The Center for Epilepsy and Seizure Education in British Columbia



2022 Annual General Meeting

Date: June 28, 2022 Time: 4:15 pm

Location: 102-32868 Ventura Ave, Abbotsford, BC V2S 6J3

A cure may be found tomorrow but someone needs your help today

"We would like to acknowledge the traditional ancestral unceded shared territory of the Sumas First Nation and Matsqui First Nation. These two First Nations are part of the Stó:lō Nation. The Stó:lō people have lived in the Fraser Valley for 10,000 years. It is for this reason that we acknowledge the traditional territory in which we reside."

Board of Directors

Our Mission Statement:

We are dedicated to creating and providing support, information and education to families and individuals who live with epilepsy, their support staff, educational personnel, friends, coworkers, health care providers and anyone else affected by epilepsy.



President & Chair – George (Ted) Downey



Treasurer - Malvinder (Fred) Grewal



Secretary - Judith (Judy) Ross



Director - Florence (Flo) Dohms



Director - Elyssa Lockhart



Director - Jagjeet (Jag) Sandhu



Director - Dr. Lakhbir Jassal

2022 Annual General Meeting Agenda

- 1. Call to Order
- 2. Attendance
- 3. Introduction
- 4. Adoption of Agenda
- 5. 2021 AGM Minutes
- 6. President Report
- 7. Treasurer Report
- 8. Executive Director Report
- 9. Client Support Report
- 10. Education & Awareness Report
- 11. Election of Directors
- 12. Appointment of Accountant 2022
- 13. New Business: No new business
- 14. 2021 Unaudited Financials

The Center for Epilepsy and Seizure Education in BC

2021 Annual General Meeting Minutes

June 16, 2021

Location: 4932 Mt. Lehman Road, Abbotsford BC, V4X 1Y3

Call to Order: 5:16pm.

Attendance:

Board Members: President: George (Ted) Downey, Chair: Dayan Muthayan, Treasurer: Florence (Flo) Dohms, Secretary: Judith (Judy) Ross, and Malvinder (Fred) Grewal.

<u>Staff:</u> Executive Director: Laura Cherrille, Client Support Coordinator: Rupinder Bhatti, Education & Awareness Coordinator: Vineetha Nakka, and Bookkeeper & Administration Coordinator: Kayleen O'Brien.

<u>Members:</u> Jag Sandhu, Don Ross, Janis Downey, Johnny McFaul, Elyssa Lockhart, Supriya Bhargavan, Odayoth Bhargavan, Garry Dohms.

Introductions: Ted Downey welcomes everyone

Adoption of Agenda:

Fred Grewal moved to adopt the agenda, seconded by Flo Dohms. Motion carried.

Approval of 2020 AGM Minutes:

Supriya Bhargavan moved to adopt the 2020 AGM minutes, seconded by John McFaul. Motion carried.

President's Report: Ted Downey thanks members, clients and families involved in the center and noted that we are doing extremely well despite the COVID pandemic. Programs have surpassed expectations. Introduced and thanked the staff and board members. Thanked and recognized support from BC gaming and other donors.

Executive Director's Report: Thank you to staff. Reflected on the challenging year with her new role as Executive Director and the COVID pandemic. All services had to be delivered virtually, including fundraising. States that creative, flexible, and passionate qualities of our staff working together is what have brought us through this difficult time.

Client Support Coordinator Report: Rupinder Bhatti described the year of challenge and the innovation it took to overcome these challenges. She gave a summary of the year's highlights, including one on one virtual client support and successful mandala painting sessions.

Education & Awareness Coordinator Report: Vineetha Nakka, who is new to the center, says it has been a year of learning and adjusting to the new role. The goal of education and awareness is to minimize stigma and increase the understanding of epilepsy. The presentations she has done this last year have been highly rated and valued by audiences.

Director announcement: Ted Downey announced that Dayan Muthayan is stepping down from the board. Having made a great contribution to the center. Certificate of appreciation for his contribution was given and Dayan accepted with thanks. Ted Downey also introduced 2 new prospective directors Elyssa Lockhart and Jag Sandhu.

Election of Directors:

Board member Judy Ross nominated Elyssa Lockhart and Jag Sandhu, asked if there are any other nominations from the floor. Judy Ross moved to accept the current slate, seconded by Garry Dohms. Motion carried.

Board of Directors

President & Chair: George (Ted) Downey

Secretary: Judith (Judy) Ross

Treasurer: Malvinder (Fred) Grewal

Director: Elyssa Lockhart

Director: Florence (Flo) Dohms

Director: Jag Sandhu

Financial Statements:

Flo Dohms moved to adopt the unaudited financial statements as prepared by Michael Forcier, CGA and seconded by Dayan Muthayan. Motion carried.

