

CLAE CONNECTIONS

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Canadian League Against Epilepsy



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It is my great pleasure to write this message for the first issue of the CLAE Connections. Canadian League Against Epilepsy (CLAE) has come a long way since its inception in 1977. This would never have been possible without the hard work, passion and selfless work of so many of its members. Before I go to business and administrative details please join me in congratulating [Dr Warren Blume](#) for receiving the Order of Canada Award for 2012 and [Dr Juhn Wada](#) for receiving the 2013 Lifetime Achievement Award by the ILAE. "This is the highest award bestowed by IBE and ILAE and recognizes exceptional personal contributions over a long period of time to advance the cause of epilepsy". Additionally, I want to extend my sincere congratulation to the winners of the CLAE 2013 Research Awards includ-

ing [Dr Demitre Serletis, Ms Kirsten Fiest and Dr Colin Josephson](#). The recipient of the CLAE fellowship award for 2013-14 will be announced in the near future. Please join me in congratulating these budding epileptologists for their hard work and excellent submissions. On behalf of the CLAE I extend my sincere gratitude to UCB Pharmaceuticals for supporting the fellowship.

I want to welcome Secretariat Central (SC) as our new management company. [Denise Crane](#) from SC is our new Association Manager. I am very thankful to RCAM for all their support and organizational help for the past 18 months.

[Dr Rajesh Ramachandran Nair](#) has kindly accepted the role of Editor-in-Chief of the CLAE Con-

nections. This newsletter will be published 4 times a year. Please feel free to submit your entries related to national and international recognitions, publications or any other subject that may be of interest to the membership.

The next CLAE Biennial Meeting will be held in London Ontario from October 17-19, 2014. This would be a joint meeting with the Canadian Epilepsy Association. Please mark your calendars.

The CLAE provides a unique opportunity for collaboration among the membership which comprises physicians, surgeons, nurses, basic science and clinical researchers, psychologists and technologists. CLAE is defined by its members. The more actively we participate and contribute in the organization, the more value we can add to the membership. I look forward to seeing all of you in Montreal for the ILAE meeting in June

Best Regards,

[S. Nizam Ahmed, MD, FRCPC](#)



WARREN T BLUME APPOINTED TO THE ORDER OF CANADA

On December 30th, 2012 Dr [Warren T Blume](#) was appointed to the Order of Canada. Dr Blume was recognized for his academic and clinical contributions to the development of epilepsy treatment in Canada.



"As a colleague of Dr Blume, I have had a ring-side seat for 30 of the 40 years he has dedicated to the management of epilepsy here at Western. Anyone who trained at Western will remember Dr Blume's enthusiastic assessment and interpretation of EEGs during reading sessions that otherwise were known for their distinct lack of brevity". [Richard S McLachlan](#), Professor of Neurology, University of Western Ontario

CLAE Award Winners

Fellow Award

Demitre Serletis
University of Toronto

Graduate Student Award

Kirsten Fiest
University of Calgary .

Mary Ann Lee Award

Colin Josephson
Dalhousie University.



FELLOW AWARD

Demitre Serletis

University of Toronto.

'Complexity and multifractality of neuronal noise in mouse and human hippocampal epileptiform dynamics'

Supervisor: Dr P Carlen

In this project, Dr Serletis and his team applied sophisticated neuroengineering techniques to dynamically characterize the background neu-

ronal noise-like activity (NLA) underlying epileptiform transitions recorded electrophysiologically at the intracellular and local network scales from two in vitro models: the intact mouse hippocampus and lesional human hippocampal slices. Their results show evidence for reduced dynamical complexity and a breakdown in signal multifractality following transition to the ictal epileptiform state.

Thus, background NLA successfully captures complex signal features.



GRADUATE STUDENT AWARD

Kirsten Fiest

University of Calgary

'Depression in Epilepsy: A Systematic Review'

Supervisor: Dr Nathalie Jette

Kirsten Fiest is a third year PhD candidate in Epidemiology at the University of Calgary, supervised by Dr. Scott Patten & Dr. Nathalie Jette. Her research focuses on the relationship between depres-

sion and epilepsy. A recent publication in Neurology titled: "Depression and Epilepsy: A Systematic Review and Meta-Analysis" reported on the prevalence of depression in epilepsy and the association between the two conditions. Kirsten's dissertation research will examine the use of numerous depression screening tools in persons with epilepsy, establish the treated prevalence of depres-

sion in this population, and explore health outcomes using hospitalization data.



