



Canadian League Against Epilepsy

MESSAGE FROM THE PRESIDENT



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Dear colleagues,

It's my privilege and honor to serve as president of the CLAE for the next two years. I would like to thank Jorge Burneo for all his good work over the last two years, for staying as past-president and for his leadership role on the new Fellowship Training Committee.

Brief come back on the CLAE Annual Meeting

Thank you to those who assisted in making this a great meeting. There were 172 attendees this year! A warm thank you for those who organized the conference: Mark Keezer (Chair) and everybody on the Education Committee (Neda Bernasconi, Paolo Federico, Mary Pat McAndrews, Gillian Reid-McDonald, Tiffany Townsend, Walter Hader, Linda Huh, David Dufresne and Ailyn Reid). And, a big thank you to the sponsors who joined the meeting. We had a total of 10 sponsors/exhibitors including: UCB, Eisai, LivaNova, Sunovion, GeneDx, Dynacare, Surgi-One, the Canadian Epilepsy Alliance, Clinique D'Épilepsie Neuro Rive-Sud, and a Supporter, the Savoy Foundation. Finally, thank you for those who participated in the Fun Run! We had 38 runners and walkers and received \$2,653.00 in donations!

2018 Awards

A few special notes for our awards this year:

Winners of the 2018 CLAE Junior Investigator Award: Drs. Colin Josephson & Mark Keezer.

CLAE was pleased to award two epilepsy fellows the opportunity to attend the 2019 J. Kiffin Penry Mini Fellowship Program. This is a prestigious four-day course that reviews the investigation, diagnosis, and management of epilepsy. For more than 30 years, this program has remained the most widely recognized post-graduate course in epilepsy in the USA. This course has previously not been available to Canadian epilepsy fellows.

Congratulations to Dr. Natarie Liu from the University of Calgary and Dr. Véronique Martel from l'Université de Montréal (CHUM) who will be attending the course this winter at Wake Forest University in Winston-Salem, North Carolina, USA. We are all very proud and excited!

As well, the CLAE Board has approved the development of 2 new travel awards, 1 for basic science and 1 for clinical research that will be available for the 2019 Scientific Meeting. Stay tuned for more details!

2019 CLAE ASM

CLAE is pleased to announce that the 2019 Annual Scientific Meeting will be held at the Fort Garry Hotel, Spa and Conference Centre, Winnipeg, Manitoba. More details to come!

Board of Directors

A sincere thank you to Drs. David Steven and Kristin Ikeda, for their time and service on the Board of Directors. I would also like to welcome Drs. Paolo Federico, Jonathan Lau and Paula Brna onto the Board. We are looking forward to having everyone on the team.

I am also very pleased to announce that the next North American Regional Meeting will be held in Canada in 2020. A meeting has been planned in New Orleans at AES to begin organizing the event. The CLAE Board members will also hold a retreat during the AES 2018 conference to develop improvements for our organization.

Lastly, I am thrilled to announce that CLAE has nominated Drs. Peter and Carol Camfield for the 2019 Ambassador for Epilepsy Award.

Wishing you and your family a happy upcoming holiday season,

Dr. Dang Nguyen



A unique event: On September 14, Epilepsy Ottawa, The Ottawa Hospital, CHEO, and Eisai teamed up for Ottawa's first program specifically for youth with epilepsy. Young people and their families were invited to Andrew Haydon Park to paint murals from the Foundation of Hospital Art, based in Atlanta.

Participants had an opportunity to mingle with other families living with epilepsy. The event helped youth who are transitioning from CHEO's pediatric epilepsy program to The Ottawa Hospital's adult program by introducing them to their new patient care teams and their local community support agency in a positive, non-medical environment. Parents, siblings, and youth with epilepsy all actively participated in creating something beautiful together. It will have a lasting impact when it resides on the walls of TOH's Neuroscience Clinic waiting room. As youth become more independent, they will see their work integrated into their healthcare environment.

The activity facilitated a sense of equality between patients and health care professionals and established a trusting relationship from the start. The group will reunite for an unveiling of the work at The Ottawa Hospital. When told about the unveiling, the participants' sense of pride was palpable.



