INTERNATIONAL LEAGUE AGAINST EPILEPSY COMMISSION ON ASIAN/OCEANIAN AFFAIRS CHAPTER CONVENTION Friday, 13th May 2016, 12:00-13:45 Convention Hall C, Hong Kong Convention and Exhibition Centre (HKCEC), 1 Expo Dr, Wan Chai,

Hong Kong

List of Attendance			
ILAE Executive Committee	Global Campaign Task Force, Ernie Somerville,		
President, Emilio Perucca ITALY	Australia		
Secretary General, Helen Cross UK	Executive Committee Liaison, Tatusya Tanaka,		
Treasurer, Sam Wiebe CANADA	Japan		
Information Officer, Ed Bertram USA	Sunao Kaneko, Japan		
Past President, Nico Moshé USA	Kheng Seang Lim, Malaysia		
	Guoming Luan, China		
Commission on Asian/Oceanian Affairs	Man Mohan Mehndiratta, India		
Chairman, Byung In Lee, Korea			
Secretary, Andrew Bleasal, Australia	ILAE Chapters		
Treasurer, Leonor Cabral Lim, Philippines	Listed on the roll call under agenda item (2)		
Research Task Force Chair, CT Tan, Malaysia			
Constitution & ASEPA Task Force Chair, John	ILAE Staff		
Dunne, Australia	Gus Egan, Chapter Services Coordinator		
Pediatric Task Force Chair, South Korea,			
Heung Dong Kim	IDM Staff		
	Richard Holmes		

(1) 12:00-12:10 Welcome Address and Opening Remarks, BI Lee, Chairman, CAOA

(2) 12:10-12:20 Introduction of Delegates, A Bleasal --- Chapter and Non-Chapter Countries

Agenda

(3) 12:20-12:30 Address by ILAE President, E Perucca, President, ILAE

- (4) 12:30-12:40 Report from ILAE, H Cross, General Secretary, ILAE
- (5) 12:40-13:30 Report from CAOA

Annual ReportBI Lee, Chair, CAOA
Budget L Cabral-Lim, Treasurer, CAOA
ASEPA JW Dunne, Chairman, ASEPA
Information CommitteeS Kaneko, Chair
Research Task ForceCT Tan, Chair
Global Outreach Task ForceE. Somerville, Chair
AOEA & Constitution Task Force (CTF)W Dunne, CTF Chair
Paediatric Task ForceHeung Dong Kim, Chair
12th AOECRichard Holmes

(6) 13:30-13:45 Q & A and general discussion

(7) 13:45 Adjourn

1) Welcome - BI Lee, Chairman, CAOA

A Bleasal opened the meeting and invited BI Lee to give his welcome/opening remarks. BI Lee explained how the region has made significant progress since the AOEC's inception. The 11th AOEC,

taking place this week, marks the 3rd decade of ILAE activity in this region and he promised that this decade will see the region take its position as a leader rather than a follower as has previously been the case. Many barriers will be overcome in the coming years and together all present can achieve common goals and deliver the AOEC's mission. He wished everyone a successful Congress.

2) Roll Call – A Bleasal, Secretary, CAOA

Rol	l cal	l – Anc	lrew E	Bleasa	

Chapter	Name
Australia	Wendyl D'Souza
Australia / Global	Ernie Somerville
Outreach Task Force	
Chair	
Bangladesh	Muzharul
	Mannan
China	Jiong Qin
China	Zhen Hong
Hong Kong	Eva Fung
Hong Kong	Howan Leung
India	MM Mehndiratta
Indonesia / ASEPA Task	Kurnia
Force Member	Kusumastuti
Indonesia	Anna M Sunarja
Japan	Makiko Osawa
Japan	Sunao Kaneko
Japan	Akio Ikeda
Korea	Sung-Pa Park
Malaysia	Raymond Azman
	Ali
Malaysia / CAOA	Kheng Seang Lim
Member	
Mongolia	Amarjargal M

Myanmar	Nyan Tun	
Myanmar	Khin Than Nwe	
Nepal	ABSENT	
New Zealand	ABSENT	
Pakistan / ASEPA TF	Zarine Mogal	
Pakistan	Hiba Mahmud	
Philippines	Ana Marie	
	Javelosa	
Singapore	Derrick Chan	
Sri Lanka	Jithangi	
	Wanigasinghe	
Sri Lanka	Ranjanie Gamage	
Taiwan	Chuang Yao	
	Chung	
Taiwan	Chien Chen	
Thailand	Anannit	
	Visudtibhan	
Thailand	Apasri Lusawat	
Vietnam	ABSENT	
Invited Countries		
Cambodia	Channara Chhour	
Laos	Phetvongsinh	
	Chivorakoun	

