

IBE International Bureau for Epilepsy
International Executive Committee
European Committee

Odense June 26, 2008

Dear IBE,

The Nordic Meeting was held in Iceland from May 16 through May 18 2008. Epilepsy Associations from Finland, Sweden, Norway, Iceland and Denmark, who are all members of IBE, took part. The Faroe Islands, who are not an IBE member, also participated.

IBE was up for discussion.

Most participants at the Nordic Meeting were board members of the national epilepsy association and many of them have heard very little about IBE, a fact for the national associations to try and remedy.

The European dimension, particularly, was discussed, including the European Conferences on Epilepsy and Society. And not least the relations with the European Committee were up for discussion.

For the time being The European Committee consists of 4 out of 5 Nordic members (Peter Dahlqvist, Andreas Habberstad and Seppo Sarkkula. The fourth Nordic member, Jonina Gudmundsdottir, however, has sadly passed away since the meeting). Seppo Sarkkula took part in the meeting.

The participants thought that they lack contact to The European Committee. How is the contact throughout the rest of Europe, one might ask?

With the aim of becoming some sort of communications link the European Committee once split up the European members among themselves. However, for a very long time there has not been any exchange of communication at all except for information concerning the Marseilles Conference.

A lot of the Nordic members of the European Committee are now only loosely connected to the national epilepsy association. Peter Dahlqvist is no longer working with the Svenska Epilepsiforbundet (The Swedish Epilepsy Association) and Andreas Habberstad is no longer working with the Norsk Epilepsiforbund (The Norwegian Epilepsy Association) while Jonina Gudmundsdottir of the LAUF was on long term sick leave and has since passed away.

This is the basis on which we discussed the Constitution and Bye-Laws of the IBE as concerns the election of members for the International Executive Committee and especially the Regional Committees.

Elections to the Regional Executive Committees

All candidates shall personally be a member or employed staff of an IBE Full Member or shall personally be a member or employed staff of an official affiliate of an IBE Full Member etc.

I.e. it suffices to be a personal member while being a member of the board is not required for those candidates who are not working in the association.

A person is not likely to be suggested or elected without him or her being either employed or a member of the board at the time when s/he is recommended for candidacy. However, the Bye-laws do not take into account the situation in which an elected member quits his or her job or leaves the board of the IBE member. In that case it would be obvious if there was no contact between an IBE Full Member and the elected person and no contact to epilepsy or to the international organisational work. The situation in which an elected member is excluded by IBE Full Member has not been into consideration either.

How is this problem to be solved?

It should be considered whether a demand should be made that a person who is not an employee shall not only be a member of IBE Full Member but also a board member of the IBE Full Member.

Furthermore, the employee and the board member are to leave their position if the initial demands for the candidate are no longer fulfilled.

Then there is a call for an early election for the rest of the period. Alternatively, an election for substitutes shall be called for whereby a substitute joins for the rest of the period.

Substitutes must meet the same demands.

At least a Chair, a Vice Chair and a Secretary shall be elected.

We do not find the present procedure suitable. When there is a direct election for Chair, Vice Chair and Secretary, the votes are spread, we saw that last time.

An example:

A candidate decides to run for Chair, Vice Chair or Secretary. In case the candidate does not succeed in getting the intended post, s/he instead wishes to become member of the Committee. It is possible to vote for the same person for a certain post or for the member of the Committee. With only few votes at the latest election a candidate was elected while another candidate, who did not succeed in getting elected as Chair, received considerably more votes missed the opportunity of becoming member of the Committee because of the direct election.

Proposal:

- I. If a person candidates for a certain post which s/he does not succeed in getting, the given votes are transferred to the post as member of the Committee.
- II. Alternatively, five members are elected by the Committee then they constitute themselves with a Chair, Vice Chair and Secretary. This might be the best solution as

they then know the sum of resources of the Committee and because it gives them the opportunity of re-constituting if there are changes within the Committee.

Wishes for the IBE Meeting in connection to the European Conference on Epilepsy and Society in Marseilles.

We wish to have these issues put on the agenda for discussion in Marseilles.

Yours sincerely,

Of the Dansk Epilepsiforening (The Danish Epilepsy Association) – Lone Nørager Kristensen, President, and Jutta Houmøller, CEO.

Of the Norsk Epilepsiforening (The Norwegian Epilepsy Association) – Stine Jakobsson Strømsø, Acting Secretary General.