EEA ANNUAL REPORT

EEA
Ask Me Why

2021

Edmonton Epilepsy Association

www.edmontonepilepsy.org

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Message from the President

This past year, the Edmonton Epilepsy Association (EEA) continued to build on our collaboration in the community, with the Epilepsy specialist care teams and with all of you, our members, to find ways to stay connected while apart. Continuing to navigate COVID protocols created new challenges and new opportunities for all of us.

Our Executive Director and Chief Operating Officer, Valeria Palladino, hit her stride this year, leading the EEA office, the dedicated volunteer team and found ways to deliver on our strategic plan. I would like to express the Board's deepest gratitude for her unwavering positivity and creative spirit, as she continually finds new ways to support and connect with our members and the community.

The EEA's new collaboration with the Epilepsy Association of Calgary has resulted in the Alberta Epilepsy Education series. This series of online forums provides information for social support and medical needs, to help navigate life with epilepsy. These sessions are archived on a special website for everyone to access on demand.

Another highlight from 2021 was the launch of our on-line conversation programs. The Families Online Conversation (FOCs) is an opportunity for parents and children living with epilepsy, to connect and share stories, ideas and strategies for success, on a monthly basis. We also have the Members Online Conversation, a place for adults living with epilepsy, to connect and share ideas for social and community-building activities. We hope you will take a few moments to discover all of the resources available to you and your families on our website and in the EEA newsletter.

Our major fundraiser was a go this year, as we were one of the first charities to work a Casino during the reopening this summer. This has helped our balance sheet significantly. The funding we received from Casino can only be used for programs and services to support those living with epilepsy and their families. Thank you to all of our volunteers for making this happen! We were also eligible for Government Grants to provide some much needed financial support but, it is not enough to cover all of our operating expenses. Unfortunately, Casino funds remain limited in their use, so the Board of Directors continues to explore a number of fundraising options, for sustainable funding, to ensure all of our programs and services can be maintained and expanded in the future.

There were a number of achievements in 2021 and the following pages contain a summary of such activities. The Board respectfully submits this Annual Report for review and approval at the A.G.M. for all EEA members in good standing.

I close with a sincere thank you for the continued passion of our volunteers, Board of Directors, committee members and of course our hardworking team in the office. They continually strive to promote an improved quality of life for those living with epilepsy and the families supporting them.

Thank you for being an active member of the association. It was a privilege to have served as your EEA Board President for the last three years. I look forward to serving on the board for one more year to assist with the Board with its transition to a newly elected President.

I'm hopeful we will all be able to gather together again in the months to come. I look forward to seeing you soon, take care.

Colleen Matvichuk

Message from the Executive Director

2021 was a challenging and exciting year for everyone, and our association, that we like to refer to as a "Small but Mighty" charity , was no exception!

It was an absolute privilege and pleasure for me to serve as Executive Director and Chief Operating Officer of the EEA in 2021. While most of our programs and services took place online, as we kept each other safe and healthy during 12-months of full pandemic mode, we maintained our focus on reaching out and keeping our connections alive with everyone. Amongst our current members in good standing, we have about 30% of individuals and families who are not connected online, for a variety of reasons.

For this purpose we ensure that our bi-monthly newsletters contain all the details on our programs, past and future activities and programs, we offer our members to improve the quality of life of those who live with epilepsy. These newsletters are mailed out to all our members who request the old-fashioned way of reading news. In addition to newsletters, we also make regular calls to members and their families, to check in with everyone, especially in these times of isolation. We take pride in always following up on any questions from those who reach out to our office.

In December 2021 we run an old-fashioned Holiday Greeting Cards Program, with the help of member artists and skilled volunteers, and everyone received a handwritten greeting, with all our best wishes for the new year. Many members take the time to write back to us, or call our office and thank us for these small but significant gestures.

Funding initiatives throughout the year, saw us creating new channels for donations and fundraising, and many members supported us along the way. As an independent, registered charity, your financial support makes all the difference to keep our doors open! We continue to be the only agency, north of Red Deer, in Alberta, to offer social, education, awareness and other types of supports, for individuals diagnosed with epilepsy, their families and caregivers.

