

Global Campaign Against Epilepsy

A survey of IBE members and ILAE chapters to assess activity carried out at national level in relation to the Global Campaign Against Epilepsy

February – March 2008

**Philip Lee
Co-Chair, Global Campaign Against Epilepsy**

CONTENTS

Executive Summary.....	3
Purpose and Objectives.....	4
Methodology.....	4
Response.....	4
Organisations and countries claiming not to have used the Global Campaign.....	7
Regional distribution.....	7
Economic profile.....	7
Reasons given for not using the Global Campaign.....	8
Future use of the Global Campaign.....	8
Organisations and countries claiming to have used the Global Campaign.....	9
Regional distribution.....	9
Economic profile.....	11
What the Global Campaign has been used for.....	12
When the Global Campaign has been used.....	13
How the Global Campaign has been used.....	13
The success of Global Campaign activity.....	14
Future use of the Global Campaign.....	15
Limitations.....	16
Conclusions.....	16
Recommendations.....	17
Appendix 1... Survey Questionnaire	17
Appendix 2... Additional comments from questionnaires	24
Appendix 3... List of responding countries	30

Executive Summary

- The survey was conducted to quantify activity undertaken at national/local level in support of or on behalf of the Global Campaign against Epilepsy and to make a limited assessment about the impact of that activity.
- 96 ILAE chapters, 88 IBE full members and 20 IBE associate members in 111 countries were contacted by email with an English language questionnaire containing seven closed questions.
- 75 organisations from 60 countries responded to the survey. 51 organisations (68%) were IBE members. 24 (32%) were ILAE chapters.
- 16 organisations from 14 countries reported no activity. Inactivity is a consequence of a lack of understanding and awareness about how to access the Campaign. It is not the result of any antipathy toward the Campaign.
- 59 organisations in 48 countries reported some sort of activity. 41% of the countries represented are European. The combined population represented by the 48 countries is 3.81 billion people, 56% of the world's population.
- 30 of the 48 countries (62%) are classified by the World Bank as high income or upper middle income countries. Only 8 (17%) are classified as low income countries.
- The types of activity carried out reflect the Campaign's priorities. Public awareness and stigma reduction programmes are the most frequently reported activity.
- Participation in the Campaign has grown steadily but has levelled off since 2005. However, 53 organisations (71%) in 41 countries (68%) report they will be using the Campaign in the future regardless of whether or not they have used it in the past. Only 1 organisation said it wouldn't be using the Campaign.
- The most popular use of the Campaign is the slogan "Out of the Shadows", used by 71% of actively involved organisations.
- 39 organisations (66%) report their Campaign activity to be either very successful or moderately successful. Only 4 (7%) report their activity was not very successful and only 1 (2%) reports no success at all.

Purpose and Objectives

To identify and simply classify activity undertaken at national/local level in support of or on behalf of the Global Campaign Against Epilepsy and to make a limited assessment about the impact of that activity.

Methodology

A survey questionnaire in English was sent out by the Executive Director of IBE in the name of the Global Campaign Co-Chair, Philip Lee, by email attachment on 25-27 February 2008 to 204 organisations, 96 ILAE Chapters, 88 IBE Full members and 20 IBE Associate members in 111 countries. A follow up reminder email with the same questionnaire was sent to the same email list on 25 March 2008. A list of the countries that responded to the survey is presented in Appendix 3.

It is believed that in 5 countries the ILAE Chapter and the IBE member are in effect the same organisation, (Bangladesh, China, Guatemala, Senegal and Slovenia), and in a further 2 countries it is likely that they are the same organisation, (Cuba and Uganda). Adjusting for this duplication would reduce the size of the survey to 197 organisations.

A copy of the survey questionnaire is appended to this report in Appendix 1.

The survey contained 7 questions in total. 3 questions applied to organisations that were not active in the Campaign, 6 questions applied to those that were active. All questions were closed but 4 had open sections for a narrative response. The narrative responses are reported in full in Appendix 2.

The questionnaire was headed by a request for some personal data of the person completing the form. This was used to validate the response as being from a credible source.

Response

To 16 April 2008, 75 organisations responded (37% of 204) from 60 different countries (54% of 111).

These 60 countries represent a combined population of 4.2 billion people, (63% of the world's estimated total population at March 2008 of 6.7 billion).

51 IBE members responded (47% of all IBE members contacted and 68% of the total response). 24 ILAE chapters responded (25% of all ILAE chapters contacted and 32% of the total response).

In the case of only 12 countries was there a response from an ILAE chapter and an IBE member.

In 6 instances (Argentina, Australia, Greece, Malaysia, Mexico and India) the chapter and the member submitted separate responses. With the exception of Australia and Mexico, the separate responses were consistent in reporting that there was activity.

In the case of Australia, the ILAE chapter did not identify any Campaign activity. One IBE member did identify activity and one other did not. In the case of Mexico, the IBE member identified Campaign activity but the ILAE chapter did not.

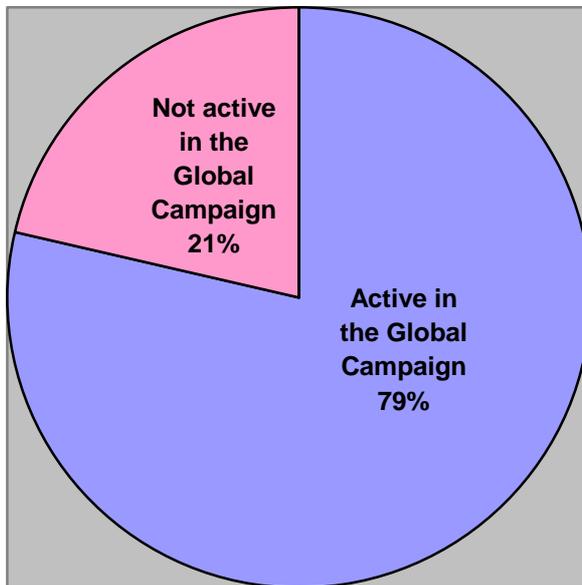
In 6 instances (Bangladesh, Belgium, China, Mongolia, Slovenia and Venezuela) one response was submitted on behalf of both the ILAE chapter and the IBE member.

There were responses from 3 different IBE members in Switzerland. Each one identified Campaign activity.

16 organisations (21% of the 75 responding organisations) in 14 countries (23% of the 60 countries responding) said they had not used the Global Campaign.

59 organisations (79% of the 75 responding organisations) in 48 countries (80% of the 60 countries responding) said they had used the Global Campaign.

Figure 1: 75 organisations active or not active in the Global Campaign



The regional distribution of the survey as a whole matches well with IBE's overall regional distribution across 89 countries. It is not such a good fit with ILAE. This reflects the 2:1 bias in favour of IBE in the responding organisations.

