Edmonton Epilepsy Association | The Epilepsy Association of Northern Alberta

Annual Report

www.edmontonepilepsy.org

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MESSAGE FROM THE PRESIDENT

This past year was an exciting one for the Edmonton Epilepsy Association (EEA). Our year began with our 2022 Annual General Meeting where a new executive was chosen. I was honored to be selected as President and I have appreciated the support of the other executive members and the Board of Directors this past year. Together, with the help of Valeria Palladino, our Executive Director and Chief Operating Officer, we saw the EEA deliver on the goals in our strategic plan and return to hosting a number of in-person events. While we did face some challenges throughout the year, we still managed to find opportunities and expand our small but mighty charity.

New initiatives this past year included the Edmonton Oil Kings 50/50, Epilepsy 101 Family Presentations, and organized children's outings. In the spring we launched the Epilepsy Web 4 Kids website, which was a major accomplishment with great potential to build awareness and understanding of epilepsy. We also introduced a new June awareness campaign, 25 Days for Epilepsy, which we capped off with a backyard party. For the first time our Kids on the Block puppet show brought epilepsy awareness to the International Children's Festival held in St. Albert, and several live shows were also held as part of the Edmonton Fringe Festival in August. Wednesday teas at the office also became a regular member event this year.

Other successes included the reintroduction of our Christmas Party and the reprise of Member Bingos. Thanks to assistance from l'Épilepsie section de Québec and many volunteer hours of editing we were also able to update our French booklets ensuring that all titles are current and available in both English and French. One final success this year was our participation in the Birdies Fundraiser. Thanks to generous donations, fundraising by members, and Birdies matching monies, we were able to secure funding for a number of children's programs.

Our Board of Directors continues to investigate grants and fundraising opportunities to ensure a positive cash flow. Increased operating costs this past year and tighter budgets for many of our supporters proved challenging. We hope to raise new and stronger funds and engage in new and exciting activities in 2023.

Our association is made stronger by the contributions of so many. Thank you to Sharon Otto and Valeria Palladino, our dedicated staff, and to our Board of Directors for contributing to another amazing year at the EEA! And a special thank you to all our members for their continued support. Together we are empowering people who live with epilepsy and improving the quality of life of people who live with epilepsy, the families and caregivers.

MESSAGE FROM THE EXECUTIVE DIRECTOR

As we said goodbye to 2022 at our first post-pandemic members' party, on December 10, 2022, there was a certain electricity in the room, with over one hundred people enjoying each other's company, a good meal and some fun together! I welcome everyone who reads through these pages, to think of 2022 as the year we started adjusting to new ways of life, in our families, in our community and around the world, with different sensitivities, different perspectives and a growing sense of hope things will get better as we move along.

The dedication and commitment of our core volunteers and members to the Edmonton Epilepsy Association, marked another year of successes, new initiatives, re-starting of traditions and growing impact of our vision to Empowering People Who Live With Epilepsy.

Amongst the newest additions to our programs and services, we list the launch of the new kids' website, we call **Epilepsy Web For Kids**, live at https://epilepsyweb4kids.ca/ , a unique platform where we curate resources for kids and younger adults, about epilepsy, seizures, the brain and how to be a friend to those impacted by this neurological disease. The Shaw Charity Classic, Birdies for Kids fundraising initiative, along with other major sponsors, helped us launch the site, and we plan to add new projects under this platform, working with younger ones and their families, for years to come.

We launched a new awareness campaign, we call **"25 Days for Epilepsy",** which will now take place during the month of June on a yearly basis, placing our three key campaign throughout the year, in March, in June and in October. In 2022 the campaign focused on movement and exercise as supporting management of seizures, with champions fundraising through their physical goals during the month of June. We celebrated the end of the campaign with a backyard party at the EEA office.

For the first time in our history, our Kids on the Block puppet show was performed over one full week in August, at the Kids Fringe in Edmonton. We reached out to kids and families throughout that week and collected wonderful stories and anecdotes from parents who came along, welcoming the education side of this unique show.

