



# International Bureau for Epilepsy

## Benefits and Privileges of Membership

### Executive Summary

Founded in Rome in 1961, the International Bureau for Epilepsy (IBE) is the international umbrella body for national epilepsy associations whose goal is to improve the quality of life of all people with epilepsy and those who care for them.

IBE offers three types of Membership: Full Membership, Regional Membership and Associate Membership.

All Members have constitutional rights including:

- the right to receive support;
- the right to information;
- the right to participate in IBE activities;
- the right to promote their IBE membership.

In addition, Full and Regional Members have the right to be nominated for election to the International Executive Committee and relevant Regional Executive Committee and to vote in ballots, polls and elections conducted by IBE.

Membership provides a wide range of benefits such as:

- involvement in the close working relationship that exists between IBE and the International League Against Epilepsy;
- participation in collaborations in which IBE is involved, such as the ILAE/IBE/WHO Global Campaign Against Epilepsy ‘Out of the Shadows’; IBE/ILAE Global Outreach Program; the United Nations Economic and Social Council (ECOSOC); CoNGO, the Conference of NGOs with Consultative relationship with the United Nations; and the World Health Organization (WHO/OMS); and Pan American Health Organization (PAHO)
- the invitation to play an active part in IBE programs and activities, such as the Promising Strategies Program, international and regional congresses, and awards;
- participation in regional Epilepsy Days, such as European Epilepsy Day (2<sup>nd</sup> Monday in February each year) and Latin American Epilepsy Day (9<sup>th</sup> September each year);
- the invitation to be a member of an IBE User Group, such as the Editor’s Network and the Chief Executive Officers Network; This document contains full details of the rights and benefits that IBE membership offers.

## Introduction

The IBE is an incorporated, not-for-profit, international organisation constituted in accordance with law and registered in the District of Columbia, USA. (Charter ID 721834-DNP). Founded in Rome in 1961, the goal of IBE is to improve the quality of life of all people with epilepsy and those who care for them.

IBE is the international umbrella body for national epilepsy associations that represent people with epilepsy, their families and all those who care for them. The organisation is governed by its General Assembly of all Full Members and by the International Executive Committee. At the end of April 2014, IBE had a membership of 135 Full and Associate Members in 100 countries world wide.

In order to accomplish its objectives of organisation, support, communication, education and representation, IBE:

- 1 Promotes, stimulate and assists in the formation and continued development of organisations of people with epilepsy and those who care for them in all countries.
- 2 Encourages relevant epilepsy organisations to become members of IBE.
- 3 Publish information about epilepsy and about the IBE, which is disseminated as widely as possible.
- 4 Promote the exchange of information and co-operation between organisations concerned with epilepsy.
- 5 Stimulates research into epilepsy.
- 6 Encourages education and training with respect to epilepsy.
- 7 Organises and facilitates international and regional conferences, congresses, meetings and seminars on epilepsy.

## Membership

**IBE has three types of membership:**

National epilepsy associations with a focus on the social aspects of epilepsy may become **Full Members**, with voting rights. Only one Full Member per country is permitted. On 30<sup>th</sup> April 2014, IBE had 98 Full Members.

Some countries have a population number that is so small, or a level of development that is so low, that it is not possible to sustain a national epilepsy association. By acting collectively with other similar countries, it may be possible to sustain an association that covers more than one country – a regional epilepsy organisation. Such an organisation can apply for **Regional Membership**.

Other organisations with an interest in epilepsy may become non-voting **Associate Members**. On 30<sup>th</sup> April 2014, IBE had 37 Associate Members.

According to the IBE Constitution, every Full Member is entitled to the following rights:

- (a) To receive such support as can reasonably be expected from the IBE for the endeavours undertaken by the Full Member to improve the quality of life of people affected by epilepsy.
- (b) To receive such information as can reasonably be supplied to make an informed decision on matters affecting the IBE.
- (c) To vote in ballots, polls and elections conducted in the course of IBE business.
- (d) To be a Full Member of an IBE Regional Committee and to participate in its affairs and activities.
- (e) To advertise and promote their membership of the IBE.
- (f) To exercise such other rights as may from time to time be determined by the Full Members of the IBE.

Every Associate Member is entitled to all of these rights, with the exception of the right to vote in ballots and elections.

As an IBE Member, an epilepsy association gains access to a large and impressive network that spans the globe. IBE is represented in every region of the world and its Membership is richly diverse. As an international organisation with strong and important links to international agencies, IBE is held in high regard and has an impressive international reputation. As a Member of IBE, a national association can benefit from this excellent reputation and can advertise its IBE membership through permission to use the IBE logo to indicate membership on letterheads, publications and on websites.

