

ANNUAL REPORT 2012



International Bureau for Epilepsy



Our Vision

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

Our Mission

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

Our Goals:

Organisation: To provide an international organisation for national epilepsy organisations and other epilepsy organisations whose primary purpose is to improve the quality of life of people with epilepsy and those who care for them.

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 cooperation and contact between members.

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

Education: To increase awareness, understanding and knowledge of epilepsy and to increase awareness, understanding and knowledge of how best to meet the needs of people with epilepsy and those who care for them.

Representation: To provide an international and global platform for the representation of epilepsy in relation to national and international organisations and governments.

Partnerships

- Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC)
- Official working relations with the World Health Organization (WHO)
- Member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)
- Member of the European Federation of Neurological Associations (EFNA)
- Close working partner with the International League Against Epilepsy (ILAE)

International Executive Committee 2009-2013

President: Mike Glynn (Ireland), **Secretary General:** Carlos Acevedo (Chile), **Treasurer:** Grace Tan (Singapore),

Immediate Past President: Susanne Lund (Sweden)

Vice Presidents:

VP Africa: Anthony Zimba (Zambia), *VP Eastern Mediterranean:* Abdulaziz Al Semari (Saudi Arabia),

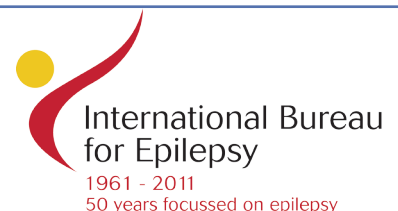
VP Europe: Janet Mifsud (Malta), *VP Latin America:* Lilia Núñez (Mexico), *VP North America:* Mary Secco (Canada),

VP South East Asia: Vinod Saxena (India), *VP Western Pacific:* Shunglon Lai (Taiwan)

ILAE Ex Officio Members:

ILAE President: Nico Moshé (US), *ILAE Secretary General:* Sam Wiebe (Canada), *ILAE Treasurer:* Emilio Perucca (Italy)

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PRESIDENT'S REPORT



It is with some sadness that I write this, my last President's message for the IBE Annual Report. However, quite a lot of success has been achieved in the last four years by our Executive Committee. I want to thank all my colleague Executive Committee members for their hard work and efforts during the term. I would particularly like to thank two people who leave the Executive after long and productive spells. They are Susanne Lund, Immediate Past President, my inspiring predecessor as President and Carlos, outgoing Secretary General and Editor of IE News, whose wisdom and friendship are the stuff of legend.

Great progress has been made for people with epilepsy by IBE around the world since the 29th International Epilepsy Congress in Budapest, at which time I began my four year term. Our Promising Strategies initiative grew during the period to target ever more closely those people with epilepsy in the developing world. Our joint regional conferences grew considerably in all regions where they existed. The one exception to this was the Eastern Mediterranean region, where the political problems in the Middle East made it impossible to have a 3rd congress. However, I am sure that we will continue to look for opportunities to hold this meeting and, in the meantime, the next International Epilepsy Congress will be held in Istanbul in 2015, which may offer opportunities for IBE members from the Eastern Mediterranean region to meet.

One of the great successes of this Presidency was the holding of the 1st African Epilepsy Congress in Nairobi in 2012 and plans are far advanced for the second African congress in Cape Town in 2014. In addition, the Global Campaign Against Epilepsy (GCAE) is again active in Africa and, having learned the lessons from earlier initiatives, there are prospects of real successes which can be scaled up across the continent.

The GCAE has also been putting epilepsy to the forefront at World Health Organization (WHO) Headquarters in Geneva

and in other demonstration projects in the developing world. IBE has used its relationship with WHO to put its case in the WHO's regional structures. It is likely that IBE may also be able to use its status at the United Nations (UN) to further its anti-stigma work under the UN Convention on the Rights of People with Disabilities, now that many countries have signed up to this.

Perhaps the greatest outcome yet from IBE's relationship with WHO is the Pan American Health Organization (PAHO) initiative, which continues to gain momentum in Latin America and the Caribbean under Carlos Acevedo's great leadership. In our Asian region the success of countries like Korea, in changing the negative symbols for epilepsy, gives hope that stigma can be challenged everywhere. In North America, the landmark Institute of Medicine (IOM) report on epilepsy will provide a great weapon to all involved in epilepsy there, especially IBE's member in the US - Epilepsy Foundation - which was among the prime movers in the preparation of the IOM report. Some of our best successes were in Europe, including the launch of the 1st European Epilepsy Day in 2011 and the second event in 2012, which led to the European Written Declaration on Epilepsy being approved by a majority of Members of the European Parliament.

