

Influencing government policy: The European experience

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To influence governments and other health authorities about epilepsy is of vital importance. But it is also difficult, and the prejudices about and discrimination against people with epilepsy may be sharply felt especially when attempts are made to change it. Health authorities often think they know best and do not need to be told about anything. When asked for economic support, they usually have disposed of the funds they have available long ago, and the funds are too small anyway. The first rule therefore is to primarily approach the authorities about health political issues. We have in the recent years made some progress in this field, much of which is related to the Global Campaign Against Epilepsy (GCAE), an initiative of the ILAE, which are conducted with the IBE and the WHO.¹

For the Global Campaign, it was of utmost importance to have the WHO as a partner. This is because governments in many countries are much more willing to listen to the WHO than to their local experts. We were able to involve the WHO, because WHO was impressed by how the international professional and lay organisations for epilepsy (i.e. ILAE and IBE) cooperate. This seems to be unusual. Therefore the second rule is that we should view professional and lay cooperation as our particular strength, and should rely upon it more, on the regional and national levels.

Within the GCAE we have created political tools. During a series of regional conferences on *Epilepsy as a Public Health Priority*, held in Europe, Africa, Asia/Oceania, and the Americas, regional *Declarations on Epilepsy* have been adopted and published.² Each of these consists of a brief description of the most pressing regional problems in epilepsy care, a call for action, and a list of problems to be addressed. To prepare the meetings, analyses of the local conditions of epilepsy were undertaken in some regions³, and national health ministers and other politicians were invited to participate in these meetings. In one instance, the *Declaration* was read in public

by the host country's Health Minister⁴, who also presented a national plan for epilepsy.⁵

In Europe, a White Paper on Epilepsy⁶ was compiled and published as a consequence of the European Declaration. Due to the support of John Bowis, a Member of the European Parliament, it could be officially presented to the European Parliament in Brussels, and has since been used for the political promotion of epilepsy.

An important background for our progress was the 1994 decision of the newly founded ILAE Commission on European Affairs, to set an equally high quality of epilepsy care in all parts of Europe as the priority goal. This was partly because of the problems related to the political system shift in Europe, to integrate the countries of the former socialist block. Guidelines and surveys of existing services were produced and published. These included guidelines for appropriate epilepsy care across Europe⁷, the use of EEG for epilepsy diagnosis⁸, and a survey of the existing EEG services.⁹

Declarations, guidelines and white papers do not act by themselves. They need to be used as health political tools. They can then, be very helpful. It is important to get politicians interested. This has been successfully done both by self-help groups, and by epilepsy centres who approached their local members of parliament. The politicians need to understand that epilepsy and its consequences affect 5% or more of the general population. Those affected were the epilepsy sufferers, the family and related community. Many parliamentarians are dedicated people who would consider a health problem of this size as serious, challenging, and their responsibility. They can in turn convey the message to the right place and follow it up. They also want to be re-elected. Thus, the third rule is: talk to your local member of parliament.

In the European Union, with initiatives of some individuals, an all-parties parliamentary support group of Members of European Parliament was established. The support group is willing to

back initiatives, which we develop out of ILAE and IBE. With the joint actions of GCAE representatives, local epileptologists, helpful members of parliament and using our documents, we have succeeded to get epilepsy into the national health plans of several countries. We are fighting for a good and important cause, and need not hesitate to ask for politicians' attention. When we are conscious of this, we can have surprising success.

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