when I need support. Currently, I am attending Alberta University for the Arts, and I have taken it upon myself to bring awareness to my campus. In doing so, it was quite disheartening to learn that an instructor didn't know what to do when one of their students from the previous semester had a seizure. This conversation did evolve to how we could get training for staff. Once again, with the help of the EEA, I have forwarded contact information to help facilitate some training. I have also begun putting up first aid posters and cards on safety boards.

In this current chapter of my story, I have learned there is so much more advocacy to do. I'm hoping to add seizure first aid pamphlets to all the health and safety boards, as well as increase access to additional resources in case someone wants to learn and help spread awareness.

CELEBRATING OUR 2026 SCHOLARSHIP AND QUILT PROGRAM RECIPIENTS (CONT.)

Wrapping Our Community in Care

This spring also brought two special presentations through our Quilt Program, made possible through the generous support of the Alberta Blue Cross Hearts of Blue Foundation. Their funding enabled us to commission two beautiful, handmade quilts created especially for individuals living with epilepsy.

Our first recipient was Teasha Moore, a new member of EAENA who lives with epilepsy and other health conditions. On May 9, 2026, Teasha joined a small gathering at our Crestwood office with her mother, Patrina, EAENA staff, community members, and Maria Donnelly, representing Alberta Blue Cross. While the presentation was simple and informal, it became an unforgettable moment as Teasha unwrapped her quilt and her face lit up with joy at the beautiful creation made especially for her.

Our second recipient is Zoey, whose quilt has also been completed through the Hearts of Blue Foundation. We look forward to sharing photos and her story later this summer when she and her mother visit our Edmonton office.

These quilts are far more than beautiful blankets. They are tangible reminders that no one living with epilepsy walks their journey alone. Each stitch represents compassion, encouragement, and the collective support of a community that understands the challenges epilepsy can bring. We hope every recipient feels wrapped not only in warmth, but also in the knowledge that they are valued, supported, and surrounded by people who believe that life can still be filled with hope, joy, and meaningful possibilities.

Finally, we extend our sincere thanks to the Van Erve family, who generously donated two additional handmade quilts to our program. These quilts are now awaiting two future recipients who will treasure them for years to come. If you know someone living with epilepsy who could benefit from receiving one of these special quilts, we encourage you to contact our office. We would be honoured to help coordinate the nomination and donation process.

Quilt recipient and Maria D., representing Blue Cross, hearts of Blue who donated the quilt.

EPILEPSY 101 PRESENTATIONS

In addition to our awareness tables, community fairs, Know Our Brains (KOB) puppet shows, and special events throughout the year, we also offer free professional development sessions called Epilepsy 101.
These presentations are available in person, online, or in a hybrid format, providing participants with a foundational understanding of epilepsy, how the brain works, different types of seizures, seizure first aid, and practical ways to support and accommodate people living with epilepsy. Every presentation is tailored to the audience, ensuring the information is relevant to their environment and needs.

For employers, we focus on creating supportive workplaces by highlighting simple accommodations, workplace safety, and ways to help employees living with epilepsy feel safe, included, and empowered to succeed.

In school settings—from elementary classrooms to post-secondary institutions—we discuss strategies that help students with epilepsy thrive academically and socially while reducing seizure triggers such as stress and unsafe environments. We are also proud to present Epilepsy 101 sessions as part of teachers' conventions and other professional development opportunities for educators.

On May 19, 2026, we had the pleasure of delivering an Epilepsy 101 presentation to the staff at Cornerstone Counselling, an organization many of our members know through the psychotherapy services they provide. The discussion was engaging and insightful, as these dedicated mental health professionals sought to deepen their understanding of epilepsy and explore the important relationship between seizures and mental well-being. Their thoughtful questions and genuine desire to better support individuals living with epilepsy made for an outstanding learning experience.

Whether you represent a workplace, school, healthcare organization, community group, or service agency, our Epilepsy 101 presentations can help build understanding, reduce stigma, and create safer, more inclusive environments for people living with epilepsy.

To book a free Epilepsy 101 presentation for your organization, contact our office today. Together, we can increase awareness, improve safety, and strengthen support for everyone impacted by epilepsy.

Epilepsy: Caring for & Understanding the Condition

A webinar presentation by the Epilepsy Association of Edmonton and Northern Alberta

BINGOS

We only held one Bingo game during the last few months, back in April 2026. Between weather conditions and other challenges, it can sometimes be difficult to coordinate an event for individuals living with epilepsy, many of whom live independently and have limited access to transportation and additional support.

While the frequency of our Bingo games has decreased over the past few months, we believe this opportunity remains important. We value being able to offer our members and a long-standing group of friends the chance to gather for a few hours to enjoy coffee, treats, conversation, and free prizes.

Thank you to Assif Law for their generous donation of small gifts for these games, which the group always appreciates. Be sure to check our calendar for upcoming Bingo dates and times, and contact our office to learn more about how this recurring event works and how you can participate.

HOBSCOTCH AND MENTORSHIPS

Like many epilepsy organizations across Canada, our association offers the HOBSCOTCH program—a structured memory coaching program designed specifically for adults living with epilepsy.
The program consists of eight weekly one-hour sessions held on the same day and at the same time each week. Together, participants and trained coaches explore practical memory strategies and establish routines that help address cognitive challenges resulting from seizure activity and/or the side effects of anti-seizure medications. Through guided reflection and cognitive-behavioural techniques, participants gain tools that can improve confidence and day-to-day functioning.

We are pleased to welcome two newly trained volunteer HOBSCOTCH coaches, Jack M. and Kimberly A., who are now working with members enrolled in the program. Their dedication allows us to support more individuals who can benefit from this evidence-informed approach to memory coaching. If you or someone you know is experiencing memory difficulties related to epilepsy, we encourage you to contact our office to learn more about the program and how to get started.

Alongside HOBSCOTCH, our Mentorship Program continues to grow and make a meaningful difference in the lives of our members. This program connects trained volunteer mentors with newer members of our association, creating opportunities to share experiences, offer encouragement, and provide compassionate peer support from someone who truly understands the challenges of living with epilepsy.

We are currently supporting three active mentorship matches, with several more participants preparing to begin. Sometimes, one of the most valuable forms of support is simply having someone who listens without judgment—someone whose life experiences are similar to your own and who understands the unique realities of living with seizures.

While the HOBSCOTCH program is available exclusively to adults living with epilepsy, our Mentorship Program is open not only to individuals living with epilepsy but also to their primary caregivers, including parents, spouses, and partners. If you would like to learn more about either the HOBSCOTCH Memory Coaching Program or our Mentorship Program, **please contact our office.** We would be happy to answer your questions and help determine which program is the best fit for you or your family.

GLOBAL EPILEPSY ADVOCACY: A LANDMARK STUDY

One of the additional benefits of EAENA's membership in the Canadian Epilepsy Alliance (CEA) is access to a wide range of shared information, resources, and learning opportunities provided through national partners, vendors, and pharmaceutical collaborators. This allows us to bring timely and relevant tools directly to our community.

In April, we participated in an information session highlighting a free digital tool called Seizure Tracker, an app designed to support individuals living with epilepsy in tracking and understanding their seizure activity in greater detail.

Unlike basic logging tools, Seizure Tracker allows users to record not only the frequency of seizures, but also important contextual information such as seizure type, triggers, duration, recovery time, and the physical and emotional impact experienced before and after an event. Over time, this detailed tracking can help individuals, caregivers, and healthcare providers identify patterns and make more informed decisions about care and treatment strategies.

We encourage members of our community to explore this tool and determine whether it may be helpful in their personal epilepsy management journey. As with any health-related app or tool, we recommend discussing its use with your healthcare provider to ensure it aligns with your individual needs and care plan.

If you would like more information about this resource or other tools available through our network, please contact our office. We are always happy to help connect individuals and families with supports that may enhance day-to-day living with epilepsy.

Seizure Tracker App: Free Tool for Seizure Monitoring

Seizure Tracker®
be aware. track it.

One of the additional benefits of EAENA's membership in the Canadian Epilepsy Alliance (CEA) is access to a wide range of shared information, resources, and learning opportunities provided through national partners, vendors, and pharmaceutical collaborators. This allows us to bring timely and relevant tools directly to our community. In April, we participated in an information session highlighting a free digital tool called Seizure Tracker, an app designed to support individuals living with epilepsy in tracking and understanding their seizure activity in greater detail. Unlike basic logging tools, **Seizure Tracker allows users to record** not only the frequency of seizures, but also important contextual information such as seizure type, triggers, duration, recovery time, and the physical and emotional impact experienced before and after an event. Over time, this detailed tracking can help individuals, caregivers, and healthcare providers identify patterns and make more informed decisions about care and treatment strategies.

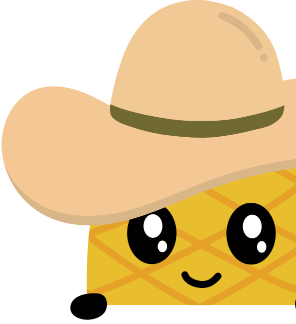
We encourage members of our community to explore this tool and determine whether it may be helpful in their personal epilepsy management journey. As with any health-related app or tool, we recommend discussing its use with your healthcare provider to ensure it aligns with your individual needs and care plan. If you would like more information about this resource or other tools available through our network, please contact our office. We are always happy to help connect individuals and families with supports that may enhance day-to-day living with epilepsy.

WEBINARS, INFORMATION SESSIONS AND COMMUNITY CONNECTIONS

Over the past few months, we have continued to coordinate webinars and educational information sessions to ensure that everyone seeking information about epilepsy has access to a broad range of treatment and support options. Every person living with epilepsy experiences the condition differently, making access to reliable information and shared experiences especially valuable.

