

## CHAPTER CODE

*The member organisations of IBE are known as its chapters.*

*This Chapter Code provides a guide to membership categories, criteria, rights, duties and principles.*

*In this document, 'chapter(s)' refers to full, associate and affiliate chapter members unless otherwise stated.*

*All chapters shall abide by IBE's Bylaws, policies, and procedures; and chapters' bylaws shall not conflict with those of IBE.*

*Full legal information on IBE Membership can be found in the ByLaws (last updated: February 2025).*

### **Membership Criteria:**

#### **Full Chapter Membership**

Full Chapter Members are **national organizations** that serve the unmet needs of all people with, and affected by, epilepsy.

Full Chapter Members must ensure that **people with, and affected by epilepsy, are central in the decision-making, strategy, and evaluation** of the organization.

This includes representation on the Full Chapter Member's Board of Directors, or equivalent.

Full Chapter Members must be **incorporated as a non-governmental/non-profit organisation**, and be in good standing, within their country of incorporation.

Full Chapter Members must offer **membership, or equivalent, to all eligible people or organisations within the country**.

Full Chapter Members shall **engage in at least two (2) of the following activities** to remain in good standing:

- Provide reliable and evidence-based information and advice to people with epilepsy and those who care for them at a national level.
- Conduct awareness-raising activities and/or campaigns for - and with - people with, and affected by, epilepsy across different regions of the country.
- Engage in advocacy for - and with - people with, and affected by, epilepsy to influence policy and decision-making based on the needs and preferences of those with lived experience.
- Provide services and supports for people with, and affected by, epilepsy across different regions of the country.
- Lead, support and/or ensure the participation of people with, and affected by, epilepsy in research.

Full Chapter Members shall be voting members of IBE with one (1) full vote per Full Chapter Member.

### **Associate Chapter Membership**

Organizations that are not recommended for Full Chapter Membership, or that do not fully meet the criteria for Full Chapter Membership, may apply – or be considered – for Associate Chapter Membership.

Associate Chapters may include:

- Organisations that are focussed on a specific sub-population of people with epilepsy.
- Organisations that only operate at a local or regional level within a country.
- Organisations that are a sub-entity of a larger institution.
- Organisations for healthcare professionals that conduct activities with, and for, people with and affected by epilepsy – in the absence of a dedicated national organisation for people with epilepsy/families e.g. ILAE chapters with a dedicated programme of activities for PWE.

Associate Chapter Members shall be voting members of IBE with a weighted vote of 20% of one full vote. However, the combined vote of Associate Chapter Members in one country should not exceed the total vote (1) of the Full Chapter Member in that country, so may be weighted downwardly.

Associate Chapter Membership shall entail all membership privileges.

### **Affiliate Chapter Membership**

Affiliate Chapter Members are those entities that:

- are not specifically working on epilepsy but have some initiatives of relevance; or
- are members of an existing IBE Full/Associate Chapter.

Affiliate Chapter Membership shall entail all membership privileges other than the right to vote.

### **Membership Rights:**

- To receive such support as can reasonably be expected from the IBE for the endeavours undertaken by the Chapter to serve the unmet needs of all people with, and affected by, epilepsy.
- To receive such information as can reasonably be supplied to make an informed decision on matters affecting the IBE.
- To vote in ballots, polls and elections conducted in the course of IBE business (full/associate chapters only).
- To be a Chapter of an IBE Regional Committee and to participate in its affairs and activities.
- To advertise and promote their membership of the IBE.
- To setup a profile and engage on the IBE community engagement platform: The Knowledge Hub.
- To be invited to attend the regional chapter convention and engage in inter and intra-regional activities open to IBE chapter representatives.