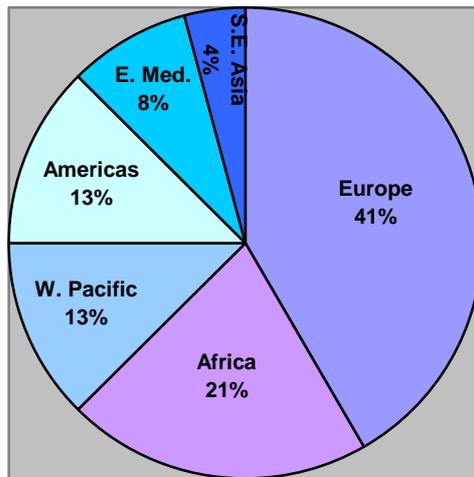


Figure 2: Survey responders

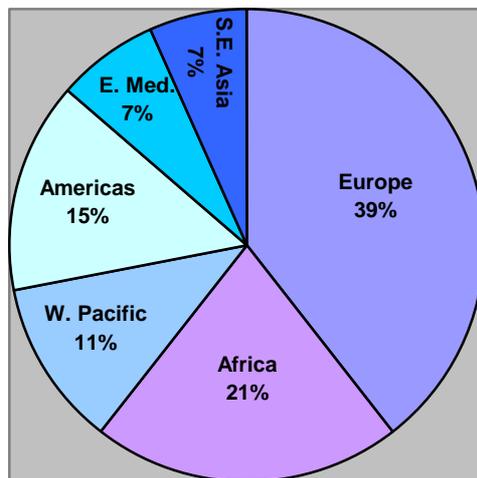


Figure 3: All IBE members

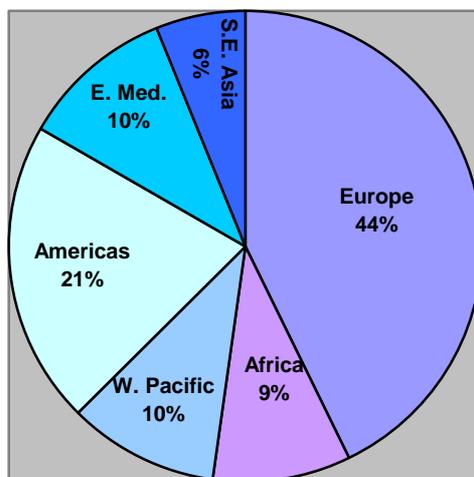


Figure 4: All ILAE chapters

Organisations and countries claiming not to have used the Global Campaign

16 organisations (21% of the 75 organisations responding) in 14 countries (23% of the 60 countries responding) said they had not used the Global Campaign. 10 organisations were IBE members. 6 organisations were ILAE chapters.

Table 1: Organisations and countries claiming not to have used the Global Campaign

COUNTRY	IBE	ILAE
Albania		✓
Australia	✓	✓
Bangladesh	✓	✓
Colombia	✓	
Hong Kong	✓	
Iran	✓	
Jamaica	✓	

COUNTRY	IBE	ILAE
Lebanon	✓	
Lithuania	✓	
Mexico		✓
Netherlands		✓
Taiwan		✓
Thailand	✓	
Togo	✓	

Table 2: Regional distribution

There is no apparent significance in the regional distribution of countries not participating in the Campaign.

Region	Number of organisations	Number of countries
South East Asia	4	3
Eastern Mediterranean	2	2
Europe	3	3
Western Pacific	3	2
Americas	3	3
Africa	1	1
Total	16	14

Table 3: Economic Profile – World Bank Income Group, (based on 2006 GNI data)

5 countries are classified by the World Bank as high income countries. 2 are classified as low income countries.

Gross National Income	Number of organisations	Number of countries
High income, \$11,116 or more.	6	5
Upper middle income, \$3,596 - \$11,115	2	2
Lower middle income, \$906 - \$3,595	5	5
Low income, \$905 or less	3	2
Total	16	14

Table 4: Reasons given for not using the Global Campaign

Reason for not using the Global Campaign	Number of organisations	Number of countries
We do not know how to use the Campaign	9	8
We did not know we could use the Campaign	6	5
We do not know why we have not used the Campaign, we just haven't.	3	3
The Campaign is not relevant or useful to our activities	1	1
Other reason(s) New member of IBE (x2) New person in organisation (x1) Lack of support from WHO (x2) Lack of support from Global Campaign (x1) Unsure of how to apply (x1)	7	7

The two most commonly given reasons for not using the Campaign were not knowing how to (nine organisations) and not knowing it was possible to do so (six organisations). Two organisations claimed lack of support and co-operation from WHO locally had prevented their participation. One organisation said lack of support from the Campaign itself had stopped them.

It is apparent that it is not antipathy towards the Campaign that prevents ILAE chapters and IBE members from becoming involved. The obstacles are more practical and can be removed by clearer information on how to access the Campaign.

Future use of the Global Campaign

Twelve organisations said they would use the Campaign in the future. Only one said it wouldn't. One didn't answer and two didn't know.

Organisations and countries claiming to have used the Global Campaign

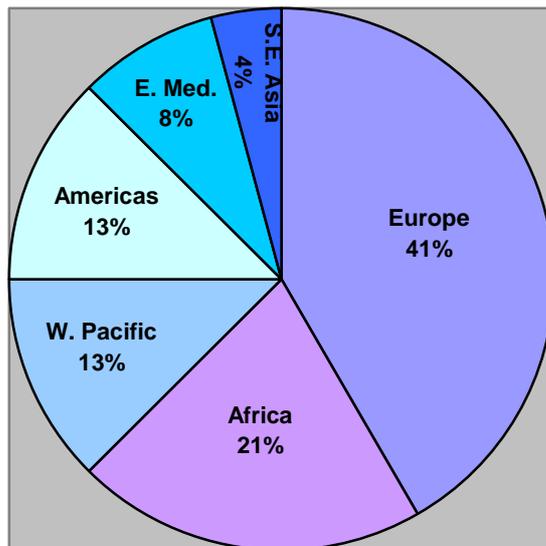
59 organisations (79% of the 75 organisations responding) in 48 countries (80% of the 60 countries responding) said they had used the Global Campaign.

Of the 59 organisations claiming to have used the Campaign, 41 were IBE members (70%) and 18 were ILAE chapters (30%).

