



# LOOKING FORWARD

## IBE reviews its Strategic Plan

*In this modern fast-changing world, where innovation is key and where no idea remains new for long, the need to adapt is key to providing the support and services that IBE chapters deserve. Recognising the importance of regular reviewing where we are and where we need to be is vital. With this in mind, in January, IBE held a meeting in London to review the strategic plan already in place and to consider the changes needed to ensure that its future direction continued to be in line with its core mission. The meeting was attended by a number of invited stakeholders representing people with epilepsy and their care-givers, along with the members of the International Executive Committee. Noémi Ambrus, a professional consultant from Hungary, facilitated the event. Here you can read the full report.*

### Introduction

In preparing for the meeting, Noémi Ambrus had held telephone interviews with a number of stakeholders and a wider group had also been invited to participate in an online survey. From these activities, five pertinent issues had been identified as requiring discussion, to ensure that the IBE's future strategy was fit for purpose:

1. Roles and responsibilities of board members
4. INTERNATIONAL EPILEPSY NEWS

2. The difference between a 'working board' and a 'governance board'
3. Patient involvement and representation in IBE
4. Changes in the current strategy

On the day of the meeting, and in advance of considering the current strategy and considering how well this had been implemented, each participant was asked to share their expectations for the workshop. Some of the comments expressed included:

- To have a clear view on strategies
- To establish a concise 'doable' plan
- To implement what we plan
- To agree on 'the basic things'
- To generate genuine engagement of stakeholders
- To establish a plan of action
- To set priorities
- To have a common theme implemented across all IBE regions



- To strengthen activities at the grass-root level
- To establish clarity of role for IBE
- To introduce a funding plan and the best practice to do so

### General Discussion

It was generally agreed that the current Strategic Plan (2016-2019) was still relevant but required an implementation plan. The current plan identifies goals but does not include the ‘who, how, when’ nor does it identify a budget to achieve the goals.

The facilitator stated that boards should review their strategic plan at least every six months to measure progress towards implementation and this is something that IBE is taking on board for the future.

It was also stated that with 1.2 full-time paid staff, the board needed to be an active hands-on ‘working board’ but was currently operating as a ‘governance board’ without any direct involvement in day to day operations.

A discussion about staffing needs of the IBE

followed and the following considerations were raised:

- Should IBE consider hiring a paid fundraiser?
- Could we identify existing projects that are attractive for funding?
- How can we reduce the burden on our Executive Director?

It was agreed that the Executive Director should identify tasks that could be completed by an assistant and to create a job description for this role. It was also agreed that funding should be allocated so that the Executive Director could hire an assistant to lessen her workload.

The board was advised that it should be mindful that it had legal oversight and responsibility for IBE and needed to know that there is an expectation that board members will provide time and treasure to the organization. Board members should consider what value they bring to the board in respect to IBE’s goals and objectives.

IBE should also consider including people on the board with specific expertise: com-

munications experts, fundraisers, human resource professionals, lawyers, chartered accountants, etc.

The Treasurer has responsibility for fiscal oversight and our lack of oversight puts the organization at risk. The group then discussed the financial position of the IBE and the need for a diversified sustainability plan. It was agreed that there is a need for a clear dual objective: that of the internal operational plan and the external priorities of raising awareness, and how it is important not to neglect either.

The group discussed Jim Collins’ model for organisations, which is based on Mission, Capability and Funding, and how sustainable operations are needed in all three areas. Our organisation needs to increase our sustainability which is small. In order to do this the organisation needs to grow its capacity first, and acquire funding which will then enable capability. A business case needs to be developed to result in support.

It was proposed that the board identify ‘working groups’ and that board members



be encouraged to join a working group or appoint people from their region to a working group. Four groups were proposed: Stakeholder Engagement, Sustainability, Capacity Building and Communication. It was also suggested that Youth Engagement be made a priority.

The group went through each of the goals of the current strategic plan to identify how they aligned with the proposed leadership groups.

There were 3 goals that need to be revised by the executive committee:

1. Promote the prevention of epilepsy
2. Promote access to currently available treatments
3. Promote the value of research and new therapies to stop seizures and cure epilepsy.

The following was proposed:

1. The Executive Director would be a member of each working group and would oversee the progress of the strategic plan.
2. The Chairs of each working group would be invited to join the IBE Executive Committee, where this was not already the case.
3. The Chairs of each working group would form a leadership team with the IBE Management Committee. They would meet on a regular basis and would provide accountability for the implementation of the IBE Strategic Plan.

4. It was agreed that the current strategic plan would be extended to cover the period 2019 - 2023.

### Stakeholder Engagement Working Group

Members Francesca Sofia (Italy) Chair Italy, and Carol D'Souza (India), agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date.

It was proposed:

- That by 2023, a minimum of 50% of the board should be stakeholders (persons with epilepsy (PWE), care providers, staff of not for profit epilepsy organisations). It was noted that guidelines or byelaws needed to be drafted.
- IBE should look to develop advocacy training. This needed three separate approaches for chapters in high-, middle- and low-income countries and tailored as needed.
- Define 'who' are our stakeholders?
- People living with epilepsy need to have access to becoming a board member.
- Group to work together to develop a letter to explain a proposed engagement programme.
- An element of the engagement programme could be to develop a summer school to train stakeholders on how to be more engaged.
- That a list of possible outstanding

"champions" would be drafted; people in the list would be contacted and asked to join the group. The Group will continue to monitor the stakeholder landscape over time, to find and involve more "champions".

