

LONG TERM STRATEGY 2009 – 2013

A future for the International Bureau for Epilepsy

IBE International Executive Committee
Rome, Italy
November 2009

Introduction and background

- IBE was established in 1961. It is the recognised international umbrella body representing national epilepsy organisations that have a specific interest in improving the social condition and quality of life of people with epilepsy and their carers.
- Since its establishment, IBE has grown and is continuing to grow, measured by the number of its members, with 120 Full and Associate Members in 92 countries.

There is no other similar credible organisation with the same broad Goals and Objectives or the same constituency of stakeholders as IBE.

- Epilepsy and those affected by the condition are experiencing a process of dynamic change reflected by changes in world-wide economic, technological, medical, political and social circumstances.
- The current and forecast future demand on IBE's resources outweighs the organisation's ability to satisfy the demands and expectations being placed upon it.
- This document presents a strategic response to this situation. It offers a way forward to ensure that IBE has a practical, relevant and meaningful future.
- Once agreed, it will be the International Executive Committee's task to ensure the strategy is delivered through action plans and outcomes that should be reported back to the Members and other stakeholders.
- This document is an updated version of the previous Strategic Plan that was in place from 2005-2009.

Strategy

Vision – IBE has a vision of the world where everywhere ignorance and fear about epilepsy are replaced by understanding and care.

Mission – IBE exists to improve the social condition and quality of life of people with epilepsy and those who care for them.

Goals – To achieve its vision and mission, IBE has set the following Goals:

1. Organisation

To provide an international umbrella organisation for national epilepsy organisations (Members of IBE) whose primary purpose is to improve the social condition and quality of life of people with epilepsy and those who care for them.

2. Support

To provide a strong global network to support the development of new Members, to support existing Members to develop to their fullest potential and to encourage co-operation and contact between Members.

3. Communication

To promote the facts about epilepsy and to communicate IBE's vision, mission and messages to the widest possible audience.

4. Education

To increase understanding and knowledge of epilepsy.

5. Representation

To provide an international and global platform for the representation of epilepsy.

GOAL 1- ORGANISATION:

To provide an international umbrella organisation for national epilepsy organisations (Members of IBE) whose primary purpose is to improve the social condition and quality of life of people with epilepsy and those who care for them.

<p>1. To ensure IBE is governed and led in an open, democratic and transparent way such that it commands the fullest confidence, participation and support of its Members Friends and other stakeholders.</p> <p>2. To ensure IBE is governed and led in an open, democratic and transparent way such that it commands the fullest confidence, participation and support of its Members Friends and other stakeholders.</p>	<p>1. Follow up the new constitution</p>		
	<ul style="list-style-type: none"> • Surveying Members on their experience with the new constitution & general activities 	<ul style="list-style-type: none"> • International Executive Committee • President • Executive Director 	To be addressed
	<ul style="list-style-type: none"> • Strengthening the connection with Members 	<ul style="list-style-type: none"> • International Executive Committee • President • Executive Director 	Ongoing
<p>3. To organise and manage IBE's resources so that they are used in the most effective and efficient manner possible to achieve IBE's stated goals.</p>	<p>3. Development of the Office and Administration</p>		
	<ul style="list-style-type: none"> • Office move 	<ul style="list-style-type: none"> • President and Executive Director 	Completed 2006 and 2007
	<ul style="list-style-type: none"> • Review of equipment • Additional staff 	<ul style="list-style-type: none"> • President and Executive Director 	Reviewed on ongoing basis

	<ul style="list-style-type: none"> • Review of ED duties • Systems and Procedures 	<ul style="list-style-type: none"> • President • International Executive Committee • Executive Director 	Further development on ongoing basis
4. To provide a sound and realistic financial platform to enable IBE to carry out its plans.	Financial Management Plan		
	<ul style="list-style-type: none"> • Development of the Financial procedures 	<ul style="list-style-type: none"> • International Executive Committee • Executive Director 	Completed
	<ul style="list-style-type: none"> • Identifying new fundraising and sponsorship opportunities 	<ul style="list-style-type: none"> • International Executive Committee • Regional Committees • Fundraising Task Force • Executive Director 	Phase 1 completed

GOAL 1- ORGANISATION:

To provide an international umbrella organisation for national epilepsy organisations (Members of IBE) whose primary purpose is to improve the social condition and quality of life of people with epilepsy and those who care for them.

OBJECTIVES	ACTION	Action by	Timetable
<p>1. To ensure IBE is governed and led in an open, democratic and transparent way such that it commands the fullest confidence, participation and support of its Members Friends and other stakeholders.</p> <p>1.2 To ensure IBE is accessible to all those for whom it is established, recognising the diversity of needs and demands.</p> <p>2. To organise and manage IBE's resources so that they are used in the most effective and efficient manner possible to achieve IBE's stated goals.</p> <p>3. To provide a sound and realistic financial platform to enable IBE to carry out its plans.</p>	<p>1. Follow up the new constitution</p> <ul style="list-style-type: none"> • Surveying Members on their experience with the new constitution & general activities • Strengthening the connection with Members <p>2. Development of the Office and Administration</p> <ul style="list-style-type: none"> • Office move • Review of equipment • Review of ED duties • Additional staff • Systems and Procedures <p>3. Financial Management Plan</p> <ul style="list-style-type: none"> • Development of the Financial 	<ul style="list-style-type: none"> • International Executive Committee • President and Office <ul style="list-style-type: none"> • Executive Director • International Executive Committee • President and Executive Director <ul style="list-style-type: none"> • International Executive Committee 	<p>Spring 2008</p> <p>Completed 2006 and 2007!</p> <p>Further development on ongoing basis</p> <p>Completed</p>

	procedures <ul style="list-style-type: none"> Identifying new fundraising and sponsorship opportunities 	<ul style="list-style-type: none"> Executive Director Regional Committees Fundraising Task Force 	Phase 1
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GOAL 2 - SUPPORT:

To provide a strong global network to support the development of new Members, to support existing Members to develop to their fullest potential and to encourage co-operation and contact between Members.