On May 28, we hosted a virtual presentation by Lions Foundation of Canada Dog Guides on Seizure Response Dogs. Participants learned about the program, the role these specially trained dogs can play in supporting individuals with epilepsy, and the eligibility requirements for applicants. If you were unable to attend, a recording of the presentation is **available through the logo image below.**

LIONS FOUNDATION OF CANADA
DOG GUIDES
La Fondation des Lions du Canada
CHIENS-GUIDES



More recently, our President, Susan W., and Valeria were invited to participate in an interview with Cam Wells, a radio host and podcaster based in Windsor, Ontario. Cam produces a syndicated program highlighting the experiences of people living with disabilities and chronic health conditions, while exploring topics such as accessibility, healthcare, technology, arts, sports, and community services.

During the interview, we discussed epilepsy, the challenges faced by individuals living with seizures, and the important role that organizations like ours play in providing education, advocacy, and a welcoming community of support. You can listen to the full interview at this link (https://www.youtube.com/watch?v=UAZ4LfqIcjo)

Looking ahead, we are also preparing to participate as panel presenters in an international webinar taking place in mid-July. We are excited to represent our community on a broader stage and to contribute to conversations about epilepsy awareness and support around the world. More information about this opportunity can be found in the Upcoming Events and Programs section of this issue.

SPECIAL PROJECTS UPDATES

Our Special Projects portfolio continues to grow thanks to the generous support of our funding partners and the dedication of our volunteers. We are pleased to share updates on several exciting initiatives currently underway.

French Epilepsy Audiobooks Project

We are proud to announce the successful completion of the first phase of our French Epilepsy Audiobooks Project, which concluded in late March. The first two French-language epilepsy book titles have now been professionally transformed into audiobooks and are available on more than 29 online platforms, including Hoopla and Google Play. To access the audiobooks and find links to all available platforms, visit: https://edmontonepilepsy.org/frenchtitles/

We are equally excited to share that Phase II of this project has received partial funding from the Edmonton Community Foundation (ECF). This next phase will allow us to produce five additional French-language audiobooks while expanding the distribution of our French-language epilepsy resources throughout Northern Alberta. We look forward to connecting with Francophone communities across the region to improve access to epilepsy education and support in French.

Seniors Project

Our Seniors Project also reached an exciting milestone with the delivery of our first free workshop on May 4, 2026, at WeSeniors Strathcona in Sherwood Park. The session was a wonderful success and provided an excellent opportunity to pilot the workshop format while ensuring it remained engaging, informative, and enjoyable for participants.

Lead volunteers Val G. and Noella D. also represented EAENA at several seniors' fairs during the first week of June, helping introduce the program to older adults and community organizations.

We are now preparing to offer additional workshops throughout the Edmonton region. These interactive sessions invite seniors to learn about brain health, seizures, epilepsy, medications, and seizure first aid through conversation, hands-on activities, social games, and crafts. More importantly, they create welcoming spaces where seniors can ask questions, share experiences, and discuss health concerns in a supportive environment.

We are currently accepting requests from organizations interested in hosting these workshops, free of charge, throughout Edmonton and the surrounding communities. For more information, please contact our office at 780-488-9600.

Kids Mental Health Project – Phase II

Work has officially begun on Phase II of our Kids Mental Health Project. This next stage focuses on organizing brainstorming and co-design sessions to develop proof-of-concept resources that will support children living with epilepsy as they navigate the emotional and mental health challenges that can accompany the condition. Young people with epilepsy may experience anxiety, confusion, stress, social isolation, or symptoms of depression, and our goal is to create resources that acknowledge these realities while providing meaningful support.

We are grateful to have received seed funding from the Gloria Baylis Foundation and the Allard Foundation, making it possible to begin this important work. Over the coming months, we will be inviting children, youth, families, and community members to participate in the creative process. Their voices and lived experiences will help shape resources that truly resonate with young people and provide practical support for managing the everyday challenges of living with epilepsy during their school-age years. We invite you to learn more about this exciting initiative in the feature dedicated to the project elsewhere in this publication.

A SPECIAL GIFT

Earlier this spring, we received a truly meaningful gift from one of our newest members, Amika Michaud.

Amika first connected with the Epilepsy Association of Edmonton and Northern Alberta through social media before becoming a member of EAENA. Along the way, she generously shared her personal journey of living with epilepsy and the challenges and triumphs that have shaped her life. Wanting to give back to the community, Amika donated one of her beautiful original paintings to our association.

We are incredibly grateful for this generous contribution and for the opportunity to share her talent with our community.

The painting will be raffled off during our upcoming Holiday Party, with proceeds supporting EAENA's programs and services. Before we present her artwork, we invite you to read a little about Amika's journey, in her own words.

About the Artist

My name is Amika Michaud, and I'm an artist, psychology student, and former Occupational Health & Safety Advisor. After working in health and safety for several years, my own health journey led me down a new path - one that inspired me to pursue a degree in psychology with the long-term goal of contributing to a greater understanding of neurological and chronic health conditions through research.

I was diagnosed with epilepsy after experiencing focal seizures, and like many others living with chronic illness, I've learned firsthand how profoundly an invisible condition can affect every aspect of daily life. My journey has deepened my passion for advocacy, education, and creating spaces where people feel seen and understood.

Alongside my studies, I create nature-inspired artwork that explores the intersection of science, health, and the natural world. My work has been recognized as a Top 3 group finalist in Johnny Depp's People's Artist Competition, and I recently published my first book, Becoming in the Space Between, which reflects on healing, resilience, and personal growth.

Through both my art and advocacy, I hope to encourage conversations around invisible illnesses, mental health, and the strength found in community. It was truly an honour to donate this painting to the Epilepsy Association of Edmonton & Northern Alberta in support of a cause that is so deeply personal to me.

Thank you again for everything you do for the epilepsy community. I look forward to hearing from you!

Warm regards,

Amika Michaud

FINANCIAL UPDATE

This segment is a regular feature in every issue of our magazine. While we realize that discussing financial stability may not be the most exciting topic, we believe it is important to keep our community informed about the realities of running our organization. It also serves as a reminder that charities—especially independent, community-based nonprofit organizations like ours—can only make meaningful things happen when we have access to the necessary resources: funding, time, and skilled people.

Fortunately, there is no shortage of passion, dedication, or talent within our community. We are continually inspired by the volunteers, supporters, and professionals who contribute their time and expertise. The reality, however, is that every program, service, event, and resource we provide—many of which are offered free of charge—comes with a financial cost. Like everyone else, we face rising operating expenses, higher service fees, and the increasing costs associated with delivering high-quality programs to the people who need them.
As a charity that receives no ongoing funding from any level of government, we rely on community fundraising campaigns, generous donations from individuals and foundations, project-based grants, and our biannual casino fundraiser to sustain our operations. This funding model gives us the freedom to determine our own priorities and develop programs that directly reflect the needs of our community. The trade-off, however, is financial uncertainty. Every new initiative requires careful consideration, and we often have to pause before committing to new programs, services, or events.

It is a familiar story, and in many ways the message remains unchanged: funding is becoming increasingly difficult to secure, even when we know the services we provide are valuable, unique, and life-changing for those who rely on them.

So, where do we stand today?

At the time of publishing this issue, our total income for the year stands at approximately $77,000, while our expenses have exceeded $127,000. Although this gap remains significant, we are in a stronger financial position than we were at this time last year, which provides some encouragement as we continue moving forward.

Our shorter fundraising initiatives, such as our 50/50 raffles—which have the potential to generate up to $10,000—have unfortunately not produced the results we had hoped for. Likewise, our largest annual fundraising initiative, the Birdies Campaign, has tremendous potential for growth but has generated only modest revenue to date.

FINANCIAL UPDATE (CONT.)

We also recognize that many of the individuals and families we serve have limited discretionary income. With the rising cost of living, we understand that charitable donations are often difficult to prioritize. At the same time, we remain committed to keeping our programs and services as accessible as possible, ensuring that financial barriers do not prevent people from receiving the education, support, and community they need.
The challenge remains simple: without financial resources, programs cannot happen.

If you know of an individual, business, foundation, or organization looking to support a worthwhile cause, we would be grateful for an introduction. We would welcome the opportunity to share our story, demonstrate the impact of our work, and explain how our programs improve the lives of people living with epilepsy and their families throughout our region.

We know there are people who want to make a meaningful difference. Perhaps we simply have not had the opportunity to meet them yet. You could be the person who helps create that connection and shorten the journey between a willing supporter and a community in need.

Finally, to everyone who already donates—whether it is $20, $200, or any amount in between—please know that your generosity truly matters. Every contribution helps us continue providing education, advocacy, support, and opportunities for people living with epilepsy. We are sincerely grateful for your ongoing trust and commitment to our work.

We hope that one of our upcoming fundraising opportunities will provide you with another chance to invest in the future of our organization and the community we are privileged to serve.

Your donation is matched up to 50% by Rogers Birdies for Kids presented by Altalink

Edmonton Epilepsy Association

Donate Online:

FINANCIAL UPDATES

BIRDIES AND UPCOMING SPECIAL EVENTS

Our largest fundraising initiative of the year is still underway! The Birdies for Kids Campaign, which runs from March through August 2026, offers an incredible opportunity to support our Kids Mental Health Project – Phase II.

Our goal is to raise up to $25,000, and thanks to the Birdies for Kids matching program, every dollar donated has the potential to be matched by up to 50%. That means a $10 donation could become $15, stretching your generosity even further and maximizing the impact of every contribution.

