

IBE Enlargement Commission **Membership Development Checklist**

December 2007

The following is a checklist of ideas and suggestions developed by IBE's Enlargement Commission to assist each region in developing the number of IBE Full Members in their region. It includes suggestions put forward by regional representatives and others at the Commission's open meeting in Singapore in July 2007.

A useful initial source of ideas has also been the European Region's Membership Action Plan, 2007/08 and the Commission would like to acknowledge this and recommend it to other regions.

Checklist

1. Make membership development a priority activity in your region.
 - a. Include it within your regional strategy and/or work plans.
 - b. Allocate time.
 - c. Allocate money from the regional budget.
 - d. Allocate responsibility to a person or to a group of people.
 - e. Draw up an action plan.
2. Liaise with the IBE office. This can supply development materials such as a model constitution, guidance notes for interested organisations... It also manages, records and co-ordinates all membership development activity including keeping a record of all individual contacts.
3. Identify target countries within your region where there is no IBE Full Member; prioritise and divide the target countries between designated people to spread the work and to personalise the contacts.
4. Research the target countries for existing resources.
 - a. Is there an existing epilepsy Association that could apply for IBE Full Membership?
 - b. If there is more than one, which is the most appropriate to develop for Full Membership?
 - c. If there is no existing organisation(s), are there known individuals who could establish a new Association?
 - d. Are previous contacts of any future use?

5. What other sources might be able to help: -
 - a. Is there an ILAE Chapter in the country that might be able to help?
 - b. Is there an IBE Member in a neighbouring country?
 - c. Other Neurological or General Medical Societies in the country?
 - d. National patient associations – general or neurological – in the country?
 - e. Representative groups of patient associations in the country?
 - f. General disability groups in the country?
 - g. Ministry of Health in the country
 - h. International NGOs working in the field.

6. To be aware of: -
 - a. Cultural tradition – The concept of a lay association for people with epilepsy, or more broadly the idea of a representative group for people with a medical condition or a disability, is not well established or even recognised in every cultural tradition.
 - b. Cultural difference – Even where lay associations do have a tradition, cultural differences between countries might make them difficult to identify as such.
 - c. Political setting – different political systems allow different levels of independence for NGOs. Some systems do not permit independent NGOs. Be aware of the political situation in the target country.

7. What other obstacles might be preventing the development of an Association for people with epilepsy and can you affect these?
 - a. Lack of money
 - b. Apathy
 - c. Lack of local leadership
 - d. Lack of collective identity amongst people with epilepsy
 - e. Poor communication
 - f. Fragmentation of potential support – different small groups not united
 - g. Lack of example
 - h. Lack of knowledge in knowing how to set up an Association.

8. Offer bursaries for representatives from newly inaugurated epilepsy organisations to attend your regional congress.

9. Offer a mentoring service for newly developing epilepsy associations whereby they are linked to an established IBE Full

Member within the region which then provides support, experience, expertise... (not necessarily money).

10. Be prepared to visit the target country.