

# **A Brief History of the Canadian League Against Epilepsy (CLAE)**

by Juhn A. Wada, O.C., D.Sc., M.D., Med.Sc.D.,FRCP (C)

CLAE Founding President

Professor Emeritus, Neurosciences & Neurology

University of British Columbia

## **Prologue**

The year 2007 will mark the 30th anniversary of the Canadian League Against Epilepsy (CLAE). Active planning for the celebration of this event is in progress under the leadership of the incumbent 14th CLAE president, Dr. Lionel Carmant. The 30th anniversary represents a youthful maturation of an established organization with intrinsic growth, equipped with the wisdom and extrinsic evolution to meet future challenges. Dr. Carmant has made a timely decision to document the progress of the League since its inception. The ready availability of this historical overview and perspective is a landmark that will not only strengthen our resolve to invigorate the epilepsy movement, but also undoubtedly help to chart our future course.

## **Background**

Back in 1956, the stark reality was a state of general inertia on epilepsy in British Columbia (BC) as the writer arrived in Vancouver from Montreal, where a vibrant activity existed. The situation in BC at that time was probably not too different from that in other provinces and territories outside of Quebec. This realization became the driving force to search for mechanisms to invigorate the epilepsy movement in subsequent years.

As we shall see in this historical overview, the creation of CLAE was deeply rooted in the hopes of boosting the epilepsy movement in Canada through a high-profile public event. It was thus intricately intertwined with events leading to the 10th International Epilepsy Congress in 1978, held in Vancouver. It was during the planning process for this Congress that the necessity of a national

professional organization capable of hosting such a world-class event surfaced in our awareness.

### **Canada's Role in the North American Epilepsy Movement**

During the mid–twentieth century, the Montreal Neurological Institute (MNI) was a prominent centre of excellence in neurology in general and epileptology in particular. Due to the personal interest of its founding director, Dr. Wilder Penfield, Canada became the cradle of epileptology, contributing more than its share of the world's knowledge and training a number of outstanding specialists worldwide.

Historically, the North American epilepsy movement began largely in the eastern United States, to which Montreal had ready access. In 1898, the National Association for the Study of Epilepsy and the Care and Treatment of Epileptics was founded and in 1901 held its first meeting in Washington, DC. In 1909, it became the American affiliate of the International League Against Epilepsy (ILAE). In 1936, the American Branch of the ILAE was organized and the study of epilepsy naturally thrived through intimate interaction and collaboration among interested Canadian and American colleagues. The following served as presidents: Dr. William G. Lennox(1937-38), Dr. Temple Fay (1938-39), Dr. Irving McQuarrie (1939-40), Dr. Tracy J. Putnam (1940-41), Dr. H. Houston Merritt (1941-42), Dr. Wilder Penfield (1942-43), Dr. T.C. Erickson—who had earlier made a historic study on the role of corpus callosum in partial onset generalized seizure at MNI—(1943-44), Dr. C.D. Aring (1944-45). The first meeting following World War II took place in New York in 1946. Subsequently this date has been identified as the founding date of the American Epilepsy Society (AES) of today, and Dr. Francis McNaughton of Montreal was its first president (1948-49). The AES has served and represented the interests of both the United States and Canada without discrimination. This tradition of AES continued as reflected by the fact that four more Canadians served as its president: T. Rasmussen (1961-62), P. Robb (1965-66), P. Gloor (1975-76), and J. Wada (1988-89). It seems that

there was no particular need or reason to have a separate Canadian Epilepsy Society.

However, despite what appeared to be a seamless representation of both Canadian and American interests, there was a substantial need to implement new knowledge at local and provincial levels across the vast landscape of Canada, particularly outside of Quebec. It was under such circumstances, that Dr. Wada attended quadrennial Neurological Congresses: in Vienna (1965), where he heard Dr. F. McNaughton speak eloquently on the need for an accelerated epilepsy movement at the ILAE Congress, and in New York (1969), where he met Dr. Jerome Merlis, then president of ILAE and a past president (1956-57) of the AES, who spoke on North American participation in a worldwide endeavour against epilepsy. These events provided Dr. Wada an important insight into local and national efforts within the international context and perspective.

