

INTERNATIONAL LEAGUE AGAINST EPILEPSY
COMMISSION ON EUROPEAN AFFAIRS CHAPTER CONVENTION
Thursday, 7th August 2014, 12:00-13:45
Canary Room, Level Four, Grand Copthorne Waterfront Hotel,
392 Havelock Rd, Singapore 169663

MINUTES

List of Attendance

ILAE Executive Committee

President, Emilio Perucca ITALY
Secretary General, Helen Cross UK
Treasurer, Sam Wiebe CANADA
Information Officer, Ed Bertram USA

Heung Dong Kim
Executive Committee Liaison, Tatusya Tanaka,
Japan
Guoming Luan, China
Man Mohan Mehndiratta, India
Sunao Kaneko Meir Bialer, Chair, CEA, Japan

**Commission on Asian/Oceanian Affairs
(CAOA)**

Chairman, Byung In Lee, Korea
Secretary, Andrew Bleasal, Australia
Treasurer, Leonor Cabral Lim, Philippines
Research Task Force Chair, CT Tan, Malaysia
Constitution Task Force Chair, John Dunne,
Australia
Paediatric Task Force Chair, South Korea,

ILAE Chapters

Listed on the roll call under agenda item (2)

ILAE Staff

Gus Egan, Chapter Services Coordinator

IDM Staff

Richard Holmes

Agenda

- 1) Welcome Address and Opening Remarks, BI Lee, Chairman, CAO A
- 2) Introduction of Delegates by A. Bleasal, Chapter and Non-chapter Representatives
- 3) Address by ILAE President, E Perucca, President, ILAE
- 4) Report from ILAE, H Cross, General Secretary, ILAE
- 5) Report from CAO A, Byung- In Lee, CAO A
- 6) Annual Report, BI Lee, Chair, CAO A
- 7) Budget, L Cabral-Lim, Treasurer, CAO A
- 8) ASEPA, SH Lim, Chairman, ASEPA
- 9) Information Committee, S Kaneko, Chair
- 10) Research Task Force, CT Tan, Chair
- 11) Global Outreach Task Force, E. Somerville, Chair
- 12) AOEA & Constitution Task Force (CTF), JW Dunne, CTF Chair
- 13) Paediatric Task Force, Heung Dong Kim, Chair
- 14) 11th AOEC TBC
- 15) Q & A and general discussion

1) Welcome - BI Lee, Chairman, CAO

BI Lee opened the meeting and thanked everyone for attending. He noted that the ILAE's Asia/Oceania region is the most progressive region within the ILAE but asked for continued feedback from all present to ensure continued progression. He thanked SH Lim and D Chan for the organisation of the congress under the Singapore Epilepsy Society.

2) Roll Call – A Bleasal, Secretary, CAO

Roll call taken by A. Bleasal.

Chapter	Name
Australia	Wendyl D'Souza
Australia / Global Outreach Task Force Chair	Ernie Somerville
Bangladesh	Muzharul Mannan
Bangladesh	Shaheen Akhter
China	Shichuo Li
China	Zhen Hong
Hong Kong	Colin Lui
Hong Kong	Eva Fung
Hong Kong	Howan Leung
India	Manjari Tripathi
Indonesia	Kurnia Kusumastuti
Indonesia	Dede Gunawan
Indonesia	Fitri Octaviana
Indonesia	Endang Kustiowati
Japan	Makiko Osawa
Japan	Masako Watanabe
Japan	Sunao Kaneko
Japan	Akio Ikeda
Korea	Eun-ik Son
Malaysia	Sherriru Bazir Ahmed
Malaysia / CAO Member	Kheng Seang Lim
Mongolia	ABSENT
Myanmar	Nyan Tun
Myanmar	Win Min Thit
Nepal	Thapa Prashwas

Nepal	Paudel Raju
Nepal	Rabindra Shrestha
New Zealand	Lynette Sadleir
Pakistan	Zarine Mogal
Pakistan	Hiba Mahmud
Philippines	Josephine C. Gutierrez
Philippines	Jean Marie Ahorro
Philippines	Marilyn H. Ortiz
Singapore	Demik Chan
Singapore / ASEPA Chairman	Shih-Hui Lim
Sri Lanka	Jithangi Wanigasinghe
Sri Lanka	Ranjanie Gamage
Taiwan	ABSENT
Thailand	Anannit Visu
Thailand	Somchai Towanabut
Vietnam	ABSENT
Invited Countries	
Cambodia	Devender Bhalla
Laos	Somchit Vorachit

3) Address by ILAE President, E Perucca, President, ILAE

Emilio Perucca began by giving a brief outline of the ILAE's strengths in 2014. He outlined the recent history of the ILAE since 1995 describing the growth in chapter membership and regional diversity.