RISING STAR



Dr. Gavin Winston is an Adult Neurologist and Epileptologist who joined the Department of Medicine, Division of Neurology at Queen's University in Kingston, Ontario in November 2018. He undertook his undergraduate training in pharmacology at the University of Cambridge, his medical degree at University of Oxford and his residency at the National Hospital for Neurology and Neurosurgery, Queen Square, London, UK where he first became interested in epilepsy.

Dr. Winston is passionate about research and undertook a 4-year Clinical Research Training Fellowship funded by the Medical Research Council and supervised by Professor John Duncan leading to a PhD from the Department of Clinical and Experimental Epilepsy, UCL Institute of Neurology, Queen Square, London. He established a collaboration with the UCL Centre for Medical Image Computing to develop and translate novel imaging techniques into clinical use for patients with refractory focal epilepsy undergoing surgery.

He implemented real-time image-guided surgery in an intraoperative MRI suite to reduce the risk of visual field deficits following ATR and made available a free online automated hippocampal segmentation tool. For this work, he received the Sir Peter Mansfield Prize for innovative technical developments in the field of magnetic resonance in medicine and biology from the British Chapter of the ISMRM in 2011 and it featured in the BBC television programme "How Science Changed Our World" describing the top ten scientific breakthroughs in the past 50 years.

Following his residency, Dr. Winston was until recently working as an MRC Clinician Scientist (Assistant Professor) and Consultant Neurologist at Queen Square and the Chalfont Centre for Epilepsy, UK and his clinical interest is refractory focal epilepsy amenable to surgical intervention. He spent a year as Visiting Professor in the Neuroimaging of Epilepsy Laboratory at the MNI with Professor Andrea Bernasconi before relocating permanently to Canada.

His research aims to improve the detection of the underlying abnormality in patients with normal conventional MRI scans using novel imaging contrasts and machine learning techniques. He has also been working with colleagues to develop image-guidance to improve the safety of utility of SEEG electrode placement. This year, he is the recipient of an AES Young Investigators Award and an ILAE Europe Leadership Development Scholarship.

Dr. Winston was a member of UCL Academic Board from 2010 until 2016, acts as a peer-reviewer for numerous international journals and has been on the editorial board of Quantitative Imaging in Medicine and Surgery since its inception. He has chaired sessions at international conferences, given invited lectures internationally and also spoken at events aimed at the general public. He also enjoys teaching including lecturing on the Epilepsy Neuroimaging courses run by both the ILAE UK and the MNI and was this year elected an Associate Fellow of the UK Higher Education Academy.

He looks forward to contributing to the CLAE and treatment of epilepsy in Canada.

A Unique Educational Opportunity for Children with Epilepsy

A collaboration between the Brain and Mental Health Program at The Hospital for Sick Children and the Ontario Ministry of Education provides a unique educational opportunity – a classroom dedicated to the needs of children with epilepsy. The classroom is a Section 23 program of the Ministry, a designation for programs for students whose medical, behavioural, or emotional needs are not being met through the regular school program.

Children attending the Epilepsy Classroom are initially screened with a comprehensive cognitive, psychological and psycho-social assessment. Once in the program, they are supported by a multi-disciplinary team, consisting of a neuropsychologist, social worker, developmental pediatrician, neurologist, nurse practitioner and psychiatrist, in addition to the core education staff of a teacher and two classroom assistants. This team collaborates with the student, the student's family, and the student's home school. To assist in the transition of children back to their home schools, and to provide information for teachers about the educational needs of children with epilepsy, an Individual Education Plan is developed for each student, and a case conference is held at the end of the year with the classroom team, parents, and school representatives.