### **The Genesis of CLAE**

The most critical opportunity presented itself in 1973 following the International EEG & Clinical Neurophysiology Congress in Marseille. Dr. Wada was heading for Barcelona, where both Neurological and ILAE Congresses were to be held. At the Marseille train station, Dr. Wada found his friend Dr. David Daly as a fellow traveller to Barcelona. Dr. Daly had served as AES president (1966-1967) and was then about to become the ILAE president in Barcelona. Conversation during their train ride centred around the workings and mandates of AES and ILAE. Attendance at subsequent ILAE-related European Epilepsy Congresses brought Dr. Wada into closer contact with not only ILAE executives but also Mrs. Ellen Grass, who represented the International Bureau for Epilepsy (IBE), a lay organization. These events nurtured Dr. Wada's vision of enhancing public awareness of research frontiers of epilepsy and changing public attitudes towards epilepsy through holding a similar high-profile meeting on Canada's Pacific Coast. At the Brussels Congress (1974), Dr. Wada discussed this

possibility with Dr. Daly and Mrs. Grass. There were strong arguments in favour of this idea: there had not been any precedent of an Epilepsy Congress on the west coast of North America, Canadian provinces outside of Quebec needed an invigorated epilepsy movement, and Vancouver is strategically located for direct access from the American, European, and Asian continents. Both Dr. Daly and Mrs. Grass were highly supportive of the idea, but at the same time it became clear that the ILAE Congress would require a national professional epilepsy society to host the event. It suddenly dawned on Dr. Wada that, despite its prominence in the profession, Canada did not have its own national society, possibly due in part to its very close involvement in the AES. When the question was posed about this issue, Dr. Wada was reminded that he was also an AES member, and consequently the AES could easily host it on Canada's behalf. Despite this generous American gesture, Dr. Wada still felt very strongly that Canada must have its own national society. It was a natural response for him since he was born and educated in Japan, came to Canada via the United States, and had made a conscious decision to be an adopted son of Canada.

### **Creation of a National Society: Canada to Host International Congress**

At the 1975 Canadian Neurological Congress in London, Ontario, Dr. Wada discussed with a number of colleagues the idea of boosting nation-wide the clinical and basic research effort on epilepsy and increasing public awareness on the research frontiers of epilepsy through developing a professional Canadian organization. Those colleagues were Dr. Norman Auckland (BC), Dr. Frederick Andermann (PQ), Dr. Warren Blume (ONT), Dr. Henry Dunn (BC), Dr. Keith Meloff (ONT), and Dr. Allan Sherwin (PQ). It was their unanimous decision to create a Canadian national epilepsy society, and they agreed to become the six founding members. Legal groundwork began immediately to incorporate the Canadian society, with assistance from lawyer Mr. Kay Collins and his associate Mr. Will Geselbracht of Vancouver. Constitution and bylaws were drawn up and the proposal was submitted to Ottawa. The Congress proposal was then submitted to ILAE at the Berlin Congress in 1975, pending admittance of our

society as the Canadian Chapter of ILAE. Our Vancouver Congress proposal was formally approved at the Dublin Congress in 1976. The proposed name of our national society was initially Epilepsy Canada. However, we were informed by Ottawa that the name was already claimed by a lay organization, then the Canadian Epilepsy Association. Thus, the new national society was formally baptised as the Canadian League Against Epilepsy.

### **1977 Inaugural CLAE Symposium, Proceedings, and the Wilder Penfield Gold Medal**

On May 20 and 21, 1977, inauguration of the Canadian League Against Epilepsy was celebrated by holding an International Symposium in Vancouver. Greetings and support were received from both the AES (Dr. D. Purpura) and the Japan Epilepsy Society (JES, Dr. H. Akimoto). Participants included clinical and basic scientists from both Canada and the United States in addition to the presidents of both ILAE and IBE. The proceedings were published as *Modern Perspectives in Epilepsy* (J.A.Wada, ed., Eden Press, 1978).

In 1977, the CLAE had 171 paid-up members. The tenure of presidency was set for two years; the secretary-treasurer was chosen locally to make future efforts easier. In addition, the CLAE developed an Awards Program and engaged jeweller Henry Birks to develop the Wilder Penfield Medal. This Gold Medal was to be given for outstanding service in clinical and research accomplishments on epilepsy. (The medal was subsequently made available to MNI for its 50th Anniversary celebration but the original cast remains with CLAE). Lists of past presidents and Penfield awardees are appended at the end of this document.

### **Preparation for the 1978 International Congress, Program, and Proceedings**

Having created our national society, an intensive race to work out the details of the Vancouver Congress began. Countless formal and informal meetings and transactions took place locally, nationally, and internationally. We found ourselves in totally unknown territory with a huge financial undertaking. Yet our

spirits soared as we took the concrete steps towards achieving our ultimate goals of raising public awareness on research frontiers of epilepsy and generating a sense of urgency on epilepsy among our colleagues by hosting the International Congress in Canada.

### *Financial and Legal Undertaking*

The most serious initial challenge was financial in nature, but this was overcome by substantial private mortgage financing from the founding president.