If you have been considering making a donation, now is the perfect time. Please help us take advantage of this remarkable opportunity while the campaign is still active.

We are also excited to announce a very special fundraising event: A Night in Egypt!

On August 15, 2026, we will host an unforgettable evening featuring an authentic Egyptian meal, cultural experiences, and a wonderful opportunity to connect with members of our community while supporting the work of EAENA. Members will receive a discounted registration rate, and the event is designed to be family-friendly, making it the perfect outing for all ages. For more information and registration details, please see page 60. We hope you will join us for what promises to be a truly memorable evening.

Finally, congratulations to Shelley G., the winner of our most recent 50/50 raffle, which was held during our Seize the Day Community Fun Fest on June 20. Thank you to everyone who purchased tickets and helped support our organization.

We plan to host at least one more 50/50 raffle before the end of the year, so stay tuned for another chance to participate. As you continue reading this issue, you will also discover several other ways you can support the financial sustainability of our organization and help ensure our programs continue to serve individuals and families living with epilepsy throughout our community.

EAENA PRESENTS

PHARAOHS RESTAURANT
AUTHENTIC FOOD

SAT AUG 15, 2026

Experience Egypt

Radwa the Dancer will host a cultural show during the event!
We will host Egyptian photo booth and special namesake gifts for all who join our special event!

5524 CALGARY TRL NW, EDMONTON

A Restaurant & Cultural Evening Fundraiser

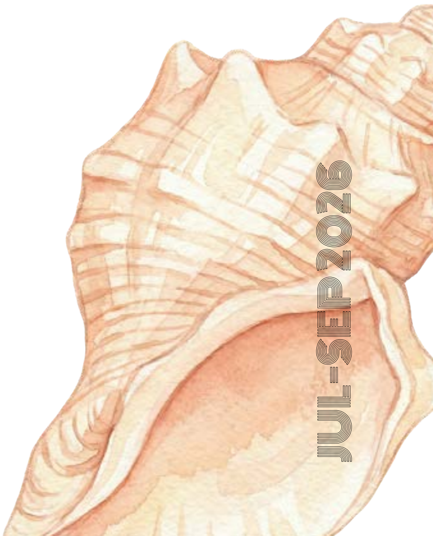
- Book your spot today for an unforgettable journey to Egypt!
- Savour authentic Egyptian cuisine, discover rich traditions and culture, and enjoy an evening filled with vibrant music and captivating dance entertainment.
- Join friends, family, and community members for a unique cultural experience while learning more about epilepsy and supporting programs and services that benefit individuals and families affected by epilepsy in our region.

Experience the flavours, culture, and hospitality of Egypt — all while making a difference in the lives of people living with epilepsy.

TX: $35 EAENA MEMBERS
$40 NON-MEMBERS AVAILABLE AT:

EAENA

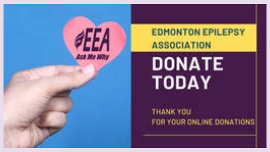
epilepsyalbertanorth.ca



WAYS *TO SUPPORT US IN 2026!*

We strive to provide everyone who wishes to support us financially with the best possible ways to donate. By visiting this page: https://edmontonepilepsy.org/supporters/, you will discover all the ways you can contribute to the EEA. For potential sponsors, please reach out to us directly—we would be happy to work with you to tailor a sponsorship that offers the best possible exposure and meaningful connection to our community.

- Sign-up for an account with **SkipTheDepot** and donate the profits from your recyclables to the EEA.
- You can donate to us through **PayPal Giving Fund**. This is an easy way to use your credit card.
- **CanadaHelps** is also a very popular way folks like to donate to us.



- Our preferred option remains **Zeffy** - as this platform gives us 100% of every dollar you donate to us.
- We also accept donations from **DONATE A CAR Canada** - just check the link for details.

- We accept donations for our **QUILT** program to embrace a newly diagnosed person with epilepsy with community warmth.

- We always **accept cheques or cash** and ensure you get your tax receipt for your contributions.
- And for those wishing to sponsor any one of our events, activities and programs, check out our **sponsorship page.**

INFLAMMATORY CYTOKINE SIGNATURES IN EPILEPSY: DISTINGUISHING DRUG-RESISTANT FROM DRUG-RESPONSIVE PATIENTS

Inflammation in the brain has been identified in the past as having an important role in epilepsy. Recently, new studies have been done to show how cytokines, small signaling molecules that are made by the immune system which can cause inflammation, can affect seizure severity and treatment resistance. Researchers have found specific cytokines to have increased levels in patients with more severe epilepsy and that the higher the level of these cytokines the greater chance of treatment resistance. These results are important as it can act as a marker for doctors to use so they can identify disease severity and treatment resistance ahead of time so a unique plan of action can be implemented for patients.

A recent study adds to growing evidence that inflammation in the brain, known as neuroinflammation, may play an important role in epilepsy and in why some patients do not respond well to anti-seizure medications. Researchers focused on cytokines, small immune signaling proteins that help regulate inflammation and immune activity, to better understand their relationship to seizure severity and treatment resistance.

The study included 90 participants: 30 people with drug-resistant epilepsy (DRE), 30 with drug-responsive epilepsy (DREsp), and 30 healthy control participants. Researchers measured blood levels of five inflammatory cytokines — IL-1β, IL-6, IL-8, IL-17, and IL-18 — using laboratory testing methods designed to detect immune proteins in serum samples. All five cytokines were significantly elevated in people with epilepsy compared to healthy controls, with the highest levels seen in patients with drug-resistant epilepsy. Among the markers studied, IL-6 and IL-8 were particularly effective at distinguishing people with epilepsy from healthy individuals, while IL-6 also showed a strong ability to differentiate drug-resistant epilepsy from drug-responsive epilepsy. IL-1β showed the strongest association with seizure frequency, with levels increasing progressively from healthy controls to drug-responsive epilepsy and then to drug-resistant epilepsy.

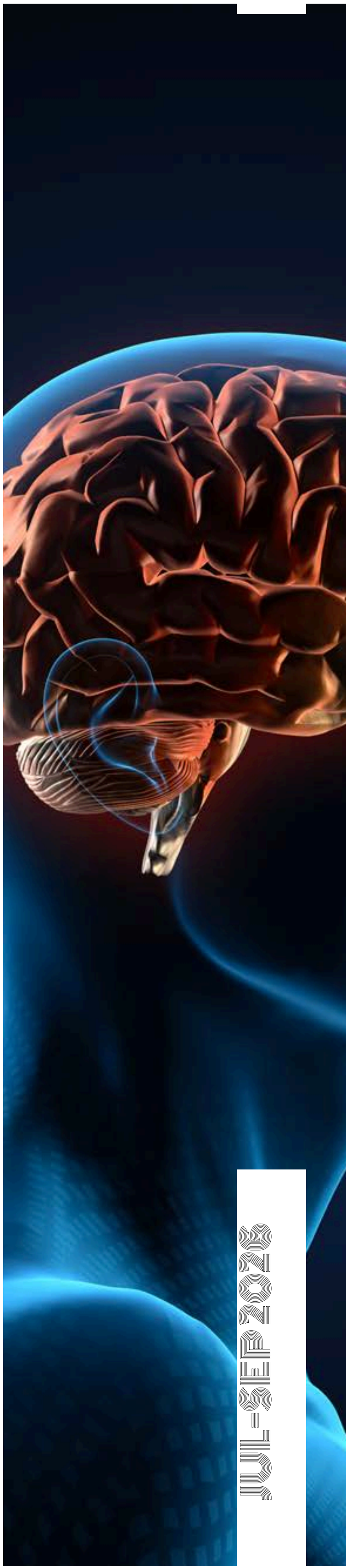
The researchers also found a stepwise increase in cytokine levels as seizure frequency increased, further supporting the connection between ongoing inflammation and more severe epilepsy. These findings strengthen the idea that immune system activity and chronic inflammation may contribute not only to the development of epilepsy, but also to treatment resistance in some patients.

The study suggests that inflammatory cytokines could eventually serve as biomarkers to help predict disease severity or treatment response. In the future, therapies that target inflammation and immune signaling pathways may offer new treatment options for people with drug-resistant epilepsy, particularly for patients who do not respond to standard anti-seizure medications.

Retrieved from https://www.cureepilepsy.org/news/inflammatory-cytokine-signatures-in-epilepsy-distinguishing-drug-resistant-from-drug-responsive-patients/ on June 25, 2026

THE BRAIN HAS A WARNING SYSTEM FOR ITS OWN ELECTRICAL MISFIRES, AND WE CAN NOW READ IT

In patients with epilepsy, there are many small electrical disruptions that can happen in the brain. Though these disruptions often go unnoticed, they can still cause problems in a person's everyday life such as in the form of disruptions in thoughts, actions, or sleep. A researcher has recently developed a new technology called Neuropixels which allows for more sensitive measurements of the brain electrical signals. What they have discovered is that there are actually warning impulses that occur in the brain before the actual disruption occurs. With this information, the scientist hopes to stop these small electrical disruptions before they occur, helping to reduce these problems in epilepsy patients' thoughts, actions, or sleep.



Every second of the day, in roughly half of the 50 million people living with epilepsy, the brain stages tiny rebellions. Not seizures, exactly, but something almost as disruptive: brief electrical storms that flare and die so fast most patients never consciously notice them. What they do notice, over time, is that words keep slipping away mid-sentence, that following a conversation takes more effort than it should, that sleep never quite feels restorative. These millisecond glitches, known as interictal epileptiform discharges, can fire thousands of times in a single day. For years, neurologists assumed they were essentially random, noise in a faulty system. A study published this week in Nature Neuroscience suggests they are anything but.