Next he listed some of the recent achievements of the organisation:

- Approval of a modern Constitution, ensuring that all regions are represented in the Executive Committee
- 14 Commission Reports in 5 years
- Expanded educational programme, including Virepa
- Major advocacy achievements (European Declaration, IOM Report, PAHO, the Sports Initiative)
- Acquisition of Epileptic Disorders as our educational journal, further development of Epilepsia
- Improved organizational structure and governance

He also outlined some strengths and weaknesses of the ILAE. These included;

- Regional structure could be a weakness as well as a strength – need to work together for a common cause!
- Pressure on the time that volunteers can dedicate to the organization
- Costs involved in addressing increasing demand
- Revenue entirely dependent on Epilepsia and the congresses – both of which are under threat as a source of income

Moving on he also explained the 'new scenario' and the challenges that are being faced due to the decline in revenue from Satellite symposia, stricter regulations preventing industry support to individual delegates and the declining availability of public funds to support participation of physicians to scientific meetings.

He continued his discussion by highlighting the estimated surpluses from European Epilepsy Congresses 2006-2014. These figures are fully listed in the attached 'PERUCCACHapterConvention_ECE2014'.

He outlined planned actions to be taken to help face the rising challenges he had previously outlined. These included taking steps toward;

- Improving governance through reduction of operational costs – explore ways to diversify income

- Continuing support to our Commissions and Task Forces – from \$ 650,082 in 2012 to \$ 1,277,609 in 2014
- Maintaining investment into distant education, and expand bursary allocations whenever possible
- Improving services to our members by reducing registration fees at international congresses
- Ensuring financial viability of the League by maintaining the ‘endowment’ strategy

He continued by explaining with regard to the ‘Endowment’ strategy as of May 2014, investments totaled \$15,472,000. The goal was to build an endowment of \$20 million to generate \$1 million annually to support the activities of the League. He proceeded to state that with earlier than expected cash withdrawals, the Finance and Advisory Committees were considering adjusting their goals, possibly settling on an endowment fund closer to \$ 15 million

He concluded by stating that although the league continues to grow so do some of the challenges and hence there is a need for the organization and its members to deal with them by working together.

Questions and Comments:

MM Mehndiratta asked on what was the interest spent. E Perucca stated that it was not very high. Another question came from the floor enquiring how long it will take to reach US\$20m. E Perucca stated that initially it was predicted for 2018 but now a more realistic figure of US\$18m has been predicted by that time.

4) Report from ILAE, H Cross, General Secretary, ILAE

H. Cross opened her report entitled ‘News for ILAE’ with some statistics showing the countries represented by the ILAE both globally and within the CAO A region. She stated a few points about the aims of the ILAE that she was going to cover within her presentation;

- 1) International Epilepsy Day
- 2) Harmonisation of rules for election across regions
- 3) Criteria for ILAE endorsement of meetings
- 4) Journals
- 5) Publication in other languages

International Epilepsy Day

H Cross stated that there was a consensus amongst the epilepsy community as to the existence of an International Epilepsy Day. She stated that three dates were proposed – March, June and September. She explained that none of these dates were ideal, hence the proposal from IBE of the 2nd Monday in February (European Epilepsy Day) was carried forward. She, however, went on to state that this does not preclude individual countries continuing to celebrate their own existing epilepsy days

Harmonisation of rules for election across regions

An election 'Harmonisation Task Force' has been established; it's work is ongoing.

Criteria for ILAE endorsement of meetings

H Cross discussed that the first approach must come through Regional Commission Chair (+/- Topic Orientated Commission). It must be done at least 6 months in advance of event. She stated however that there is a need to review the process. Hence it must be;

- a) In line with the aims, and values of the ILAE
- b) It must represent value added for the community and participants,
- c) Ensure it does not conflict with ILAE Congresses. International or regional meetings scheduled within four months before a major ILAE conference are generally not endorsed if they are considered to compete for delegates and sponsors.

Journals

Epilepsia and Epileptic Disorders are the publications of the ILAE. Epilepsia is piloting availability of certain articles in other languages;

Chinese (in collaboration with Chinese Chapter)

Spanish (in collaboration with Chilean Chapter)

She announced that the ILAE definition of epilepsy is to be published through Epilepsia in English, Spanish, Russian, French, Japanese, Italian and Chinese.

Questions and Comments:

S. Li of the Chinese Chapter stated the 2nd week of February is not suitable for the Chinese as it coincides with New Year and is also too cold a time of year for such an event.