Subsequently, a chance encounter on a plane with Senator Ray Perrault led to a successful federal grant application. Countless advice from others helped us to obtain further funding from both federal and provincial (*per* Professor Richard Splane, Social Work) and private (*per* former UBC Dean of Medicine, Dr. John McCreary, Woodward Foundation Director) sources. Since ILAE did not allow us to hire a professional accounting firm, we enlisted voluntary assistance from personal friends on the UBC campus: Faculty of Commerce (then-Dean Peter Lustzig) and Faculty of Law (Professor Ralf Loffmark). Our close ties with colleagues in a multi-faculty university proved to be an enormous asset as we grappled with the financial and legal implications of our undertaking.

To host the International Congress, there was a need to consolidate our national resources. Thus, the Canadian Epilepsy Association moved its headquarters to Vancouver from Toronto to maximize our national potential along with CLAE. Retrospectively, the 1978 Vancouver Congress not only created CLAE but also revitalized the lay organization, known as Epilepsy Canada.

### *Congress Program*

Conceptually, the Vancouver Congress was unique. While it was held on Canada's Pacific Coast and hosted by the CLAE, it was considered important to join forces with professionals from other Pacific Rim regions. The outcome of this initiative was that CLAE was joined by the AES (President: F. Dreifuss), the (U.S.) Western Institute of Epilepsy (WIE, President: J. Wada), and the Japan

Epilepsy Society (JES, President: H. Akimoto), in becoming the moving force while retaining their own themes within the Congress program. Additional program contributions were made by lay organizations: the British Columbia Epilepsy Society (BCES), the Canadian Epilepsy Association (CEA), and the Epilepsy Foundation of America (EFA). Thus, the major themes that evolved were AES – Intensive monitoring; CLAE – New surgical treatment through experimental models; JES – Natural history and prognosis; WIE- Neurotransmitters, Behaviour and Teratogenicity; ILAE – New drug testing, marketing and availability; BCES/CEA and EFA – Comprehensive care. Finally, IBE supported a special lecture at which Dr. Robert Naquet of Paris spoke on “Limits and Perspective of Our Knowledge: Progress from Research.” Following the Congress, a Public Seminar on “What’s New on Epilepsy,” with prominent participants of the Congress as speakers, was held at the University of British Columbia Hospital.

#### *Congress Registration and Media Coverage*

Over 1,200 people registered for the Congress—this was in contrast to the 150-300 registrants on previous occasions—and Public Seminar (500 registrants). The events were successfully presented with the voluntary assistance of many local professionals and lay people. Extensive media coverage highlighted the research frontier of epilepsy and the problem of epilepsy as an important public health issue.

#### *Publication of Proceedings*

Proceedings of these events were published: ILAE: *Progress in Epileptology* (eds. Wada & Penry); CLAE / WIE: *EPILEPSY - Neurotransmitter, Behavior and Pregnancy* (ed. Wada) and CLAE: *What’s New on Epilepsy* (ed. Wada). The latter was reprinted in the *BC Medical Journal* and was widely distributed to enhance the sense of urgency among professionals.

#### *Local Consequence*

One substantial benefit was the development of a dedicated Seizure Investigation Unit. This state of the art clinical facility enabled to complement and integrate existing basic research facility at the University of British Columbia Hospital in 1979.

### **Consolidation of National Resources**

Reflecting the subsequent increased awareness of epilepsy, there has been a remarkable proliferation of epilepsy-related groups between 1980 and 2006 such as the Canadian Epilepsy Consortium (CEC), Canadian Epilepsy Research Institute (CERI), Canadian Epilepsy Data Resource (CEDAR), and Canadian Pediatric Epilepsy Network (CPEN) within Canada, independent of the CLAE. Although these groups were all highly worthwhile, it was felt that a nation-wide integrated approach using the legally established CLAE entity would streamline various facets of the epilepsy movement. In March 2001, a suggestion was made by Dr. Peter Carlen and Dr. Warren Blume that all people interested in epilepsy get together.

Under the leadership of the 12th President, Elout Starreveld (2001-03), this issue was addressed, the aim being to broaden the perspective of the Canadian Epilepsy movement by an initiative formally linking the CLAE with other organizations and inviting representatives of the CEC (Dr. Neelan Pillay), CPEN (Dr. Lionel Carmant), CERI (Dr. Peter Carlen), Neurology/Neurosurgery residents (Dr. Nathalie Jette), and Epilepsy Canada (Dr. Donald Weaver) to join the CLAE Board. The resulting high-spirited mutual collaboration with Epilepsy Canada (EC, President Tim Ryan) resulted in the CLAE President sitting also on the Board of Epilepsy Canada.

