



Dear IBE friends

It is difficult to believe that we are coming towards the end of another year and the end of the first decade of the new century. The close of each year is the occasion for looking back and reflecting on our successes, as well as our disappointments. It is also the time to look forward and to plan for the future.

In the coming weeks epilepsy associations will be drawing up plans of action and reviewing long term strategies. In the current financial climate, identifying programs that will generate both awareness and financial support is becoming more difficult and organisations find that they have to cast their nets ever wider.

Lending support

IBE is always happy to encourage members in their projects, through letters of support and approval, and through the use of the IBE logo. However, it is vital that members make contact with the Bureau at the very start. By building a consultation process with IBE into the planning stage of a project, IBE will be able to suggest ways that can enhance the initiative and ensure that it is structured in a way that IBE can fully support.

Unfortunately, in the past IBE has sometimes been asked to provide statements of approval when a project is already 'well down the line' in a way that would set a precedent and might indicate that the Bureau was dealing unfairly with some members compared to others or, worse still, was supporting activities that could be in conflict with IBE policies. This is something that I see as regrettable because I am aware of the tremendous dedication and personal sacrifice that those working in lay organisations give to their work.

During the coming year I look forward to working with all IBE members in order provide IBE support to your projects. As an international organisation, now represented in 92 countries worldwide, with close affiliation with the WHO and consultative status on the UN Economic and Social Council, working together can raise the bar for people with epilepsy around the world.

The 'E' word

Many of you may be aware that, over time, I've campaigned doggedly to eradicate the use of the term "epileptic" when describing a person with epilepsy. Considerable progress was made and, in the developed world at least, the term seemed largely to disappear. However, recently there has been an alarming proliferation amongst journalists of the use of this appalling term. So I will continue with the campaign to get rid of the use of this word as a noun and I hope that you will also come on board in this struggle.

Unfortunately, part of the problem lies at our own doorstep, with a small number of IBE members using the term 'epileptic' in their association name or website address. This, I understand, is often the result of translation from another language to English. So, may I set a New Year's Resolution for all IBE members: to erase the term wherever it appears and to be vigilant in encouraging others to do likewise. I believe that this is an area where we may be able to call on our contacts at the WHO and the UN to help spread the gospel in eradicating this term in the same way that the words "cripple" and "spastic" are no longer acceptable in modern parlance.

In closing, may I take this opportunity, on behalf of all members of the IBE International Executive Committee, to wish you and your association a Happy, Peaceful and Prosperous New Year; I look forward to working with you in 2010!

All the best,

Mike

Mike Glynn
President