MARY ANN LEE AWARD

Colin Josephson

Dalhousie University

'Systematic review and meta-analysis of standard versus selective temporal lobe epilepsy surgery.'

Supervisor: Dr Mark Sadler

"We performed a systematic review and meta-analysis comparing standard anterior temporal lobectomy (ATL) to selective amygdalohippocampotomy (SAH) for postoperative seizure control in tem-

poral lobe epilepsy. Patients were statistically more likely to achieve an Engel Class I outcome after ATL (risk ratio 1.32, 95% confidence interval [CI] 1.12-1.57; $p < 0.01$) in 11 studies comprising 1,203 participants. The summary risk difference of 8% (95% CI 3%-14%) translates to a number needed to treat of 13 (95% CI 7-33). Improved seizure freedom must be balanced against the neuropsychological impact of

each procedure. A randomized controlled trial is justified", Dr Josephson added.



RISING STARS

*In this issue of CLAE Connections we introduce **Mark Ferro, PhD;***

McMaster University

Dr. Mark Ferro is a Postdoctoral Fellow at the Offord Centre for Child Studies and the Department of Psychiatry and Behavioural Neurosciences at McMaster University. He earned a BSc(Hon) in Biochemistry from McMaster University (2004), MSc in Community Health and Epidemiology from the University of Saskatchewan (2006), and completed his PhD in Epidemiology and Biostatistics from Western University (2011). Dr. Ferro is the recipient of numerous awards, including the Banting Postdoctoral Fellowship from the Government of Canada (2012-2014), Trainee of the Year from the Children's Health Research Institute (2011), and Young Investigator Award from the American Epilepsy Society (2009). He has published widely, including papers in Neurology, Epilepsia, Health Psychology, Journal of Pediatric Psychology, and Social Psychiatry and Psychiatric Epidemiology.

Dr. Ferro's program of research aims to understand quality of life and psychiatric comorbidity in children with chronic health conditions, with particular emphasis on children with epilepsy. His research takes a developmental approach to elucidate how a diagnosis of epilepsy in childhood impacts children and families, and in turn, how family processes, including parental depression and family functioning, influence child self-concept and condition risk for psychiatric disorder in this vulnerable population of children. In addition to his substantive research interests in childhood epilepsy, Dr. Ferro has methodological interests incontd Page3



NEW PROGRAM

EpLink – The Ontario Brain Institute Epilepsy Research Program (M Burnham)

About three years ago, the Government of Ontario established a new institute devoted to CNS disorders - the Ontario Brain Institute or "OBI". On Tuesday, March 5th, 2013 the Provincial Government announced that funding for the OBI will be continued for at least five more years. What this means to the Epilepsy Community is that there will be at least five more years of EpLink - the Epilepsy Research Program founded by the OBI. The EpLink Epilepsy Program is unique in Canada. It involves more than twenty-five researchers (working at nine different university and hospital sites across Ontario), five industry partners, and five non-profit advocacy groups. The EpLink Program will bring these workers more the \$2 million per year in research support.

The goals of the EpLink Program are translational in nature. Although its studies involve cutting edge science, its major focus is to improve clinical care for epilepsy in the very near future. To accomplish this goal, EpLink is partnering with industry, since industry support is necessary to bring new discoveries from bench to bedside. EpLink is also partnering with non-profit regional and provincial epilepsy associations in Ontario.

While EpLink is a provincial initiative, its importance is not limited to Ontario. It is hoped that its influence will spread far beyond Ontario's borders and that it will form a template that can be adopted by provincial governments all across Canada.

The research projects supported by the EpLink Program involve almost every area of epilepsy care. They are divided into six different themes: 1) *Epidemiology and Diagnosis*, 2) *Medical Control of Seizures – Pharmacological*, 3) *Medical Control of Seizures – Non-Pharmacological*, 4) *Imaging for Surgery*, 5) *Surgery and Stimulation* and 6) *Genetics and Epigenetics*.