One substantial outcome of this initiative was an organic union with CERI. The CERI September 2001 meeting, held at the MNI, became a historic event when the more than one hundred attendees voted unanimously to join the CLAE as a section, paving the way for an organic union of basic and clinical national

resources under the CLAE umbrella. With this formal link in place, the concept of an annual conference, either preceding the Canadian Congress of Neurological Sciences (CCNS) or as a stand-alone symposium in the fall was realized. Thus, the 2005 London Conference on Intractable Epilepsy was organized, with basic and clinical resources mobilized by Dr. Warren T. Blume, who ceaselessly worked towards a unified front. The proceeding of this symposium was also published (Blume et al., eds. *Intractable Epilepsy: Advances in Neurology*, vol. 97, 2005).

### *Legal Status*

In the meantime, the by-laws of the CLAE were amended to accommodate the changes that had taken place and to ensure continuity of an effective Board composition and representation.

Another important issue addressed was an obvious shortcoming of the status of CLAE: as a charitable organization rather than a foundation or corporation, it was legally required to expend 80% of annual revenue. This limitation was legally rectified in subsequent years. The amended by-laws now enable the CLAE to adapt to the changing circumstances of the twenty-first century.

### *Awards*

It was also under Dr. Starreveld's presidency that the Mary Anne Lee Award was established to honour the late Dr. Mary Anne Lee, a highly respected epileptologist from Calgary. This award is made annually and is open to a resident in training in Neurology, Neurosurgery, or Paediatric Neurology, or to a medical or basic science student under certain criteria. (See also the "New Directions" section for the expansion of the awards program.)

### **New Directions of Endeavour**

Under the leadership of the 13th President, Dr. S. Wiebe, there has been an additional intrinsic growth spurt corresponding to a new era of an extrinsic high-profile CLAE activity.

#### *National Activities*

- Further promotion of CLAE as a platform for dialogue among the many Canadian epilepsy organizations resulted in the inclusion of the Canadian Epilepsy Alliance (CEA) in the CLAE Board. Membership was opened to a wider population, including allied health care workers and other interested individuals.
- Half-day Epilepsy Course on various topics are offered by the CLAE education committee under the leadership of Dr. Neelan Pillay at The Canadian Congress of Neurological Sciences.
- An endowment was established for CLAE research awards geared towards medical and basic science students, clinical fellows, and allied health personnel. These awards are part of the Mary Anne Lee Award. All four awards are made annually now since 2006.

#### *International Activities*

- Provision of international leadership: the CLAE president is chairing the newly created ILAE North American Region Commission on epilepsy. The latter with representatives from Canada, Jamaica and the United States have a broad mandate to foster epilepsy care and education in North America and the Caribbean.
- New relationship with AES: participation of CLAE president in the AES Board and CLAE / AES hosting of the Biennial North American Congress, beginning in 2006.

## **Epilogue**

The intrinsic growth and extrinsic evolution of the CLAE with an expanding role and forum will enable Canada to contribute its traditional strength more effectively to explore new horizons for further invigoration of the North American Epilepsy movement, hand-in-hand with our American and regional colleagues.

This spirit of mutual collaboration is highly reminiscent of previous AES arrangements that represented both American and Canadian interests. The future is with us here today and we are all thrilled with this dynamic transformation of the CLAE as it expands and fulfils its role more forcefully and effectively, thus escalating the North American drive as an integral part of a global campaign against epilepsy. At this time, we look forward to the 30th Anniversary Symposium in October 2007 featuring an overall review of significant topics on epilepsy relevant to Canada that will be the most prominent event in CLAE history.

## **Appendix**

### **Past CLAE Presidents**

1977-79 Juhn Wada  
1979- 81 Norman Auckland  
1981- 83 Henry Dunn  
1983- 85 Warren Blume  
1985- 87 Frederick Andermann  
1987-89 Allan Sherwin  
1989-91 Joseph Bruni  
1991-93 Alan Guberman  
1993-95 Mark Sadler  
1995-99 Richard McLachlan  
1999-01 Michael Jones  
2001-03 Elout Starrveld  
2003-06 Sam Wiebe  
2006- Lionel Carmant

### **Wilder Penfield Gold Medal Awardees**

1982 Dr. Theodore Rasmussen  
1984 Dr Brenda Milner  
1986 Dr Preston Robb  
1987 Drs Katherine and Julius Metrakos  
1988 Dr Juhn Wada  
1990 Dr Pierre Gloor  
1997 Dr Warren Blume  
1999 Dr Frederick Andermann  
2001 Dr St Hilaire  
2003 Dr Peter Camfield  
2005 Dr Brenda Milner  
2006 Dr Jean Gotman

### **Mary Anne Lee Awardees**

2002 N. Jette  
2003 P. Tai  
2004 A. Kirton  
2005 S Hussein  
2006 J Wong (Resident/med student)  
J Tellez-Zenteno (Fellow)  
M Robertson (Allied Health)  
P deGuzman (Grad student)