Amongst some of the activities we picked up from our pandemic pause, were our office bingos, one day a month to come along for a coffee or tea and some informal chat, and the members' holiday party. We also continued our monthly information webinars in collaboration with the Calgary Association for Epilepsy, under the project for the Alberta Epilepsy Education Webinar series (https://albertaeweb.ca/) and of course, maintained our Epilepsy Information Booklets program, gaining printed requests back to pre-pandemic times (over 30,000 paper copies shipped free of charge across Canada in 2022).

While challenges remain in securing longer-term funding, we believe our association grew, not only in membership numbers but in exposure to the larger community to increase awareness and education about epilepsy, in service of the more than 26,000 people in our region. And our EEA staff, core volunteers, directors and champions of our association can be proud of another successful year in service of our community.

Our Vision

Empowering people who live with epilepsy.

Our Mission

To assure the wellbeing of persons with epilepsy through increased public awareness and education and further, to address specific concerns, both personal and social, that these individuals experience. The objective of the Edmonton Epilepsy Association is to promote, in any way possible, an improved quality of life for persons with epilepsy, their families and caregivers. In order to work towards this objective, the Association may establish, maintain, assist, or promote:

- Programs of assistance and support for persons with epilepsy and their families;
- Programs of education for persons with epilepsy and their families;
- Programs of public education;
- Fund raising programs;
- Recreational activities for persons with epilepsy, their families and friends;
- Programs of research.

OUR VALUES

Empowerment | Respect | Compassion | Dedication| Integrity

About Us

The Edmonton Epilepsy Association was formed in 1960, having evolved from the Western Canada Epilepsy League (Edmonton Branch). In 1961, the Edmonton Epilepsy Association was accepted as a member of the United Community Fund (now the United Way). While the Association endeavours to provide information services to Central and Northern Alberta, over 80% of its services are within the greater Edmonton area. Over the past 62 years, the association has served a yearly average of 5,000 individuals and their families and caregivers, who live with epilepsy, in the Edmonton area, as well as the northern Alberta, Yukon and Northwestern Territories, Our potential outreach expands to more than 26,000 individuals who are impacted by the brain disorder.

Since 1960, the Edmonton Epilepsy Association has helped to improve the lives of persons living with epilepsy by providing information, referral, and support services as well as engaging in impactful awareness and education campaigns.

The association runs its flagship program of a series of 11 epilepsy information booklets. We continue to distribute these for free in Canada, and receive digital downloads in the thousands from all over the world. Another important element of the EEA is its rich website and its freely available bi-monthly newsletter.

The EEA is a member of the Canadian Epilepsy Alliance, CEA, and as such it is connected to the International Bureau of Epilepsy (IBE) and the International League Against Epilepsy (ILAE). With a small but mighty staff of two and a core team of faithful and committed volunteers, the association has been a point of reference and a main source of support for its members for over 62 years.

J'apprends ce qu'est l'épilepsie

Our Team

The EEA operates an office with one full-time staff and one part-time staff. Valeria Palladino is the Executive Director, and Sharon Otto is the Program Manager. Over 85% of all activities and programs are directly impacted and supported by faithful, committed and enthusiastic volunteers, who truly shine in all we do.

In 2022 we received over 1,860 worth of volunteer work, support and sharing of skills, expertise, fundraising assistance and governance leadership. The equivalent of a full time salary of in-kind contributions! Thank you to all who dedicate so much to the Edmonton Epilepsy Association!