Direction of the EpLink Program is provided by [Jorge Burneo](#) in London and [McIntyre Burnham](#) in Toronto (Co-Directors). [Kathryn Hum](#) is the Project Manager of EpLink. Readers interested in more information can email [Dr. Hum](mailto:Dr.Hum@eplink.obi@gmail.com) at eplink.obi@gmail.com or access the EpLink website at www.eplink.ca.



..longitudinal analysis, measurement (factor analysis, invariance testing), and missing data.

Dr. Ferro was the recipient of the 2012 CLAE Fellow Research Award based on research from his doctoral studies in which he demonstrated that mothers of children with new-onset epilepsy consisted of heterogeneous subgroups with distinct trajectories of symptoms and risk for clinical depression. Evidence also suggested maternal depression had no adverse impact on child health when adequate family resources were present. The CLAE Research Award provided Dr. Ferro the opportunity to attend the 2012 American Epilepsy Society meeting whereby he presented findings showing that family factors have a more prominent influence compared to clinical characteristics of epilepsy in predicting quality of life in children. Dr. Ferro's aspiration is to continue to develop his program of research in an effort to improve the lives of children with epilepsy and their families, and acknowledges the CLAE as instrumental to facilitating this important goal.



EDITOR'S PICK: NOTABLE PUBLICATIONS FROM CANADA IN 2012-2013

1. Salam MT, Mirzaei M, Ly MS, Nguyen DK, Sawan M. An implantable closed loop asynchronous drug delivery system for the treatment of refractory epilepsy. *IEEE Trans Neural Syst Rehabil Eng.* 2012 Jul;20(4):432-42.

Polystim Neurotechnologies Laboratory, École Polytechnique de Montréal, Montréal, QC, Canada.

2. Speechley KN, Ferro MA, Camfield CS, Huang W, Levin SD, Smith ML, Wiebe S, Zou G. Quality of life in children with new-onset epilepsy: a 2-year prospective cohort study. *Neurology.* 2012 Oct 9;79(15):1548-55.

Department of Paediatrics, University of Western Ontario, London, Canada.

3. Fiest KM, Dykeman J, Patten SB, Wiebe S, Kaplan GG, Maxwell CJ, Bulloch AG, Jette N. Depression in epilepsy: A systematic review and meta-analysis.

Departments of Community Health Sciences, Psychiatry, Clinical Neurosciences, and Medicine, University of Calgary, Canada and Health Systems & School of Pharmacy, University of Waterloo, Canada



NOVA SCOTIA EPILEPSY COHORT: A SUCCESS STORY

The Nova Scotia Pediatric Epilepsy Cohort Study (Carol Camfield & Peter Camfield)

Your CLAE news editor (Dr. RamachandranNair) asked if we would write about the history, reason for success, funny stories and challenges associated with the NS epilepsy cohort – two whole careers in < 1500 words.

Nova Scotia is a special place. Not only is the rugged coastline beautiful but is inhabited by friendly people. There is a single tertiary care pediatric hospital (the IWK Health Centre) that embodies a strong sense of responsibility for care of all children in the Province. The IWK is a teaching hospital for Dalhousie University, so there is a strong link between patient care and academic pursuits. Everyone in NS knows the IWK and if you work there as a physician, everyone trusts you.

The beauty of clinical research is that it is possible to apply the results to the very next patient you see. In 1977 when we moved to work in Nova Scotia there were a million unanswered basic questions about the natural history of epilepsy in children. We started at the beginning of the story with the question – what is the chance of recurrence after a first unprovoked seizure? The clue to an unbiased case finding method became quickly clear when we realized that along with our colleague Dr. John Tibbles, we read every pediatric EEG generated in Nova Scotia. A survey of all pediatricians in the province and a random sample of 100 family physicians indicated that if they saw a child with a seizure, they ordered an EEG. What a gold mine! – A simple, comprehensive case finding technique. Obviously an EEG request does not mean a confirmed diagnosis of a seizure or epilepsy, but it opens the door. We searched the EEG records, reviewed clinical charts and called up the families for further details. We identified 168 children with a first unprovoked seizure: the recurrence rate was about 50% with ~ 80% of those with a recurrence going on to further seizures. Therefore, epilepsy could be confirmed after a second seizure. This data seems mundane now, but in the late 1970's it was very hot.