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

E Perucca began by welcoming Myanmar as the newest Chapter of the region. He also congratulated Sam Wiebe as the President Elect for the Term 2017-21. He stated that Sam Wiebe sent his apologies as he was unable to attend because his daughter was getting married. He remarked that his previous contributions to the Executive Committee have been outstanding and he is confident that he will be a great President. The next step of the elecitons will be for the Management Committee and he urged all Chapters to participate fully.

Continuing, he highlighted the ILAE's latest initiative, a new journal called Epilepsia Open (EO). He likened it to a a daughter or son of Epilepsia. The difference is that EO is an open access journal. Currently there are three editors in chief: Dieter Schmidt Germany

Xuefeng Wang – China

Gary Mathern – USA (also a co-editor of Epilepsia). We want the two journals to work together, hence Gary's appointment.

The primary aim of EO is to rapidly publish robust high quality results that provide insights in all aspects of epilepsy research. Sepcifically, EO will publish peer reiewed, high quality open access articles covering the entire breadth of basic, translational and clinical research in epilepsy. The spectrum of articles may include all disciplines of life and health sciences such as public/global health science and societal impact studies. Article Publication Charges: As a fully open access journal EO requires and articale publication charge ranging from US\$1000 to US\$2000. Waivers and discounts are available. There is an objection that public funded research is then made to be paid for through publishers. The most appropriate way in the future is that people pay a fee to submit papers.

Articiles will be immdeiately open access and freely available to read and download. The journal maintains the highest standards and a rigourouspeer review process. EO ensures quality and reputation supported by the ILAE and Wiley. Authors retain copyright, publised under a Creative Commons license. EO is in compliance with instituional mandates. Authors will benefit from rapid publication.

He thanked the editors for putting together the slides for his presentation to give an introduction for this journal. Today marked the first announcement of this journal. Within the next few weeks the first articles will appear. He thanked everyone for their attention and stated that the CAOA is doing a wonderful job.

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

Helen Cross began by welcoming representatives from Laos and Cambodia where applications to establish Chapters in ongoing. She also welcomed Myanmar as the newest Chapter.

She moved on to explain how the ILAE is formulated into Regional and Topic commissions. One thing that is top of the agenda for the current Executive Committee (EC) is education. How can we initiate more global education? We have some initiatives we wish to share globally.

She described that with regard to Topic Commissions, one of my her tasks as Secretary General is to focus on papers that have been submitted with regard to different topics that have been discussed. Position papers with regard to the managment of learning disability and also management of non-epipleptic seizures.

The coming Sunday, will see a debate between herself and E Somerville regarding the ugrading of classification of the epilepsies for the Taskforce for the definition and description of seizure types. She explained that this information is on the website for the following three weeks and she invited feedback from all attendess.

She moved on to global research priorities and explained that there were papers from the Asian/Oceanian region and Europe on this topic being published in Epilepsia. However, she highlighted the need for a global perspective. Those that have been received are on the website and she invited feedback.

5) Report from CAOA

Annual Report, Byung-In Lee, Chair, CAOA

BI LEE began by stating the John Dunne is the new ASPEA chair and explained that the past year has seen exciting programs.

The 10th AEOC in Singapore saw 1300 delegates attend and he expressed his hope that higher numbers would attend this week at the 11th AOEC. In 2018 the AOEC will go to Bali and that preparations to begin the organisation of that Congress would begin this week.

He moved on to explain the aims and missions of the CAOA which were established in 2006 and the newly added Action plans that were set in place in 2013.

Budget, Leonor Cabral Lim, Treasurer, CAOA

International League Against Epilepsy Asian & Oceanian Affairs - 30			
GL Acc	et Description	Jan-Dec 2015	Budget 2015
	REVENUE		
	EXPENSES		
5083	Publications	\$3,000	\$3,000
5087	Fellowships	\$14,000	\$14,000
5073	Bursaries	\$0	\$0
5088	Awards	\$0	\$0
5096	Meetings	\$1,849	\$22,600
5108	Chapter Convention	\$0	\$0
5097	Other	\$0	\$4,800
5099 5104	Prior Year Courses	\$0	\$0
5104 6152	Website	\$15,836	\$37,000
7111	Other Projects	\$2,000 \$0	\$3,000 \$0
7116	Laos Training Project-S Keosodsay	\$6,000	\$11,400
	TOTAL EXPENSES	42,685	95,800