Researchers at UC San Francisco have found that these discharges follow a predictable choreography, orchestrated across different layers of the brain's cortex by distinct populations of neurons playing different roles at precisely timed intervals. More striking still, the warning signs appear a full second before the discharge itself becomes detectable on standard monitoring equipment.

A View No One Had Ever Seen Before

The tool that made this possible is called Neuropixels. Thinner than a human hair, the probe is lined with hundreds of sensors capable of recording from individual neurons, not the averaged electrical blur that conventional electrodes pick up from thousands of cells at once. Edward Chang, chair of Neurological Surgery at UCSF and a pioneer in adapting the technology for use in awake human patients, placed the probes seven millimetres deep into brain tissue that would subsequently be removed as part of epilepsy surgery, giving the team an ethically clean window into living cortex. Across four patients and more than 1,000 neurons, they watched 1,094 separate discharges unfold in granular, neuron-by-neuron detail. What they saw upended the prevailing model. The old assumption was that a discharge represented a sudden, synchronised mass firing, hundreds of neurons recruited simultaneously into abnormal activity. Instead, the process turned out to be sequential and structured, almost like a relay. “We could see individual neurons that were just microns apart from each other playing different roles in the process,” said Alex Silva, a medical student and the study's first author. “It was really striking.”

Three distinct populations of neurons emerged from the data. One group became active roughly a second before the discharge peaked, its inhibitory cells gradually going quiet in what looks like a decay of the normal brakes on neural excitation. A second group fired at the sharp peak of the discharge itself, concentrated in the superficial layers of the cortex and apparently responsible for generating its amplitude. A third group became active only as the discharge wound down, shaping the slow wave that follows.

THE BRAIN HAS A WARNING SYSTEM FOR ITS OWN ELECTRICAL MISFIRES, AND WE CAN NOW READ IT (CONT.)

The Cognitive Cost of Being Interrupted

The fact that these events disrupt cognition is not new knowledge, but what the UCSF team found at the cellular level makes the mechanism vivid in a way it never was before. Nearly 80 percent of the neurons involved in generating discharges were, under normal circumstances, doing something else entirely: encoding language and perception, participating in the brain's routine processing of the world. When a discharge fires, it essentially commandeers these cells mid-computation. One patient, performing a word-association task during the recording, showed measurably longer reaction times on every trial that coincided with a discharge in the preceding second and a half. The cognitive disruption, in other words, is not an indirect consequence of the electrical event. It is what happens when the very neurons responsible for a particular thought get pulled into an epileptic circuit before that thought completes.

Jon Kleen, the study's co-senior author and an associate professor of Neurology at UCSF, has spent years documenting the quieter toll that epilepsy takes between seizures. “We've gotten a view into new ways we might address a debilitating aspect of epilepsy that we haven't been able to tackle,” he said.

From Reactive to Proactive

The clinical stakes of the prediction finding are considerable, and the team is careful to frame them as a direction rather than an arrival. Current implantable neurostimulators for epilepsy operate on a reactive principle: they detect abnormal electrical activity and deliver a pulse to interrupt it, after the fact. The devices work, modestly and slowly, with fewer than 20 percent of patients achieving seizure freedom even after years of use. The UCSF data suggests an alternative. Because the inhibitory neuron population begins its characteristic drop in activity up to a thousand milliseconds before the discharge becomes visible in the local field potential, a device that could monitor that specific cell type in real time might have enough lead time to intervene before the discharge forms. The logic is straightforward even if the engineering remains daunting: instead of responding to a fire already burning, watch for the conditions that precede ignition. “That would be a major step forward, changing treatment from reactively responding to abnormal brain bursts to proactively preventing them in the first place,” Kleen said.

The researchers also showed they could predict, from neuronal firing patterns, not just whether a discharge was coming but what kind. Discharges that would cascade into a rapid series of further events, which tend to cause greater cognitive disruption, showed distinct signatures in the preceding firing patterns, distinguishable from isolated discharges up to half a second before the first one peaked. High-amplitude discharges, similarly, had predictive signatures. This level of granularity suggests that a future device might tailor its intervention to the severity of the event it is trying to prevent, rather than treating every discharge identically.

THE BRAIN HAS A WARNING SYSTEM FOR ITS OWN ELECTRICAL MISFIRES, AND WE CAN NOW READ IT (CONT.)

There are real limitations. The cohort was small, four patients, all with epilepsy arising in the lateral temporal cortex, and intraoperative recordings last only as long as the surgery itself. Translating the approach to a chronic implant capable of tracking stable individual neurons across weeks or months is a different class of engineering problem from anything currently available.

The Neuropixels probe, for now, records in the operating theatre. Whether something comparable can work reliably over the long term in a freely moving person remains an open question. The researchers acknowledge it, though rapid progress in single-neuron brain-computer interfaces offers at least a plausible roadmap.

What the study establishes, regardless of how the technology develops, is that the brain's interictal discharges are generated by a structured, readable process with an internal logic that can be learned. “Being able to prevent these brain blips would be revolutionary for patients' quality of life,” Kleen said. The word choice is carefully restrained. The result is not a treatment. But for a problem that has resisted treatment while quietly eroding the cognition of millions of people, knowing when and how to look is a genuinely different place to be standing.

Source: Silva et al., Nature Neuroscience, 2026

UNDERSTANDING GENETIC EPILEPSY

Advances in medical research over the past decade have significantly improved our understanding of the role genetics plays in epilepsy. While approximately 20–30% of epilepsy cases are linked to acquired causes—such as stroke, brain tumors, infections, or traumatic brain injuries—the remaining cases are often associated with genetic factors. These may involve changes in a single gene, multiple genes, or complex interactions between genes and environmental influences.

Epilepsy is considered to have a genetic cause when seizures result from a change (or mutation) in a person's DNA. These genetic changes can affect the structure, function, or production of proteins that are essential for normal brain activity. When these proteins do not function properly, the resulting disruption in brain signaling can lead to seizures.
Some genetic changes are inherited, meaning they are passed down through families and may result in epilepsy occurring in multiple relatives. Others arise as spontaneous, or de novo, mutations, meaning they occur for the first time in an individual and are not present in either parent. In some cases, genetic factors may increase a person's susceptibility to epilepsy, but seizures develop only when combined with certain environmental influences.
Genetic epilepsies can present in many different ways. They may involve various seizure types, begin at different ages, occur on their own, or be part of a broader genetic syndrome with additional neurological or developmental features. A genetic cause may be suspected when there is a strong family history of epilepsy, when seizures are difficult to control with medication, or when epilepsy begins during specific stages of development and is accompanied by other characteristic symptoms.

Researchers have identified approximately 1,000 genes associated with epilepsy. As a result, genetic testing has become an increasingly important part of evaluating many individuals with epilepsy, particularly those with epilepsy syndromes that are suspected to have a genetic basis. Standardized epilepsy gene panels can identify disease-causing genetic variants and help guide diagnosis. In some situations, especially when additional developmental or medical concerns are present, more comprehensive genetic testing may be recommended.

Some well-known genetic epilepsies and epilepsy-related syndromes include:

- Angelman syndrome
- CDKL5 Deficiency Disorder
- PCDH19-related epilepsy
- Ring Chromosome 20 Syndrome
- SCN8A-related epilepsy
- GLUT1 Deficiency Syndrome (SLC2A1)
- Rett Syndrome (MECP2)
- FOXG1 Syndrome
- Dup15q Syndrome
- SYNGAP1-related disorder
- KCNQ2-related epilepsy
- STXBP1-related disorder
- SCN1A-related epilepsy, including Dravet syndrome
- SCN2A-related disorders
- CHD2-related epilepsy
- GRIN2A-related disorders
- CACNA1A-related disorders
- SLC6A1-related disorders

UNDERSTANDING GENETIC EPILEPSYN(CONT.)

Epilepsy is a complex neurological condition, and its management often requires an individualized approach. The rapid advances in genetic research and genomic technologies are creating new opportunities for earlier diagnosis, more personalized treatments, and improved outcomes.

One important example is Dravet syndrome, which is most commonly caused by changes in the SCN1A gene. Identifying this genetic cause helps healthcare providers choose medications that are more likely to be effective while avoiding others that may worsen seizures. This demonstrates how understanding the genetic basis of epilepsy can directly influence treatment decisions and improve quality of life.

Looking ahead, researchers are also exploring gene-based therapies and other precision medicine approaches. Although many of these treatments remain under investigation through clinical trials, they offer promising hope for individuals and families affected by genetic forms of epilepsy.

By Mai Abou Heikal
A pediatrician with interest in Pediatric Neurology from Egypt
And EAENA volunteer

EAENA
Epilepsy
Association
Edmonton &
Northern AB

AWARENESS • EDUCATION • ADVOCACY
UNDERSTANDING CHANGES LIVES

ALBERTA'S NEW DISABILITY ASSISTANCE PROGRAM: WHAT IT COULD MEAN FOR OUR COMMUNITY

Navigating government programs can be challenging at the best of times—especially when changes are introduced. If you or someone you care about receives disability benefits, you may have heard about Alberta's new Alberta Disability Assistance Program (ADAP). While not everyone will be affected by these changes, understanding how the program works can help you make informed decisions about your future.

ADAP was introduced to better support Albertans with severe disabilities who are able to participate in the workforce. The program recognizes that many people want to work to the extent they are able but often face barriers that make employment difficult. One of ADAP's primary goals is to reduce those barriers by allowing participants to earn more employment income while continuing to receive financial and health benefits. Beyond monthly financial assistance, ADAP also provides access to employment supports such as career planning, skills development, assistive technology, workplace accommodations, and job placement services. The intention is to create greater flexibility so that people can pursue employment opportunities without worrying that taking on work will immediately result in the loss of essential supports.