So we moved on. Why not study the natural history and evolution of all childhood epilepsies? The same EEG requests supplemented with chart review and direct patient contact should identify them all. We selected all those with epilepsy onset (≥ 2 seizures) between 1977-1985 and then followed them up.

We screened 10,000 EEG requests, read 4-5000 charts and called those who might have epilepsy – a monstrous task but highly useful. There were 693 with new onset epilepsy, although 20 years later we discovered one double entry – our cohort shrunk to 692. Remarkably, over the next 25 years we encountered only one patient that we had missed, a brother with the same last and similar first name.

Since then we have tried to stay in touch with the cohort every 5-10 years. This is very labour intensive – we personally do the sleuthing to find patients and we make the phone calls. Few people are home during the day so this is a labour of nights and weekends, lots of them.

Carol has been particularly devoted to these activities and our house is full of de-identified coding forms. We personally enter most of the data and have been helped a great deal by two statisticians and colleagues. We have written papers at work, at home, on our boat, at our cabin and everywhere else we travel. The cohort is a big part of our lives and the story of epilepsy in children has become so much clearer to us.

Here are just a few examples of the type of information that we have been the first to discover. Did you know that SUDEP is extremely rare in childhood onset epilepsy and that nearly all deaths are related to the underlying etiology and neurological disability? Did you know that the failure of the first AED in childhood is a risk factor for intractability but that the majority still come under control and enter permanent remission? Did you know that there are almost no preventable causes for the combination of epilepsy and mental retardation? Did you know that status epilepticus in children with epilepsy has no effect on the long term outcome? Children with complex partial seizures have an ominous 30 year prognosis compared to those with focal seizures with secondary generalization. These ideas are relevant and useful for clinical practice and supplemented by many more from ~30 publications based on the Nova Scotia Cohort.

Why did this effort work? Personal devotion is the number one reason. Most of these children were our patients who we were attached to and years later the families are still grateful for the care and pleased to help us and the IWK.

It worked because we were encouraged by our colleagues in Halifax and around the world. Meetings, abstracts, lectures, papers, book chapters all created a kind of roller coaster with no landing station. The more data we produced, the more interested people seemed to be. At first it was the seizure outcome that seemed important, but over time we have realized that the social outcome is even more important. Our interventions may control seizures but in the long run, do our patients turn out to be happy productive members of society or reclusive misfits? Now the cohort members are in their 40's. It is a bit depressing to learn that so many (~50%), even those with "epilepsy only", have had major problems in life with unsuccessful schooling, unemployment, social isolation, inadvertent pregnancy and depression. There are accomplished professionals in the cohort with good marriages and meaningful community activities, just not many.

Are there funny stories? One day Peter was looking at some coding forms at home and was startled to see tire tread marks across several pages. He questioned Carol who admitted that she had the data in her bike basket, there was a big gust of wind and hours of work was spread under the wheels of cars on South Street. She was able to gather up every piece of paper and had hoped I would not notice. These were the only copies of the data – we started making copies to leave at the hospital before cycling home.

The first seizure data was backed up onto magnetic computer tape – no need to keep a paper copy – "State of the art technology sir!" Twenty years later we were asked some questions about this data and of course, we still had the magnetic tape in our study at home. However, we were unable to locate a single working machine in Canada that could play back this tape.

There are lots of challenges, some very frustrating. We wish we had recruited a control group of unaffected children to measure social outcome. We wish that the cell phone had not been invented. There is a telephone directory for landlines but there isn't one for cell phones – it makes sleuthing very difficult. We wish that the classification of epilepsy had not been changed. The concept of syndromes was introduced only after our study was underway. We are now reporting outcomes in a series of papers that are based on syndromes. Did you know that 30-40% of children with JME will have remission in adulthood. The ILAE has adopted a variety of definitions that are not quite the same as ours. For example, we defined "remission" as seizure-free and no longer taking AED treatment. We have our own definition of intractability. It is difficult to adapt our coding system to the new ILAE definitions which makes it a bit more of challenging to compare NS data with others.