CAOA Fund Balance:Balance per 2014 Audit Report(258,791)Plus: Singapore Congress Surplus-50%43,877Less: 2015 Expenses(42,685)Fund Balance to date: (257,599)

	2016 Activity	2016 Amount Requested	2016 Amount Approved	Notes
	ASEPA Teaching Courses	\$40,000	\$36,000	Reduced due to budgetary constraints
	ASEPA EEG Examinations ASEPA Fellowship	\$7,500 \$14,000	\$7,500 \$14,000	с <i>г</i>
	11th AOEC Bursaries	\$7,500	\$6,000	Reduced due to budgetary constraints. Please provide information on who will attend the Hong Kong course. Can't this be incorporated into the congress budget?
	Chapter Convention - 11th AOEC	\$6,300	\$6,300	
CAOA	AOEC Awards Joint Symposium with AESC, ISS, AOCN	\$1,000 \$10,800	\$1,000 \$5,400	Reduced due to budgetary constraints
	Summer School in Epilepsy	\$10,000	\$10,000	Due to budgetary constraints, unable to
	Research Task Force	\$3,000	\$0	provide funding. This was scored low by the Budget Committee- more structured initiative required
	Global Campaign: Mandalay, Myanmar	\$8,400	\$8,400	
	Website	\$3,000	\$3,000	
	Newsletter San Servolo Bursary Support	\$3,000 \$6,000	\$3,000 \$6,000	
	Business Meetings (3) - Hong Kong TOTALS:	\$10,360 \$10,860 \$130,860	\$6,000 \$10,360 \$116,960	

International League Against Epilepsy Asian & Oceanian Affairs - 30				
GL Acct	Description	Jan-Mar 2016	Budget 2016	
	REVENUE Seino Fund Support - UCB Japan EXPENSES	2,500		
5083 5087 5073 5088 5096 5100 5108 5097 5099 5104 6152 7111 7116	Publications Fellowships Bursaries Awards Meetings San Servolo Support Chapter Convention Other Prior Year Courses Website Other Projects Joint Initiatives	\$0 0 0 0 0 0 0 0 3,792 0 0 0 0	\$3,000 14,000 6,000 1,000 10,360 6,000 6,300 0 53,500 3,000 0 13,800	
	TOTAL EXPENSES	3,792	116,960	

ASEPA, John Dunne, Chair ASEPA

John Dunne began by stating that above all else we must remember that we are a community. It doesn't matter if it's the ILAE or CAOA; we all have a common purpose, as colleagues and friends, to work together to help our patients. He listed the ASEPA committee members and thanked them for their work.

He explained to all present that the goal of ASEPA is to help their communities by creating initiatvies. He expressed their desire to hear from the Chapters and asked them to approach any of the ASEPA members that he had just listed. ASEPA want to know what they can do to help everyone's communities with regard to education to ultimately help people with epilepsy. He explained that ASEPA has organised educational events in epilepsy care. The clinical epilepsy educational activities ASEPA can deliver include:

- primary care,
- workshops,
- visiting professorships in how to get an epilepsy surgery activity going.

These activities allow ASEPA to link up with new colleagues and friends. He stated that when he doesn't know how to work with a patient, he needs a friend and with the internet he can stay in

touch; everyone can stay in touch. He highlighed the need to create networks where everyone can share eachother's burdens. ASPEA provides support for Congresses and content of same.

Japan Epilepsy Society (JES) offers clinical fellowships in Epilepsy skills. In Australia they offer three monthly fellowships. ASEPA can sponsor people to get to the AOEC meeting and other important meetings in the region. The message is singular – speak to us, tell us what you need. Perhaps it's Primary Care or Presurgical workshop or EEG introductory sessions. ASEPA can deliver this. A lot can be done with a small amount of money. We are all the same, friends working together with the resources that we have to make our community better.