For members of the epilepsy community, these changes may open new possibilities. Many people living with epilepsy are eager to work but may need flexibility, accommodations, or ongoing health benefits to do so successfully. Others continue to experience frequent or unpredictable seizures that make regular employment impossible. The province recognizes that disability is not one-size-fits-all, and eligibility for ADAP or the existing Assured Income for the Severely Handicapped (AISH) program depends on each person's individual circumstances.

Importantly, AISH is not disappearing. Many current recipients will remain on AISH, particularly those whose disabilities prevent them from working. Others may transition to ADAP if they meet the new eligibility criteria. The Government of Alberta has also introduced transition measures to help ensure that individuals moving from AISH to ADAP do not experience an immediate reduction in financial support during the transition period. As with many government programs, the details can be complex. If you receive AISH or are considering applying for disability assistance, it is worth taking the time to learn about the new program and discuss your situation with your caseworker or an Alberta Supports representative. Understanding your options can help you make the choices that best support your health, financial security, and personal goals.

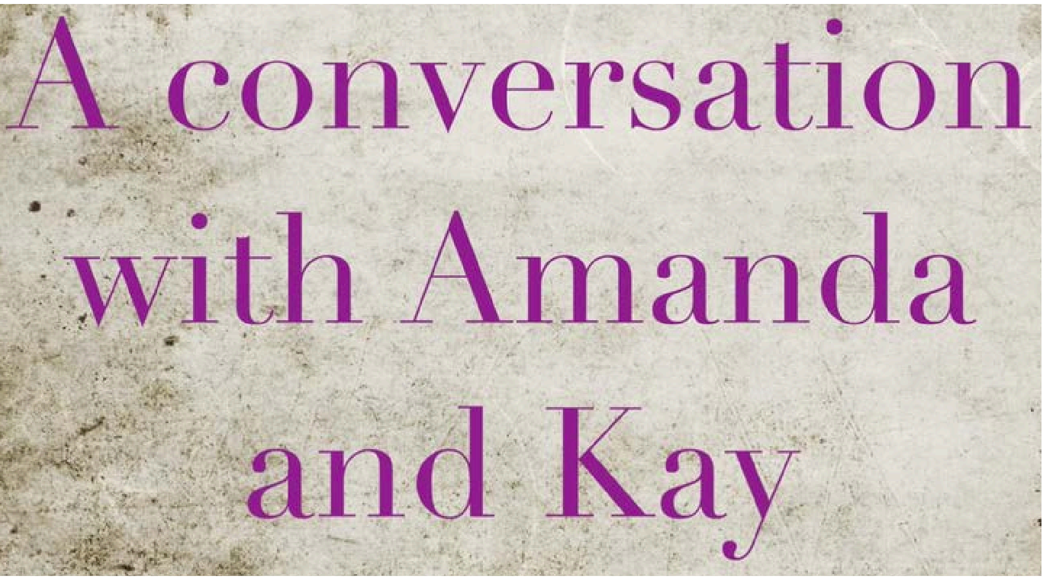
At EAENA we know that living with epilepsy often means navigating many systems—from health care and employment to education and income support. We encourage our members to stay informed, ask questions, and reach out for assistance when needed. Whether your goal is returning to work, maintaining your current supports, or simply understanding what these changes mean for you, you do not have to navigate the process alone.

Learn More

For the most up-to-date information about the Alberta Disability Assistance Program (ADAP), including eligibility criteria, application details, and available employment supports, visit the Government of Alberta's ADAP webpage or contact Alberta Supports. An Alberta Supports representative can help answer your questions and explain which program may be most appropriate for your individual circumstances.

To learn more visit this link or call our office for additional resources.

AMANDA AND KAY' STORY



Click Here

TO WATCH THE WHOLE VIDEO INTERVIEW

We sat down with two longtime members of EAENA, Amanda and Kay W., who generously agreed to be interviewed for our Association Stories segment and to share a part of their journey with epilepsy—both as a person living with the condition and as a close caregiver. As we know, epilepsy not only impacts the life of the person diagnosed but also those who care for them. It is important to keep in mind the broader community affected by this condition.

You can listen to and watch the full interview on our dedicated page on our website.

Amanda shares that she has been connected with the Epilepsy Association of Edmonton & Northern Alberta for about three years. Living with epilepsy has meant navigating three types of seizures—absence, focal, and partial—that remain unpredictable and unmanaged. That unpredictability shapes almost every part of her life.

Plans are often uncertain. Moments that begin with excitement can change suddenly when a seizure occurs, leading to cancellations, recovery time, and emotional disappointment. After a seizure, she may not immediately remember what happened, sometimes only realizing hours later that an episode occurred. The aftermath can include fatigue, migraines, and memory gaps that make even joyful experiences harder to recall.

Her mother, Kate, describes the constant balancing act—supporting her daughter through seizures, OCD, and memory challenges while also managing her own emotional burden. She explains how seizures can disrupt daily life entirely, sometimes requiring days of recovery and ongoing care and supervision.

AMANDA AND KAY' STORY (CONT.)

Despite these challenges, there is adaptation. Notes, calendars, routines, and 24-hour support help structure daily life. Samantha lives in supported housing where staff assist around the clock, although understanding of epilepsy still varies. Still, there is a sense of safety in knowing help is always present.

Samantha also speaks with quiet resilience. She smiles often, even through pain and uncertainty. Her mother describes it as a kind of steady optimism—an ability to keep going even when things are difficult.

And in the middle of everything, there are moments of joy: skiing with a disability sports group, volunteering as a Girl Guide leader, attending camps, playing bingo, and spending time in community spaces where she is understood and accepted.

Kate emphasizes that while nothing can be controlled or "fixed," life has become about adaptation—making space for joy where it exists, adjusting when needed, and focusing on what is still possible rather than what has been lost.

Samantha's story becomes one of unpredictability, yes—but also of persistence, community, and finding ways to keep living fully, one day at a time.

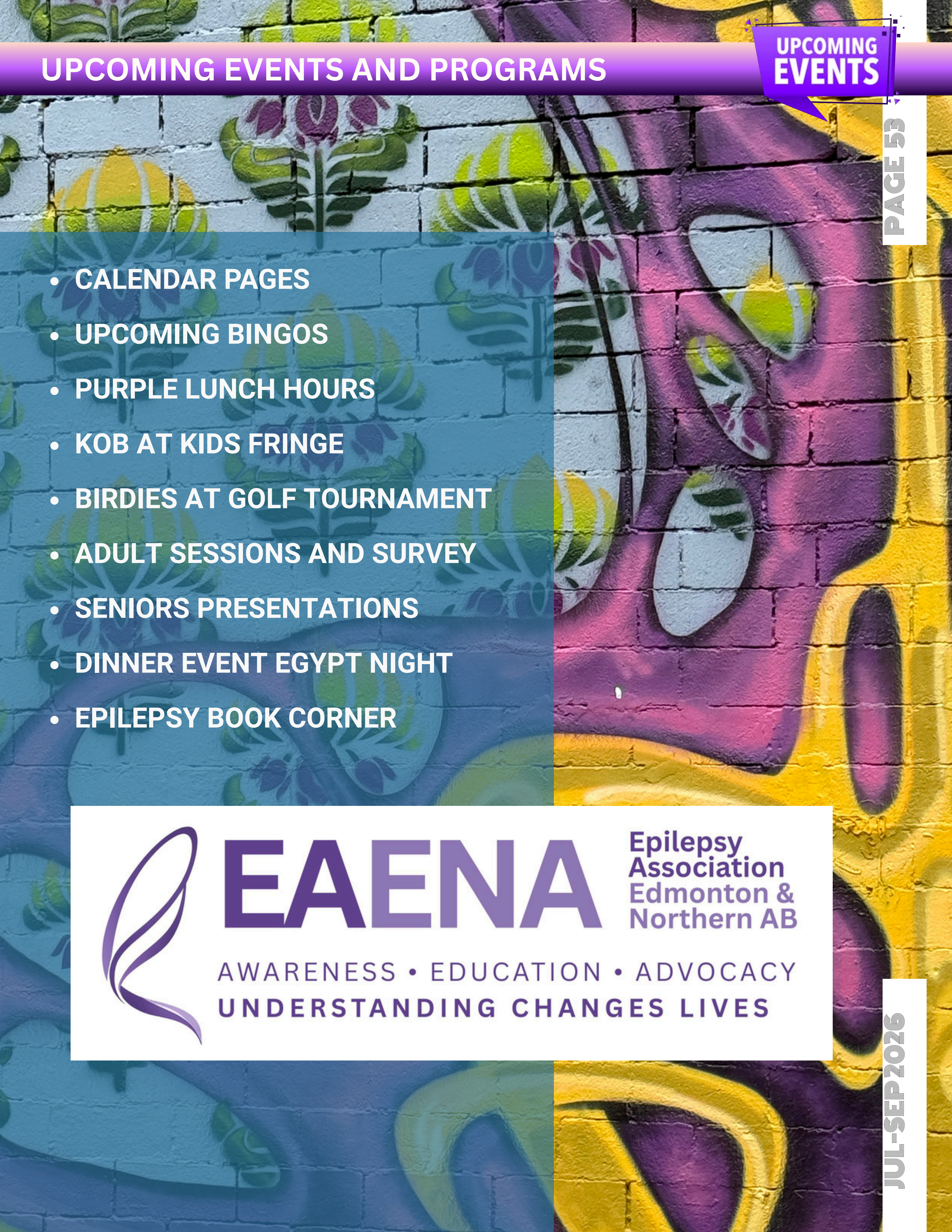
Click Here

TO WATCH THE WHOLE VIDEO INTERVIEW

We love to feature stories and lived experience of life with epilepsy. If you feel comfortable sharing, reach out to our office (info@epilepsyalbertanorth.ca) and we will coordinate a session for a live video interview. Courageous community members sharing their stories can offer hope and resilience to others, showing that life with epilepsy is possible and so is reaching your dreams.

