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

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

Our Goals
- ORGANISATION
  To provide an international umbrella organisation for national epilepsy organisations whose primary purpose is to improve the social condition and 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 Chapters, to support existing Chapters to develop to their fullest potential and to encourage co-operation and contact between Chapters.
- COMMUNICATION
  To promote the facts about epilepsy and to communicate IBE’s vision, mission and messages to the widest possible audience.
- EDUCATION
  To increase understanding and knowledge of epilepsy.
- REPRESENTATION
  To provide an international and global platform for the representation of epilepsy.
During my fifteen years working, first in the British Parliament and Government and now in the European Parliament, I have seen and welcomed an ever-increasing awareness of the importance and benefits of strong partnerships. Networks and alliances are more than just “buzz words” – they are proven methods of achieving desired goals. They may not be easy to achieve, but, once in place, they make it simpler for patients, carers, professionals and academics to explain health needs and options for action and they make it easier for policy-makers to listen and to understand what is needed.

The International Bureau for Epilepsy is already building admirable networks; with its international membership it can effectively advocate the need to put epilepsy higher on the agendas of governments and international health agencies around the world. In Europe I was privileged to participate in the Heidelberg Declaration on Epilepsy and then to facilitate and witness the launch in the European Parliament of the European White Paper on Epilepsy and the activities that this initiative has since instigated. One of these has been our Advocate Group of MEPs in the European Parliament, supported by EUCARE. I am delighted that EUCARE is now moving into its second phase. I very much welcome its plans for public education and research activities.

On a wider scale, I believe that the Global Campaign Against Epilepsy, a partnership with the International League Against Epilepsy and the WHO, is having a significant impact on government thinking on every continent. Ensuring that national governments worldwide remain aware of the need to improve services for people with epilepsy is not always easy to achieve, as I know from my own experience. We must, however, remain encouraged and determined, never losing faith in the power that ordinary individuals can create, when they come together to work for a common cause.

I am convinced that our ever-strengthening partnership of doctors, nurses, researchers, families, people living with epilepsy, managers and politicians in national and international parliaments – all working together – can and will succeed in improving the quality of life for people with epilepsy. Together we shall make a difference.

John Bowis MEP
Member of the European Parliament
Dear Friends

During 2003 IBE has continued to develop, progress and move forward, and its future is now looking brighter than ever. Ten years ago, in 1993, our annual report indicated membership of 39 Chapters and 16 Friends – by the end of 2003 these figures have risen to 69 Chapters and 32 Friends; almost doubling our presence throughout the world.

IBE’s dynamism is evident in our new look Annual Report. Its design and layout have been created to show not only our recent achievements and our confidence for the future, but, more importantly, how the plans of IBE directly reflect the aspirations and objectives of all of our members.

The 25th International Epilepsy Congress in Lisbon was the highlight of the year’s events. No less than 38 Chapters were represented at the General Assembly Open Forum for discussions on IBE’s Constitution and its review. The task of reviewing IBE’s Constitution is ongoing, but we are confident that by early 2005 we will have a new Constitution bearing the stamp of approval of our members and valid to serve IBE’s future development. In addition, a Strategic Plan, which will carry IBE forward with the mechanisms required to meet future challenges and opportunities, was approved during the General Assembly. Since then work has begun on its implementation.

IBE continues to develop strong regional structures through its three Regional Committees in Asia-Oceania, Europe and Latin America. My thanks to the three Chairs of these Committees, respectively Marshal Mo-Song Hsi, Hilary Mounfield and Carlos Acevedo.

Dr Thanos Covanis, IBE Vice President, Chairs the Eastern Mediterranean Region Task Force, which is working to attract new members from that region. To encourage IBE enlargement in Africa we have a Commission for Africa, co-Chaired by Hanneke de Boer and Kathy Pahl during 2003.

I would like to use this opportunity to thank the Chairs of our other Commissions also – John Chaplin, Employment; Susanne Lund, Public Education; JoAnne Dahl, Psychological Approaches to Epilepsy; Gus Baker, Research; and Ann Jacoby, Risks and Insurability - for their efforts over the past twelve months.