Appointment of Accountant for 2021:

Supriya Bhargavan moved to accept Michael Forcier, CGA, Inc. as our accountant for 2021, seconded by Don Ross. Motion carried.

Old Business: No old business.

New Business: John McFaul moved to adopt the vote to increase the membership fee from \$2.00 to \$5.00, seconded by Garry Dohms. Motion carried.

Appointment of legal services for 2021:

Fred Grewal moved to accept Kuhn LLP for our 2021 legal services, seconded by Supruya Bhargavan. Motion carried.

Adjourned: 6:00pm. Dayan Muthayan moved to adjourn the meeting, seconded by Don Ross. Motion carried.

President

Dear Members:

Thanks to all of you for attending tonight, your support through this last year and continued trust into the future. These past years have been a challenge to say the least, Covid-19 and it's variants have challenged us at every turn. Through all of these our office staff have maintained an exceptional level of professionalism and fortitude to carry out the mandate set by the board of directors years ago to support those living with epilepsy, their families and friends who are our constant immediate support system. Our Executive Director, Laura Cherrille, Client Support Coordinator, Rupinder Bhatti, Education & Awareness Coordinator, Vineetha (Vinee) Nakka and our front office Bookkeeper & Administrative Coordinator, Kayleen O'Brien have done an outstanding job through this and everyday, to ensure those struggling with epilepsy are given the latest of information and type of information, support they are needing. I would like to express my appreciation to our Board of Directors, Secretary, Judy Ross, Treasurer, Fred Grewal, Director, Elyssa Lockhart, Director Dr. Lakhbir Jassal, Director, Jag Sandhu and to our out going, longest serving, Past Treasurer and a great thermometer in working with and all those challenges having a son with epilepsy, Flo Dohms. We thank you for the many years of service and dedication to the Board of Directors, the staff and those with epilepsy. In closing, we would like to recognize the financial support from B.C. Gaming, the many donors, who without all of you, our society would not operate. Thank you for attending, as continuing to support to those is important to us and everyone of our clients.

Sincerely,

George E (Ted) Downey

President



Treasurer

A review of the Statement of Operations which is a summary of the entire year shows that in 2021 there was an increase in gaming revenue from 2020. Overall receipts increased in 2021 by \$35,000 from 2020 with this largely resulting receipt of government programs related to Covid-19. We saw an increase in our expenses that is in line with the increase in revenue. There was also much needed upgrade to computer equipment. Disbursements and expenditures increases in line with receipts with the resulting in a small deficiency of \$735 for 2021.

The Statement of Financial Position (aka Balance Sheet) shows a snapshot of one date being December 31, 2021. The 2021 balance sheet is very much comparable to the 2020 balance sheet with overall decrease in assets from \$237,000 to \$221,000. This is made up of the various cash accounts which represent the deferred revenue from BC Gaming and Jaymie-Lynn Robertson Fund.



Executive Director

Welcome everyone, and it is with great pride that we present our 2021 annual report, and it is hard to believe that it has been a year since our last AGM. I want to take this time and thank the staff (Rupinder, Vinee and Kayleen), all our members, board of directors and volunteers for your passion, hard work and support for the center.

As Covid 19 continued to affect everyone's lives in 2021, we continued to offer most of our presentations and group sessions online. Individual client support was offered via telephone, email and zoom. We were able to put together quite a line-up of professional presentations on topics such as the ketogenic diet, CBD Oil, mindful meditation, yoga in the park and VNS devices, to name a few.

Since the ability to host in person fundraising events was still not an option, we had to find other creative ways to raise funds. Many grants were written, and we were thrilled to receive funding from BC Community Gaming, Kalamalka (Vernon) Rotary, First West Foundation, Langley Rotary and Mission Rotary. We also received a one-time funding grant of \$10,000.00 from Community Gaming to upgrade our IT and software systems which was so helpful with so many programs, meetings and support done online.

Many individuals participated in our annual Purple Day walk virtually by walking in their own neighbour-hoods in support of this important day. We had thirty-one monuments lit up purple across the province for epilepsy awareness. We had the support of Global BC to spread the word through media.

2021 was significant in terms of educational presentations. Several rotary clubs across the province received a presentation via zoom. As well, other community organizations and various groups received presentations tailored to their needs.