Working together on the Nova Scotia Cohort has been wonderful for both of us. We have complementary skills. It has allowed us to travel the world together and develop a large network of colleagues and friends with similar interests. In our semi-retirement we continue to work away staying in contact with the cohort and analyzing the data. We are very grateful to the members of this cohort and their parents for their willingness to generously share their continuing life stories.



Carol Camfield obtained her MD and pediatric training from the University of Michigan and Peter Camfield received his MD at Harvard Medical School. They met during residency training at the University of Michigan. Peter did a Neurology fellowship at McGill University and while Carol was a Robert Johnson Foundation Clinical Scholar in Epidemiology at McGill University. They joined the Pediatric Department at Dalhousie University in 1977 and retired as Professors Emeritus 2 years ago, now continuing to do research and enjoying teaching in developing countries as well as sailing, skiing and traveling to see family and the world. They have each published >200 peer-reviewed papers and endless book chapters and have delivered >250 invited lectures around the world. Together they received the Penfield Award from the CLAE (2003) and the Career Research Award from the Canadian Pediatric Society (2010). Peter is the recipient of the Hower Award from the Child Neurology Society (2009).



Canadian League Against Epilepsy

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.

NOTE FROM YOUR EDITOR

The second issue of CLAE Newsletter (June 2013) will include meaningful and relevant information to CLAE members, including but not limited to the following:

1. CLAE Stars: A member who has received local, national or international recognition for his/her research, teaching, innovation or advocacy.
2. Innovative new programs and services (clinical, research or advocacy). These include, but are not restricted to: new major regional/institutional or provincial clinical programs, new research themes, platforms, consortium and networks, outreach programs in vulnerable/marginalized communities, innovative educational programs and advocacy initiatives/projects.
3. Major publications by Canadians in the field of epilepsy during the last 6 months.
4. Information on epilepsy meetings, and epilepsy related social events.
5. Information on recruitment of patients for research studies and opportunities for research, educational and clinical collaboration.
6. Success and success stories in major grant competitions.
7. Colleagues we recently lost /an In Memorium section.

If you are interested in contributing and providing content to the CLAE Newsletter, please contact Rajesh Ramachandran Nair (rnair@mcmaster.ca) before May 15, 2013.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

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UPCOMING PROGRAMS

Sudden Unexpected Death in Epilepsy (SUDEP) Professional Development Day for Epilepsy Support Organization Workers and Non-physician Epilepsy Care Providers

Increasingly, people with epilepsy, their families and caregivers are asking for information about SUDEP. To help answer these questions, encourage discussion, provide consistent messaging and keep informed of latest developments, SUDEP Aware will host a SUDEP Professional Development day for members of the Canadian Epilepsy Alliance and non-physician care providers of epilepsy treatment centers across Canada.

With presentations from leading experts in the field and interactive

discussion periods, the day will aim to provide valuable insight into the issues concerning SUDEP, as well as the tools and knowledge share to best assist and support the 300,000 families living with epilepsy in Canada.

This event is open to non-physician carers who support epilepsy families (such as clinic RNs, advanced practice nurses, social workers, epilepsy support organization staff) and will take place June 27 2013, in Montreal, to coincide with the International Epilepsy Congress.

To register, or for more information, please contact Deb at [SUDEP Aware](mailto:SUDEPAware) on 1-855-85-SUDEP (78337), ext 2 or email pdday@sudepaware.org Book ASAP as spaces are limited!

30th International Epilepsy Congress,

Palais des congres de Montreal

June 23-27, 2013

www.epilepsymontreal2013.org

Later breaking abstracts can be submitted till May 5th, 2013.

CME accreditation: The 30th International Epilepsy Congress has been approved for up to 29 credits by the Office for Continuing Health Professional Education (CHPE).

American Epilepsy Society Annual Meeting, 2013

December 6-10, Washington DC , Washington Convention Center



The next CLAE Biennial Meeting will be held in London, Ontario from October 17-19, 2014. This would be a joint meeting with the Canadian Epilepsy Association. Please mark your calendars.