

Canadian League Against Epilepsy (CLAE) 2021-2022 Report

CHAPTER OFFICERS

Mary Connolly, President
Paolo Federico, Past President
Danielle Andrade, President Elect
Lysa Boisse Lomax, Treasurer
Esther Bui, Education Director
Lauren Strasser, Junior Member Representative



Officer Election Date

Even years: President-Elect, Treasurer and Junior Member Representative

Odd years: Secretary and Director of Education.

ACTIVITIES AND ACCOMPLISHMENTS

- The 2021 CLAE Scientific meeting was held virtually 24 – 26 September 2021, with over 220 registered. The topics included: Epilepsy is a Global Health Priority, The Past and the Future of Intracranial EEG Investigations with case studies, New Models and the Quest for Novel Therapies for Epileptic Encephalopathies, Human Cerebral Organoids for the Pathophysiology and Treatment of Epileptic Encephalopathies, Gene Editing in Rodent Models of Infantile Spasms: Progress and Opportunities, Modelling and Treating KCNQ2 DEE: Pitfalls and Progress, Molecular and Network Mechanisms of CACNA1A-associated Epileptic Encephalopathies, and something to GRIN about: The NMDA Receptor as Both a Site of Pathogenesis and a Therapeutic Target in Epileptic Encephalopathy.
- The 2022 CLAE Scientific meeting and CERI Meeting were held in person in Kelowna, B.C., and were a huge success with 163 registered. This year CLAE received the largest number of abstract submissions. The Gala Dinner was held off site at the 50th Parallel Winery and was well received by registrants. Topics from the 2022 ASM included: The Intracranial Investigation Was Key to Surgical Success, Surgical Results after Intracranial EEG: Not Great, When Are They Good, When Are They Bad? Human Cerebral Organoids for the Pathophysiology and Treatment of Epileptic Encephalopathies, Gene Editing in Rodent Models of Infantile Spasms: Progress and Opportunities, Neuromodulation in Epilepsy, Vagus Nerve Stimulation in Epilepsy, and more.
- The 2023 CLAE Scientific meeting will be held in-person in Charlottetown, Prince Edward Island, from 13 – 15 October 2023.

CHALLENGES FACED IN 2021 AND 2022

Due to COVID-19, the 2021 Annual Scientific Meeting was virtual. During the 2022 Scientific Meeting last minute changes were required due to members not being able to attend due to COVID-19.

FUTURE PLANS FOR 2023

- Establish a Canadian Task Force to help support local health initiatives in epilepsy across Northern Canadian Provinces and within Indigenous Peoples.
- CLAE is in the process of establishing a Jean Gotman and Marilyn Jones Gotman Lectureship.
- CLAE will be working with the Camfield's to host a Camfield Fundraiser Dinner with Elizabeth Donner chairing the Planning Committee.

RESEARCH AND PUBLISHED ARTICLES

- CLAE Newsletter distributed on a quarterly basis which now includes a French version.
- The Communications Committee has been focusing on rebranding the newsletters, the website and providing a social media strategy for CLAE.
- The French Language Committee is working closely with the Communications Committee to provide publications in both French and English.

MEETINGS

- 2021 Annual Scientific Meeting was virtual.
- 2022 Annual Scientific Meeting was in Kelowna, B.C.

AWARDS

- One Canadian Epilepsy Fellow was awarded the 2021 UCB-CLAE fellowship.
- Two Canadian Epilepsy Fellows were selected in 2022 to attend the 2023 J. Kiffin Penry MiniFellowship Program.
- We awarded our usual trainee/allied health awards for best publications (fellow award, grad student or medical student award, resident award and allied health student award).

FUNDRAISING

- CLAE Fundraising dinner in honor of Jean Gotman and Marilyn Jones-Gotman was held on 27 May 2022 with 107 in attendance and was a huge success with a profit of \$29,420.75.
- The 2022 Fun Run held at the CLAE Scientific Meeting raised \$3,485.
- Additional fundraising efforts included selling logo merchandise such as water bottles, lanyards and pens.

ADVOCACY

- Supporting Health Canada to understand the severity of certain drug shortages; thus, deciding with good and reliable information to upgrade tier status to facilitate access to those medications by our patients. This was particularly important for Vigabatrin sachet and Zonisamide tablets this year.

- Keeping our CLAE members up to date on current shortages that could have an impact on their practice and advising on how to overcome the challenges (i.e., Vigabatrin tablets use instead of sachet).
- Preparing a systematic review on how to handle drug shortage and use Anti-Seizure Medications to temporarily cover the lack of primary treatment. This is a work in progress which may take more than 12 months to finish as we are screening more than 7,000 articles.
- Collaborating and educating some pharmaceuticals on what medications may be helpful to our Canadian patients when introduced in our market, i.e., Cenobamate.
- The Women's Issues in Epilepsy Committee completed the data collection of its national survey on current practices of healthcare providers caring for women with Epilepsy and will now work on a pan Canadian Publication.
- The Canadian Epilepsy Teaching Network (CTEN) which is available for all interested physicians in Canada is now a successful series of lectures from internationally recognized experts.
- The new Canada-Wide e-Journal Club for Epilepsy Fellows is co-lead with Dr. Esther Bui and Paula Marquez. This successful program is hoping to expand to include out of Canada and contribute to education not just nationally, but internationally.



The CLAE annual Fun Run at the 2022 Scientific Meeting in Kelowna



Presentation at the 2022 Scientific Meeting in Kelowna

Awards handed out at the 2022 Scientific Meeting in Kelowna



Report submitted by Tammy Malcolm