I conducted an internal review of the personnel and office policies and procedures. In turn, this created a need for a closer look at policies. Staff policies and procedures manual was reviewed, revised and updated. A new board governance manual was put together, approved and implemented also. Marketing materials and pamphlets were also reviewed and revised with a fresh new look. The website was reviewed on a quarterly basis to ensure we had the most up-to-date and relevant information available for the public to access.

In summary, the pandemic challenges that were presented continued to teach us that being creative, flexible, and passionate about what we do and the people we serve, enabled us to keep our programs running

efficiently. It also continued to teach us to appreciate each other and to value the ability to work together as a team during these challenging times.

With Gratitude, Laura Cherrille



Executive Director - Laura Cherrille

Client Support

Reflecting closely over the last year, I'm proud of how successful our team has been in creating new connections and building relationships with clients and supporters. We have considerably expanded our client support program over the previous year, allowing us to focus on attracting new clients from all around British Columbia. Individuals who contact us range from the recently diagnosed and overwhelmed to those who have had epilepsy for a long time but have not had access to critical support services. We also started releasing biweekly "Did You Know Facts" on our social media platforms to keep our clients and supporters engaged.



Client Support Coordinator - Rupinder Bhatti

One-on-One Support

One-on-one support is offered in person, phone, e-mail, and Zoom. Due to Covid-19, all appointments were held virtually and over the phone.

Over the last year, we provided individual and family support, advocacy, supported clients who faced work-place harassment, discrimination, and students having difficulties within the school setting. We made referrals to other community agencies that addressed specific needs for individuals like dental, medical, and housing support. We also helped clients prepare for doctor's visits and connect them with neurologists and doctors in their community. In addition, we assisted our clients with application forms and searching out benefits tailored to their individual needs.



Mandala Art Program

Individuals with epilepsy face many challenges including coping with the unpredictability of seizures, possible side effects of medications, perception or fear of stigma associated with their medical condition, and social barriers. Art groups provide an opportunity for individuals living with epilepsy to creatively explore some of their experiences — including their resources and strengths — in a safe and supportive environment. In 2021, we proceeded to expand our program by improving the quality of each session and adding new topics to keep our clients interested.

Client Support



Mindful Meditation with Wendy Weymann

To give our clients with the most up-to-date information on treatments and complimentary therapies, we attempt to focus on emerging studies and research. Despite continuous advances in treatment, more than 30% of persons with epilepsy do not achieve seizure freedom with medication. The increasing prevalence of drug-resistant epilepsy motivates researchers to seek out novel treatments. Despite the lack of a comprehensive study design, early investigations of mindfulness-based epilepsy therapy revealed encouraging effects in reducing seizure frequency.

Yoga in the Park

Incorporating yoga into your routine can help enhance your health, increase strength and flexibility, and reduce symptoms of stress, depression, and anxiety. Yoga is increasingly becoming a focal point of therapy and research in treating epileptic seizure disorders. It offers an ancient, yet modern approach to treating seizures. As therapy, the physical discipline of yoga seeks to re-establish a balance between those aspects of a person's health that cause seizures. Research found that meditation improved the brain wave activity of people with seizure disorders leading to a reduction in seizures. It is found that patients who learned to control their breathing had an improvement in their seizure frequency.

YOGA IN THE PARK
ONLINE
WITH WENDY WEYMANN
TO PARTICIPATE VISIT:
WWW.FACEBOOK.COM/CENTERFOREPILEPSY
FOR A VIRTUAL YOGA SESSION

EPILEPSY & SETTURE
EDUCATION
IN INTERCOMMAR

Warmly, Rupinder

Education & Awareness



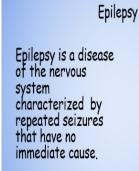
Education and Awareness Coordinator · Vineetha Nakka

Navigating the challenges of 2020 has prepared us to have a more productive year through 2021. Although we were still limited due to COVID restrictions, we were able to make great strides towards our goal of educating the public on epilepsy and seizures to minimize the stigma and misinformation, along with promoting better understanding. We started the year strong with our presentations and have reached about 550 individuals throughout the province.

Mini-Presentations

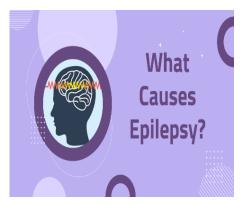
The slower months of 2021 gave me the opportunity to work on creating 6 mini videos that were posted on our social

media platforms. The topics were: basic information on epilepsy, seizure first aid, causes of epilepsy, what to expect when being diagnosed with epilepsy, tips on staying seizure safe, and the various treatment options available. These videos allowed us to reach even more individuals throughout the province. These videos have received over 950 views across the center's YouTube, Facebook and Instagram pages.