Under the diligent and enthusiastic leadership of our volunteer Board of Directors, we set a course through the Strategic Plan, which is updated annually, set Key Performance Indicators (KPIs), and success targets to direct our efforts towards tangible results. We do not always meet all the target we set, but we have a path and we know our way. We set to increase our membership by 25% and reached an increase of 24% in 2021! **That is success!** We set to innovate the delivery of education programs, and in our collaboration with the Epilepsy Association of Calgary, we offered 7 phenomenal webinars, along with edited recordings for everyone to access on demand, while starting a brand new partnership called the Alberta Epilepsy Education Webinars! **That is success!** We offered monthly online forums for families of children living with epilepsy, we call Families Online Conversations (FOCs), and engaged with experts, created community and built resources together! **That is success!**

You will read along many other specific successes we achieved together in 2021 in this report, and things can only get better from here onward.

It is an honour to be your servant leader.

Valeria Palladino

Our Story So Far

Who We Are

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 61+ 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, while its potential outreach expands to more than 20,000 individuals who are impacted by the brain disorder in the region.

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 13 epilepsy information booklets that are fully funded by a partner sponsorship with UCB, Canada, which allow us to share information about epilepsy to a diverse audience, from kids to teens, to adults, to women, caregivers, seniors, and many others, with a specific focus on the different audiences.

Through a rich and dynamic website, a bi-monthly newsletter, and social media posts, we keep in touch with our members and the community at large. 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 almost 62 years.

We are a small but mighty charity!

Our Journey in 2021

A Year of Pandemic Proportions

2021 will go down in history as the Year of the COVID-19 Pandemic. We faced it in strides, at the association, reinventing ourselves and findings ways to stay connected, along with all the added challenges that the world, Canadians and Albertans have been facing for the past 24 months!

A small but might charity such as ours, embraced the health restrictions and stayed connected with our members and our larger community, by pivoting the majority of our services and programs online. And to ensure we could continue to be of service of those in our family who have limited access to digital connections, we received an important support from the Telus Community Foundation, in the form of 50 Digital Tablets, to add to our lending library. Throughout the year, members have been accessing these tools, along with 15 hours of training and individualized support, to expand connections for members who felt most isolated from the COVId-19 restrictions.

We launched the Families Online Conversations (FOCs) for members of our association and all throughout the province. We built a new provincial education project in collaboration with the Epilepsy Association of Calgary (EAC), we call the Alberta Epilepsy Education Webinars, hosted at www.albertaeweb.ca.

We continued to host our summer community garden, and launched a Youth Garden Project, funded by one of our members.

We partnered with the Voices of Albertans with Disabilities (VAD) and led some important projects with the Canadian Epilepsy Alliance.

March 2021 saw us hosting special events online, including two special shows of our Kids on the Block (KOB) performances across Canada. The KOB shows were also part of the Fringe Festival Online for the first time.

Our Journey in 2021 (cont.)

Our Epilepsy Information Booklets program, with its 13 original titles continued to be offered, online and in print, free for all visitors to our website and for any Canadian online order, thanks to our sponsorship with UCB Canada.

We published six informative and insightful newsletters, and added a special new section called "Attitude of Gratitude" to our publications, also available through the "Members' Stories" section on our website, where EEA members share their life journeys with epilepsy.

Scholarships and members' activities continued in 2021, and we hosted a Family Online Music Bingo Night, to build community amongst younger (and younger at heart) members. We also established a direct connection with the agency Kids Up Front, and have been hosting access to free events, like festivals and sport games, for free, to any members who have families with little ones.

We landed some media attention, through Radio and TV interviews, thanks to the leadership of some of our younger members, for March Epilepsy Awareness Month and in conjunction with our second annual Halloween Purple Haunted House Project.

The Memory Coaching Program, HOBSCOTCH was also successfully delivered to our requesting members, as a specific Cognitive Behaviour Therapy-based program for people who live with epilepsy, and who face memory challenges, due to seizures and anti-seizure medication.