With Members in 100 countries around the world, IBE's network forms a strong and impressive body that facilitates the sharing of information, news and experiences, thereby assisting its members to develop new and improved methods in order to achieve its goals.

IBE also has a very close working relationship with the International League Against Epilepsy (ILAE) and works jointly with ILAE on a range of special initiatives. This relationship between a lay organisation and its medical counterpart is considered unique in the medical world and provides an excellent opportunity to work in partnership to improve the quality of life of persons with epilepsy in every area of their lives.

While not exhaustive, the following information provides a more detailed account of the services that IBE membership provides; the collaborations in which it is involved; and the important partnerships that have been formed in order to benefit members and to improve the quality of life of people with epilepsy.

### **Economic & Social Council of the United Nations (ECOSOC)**

IBE achieved Special Consultative Status on the Economic & Social Council of the United Nations in 2007. It is a prestigious status from which all IBE Members can benefit and helps to ensure that the voice of epilepsy is heard within the United Nations.

ECOSOC serves as the central forum for discussing international economic and social issues, and for formulating policy recommendations addressed to Member States and the United Nations System. It is responsible for promoting higher standards of living, full employment, and economic and social progress; identifying solutions to international economic, social and health problems; facilitating international cultural and educational cooperation; and encouraging universal respect for human rights and fundamental freedoms.

As an NGO recognised by ECOSOC, IBE is in a position to contribute to the programs and goals of the United Nations by serving as experts, advisors and consultants to governments and to the Secretariat. From time to time there is the opportunity to participate on an advocacy group in implementing plans of action, programmes and declarations, adopted by the United Nations.

### **Conference of NGOs (CONGO)**

As an NGO with Special Consultative Status at the UN, IBE was invited to join the Conference of NGOs (CONGO) in 2007.

CONGO is an international membership association that facilitates the participation of NGOs in United Nations debates and decisions. Founded in 1948, CONGO's major objective is to ensure the presence of NGOs in exchanges among the world's governments and United Nations agencies on issues of global concern. CONGO has its offices and international secretariat in New York, Geneva and Vienna.

As a member of CONGO, IBE and its Members have an additional means of liaising with other international associations to make new connections and to establish new methods to achieve goals.

### **Organisation Mondiale de la Santé/World Health Organization (OMS/WHO)**

For many years IBE has been in official relations with the World Health Organization (OMS/WHO). This is a very important relationship from which all IBE Members can benefit, since it facilitates contact with WHO Health Advisors and their offices at international and regional levels.

As an NGO with official relations with the WHO, IBE has the privilege of attending meetings of WHO Governing Bodies as well as the right to make a statement. NGOs in official relations may also submit a memorandum to the WHO Director General who, in turn will determine how widely the memorandum will be circulated, including its possible inclusion in the agenda of the WHO Assembly. This gives IBE, on behalf of its Members, direct access to influential and prestigious decision makers at the highest level.

## **EFNA**

IBE has is a member of the European Federation of Neurological Associations (EFNA). EFNA is a federation of European umbrella organisations of neurological lay advocacy groups that facilitates collaboration with other associations in the field of neurology, including the European Federation of Neurological Societies (EFNS).

It's vision is a better quality of life for people in Europe living with a neurological disorder. EFNA's objectives include influencing of policy makers in Europe to allocate the necessary resources to reduce the burden for people living with a neurological disorder and to achieve positive change and to establish strong working partnerships with relevant stakeholders, with the aim of improving quality of life, promoting better access to diagnosis, treatment and information and improving public awareness and understanding.

EFNA works with the European Commission and the European Parliament, relevant health professionals and other groups. Its activities include organising conferences and educational workshops, campaigning at European level and production of newsletters and information leaflets. Other members of EFNA include Stroke Alliance for Europe, Motor Neurone Disease Association – Europe, European Multiple Sclerosis Platform, European Headache Alliance, and International Brain Tumour Alliance.

## **PAHO**

The Pan American Health Organization (PAHO), founded in 1902, is the world's oldest international public health agency. It provides technical cooperation and mobilizes partnerships to improve health and quality of life in the countries of the Americas. PAHO is the specialized health agency of the Inter-American System and serves as the Regional Office for the Americas of the World Health Organization (WHO). Together with WHO, PAHO is a member of the United Nations system.

## **European Medicines Agency (EMA)**

The European Medicines Agency is a decentralised agency of the European Union, located in London. The Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union. IBE is an observer of EMA.