Education & Awareness

With about a third of those with epilepsy having seizures that are difficult to control with medications alone, information on complementary therapies was essential to our resources. Throughout 2021, we received virtual presentations from various professionals to provide up-to-date information on their respective specialties.

Ketogenic Diet

Mainstream ideas of the ketogenic diet created the potential for misinformation when it comes to the medical uses that the diet is intended for. On March 3rd, 2021, we hosted Alex Printis (a registered dietician) to educate on the use of the ketogenic diet for treating epilepsy. She shared the exact nature of the ketogenic diet, along with its history, variations of the diet, side effects and additional resources. The session received 137 views.



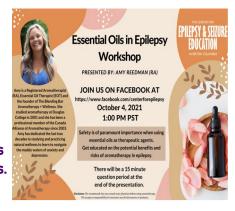


Medical Cannabis

We had the opportunity to host neurologists Dr. Abhishek Purohit and Dr. Evan Cole Lewis on April 9th, 2021 for a patient information session on the use of medical cannabis. Dr. Purohit and Dr. Lewis explored the various components of cannabis used for many purposes, its function, history, legalization in Canada and the products available in Canada. The video received 138 views.

Essential Oils and Epilepsy

The therapeutic effects of essential oils can be beneficial for many, but certain scents and combinations can trigger seizures for those with epilepsy. On October 7th, 2021, Amy Reedman did a presentation on exploring the use of essential oils and safety concerns associated with certain oils. Amy highlighted how to safely use oils as well as certain oils that should be avoided if you have epilepsy. The video received 130 views.





Vagus Nerve Stimulation

On November 2, 2021 we posted a video on VNS, and it received 44 views over the period of 3 days that it was posted on social media. It can be difficult to live a regular life if you have drug-resistant epilepsy. VNS Therapy attempts to prevent seizures from occurring and to stop them once they happen. A VNS device may be able to give someone hope, peace of mind, and the ability to live a regular life.

Warmly,

Vineetha (Vinee) Nakka

Purple Day

awareness efforts.

Purple Day, March 26, is the National Day for epilepsy awareness. It began with an 9 year old girl, Cassidy Megan, with epilepsy from Nova Scotia who felt isolated and alone because she couldn't talk to anyone about epilepsy because none of her friends knew what it was. Cassidy started Purple Day to teach her friends that she was as capable as they were. She also wanted other children with epilepsy to know that they did not need to feel alone. The Purple Day movement, which began in 2008 is now celebrated on every continent and over 100 counties around the world. Purple Day is one of our major

In 2021, we celebrated Purple Day virtually due to COVID-19. Even virtually we had a great turnout of 75 participants taking part in their own communities. With donations, registrations and merchandise sales we raised close to \$900.00 with no expenses.

We appreciate everyone who participated, even though we couldn't be together.

Without being able to meet in person, we concentrated on trying to get as many landmarks lit **purple** as possible to spread the word about Purple Day. We had 33 BC landmarks light up, 14 of those made a post about Purple Day, 9 of which tagged us on their online platforms and Mayor Henry Braun of Abbotsford made a personal post about Cassidy Megan and Purple Day.

We are looking forward to the next Purple Day Event, hoping for it to be in person!



Fundraising



We had a 3rd Party fundraiser put on by Dr. Lakhbir Jassal and Alex Siemens. Alex ran a WHOPPING 80KM in 7.5 hours! 2 of our staff members were there to see Alex cross the finish line after this incredible feat, along with Alex's friends and family who were along side her for the journey. Together Dr. Jassal and Alex brought in over \$2000.00 in donations! We cannot thank them enough for supporting The Center.

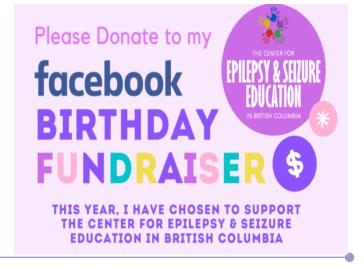


In 2021 we continued to sell \$3820.00 in 50/50 tickets.

With \$1910.00 going to The Center. Thank you to all the board and staff members who took part in selling these tickets.

One staff member chose to do a birthday fundraiser for The Center raising \$145.00.

If you would like to support The Center by doing a birthday fundraiser we have the link already to go through Facebook.