Table 5: Regional distribution

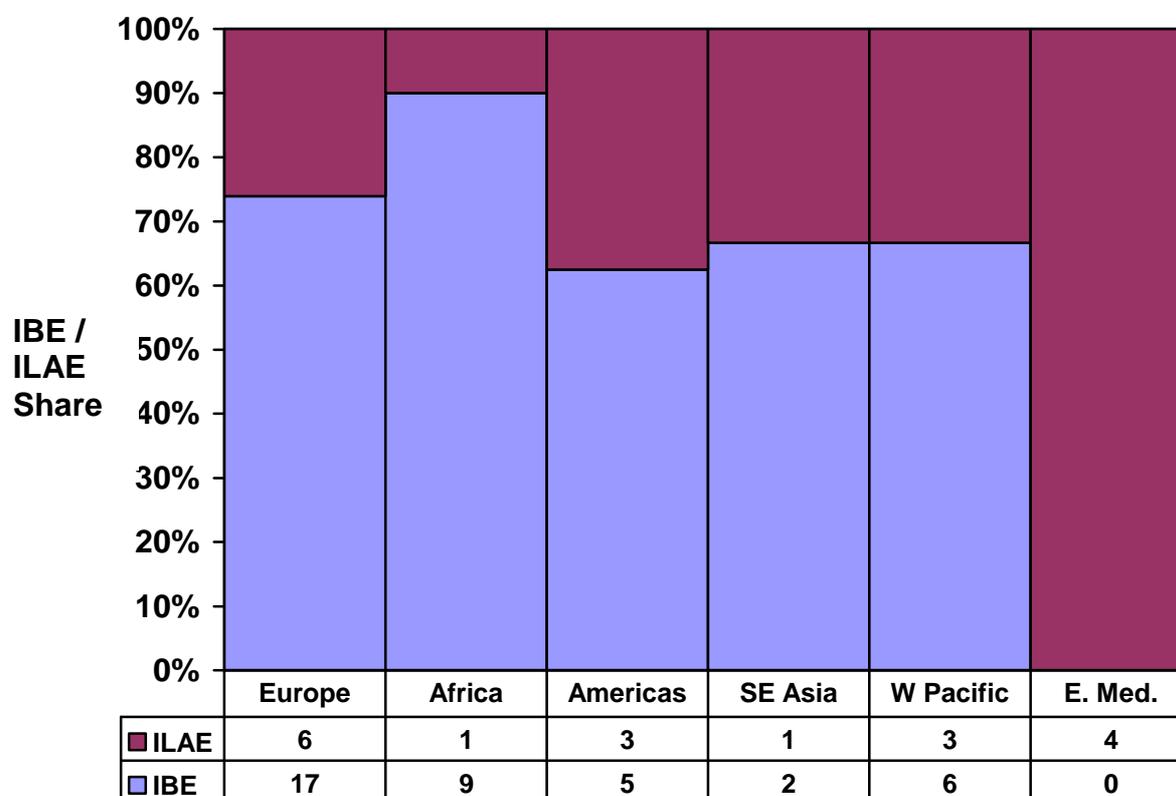
	IBE		ILAE		Total	
	Number of members	Number of countries	Number of chapters	Number of countries	Number of organisations	Number of countries
Europe	19	17	6	6	25	20
Africa	9	9	1	1	10	10
Western Pacific	6	6	3	3	9	6
Americas	5	5	3	3	8	6
E. Mediterranean	0	0	4	4	4	4
South East Asia	2	2	1	1	3	2
Total	41	39	17	17	59	48

Figure 5: Regional distribution of 48 countries reporting Global Campaign activity



41% of the total response came from Europe, perhaps reflecting IBE's and ILAE's European predominance.

Figure 6: Regional distribution of 48 countries active in Global Campaign – IBE/ILAE share



Number of countries active in Campaign

This shows the dominance of IBE members over ILAE chapters in the survey in every region except the Eastern Mediterranean where no IBE member reported any activity. The responses from Africa and Eastern Mediterranean perhaps reflect the relative strengths of IBE and ILAE in these regions.

Note that 48 countries in total reported activity but this analysis shows 57 countries. This is because there was a response from both the IBE member and the ILAE chapter in 9 countries.

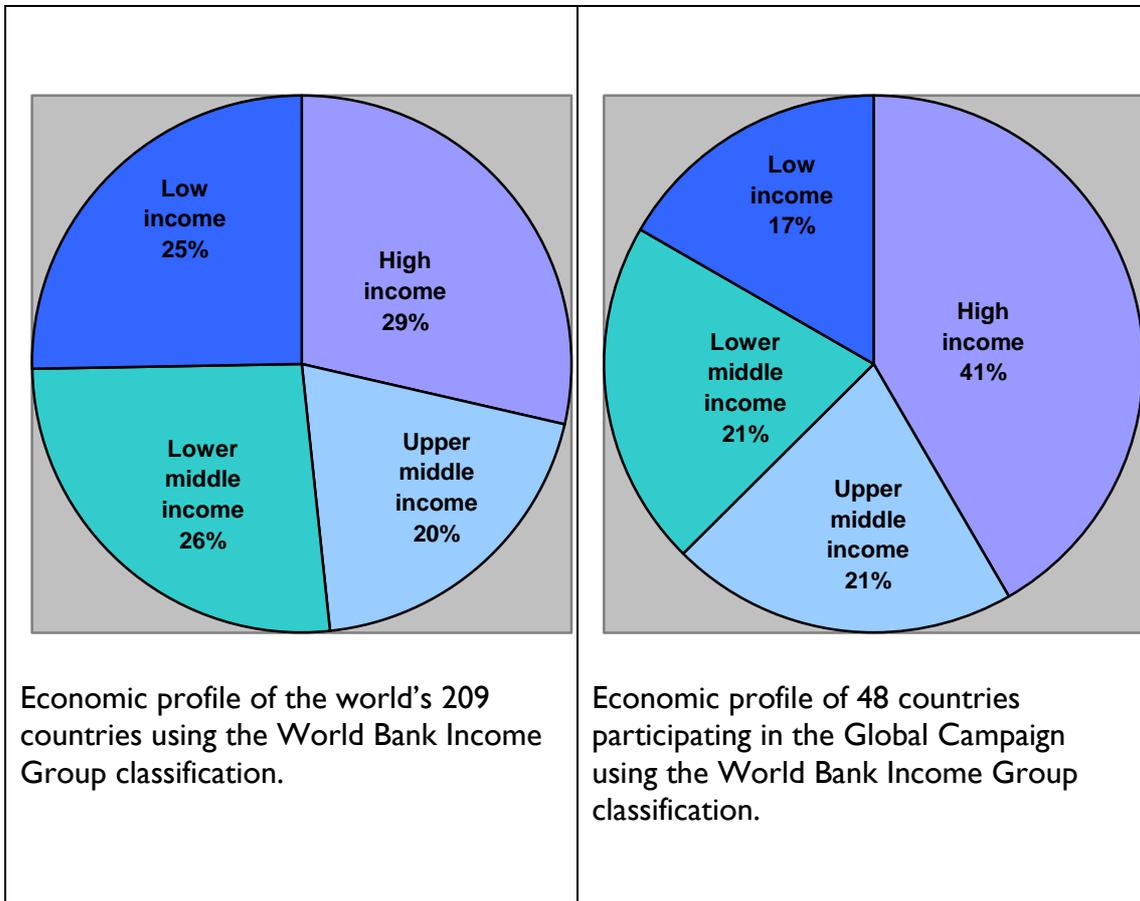
The 48 countries reporting Global Campaign activity represent a combined population of 3.81 billion people, (57% of the world's estimated total population at March 2008 of 6.7 billion). However, activity in China and India alone represents 2.4 billion people.

