



European Declaration on Epilepsy

25 October 1998

At a meeting in Heidelberg, Germany on 25 October 1998, over 100 leaders of European professional and lay bodies, WHO representatives and health experts from governments and universities unanimously agreed the following declaration:

- Six million people in Europe currently have epilepsy. Fifteen million will have epilepsy at some time of their lives.
- Epilepsy has profound physical, psychological, and social consequences
- Children, adolescents and the elderly are especially afflicted by non-detection and under-treatment.
- With appropriate treatment over three quarters of people with epilepsy could lead normal lives free of seizures.
- Epilepsy costs the countries of Europe over 20 billion ECU every year, an amount that could be significantly reduced with effective action.

We call on the governments of Europe, the European Union, and all health care providers to join us in taking strong and decisive action to meet the objectives of the Global Campaign against Epilepsy launched by the ILAE, IBE and WHO.

Specifically, we urge action:

- to improve public understanding of epilepsy and thereby reduce its stigma
- to remove discrimination against people with epilepsy in the workplace -to help people with epilepsy to understand their condition and to empower them to seek appropriate treatment and lead fulfilled lives
- to improve the knowledge of health care professionals and other professionals about epilepsy, before and after graduation
- to ensure the availability of modern equipment, facilities, trained personnel and the full range of antiepileptic drugs, so that an accurate diagnosis can be made leading to the most effective treatment
- to encourage research on epilepsy and its management
- to encourage close liaison among governments, health and social authorities and agencies, and the national chapters of the ILAE and IBE
- to support the publication of a white paper as a detailed Public Health statement on Epilepsy in Europe
- to provide practical assistance for countries with underdeveloped epilepsy services within and beyond Europe.

Background Note

Epilepsy is the commonest serious brain disorder in every country, and probably the most universal of all medical disorders. It occurs at all ages, especially in childhood and old age, and in all races and social classes. At least 40 million people worldwide have epilepsy. One hundred million people will have epilepsy at some time in their lives.

Epilepsy is widely misunderstood, leading to fear, secrecy, stigmatisation, and the risk of social and legal penalties. In some European countries it is still not recognised as a brain disorder and up to 40% of people with epilepsy may be untreated _ the treatment gap. The life span of people with epilepsy is reduced. Indeed, in specific risk groups the mortality may be twice or more that of the general population.

The ILAE has published a document on "Appropriate standards of epilepsy care across Europe". However, professionals treating people with epilepsy often do not have sufficient specialised knowledge about the condition. In some countries, antiepileptic drugs are not always available or are unaffordable. In a number of European countries diagnostic facilities are lacking or inadequate.

Although WHO and World Bank studies have shown that epilepsy is a considerable economic burden, very few European countries have national plans for epilepsy.

Epilepsy has profound physical, psychological, and social consequences:

- Many children with epilepsy receive inadequate schooling.
- The rate of unemployment is disproportionately high for people with epilepsy mainly due to the ignorance of employers. It is two to three times greater than the general rate, and more than for people with other disabilities.
- Many people hide their condition. This contributes to social isolation, low self esteem, and can lead to helplessness and depression.
- Many people with epilepsy lack knowledge about their condition. Women with epilepsy often have inadequate information about pregnancy and child-bearing.
- The quality of life in elderly people is often impaired due to unrecognised epilepsy.
- Many people with epilepsy have a severe problem with independent mobility.

The objectives of the Global Campaign against Epilepsy of the World Health Organisation, International League Against Epilepsy, and International Bureau for Epilepsy are:

- to increase public and professional awareness of epilepsy as a universal, treatable brain disorder
- to raise epilepsy to a new plane of acceptability in the public domain
- to promote public and professional education about epilepsy
- to identify the needs of people with epilepsy on a national and regional basis
- to encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services, and prevention.