



INTERNATIONAL BUREAU FOR EPILEPSY

NGO in Special Consultative Status with the Economic and Social Council of the United Nations and in official relations with WHO



International Bureau
for Epilepsy

1961 - 2011

50 years focussed on epilepsy

A Strategic Plan for Epilepsy for WHO Europe

Epilepsy is one of the world's most common chronic neurological disorders. Approximately 50 million people have been diagnosed worldwide, 6 million of them in Europe, with 300 000 new cases diagnosed each year including children, women, elderly, adolescents. Furthermore, the stigma attached to people with epilepsy is a barrier to the exercise of their human rights and social integration. It is important to note that, while scientific advances have improved the understanding and management of epilepsy and up to 70% of people with epilepsy could be seizure-free with appropriate treatment, 40% of people with epilepsy in Europe do not receive such treatment. In addition, 40% of children with epilepsy have difficulties at school, and people with epilepsy in Europe experience high levels of unemployment, and are exposed to stigma and prejudice. Epilepsy also disrupts every aspect of life, and can impose physical, psychological and social burdens on individuals and families,

These facts make it the right time for the WHO Regional Committee of Europe to make epilepsy a priority in public health issues. Epilepsy has already been selected as a priority in other regions. In 2011, the Directing Council of the Pan American Health Organization (PAHO), passed a resolution supporting the Strategy and Plan of Action on Epilepsy (CD51/10). This action formally establishes epilepsy as a health care priority in the region. In addition, IBE/ILAE have undertaken key programmes of its global campaign program Out of the Shadows in China and Vietnam in Western Pacific region, in partnership with regional WHO office, and there soon will be a new program in Vietnam. These activities all address the principal work areas and define technical cooperation lines needed to meet the different needs of the countries. In Europe, the first steps have already been undertaken by the EU European Parliament who, by an overwhelming majority, approved the 0022/2011 Written Declaration on Epilepsy in September 2011. In addition, a pilot ILAE/IBE/WHO Global Campaign project is being carried out in Georgia.

A call is thus being made for WHO Europe to agree to the preparation of a strategic plan in order to strengthen an integrated response to develop lifelong programs for people with epilepsy which will include prevention, treatment, and rehabilitation. Some of the driving principles behind such a resolution would include emphasis on universal access to care, respect for human rights and protection of vulnerable populations, while maintaining respect for the historical and cultural identities of the communities.

Key areas to be addressed in such a strategy include:

- prioritising epilepsy as a major disease that imposes a significant burden across Europe and to focus on reducing existing treatment gaps;
- taking initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice;
- encouraging research and innovation in the area of prevention and early diagnosis and treatment of epilepsy;
- strengthening legal frameworks as appropriate in order to protect the human rights of people with epilepsy and ensure effective enforcement of the laws;

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- promoting universal equitable access to medical care for all people with epilepsy by strengthening health services in systems based on primary health care and integrated service networks
- ensuring the availability of the antiepileptic drugs considered essential for treating people with epilepsy, especially at the primary care level;
- strengthening neurology services as support for case detection and management at the primary care level,
- supporting effective participation by the community and associations of users and family members in activities designed to secure better care for people with epilepsy;
- strengthening human resources as key to improving national epilepsy programs, through systematic training geared especially to the personnel in primary health care;
- promoting intersectorial and educational initiatives directed to the population to combat the stigma and discrimination suffered by people with epilepsy
- close the information gap in the field on epilepsy by improving the production, analysis, and use of information, including research; strengthen partnerships between the health sector, other sectors, and nongovernmental organizations, academic institutions, and key social actors.
- assisting the Member States in the preparation and execution of national epilepsy programs within the framework of their health policies, taking this strategy and plan of action into account, with a view to correcting inequities and giving priority to the care of vulnerable and special needs groups, including indigenous populations;
- facilitating the dissemination of information and the sharing of positive innovative experiences, and promote technical cooperation among the Member States; promote partnerships with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), as well as international agencies, governmental and nongovernmental organizations, and other regional actors in support of the broad multisectoral response needed for the execution of this strategy and plan of action; evaluate the implementation of this strategy and plan of action and report the advances to the involved institutions.

This statement is being submitted for consideration to be included in the Agenda for the annual WHO REGIONAL COMMITTEE FOR EUROPE Sixty-second session, Malta, 10-13 September 2012, under the technical item

5(a) Health 2020: a European policy framework supporting action across government and society for health and well-being.