Table 6: Economic Profile – World Bank Income Group, (based on 2006 GNI data)

30 countries (62%) are classified by the World Bank as high income or upper middle income countries. Only 8 (17%) are classified as low income countries.

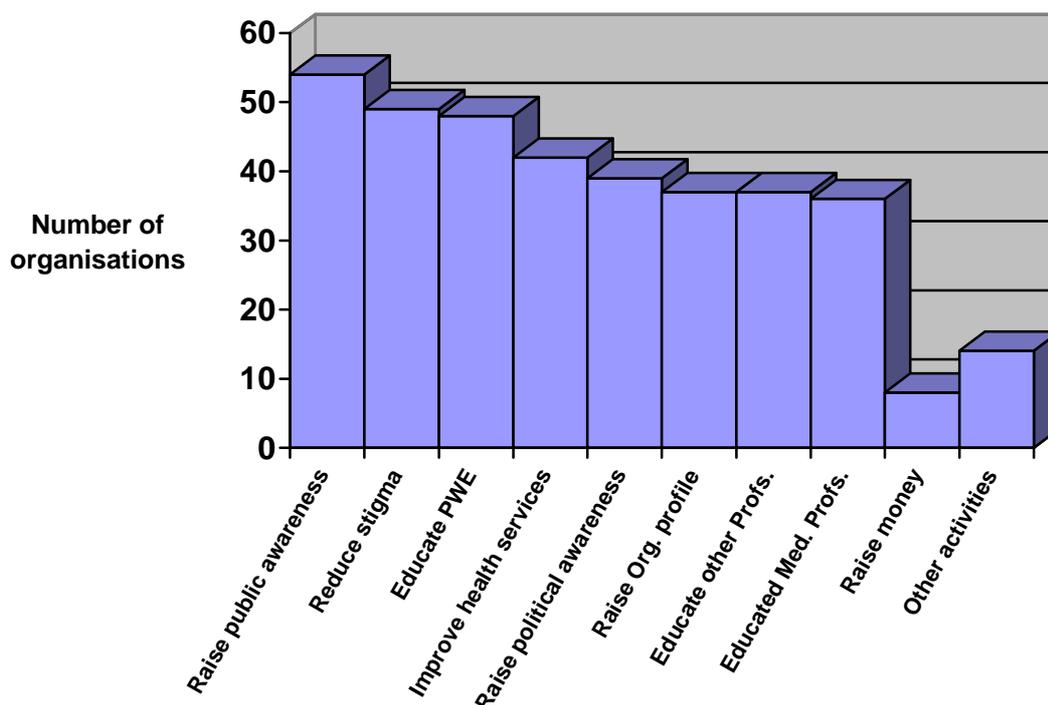
Gross National Income	Number of organisations	Number of countries
High income, \$11,116 or more.	25	20
Upper middle income, \$3,596 - \$11,115	13	10
Lower middle income, \$906 - \$3,595	11	10
Low income, \$905 or less	10	8
Total	59	48

Figure 7: Economic Profile – World Bank Income Group, (based on 2006 GNI data)



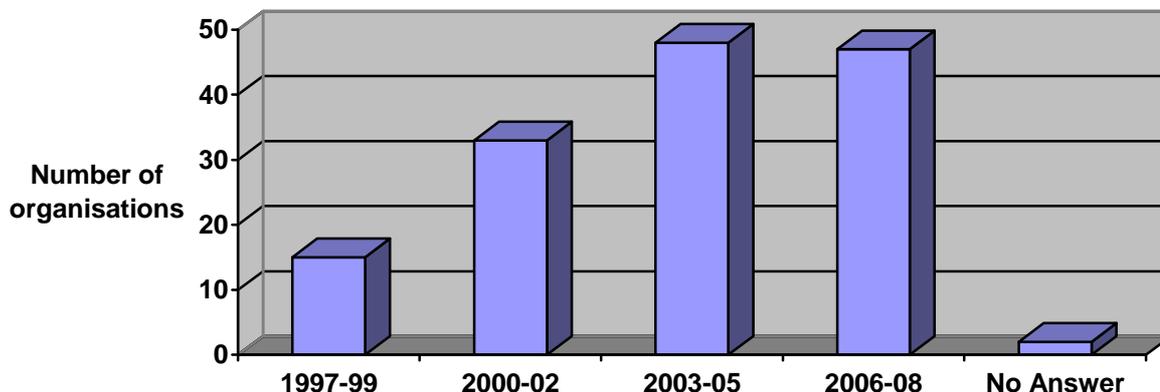
51% of the world's countries are classified by the World Bank as either low income or lower middle income. By comparison, these income group countries make up only 38% of the 48 countries reporting Global Campaign activity. Comparison of the above shows a disproportionately high number of high income countries participating in the Campaign and a correspondingly low number of low income countries.

Figure 8: What the Global Campaign has been used for



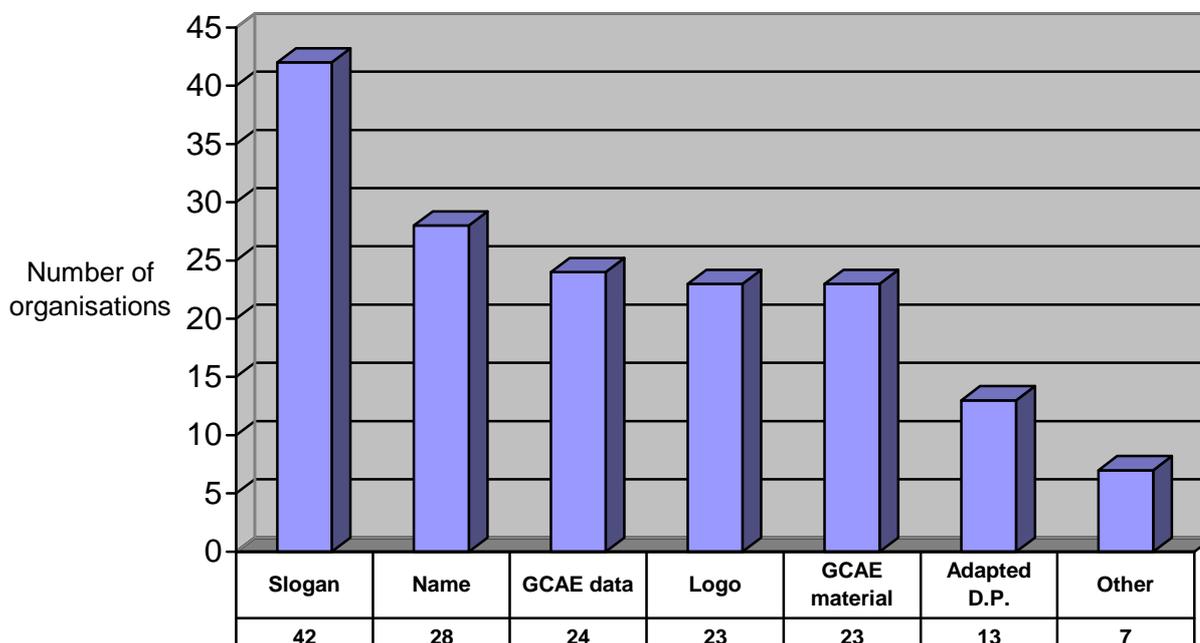
These activities and their frequency of occurrence seem to reflect the priorities of the Campaign. Only 5 organisations did not report public awareness as one of their activities. Only 9 did not report stigma reduction activity. The education of people with epilepsy and their families was more reported than the education of medical professionals or other professionals. This probably reflects the bias of IBE members in the overall response. There were only 8 reports of the Campaign being used to raise money.