Valeria Palladino
Executive Director

Allie Wiks
Volunteer

Angela Wilm
Volunteer

Angie Chen
Volunteer Coordinator

Ariel Lowes
Volunteer

Cameron Reid
Volunteer Coordinator

Cheryl Gillie
Volunteer

David Walsh
Volunteer

Julia Gallant
Volunteer

Justine Beghin
Volunteer

Laura Jurasek
Volunteer

Marika Lopez
Volunteer

Rob Beghin
Volunteer

Sandra Tkachuk
Volunteer

Tanja Penina
Volunteer

Todd McCarter
Volunteer

Virginia Nason
Volunteer

Sharon Otto
Program Manager

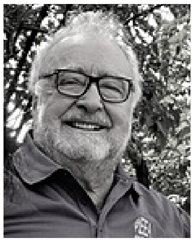
Our Board of Directors

Tammy Tkachuk
President

Colleen Matvichuk
Past-President

Katrina Breau
Vice-President

Tammy Humphreys
Secretary



Terry Mahon
Treasurer

Noella Desaulniers
Director

Kris Zielinski
Director

Shandea Patras
Director

Anna Pagliuso
Director

Susan Wilkie
Director

Brand Brost
Director

Dr. Kassiri
Director

A Year in Review

2022 was a year of adjustments, reflections and regrouping, for many in the non-profit sector. With the word "*pandemic*" still so present in our minds and everyday life, we have all experienced a need to energize, to count on each other to continue on our paths. With world events and often sad news, surrounding our conversations, we can hardly escape a sense of things feeling harder than usual.

Economic changes have impacted everyone, in 2022, but especially more vulnerable people, and people living with invisible disabilities, such as epilepsy. The vision and mission of the Edmonton Epilepsy Association have never been more important, relevant and essential to our community, of over 5,000 people we serve each year. With all we offer, to members, the community at large and as part of the world-wide conversation about increased awareness and education about this neurological disease.

As we look back at 2022, we continue to feel proud of all the small and significant impact we continue to make, and count on the positive ripple effects of all we strive to stand for, as we reach a wider audience, along with strengthening the relationships we build through our programs and services. This report summarizes the yearly successes and challenges, and is a testimony to the strong ongoing dedication of so many in our community, to stand together, take care of one another, and speak out about epilepsy, those who live with it and those who care for them. We are stronger together, and we add our voices to the provincial, national and international conversation about all the contributions people with epilepsy make everyday!

Our key goals for 2022, based on our Strategic Plan and through our four key areas of focus included:

- ORGANIZATIONAL SUSTAINABILITY
    - Organize new membership model
    - Support financial viability of the association
    - Increase fundraising capacity
- COMMUNICATION AND ADVOCACY
    - Determine levels of awareness about epilepsy and the EEA in the community
    - Identify gaps and needs in the epilepsy conversations
    - Increase social media presence
    - Establish ongoing awareness campaigns
    - Expand collaboration opportunities
- AWARENESS AND EDUCATION
    - Grow education and awareness support through traditional and innovative ways
    - Strengthen relationship with healthcare providers
    - Establish new programs in support of epilepsy patients and caregivers
- MEMBERS SERVICES
    - Increase membership by 25%
    - Create member services pathways
    - Strengthen members' support
    - Improve and strengthen volunteer programs

A Year in Review (cont.)

Our 2022 journey begins, as in every other year, with a reflection on our past successes as we set to host our **Annual General Meeting**, on the last Thursday of February. As in the previous year, we hosted the AGM entirely online, as we were following the stricter health regulations in a world still in the full presence of a pandemic. Attendance to the AGM was facilitated by the landing program of our tablets from the grant we received from the Telus Community Foundation. And, on the positive side of the digital format, Zoom allowed us to expand our outreach and meet also the needs of many members, who could attend from the comfort of their own homes.

