



# International Bureau for Epilepsy

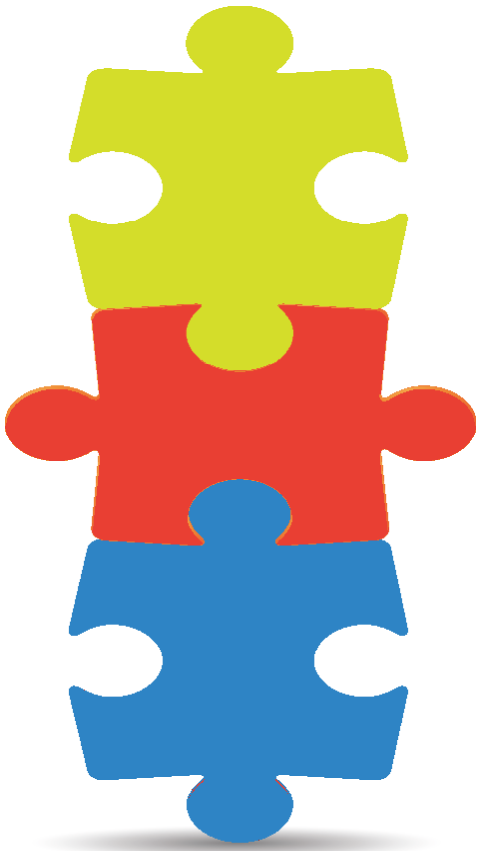
## MEMBERSHIP GUIDE Benefits and Responsibilities



IBE is an international umbrella network organisation comprised of more than 130 national epilepsy patient education and advocacy associations worldwide

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

# OUR PHILOSOPHY



## MISSION

To improve the social condition and quality of life of people with epilepsy and those who serve them

## VISION

A world where ignorance and fear about epilepsy are replaced by understanding and care

## VALUES

Our members are patient/family focused & driven organisations

We work collaboratively with our professional & government partners worldwide

We support the development of new member organisations in underserved areas

## WHO WE ARE

The IBE is an international organisation for national epilepsy organisations (IBE members), that exists to provide support for a strong global network, encourage the development of new members in underserved areas of the world, and to encourage communication and collaboration among all members so as to meet our mission and vision. We strive to add capacity to our chapters - allowing them to be the most effective advocates possible for epilepsy

## OUR GOALS

- To make epilepsy a worldwide health concern and priority
- To advocate for improved human and civil rights for people with epilepsy worldwide
- To empower people with epilepsy and their families to maximise quality of life
- To promote prevention and research focused on care and treatment of epilepsy, and its consequences worldwide
- To improve the unity, sustainability and communication of the IBE

# HOW CAN YOU GET INVOLVED?

IBE offers three types of membership: Chapter, Regional Chapter and Associate Chapter.

A national epilepsy association with a focus on the social aspects of epilepsy may apply to become a Chapter, with voting rights. Only one Chapter per country is permitted. The IBE has more than 100 Chapters.

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 to be a Regional Chapter.

Other organisations with an interest in epilepsy may become non-voting Associate Chapters.

Once an membership application has been approved by the International Executive Committee and in advance of its ratification by the General Assembly, the applicant association receives Provisional Chapter status. Each category of Chapter has 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, Chapters and Regional Chapters 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.



*In order to support our stakeholders it is essential to harness the voice of the millions of people with epilepsy across the world who are affected by epilepsy. IBE is uniquely placed to act as a dynamic force for collaboration between the diverse group of epilepsy patient associations that make up our network.*

# WHY SHOULD YOU GET INVOLVED?

As an IBE Chapter, an epilepsy association gains access to a large and impressive network that spans the globe. The 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, the IBE is held in high regard and has an impressive international reputation. As a Chapter of the 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, on publications and on websites.

With Chapters in more than 100 countries around the world, the 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 patient 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.

# WHAT DOES IBE OFFER?

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.

## INTERNATIONAL LIAISON

**Economic & Social Council of the United Nations (ECOSOC):** The IBE achieved Special Consultative Status on ECOSOC in 2007. This is a prestigious status from which all IBE Chapters can benefit and helps to ensure that the voice of epilepsy is heard within 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). CONGO is an international membership association that facilitates participation of NGOs in United Nations debates and decisions.

**Organisation Mondiale de la Santé/World Health Organization (OMS/WHO):** The IBE is in official relations with the World Health Organization (OMS/WHO). This is a very important relationship from which all IBE Chapters can benefit, since it facilitates direct access to influential and prestigious decision makers at the highest level. It has led to the creation of the ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadow', which was launched in 1997, and to the World Health Assembly/WHO Resolution on the global impact of epilepsy, which was approved in 2015.

**European Federation of Neurological Associations (EFNA):** As a member of EFNA, the IBE is part of an umbrella of European patient organisations focussed on neurological disorders which has a strong voice in influencing policy-makers and legislators in Europe to prioritise resource allocation to reduce the burden for people living with a neurological disorder.

**European Patient Forum (EPF):** EPF is one of Europe's strongest collective patients' voices and promotes public health issues that surround equitable access, affordability and quality of health-care at the European Union level.

