

## Strategic Plan 2019-2023

### *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 focused and mission-driven organisations

We work collaboratively with our professional and 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 patients 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

## 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 LEADERSHIP GROUP PLAN

### **Stakeholder Engagement Working Group**

- Encourage all chapters to include people impacted by epilepsy on their boards, in their planning and in their activities.
- 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.
- Ensure that all international, regional and national meetings in which IBE is involved, include tracks for community organisations, social services and people and families affected by epilepsy.
- Assist with the development of new chapters in areas that are not currently served.
- Encourage youth councils in member organisations.

## **Sustainability Working Group**

- Seek support to allow community organisations and people with epilepsy to attend IEC meetings or regional meetings.
- Evaluate dues and means of financial support for IBE and make recommendations for changes to improve IBE's financial status, sustainability and independence.
- 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.
- 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.

## **Capacity Building Working Group**

- 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.
- Encourage and incentive 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.
- Create and share model legislation and guidelines with IBE chapters, and offer mentoring to member countries from those who have successfully made impact.
- Encourage regions to identify epilepsy-focused human and civil rights goals for their member organisations.
- 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.
- 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.
- 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.
- Establish a mentoring program where chapters offer to provide information exchange.

## **Communication Working Group**

- Work with Stakeholder Engagement Working Group to 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 and WHO in collaboration with partner organisations like ILAE.
- Encourage and incentive 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.
- 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.
- 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.
- Promote the use of electronic and social media to inform and exchange information, as well as to create communities among people affected by epilepsy.
- Ask member countries and community partners to link to IBE website and track growth in participation.
- Encourage chapters to pursue awareness and education campaigns about current concerns of epilepsy, prevention, need for better treatment for those affected.
- Utilize electronic platforms for meetings within regions and cross regionally to promote information exchange and to support the creation of collaborative learning groups.
- 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.