Figure 9: When the Global Campaign has been used



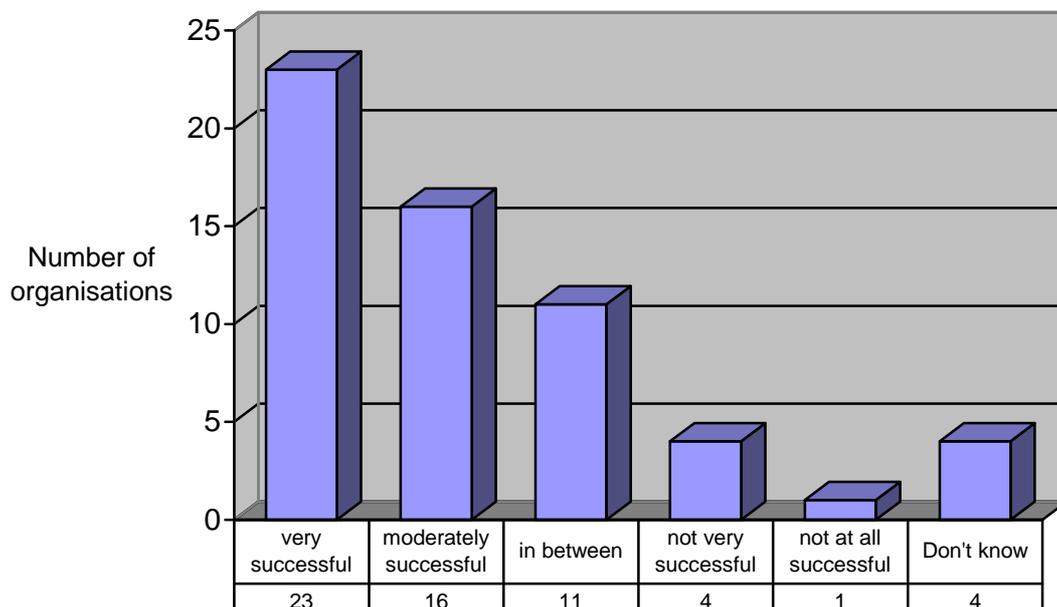
The number of organisations active in the Campaign has grown steadily since 1997. Since 2003-05 the number has declined from 48 to 47.

Figure 10: How the Global Campaign has been used



The most popular use of the Campaign is its slogan “Out of the Shadows”. There is some evidence that the products of the Campaign are being picked up and used at national level. 13 organisations claim to have adapted one of the demonstration projects.

Figure 11: The success of Global Campaign activity

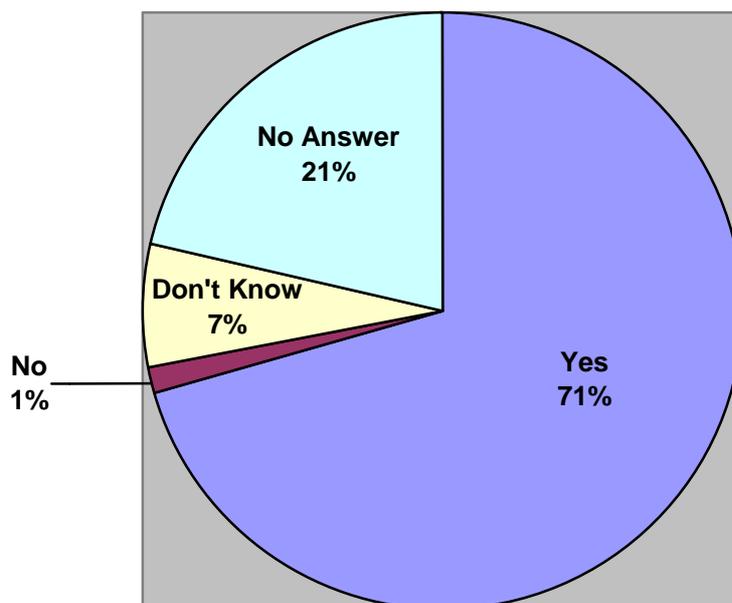


39 organisations (66%) report their Campaign activity to be either very successful or moderately successful.

23 organisations (39%) report their Campaign activity has been very successful. A further 16 (27%) report moderate success.

Only 4 (7%) reported their activity was not very successful and only 1 (2%) reported no success at all.

Figure 12: Future use of the Global Campaign



53 organisations (71%) in 41 countries (68%) report they will be using the Campaign in the future regardless of whether or not they have used it in the past. 16 organisations (21%) did not answer this question. This may be more to do with the question's placement at the end of the questionnaire than a conscious decision not to answer. Only 1 organisation said it would not be using the Campaign in the future and a further 5 did not know if they would or not.

Limitations

This survey has some limitations which require the results to be treated with some caution.

63% of all organisations contacted and 46% of countries did not participate in the survey.

53% of IBE members did not respond and 75% of ILAE chapters did not respond.

The level of understanding of English may have limited the number of responses.

IBE members outweigh ILAE chapters by more than two to one in the survey.

Two countries (Poland and Sri Lanka) were not included because no email address was available.

Conclusions

The Global Campaign is alive and well. 79% of organisations and 80% of countries responding to the survey say they are or have been active in the Campaign.

The reasons why more organisations have not become involved in the Campaign are because they do not realise they can or they do not know how to.

There is evidence in some countries at least based on different answers given to the same question that IBE members and ILAE chapters do not work together on Global Campaign projects and may not be close in general.

There are possible explanations for the inconsistent reporting by IBE and ILAE in the same country: -

- People answered the questionnaire on behalf of their organisation rather than their country.
- The IBE member(s) and ILAE chapter are not close and do not know what the other is doing. (Australia). There is evidence in some countries at least based on different answers given to the same question that IBE members and ILAE chapters do not work together on Global Campaign projects.
- Some people new to epilepsy might not be aware of activity that took place at the beginning of the Campaign. (Mexico).

