EDMONTON EPILEPSY ASSOCIATION

65 YEARS OF HOPE: FROM SHADOWS TO LIGHT

CHALLENGING EPILEPSY STIGMA, ONE CONVERSATION AT A TIME

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An anniversary book to celebrate 65 years of community work and impact in the epilepsy community by the Edmonton Epilepsy Association (EEA). This book was created through the contributions of many volunteers and EEA staff, in 2024/25, to build a testimonial about our registered charity and its 65 years of operations.

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INSIDE OUR STORY

MESSAGE FROM THE EEA PRESIDENT

As we celebrate 65 years of the Edmonton Epilepsy Association, may we reflect on the incredible journey our community has taken together, as documented in the pages of this book.

As I look through this book, it is clear that over the decades, our members have been the heart of the association. Through members sharing their stories, attending various events from conventions to film viewings, or contributing countless volunteer hours, the work of the association truly helps to build a community for those living with epilepsy and their caregivers. From shifting perspectives about epilepsy, to the progress we've seen in medical treatments, the EEA has been a true leader of advocacy and education.

I hope as you read this book you feel the same mixture of hope, optimism and pride that I feel. As a caregiver of a child with epilepsy and not a person living with epilepsy, I find the history of the association and the member stories to be inspiring and empowering.

The future is full of promise, and with the continued strength of our members, volunteers, and supporters, we will grow even stronger as an association. May we continue to shine a light on epilepsy and create a world where everyone affected by epilepsy can live fully and without stigma. Here's to the next 65 years!

Susan Wilkie, EEA President, June 2025


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THE 1990S

“If I had a convulsive seizure, would you know what to do to help me?”

Advocacy, growth, and community support for people with epilepsy in our region experienced remarkable strides during the 1990s. This decade marked a period of maturation for the Edmonton Epilepsy Association (EEA), characterized by both internal growth and increased visibility. As new national groups and alliances were formed, the EEA played a pivotal role in driving change.

In 1990, March was officially declared Epilepsy Awareness Month in Canada, further bolstering the EEA's efforts to improve the lives of those affected by epilepsy. During this time, the association strengthened and expanded its services to include individual counseling, educational programs, and advocacy. One of its most ambitious projects was a video production that shared the stories of families with children living with epilepsy, alongside medical professionals. The goal was to distribute this video in schools to raise awareness. The EEA also took pride in its participation in Klondike Days, showcasing an Epilepsy float that symbolized its growing presence in the community.

By 1991, the EEA had firmly established itself as an essential part of the community. In partnership with Alberta Education, it incorporated Lorraine Crawford's Epilepsy in Education resource into the Child and Health 36 course. However, the association also made the decision to step back from participating in Klondike Days floats. Although they were a source of pride, the effort was not yielding the reach they had hoped for. Volunteers remained central to the association’s work, and its programs continued to evolve. New initiatives like "Face to Face" were launched to address the employment challenges faced by people with epilepsy.

1992 saw the beginning of several key collaborations, including a partnership with the Body Shop at Edmonton’s Eaton Centre for Van Gogh Day. This event provided children and families with an opportunity to create crafts, while also raising awareness about epilepsy. Additionally, the EEA continued producing educational materials, including brochures and videos about epilepsy medication, seizure effects, and cognition.

THANK YOU!

Many thanks to the folks at Marion Merrell Dow for their support of our education program. Pictured are Lori Maller, Manager, Government Affairs, for Marion Merrell Dow presenting a cheque for $5,000 to Edmonton Epilepsy Association’s President Joanne Medisky.

THE 1990S

Our outreach expanded with public service ads on buses and LRT transit in Edmonton, as well as fashion shows. These initiatives underscored the EEA's commitment to representing all individuals affected by epilepsy, not just those with easier or more positive stories to tell.

Annual reports and newsletters reflected the association's growth as a community presence, with a focus on serving both its members and the broader public. Conversations about diversifying fundraising methods and responding to tightening budgets from primary funders like the United Way demonstrated the EEA's ongoing efforts to increase financial sustainability. The association's collaboration with other community groups, both provincially and nationally, created unexpected synergies and opportunities.

In 1993, the EEA celebrated the achievements of dedicated volunteers like Cam Reid, who received the Outstanding Volunteer of the Year award. Notable partnerships during this period included collaborations with organizations such as Glenrose Rehabilitation Hospital, where epilepsy awareness talks were held, and the "Employ Abilities" workshop, which helped individuals with epilepsy navigate employment challenges. By 1994, the EEA's fundraising efforts had grown significantly, with events such as a ski fundraiser at Marmot Basin Ski Resort. In 1995, the association launched new awareness campaigns, including a "Spot the Sign" contest that encouraged businesses to display purple epilepsy signs during March. The year also marked the launch of their first casino fundraiser at Palace Casino.

In 1995, we proudly celebrated our 35th anniversary. By 1996, the EEA's budget had surged to $135,000, with public education programs increasing by 13%. This year also marked the association's venture into the digital world with the launch of its website, a milestone that expanded its outreach and communication capabilities. In 1997, the EEA's community presence continued to solidify, and the organization achieved significant milestones, including joining Epilepsy Canada to form a united front for advocacy and support. This year also saw the approval of the Vagus Nerve Stimulation (VNS) system in Canada, a major advancement in epilepsy treatment.

By 1999, the EEA had not only cemented its position as a key player in Canada but had also joined forces with 16 other agencies to form the Canadian Epilepsy Alliance (CEA), ensuring that individuals with epilepsy had a unified voice in national conversations. Through a combination of education, advocacy, and community support, the Edmonton Epilepsy Association has had a profound impact over the years. From humble beginnings, the EEA has grown into a formidable force for change. With continued dedication to raising awareness, improving lives, and fighting for the rights of people with epilepsy, the association has set the stage for an even brighter future.