UPCOMING EVENTS AND PROGRAMS

UPCOMING EVENTS



- CALENDAR PAGES
- UPCOMING BINGOS
- PURPLE LUNCH HOURS
- KOB AT KIDS FRINGE
- BIRDIES AT GOLF TOURNAMENT
- ADULT SESSIONS AND SURVEY
- SENIORS PRESENTATIONS
- DINNER EVENT EGYPT NIGHT
- EPILEPSY BOOK CORNER

EAENA
Epilepsy Association Edmonton & Northern AB
AWARENESS • EDUCATION • ADVOCACY
UNDERSTANDING CHANGES LIVES

JULY

2026

Volunteers are the heart of the EEA community!

JULY

It is important to maintain a healthy and well-balanced lifestyle. Monitoring what may trigger a seizure is helpful for people with epilepsy.

Learn all about it at www.epilepsyalbertanorth.ca

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KEY ACTIVITIES THIS MONTH:

- July 1 - Office closed for CANADA DAY
- July 13 - XLSU Live Webinar: How Advocacy Perspectives Can Improve Neurology Research
- July 14 - Board of Directors Meeting
- July 28 - Purple Lunch Hour Session

AUGUST

2026

EEA offers a special quilt program for people with epilepsy!

AUGUST

Scholars have long been fascinated by evidence that prominent religious leaders, political leaders, philosophers, and many who achieved greatness in the arts and sciences suffered from epilepsy.

Learn all about it at www.epilepsyalbertanorth.ca

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KEY ACTIVITIES THIS MONTH:

- August 3 - Office Closed for heritage Days
- August 15 - Egypt Night! A Cultural Fundraiser!
- August 19 - KOB at Kids Fringe
- August 20-23 - BIRDIES Golf Tournament in Calgary
- August 25 - Purple Lunch Hour Session
- Augsut 27 - BINGO at the office

SEPTEMBER

2026

SEPTEMBER

Many of the world's most famous people are historically recorded as having had seizures. People with epilepsy have excelled in every area.

Learn all about it at www.epilepsyalbertanorth.ca

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Community events that welcome all: that is what EEA is all about!

KEY ACTIVITIES THIS MONTH:

- September 3 - Discover our Books Session at the EAENA Office
- September 5 - WEM E360 Awareness Booth
- September 7 - Office closed for LABOUR DAY
- September 8 - Board of Directors Meeting
- September 8 - Awareness table at Stollery Children's Hospital
- September 15 - Awareness table at Kaye Clinic
- September 26 - Board of Directors Retreat
- September 29 - Purple Lunch Hour Session

UPCOMING NEXT

BINGOS

Our next informal bi-monthly bingo gathering will take place on Thursday, August 27, 2026, from 12:30 to 2:30 p.m. at the EAENA office.

If you're one of our regular attendees, be sure to mark your calendar—you won't want to miss this opportunity to catch up with friends, enjoy some laughs, and spend an afternoon together.

New to EAENA? We'd love to welcome you! Your first bingo event is free—simply call our office to reserve your spot. Enjoy:

- Fun bingo games
- Great prizes
- Light refreshments
- Friendly conversation and plenty of laughter

Come join us for an afternoon of fun, friendship, and community. We look forward to seeing you there!

KOB AT THE FRINGE FESTIVAL

We invite all EAENA member families to join us on Wednesday, August 19, 2026, at the Kids Fringe Park. Whether or not your family includes a child living with epilepsy, everyone is welcome to attend this special event.

Admission to the Kids Fringe Park is free for adults accompanying children, and our show begins at 1:00 p.m. Best of all, it's completely free!

Come help us raise awareness about epilepsy in a fun and engaging way. Together, we'll teach children and families about seizures, seizure first aid, and how to be a supportive and compassionate friend to someone living with epilepsy.

We hope you'll join us for an afternoon of learning, laughter, and community as we help make epilepsy more understood—one family at a time.

PURPLE LUNCH HOURS

Our monthly educational sessions will continue throughout the summer, offering EAENA members the opportunity to learn, connect, and engage in meaningful conversations about epilepsy. Members receive regular invitations and reminders for each upcoming session.
Do you have a topic you'd like to learn more about? We'd love to hear from you! Share your suggestions by emailing info@epilepsyalbertanorth.ca or by calling our office and leaving a message. We do our best to invite knowledgeable presenters and specialists who can share their expertise, provide practical information, and answer questions from our live audience.

Upcoming Session Dates:

- July 28
- August 25
- September 29

We look forward to learning together with you!

Register here

SENIORS PROJECT

We invite all EAENA member families to join us on Wednesday, August 19, 2026, at the Kids Fringe Park. Whether or not your family includes a child living with epilepsy, everyone is welcome to attend this special event.

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We hope you'll join us for an afternoon of learning, laughter, and community as we help make epilepsy more understood—one family at a time.

BIRDIES 2026

Your donation is matched up to 50% by Rogers Birdies for Kids presented by Altalink

Help Us Go Further: EAENA Returns to the Rogers Charity Classic

The Edmonton Epilepsy Association is proud to once again participate in one of our most impactful and anticipated annual fundraisers—the Rogers Charity Classic.

Each year, this remarkable event brings communities together to support children and youth across Alberta. While world-class golf takes center stage, the tournament's greatest legacy is its generosity. To date, more than $164 million has been raised for 316+ charities, creating lasting change for thousands of children, youth, and families.

This year, we're honoured to continue that legacy by raising funds for Phase Two of our Kids with Epilepsy: Mental Health Challenges, Explorations and Solutions project.

Why This Project Matters

Living with epilepsy is about far more than managing seizures. For many children and youth, it also means facing:

- Anxiety and depression
- Social isolation and stigma
- Challenges at school and in friendships
- Uncertainty about the future

Time and again, families tell us that mental health support is one of the most urgent—and least accessible—needs in their epilepsy journey. Through Phase One of this project, we listened. We gathered valuable insights from children, youth, families, and caregivers to better understand the mental health challenges they experience every day. Now, Phase Two is about turning those insights into action.

With your support, we will:

- Develop practical, accessible mental health resources designed specifically for children and youth living with epilepsy
- Equip families with tools and strategies they can use in their daily lives
- Collaborate with educators and healthcare professionals to improve understanding and support
- Create solutions shaped by the voices and lived experiences of the families we serve

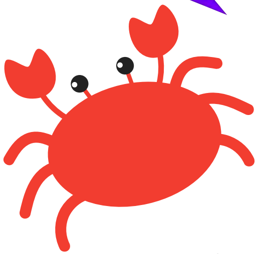
This is more than a research project. It's an opportunity to build meaningful, lasting supports that will improve the well-being and quality of life of children with epilepsy and the families who stand beside them.

Help Us Make a Difference

Every donation helps us move this important work forward. Together, we can ensure that children living with epilepsy receive not only the medical care they need, but also the mental health support they deserve.

Click here to donate and help us create a brighter future for children with epilepsy.

ADULT SESSIONS AND MEMBER SURVEY



One of the initiatives we are currently developing is the return of adult support and educational sessions for people living with epilepsy.

Before the pandemic, these gatherings were an important part of our association's programming. They provided opportunities for adults living with epilepsy to come together, learn from one another, hear from healthcare professionals, and realize they were not alone in their journey. Like many organizations, we successfully adapted to the digital world when circumstances required it. Online programming has allowed us to reach more people than ever before, and it continues to be an important part of what we do.

At the same time, we recognize that there is something uniquely valuable about meeting in person. Sharing a room with others who understand the lived experience of epilepsy creates meaningful connections, reduces feelings of isolation, and reminds us that we are part of a caring and supportive community.

We are currently working with healthcare professionals and community partners to develop a series of sessions that will address topics such as the realities of living with epilepsy, practical strategies for managing the challenges of seizures, emotional well-being, independence, relationships, employment, and other issues that matter to adults living with this neurological condition. While we are not yet ready to announce dates, planning is well underway, and we look forward to sharing more information soon.

As we shape these future programs, we want your voice to guide us.

During the first week of July, we will launch our 2026 EAENA Member Survey, which will remain open for one month. This survey is one of the most important planning tools we have. It gives our members the opportunity to tell us what has been working well, what services have made the greatest difference, and what new programs or supports they would like to see in the years ahead.

We conduct this survey every few years because we believe our members should help shape the future of our association. Your experiences, ideas, and priorities directly influence the programs we develop and the services we provide. All current EAENA members in good standing who receive communications electronically will receive a link to the anonymous online survey. Members who receive this magazine by mail will also receive a printed copy that can be completed and returned to us.

The survey should take approximately 15 minutes to complete, and the time you invest will help us continue building programs that have a meaningful impact on the quality of life of people living with epilepsy and their families. We will share a summary of the survey's aggregate results in our final magazine issue of 2027, along with how your feedback has influenced our future planning.

If you are a current member and do not receive a survey by mid-July, please contact our office. We want every member to have the opportunity to participate. Together, we can continue building an association that reflects the needs, hopes, and lived experiences of the community it serves. Thank you for helping shape the future of EAENA.

A NIGHT IN EGYPT!

This is an exciting new event that we are planning for Saturday, August 15, 2026!