The regional distribution of those active in the Campaign reflects the general regional distribution of IBE members. This is probably a consequence of IBE members dominating the survey sample.

The economic profile of the countries involved in the Campaign is skewed in favour of higher income countries. Should we be surprised that the Campaign appears to be more actively picked up in relatively wealthier countries? This could be because

these are the countries with the most resources to carry out activities and that have the most developed and more experienced and confident organisations. This might also indicate that the need for the Campaign is as compelling in high income countries as it is in low income countries.

However, if low income countries and lower middle income countries are particular targets, then more needs to be done to make the Campaign more accessible to them by identifying the obstacles to their participation and putting in place strategies to assist them.

Public awareness and reducing stigma are the most frequently occurring activities. This reflects the Campaign's early and continuing emphasis on these issues.

The symbols of the Campaign (slogan, name and logo) are its most used assets. However, data and materials produced by the Campaign are also well used.

Campaign activity has grown steadily up to 2003/05 since when it has levelled off.

Judged by the organisations themselves, Global Campaign activity has been successful. More than one third of organisations active in the Campaign say that their activity has been very successful.

There is strong support for the Campaign in the future. Only one organisation reported it would not be active in the Campaign in the future. 53 organisations (71%) in 41 countries (68%) report they will be using the Campaign in the future regardless of whether or not they have used it in the past.

There has been a large amount of different types of activity in many different countries all around the world right from the beginning of the Campaign in 1997. Even so, this activity appears to be disparate and uncoordinated

Recommendations

Whilst encouraging local responses to local needs it might also be useful to co-ordinate activity across countries at regional level and at national level between IBE members and ILAE chapters.

Increase the ownership of the Global Campaign among IBE members and ILAE chapters and encourage and stimulate them to get involved in Campaign activities: -

- More frequent and detailed reporting of Campaign related activities by members and chapters.
 - Develop a section on the website to provide ongoing reports of outcomes and impact of activities.
- Clarify points of contact within the Campaign for the giving and receiving of information.
- Produce clear guidelines that explain how to participate in the Global Campaign and make these easily available.
- Consider producing Campaign core materials in languages other than English.

- Establish and publicise criteria for demonstration project applications and a process for assessing applications.
- Establish and publicise guidelines for applying for Global Campaign project or activity status including: -
 - Qualifying criteria that defines what a Global Campaign activity or project is.
 - A process for assessing applications for recognition of Global Campaign status.
- Consider what might be done to increase the presence of the Global Campaign in low income countries and lower middle income countries. Arguably these need the Global Campaign most and yet they appear less willing or able to participate. Identify any special needs they might have and put strategies in place to assist them.
- Identify and publicise what the Global Campaign has to offer and how organisations can participate.
- Identify and publicise the availability of Global Campaign materials.
- Consider the need for guidelines for developing trans-national projects based in low income countries (in line with ILAE Australia's suggestion).
- Improve mechanisms for IBE members and ILAE chapters to report on their Global Campaign activity.

Appendix I: Survey Questionnaire

Survey of ILAE chapters and IBE members about the Global Campaign against Epilepsy

The Global Campaign against Epilepsy has been going now for 10 years. In that time IBE, ILAE and WHO have used it to conduct numerous demonstration projects and other activities. However the Campaign has also inspired many ILAE chapters and IBE members to undertake their own activities using the Campaign's name, its eclipse logo and/or its "Out of the Shadows" slogan.

Not all of these chapter/member based activities are very well known outside of the country or region where they have taken place. Now, IBE and ILAE want to try and quantify the scope and scale of all the Global Campaign related activity that has taken place since the Campaign began. With this information we shall all have a much better idea of how the Campaign has been used and how well it has succeeded.

I hope you can spare a few moments of your time to help us with this survey. The results will ultimately be shared with every ILAE chapter and IBE member.

When completed please return your survey form to: -

Philip Lee
Co Chair Global Campaign against Epilepsy
Epilepsy Action
New Anstey House
Gate Way Drive
Yeadon
Leeds LS19 7XY
England

Email: plee@epilepsy.org.uk
Tel. +44 (0) 113 210 8800
Fax: +44 (0) 113 391 0300

Note that the closing date for the return of your form is 31 March 2008.

Thank you very much for your help.



Philip Lee
Co-Chair
Global Campaign against Epilepsy

Chapter / Member Details

The name of your organisation:			
Country:			
Tick this box if you are you an <u>ILAE chapter</u> →		Tick this box if you are you an <u>IBE member</u> →	
The name of the person completing this form:			
Your position or title in the ILAE chapter / IBE member:			
Your postal address in case we need to contact you:			
Telephone number:		Fax number:	
e-mail address:			

Q.1	Have you ever used the Global Campaign name, its eclipse logo, its “Out of the Shadows” slogan or any Global Campaign products (like reports) in any of your activities?	
a	If YES please tick this box → and then continue to Q.2	
b	If NO please tick this box → and then go straight to Q.6	
c	If DON'T KNOW please tick this box → and go straight to Q.7	

Q.2	What have you used the Global Campaign for?	Please mark <u>as many boxes</u> as apply ↓
a	To help raise public awareness about epilepsy	
b	To help raise the profile of our organisation	
c	To educate people with epilepsy and/or their families	
d	To educate medical professionals	
e	To educate other professionals (e.g. teachers)	
f	To raise money	
g	To raise the awareness of politicians or health officials about epilepsy	
h	To improve health services for people with epilepsy	
j	To reduce stigma against epilepsy	
k	Other activities... (can you please tell us what these are)	

Q.3	When did you use the Global Campaign?	Please mark <u>as many boxes</u> as apply ↓
a	1997 – 1999	
b	2000 – 2002	
c	2003 – 2005	
d	2006 – 2008	

Q.4	How have you used the Global Campaign?	Please mark <u>as many</u> <u>boxes as apply</u> ↓
a	We have used the Campaign name as an endorsement to give our organisation more authority.	
b	We have used the Campaign logo of the eclipse	
c	We have used “Out of the Shadows” as a slogan.	
d	We have adapted a Campaign demonstration project and run it in our country.	
e	We have used publicity and promotional material produced by the Campaign about epilepsy.	
f	We have used data collected by the Campaign to inform our work.	
g	Other ways we have used the Global Campaign... (can you please tell us what these are)	

Q.5	If you have used the Global Campaign, has it been successful for you?	Please mark <u>one of the</u> <u>boxes below</u> ↓
a	Yes, very successful	
b	Yes, moderately successful	
c	In between	
d	No, not very successful	
e	No, not successful at all	
f	Don't know	

Q.6	Why have you not yet used the Global Campaign? Answer this question only if you have not yet used the Global Campaign.	Please mark as many boxes as apply ↓
a	We did not know we could use the Campaign	
b	We do not know how to use the Campaign	
c	The Campaign is not relevant or useful to our activities	
d	We do not know why we have not used the Campaign, we just haven't.	
e	Other reason(s)... (can you please tell us what these are)	

	If YES please tick box below ↓	If NO please tick box below ↓	If DON'T KNOW please tick box below ↓
Q.7	Whether or not you have used the Global Campaign in the past, do you think you will use it in the future?		
If you don't think you will be using the Global Campaign in the future, can you please tell us why?			

