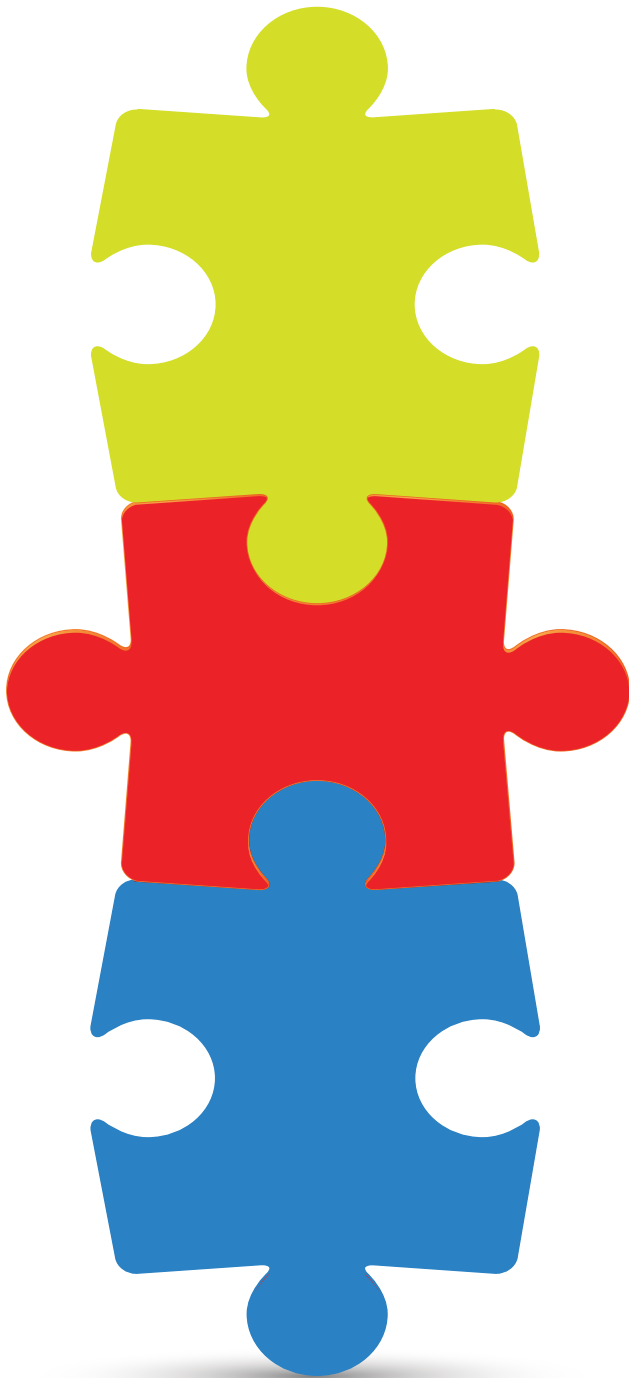




INTERNATIONAL BUREAU FOR EPILEPSY

Strategic Plan 2016-2019



Our Philosophy

MISSION

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

VISION

A world where understanding and care replace ignorance and fear of epilepsy

VALUES

Our members are patient/family focussed and mission-driven organisations

We work collaboratively with our professional & government partners worldwide

We support the development of new member organisations in underserved areas

IBE is an umbrella organisation comprised of more than 130 member international patient education and advocacy organisations worldwide

Strategic Priorities



Epilepsy is a health priority worldwide



Human and civil rights of people with epilepsy are enhanced and protected worldwide



People with epilepsy are empowered to maximise quality of life



Promotion of research into prevention, treatment, care and consequences of epilepsy

Programs

Public Information and Health Education

Advocacy

International Best Practice Exchange

Helping Build Communities of Care

WHO WE ARE

IBE is an international organisation for national epilepsy organisations (IBE chapters), that exists to provide support for a strong global network, encourage the development of new chapters in underserved areas of the world, and to encourage communication and collaboration among all chapters so as to meet our mission and vision.