Immediately following the AGM plans, are the plans for **March Epilepsy Awareness Month**, and our dedicated website page, with all the various activities we host to create awareness and build education about this neurological disease. **On March 26, 2022, International Purple Day,** we also launched a brand new website explaining epilepsy to kids and younger adults, available at: https://epilepsyweb4kids.ca/ . Thanks to a new list of sponsors and donors, along with the largest fundraising initiative, through the **Shaw Classic, Birdies for Kids,** we raised over $60,000 to support a great number or activities and programs to populate the website, curate content from around the world and add new resources to ensure everyone, at any age, has a better understanding of this brain disorder, and creates a more inclusive community for everyone. In March we also launched a new fundraising partnership with the **Oil Kings**, and raised funds through their 50-50 raffle. Bridge banners, a special newsletter issue and daily social media entries were all part of the month- long effort in support of the epilepsy conversation.

The **Alberta Epilepsy Education Webinars** series was stronger than ever, as a collaboration with the Epilepsy Association of Calgary, and our **Epilepsy Information Booklets** program, unique to our agency and across north America, reached pre-pandemic numbers, in terms of printed booklets shipped, free of charge, across Canada, and digitally downloaded from around the world. 2022 also saw us **updating** the **French titles,** in collaboration with a sister agency in Quebec and additional editing work from our bilingual volunteers.

June 2022 saw us launch a brand new yearly campaign, we called **"25 days for epilepsy"**, where champions across the province promoted information, awareness and specific focus on the health benefits of physical movement for people with epilepsy. We added daily social media posts to our campaign and raised funds through the Birdies for Kids campaign.

In the summer of 2022 we also managed to add the **Kids on the Block live puppet shows to the St. Albert International Children's Festival** as well as the **Kids Fringe Festival in Edmonton.** The shows were well attended and added the perfect mix of entertainment with education about epilepsy and encouraging all kids and their families to be inclusive of everyone who lives with a disability.

For our members we resumed in-person social events, on monthly dates, **playing bingos** and just enjoying **a tea or a coffee with treats**, at our renovated office. We also resumed the traditional members' holiday party, which was attended by over 100 members, in Edmonton.

Along with social activities, our **individual members' support**, with **system navigation needs**, connecting with specific healthcare providers, directing members and inquiring individuals towards the right specific resources to learn more about epilepsy, and working collaboratively with other agencies continued.

A Year in Review (cont.)

The **Mentorship Program,** along with the **Memory Coaching Program, called HOBSCOTCH,** were also part of our offering for adult members living with epilepsy, as well as caregivers.

Support for families with children diagnosed with epilepsy was stronger than ever in 2022, as we transitioned from the Families Online Conversations (FOCs) to **Families and Youth resources and activities**. In addition to online presentations about epilepsy which focus on the family experience, we set out to have **fun outings with kids** and their families, and had special times bowling together, as well as painting purple pumpkins in October.

Our **October Awareness Campaign focused on Famous People with Epilepsy,** and saw us build a special page on the kids' website, to teach a bit about 31 famous people, in history, who lived and live with this neurological disease and have contributed greatly to their communities, in everyway possible, from sports, to arts, to leadership, politics, literature and much more.

The **Focus on Epilepsy bi-monthly newsletter** grew in 2022, in number of sections and updates about our programs, as well as overall distribution, as we reached our goal of **a membership increase** of at least 25% from the previous year.

Our long-standing volunteers continued their hard work for our charity, and we gained **new volunteers** in 2022, to assist with project-specific goals, be there hands-on programs or digital tasks to support social media and website entries. Our **social media** platforms grew **followers** to amazing numbers, and we broke the record of over 500 followers on our Instagram account alone!

Our **Board of Directors elected a new President, Tammy Tkachuk,** and maintained a strong leadership presence, with regular meetings, strategic retreats and attendance to key agency events, while directly supporting our charity in very concrete ways.

We also completed the full cycle of **updating our Bylaws** and implementing a **brand new**, and more inclusive **membership model,** which includes a new online platform on our website, and a new membership format which includes families.

Successes and challenges

We list key achievements in 2022 as well as some critical challenges we faced in this past year.