Thank you again for your time in completing this survey. Please return your form by email attachment to plee@epilepsy.org.uk . Alternatively you can post your form to Philip Lee, Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds, LS19 7XY, England

You can also fax your form (marked for the attention of Philip Lee) to:
+44 (0) 113 391 0300

Note that the closing date for the return of your form is 31 March 2008.

Appendix 2: Additional comments from questionnaires

These are the narrative comments provided to explain or add to answers given in the closed questions.

What have you used the Global Campaign for?

IBE - Australia

Utilised Campaign documents *Epilepsy care in the world 2005* and *Epilepsy in the Western Pacific Region: A call to action 2004*.

- To inform Epilepsy Action's key messages and development of our national services strategy.
- To inform our strategic intent in Australia and our region.
- As source documents for case for support and research proposal.
- As source document for Epilepsy Action (Australia) educational materials & presentations and conference presentations.

IBE - Cameroon

Formation Permanente du personnel de la Santé sur l'é. Intervention des spécialistes médecin, épiléptologues, techniciens italiens qui viennent régulièrement pendant l'année, pour la formation, la supervision et les consultations gratuites pour les maladies de l'association

Ex. EEG CHAQUE MOIS AVEC envoi du trace par Internet au Policlinique S. Matteo de Pavia, Italie et renvoi de l'interprétations par des épiléptologues.

Enquête « porte à porte » pour le recensements des maladies dans les villages faites par le personnel de la santé, et beaucoup d'autres activités que je devrais écrire à part une relation.

IBE - Finland

Training of ambassadors of epilepsy - persons with epilepsy who are willing and suitable to tell about their life with epilepsy in the media.

IBE - Indonesia

Drawing contest.

IBE - Korea

We had two public outdoor concerts under the title of "Out of Shadow" to raise public awareness. (2005 in Seoul, 2006 in Daegu, Korea)

IBE - Namibia

Epilepsy Namibia is still a young organization, but we have included the slogan on our membership form and on business cards. The first annual Epilepsy Day planned for 21 June each year on the winter solstice has the slogan "Epilepsy: Out of Shadows into Light".

IBE - Romania

We have used the Campaign to try and develop a demonstration project protocol (without success) to enhance epilepsy health services in Romania.

IBE - Switzerland

- Motivation to publish a “Swiss Epilepsy Report” in 2002.
- Motivation to organise an annual national “Swiss Epilepsy Day”.
- Global Campaign as a global frame for national public awareness activities.
- All undertaken in conjunction with ILAE Switzerland as joint projects.

IBE/ILAE - China

- 1) Extension of the demonstration project onto 15 provinces’ epilepsy management in rural area with Phenobarbital treatment of convulsive epilepsy. This program covers 30 million population and around 20,000 patients under treatment.
- 2) Call on “International Epilepsy Care Day” on June 28th every year. Celebrated in 36 cities last year (2007) around June 28th. Now, eight countries and regions responded positively to this.

ILAE - Argentina

To educate priests.

ILAE – Pakistan

The main purpose of us using the GCAE logo is to maintain our affiliation with the international community. We have developed and tested an indigenous model which can be replicated in other developing countries; this has **“no input - financial and technical”** from ILAE/IBE/WHO. Our sponsors remain a number of gracious local voluntary donors. Global Campaign projection material includes Pakistan as a demonstration project of the GCAE. This may cause confusion as to the nature of the model. Our model is certainly not what GCAE is doing in China which is perceived as a demonstration model by most people concerned in this field. We are available for anyone who would like to have our assistance in replication of our model in any form.

ILAE - Qatar

Local conference activities; attending international epilepsy conferences; regular teaching of neurological and medical staff and public about epilepsy.

ILAE - Tanzania

Annual epilepsy campaign in primary school students which takes place in August each year.

How have you used the Global Campaign?

IBE - Denmark

We have sometimes used information from the Campaign because it is in English. For instance when preparing a speech for our chairman.

IBE - Ireland

We have dedicated several publications to the Global Campaign as Brainwave's contribution to the Campaign.

IBE - Mexico

We inform people (physicians, patients, relatives, etc.) about the existence of the Global Campaign in many countries and the lack of response of the Mexican authorities to our proposal to join the campaign. We suggest that authorities of IBE could help us sending letters to the Health Ministry introducing our organization as representative of IBE in order the Ministry pay attention to our work and the social problems of persons with epilepsy, asking to officially join to the Campaign.

IBE - Namibia

The WHO office gave us some "Epilepsy in the WHO African Region" reports. I give them to committee members, seriously interested government departments and businesses – sometimes to give credibility to the organization. I also use information from this report in training.

IBE - Norway

In our magazine Epilepsinytt.

IBE - Romania

We have attempted to start a demonstration project, but unfortunately we did not reach the proper level of co-operation between the local ILAE and WHO offices and our own organization.

IBE - Switzerland

World atlas on epilepsy and regional reports on epilepsy.

IBE/ILAE - Belgium

We use the logo of the eclipse as a poster. We use the name "Out of the shadows" for a video, a TV spot, conferences, leaflets...

ILAE - Argentina

Pilot project global campaign PAHO. Some activities demonstration project Global Campaign; some activities in LACE.

If you have used the Global Campaign, has it been successful for you?

IBE - Swaziland

Not very successful due to lack of resources.

Why have you not yet used the Global Campaign?

IBE - Colombia

We are trying to consolidate in Colombia the strategic association between the Colombian League against epilepsy in the same way it is done internationally. But we have no relation with WHO here. We don't know if the Pan-American Health Organization (OPS), which is the Pan-American member of WHO, knows the program of Global Campaign. Anyways you should contact WHO, remember to make a communication to our countries and let us know about the matter, in order to contact the respective office. (We could take advantage of the visit of Carlos Acevedo and Hanneke de Boer to Colombia for actualising the strategy of Global Campaign in Latin America).

IBE-Lithuania

Only been a member of IBE for less than 6 months.

IBE - Thailand

The Global Campaign is good. Some activities can be applied to be used in our society.

IBE – Togo

We are new associate member.

ILAE-Albania

We asked for collaboration, but unfortunately, we had not any positive answer.