OBJECTIVES	ACTION	Action by	Timetable
<p>1. To provide relevant and useful support to existing Members, recognising their diverse needs and demands.</p> <p>2. To encourage the development of new Chapters.</p> <p>3. To encourage the participation of Members in IBE's activities.</p>	<p>Membership Enlargement</p> <ul style="list-style-type: none"> Support and develop existing Members Identify and recruit new Members Membership Drive Facilitate the formation of new lay associations Facilitate networking Promising Strategies initiative Volunteer Award Solidarity Fund Congress Bursaries <p>Global Campaign Against Epilepsy</p> <p>IBE/ILAE Joint Task Force Programme</p>	<ul style="list-style-type: none"> Commission for the Regions Enlargement Commission Editors Network International Executive Committee Executive Director <p>IBE Co Chair GCAE</p> <p>IBE Members of Joint Task Force – Epilepsy Advocacy Europe</p>	<p>Ongoing</p> <p>Introduced!</p> <p>Put in place</p> <p>Ongoing</p> <p>Ongoing</p> <p>Ongoing</p> <p>Ongoing</p>

GOAL 3 - COMMUNICATION:

To promote the facts about epilepsy and to communicate IBE's vision, mission and messages to the widest possible audience.

OBJECTIVES	Action	Action by	Timetable
<p>1. To facilitate the exchange of information, knowledge and experience about epilepsy between Members.</p> <p>2. To ensure IBE communicates effectively with all its identified audiences.</p>	<p>Communications</p> <ul style="list-style-type: none"> • Re-launch of website • Publications for download • Review IBE leaflet • New House Style • Electronic newsletter • Annual Report • IE News • General Assembly • IBE Promotion and Marketing • Letter from the President • Freedom in Mind and Wish Wall • Brain Storm • Future in Mind • Talk Epilepsy <p>Regional Initiatives</p> <ul style="list-style-type: none"> • Web pages • Newsletters <p>Member Initiatives</p> <ul style="list-style-type: none"> • Web sites • Newsletters and magazines • Networking 	<ul style="list-style-type: none"> • Website Task Force • International Executive Committee President and Office • Editors Network • Executive Director • IE News Editor • International Executive Committee and Executive Director • IBE President • International Executive Committee and Executive Director • Regional Executive Committees • Commission for the Regions • Members 	<p>Ongoing!</p> <p>Ongoing</p> <p>Spring 2008</p> <p>Spring 2008</p> <p>Spring 2008</p> <p>Annually</p> <p>Quarterly</p> <p>Biennially</p> <p>Ongoing</p> <p>Completed</p> <p>Completed</p> <p>Completed</p> <p>Ongoing</p> <p>Ongoing</p> <p>Ongoing</p>

GOAL 4 - EDUCATION:*To increase understanding and knowledge of epilepsy.*

OBJECTIVES	ACTION	Action by	Timetable
<p>1. To promote educational initiatives about epilepsy.</p> <p>2. To support international research into epilepsy.</p> <p>3. To further knowledge about epilepsy and to spread its understanding</p>	<p>Education Plan</p> <ul style="list-style-type: none"> • International Congresses • Regional Conferences • Research programme • Publications and dissemination • Educational workshops • Future in Mind – IBE Survey <p>Global Campaign Against Epilepsy</p> <p>IBE-ILAE Joint Task Force Programme</p>	<ul style="list-style-type: none"> • International Executive Committee • Regional Committees • Commission for the Regions • Executive Director • International Executive Committee • IBE Co Chair Global Campaign • IBE Members of the Joint Task Force – Epilepsy Advocacy Europe 	<p>Ongoing!</p> <p>Ongoing</p> <p>Ongoing</p> <p>Completed</p> <p>Completed</p> <p>Ongoing</p> <p>Ongoing</p>

GOAL 5 - REPRESENTATION:

To provide an international and global platform for the representation of epilepsy.

OBJECTIVES	ACTION	Action by	Timetable
1. To campaign and lobby with a global perspective on behalf of people with epilepsy and their carers.	UN ECOSOC	<ul style="list-style-type: none"> President and International Executive Committee and Executive Director 	Ongoing!
2. To highlight issues of particular concern and to lobby, persuade and campaign for change and improvements.	Campaigns Plan	<ul style="list-style-type: none"> Regional Committees 	Ongoing
3. To provide a worldwide unified voice for people with epilepsy and their carers.	Global Campaign Against Epilepsy	<ul style="list-style-type: none"> IBE Co-Chair Global Campaign Against Epilepsy 	Ongoing
4. To represent epilepsy in appropriate and relevant international forums.	IBE-ILAE Joint Task Force	IBE Members of the Joint Task Force Epilepsy Advocacy Europe	Ongoing
	Regional Campaigns	President, International Executive Committee and Executive Director	Ongoing
	EPICURE		Completed