The great work by the members of IBE's Task Forces in Research, Governance and Elections must also be thanked for their ongoing efforts. The work of the Governance Task Force has revealed that there are major gaps in IBE's governing documents. Its work is still ongoing but, when finished, will give clear direction to the new committee on the changes required to the IBE Constitution.

I would like to thank Ann Little for all of her work over the past term, which was invaluable. My thanks too to Karen Harvey for her support to Ann since she came on board.

One of the highlights of the past four years was the strengthening of the bond between IBE and ILAE. For this, much thanks to Nico Moshé, Emilio Perucca, Sam Wiebe and others. I hope that together we can continue to stand very strongly together for epilepsy.

With best wishes to all!

Mike Glynn
President 2009-2013

FINANCIAL REPORT

Income and Expenditure Account

Year ended 31st December 2012

With comparative totals for 2011

	2012 US\$	2011 US\$
INCOME	843,301	2,574,239
EXPENDITURE	(1,101,461)	(1,597,933)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>(258,160)</u>	<u>976,306</u>

Balance Sheet

Year ended 31st December 2012

With comparative totals for 2011

	2012 US\$	2011 US\$
CURRENT ASSETS		
Debtors and prepayments	166,381	173,159
Cash in hand and at bank	3,082,949	3,540,934
Amount held on behalf of the IBE/ILAE Joint Task Force	242,316	310,699
	<u>3,491,646</u>	<u>4,024,792</u>
CREDITORS (Amounts falling due in one year)	(635,469)	(910,455)
NET CURRENT ASSETS	<u>2,856,177</u>	<u>3,114,337</u>
NET ASSETS	<u>2,856,177</u>	<u>3,114,337</u>
CAPITAL AND RESERVES		
General Reserve	2,772,233	3,044,534
Restricted and designated fund	83,944	69,803
	<u>2,856,177</u>	<u>3,114,337</u>

The financial statements were approved on 9 July 2013 and signed by:

Athanasios Covanis, President

Ann Little, Executive Director

Statement of Income and Expenditure

Year ended 31st December 2012

With comparative totals for 2011

	2012	2011
	US\$	US\$
INCOME		
Congress income received	584,854	1,488,131
Congress income receivable	69,195	670,766
Corporate donations	69,255	204,284
IBE/ILAE JTF management fee	19,885	39,076
IBE/ILAE JTF reimbursement of expenses (IBE 50%)	24,248	75,695
Membership dues and solidarity fund	15,696	21,136
Investment income	26,796	52,887
EPICURE grants	33,045	20,386
Miscellaneous income	327	1,878
	<u>843,301</u>	<u>2,574,239</u>
EXPENDITURE		
Congress expenditure	680,971	1,008,964
Office expenses	23,470	19,248
Printing and postage	3,690	13,790
Printing and postage - International Epilepsy News	35,464	29,755
Travel	61,522	27,530
Global Campaign costs	30,000	43,580
Accountancy fees	3,925	10,626
Audit fees	9,158	7,000
Administrator costs	144,861	166,734
Bank charges	2,055	595
Rent	15,700	30,514
Promising Strategies	40,144	45,811
Website costs	16,935	3,943
IBE JTF expenditure	24,248	75,695
EPICURE costs	-	20,386
Depreciation	-	1,772
1st EED costs	-	62,595
	<u>1,101,461</u>	<u>1,568,538</u>
Loss of foreign exchange	9,318	29,395
	<u>1,101,461</u>	<u>1,597,933</u>

FINANCIAL REPORT continued

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2012

IBE/ILAE Joint Task Force

The IBE/ILAE Joint Task Force programme is a joint 50:50 initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). Its aim is to raise the profile of epilepsy across Europe by undertaking new research and educational activities. The initiative received corporate sponsorship and the fund is jointly owned by IBE and ILAE. IBE administer the programme and the fund, and received a management fee of US\$19,886 (2011: US\$39,076).

	2012 US\$	2011 US\$
Opening balance	310,699	454,137
Bank interest received	4,856	7,952
Expenditure incurred	(73,239)	(151,390)
Closing balance	<u>242,316</u>	<u>310,699</u>

Congress Financial Information

The International Bureau for Epilepsy and the International League Against Epilepsy (ILAE) engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 2 February 2010. The IDM is charged with the organisation of various European and International Congresses.