ILAE - Australia

Comments provided by Ernie Somerville. *The ESA participates in training activities in SE Asia and provides a training scholarship for Asian neurologists. These are not specifically GCAE projects. (Just finished an ASEPA workshop in Bangladesh with CT Tan, John Dunne, Lakshmi and Wendy)*

Dr Somerville has conducted a project in East Timor and his comments are provided below: When first looking at setting up a project in E Timor, I contacted all of the then GCAE players (at ILAE, IBE and (WHO) and received no offers of help and minimal advice. Subsequently, I have been asked to present on the project on 2 occasions at GCAE sessions at AOEC meetings. Hanneke de Boer offered to provide GCAE branding, suggesting that it would make it easier to attract funds. At that stage (before we had AusAID funding) I feared that it would have the opposite effect, as people would think this was an already-funded project. Later, when funding became

more secure, I suggested to Hanneke (and I think Phillip Lee at the AOEC meeting in KL) that it could be "endorsed" by the GCAE, which would allow the GCAE to say it had a project in Timor. There was also an ironic situation a couple of years ago where the WHO (in E Timor) offered me a short-term consultancy to develop a program to train nurses in epilepsy in E Timor. This seemed a little odd, as we were already doing that and when I expressed some hesitation, the offer was withdrawn.

Setting up an aid project in a foreign country is extraordinarily challenging. There is no way we could have done it without the help and advice of the E. Timor Mental Health Project (who asked me to go there in the first place) - there is too much local knowledge and experience required. The GCAE might think about setting up a system to advise and help those interested in setting up projects. This would not be so important for countries where the project is being developed from within the country.

ILAE-Mexico

I've have just been designated as the chapter's president and I'm just learning of the Global Campaign.

Whether or not you have used the Global Campaign in the past, do you think you will use it in the future?

IBE - Denmark

We never think of the campaign, only if we receive some material. It has no place in the memory of DEA. I am sorry to tell that because I am impressed every time I hear Hanneke tell about the campaign.

IBE Malta

I think using the Global Campaign is of utmost importance for us since raising public awareness is one of the main objectives of our association. As time goes by we are realising even more about the need to make epilepsy, its effects and its management more known across society. No matter how much is done people are so thirsty to get more information and support (i.e. people with epilepsy, their families and people in general).

IBE - Romania

We have not used the Global Campaign name, logo or slogan, because it was our understanding that the campaign works under a well defined set of rules and that its name, logo and slogan are not to be used freely.

IBE - Swaziland

Yes, but we need it unpacked for us.

IBE/ILAE - Venezuela

Yes we will be using it in the future, even we need to improve the projects in order to obtain economical support, especially at this time because we are in critical conditions.

ILAE Yugoslavia

Our Chapter stated that we need more time to promote Global campaign in our often difficult conditions. There some positive effect of the Campaign on the reduction of stigmatisation and social isolation of epileptic population, increasing awareness of public on problems encountered by epileptic patients, education of medical professionals. The Chapter will try to establish better connection with national IBE in order to realise together some local projects.

Other general comments

IBE - Romania

Some difficulties in deciding how to complete the questionnaire form. While it is true that many of our activities were inspired by the Global Campaign or were similar to the activities of the Campaign, it is also true that our organization has never used the Campaign name, logo or slogan as such. It has always been our understanding that using any part of the Campaign without the agreement of its coordinators would be intellectual theft. Everything in relation to the Campaign is intellectual property of the Campaign and not public property and I still believe that today. The conference in 2005, was Epilepsy beyond the dark. It was inspired by the Out of the Shadows slogan and logo, but then again most of what people do in the epilepsy field around the world aims at same goals, so it is very likely that many people have similar ideas (many organizations have logos that suggest the idea of light, whether it's a candle, a sun, a moon, a light bulb etc., because most people who work in this field feel that epilepsy is unknown, in the shadows).

Completing the form presented 2 options: 1. we have not used the Campaign at all, because we have never actually used any part of it as such or 2, we have used the Campaign, in the sense that we were inspired by its activities. Our response is based on being inspired by the Campaign.

We would like to suggest that epilepsy organisations around the world can make good use of the campaign in other ways than actually developing demonstration projects in their own countries. We suggest a new set of rules regarding how the Campaign works and can be used. I think that would be very useful at least for East European countries and probably others as well.

Appendix 3: List of responding countries

				Active in Campaign?	
AFRICA		IBE Member	ILAE Chapter	Yes	No
1	Cameroon	✓		✓	
2	Gambia	✓		✓	
3	Ghana	✓		✓	
4	Mauritius	✓		✓	
5	Namibia	✓		✓	
6	Sierra Leone	✓		✓	
7	South Africa	✓		✓	
8	Swaziland	✓		✓	
9	Tanzania		✓	✓	
10	Togo	✓			✓
11	Zambia	✓		✓	
		10	1	10	1

				Active in Campaign?	
AMERICAS		IBE Member	ILAE Chapter	Yes	No
1	Argentina	✓	✓	✓	
2	Colombia	✓			✓
3	Ecuador	✓		✓	
4	Honduras		✓	✓	
5	Jamaica	✓			✓
6	Mexico	✓	✓	✓ (IBE)	✓(ILAE)
7	USA	✓		✓	
8	Venezuela	✓	✓	✓	
		7	4	5	3

				Active in Campaign?	
EASTERN MEDITERANNEAN		IBE Member	ILAE Chapter	Yes	No
1	Iran	✓			✓
2	Lebanon	✓			✓
3	Pakistan		✓	✓	
4	Qatar		✓	✓	
5	Syria		✓	✓	
6	Tunisia		✓	✓	
		2	4	4	2

				Active in Campaign?	
EUROPE		IBE Member	ILAE Chapter	Yes	No
1	Albania		✓		✓
2	Belgium	✓	✓	✓	
3	Bulgaria		✓	✓	
4	Czech Rep.	✓		✓	
5	Denmark	✓		✓	
6	Finland	✓		✓	
7	France	✓		✓	
8	Georgia	✓		✓	
9	Greece	✓	✓	✓	
10	Ireland	✓		✓	
11	Israel	✓		✓	
12	Latvia		✓	✓	
13	Lithuania	✓			✓
14	Malta	✓		✓	
15	Netherlands		✓		✓
16	Norway	✓		✓	
17	Portugal	✓		✓	
18	Romania	✓		✓	
19	Slovenia	✓	✓	✓	
20	Sweden	✓		✓	
21	Switzerland	✓ (x3)		✓	
22	U.K.	✓		✓	
23	Yugoslavia		✓	✓	
		20	8	20	3

				Active in Campaign?	
S.E. ASIA		IBE Member	ILAE Chapter	Yes	No
1	Bangladesh	✓	✓		✓
2	Hong Kong	✓			✓
3	India	✓	✓	✓	
4	Indonesia	✓		✓	
5	Thailand	✓			✓
		5	2	2	3

				Active in Campaign?	
W. PACIFIC		IBE Member	ILAE Chapter	Yes	No
1	Australia	✓ (x2)	✓	✓ (IBE)	✓(ILAE)
2	China	✓	✓	✓	
3	Korea Dem. Rep.	✓		✓	
4	Malaysia	✓	✓	✓	
5	Mongolia	✓	✓	✓	
6	Singapore	✓		✓	
7	Taiwan		✓		✓
		7	5	6	2