For our Christmas Special Event, while remaining unable to offer access to a live, in-person gathering for members, we called upon the wonderful skills of member artists and special volunteers, to create old-fashioned, home-made holiday cards, handwritten and delivered through post, in the traditional way, to tell all our members how much we value your support and your desire to build our community, year after year.

Our 2021 Goals

The key goals for 2021 were set in our strategic plan for 2021-2023, and included the following:

1. Ensure the long-term health and sustainability of the EEA
2. Build a supportive community for people living with epilepsy
3. Promote awareness and education about epilepsy
4. Strengthen and expand EEA member programs

1 Ensure the long-term health and sustainability of the EEA - Key Successes

- Set Fundraising Pillars Strategy
- Diversified and increased funding
- Run successful Casino, in June 2021
- Run multiple online fundraising events
- Received Telus Community Foundation Tablets Grant
- Established online donation platforms, such as SkipTheDepot, Donate a Car
- Received CEWS federal funding from COVID-19 funds
- Updated EEA Policies, including creating a Sponsorship Policy (new)
- Run Board meetings and Committees of the Board Meetings uninterrupted
- Maintained a varied and supportive Board of Directors team
- Run a membership model survey
- Increased EEA membership by 24% (target was 25%)
- Sold hand-made face coverings and Dr. Starreveld's Novel "Oscar"

2 Build a supportive community for people living with epilepsy - Key Successes

- Run successful March Epilepsy Awareness Month and Halloween Purple Haunted House Awareness Campaigns
- Maintained and expanded website, social media channels and public media presence
- Received free digital audit, increased video resources on VIMEO channel, added members' interviews to sharing stories about epilepsy
- Strengthened relationship with EAC (Calgary) and CEA.

Our 2021 Goals (cont.)

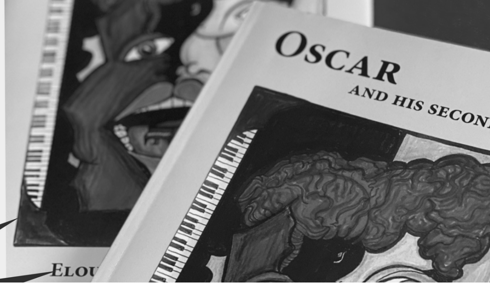
3. Promote awareness and education about epilepsy - Key Successes

- Offered Epilepsy 101 on demand, online webinars
- Run EEA Epilepsy Information Booklets Program (online and in-print)
- Run on-demand KOB shows across Canada
- Participated in Fringe Festival Online with KOB shows
- Initiated Alberta Schools Provincial Contacts Database
- Run new volunteers program and supported volunteers throughout the year
- Conducted members' Survey online and through the phone
- Established the Alberta Epilepsy Education Webinars with EAC and run successful education sessions throughout the year
- Increased direct connections with clinics, hospitals and epilepsy-centres in northern Alberta

4. Strengthen and expand EEA member programs - Key Successes

- Run Community Garden Program
- Established new Youth Garden Project (new)
- Run yearly Scholarship Programs
- Hosted Family Online Bingo Night
- Run Kids Up Front free event-tickets program (new)
- Run Members' Tablets Lending Program (new)
- Run HOBSCOTCH memory coaching program
- Run Families Online Conversations (FOCs) sessions throughout the year (new)
- Continued to receive over 80% satisfaction feedback from services and programs offered

OSCAR AND HIS SECOND LIFE



Our 2021 Strategy

Based on the approved Strategic Plan for 2021-2023, the EEA set specific directions and strategies to achieve its key outcomes and goals for the fiscal year.

These included:

- **Strengthen the digital footprint of the association**
    - Expand and enrich the EEA website (www.edmontonepilepsy.org)
    - Increase social media presence with daily postings and updates
    - Access available resources from improving communication and increasing connections with current and future members
    - Utilized online platforms in the most efficient and effective ways
    - Create and utilize digital directories to increase ongoing communication with membership and other contacts
- **Grow, maintain and nourish epilepsy-related networks**
    - Expand epilepsy relationships with an increased number of clinics, specialists and other medical teams in the northern-Alberta region
    - Establish direct collaborations with other agencies focused on epilepsy and other neurological disorders (EAC and the Brain Care Centre, in Edmonton)
    - Engage with epileptologists and neurologists, as well as healthcare professionals who directly deal with and support epilepsy patients

EEA
Ask Me Why

TELUS Friendly Future Foundation

DIGITAL TABLETS LENDING PROGRAM

The EEA invites members in good standing, who have limited means to gain access to the Internet, or wish to learn new browsing skills, to apply to this lending program. Priority

Our 2021 Strategy (cont.)