Keliah's Story

Keliah is a vibrant 12-year-old in Grade 7, brimming with enthusiasm for life. She thrives on sports and a variety of activities, always ready to embrace new experiences with joy.

Her hobbies include video games, playing water polo – where she trains 3 times a week and will be attending provincials with her team this 2024/25 season—hockey, swimming, and she also participates in online competitive games involving AI. Diagnosed with epilepsy early in her life, Keliah faced significant challenges. By Grade 1, her seizures were not well controlled, leading to nearly two years of missed elementary education. However, she has since made remarkable strides and now excels in her studies, as her mother, Shandea, shares. The early years were filled with fear for the whole family, and it took time to find the right medications and routines to support her development and allow her to engage in activities typical for her age.

Keliah identifies missing medication as a major trigger for her seizures. Other common causes include unexpected lack of sleep, illness, bumps during sports, overheating, or fatigue. Despite these obstacles, which might discourage others, Keliah continues to lead with resilience.

The Edmonton Epilepsy Association by Numbers

3	Scholarships offered each year to youth with epilepsy.
3	Special awards to recognize individuals and agencies that support the epilepsy cause.
10	Audiobook titles, available on 29 platforms online to learn about epilepsy.
11	Titles of epilepsy information books, published professionally and distributed since 2010.
14	Volunteer directors to govern the Edmonton Epilepsy Association.
65	Years in operations, supporting the epilepsy community in northern Alberta.
1 in 100	Average of people impacted by epilepsy around the world.
5,000	People served and connected to on a per-year basis.
30,000	Copies of epilepsy information books distributed per year.
400,000	Canadians suffering from epilepsy each year.


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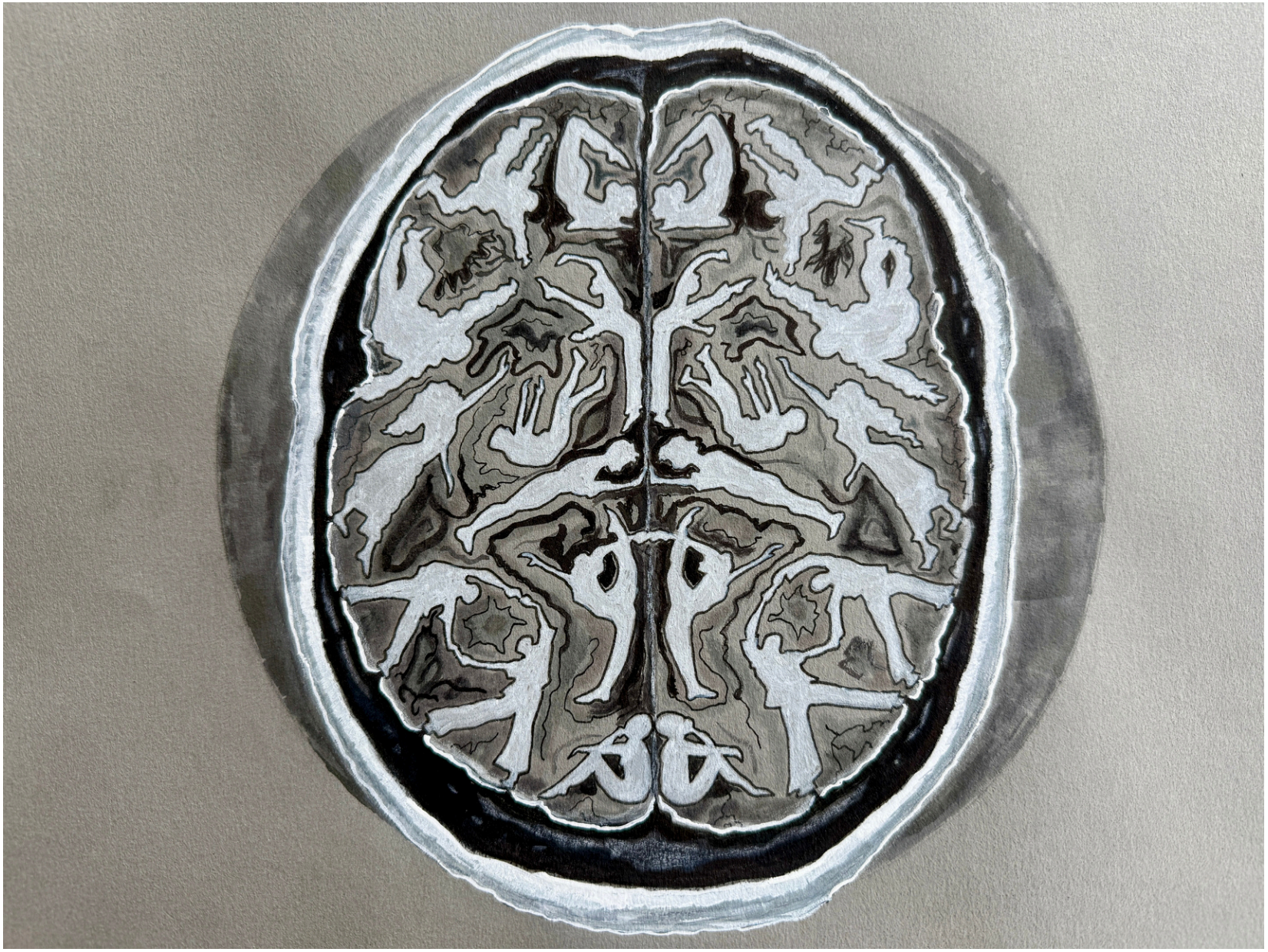

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