The 2012 financial statements reflect the portion of assets, liabilities, net revenues and expenses held by the International Director of Meetings on behalf of the International Bureau for Epilepsy. An analysis of the proportion of congress assets, liabilities, income and expenses applicable to the Bureau is as follows:

	2012 US\$	2011 US\$
Cash at bank	243,643	310,699
Debtors and prepayments	99,178	155,928
Creditors	(56,918)	(110,222)
Deferred income	(111,169)	(340,448)
IDM-Congress income received	584,854	1,488,131
IDM-Congress income receivable	69,195	670,766
IDM-Congress expenses	<u>(680,971)</u>	<u>(1,008,964)</u>

Solidarity Fund Donations 2012



IBE acknowledges the very generous support of the member associations listed below, whose donations to the Solidarity Fund in 2012 helped to meet the membership dues of members in emerging nations who might, otherwise, have been unable to meet their dues payments.

US\$2,000

- Epilepsy Hospital Bethel, Japan

US\$1,500

- Swedish Epilepsy Association, Sweden

US\$200

- Indian Epilepsy Association, India

US\$150

- ANLICHE, Chile
- AURA, Slovakia

US\$100

- Epilepsy Australia, Australia
- Joint Epilepsy Council of Australia, Australia
- Canadian Epilepsy Association, Canada
- Greek Association Against Epilepsy, Greece
- Epilepsy Vereniging Nederland, The Netherlands
- Epilepsy Connections, Scotland

Under US\$100

- Epilepsy Association of SA & NT, Australia
- Epilepsy Queensland, Australia
- China Association Against Epilepsy, China
- Slovenian League Against Epilepsy, Slovenia
- ParEpi, Switzerland
- Japanese Epilepsy Association, Japan
- Taiwan Epilepsy Association, Taiwan
- Epilepsy & Environment, Georgia
- Caritas Malta Epilepsy Association, Malta

Members supported by the Solidarity Fund

- | | | | |
|-----------------------|---|--------------------------|---|
| 1. ALBANIA: | Albanian Association of Epilepsy | 12. NEPAL: | Nepal Epilepsy Association |
| 2. BANGLADESH: | Bangladesh Epilepsy Association | 13. NIGER: | LNCENMNC, Service de Psychiatrie |
| 3. CAMEROON: | Association Camerounaise Contre l'Epilepsie | 14. NIGERIA: | Epilepsy Association of Nigeria |
| 4. CAMEROON: | Community Development and Epilepsy Foundation | 15. PAKISTAN: | FLAME |
| 5. CONGO: | MHCD Centre for prevention and treatment of Epilepsy | 16. SENEGAL: | Ligue Senegalaise contre l'Epilepsie |
| 6. ETHIOPIA: | Epilepsy Support Association | 17. SIERRA LEONE: | Epilepsy Association of Sierra Leone |
| 7. GAMBIA: | Gambia Epilepsy Association | 18. SWAZILAND: | Swaziland Epilepsy Association |
| 8. GHANA: | Ghana Epilepsy Association | 19. TANZANIA: | Parents Organisation for Children with Epilepsy |
| 9. HONDURAS: | Fundación Hondureña de Epilepsia | 20. TOGO: | Association Clinique de l'Epilepsie |
| 10. KENYA: | Kenya Association for the Welfare of People with Epilepsy | 21. UGANDA: | Epilepsy Support Association |
| 11. MONGOLIA: | Mongolian Epilepsy Association | 22. ZAMBIA: | Epilepsy Association of Zambia |
| | | 23. ZIMBABWE: | Epilepsy Support Foundation |

CONTACT DIRECTORY 2013

The new term for Committees, Task Forces and Networks began at the time of the General Assembly in June 2013. The contact information, detailed below, relates to the term 2013-2017.

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Emilio Perucca, President
Helen Cross, Secretary General
Sam Wiebe, Treasurer

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CEO Network

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Governance Task Force

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Global Campaign Against Epilepsy

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IBE/ILAE Joint Task Force Europe

Administration: Ann Little
Co-chairs: Athanasios Covanis,
Philippe Ryvlin
Members: Sari Tervonen, Hannah
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Mitchell MEP, Christian Elger

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2nd AFRICAN EPILEPSY CONGRESS
CAPE TOWN, SOUTH AFRICA
22nd – 24th May 2014



11th European Congress on Epileptology
STOCKHOLM
29th June - 3rd July 2014



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Epilepsy
CONGRESS

SINGAPORE 2014
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17-20 Setiembre 2014
BUENOS-AIRES
VIII CONGRESO LATINOAMERICANO DE EPILEPSIA



31st International
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06-10 September 2015
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