

## *The ILAE/IBE/WHO Global Campaign against Epilepsy: an IBE perspective*

Needless to say, the ILAE/IBE/WHO Global Campaign also featured during this conference. On the Sunday afternoon at the close of the conference a plenary session was organised for all participants, including the medical professionals.

During this session a special emphasis was placed on the role of IBE commissions in the Campaign. A number of ILAE Commissions are already involved in the Campaign, for instance the Commission on the Burden of Disease. It's sub-commission on Outcome Measures and Personal Aspects of the Burden of Epilepsy, under the leadership of Gus A. Baker who, incidentally, is also the chair of the IBE Commission on Research, developed outcome measures. These can be used in the Demonstration Projects in order to prove that treatment is cost-effective and beneficial to the economy of a country.

However, no clear statements had ever been made about what IBE Commissions can do for the Campaign or for that matter what the Campaign can do for the Commissions.

In order to shed more light on the role of our Commissions, the chairpersons of the following three Commissions were invited to talk on this topic:

- John Chaplin on the Campaign and Employment
- Judy Cochrane on the Campaign and Education
- Philip Lee (\*) on the Campaign and Fundraising

John explained that in many countries with developing economies, people with epilepsy are unable to obtain the medication that would relieve them from experiencing seizures. As a consequence they are unable to fulfil their potential, particularly in the realm of employment. The loss of a potential workforce and the economic and financial benefits that are lost as a result of this is a handicap that no person or country should endure. However, convincing arguments in favour of allocating resources to closing this treatment gap have to be based on hard evidence.

Employment is a crucial element in building a useful and valuable life and therefore should play a decisive role in the Campaign. The role of the Employment Commission is to encourage dialogues on employment. These dialogues should aim at identifying the economic burden of epilepsy in terms of loss of employment and earnings. Furthermore, dialogues should be developed between employers and people with epilepsy and their representatives on how to overcome the barriers to employment. The latter dialogue can be initiated by setting up employers' forums similar to a European initiative. Also, employment projects can be set up to demonstrate that people with epilepsy can make a real contribution to their community. Attempts should be made not only to involve WHO and its Regional Offices but also other UN Agencies such as the International Labour Office.

Judy Cochrane, together with Stefan Heiner and Susanne Lund reported on the role of our Public Education Commission in the Campaign. Together they highlighted a number of activities of this Commission. They spoke about the Moses project, which was developed

by Sybille Ried, a member of the Commission, which aims at the education of the person with epilepsy. Furthermore, they spoke about their ideas concerning the production of a non-verbal video, under the aegis of the Campaign, which could be used globally and still send out the powerful message of what people with epilepsy can achieve rather than what they cannot achieve.

Phil Lee stood in for the chair of the Commission on Fundraising (\*) and explained how the Global Campaign may be used by chapters and Commissions in order to raise not only awareness but also funds.

He explained that the ILAE/IBE/WHO Campaign against Epilepsy is raising the world's awareness of epilepsy, which creates numerous opportunities, for instance for the IBE chapters to enhance their fundraising. He then gave 5 examples to explain the meaning of his words:

***The Global Campaign Brand provides:***

- a clear, simple and recognisable logo
- a clear and consistent message: “Out of the Shadows”
- the endorsement from IBE, ILAE and WHO; endorsement builds authority which creates trust and confidence
- the Global Campaign is relevant to every country, it has universal appeal

***Global Campaign Materials are provided, such as:***

- Regional Declarations as campaigning tools: a European and an African declaration have already been developed and have been adopted in the respective regions
- reports on the current states of epilepsy services
- proposals for change
- Demonstration projects: The ILAE/IBE/WHO Campaign in action!
- Promotional materials such as posters, leaflets, brochures, reports, etc

***Increased Awareness***

The Global Campaign is raising people's awareness. This increased awareness can be turned into money as well as changing attitudes. It is clear that the following audiences are becoming more aware of epilepsy and are at the same time providing fundraising targets:

- the general public: they provide private donations
- people with epilepsy and their families: they offer membership opportunities
- the media: they offer support for your fundraising messages
- the corporate sector, trust funds and foundations: they provide donations
- governments and departments of health: they offer grants

***Global Epilepsy Day***

- national Epilepsy Days/Weeks already exist in many countries
- a Global Epilepsy Day is one ambition of the Global Campaign: this will provide a positive focus for interest, activity and fundraising projects

### ***Building of long-term fundraising capacity***

This may be done by:

- using the Global Campaign and its opportunities as a start and not as an end
- following up the contacts made, thus establishing long relationships with supporters and donors: go back and ask again, again and again.....

In short, he said: take advantage of the Campaign brand and the Campaign's materials, and use the increased awareness to raise money. Furthermore, support and use the Global Epilepsy Day as a focus, and finally, plan for the long term.

Phil finished his presentation by emphasising that fundraising does not happen by itself: the opportunities are there but the Chapters have to act to take advantage of them and to capitalise on the Global Campaign. The Campaign is the vehicle. However, the appeal is for epilepsy and for people!

Three of the IBE Commissions, through their chairs, explained how they could contribute to the Campaign by offering their knowledge and expertise, but also how the Campaign can assist them in the work they are doing. And this is in fact what the Campaign is all about: it is a partnership, it involves joining forces, for that is the only way in which we can conquer myths and prejudice and offer appropriate knowledge and training instead. In doing so we will be working towards diminishing the treatment gap. We will help and create a world where treatment is available and affordable to all people with epilepsy, wherever they live! With the support of our partners, ILAE and WHO, our Commissions and our Chapters we will be doing just that!

(\*) Philip Lee was the previous chair of this Commission, he is now IBE's President.

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