OUR CORE VALUES

- We are passionate about improving quality of life for people facing a diagnosis of epilepsy
- The person with epilepsy is our primary stakeholder and all we do is focused on helping that person
- We work collaboratively with our partner epilepsy related organisations, professional, lay and governmental
- We are transparent and democratic in our governance and decision-making

OUR GOALS



Make epilepsy a worldwide health concern and priority

- a. Advocate with WHO, UN to recognize epilepsy as a worldwide need and to aggressively pursue strategic global outreach – develop a global action plan for IBE advocacy with WHO in collaboration with partner epilepsy organisations like ILAE
- b. Encourage each chapter to support making epilepsy a health priority within their respective country, and encourage mentoring within regions to promote epilepsy as a public health priority
- c. Encourage and incentivize each IBE member country to report on progress on strategic global outreach targets to IBE and regularly share information with WHO and others on progress
- d. Share and promote accurate, up to date information about the impact of epilepsy in different regions, its treatment and its consequences through website, newsletter, conferences



Advocate for improved human and civil rights for people with epilepsy worldwide

- a. Create and share model legislation and guidelines with IBE chapters, and offer mentoring to member countries from those who have successfully made impact
- b. Encourage member countries to implement legislative and regulatory changes within each country to promote human and civil rights for people living with epilepsy, and report on progress to IBE
- c. Encourage regions to identify epilepsy-focussed human and civil rights goals for their member organisations
- d. Encourage all chapters to include people impacted by epilepsy on their boards, in their planning and in their activities



Provide resources for people with epilepsy and their families to maximize quality of life

- a. Provide accurate information exchange on evidenced based best practices in self-management of epilepsy, epilepsy in schools, youth and young adult programs, and other identified programs through face to face meetings, digital platform (website), newsletter, and other identified means
- b. Promote the use of electronic and social media to inform and exchange information, as well as to create communities among people affected by epilepsy
- c. Ensure that all international, regional and national meetings in which IBE is involved, include tracks for lay organisations, social services, and for people and families affected by epilepsy
- d. Seek support to allow lay organisations and people with epilepsy to attend IEC meetings or regional meetings
- e. Assist with the development of new chapters in areas that are not currently served
- f. Ask member countries and community partners to link to IBE website and track growth in participation
- g. Encourage youth councils in member organisations



Promote prevention and research focused on care, and treatment of epilepsy and its consequences worldwide

- a. Encourage chapters to pursue awareness and education campaigns about current concerns of epilepsy, prevention, need for better treatment for those affected

(NOTE - member countries may have very different priorities here: many may be focused on public education and awareness campaigns focused first on improving social conditions, and on securing access to currently available treatment. But to the extent each country has its own research activities and budgets, epilepsy should be on the list)

- b. Promote the prevention of epilepsy
- c. Promote access to currently available treatments
- d. Promote the value of research and new therapies to stop seizures and cure epilepsy



Improve the unity, sustainability, and communication of the IBE

- a. Evaluate dues and means of financial support for IBE and make recommendations for changes to improve IBE's financial status, sustainability and independence
- b. Create representative inter-regional and cross-regional task forces for each IBE goal to foster inter-organisational mentoring, best practice exchange, and to support the development of action plans and recommendations on standards and strategies for action for regions, for countries, and for IBE
- c. Utilize electronic platforms for meetings within regions and cross regionally to promote information exchange and to support the creation of collaborative learning groups
- d. IBE and all its chapters have the opportunity to meet electronically at least 2x a year through resources such as Webinex or GoToMeetings or Skype
- e. Establish a mentoring program where chapters offer to provide information exchange
- f. Utilize all communications vehicles (available as identified in opportunities document) to implement goals

NOTE: *These strategic goals will, at all times, be subject to IBE having the available funds to implement them.*