5) & 6) Report from CAO A and Annual Report, Byung-In Lee, Chair, CAO A
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BI Lee started his report by listing the current Chapters and the members of CAO A 2013-2017 and ASEPA 2011-2015.

Byung – In Lee listed the meetings that the CAO A had held in 2013/2014, which included Seoul and Stockholm. He listed the Action Plan of the CAO A from 2009-2013 and followed it by presenting the new plan for 2013-2017 as outlined below;

- 1) Enact written "Bylaw of CAO A" by the CAO A –constitution TF.
- 2) Promote diagnosis and treatment of neonatal and childhood epilepsies in the region by Paediatric TF.
- 3) Implement CAO A-demonstration projects for reduction of Treatment Gap in the region.
- 4) Promote Career Development Programs for young talented epileptologists in the region.

◇ Expand epilepsy fellowship programs

◇ Exchange programs for young research fellows

◇ Regional Epilepsy School in collaborations with ILAE

He highlighted the main points discussed at the Executive Meeting held in Stockholm in June, including the treasurers' report, Epilepsia in other Languages, TF for Global Research Priority Project, the ILAE –Web site and International Epilepsy Day.

He brought his presentation to a close by discussing the travel bursaries available for CAO A chapter conventions. He stated that all chapters are responsible for their participation to the chapter convention at AOECs. He continued by explaining that the CAO A cannot provide any bursaries officially to delegates for their participation to chapter convention

He acknowledged that CAO A may be able to provide a bursary to delegates from non-chapter countries to encourage their interactions with CAO A-chapters and he put forward some methods to support official delegates from the Low-income and the Low-middle income chapters. These methods included;

- 5 chairs of ASEPA-didactic lectures
- Speakers of scientific sessions
- Abstract-based bursaries

He stated that they encourage close communications with the General Secretary of CAO A at least 6 months before the chapter convention to ensure clear and beneficial meetings.

7) Budget, L. Cabral-Lim, Treasurer, CAO A

L. Cabral- Lim reported on the CAO A budget for 2014 which totalled at USD142,500.00. She noted that 1/3 of the ILAE's budget deficit is attributable to the CAO A. Congresses have been the only source of income and this is no longer enough to sustain the budget. Details of her presentation with regard to the figures can be found attached in LCLIM_CAObudget2014.ppt.

8) ASEPA, SH Lim, Chairman, ASEPA

Sh Lim began his presentation by introducing the ASEPA committee 2011-2015. He outlined what he was going to cover in his presentation with regards to ASEPA activities and began with his first topic which was Teaching Courses and Workshops.

Under **Teaching Courses and Workshops** he outlined the ones that were taking place over the coming week in Singapore. He also highlighted courses and workshops that had taken place in general since 2013. These included;

- Teaching Course during 30th International Epilepsy Congress, 23rd to 27th June, Montreal, Canada
- Joint Symposia & Teaching Course During 14th Asian Oceania Congress of Neurology, 2nd to 5th March 2014, Macao, China
- Teaching Course Before 10th Asian Oceania Epilepsy Congress, 7th August 2014, Singapore
- ASEPA Didactic Lectures during 10th Asian Oceania Epilepsy Congress, 8th, 9th & 10th August 2014, Singapore

He then went on to discuss **ASEPA-ASNA EEG Certification Examination**. He stated that its aim was to set and improve the standard of practice of EEG in the Asian Oceanian region. He gave details about the exam itself stating that it would be both a written and oral exam with a pass rate of 40%. He listed the relevant examiners and showed an example of the certificate which would be awarded to the successful candidates.

Next he discussed the **ASEPA Epilepsy Fellowship**, listing those involved from 2003-2014 in tables. Finally he concluded his presentation with information regarding **AOEC proceedings** which are published in Neurology Asia.

9) Information Committee, S Kaneko, Chair

S. Kaneko gave a presentation on the information committee. He began by listing the members and outlined their activities.

2013 to 2014 activities:

- Publication of CAO-Newsletter No.2 (27pages) on November, 2013
- Printed Newsletter has been sent to all CAO chapters and was also uploaded to CAO website
- Sent 200 copies to the 14th AOCN in Macau (Mar 2nd-5th, 2014) for CAO exhibition booth display (Costs of printing shipment fee were absorbed by JSE, a company responsible for CAO website)
- CAO-website renewed in Dec, 2013, according to the suggestion by ILAE and it was to be updated monthly basis.

He gave information on the Meeting of the information committee stating that their main focus was on a new co-chair for management of increasing tasks and better coordination with ILAE and chapters and that they needed a system to collect more information for website and Newsletter.

Finally he presented those present with a model of the new CAO website and informed all present that if they wanted to post something on the website to contact him directly.

