

Meeting of the ILAE/IBE/WHO Global Campaign Against Epilepsy

Friday 22nd October 2010 – Melbourne

Held at the time of the 8th Asian Oceanian Epilepsy Congress

Participants: John Dunne (Australia), MM Mehndiratta (India), Leonor Cabral Lim (Philippines), Shaheen Akhter (Bangladesh), Jeanne Khonghun (Philippines), Josephine C Gutierrez (Philippines), Denise Chapman (Australia), Robert Cole (Australia), Mamta Singh (India), Kavita Shanbhag (India), Manen Gorkhaly (Nepal), Jagdish P Agrawal (Nepal), Frank Gouveia (New Zealand), Grace Tan (Singapore), Tatsuya Tanaka (Japan), Hubert Barennes (Laos), CT Tan (Malaysia), Wenzhu Wang (China), Andrew Beasel (Australia), HV Srinivas (India), Sam Wiebe (Canada), Nico Moshé (USA), Chong Wong (Australia), Toh Wong (Australia), Zarine Ratansha Mogal (Pakistan), Hasan Aziz (Pakistan), Edward Bertram (USA), Byung In Lee (South Korea), Mike Glynn (Ireland)

Present: Richard Holmes and Gus Egan (IDM Office)

In the Chair: Ernest Somerville (Australia), GCAE Task Force for the Asian Oceanian Region

Minutes: Ann Litte

Opening and Welcome

The Chair:

1. Welcomed all those attending and indicated that the main issues to be discussed were
 - o Form Membership of the Asian Oceanian Global Campaign Task Force;
 - o Establish the role of the Task Force;
 - o Report on activities already underway in the region (both GCAE and non-GCAE) or planned for the future;
 - o Suggestions for future activities;
2. Outlined that the first issue was to form the Task Force and to then consider which activities would be undertaken;
3. Suggested that membership of the Task Force could begin with a representative from each ILAE chapter and IBE member association in the region;

Introductions and Reports

The Chair reported that:

1. A first step was to identify activities already underway in the region; the WHO Atlas of Epilepsy Care in the region had been published a few years prior and this report demonstrated what was available;

2. There was a need to complement the epilepsy Atlas by reporting on what was being done to address the issues highlighted in the document. The initial goal was to compile a register of what was available in order to avoid 'reinventing the wheel'. This should apply to both GCAE and non-GCAE activities

Dr HV Srinivas (India) reported that:

1. An important activity in the Bangalore region covering both semi-urban and rural areas, was the street plays or 'skits' that had been used as an educational tool for more than 10 years;
2. On one Sunday each month, a group from the Indian Epilepsy Society travelled to outlying villages to show, through the use of street theatre, the correct facts about epilepsy. The play used a demonstration of a seizure, the common misunderstandings of the condition and its treatment;
3. An important element of the activity was to explain that epilepsy was a treatable disease but that diagnosis and treatment by medical professionals was the correct path to follow;
4. The activity, including a short question and answer period took no more than 15 or 20 minutes and the group then moved to another village. An average of four or five shows were arranged each month;
5. In a country where there was still a very high level of illiteracy, particularly in rural areas, this was a very important and successful way of educating people about epilepsy.

Dr WU Jianzong (China), representing Dr Li Shiduo, reported that:

1. The WHO Demonstration Project in China had been extremely successful and had not been extended further;
2. Government support to people with epilepsy in rural areas, through the provision of free medication had begun in six areas. In 2005, the project had been extended to 10 regions and by 2007 this had increased to 13 provinces. The project was now a national initiative covering 15 provinces/132 counties, representing a population figure of 17 million;
3. The initiative to reduce the treatment gap, included training in town hospitals and the provision of free Phenobarbital. It had been established that the project continued to decrease the prevalence of epilepsy in rural areas.

Dr Hubert Barennes (Laos) reported that:

1. He had begun working in Laos in 2008. Laos was a multi-ethnic country with a population of 6.5 million. Most of the population worked in the cities and it was estimated that there were 52 thousand people with epilepsy;
2. In Laos, epilepsy was known as mad pig disease and even medical staff were ignorant about epilepsy and were afraid of making contact with people with epilepsy, believing the condition to be contagious;
3. Patients don't look for medical care as they have little belief in long term treatment for a disease;
4. Phenobarbital was a first line treatment but was not well known by doctors and was only available in cities. Patients came through Out Patients but there was less than one patient per month.

5. A program focusing on advocacy, awareness, training, follow-up of patients and research had begun in 2008. This program received a small amount of support from Sanofi and two other NGOs – BasicNeeds and Handicap International .

Dr Tatsuya Tanaka (Japan) reported that:

1. Five students from Japan are receiving scholarships valued at US\$5,000 each year;
2. Japan Epilepsy Society also had an international journal ‘Epilepsy and Seizure’ with free access, which was peer reviewed and an important communication tool within the region;
3. Participants to the meeting were invited to submit papers to the publication.