- **Focus on producing high quality, accessible resources about epilepsy**
    - Through partnerships and collaboration opportunities, engage with healthcare professionals, academic staff and researchers, as well as specialized service providers, to offer education sessions.
    - Record, edit and format video resources and make them available to everyone through online channels.

- **Maintain direct and ongoing connections with all EEA members**
    - Diversify communication methods to maintain active communication with all members.
    - Implement diversified ways to reach members, online, over the phone and via regular mail outs.
    - Ensure all inquiries are responded to in a timely fashion.
    - Remain welcoming and offer a safe environment for all members to express themselves, and welcome offers to volunteer and support the association in a variety of ways.

Key Achievements in 2021

A Year in Numbers

The following lists show in concrete ways, the impact all activities and programs led and supported by the EEA, have had on the epilepsy community, in Northern Alberta, and beyond.

• SCHOLARHIPS	4 scholarships awarded in 2021
• EDUCATION WEBINARS (WITH EAC)	7 webinars held in 2021
• EPILEPSY INFORMATION BOOKLETS	7,000 printed copies shipped and 700 downloads/month
• FOCS SESSION HELD	7 sessions held in 2021
• HOBSCOTCH CLIENTS SERVED	3 clients support for full program
• KOB SHOWS PERFORMED	12 shows performed in 2021
• EPILEPSY 101 ON-DEMAND WEBINARS	5 sessions offered in 2021
• MEMBERSHIP GROWTH	24% growth - 236 active members in 2021 (individuals and families)
• DIGITAL RESOURCES - TABLETS	50 new tablets acquired - 10 lent out to members in 2021
• WEBSITE VISITORS	3,000 page views /month on average
• NEW VIDEO ASSETS ON VIMEO	80 new video resources added to VIMEO
• NEW CORE VOLUNTEERS	2 new core volunteers joined the EEA
• PUBLIC MEDIA (RADIO AND TV)	1 CBC Radio interview and 1 CTV News Interview
• BOARD AND COMMITTEE MEETINGS	25 meetings held in 2021
• NEWSLETTERS PUBLISHED	6 newsletter issues published online and in print
• SOCIAL MEDIA PRESENCE	150% growth in followings amongst social media channels

BOARD OF DIRECTORS 2021

The EEA hosts a team of up to 14 Directors, including the executive Director of the association, a non-voting member of the team. Directors are elected for up to two consecutive three-year terms from members in good standing. Directors confirm the executive team of the Board, following the Annual General Meeting, on the last Thursday of every February. Directors meet the second Tuesday of every month, and hold a retreat at the end of September. Directors hold leadership positions through the Committees of the Board.

Colleen Matvichuck, President
Tammy Tkachuk, Vice-President
Katrina Breau, Secretary
Terry Mahon, Treasurer
Valeria Palladino, Executive Director
Noella Desaulniers, Director
Tammy Humphreys, Director
Dr. Kassiri, Director
Anna Pagliuso, Director
Shandea Patras, Director
Dr. E. Starreveld, Director
Kristine Zielinski, Director