10) Research Task Force, CT Tan, Chair

CT Tan began by announcing that it is currently time to apply for Fellowships and asked all Chapters to encourage young people to apply. Each application must be supported by the local Chapter and sent to CT Tan along with the applicants CV. The deadline is September and applications must state when the applicant wants to attend training.

He continued by stating that the proceedings from the last AOEC Manila 2012 were in Neurology Asia, copies of which were available at the meeting and also on the ILAE booth.

He asked that if any speakers at the AOEC Singapore were present to please write a 1000 synopsis of their speeches with references and to send directly to him by email.

On the 9th August at the Congress, the following projects will be discussed at the Research Task Force meeting:

- Relationship between public attitude to epilepsy and patients' felt stigma
- KS Lim / D Chan: HLA and SJS in antiepileptic drugs
- L Cabral-Lim: Women issues in epilepsy; "Problems facing woman in Asia & Oceania", "Attitude towards children upbringing and felt stigma", "Evolution of seizures with menopause"
- A Ikeda: Translational research in complementary treatment
- Y Chinvarun: Imaging in epilepsy
- Man Mohan M: Mobile usage in the diagnosis of epilepsy
- P Bergin: Progress of Epinet

He invited all to attend the meeting.

11) Global Outreach Task Force, E. Somerville, Chair

Ernie Somerville presented on the global outreach task force. He spoke about Myanmar and Laos with the relevant projects that were underway in each. In Myanmar he explained that the WHO project was underway in Yangon region and the ILAE-CAOA project in Mandalay region (Kyaukse) had been approved by Ministry of Health with its initial focus centre around GP training. In Laos CAOAs had funded training and he encouraged delegates to attend the Sanofi satellite at 16:30 that day to find out more on the progress being accomplished.

Two further points of discussion within his presentation focused on access to medication and networking. He stated that the aim to provide a medium for sharing information, strategies & experiences, cataloguing what is being done by whom and where needed to be created. He said that this was to be via ILAE but it must now stand alone.

He gave information on the satellite symposium that day and information on the session that was to take place the following day and concluded his presentation.

12) AOEA & Constitution Task Force (CTF), JW Dunne, CTF Chair

J Dunne opened his talk by stating that the Asian Oceanian Outstanding Epilepsy Award has been awarded during the last three AOEC Congresses. The aim of the award was to highlight outstanding contributors to care. At the opening ceremony for the current Congress awards will be given to people from China, Taiwan and the Philippines.

He continued by stating that the CAOAs are cognisant of all its members and Chapters during the elections and as such has structured its processes to be inclusive of all the people in the region. This structure conforms to the ILAE's constitution and by-laws. The ILAE aims to harmonise the process across all the regions while respecting diversity and individual differences.

At the end of his talk, A Bleasal highlighted to the assembly that JW Dunne would also be a recipient of an award.

13) Paediatric Task Force, Heung Dong Kim, Chair

As HD Kim was unable to attend the meeting, BI Lee spoke for him and began the presentation by outlining the Paediatric Task Forces action plan in 2014.

He stated that they wanted to create a network formation among paediatric representatives in chapters of CAOAs. They were also planning to organise a Paediatric expert's meeting in Singapore after the paediatric parallel session on 8th Aug to discuss about future plan of paediatric TF in their region. They further want to increase communication with chapters to support treatment gap in resource poor countries. Following this they want to increase the number of international exchange fellowship training and improve the quality of same.

Their future plan was composed of activities such as;

- Handling treatment and educational gaps
- Enhancing co-work with ASEPA
- The need increase proportion in educational subject/bursaries
- Developing new educational courses

- Paediatric EEG teaching course and certificate
- Joining together local chapters and local child neurology society, e.g. KPEP joined with ASEPA in 2010, China-Korea PEP in Beijing in 2011
- Facilitating interaction and communication with well-developed educational courses

Finishing these points he concluded his presentation.

<ul style="list-style-type: none">• 11th AOEC – Richard Holmes, IDM
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The Chapters have recently been asked if they wish to host the next meeting; so far Hong Kong and Indonesia have expressed an interest. As of yet IBE has not yet asked their member associations for expressions of interest. Therefore we may end up with a shortlist of three or four countries. He noted the need for budget restraint owing to the drop in pharmaceutical participation. He did note however that the Congress still managed to maintain its attendee numbers despite the drop in sponsorship and that for this meeting, 68% of delegates paid for their own registration. Six years ago it would have been the opposite. With this in mind he asked the CAO to be mindful of the locations chosen, pointing out that expensive countries will deter people from going there.

14) Q & A and general discussion

With no questions at this juncture, BI Lee thanked everyone for coming and closed the meeting.