### **Membership Benefits:**

Being a member of IBE, allows chapters to:

- Be part of the largest global network of organisations supporting people with epilepsy in the world.
- Access peer to peer support and mentoring, training and capacity building initiatives, and inter and intra-regional networking opportunities.
- Join special interest groups to share best practice, and benefit from pooled resources and materials.
- Participate in IBE's annual campaigns and awareness raising initiatives – such as International Epilepsy Day; with exclusive access to branded promotional assets and materials.
- Play an active part in IBE programmes and projects, such as Global Advocacy Actions, IBE-INVOLVE, international research, and more.
- Be involved in IBE's Teams, Councils, and Committees.
- Get support to attend IBE's global and regional chapter conventions, congresses, meetings and advocacy events.
- Use IBE to disseminate, amplify and/or endorse national work.
- Benefit from IBE's collaborative partnerships including the World Health Organization (WHO), Economic & Social Council of the UN (ECOSOC), Conference on NGOs (CoNGO), European Federation of Neurological Associations (EFNA), European Patients Forum (EPF) and European Medicines Agency (EMA).
- Benefit from the close working relationship that exists between IBE and the International League Against Epilepsy [ILAE].

### **Membership Duties:**

- To maintain the criteria for Chapter Membership.
- To report annually to the IBE on activities undertaken by the Chapter reflecting their continued compliance with the criteria for Chapter Membership of the IBE; as requested.
- To pay IBE dues by the due date.
- To participate as fully as possible in all relevant IBE activities, especially meetings and ballots.

### **Membership Principles:**

The below principles further build on the rights and duties of IBE chapters as contained in its ByLaws.

Chapters should commit to:

- Work in accordance with IBE's values and support IBE's vision to ensure a transformational social change for people with epilepsy worldwide.
- Work in a collaborative, non-competitive and respectful spirit as a network of organisations representing, and supporting, people with epilepsy. In countries where there is more than one IBE chapter, chapters are expected to work together.
- Be open to communicating successes and challenges, lessons learnt, and case studies to IBE and its chapters; enabling an environment for peer to peer support and learning.
- Ensure representation to IBE's Annual General Assembly and strive to actively participate in/contribute to relevant IBE-led events, initiatives, committees or sub-groups.
- Avoid defaming or libelling IBE, its chapters or the individuals involved.
- Act in an ethical manner; not using their platform – including social media postings – to advance a personal or discriminatory agenda, particularly in terms of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.
- Be transparent and to make every attempt to ensure the integrity of policy, advocacy, and communications produced and promoted.
- Avoid and disclose any real or apparent conflict of interest that may arise or any compliance risk – in line with IBE's Conflict of Interest policy.
- Recognise their responsibility for maintaining the reputation of IBE and preserving its good name, and not jeopardise any existing relationships with other IBE chapters and/or partners.
- Advise IBE if any issue emerges in their work or community that may have an impact on the reputation of IBE and its chapters.
- Respect the ownership and copyright of IBE/its members materials and initiatives, and seek permission from IBE before acting in IBE's name, or adding IBE's logo/endorsement to events, documents, etc. This does not affect the chapter's right to promote its IBE membership.
- Ensure ongoing compliance with IBE's chapter criteria (see above) and to advise IBE immediately should the organisation no longer meet the requirements.

### **Membership Approval/Removal**

Chapters who wish to be part of IBE should complete the application form and submit the listed paperwork for the consideration of the IBE Membership Committee.

The Membership Committee makes recommendations to the International Executive Committee on whether a chapter should be approved for membership, and the most appropriate membership category.

The Membership Committee is also responsible for conducting the chapter audit to ensure chapters continue to remain in compliance with the membership criteria, duties and principles.

Chapters who no longer meet the criteria for membership, do not meet the outlined duties annually, and/or who do not act in accordance with the listed principles, may be contacted by the IBE

Membership Committee and asked to provide an explanation in writing for consideration by the International Executive Committee.

Non-response or non-action to this review process will lead to the re-categorisation, suspension or removal of the chapter – permanently or temporarily – by the International Executive Committee.

**More Information**

For any questions or clarifications, please contact:

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