It was agreed that the Stakeholder Engagement Working Group would be responsible for leading the implementation of the following strategic priorities:

- 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 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.
- Encourage all chapters to include people impacted by epilepsy on their boards, in their planning and in their activities.
- 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.
- Assist development of new chapters in areas that are not currently served.
- Encourage youth councils in member organisations.

**Main photo, from left:** Athanasios Covanis, Past President; Mary Secco, Secretary General; Graeme Shears, Epilepsy Foundation Australia; Anthony Zimba, Treasurer; Satish Jain, VP South East Asia; Ding Ding, VP Western Pacific; Francesca Sofia, FIE Italy; Martin Brodie, President; Natela Okujava, VP Europe, Phil Gattone, VP North America; Carol D'Souza, India; Ann Little, Executive Director; Noémi Ambrus, facilitator; Yousouf Noormamode, Vice Chair Africa; Tomás Mesa, VP Latin America.

**Below:** Phil Gattone, Chair of the Sustainability Working Group makes a point during the breakout session

**Top right, from left:** Francesca Sofia, Carol D'Souza, Mary Secco and Ding Ding in discussion

**Bottom right:** plenary discussion, facilitated by Noémi Ambrus (back to camera).



## Sustainability Working Group

Phil Gattone (USA) Chair, Martin Brodie (Scotland), Yousouf Noormamode (Mauritius) and Thanos Covanis (Greece) agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date but will include the following:

- Recommendation of whether to hire a resource development manager.
- Build a comprehensive case for financial support.
- Attractive projects for funding included Promising Strategies, EpilepsyNext, International Epilepsy Day, IBE website, etc.
- Identify donors and a process for solicitation.
- Encourage chapters to identify large donors, 10% of any donation raised in a region could be provided to the chapter.
- Idea to develop a 'Friends of IBE' group.

The Sustainability Working Group will be responsible for leading the implementation of the following strategic priorities:

- Seek support to allow lay 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

Graeme Shears (Australia) Chair, Satish Jain (India) and Anthony Zimba (Zambia) agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date but will include the following:

- What capabilities is IBE missing?
- Who are the members of the IBE?
- Look at staffing
- Look at volunteer recruitment and mentoring
- Ways to involve PWE at all levels up to board membership. Board members should have skills and reason to commit.
- Is IBE 'for' people with epilepsy or 'of' people with epilepsy?
- Epilepsy Foundation in Australia had a project template that could be adjusted to suit IBE's requirements. This would be circulated.

It was agreed that the Capacity Building Working Group would be responsible for leading the implementation of the following strategic priorities:

1. 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.
2. 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.
- 3. Create and share model legislation and guidelines with IBE chapters, and offer mentoring to member countries from those who have successfully made impact.
- 4. Encourage regions to identify epilepsy-focussed human and civil rights goals for their member organizations.
- 5. 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.
- 6. 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.
- 7. 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
- 8. Establish a mentoring program where chapters offer to provide information exchange.

### Communications Working Group

Mary Secco (Canada) Chair, Ding Ding (China) and Carol D'Souza (India) agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date but will include the following:

- Develop a communications strategy
- Identify people with communications skills – e.g. pro bono support from ad agencies, PR companies for social media campaigns, stakeholders who are professional communicators

- The WHO Epilepsy Report will be a valuable document for communications.
- A clear professionally developed message was needed
- A style guide needed to be developed (use of terms: epileptic, patient, lay organisation, etc.).
- Consideration of a Stigma task force
- 'Understanding Epilepsy in the World' research group

It was agreed that the Communication Working Group would be responsible for leading the implementation of the following strategic priorities:

1. 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.
2. 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.
3. 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
4. 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.
5. Promote the use of electronic and social media to inform and exchange information, as well as to create communities among people affected by epilepsy.

6. Ask member countries and community partners to link to IBE website and track growth in participation.
7. Encourage chapters to pursue awareness and education campaigns about current concerns of epilepsy, prevention, need for better treatment for those affected.
8. Utilize electronic platforms for meetings within regions and cross regionally to promote information exchange and to support the creation of collaborative learning groups.
9. 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

### Facilitator's Recommendations

1. Strategy document should be on the website – transparency is key
2. The group should communicate about the meeting to the chapters and wider audience
3. In order to engage others, a description of background, focus and aim for each working group needs to be developed and posted on IBE website.
4. Job descriptions were required for each working group and staff position.
5. Exposure of IBE could be helped through aligning with human rights groups – disability, discrimination and NCD groups.
6. For financial stability the organization needs 4 types of income with no more than 50% funding from a single source. It also needs a reserve of 6 months in the bank at all times.
7. It is necessary to develop an action plan as donors will not give money to fund the operations of an organisation.
8. The Board needs to include more champions/people living with epilepsy.