Information Committee – Derrick Chan (rather than Sunao Kaneko)

D Chan began by listing the members of the Information Committee and listed it's goals:

- To promote and facilitate interactions and communications among local chapters, individual health professionals interested in epilepsy care,
- To stimulate communications related to epilepsy care,
- To facilitate communications among Commission of CAOA and Executive Committee of ILAE,
- To provide educational materials,

From the CAOA's action plan for 2013-2017 he highlighted those aims/goals that applied to the Information Committe:

- Construct CAOA and ASEPA Website with its link with ILAE Web and regional Chapter's Web, and Publish News Letter
- Organize a network consisting of information officers from each of the chapters of AOregion

1, Website

CAOA-Website (<u>http://www.caoa-epilepsy.org</u>) was opened in 2011 and has improved significantly. It is currently, under management by JSE company. The structures were remodeled by suggestions from the ILAE and it is linked to the ILAE-website. The linking of CAOA-website to that of individual chapters of the region is possible through the ILAE-Website and direct link to chapter websites is possible to 7 chapters only yet.

Contents should be included are

- ◊ Hands-on summary of epilepsy meetings in the region
- ◊ Slides of didactic lectures and workshops
- \diamond Information of meetings or epilepsy related events in the AO region
- ◊ Epilepsy treatment guidelines of each chapter, if there is any
- ◊ Reports and Documents from CAOA, ASEPA, TFs, or other organizations
- ◊ News and Advocacy from individual chapters.

The objectives of the website are:

- 1. To promote and facilitate interaction and communications among local chapters, individual health professionals interested in epilepsy care.
- 2. Provide educational materials
- 3. Stimulate communications related to epilepsy care

Links to Epilepsia and Neurology Asia are also posted along with updates to aims and missions, the current/upcoming events calendar. He invited all present to send information to be included. He gave a demonstration on how to locate everything on the website, Chapter information and how to access it from the ILAE's website.

Looking to the future he outlined what people can expect to see on the site:

- Reach out to professionals in AO region who are taking care of patients with epilepsy:
 - easier access to treatment guidelines, classification schemes, learning opportunities (e.g. ASEPA EEG exam application)
 - Archive for reports of CAOA, ASEPA and chapters.
- Web-based conferencing /forum and a web-based membership directory (confidentiality concerns)
- Any comments are welcome because we need to improve our website.

2, Newsletters

The First CAOA-Newsletter was published in December, 2012 and the original plan was publishing two times/year. One issue was published in 2013 and 2014. **Two issues in 2015.** He then described in detail the contents of each of these newsletters, back catalogues of which can be found on http://www.caoa-epilepsy.org

He expressed a need for content and invited all present to submit articles for publication especially any information on news/events from Chapters and regional activities. He asked that each Chapter appoint one or two members to liaise with the Information Committee on a regular basis with updates. He asked all submissions be sent to him at <u>Derrick.Chan.W.S@Singhealth.com.sg</u>

The target is to receive one item per Chapter per year (meetings, conferences, lay association events)

RESEARCH TASK FORCE – CT Tan, Chair

CT Tan explained how he would be reporting on behalf of Akio Ikeda who is the co-chair on this task force. The aim of this task force is to promote research in the region. The last task force published the research priorities in the region as Helen Cross mentoned earlier. This can easily be accessed on the website.

The main mean to achieve this goal is through joint research. Two years ago in Singaopore several topics were discussed. One related to stigma involving several countries in the region.

Other projects are currently pending i.e. neurophysiologiy of complimentary treatments, women's issues. He encouraged all present to submit ideas for other projects.

Plans are underway to create a joint effort with the Global Task Force regarding the burden of Epilepsy. He explained that there is a young researchers' presentation session on Sunday afternoon from 3-4pm where three papers have been selected to be presented. Hopefully this will stimulate more work.

GLOBAL OUTREACH TASKFORCE (GOTF) – Ernie Somerville, Chair

E Somerville began by listing recent achievements of the GOTF.

- Myanmar project initiated
- LAO training contiues
- WHO workshop on afdfodability of antiepileptic medications. E Somverville, Shichuo Li and E Percucca represented ILAE
- WHO mhGAP Guidelines. ES has provided input.
- AOEC Singapore Global Campaign Forum
- Numerous and diverse activities across the region by a variety of medical and non-medical organisations, some affiliated with CAOA chapters Japn, Australia.