Dr Zarine Mogal (Pakistan) reported that:

1. The treatment gap in Pakistan was 80%;
2. The first epilepsy clinic had been established in Pakistan in 1985.
3. Public health awareness through different means. The message being portrayed was that ‘epilepsy is treatable’. Means of driving home this message included the media, stickers on ambulances, published materials, school workshops for teachers and senior students;
4. Awareness posters for schools and public places were being used and free camps, providing a range of activities, were also arranged in different regions;
5. GPs were also being trained in epilepsy care with 1-week intensive learning courses. Other activities included epilepsy day, walk for awareness campaigns;
6. A national epilepsy centre was established in April 2007 and the monthly cost for AED supply was less than one dollar;
7. Awareness had been improved in 40% of the population and this was considered a good achievement. A prominent personality, a social worker of international repute, had come ‘out of the shadows’ and this had helped.

Dr Jagdish P Agrawal (Nepal) reported that:

1. There was an epilepsy clinic in Kathmandu as well as two others in the Himalaya foothills;
2. The Nepal Epilepsy Society had a monthly programme for doctors, not only in Kathmandu but also outside the capital. The programme provided updates on epilepsy care and management;
3. The mountainous terrain of Nepal made it difficult for people to access care. Unlike Pakistan, there was no organised system for raising awareness. However, AEDs were available and were subsidized.

Dr Mamta Bhushan Singh (India) reported that:

1. An unusual method of providing epilepsy care was arranged through an outreach project, the Lifeline Express Train. Dr Singh worked two to three days a month on the train, which travelled to rural India.
2. The train, which also provided care for other medical problems, such as cataracts, had been working for 20 years. The train visited a new village every month and remained in the village for about three weeks;

3. She travelled to the train once a month and spent the weekend working there. On average between 150 and 200 people with epilepsy would present at each venue and would not have had any other treatment. Where possible, a diagnosis was made and treatment started;
4. Travelling to villages also gave the opportunity to raise awareness locally and to meet local neurologists, who also helped out. In the evenings talks were given to schools and local GPs. People were still doing strange things believing these would cure epilepsy.

Dr Kavita Shanbhag (India) reported that:

1. She was attached to the Mumbai chapter of the Indian Epilepsy Association. The association provided counselling, AED support, and used drama as a means of education. The association went to schools to deliver talks;
2. A special interest of the chapter was rural camps, which were held every eight weeks at a distance of 80 km from Mumbai. The camps had a doctor and provided information on epilepsy as well as basic low cost AEDs for children. The camps were supported by the Indian Trust;
3. A follow up to the camps showed that they had improved compliance; a significant number of patients had obtained a good level of seizure control, and some had undergone surgery. Most importantly, the camps had introduced a shift in perception of epilepsy in rural areas;
4. The treatment gap of 11 years was due to non-affordability of AEDs.

Dr Leonor Cabral Lim (Philippines) reported that:

1. The Global Campaign had been launched in the Philippines in September 2001 and there were ongoing campaign activities. There had been attempts to involve the government, but without success. Activities included provision of information, awareness raising, healthcare delivery and advocacy;
2. An epilepsy week, recognised by the government, was first launched in 2001 and the 9th Epilepsy Week had been celebrated in September. The event attracted a good level of radio coverage;
3. In September 2009 a schools caravan was introduced, which went from school to school. Children were encouraged to learn about epilepsy through song and dance and already 100 schools had been covered;
4. An epilepsy camp was started in 2008, and epilepsy exemplar awards had been introduced;
5. A healthcare delivery epilepsy manager program had been created. The program ran over the course of 10 months, with intensive tutorials running for 1.5 days each month, followed by an oral exam. Each course was run in a different region and the Philippine League Against Epilepsy was now looking for two new locations for the next courses.

Dr Shaheen Akhter (Bangladesh) reported that:

1. The association in Bangladesh ran a health camp for children every Friday. This had been ongoing for about 17 years and provided a free epilepsy clinic. The camps were very crowded and it was difficult to get a full medical history. Of the 1050 children who had been examined, 77 had been diagnosed with epilepsy. The mean age was 6.4 years. In 24 cases the parents had never heard of epilepsy and were mostly underprivileged people. Usually there were other medical problems and epilepsy was not seen as a major problem;

2. The association was producing, with support from the IBE Promising Strategies Fund, a short film that will be shown on TV;
3. As a result of some community work, it had been established that information and education on issues related to epilepsy and pregnancy was required. Most people diagnosed with epilepsy had been born at home;
4. The association believed that the government should be committed to providing minimum healthcare to everyone.

Dr Man Mohan Mehndiratta (India) reported that:

1. A drama documentary, which ran for 15 minutes, had been created. The drama could be shortened to 15 – 30 seconds for us on TV;
2. A bookmark that contained information on epilepsy had been created;
3. *Guidelines on Epilepsy Management in India* had been published and was a valuable reference tool for family doctors and local physicians;
4. The Delhi branch arranged educational courses in two or three places every month.

Dr Byung In Lee (South Korea) reported that:

1. The 2003 Disability Act in Korea had established epilepsy as a separate disease. As a result, people with epilepsy cannot be discriminated against and must be recognised as persons with a disability who are entitled to support;
2. A major success was the name change for epilepsy, which was now labelled as 'cerebro electric disorders';
3. New driving legislation, adopted in 2010, allowed persons with epilepsy who were two years seizure free to obtain a licence to drive. In the case of a single unprovoked seizure, this was reduced to a one-year ban;
4. A new Korean Epilepsy Association, helping people with epilepsy to stand up for their rights, had also been founded in 2010.