Much of the work of IBE is carried out by its Committees, Task Forces and Working Groups. Involvement in one of these groups provides the opportunity to play an active high profile role within the IBE and to liaise and interact with other Members and other Organisations.

### **International Executive Committee**

The International Executive Committee serves a term of 4 years and, together with the General Assembly, governs IBE. The International Executive Committee comprises the following elected officers: President, Secretary General, Treasurer and seven Vice Presidents (one Vice President to represent each of the seven IBE regions and elected by Members from that region). The Immediate Past President also serves on the committee as well as three representatives from the Executive Committee of the International League Against Epilepsy (this presence is reciprocated by the International League Against Epilepsy).

All Full Members in good standing are encouraged to nominate candidates to stand for election to the International Executive Committee and to ballot on those nominated.

### **Regional Committees**

IBE has a regional structure based on the World Health Organization regions, and comprises 7 Regional Committees. The members of each Regional Committees are the IBE Full and Associate Members in that region.

Each Regional Committee is charged with co-ordinating IBE activities within its geographical boundaries. To facilitate this work, each region has a Regional Executive Committee, comprising, at the least, an elected Chair, Vice Chair and Secretary and the Vice President for the region who is an ex-officio member. The Chair, Vice Chair and Secretary are nominated and elected by the Full Members from within the region and are accountable to the International Executive Committee.

Each Regional Committee is provided with an annual budget with which to plan for and undertake activities in that region. The budget might involve support for Members in that region to attend a conference or meeting, the production of educational publications, or advocacy activities.

### **General Assembly**

All IBE Full Members comprise the General Assembly which, together with the International Executive Committee, governs IBE. This gives each Member both a responsibility and a privilege by having a contributory role in mapping out the future focus of IBE. The General Assembly meets in person biennially and all other communication is carried out electronically.

## Commissions, Task Forces and User Groups

**Commissions** are established to focus on broad areas of interest to IBE. Commissions are long term commitments that run for at least 4 years. Chairs of Commissions are selected by the President in consultation with the International Executive Committee. Its Members are selected by the Commission Chair in consultation with the President.

**Task Forces** are established to work on particular short term projects and to achieve specific goals. Membership of a Task Force follows the method used in creating a Commission.

**User Groups** provide support on specific areas of interest to Members. IBE has two such groups at present: **Editors Network** and **Chief Executive Officers Network**. These networks provide the ideal opportunity for Members to liaise internationally in order to share information and experiences. Much of the work is carried out electronically, facilitating the involvement of the greatest number of Members. However User Groups also try to arrange meetings at the time of International Epilepsy Congresses, whenever possible. All Members are welcome to join the IBE Networks.

## Communication

IBE's communications channels provide a two way process for Members to promote the work of their associations as well as the opportunity to identify new and innovative ways of working through the sharing of experiences by IBE and by its Members. IBE's main communication vehicles are:

### IE News

IE News is the quarterly magazine of IBE containing news, reports and articles on a wide range of topics related to epilepsy. The magazine reports on IBE activities and on the activities of its Members as well as publishing reports on international events, research initiatives, and forthcoming events. Each Member receives a number of copies of each issue by mail and the magazine is also available on the IBE website. The IE News is circulated in almost 120 countries worldwide to IBE Members, the WHO Regional and International Offices, the UN, Members of the European Union (MEPs) who have expressed an interest in epilepsy, ILAE chapters, libraries and institutes, the pharmaceutical industry, and a number of other supporters.

### Social Media

IBE utilises Facebook and Twitter to promote the activities of IBE itself and its Members.

### Website: [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

IBE's website contains a high volume of information on all IBE activities including regional events, congresses, collaborative opportunities, joint IBE/ILAE activities such as the Global Campaign and the Joint Task Force *Epilepsy Advocacy Europe*, the Promising Strategies Program, to name but a few. Through the regional pages, Members have the opportunity to have reports on events in their country or region to be made available to visitors. The site also contains links to all IBE members who have their own websites.

A closed, password protected section contains a range of reports and forms, information and downloads, arranged together for easy access by IBE Members.

### Annual Report

Each year IBE produces an annual report to highlight the successes of both IBE and its Members during the previous year. The report is circulated to Members, the UN, the WHO, MEPs and other supporters. Members are encouraged to submit content for the report, promoting initiatives and achievements.

## **Congresses**

Every two years IBE, in partnership with the ILAE, organises a major international congress. These congresses attract up to 6,000 delegates and provide the platform for presentations and debates on cutting edge medical and social topics related to epilepsy. The International Epilepsy Congress attracts the leading names in the epilepsy world both as delegates and as speakers.