As readers of our magazine and supporters of our community already know, one of our valued members, Dr. Mai Heikal, has been collaborating with and volunteering for EAENA for some time. Through her informative articles on epilepsy and pediatric health, as well as the art workshops she leads for both youth and adults, Dr. Heikal has become a wonderful contributor to our community.

Her passion for Egypt, her home country, is evident in everything she does. She recently approached EAENA with the idea of hosting a special cultural and culinary event at Pharaoh's Restaurant on Calgary Trail in Edmonton. In partnership with the restaurant, we are delighted to present A Night in Egypt.

We invite everyone to experience the sights, sounds, flavours, and traditions of another country—without needing a passport or spending hours in airport lineups! Join us for an unforgettable afternoon featuring authentic Egyptian cuisine, music, cultural performances, dance, interactive activities, and many opportunities to learn about the rich history and traditions of Egypt. As a special keepsake, everyone who registers will receive a personalized certificate with their name beautifully written in Egyptian hieroglyphics.

Simply click on the event image below to register today. EAENA members receive a discounted admission price of $35, while non-members can attend for $40.

This unique fundraising experience combines cultural discovery with community connection while also supporting EAENA's work to increase awareness and understanding of the brain, epilepsy, and seizures. We look forward to welcoming you for an afternoon of learning, celebration, and fun!

EAENA PRESENTS

SAT AUG 15, 2026

Experience Egypt

*Radwa the Dancer will host a cultural show during the event!
We will host Egyptian photo booth and special namesake gifts for all who join our special event!*

5524 CALGARY TRL NW, EDMONTON

A Restaurant & Cultural Evening Fundraiser

- Book your spot today for an unforgettable journey to Egypt!
- Savour authentic Egyptian cuisine, discover rich traditions and culture, and enjoy an evening filled with vibrant music and captivating dance entertainment.
- Join friends, family, and community members for a unique cultural experience while learning more about epilepsy and supporting programs and services that benefit individuals and families affected by epilepsy in our region.

Experience the flavours, culture, and hospitality of Egypt — all while making a difference in the lives of people living with epilepsy.

TX: $35 EAENA MEMBERS
$40 NON-MEMBERS AVAILABLE AT:

EAENA
AWARENESS • EDUCATION • ADVOCACY
UNDERSTANDING CHANGES LIVES

epilepsyalbertanorth.ca

EPILEPSY BOOK CORNER

We are excited to share two important updates about EAENA's Epilepsy Book Series—both designed to make our educational resources more accessible and available to even more people.

Expanding Our French Audiobook Collection

As we shared in previous issues, we recently completed the first phase of our French audiobook project by producing audio versions of two of our French-language epilepsy books. We are now delighted to announce that we have secured additional funding to continue this important work.

Thanks to support from the Community Initiatives Program, a provincial grant that helps community organizations launch and expand meaningful projects, we will be creating five additional French audiobooks. This funding also allows us to begin distributing our French-language epilepsy resources to Francophone communities throughout northern Alberta.

Our team is currently working on producing these new audiobook titles while also compiling a directory of French-speaking communities and organizations across the region. Over the coming months, we will begin reaching out to these communities to share both printed books and audiobook resources, helping ensure that more individuals and families can access reliable epilepsy information in the language they are most comfortable using.

A New Way to Access Our Books

We are also making significant progress on another exciting initiative that will transform how people obtain professionally printed copies of our books.

Over the past several months, we have been working closely with ION Print Solutions to develop a Print-on-Demand ordering system that will make our publications easier to access while improving the long-term sustainability of our book program. Our goal is to launch this new service by the end of 2026.

The new system will offer two convenient ordering options:

- 1 to 4 copies: Visitors will continue to order directly through the EAENA website, and we will provide these books free of charge as part of our ongoing commitment to education and awareness.
- 5 or more copies: Users will be redirected through our website to ION Print Solutions' secure Print-on-Demand portal, where professionally printed books can be ordered in larger quantities. Users will pay only the printing and shipping costs, while EAENA continues to subsidize access to the content itself.

This new approach will allow us to continue offering free educational resources to individuals and families while providing schools, healthcare organizations, libraries, and community agencies with an efficient way to order larger quantities. It also allows us to better manage our office space, reduce storage requirements, and streamline the time and resources required for packaging and mailing books.

We look forward to sharing the final details, ordering instructions, and active links in the final Focus on Epilepsy magazine issue of 2026. Together, these initiatives represent another important step toward our vision of making trusted epilepsy information accessible to everyone who needs it.

NEW! DISCOVER OUR BOOKS SESSIONS

We are excited to introduce a brand-new members' program that brings our educational resources to life: Discover Our Books Sessions.

As many of you may know, EAENA is the only epilepsy organization in North America to have developed a comprehensive series of educational books about epilepsy. These resources are distributed throughout Canada and the United States and are also accessed by readers around the world through our downloadable PDF and audiobook formats. While all titles are available in English, we continue working to expand the accessibility of our French collection, including additional audiobook editions.

Over the years, these books have become trusted resources for individuals living with epilepsy, family members, caregivers, educators, healthcare professionals, and anyone seeking reliable, easy-to-understand information. Now, we would like to take the next step by transforming these books into opportunities for conversation, learning, and community.

Our Discover Our Books Sessions will be informal, interactive evening gatherings held at the EAENA office. Each session will focus on a single book from our collection, exploring its topics in greater depth through guided discussion, practical examples, and opportunities for participants to share their own questions and experiences.

Everyone who registers will receive access to the featured book, along with additional resources that complement the discussion. If questions arise that we are unable to answer during the session, we will research them and follow up with all participants afterward, ensuring everyone leaves with the information they need.

Most importantly, these evenings are about more than learning—they are about building connections. Together, we will enjoy light refreshments while creating a welcoming space where people can learn, ask questions, exchange ideas, and support one another as we explore life with epilepsy and the many challenges and successes that accompany this neurological condition.

Our first Discover Our Books Session will be held at the EAENA office on Thursday, September 3, 2026, from 6:00 to 8:00 p.m. We will begin with one of our most requested titles, Living with Epilepsy.

Space is limited, so we encourage you to register today and join us for an evening of conversation, learning, and community. Members will receive a direct link to this session towards the end of August.

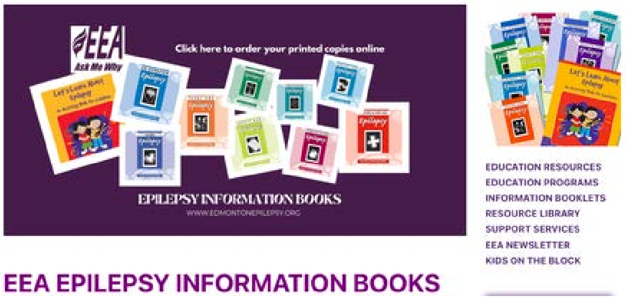
EAENA PROGRAMS

ONGOING

While we continue to develop and deliver a variety of special projects throughout the year, our core programs remain the foundation of everything we do. They allow us to achieve our strategic goals while advancing the vision that inspires our work every day: Empowering People Who Live With Epilepsy.

Within these pages, you'll also discover the many benefits of becoming part of the EAENA community. While our education, awareness, and many support resources will always remain freely available to everyone—locally, across the region, and beyond—membership offers opportunities for deeper connection, greater engagement, and additional support.

If you have any questions or would like to learn more about our programs or membership, we encourage you to contact our office. We would be pleased to hear from you.



EEA Ask Me Why

Click here to order your printed copies online

EPILEPSY INFORMATION BOOKS

WWW.EDMONTONEPILEPSY.ORG

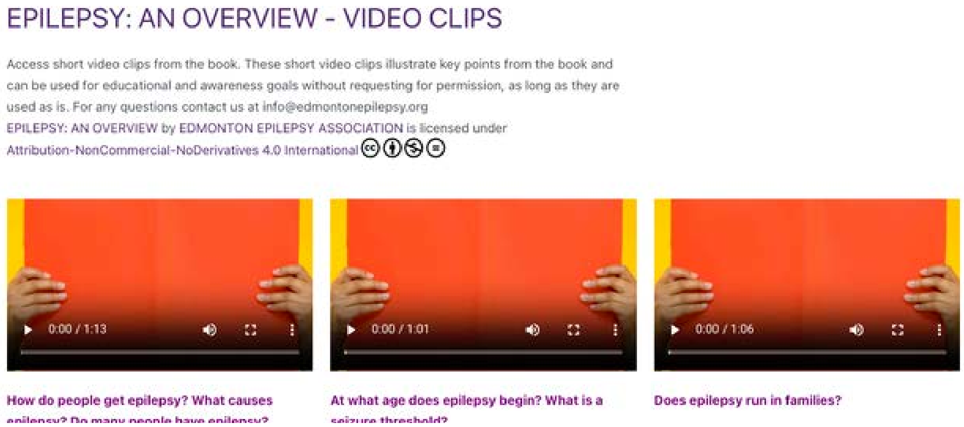
EDUCATION RESOURCES
EDUCATION PROGRAMS
INFORMATION BOOKLETS
RESOURCE LIBRARY
SUPPORT SERVICES
EEA NEWSLETTER
KIDS ON THE BLOCK

EEA EPILEPSY INFORMATION BOOKS

EPILEPSY BOOKS

We run a comprehensive 11-titles epilepsy information books. **Learn more at this link.** The books are in English and in French. All English copies are always available as audio books and audio files, and can be ordered online for free (large orders will require postage payment). We also have several titles with short video clips that can be used for learning purposes. We are happy to report that we received partial sponsorhip for our English titles from Pendopharm.

Order Books for free!



