# COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) BUSINESS MEETING

**Date:** Friday 13<sup>th</sup> May 2011

Venue: Amari Bangkok Residence, Bangkok, Thailand Present: SC Li E Somerville JJ Tsai

T Tanaka H Aziz S Kaneko
CT Tan SH Lim Y Chinvarun
V Nadkarni BI Lee J Dunne

## **ITEMS**

## 1. Welcome and Tribute to the Japanese People

BL welcomed those attending, and expressed the sadness and respect that we all feel for the Japanese people, who are suffering from the recent devastating earthquake and tsunami. A minute's silence was held in tribute to the victims of the disaster.

## 2. CAOA Reports

BL presented his recent Commission reports. He outlined the important progress being made in organising the 9<sup>th</sup> AOEC conference to be held in Manila, 21st - 25 March 2012.

## 3. CAOA Budget 2011

JJ described the allocations for the business meeting, educational projects (proceedings, epilepsy fellowships, ASEPA teaching courses, EEG certification). He indicated that we use less funds than budgeted. CT indicated that globally this is not unusual because of various factors, and that the ILAE wishes to raise capital given decreasing income. Money is often saved through sponsorships.

BL indicated the CAOA needed to have at least one face-to-face business meeting per year, and this particular meeting required only five sponsorships given support from other sources.

JJ outlined the different budget items, including: education, fellowships, publications, project planning and staff/administration, the EEG teaching course in Bangkok, and collaborative support for the Infantile Seizure Society (cancelled this year) and Asia Epilepsy Surgery Congress.

The proposed CAOA budget 2011 mirrors that of 2010, with new EEG teaching courses supported, support for the Chinese Summer School and collaboration with other regional congresses. The total request for 2011 is \$116,350.

CT indicated that the CAOA budget alternated from bigger and smaller depending on the year of the AOEC Congress, with support for Chapter participation, and other factors. His preference was to avoid supplementary budgets.

SL indicated that the Chinese Summer School already had support for teaching courses. TT indicated that the JES in order to arrange the annual project budget requires reports from ASEPA.

Action: CT will provide ASEPA report for the JES.

BL stated that it is essential for CAOA to have more interactions with other epilepsy organizations in the region, which are ISS (Infantile Spasm Society), AESC (Asian

Epilepsy Surgery Congress) and he proposed supporting the travel expenses of 2 speakers to these Congresses. Also, CAOA is going to support 3 speakers to the Chinese Summer School, the first international teaching course for young epileptologists in our region that will be held in Chengdu in August.

## 4. Progress reports.

The research task force report was presented by BL, on behalf of Patrick Kwan, summarising the meeting of 26 October 2010, held in Melbourne. A problem-oriented approach will be used with four dimensions. A further planning meeting is to occur on 1 July 2011 to determine the dimension leaders.

## 5. Information committee.

SK provided the minutes of the information committee meeting of October 2010. The CAOA website should be promoted, including being mentioned in epigraph. *Action: JD to contact epigraph.* 

In addition SK requested assistance with respect to the newsletter. JD indicated if he was provided with information that he could assist with formatting and finishing.

CT asked about web traffic and the usefulness of tracking activity. He again mentioned the need to user-friendly addresses such as Epilepsy Asia rather than just CAOA.

SK indicated that he needed information from each chapter, including from the information officers.

Action: CT suggested that the BL write to each chapter for information regarding activities, including educational programs, that could be posted on the website. YC indicated that the word name is very important, and agreed with CT with Epilepsy Asia was effective approach.

HA asked whether the website was to be limited to doctors, and the need for lay people to be informed. It was agreed that the CAOA should focus on medical communication, with the IBE on informing the community.

## 6. JES actions against national disaster.

SK presented information regarding the East Japan earthquake rescue team, outlining the provinces affected, initial difficulties with shelter, food and medications for the survivors. The JES sent 3 teams to the disaster areas, collecting and distributing medications, with a disaster headquarters and information centre in Shizuoka. Fundraising has also occurred and SK gave great thanks for the support already is received. Long-term evacuations are needed because of nuclear contamination.