The Epilepsy Classroom offers a dynamic and adaptive style of instruction that provides flexibility for each student's learning needs, and when necessary, instruction is adapted to deal with the challenges associated with seizures. The primary focus of the classroom is on remediating literacy and mathematics and on enhancing psychosocial well-being, as well as offering the core Ontario

curriculum of the standard subjects. There is time for art, music, learning-to-learn strategies, exposure to computers and training with assistive technology, field trips and physical activity. The classroom is equipped with state-of-the-art technology, including touch-screen computers, tablets, and a white board. Some of the specialized programming includes: 1) the MindUp™ program which incorporates neuroscience, positive psychology, social-emotional learning, mindfulness and teaching strategies to promote self-regulation, resilience and optimism; 2) psychoeducational group work including education about seizures, and the opportunity for students to share their experiences, talk about the impact epilepsy has on their lives and learn to self-advocate around epilepsy; and, 3) Superflex™, a social skills group to help students develop further awareness of their own thinking and social behaviours and learn strategies to develop better self-regulation skills.

Dr. Elizabeth Kerr, a Neuropsychologist who is the Program Director of the Epilepsy Classroom, reported on some of the key academic and psychological changes she has witnessed in children as a result of attending the classroom. As group, significant improvements in academic skills are observed. Students often express that it is the first time that they have met other children with epilepsy and that they feel accepted. Parents express relief in having a team that understands epilepsy and also comment on their pleasure in observing the changes in their child's self-confidence.

For more information on the classroom, visit its website: <http://www.sickkids.ca/patient-family-resources/Epilepsy-Classroom/index.html> **By Mary Lou Smith**

GLOBAL HEALTH AND CANADIAN EPILEPSY- PART 2: EPILEPSY SURGERY IN PERU

In the next few newsletters this series of articles will focus on the various global health initiatives headed by Canadian epilepsy specialists across our planet.

Many epilepsy specialists in Canada are involved in projects aimed at improving the lives of patients living with epilepsy abroad. A group of epilepsy specialists recently joined forces to explore the current landscape of global health projects under Canadian leadership as well as learn from one another and share contacts and resources. The CLAE Global Health group formed last year under the leadership of Laura Jurasek, NP, MN (Edmonton, AB) and has since been hard at work collaborating on a number of topics, including how to spur interest nationally for more global epilepsy related projects.

In this issue we wanted to highlight the work realized by Jorge Burneo, MD, MSPH from Western University. Here are some thoughts he shared with us regarding his project:

Even though epilepsy surgery is a well-established treatment for medically-intractable epilepsy, some countries around the globe do not have the facilities or the personnel to perform them, and that is what was lacking in Peru. Peru is a country of more than 30 million habitants, and like most large cities, has adequate hospital infrastructure where the population have good access to neurological care. But, sub-specialization in Neurology is non-existent. Even though sporadic epilepsy surgery occurred, no dedicated epilepsy surgery programs existed until 2011.

In 2008, I applied for support to the partnering Epilepsy centers in America (PECA) program of the ILAE-North America (formerly known as the North American Commission of the ILAE) to partner with the Instituto Nacional de Ciencias Neurológicas (INCN) in Lima (Capital of Peru). With that initial financial support, The Peruvian group, at that time lead by Dr. Lizardo Mija, and I, organized a workshop on video-EEG. During that same time in Lima, we performed an assessment to identify what was needed to start an epilepsy surgery program. This led to the purchase of a video-EEG Unit for the hospital the following year. But, "man power" was lacking. All neurologists involved in the care of those with epilepsy, were general neurologists, and even though they were doing a great job, they were lacking that extra training needed to assess a patient for surgery, as well as to perform adequately interpretation of video-EEG studies. For that reason, Dr. Jose Carlos Delgado (junior neurologist from INCN) obtained support from ILAE-Latin America to do a fellowship in Epilepsy in Brazil, after spending 6 months with the team in London, and Dr. Carlos Mao Vasquez (recently graduated neurosurgeon) obtained funding to do an epilepsy surgery fellowship in Mexico City.

Upon their return from their fellowships, Dr. David Steven (who joined me in this venture and has been instrumental in its functioning) and I, started visiting the INCN every year. Initially, to do workshops on epilepsy surgery, rounds and case discussions, as well as to get the hospital and government authorities on board. Concomitantly, we started doing Skype calls and e-mail case discussions. Over the first part of 2011, we prepared 2 cases for epilepsy surgery. One case was operated in September of 2011. This case consisted of a lesionectomy, marking the beginning of the first epilepsy surgery program in Peru. Subsequently, the London team travelled

to Peru. During this trip, Dr. Vasquez performed a left anterior temporal lobectomy in a patient with medically-refractory left temporal lobe epilepsy due to hippocampal sclerosis, under the guidance of the Canadian team. The procedure was a success, and since then, they have performed more than 100 epilepsy surgery cases, mostly temporal lobectomies and lesionectomies.