General Discussion

It was discussed that:

1. The reports had shown a lot of good ideas that could be used in other countries and it would be beneficial to have the Power Point presentations, shown during the meeting, uploaded to the Global Campaign website;
2. Participants who had used Power Point presentations in their reporting would be asked to provide their presentation to Ann LITTLE ibedublin@eircom.net, who maintained the site. Any prior permission from people shown in the presentations should be sought before submitting presentations;
3. While all of the projects reported on were very impressive, there was concern that some lacked sustainability. Efforts should be made locally to see how short term projects could be made sustainable and this could be added to the presentation;
4. In Pakistan, the involvement of young doctors in programs helped to ensure sustainability;
5. In the Philippines, projects had been ongoing for 10 years. A new government had recently assumed office and it was hoped that it would be more sympathetic towards epilepsy;

6. There were two issues to focus on for the Global Campaign: the first was diagnosis and treatment and the second was education. Treatment on its own was not sufficient. In India sustainability was an issue with regard to AED compliance. People with epilepsy had to leave their jobs to travel to health centres to obtain medication. This entailed loss of income as well as the expense of travelling to a health centre and, as a result, patients did not often adhere to their medication. To overcome this, primary care workers were provided with AEDs and travelled to patients' houses to deliver the medication.
7. While sustainability is important, short-term activities can be beneficial. For example, as diagnosis and initiation of treatment need happen only once, a short-term intensive effort to diagnose and initiate treatment may be effective. However, ongoing treatment must be sustainable. A mix of short-term and sustainable long-term approaches may be the best approach;
8. It was important to identify people with epilepsy so that they could be provided with appropriate medication. However, it was also worse to begin someone on AEDs and for the medication to then stop.

Developing a New Message

It was reported that:

1. The Global Campaign Secretariat was looking to create a new message for the campaign and invited participants to submit their ideas. For example, what one-line message would you like to give to your government - i.e. what was the one thing you would like your government to do for people with epilepsy;

It was discussed that:

1. In many countries it was an uphill battle to encourage governments to recognise epilepsy as an important health issue. This was understandable where there were other important health issues such as life-threatening dehydration. In developing countries infectious diseases were usually the focus of governments;
2. In Pakistan nutrition was a problem however, as well as providing Vitamin A doctors could also show how important it was to treat epilepsy. Parents could be shown that, unless they received AEDs, children with epilepsy would have difficulty continuing their education and ultimately finding work to support the family. These were also important issues to present to governments;
3. Epilepsy had a lot of flow on consequences in addition to seizures, such as employment, burns, drowning, etc. Epilepsy was not just seizures;
4. Until recently the Japanese government believed the Highligns Jackson definition of epilepsy. The Japan Epilepsy Society held meetings to show that epilepsy caused serious problems and could be difficult to treat. The importance of having frequent meetings between health ministries and epilepsy organisations should not be underestimated;
5. In Laos, the situation for people with epilepsy was terrible 20% of persons with epilepsy died within two years of developing the condition and the government needed to be made aware of these statistics;
6. Different slogans might be needed for different regions and for different audiences. For example, the slogan in a developed country might not translate to a developing region. Likewise a message for government that epilepsy was dangerous might not be suitable for public use. Slogans should be adapted for each audience;

7. The meeting had not discussed the major issue that people with epilepsy faced, which was stigma. In China up to 95% of persons with epilepsy were stigmatized and it was considered that more suffering was caused by stigma than by the disease itself;
8. There was a need to be aggressive in sending out messages about epilepsy. Cancer was not a benign condition and people were not afraid to say that cancer kills however many people had difficulty saying that epilepsy kills. At least in the USA, it seemed that the worst case outcome had to be used in order to raise awareness.

Plans for Future Activities

It was discussed that:

1. There was a lot of activities going on in the region and it would be beneficial to have information coordinated so that it could be shared;
2. It was likely that the Task Force would not be able to meet on a regular basis – possibly only at the time of the ADEC every two years. It might be possible to meet at the International Epilepsy Congress, but this would still limit face to face meetings to once a year. Email and the website were options for ongoing communications and any other suggestions would be welcomed;
3. It was noticeable that the WHO had not been mentioned during the meeting. Yet, without the WHO the China project would not have happened. The WHO was a partner in the Global Campaign and it would be important to use them in applying pressure to governments. IBE and ILAE had worked very hard in the Latin American region and this work was about to bear fruit with a meeting with PAHO;
4. Governments must be made aware that epilepsy can kill. How to reduce the treatment gap was important and governments needed to be informed of the benefits in this. A lot of people with epilepsy were still not treated;

It was agreed that:

1. Participants to the meeting would forward any ideas for future collaboration and future direction. In the meantime Dr Ernest Sorevil would keep in contact with the group, who were thanked for their attendance.

There being no further issues to be discussed, the meeting adjourned.