An improved treatment network, active information centres, and support and funding for the local epilepsy centres are all ongoing.

SK described how at least a number of patients died from status epilepticus because of an absence of access to medication, but no accurate numbers are available.

SK also indicated that the ISS meeting would be deferred to next year, so that there will be a combined meeting, and the venue and dates will be decided later this month.

#### 7. GCAE taskforce.

ES indicated that not a lot of activity had occurred since the AOEC Meeting in Melbourne. This meeting had been an excellent forum for gathering information

regarding the activities, initiatives and programs of the different Chapters, including diverse and creative strategies relevant to local situations.

The main challenge is to define the role of the taskforce. Its most useful function will probably be to provide a means for describing and linking various activities. There is a Global Campaign Website, but not yet a way to interact via this site. The hope is to share information about what is happening in different regions and centres.

BL indicated that many countries are working on the Global Campaign, including China, Pakistan and Timor Leste. HA wondered whether the primary goal of the Global Outreach had changed from reducing the treatment gap to public education, but SL indicated that reducing the treatment gap remained the Primary Goal, and indicated that the term "global outreach" allowed for a greater variety of initiatives, including public education.

CT felt that the CAOA task force should focus on coordination and communication, including between a number of already existing projects. CT indicated the importance of sustainability. Bangladesh has particular needs, and he described the lack of impact of a Burmese project without follow-up.

ES outlined his concern about sustainability being overemphasised, given that diagnostic and educational initiatives, even short-term, can have long-term benefit, particularly when diagnosis is made and ongoing treatment implemented. CT outlined how in Burma about 300 people were treated with phenobarb with good results, then without ongoing funding for the treatment.

VN described the rural outreach in India, with lectures to schools providing inexpensive and highly successful programs. Teaching CDs were provided for viewing in schools, a low cost and effective strategy.

SL indicated that at the forthcoming 9th AOAC meeting in Manila the chapter workshop with chapter presentations will again be very useful, and that the global campaign must work in conjunction with governments to deliver training, education and ongoing care to the poorer areas.

CT described the Laos project. Laos has a 97% treatment gap. CT has and continues to play a key role in the training of neurologists, aiming make the Laos epilepsy project sustainable. This has been possible with JES and CAOA support. So far two neurologists have been trained with a third currently in training.

The role of the short-term programs, including nursing workshops, is to be clarified. HA showed a video of the National Epilepsy Centre in Karachi. He described the public awareness programs and importance of using television and a short documentary played at prime time, with key messages that epilepsy is treatable and people with epilepsy are equal to others other respects. Mr. S Edhi is a famous and respected social worker, and he has described his own experience living with epilepsy. Mr. Edhi's involvement in epilepsy awareness has been powerful force for good within Pakistan. In the video he describes the nature of epilepsy and its treatability.

#### 8. ASEPA

CT provided reports on ASEPA activities, with the five main categories being workshops, fellowships, publication of the proceedings, the EEG certification examination and providing information to be captured for posting on the website. Workshops for 2011 were outlined. He thanked the JES in particular as well as the

pharmaceutical companies for assisting with these workshops, 11 this year.

In 2012, many workshops are already proposed and were outlined.

Fellowship applicants for 2010/2011 have been received, with 4 fellowships offered - at Shizuoka with JES support and two through ASEPA.

The AOEC proceedings will be ready within the next months.

The AOEC workshops were capturing on video and will go on the education page of the AOEC website. What workshops will be recorded at the next AOEC will need to be determined. Information can be provide both as a part of the ILAE education website as well as the CAOA website.

BL indicated that the ASEPA fellowships were variously taken up at different centres in Singapore, Australia, Malaysia and Japan. The Australian English examination provides important difficulties.