The latest trip to Lima was in 2016, when the Peruvian team performed an awake craniotomy, after they received mentoring from Dr. Miguel Arango, a neuro-anesthesiologist in our center, who joined the initiative.

The Peruvian health system is a multiple-tier system, being the three most important ones: Public system (funded by the Ministry of Health), where the INCN belongs to; the social security system (ESSALUD), mostly funded by employers; and the private system.

In the ESSALUD system, by 2013, some epilepsy surgery was done, mostly on children at ESSALUD Hospital Nacional Guillermo Almenara in Lima. But, they did not have a formal epilepsy program. In 2012, Dr. Alicia Becerra (a junior neurosurgeon) joined our epilepsy surgery program. Upon her return, she performed the first temporal lobectomy in 2014. A young graduated neurologist from her center did a fellowship in epilepsy with us, but unfortunately, due to hospital politics, he was not hired back. But, another young neurologist, who spent time with us in London (Dr. Elliot Barreto) joined Dr. Zegarra. After purchasing a video-EEG unit, the team has done more than 15 epilepsy surgeries, and more than 50 cases have been monitored with video-EEG.

During our trip in 2016, an awake craniotomy was also performed at the ESSALUD hospital under the guidance of the London team.

The initial financial funding came from PECA, but subsequent funding came from private donors and Western University.

Since their inception, the 2 surgical programs in Lima, have been independent and have continued to perform presurgical assessments, with their video-EEG units, 3T MRI, neuropsychological assessments and nuclear medicine tools they have. Surgeries are now an integral part of their program. They are currently contemplating an assessment to start doing intracranial evaluations.

The success of these two programs was based on the collaborative nature of the work, as well as on the fact that these were not traditional medical missions, but rather educational interventions.



By Jorge Burneo



CANADIAN OBSERVATIONAL STUDY ON EPILEPSY (CANOE)

It is becoming increasingly recognized that national and international consortiums are required to address treatment gaps in epilepsy. The advent of ‘big data’ is now upon us and is a welcome development as a new tool for advancing knowledge and creating breakthroughs in epilepsy care. These data benefit clinicians by permitting precise estimates of prognostic factors while also producing generalizable results since broad populations are included in the analyses. Such national registries also facilitate investigations into quality of care, regional disparities in resource provision, and adherence to consensus standards and guidelines. Finally, they provide the backbone for larger scale collaborations using data from multiple sources (e.g., electrophysiology, genetics, imaging).

To this end, with the generous support of UCB Canada Inc., we have launched the Canadian Observational Study on Epilepsy (CANOE). Led by Dr. Colin Josephson (University of Calgary) and Dr. Mark Keezer (Université de Montréal), with the critical inputs from Dr. Samuel Wiebe (University of Calgary), Dr. Mary Connolly (University of British Columbia), and Dr. Luis Bello (University of Calgary), this initiative is intended to standardize data collection in participating centres across Canada for adult and paediatric patients with epilepsy. Building upon Dr. Samuel Wiebe’s work on the Calgary Comprehensive Epilepsy Program’s registry (with over 10 years of data on more than 6,000 patients), the overarching aim of this consortium is to study and provide new insights into the descriptive epidemiology, genetics, treatment patterns, and determinants of health outcomes of epilepsy by using the data collected during routine clinical encounters in all participating sites. All data are stored on centralized secure servers hosting REDCap with access governed by two-factor authentication. All analyses are performed on pseudonymized patient data.

It is our long term goal to expand upon these local advances by substantially increasing the size of the clinical cohort, increasing external validity, and establishing national recommendations for epilepsy care. In addition to physician-led clinical inputs, patient reported outcomes will form a central aspect of this data repository with longitudinal recording of quality of life (QOLIE-10), health state valuation (EQ-5D-5L), epilepsy disability and severity (GASE, GAERD), and depression (NDDI-E). Through local linkage schemes, personalized medicine will become a reality given the ability to directly connect our core data elements to electroencephalography (EEG), neuroimaging studies, and genetic measures.