STAFF AND VOLUNTEERS

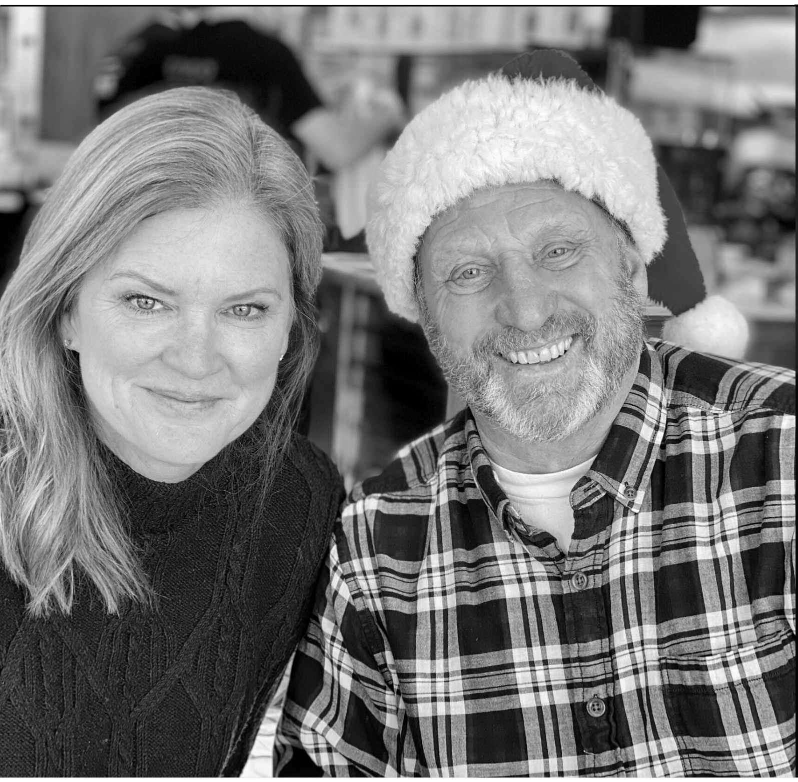
The EEA operates an office with one full-time staff and one part-time staff. Valeria Palladino is the Executive Director, and Sharon Otto is the Program Manager. 85% of all activities and programs are directly impacted and supported by faithful, committed and enthusiastic volunteers, who truly shine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

In 2021 the EEA received over 1,800 worth of qualified volunteer work, the equivalent of over $40,000 in value, or a full-time paid staff. Our Board of Directors are all volunteers.

Our core volunteers for 2021 are listed below:

- CAM REID
- JULIA GALLANT
- LAURA JURASEK
- TODD MCARTER
- JOY BERNAL
- ANGIE CHEN
- TANJA PENINA
- ANGELA WILM
- VIRGINIA NASON
- CHERYL GILLIE
- ROB BEGHIN

We thank all who donate their time and skills so generously to us!



Sponsors and Donors

A substantial portion of our annual income is derived from donations and sponsorship of our champions in the community, and across Canada. While there would not be enough space in our small document to personally thank everyone who donates to us, on a regular basis, we do wish to acknowledge some major sponsors and funders who provide significant contributions to ur major programs and our annual operations:

- UCB Canada
- The Epilepsy Trust
- The Telus Community Foundation
- Wawanesa Insurance
- Blind Enthusiasm (Biera Box Fundraising)
- Union 52 Benevolent Society
- Individual donors
- In-memoriam Donors
- EISAI
- SUNRISE BAKERY
- Alberta Blue Cross

Major funding channels for us remain:

- PayPal
- CandaHelps
- SkiptheDepot
- SimplyK
- Donate a Car CANADA
- CyberGrants
- United Way
- Cheque and cash donations

We thank everyone for your continued support in our programs.

EDMONTON EPILEPSY ASSOCIATION

2021 SCHOLARSHIP RECIPIENTS

SADIE KLINE
CONTINUING EDUCATION SCHOLARSHIP

KELSEY ELENIAK
CONTINUING EDUCATION SCHOLARSHIP

Congratulations!

JOVIAH BUTCHIKE
BRITTANY HUGHES MEMORIAL LIFE ENHANCEMENT SCHOLARSHIP FOR YOUTH

OWEN WILKIE
GARRY HANNIGAN MEMORIAL LIFE ENHANCEMENT FOR YOUTH SCHOLARSHIP

EEA Ask Me Why

www.edmontonepilepsy.org

How to Reach Us

Our office, located at 11215 Groat Road, Edmonton Alberta, operates on weekdays, between 8:30 a.m. and 4;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

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