BL wondered about setting out about criteria for training centres and their selection. CT indicated that usually Chinese fellows go to Shizuoka, and that Vietnamese medical training is basic so additional training needs be less advanced.

SHL indicated that some applicants choose the sponsoring centre before applying, and one approach is to have applicants nominate the Centre willing to sponsor their training with the application. He indicated that we could provide a list of possible sites where fellows may be able to obtain training.

HA asked about the outcome of the fellowships. CT indicated that the results were excellent, with only one person who's dropped out, a Burmese fellow who was to train in Japan. All others have made important contributions since obtaining their training. He also indicated that given the fellowships were for only \$5000-\$6000, that this amount of money would be inadequate to allow training in many places, such as South Korea and Hong Kong.

BL wondered about providing more funding. SK indicated that JES had funds for two fellows at Shizuoka, but he and TT indicated that soon other Japanese training centres would be providing opportunities to host the Fellowship.

### 9. EEG Certification Examination.

SHL outlined that now 384 people had sat the part one exam, with 239 passing. China is the biggest subscriber. For example, in April of this year 92 candidates sat the exam. The part two exam has been sat by 138 candidates with 86 passing (62.3%).

The certification is a way of assessment driving learning and is useful for raising the standards of EEG performance and reading. Further examinations are planned in Solo and Taipei.

## 10.8th AOEC, Melbourne 2010

BL reported that 1436 people attended, with 474 Australians. There were 109 speakers with 377 abstracts, and prior to the meeting the combined ANZAN/ASEPA EEG course was held.

A large part of the CAOA business meeting was occupied by ILAE executive presentations.

## 11. 9<sup>th</sup> AOEC, Manila, 22<sup>nd</sup> - 25<sup>th</sup> May 2012

The structure is similar to the previous Congress, and this was described and the program

is well advanced. Pre-Congress workshops and teaching are being arranged, and the business and other meetings are being timetabled.

The key timelines were discussed as well as the program: with main sessions, three postmain and 8 parallel sessions. CT indicated that there is a limit to speakers who could be supported outside the region beyond ILAE office bearers. Potential didactic lecture topics were discussed, as were proposed speakers. The number and nature of travel bursaries was discussed.

TT indicated that speakers from Japan would have travel expenses to Manila, so the funds saved can be used for bursaries.

CT suggested asking for 50 bursaries of \$1000 each, in addition to support for chapter representation by Mongolia, Myanmar, Nepal, Sri Lanka and Laos. CT indicated that for low income countries the bursaries were of great importance, and JD agreed that increased participation fully justified attempting to increase the support. Less income is expected from the Manila meeting.

## 12. Constitutional amendments

TT described the need to update the ILAE constitution to reflect modern times and telecommunication developments. TT has chaired the task force since 2009, and has committed two years of careful study to the process. The key amendments were discussed and a summary provided. Key changes include: 15 members comprising the executive committee, six commissions, and reducing three vice presidents to one global vice president.

All chapters will need to be encouraged to support these amendments.

ILAE election timelines are being discussed, since the election process will commence next year. Proposals are for the selection of regional chairs 14 to 16 months prior to the General Assembly.

SL indicated that prerequisite for presidential candidates is at least to served on executive committee once, and emphasized that this was important given the complexities of the job.

#### 13. Chinese Summer School.

SL described this first advance international course in clinical epileptology, that will be held from August 7-14 in Chengdu. About 80 younger neurologists will come from China and other countries. He described the course structure and program, with lectures and practical activities. SL also indicated that the summer School in China would have English as the primary language. TT indicated that participant feedback would be important to collect.

### 14. Global Campaign and Outreach.

SL outlined the Global Campaign, involving the IBE, ILAE and WHO. The Global Outreach does not involve WHO. A newsletter will be developed involving IBE and ILAE, and slogans have been considered including "Dare to dream of a future without epilepsy". Further suggestions are requested.