We also appreciate the importance of developing an intuitive and flexible platform that increases the efficiency and value of clinical care. Hence, another thrust of this program is to develop internet- and tablet-based direct patient data entry, clinic-based data visualization tools, and automated production of standard clinic notes. Currently, in conjunction with the University of Calgary’s Clinical Research Unit, we are refining the data visualization tool (insert 1) and direct patient data entry (insert 2) which will be field-tested this month.

Our first face-to-face meeting will take place this December at the American Epilepsy Society Meeting and we look forward to future successes. The meeting will take place on Sunday, December 2nd, from 6:00-7:15 pm in Salon A at the New Orleans Marriott. On behalf of the CANOE Executive Committee, it would be our pleasure to meet you there to discuss this initiative with interested centres across Canada. Additional enquires can be made to Colin Josephson (cbjoseph@ucalgary.ca) and Mark Keezer (m.keezer@outlook.com).

Insert 1: Data visualization platform:

Insert 2: Direct patient data entry:




The Canadian League Against Epilepsy is an organization of medical and basic sciences professionals including physicians, basic scientists, nurses, neuropsychologists, neuroradiologists, students and other healthcare professionals.

FAREWELL NOTE FROM YOUR EDITOR

I was approached by Dr. Nizam Ahmed during a coffee break at the 66th Annual Meeting of the American Epilepsy Society in San Diego, 2012 to discuss the possibility of a newsletter for the CLAE. First issue of the 'CLAE Connections' was published in April of 2013. It has been nearly six years, and we published 17 issues of the newsletter. I had the opportunity to e-communicate with a lot of young talented epilepsy healthcare professionals across the country. I thank Drs. Ahmed, Jette, Burneo and Nguyen for their kind support. Many members of the publication committee were consistently active. I am grateful to Dr. Mary Lou Smith and the staff at the CLAE office for the editorial support. Now it is time to hand over the responsibility to Dr. Tadeu Fantaneanu. This will be the last newsletter under my editorship. Thank you all for the support over the past six years. Please welcome Dr. Fantaneanu as the new editor of CLAE Connections.

Bye for now!

(If you are interested in contributing and providing content to the CLAE Newsletter, please contact Tadeu Fantaneanu (tfantaneanu@toh.ca) before March 15, 2019.)

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

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EDITOR'S PICK

1. The role of surgery in refractory epilepsy secondary to polymicrogyria in the pediatric population. Jalloh I, Cho N, Nga VDW, Whitney R., Jain P, Al-Mehmadi S, Yau I, Okura H, Widjaja E, Otsubo H, Ochi A, Donner E, McCoy B, Drake J, Go C, Rutka JT. *Epilepsia*. 2018; 59:1982-1996.
2. Patient satisfaction with epilepsy surgery: what is important to patients? Lunney M, Wahby S, Sauro KM, Atkinson MJ, Josephson CB, Girgis F, Singh S, Pat-ten SB, Jetté N, Sajobi TT, Hader W, Wiebe S. *Epileptic Disord*. 2018; 20:364-373.
3. Cannabis for the treatment of paediatric epilepsy? An update for Canadian paediatricians. James Huntsman R, Tang-Wai R, Acton B, Alcorn J, William Lyon A, David Mousseau D, Seifert B, Laprairie R, Prosser-Loose E, Ondrej Hanuš L. *Paediatr Child Health*. 2018; 23:368-373.

Message from Christos K. Lisgaras from the ILAE Young Epilepsy Section (YES) to all junior members of the CLAE:

The ILAE Young Epilepsy Section is planning several actions at the upcoming AES Annual Meeting in New Orleans: a board meeting, a YES Q&A session, a career funding session and a networking event. If you are interested in joining YES, please contact me at the following coordinates.

Christos K. Lisgaras, PhD Email: christos.lisgaras@einstein.yu.edu