Epilepsy Society of Australia (ESA) is also engaging in the following activities

- Observership in Australia and Myanmar
- EEG techinician from Australia has visited Yangon and Mandalay.
- Travel Shcolarships by ESA to attend EEG and Epilepsy course in Austalia
 - 2015 Phliippipnes x 4, Myanmar and Laos
 - o 2016 Cambodia x 2, Laos x 2, Phlippines x 2, Myanmar

Indonesian Summer School

- Banjarmasin, S Borneo
- 12-13 August 2016
- 70 attendess, Kalimantan prioritiy
 - Nueorlogists and Padfiatricians
 - 5 psyhchiatrists
- Case based, small group interactive
- Faculty, 7

Epilepsy Burden and Epielspy Care Gap

- Joint project of Global Campaign and Research Task Forces
- 1st meeting this Sunday 0800

On Saturday 14th May between 3pm and 5:30pm in Conference Hall C there will be a Global Campaign Task Force Session. He then listed the content of this session:

Diagnosis

- Epilepsy diagnosis by smartphones. *Victor PATTERSON, United Kingdom*
- Epilepsy diagnosis by smart nurses. Ernest SOMERVILLE, Australia
- Epilepsy diagnosis by EEG: Helpful servant or dangerous master? John DUNNE, Australia

Treatment gap

- The WHO resolution on epilepsy: What does it mean for the future? *Emilio PERUCCA, Italy*
- Overcoming the treatment gap in Laos: Epidemiology study, treatment gap project, Lao Epilepsy Society. *Phetvongsinh CHIVORAKOUN, Laos*
- Overcoming the treatment gap in Laos: Neurology training, EEG service and overcoming the management gap in epilepsy. Chong Tin TAN, Malaysia

On Friday 13 May there will be the Sanofi Satellite Symposium between 4:30pm and 6pm in Theatre 1 and described it's content as follows:

"Paving the way to better access to epilepsy care"

Co-chairs: Howan LEUNG (Hong Kong) and Pierre-Marie PREUX (France).

Improving access to epilepsy care in Cambodia: ECIR programme. *Chhour CHANNARA* (*Cambodia*)

DheVELoP programme: domestic health visitors to improve access to care for people with epilepsy in

Lao PDR – Preliminary results. *Phetvongsinh CHIVORAKOUN (Lao PDR)*

WHO: reducing the treatment gap – The Vietnam project. *Truong Le Van NGOC (Vietnam)*

Developing access to healthcare: what role for the pharmaceutical industry? *Robert SEBBAG* (France)

AOEA & Constitution Task Force (CTF), W Dunne, CTF Chair

This agenda item was not delivered.

Paediatric Task Force, Heung Dong Kim, Chair

This agenda item was not delivered.

12th AOEC, IDM, Richard Holmes

R Holmes began by stating how pleased he was to announce that the exhibition stand space was sold out for the 11th AOEC at Hong Kong. Registrations were slow to begin with and he was quite concerned for the numbers registering. The previous two weeks saw the numbers starting to swell. At the moment 1200 were registered and his hope was to suprass Singpaore. He listed attendance from the top countries as follows:

Hong Kong 256 China 167 Thailand 73 India 59 Japan 55 Indonesia 45 Australia 44 Korea 41 Singpaore 37 USA 30 Philippines 23

44 countries in total.

He expressed his hope that the Congress will be enjoyable and rewarding. He outlined the work in which the IDM Office is engaged including the Eastern Mediterranean Congress in Dubai earlier in 2016 followed by the 11th AOEC Hong Kong, 9th LACE Cancún and the 12th ECE Prague.

He announced that the next AOEC will take place in Bali in 2018 and asked all present to mark 8-11 March of that year in their diaries. Already for 2020 some Chapters have expressed an interest. Requests for more expressions of interest will go out next year.

6) Q & A and general discussion

Helen Cross took to the podium again to discuss the voting and explained that the next cycle will be nominations for the Managment Committee. Nomination forms will go out to the Chapters in late August. She urged all Chapters to participate reminding them that they can only do so if their dues are paid and up to date. She noted that should any Chapters have difficulty in settling their dues, that they can apply to use the ILAE's Solidarity Fund to which Gus Egan can help provide access.

Peter Bergin asked to deliver some information about the EPINET study. Firstly, he asked those who are not paticipating to please join and to encourage juniors to also join in. EpiNet was set up 7/8 ears ago, to increase the number of neurologists and epileptologists in clinical research; to see which treatment is more effective and to run trials. He explained that it is a sophiticated database with 9,500 patients therein, 3,500 of which are from NZ. This is 5-10% of all those with epilepsy in NZ. If they can get 1% of people with epilepsy into the database from the region then so much would be learned. He invited all present to come along to the workshop on Sunday. He also invited all present to set up their own studies and remarked that new trials are also starting this year. Should anyone desire a new trial, they are welcome to do so.

7) Adjourn

Andrew Bleasal closed the meeting