In the years when an international congress is not held, IBE and ILAE organise Regional International Congresses. These are smaller meetings, attracting from 300 to 3,000 delegates and focus on issues that are of particular relevance to the region in which they are held. Currently there are biennial regional congresses in Africa, Asia Oceania, Europe, Latin America and the East Mediterranean region.

The venue for each congress is selected on foot of an indication of interest submitted by IBE and ILAE member associations. Hosting a prestigious Regional or International Epilepsy Congress gives an association special participation in the congress and the organising committee usually includes local involvement. There is also the opportunity to use the congress as a vehicle for promoting the local associations through media and other events.

## **Congress Awards**

**Ambassador for Epilepsy:** In 1968 the Ambassador for Epilepsy Awards were introduced by IBE. Ambassador Awards are now presented jointly by IBE and ILAE every 2 years at the time of the International Epilepsy Congress and a maximum of 12 Awards are presented at any one time. The Award is given to individuals to recognise outstanding personal contributions to activities that advance the cause of epilepsy. These contributions and activities should either have been performed at an international level or have an international impact or significance. The Award reflects international peer recognition and is given for the lifetime of the recipient.

Each IBE Member is invited to nominate up to four individuals to be considered for the award every two years. All previous recipients are listed on the IBE website.

**Social Accomplishment Award:** The Award for Social Accomplishment in Epilepsy is given jointly by IBE and ILAE. The Award is made not more than once every two years and is given to an individual to recognise his or her outstanding personal contribution to activities that have resulted in a significant advance in the social well being and or quality of life of people with epilepsy.

Each IBE Member is invited to nominate one candidate to be considered for the award every two years.

**Lifetime Achievement Award:** The Lifetime Achievement Award is the ultimate award, given by IBE-ILAE to those truly exceptional persons, internationally acclaimed and with a long record of exemplary work.

IBE Members are invited to suggest candidates for consideration by the Joint Executive Committees of IBE and ILAE for the award.

## **Solidarity Fund**

The IBE Solidarity Fund was put in place in 2006 as a means of providing support to Members with very limited means. Since its introduction, IBE has been encouraged by the continuing generosity of some of its Members and other supporters who have donated generously to the fund. In putting in place the Solidarity Fund, it was envisaged that one of the purposes of the fund would be to provide financial support to those IBE members that could demonstrate financial hardship and would be used to subsidize their involvement in IBE activities.

IBE is aware that members from low income countries find it extremely difficult to meet their annual dues payments. Holding the belief that IBE Membership should never be denied, simply on the basis of genuine inability to pay dues, one of the first purposes to which the fund was put was to underwrite the annual dues of almost 20 IBE Members in countries deemed by the World Bank classification to be 'low income'.

## **Promising Strategies Program**

Another exciting initiative, which is part-funded through the Solidarity Fund, is the Promising Strategies Programme (PSP). Through this programme, IBE provides funding on a competitive basis for sustainable projects aimed at improving the quality of life for people living in developing countries. More than 30 IBE Members, based in developing countries, have benefited to date from the Promising Strategies Programme.

Through the continued generosity of our Members and from donations from nonmembers also, IBE hopes to continue to support Members with very limited means.

## **ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadow'**

The Global Campaign has been in operation since mid-1997; the longest running campaign in which IBE is involved. The breath and scope of the campaign has been enormous, with the highest number of initiatives and activities being carried out in developing countries in Africa, Asia and Latin America. Many IBE Members have been directly involved in initiatives such as Demonstration Projects, working closely with the relevant WHO Regional Offices and also benefiting from the activities and recommendations of these initiatives.

IBE's involvement with the WHO also improves its standing and status around the world. Many Members have used the campaign to enhance important national activities.

The Joint Task Force is a joint initiative of the International Bureau for Epilepsy and the International League Against Epilepsy. Its aim is to raise the profile of epilepsy across Europe through educational, research and political actions. Activities are guided by a committee of international experts. The Joint Task Force aims to develop strategies to improve the understanding of epilepsy, with emphasis on alleviating its social consequences; promoting exchange of knowledge between all disciplines providing care for people with epilepsy; supporting research into the evolution, investigation and management of seizure disorders; highlighting epilepsy as a public health priority among governments and health authorities.

The Joint Task Force was responsible for the European Written Declaration on Epilepsy, which was approved in September 2011 and for the management of European Epilepsy Day. The task force also works closely with the European Advocates for Epilepsy special interest group of MEPs in the European Parliament and organizes regular meetings and workshops with the support of the Advocates group.

*13th May 2014*