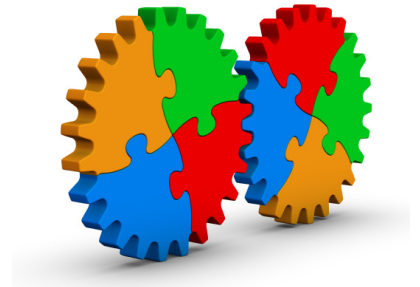
## IBE COMMITTEES, COMMISSIONS AND TASK FORCES

Much of the work of the IBE is carried out by its Committees, Commissions and Task Forces. 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 four years and, together with the General Assembly, governs the IBE. All Chapters 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:** The IBE has a regional structure based on WHO regional boundaries, that comprises 7 Regional Committees. Each Regional Committee is charged with co-ordinating IBE activities within its geographical boundaries. Facilitating this work are Regional Executive Committees, nominated and elected by the Chapters from within the region.

**General Assembly:** IBE Chapters comprise the General Assembly which, with the International Executive Committee, governs the IBE. This gives each Chapter both a responsibility and a privilege by having a contributory role in mapping out the future focus of the IBE.



**Commissions and Task Forces:** Commissions and Task Forces are established to work on particular projects and to achieve specific goals. The members of a Task Force are selected by the President in consultation with the International Executive Committee.

**Communications:** The 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 the IBE and by its members. The IBE's main communication vehicles are its website [ibe-epilepsy.org](http://ibe-epilepsy.org); social media platforms (Facebook and Twitter); and electronic quarterly magazines and Ezines.

## ACTIVITIES

**International Epilepsy Day:** The annual day for epilepsy is held on the second Monday of February and is a joint initiative of the IBE and the ILAE. Developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life, International Epilepsy Day aims to highlight that:

- epilepsy still remains a hidden disease due to the stigma attached;
- it is treatable, yet a high percentage of people do not receive appropriate treatment;
- lack of treatment imposes a huge financial burden on national health systems;
- research and legislation remain key issues in improving the quality of life of persons with epilepsy.



### International Epilepsy Day

**Congresses:** Every two years the IBE, with the ILAE, organises a major International Congress. These congresses attract up to 4,000 delegates and provide the platform for presentations and debates on cutting edge medical and social topics. The IBE and the ILAE also organise Regional Congresses. These smaller meetings, attracting 300 to 2,000 delegates, focus on issues that are of particular relevance to the region in which they are held. These take place in Africa, Asia Oceania, Europe, Latin America and the East Mediterranean region. Members of IBE chapters are entitled to substantial reductions in congress registration fees.

**Promising Strategies Program:** 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 83 projects, introduced by IBE Chapters based in 38 countries, have benefited to date from the Promising Strategies Programme.

**ILAE/IBE Global Outreach Program:** Created following the success of the ILAE/IBE/WHO Global Campaign Against Epilepsy which had been launched in 1997, Global Outreach broadens the scope and opportunities for tripartite activities involving IBE, ILAE and WHO, as well as offering a platform for joint global initiatives of the IBE and ILAE.

**EpilepsyNEXT:** A recently introduced new program that will focus on young people and will offer a range of educational modules to facilitate self-empowerment of young people affected by epilepsy

**Epilepsy Alliance Europe:** A joint initiative of the IBE and the ILAE that aims to raise the profile of epilepsy across Europe. It promotes exchange of knowledge between all disciplines providing care for people with epilepsy; supports research into the evolution, investigation and management of seizure disorders; and highlights epilepsy as a public health priority among governments and health authorities. It works closely with the European Advocates for Epilepsy group of MEPs in the European Parliament.



# GENERAL DETAILS

## CRITERIA FOR MEMBERSHIP

Before applying to join the IBE, check that your association meets the required criteria by complying with the following:

- Lay people – in particular people with epilepsy – must be able to have full membership and voting rights and be eligible for nomination and election to any elected position of the member organisation itself or of the organisations which comprise the member organisation when it is a national collective of epilepsy organisations.
- People with a professional interest in epilepsy may also be members of the member organisation.
- Activities and goals of a member organisation must be focused on improving the quality of life of people affected by epilepsy.
- Evidence must be provided of recent activity focused on improving the quality of life of people affected by epilepsy.
- The member organisation must have national status in that membership must be constitutionally accessible to all eligible people within the country; or, where the member organisation is a national collective of epilepsy organisations, membership must be constitutionally accessible to all eligible organisations; or, where the member organisation covers more than one country membership must be constitutionally accessible to all eligible people within each country.
- The member organisation must be formally organised with a written constitution agreed and in place and/or recognised by an appropriate authorising body.
- The member organisation must have a Constitution that does not conflict with that of the IBE.



## THE COST OF MEMBERSHIP

- The annual membership fee is very low. The standard rate is US\$175 for a Chapter and US\$125 for an Associate Chapter but with special rates applying to members in developing countries. Fees are due before the end of April of each year.
- In addition to the annual fee, Chapters are asked to consider making an extra voluntary donation to the IBE Solidarity Fund, which provides financial support to Chapters that can demonstrate financial hardship and is used to subsidize their involvement in IBE activities. The fund also helps to support the Promising Strategies Program.
- Chapters are also asked to confirm, at the time of membership renewal, that they continue to meet the criteria for membership as an active organisations with regular activities for their members.
- The annual membership fee form also requests Chapters to confirm their contact details, so that the IBE office can maintain an accurate database for communication.

## REQUEST A MEMBERSHIP FORM

For more information on the IBE membership application process or to request a membership form, please contact the IBE Executive Director, Ann Little, at: [ibeexecdir@eircom.net](mailto:ibeexecdir@eircom.net).

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