EPILEPSY: AN OVERVIEW - VIDEO CLIPS

Access short video clips from the book. These short video clips illustrate key points from the book and can be used for educational and awareness goals without requesting for permission, as long as they are used as is. For any questions contact us at info@edmontonepilepsy.org

EPILEPSY: AN OVERVIEW by EDMONTON EPILEPSY ASSOCIATION is licensed under Attribution-NonCommercial-NoDerivatives 4.0 International

How do people get epilepsy? What causes epilepsy? Do many people have epilepsy?

At what age does epilepsy begin? What is a seizure threshold?

Does epilepsy run in families?

EAENA PROGRAMS

ONGOING

KIDS ON THE BLOCK

Book your elementary-grades live puppet show today. More info at this link. The program is offered free of charge to schools, community centres, daycares and any other spaces that can benefit from an engaging live show, teaching younger kids the basics about epilepsy, seizures and hoe tow to be a good friend.

HOBSCOTCH MEMORY PROGRAM

Free memory-coaching program for people with epilepsy. Click here for more info. The HOme Based Self-COgnitive Training Changes lives is a cognitive program and memory coaching training program for people with Epilepsy. The EEA is pleased to launch the offering of this new service for all its members living with epilepsy. Members who apply will be screened to ensure they qualify for the 8-week program.

MENTORSHIP PROGRAM

Inquire with us about connecting with a trained EEA mentor, to get individualized support about life with epilepsy. More info here. We are accepting applications for this program from any EEA member in good standing. We also always look forward to recruiting new Mentors. To learn more about either role, connect with our office at info@edmontonepilepsy.org

EAENA PROGRAMS

ONGOING

SCHOLARSHIPS

Applications for these scholarships close March 31 every year. Learn more at this link. Scholarships are an essential part of our work, reflecting our commitment to recognizing and celebrating the achievements of people living with epilepsy across all ages. We offer three scholarships: two are open for applications from January to March each year, and one is available year-round.

AWARDS

We recognize special contributions by EAENA members living with epilepsy. More info here. In 2026, the EAENA will honour two outstanding members — the recipients of the Cam Reid Volunteer of the Year and the EEA Achiever of the Year awards. Each recipient will receive a prize valued at $250, and their names will be added to our commemorative trophies in recognition of their contributions.

FAMILY PROGRAMS

We offer education sessions tailored to families with kids diagnosed with epilepsy. Throughout the year we organize and deliver sessions specifically towards families iwth kids diagnosed with epilepsy.

KIDS AND YOUTH PROGRAMS

We run regular outings and kids-focused programs. These range from crafts and games sessions and events, to conversations about specific challenges, such as mental health. **Visit our page for updates on events and resources.**

EAENA PROGRAMS

ONGOING

SOCIAL GATHERINGS

We organize regular social gatherings for children, families, and adults living with epilepsy. These events provide a safe, welcoming space to connect, share experiences, and build supportive relationships within the community. Activities are designed to be inclusive and enjoyable for all ages. Please check our calendar for upcoming dates, times, and locations.

EPILEPSY 101 ON-DEMAND SESSIONS

We offer engaging online and in-person, on-demand educational sessions designed to build understanding and awareness of epilepsy. These sessions are suitable for individuals living with epilepsy, families, caregivers, educators, workplaces, and community groups.

Our Epilepsy 101 sessions cover essential topics such as:

- What epilepsy is and how it affects people
- Common seizure types and first aid
- Reducing stigma and supporting inclusion
- Practical tips for everyday life, school, and work

Sessions can be tailored to meet the needs of your group and scheduled at a time that works for you.

To learn more or to request a session, please contact us at info@edmontonepilepsy.org

INDIVIDUAL SUPPORT

Every person affected by epilepsy has unique experiences, challenges, and needs. That’s why our support is personalized, compassionate, and flexible. Whether you are living with epilepsy, supporting a loved one, or seeking information, we are here to listen and help. Reach out to connect with our team and learn how we can provide guidance, resources, and support tailored specifically to you.

FROM OUR ARCHIVES

STORIES FROM THE PAST

We invite you to let this photograph and accompanying newspaper article from the 1970s speak for themselves.

Although much has changed over the decades, stigma, isolation, and misconceptions about epilepsy continue to affect the lives of many people. A smiling child does not immediately tell the world that she lives with a neurological condition. Epilepsy is, for the most part, an invisible disability. What cannot be seen is often misunderstood.

Yet living with seizures remains one of the most unpredictable and challenging realities a person can face. Those who have never experienced epilepsy themselves may never fully understand the uncertainty it brings—the constant questions of when the next seizure might occur, how it may affect daily life, or what opportunities may be limited because of misunderstanding rather than ability.

Too often, people make assumptions about what someone living with epilepsy can or cannot do. Those assumptions can shape the expectations placed on a child, influence how a spouse or family member is treated, or limit opportunities for an adult pursuing education, employment, or independence. In many cases, the greatest barriers are not seizures themselves, but the misconceptions that surround them.

In a speech to her fifth grade class entitled "Epilepsy and Me" 10-year-old Epilepsy Canada poster girl Jessica (above) sums up her feelings: "Because I have seizures, I have to wear a helmet on my bike, in the tree and while skating. People always tease me about my helmet so I'm used to it but it still makes me feel badly and then I wish I didn't have epilepsy! But I do and I have to live with it. If you think about it, it's not that bad. I am just like any other person."

That is why awareness and education remain at the heart of everything we do. By sharing knowledge, challenging outdated beliefs, and creating opportunities for meaningful conversations, we can replace fear with understanding and stigma with acceptance. Every story shared, every question answered, and every person educated helps build a community where people living with epilepsy are seen not for their diagnosis, but for their strengths, potential, and humanity.

VOLUNTEERS ARE THE HEART OF EAENA

Everything we do begins with people who care.

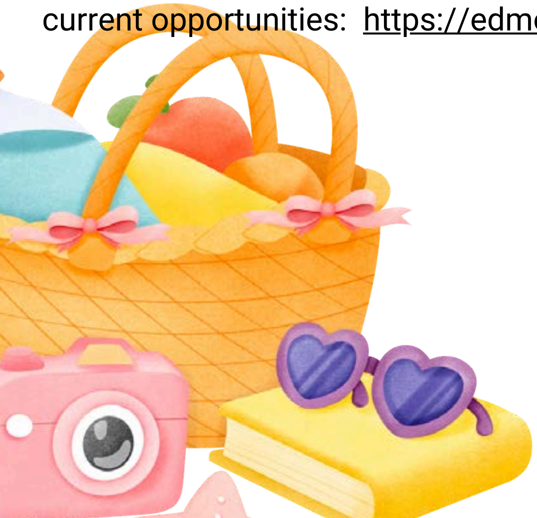
More than 85% of EAENA's programs, events, and services are made possible through the dedication of volunteers. They are students, parents, professionals, retirees, friends, and family members—many with a personal connection to epilepsy and a shared desire to make a difference. One of the biggest surprises for people who are new to EAENA is discovering that our organization is powered by just one full-time staff member and one part-time fundraising specialist. Yet together with our incredible volunteers, we are able to educate, support, advocate, and build meaningful connections throughout northern Alberta.

Our strength comes from the people who share their time, talents, and lived experiences. Every story matters. Every act of kindness helps someone feel less alone. Together, we create a community where people affected by epilepsy are met with understanding, compassion, and hope.

LLiving with epilepsy can be unpredictable. Occasionally, one of our volunteers may experience a breakthrough seizure, unexpected fatigue, or another health challenge that changes their plans. When that happens, we simply adapt. We support one another, adjust schedules, and step in where needed. That's what a community looks like. Imagine if more places embraced that same spirit of patience, flexibility, and understanding before assuming the worst about a missed call or cancelled commitment.

We're excited to see more people discovering EAENA and expressing interest in becoming part of our volunteer family. Whether you have a few hours to spare, special skills to share, or simply a passion for supporting others, there is a place for you here.

If you'd like to help create a more informed, compassionate, and inclusive community for people living with epilepsy, we'd love to hear from you. Visit our volunteer page to learn more and explore current opportunities: https://edmontonepilepsy.org/volunteer/



BOARD OF DIRECTORS

EAENA BOARD OF DIRECTORS

2026 EEABOARD

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Director

Valeria Palladino Executive Director | Chief Operating Officer

Behind every program we deliver, every family we support, and every milestone we celebrate stands an extraordinary group of volunteers: the Board of Directors of the Epilepsy Association of Edmonton and Northern Alberta (EAENA). Their dedication, wisdom, and unwavering commitment help shape the future of our organization and ensure we continue to fulfill our mission of empowering people who live with epilepsy. Our Board members generously contribute their time, professional expertise, and passion for our cause. Meeting monthly online and gathering annually for an in-person strategic retreat, they work collaboratively to uphold the vision, mission, and values that define our association. Their thoughtful leadership, careful stewardship, and willingness to ask the difficult questions provide the guidance and accountability that allow EAENA to grow, innovate, and serve our community with confidence.

The coming year will also mark an important transition. In 2027, several long-serving directors will complete six years of dedicated volunteer service and conclude their Board terms. Their legacy of leadership has helped build the strong organization we are today. By welcoming new directors before this transition, we hope to ensure a seamless continuation of the collaborative spirit, diverse expertise, and shared commitment that make EAENA the best version of itself.

If you are interested in learning more about serving as a director, we encourage you to visit our Board webpage and connect with Valeria for more information. Your skills, experience, and passion could help shape the next chapter of our story—and make a lasting difference in the lives of people living with epilepsy. Our directors will work on developing a strategic new plan on Saturday, September 26, 2026 at the EAENA office.

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JUL-SEP 2026