Program & Volunteer Statistics

Program	Statistics
Client Support	 Client Support 973 hours in client support hours for 122 clients located in 36 communities within BC. (This included in person, telephone, and email support). Mandala Rock Painting Art Livestream 586 online viewers, 52 of which ordered paint kits. Medical Cannabis in Epilepsy Presentation by Dr. Abhishek & Dr. Evan Cole Lewis 80 online viewers. Ketogenic Diet Presentations by Alex Printis 63 online viewers. Mindful Meditation Workshop by Wendy Weymann 57 online viewers. Yoga in the Park with Wendy Weymann 61 online viewers.
Education & Awareness	 Presentations 24 presentations with 550 participants provincially in 17 communities. Purple Day Event Our annual walk was done virtually but had 26 registrants. Resource Packages 28 Resource packages sent out to various towns in Northern BC, the Okanagan, Vancouver Island and in the greater Vancouver area.
Social Media	 Facebook—1260 Followers Instagram—665 Followers LinkedIn—511 Followers Twitter—2315 Followers YouTube—660 Subscribers
Volunteer	 Administration ⇒ 8 volunteers for total of 289.25 hours, In kind value of \$5785.00 Education & Awareness ⇒ 4 volunteers for total of 19 hours, In kind value of \$380.00 Events ⇒ 5 volunteers for total of 79.5 hours, In kind value of \$1590.00 IT Tech ⇒ 1 volunteer total of 8 hours of discounted rate, In kind value of \$160.00 Repairs and Maintenance ⇒ 1 volunteer total of 3 hours, In kind value of \$60.00 Total Volunteers: 19 positions providing 398.75 hours with an in-kind value of \$7975.00

Jaymie-Lynn Robertson Memorial Fund

A letter from her parents:

When our ray of sunshine, Jaymie-Lynn was diagnosed with epilepsy it sure was a shock for both her and our family. The diagnosis in September 2009 came about after a tonic clonic seizure while she was living in Brooks, Alberta. We had no idea at that time the journey we were all about to begin.

Jaymie-Lynn our most amazing child who loved swimming, life guarding, dancing, music, socializing, and movies. An avid animal lover who pursued this love by studying the veterinary assistant program. Jaymie-Lynn our Miss Hollywood because she loved to have her photo taken.



Jaymie-Lynn never let epilepsy slow her down or stop her from living life on her terms. Sure, there were challenges from loss of freedom, discrimination at work and the ongoing doctor's appointments, but there was still swimming, snowboarding and a life to be lived.

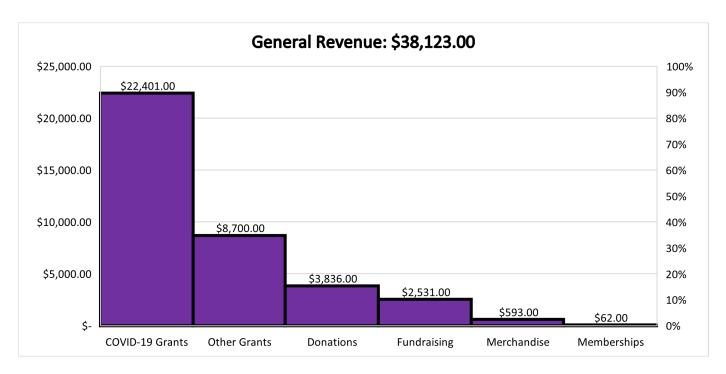
We had not heard of Sudden Unexpected Death in Epilepsy (SUDEP) prior to Jaymie-Lynn's death, but Jaymie-Lynn passed away because of SUDEP on October 5, 2011 at the age of 23. This has been devastat-

Thank you to Chad Robertson and Belinda McIsaac for their continued support of our programs in loving memory of their daughter, Jaymie-Lynn Robertson. Unfortunately due to COVID-19 we were unable to send kids to Zajac Ranch this year but we were able to provide prizes to kids in a colouring contest and provide 6 different professional presentations ranging from Ketogenic & Medical Cannabis to Aromatherapy and Mindfulness Meditation.

Special thanks to The Boiler Inspection and Insurance Company for their continued philanthropy to help us support, raise awareness for and educate families affected by epilepsy in honor of Jaymie-Lynn.



Donors & Grants — With Thanks



Gaming Grant—\$140,000.00 & \$10,000 IT Upgrades

"We acknowledge the financial support of the Province of British Columbia."

COVID-19 Grants \$22,401.00



Other Grants \$8,700.00

















Proposed Slate of Directors

George (Ted) Downey

Malvinder (Fred) Grewal

Judith (Judy) Ross

Dr. Lakhbir Jassal

Elyssa Lockhart

Jagjeet (Jag) Sandhu



Proposed Executive

President & Chair - George (Ted) Downey

Treasurer - Malvinder (Fred) Grewal

Secretary - Judith (Judy) Ross