SL described that now 18 of 31 provinces in Mainland China are involved in the rural program. The central government and local government have invested significant funds, with phenobarb available as well as sodium valproate as an alternative. A total of 91,508

people have been screened, with confirmation of diagnosis in 72,896 - most receiving treatment with phenobarb and 3,664 with sodium valproate.

SL described International Caring Day held since 2007 in China. The 2011 theme will be relating to guiding treatment.

The possibility of an Asia-Pacific epilepsy day was discussed. In Europe, Epilepsy Day is May18th. In the USA, Purple Day is March 26. BL recommended that and Asia-Pacific Epilepsy Day or week be considered at the next Chapter convention.

ES indicated that the IBE chapter should drive this initiative. BL agreed, but felt that in countries with little IBE activity that the ILAE Chapter could take the initiative. HA indicated that epilepsy needs to be marketed, and the higher the profile the better.

## 15. The 5th AESC

BL indicated that the fifth Asian epilepsy surgery Congress is to be held from November 10- 12th 2011, in association with the annual scientific meeting of Hong Kong Neurosurgical Society. Rather than providing funds for 2 CAOA speakers BL proposes arranging a joint session with 4-5 speakers.

TT, one of the founders of the AESC, felt that it was important to join together rather than keep separate. CT agreed, and felt that the separation of the medical and surgical aspects of epilepsy care diminishes both, as does meeting separately. JD agreed that a combined session of the AESC and CAOA was a useful bridge. SHL felt that financial support was less important than building working relationships. SHL indicated that when he was chairman of the CAOA it was suggested that epilepsy neurosurgery be a subcommission, but the neurosurgeons preferred to have an independent and separate body. BL felt that useful starting point would be a joint symposium.

## 16. Mongolian Epilepsy Project.

BL described the national epilepsy program in Mongolia, including difficulties with limited resourcing large, distances and the high costs of transport. A number of health initiatives have been occurring, and the Mongolian Epilepsy Society has an ambitious plan outlined the submission to the CAOA. The submission was discussed in detail. The key issue is what practical support the CAOA can provide. CT described the situation in Mongolia, with 200 neurologists for 2.7 million people. A one-year university course allows someone to be described as a neurologist. The neurologists in Mongolia are therefore poorly trained and there is a large competition for the small population. Another issue is that the CAOA is not a funding foundation. We cannot provide substantial funds, but are able to assist with training key people with epilepsy. SL indicated that some Mongolian patients are referred to Beijing, and that in 2009 proposed visit was unable to proceed because of organisational difficulties. SHL described similar requests when he was chairman of CAOA and reiterated the fact that CAOA is not a funding organization, but we can assist in practical ways with educational workshops and seminars. VN indicated that India had provided assistance to Mongolia in 1998 and she would discover the outcome. TT agreed with the concerns of others with respect to the nature of resourcing. For example EEG machinery was provided to Mongolia, but electricity is unreliable and without maintenance machinery had limited use. CT also described how he arranged air transport fees for transfer of EEG equipment from Australia to Mongolia, with similar results. It was agreed that the CAOA should encourage the Mongolian

Epilepsy Society and provide educational support.

## 17. Epilepsy Outstanding Achievement Award.

It was agreed that the Awards have been a successful initiative, albeit with some teething problems. For the next Awards information will be amended and posted on the website, with amended criteria amended as already discussed in Melbourne, and the possibility of advocacy for the candidates by the nominating chapter could the arranged.

## 18. Travel Support for Chapter Convention in Rome.

It was agreed that using World Bank criteria the poorest countries that Bangladesh, Nepal, Mongolia, Vietnam be supported. Laos and Sri Lanka are currently do not have Chapters, but should be supported if possible.

### 19.Other business.

The neurobiology commission wishes to reach out. SHL indicated they should use their own commission's budget.

An epilepsy surgery in Asia proposal for a demonstration project should be discussed at the AESC.

Recorded by John Dunne, Secretary, CAOA Vetted by Byung-In Lee, Chairman, CAOA