SCHOLARSHIPS	1 scholarship awarded in 2022
EDUCATION WEBINARS (WITH EAC)	8 webinars held in 2022
EPILEPSY INFORMATION BOOKLETS	30,000 printed copies shipped across Canada
FOCS SESSION HELD	3 sessions held in 2022 and transition to Families and Youth Resources
KIDS UP FRONT EVENTS	Value of experiences in 2022 over $11,000
HOBSCOTCH CLIENTS SERVED	5 INDIVIDUAL PROGRAMS OFFERED
KOB SHOWS PERFORMED	13 SHOWS performed- over 800 participants through summer festivals
EPILEPSY 101 ON-DEMAND WEBINARS	8 ON DEMAND PRESENTATIONS OFFERED
MEMBERSHIP	25% growth - 290 members at end of 2022
WEBSITE VISITORS	3,000 page views /month on average on two websites
PUBLIC MEDIA (RADIO AND TV)	Magazine article on epilepsy (Healthing.ca)
BOARD AND COMMITTEE MEETINGS	25 meetings held in 2022
NEWSLETTERS PUBLISHED	6 newsletter issues published online and in print
SOCIAL MEDIA PRESENCE	150% growth in followings amongst social media channels

> For the first time in EEA history we performed at the Kids Fringe Festival, in Edmonton! We reached over 400 people through 8 performances that week.!

Successes and challenges

COLLABORATION WITH AGENCIES	Joined the Human Rights Provincial Table for the Alberta Abilities Network. Board participation with Voices of Albertans with Disabilities (VAD)
PARTNERSHIP WITH POST-SECONDARY EDUCATION PROGRAMS	NorQuest College Disability Studies Student Internship
AWARENESS CAMPAIGNS	March, June and October Campaigns
POLICIES AND BYLAWS	Updated Membership Bylaws and new Membership Model
FRENCH BOOKLETS 2022 REVISION	Completed French Epilepsy Information Booklets update
COMMUNITY IMPACT	Over 5,000 people impacted by our programs, services and campaign initiatives in 2022

Critical challenges we faced in 2022 include:

- increased operational costs
- donations
- greater media exposure

We plan to address these challenges through strategic partnerships, increased grant requests and applications and even stronger awareness campaigns in 2023.

Sponsors and donors

Sponsors, donors and champions keep our doors open, and allow us to cover operational costs, most of our awareness and education campaigns, including the ongoing and popular programs such as the Epilepsy Information Booklets and the Kids on the Block shows.

While we received numerous ongoing and one-time donations from individuals who are too numerous for us to list here, we do wish to acknowledge key supporters, who financially contribute to our charity, year after year.

- Terry Mahon
- The Epilepsy Trust
- The Telus Community Foundation
- Union 52 Benevolent Society
- Individual donors
- In-memoriam Donors
- Alberta Blue Cross
- ATB Financial
- CSU 52 Benevolent Society
- UCB funding for Alberta Epilepsy Education Webinars

Major funding channels for us in 2022 included:

- PayPal
- CandaHelps
- SkiptheDepot
- SimplyK
- Show Charity Classic - Birdies for Kids
- Donate a Car CANADA
- CyberGrants
- United Way
- Cheque and cash donations

We thank everyone for your continued support in our programs.

How to reach us

Our office, located at 11215 Groat Road, Edmonton Alberta, operates on weekdays, between 8:30 a.m. and 3:30 p.m. However, due to provincial restrictions, in-person visits are confirmed by appointments only, and emails and phone calls, as well as Zoom-mediated video chats are encouraged.

Our website, www.edmontonepilepsy.org remains the most updated form of communication about activities, programs, initiatives and much more about the EEA.

You can also follows us on social media at these handles:

https://twitter.com/eedmonton

https://www.facebook.com/edmonton.epilepsy/

https://www.instagram.com/edmontonepilepsy/

Contact

EDMONTON EPILEPSY ASSOCIATION
111215 GROAT ROAD
EDMONTON, AB, T5M3K2
780-488-9600
www.edmontonepilepsy.org
info@edmontonepilepsy.org