Together with ILAE, we have successfully negotiated with UCB Pharma to sponsor the EUCARE programme in Europe. EUCARE’s focus will be to establish a European-wide observational research study into the outcomes of treatment and quality of life issues and to develop activities in public policy campaigning and lobbying as part of the follow up to the European White Paper on Epilepsy.

We have continued to develop the ILAE/IBE/WHO Global Campaign Against Epilepsy as a model partnership between Non Governmental Organisations (NGOs) and the World Health Organisation (WHO).

Let me finish by expressing my thanks to all those who have helped and supported IBE. In particular, my thanks to all the Chapters and Friends of IBE. Your work in countries around the world is truly inspiring. One of IBE’s major strengths lies in the tremendous diversity of its membership; we hope that this report adequately reflects this.

Philip Lee
President
In reviewing our Constitution, we are working to ensure that IBE is governed and led in an open, democratic and transparent way such that it commands the fullest confidence, participation and support of its Chapters, Friends and other stakeholders.

Over the past decade IBE’s membership has increased almost twofold, and is set to continue increasing dramatically over the coming years. In addition, epilepsy and those affected by the condition are experiencing a process of dynamic change reflected by changes in global economic, medical, technological and political circumstances.

In response to this, a Long Term Strategy, which identifies objectives and actions required by IBE in order to meet future demands on its resources and to ensure that the Bureau can satisfy the demands and expectations placed on it in the future, was adopted by the General Assembly when it met during the 25th International Epilepsy Congress in Lisbon in October 2003.

A component of this plan is a radical revision of IBE’s Constitution, which began with the establishment of a Constitutional Review Task Force charged with overseeing the review process. The members of the Task Force comprise the Chairs of the Regional Committees of Asia Oceania, Europe and Latin America, IBE President and the IBE 1st Vice-President.

Since the General Assembly, work has progressed apace; discussion papers were circulated to all stakeholders for their views and suggestions in late October and feedback received influenced a first draft Constitution, reviewed by the Constitutional Review Task Force early in April 2004.

At the beginning of June 2004 a first exposure Draft Constitution was circulated, together with a Consultation Questionnaire. This phase of the review will end at the end of July after which a final draft will be produced by the Task Force for presentation to the Executive Committee and thereafter to IBE members.

By early 2005, a new Constitution, whose content will have been influenced by IBE’s members – those associations to which it ultimately relates – will be ready for voting on. We are excited by the prospect of a new Constitution that will take IBE confidently forward to meet demands placed on it in the coming years.
Providing a Strong Global Network

Throughout 2003 we worked to provide a strong global network to support the development of new Chapters, to support existing Chapters to develop to their fullest potential and to encourage co-operation and contact between Chapters.

• The **IBE Long Term Strategy 2003 – 2005** presents a way forward to ensure that IBE has a practical, relevant and meaningful future; its adoption by the General Assembly in Lisbon marked a first step in realising this long term plan.

• To implement the Long Term Strategy, work began on the development of a range of Operational Action Plans, including work on a **Communications Plan** and an **Education Plan**. A review of IBE’s Administration has also begun.

• One of the major steps in providing appropriate support for members lies in creating a new **Constitution**. The Open Discussion Forum at the General Assembly in Lisbon provided the opportunity for Chapters and other stakeholders to express their views on significant elements of the Constitution.

• The **Regional Committees** in Asia Oceania, Europe and Latin America are uniquely positioned to support members in their regions; recognising issues specific to their region and encouraging the development of new epilepsy organisations. During 2003 IBE welcomed new Chapters and Friends in Venezuela and Jamaica (Latin America); Thailand, Hong Kong and Australia (Asia Oceania); Switzerland, UK, Cyprus and Romania (Europe).

• A newly created **Eastern Mediterranean Task Force** held a successful launch at the Lisbon congress. There are very positive signs that IBE’s presence in the region will increase significantly in the near future with prospective new members in Morocco, Lebanon and Egypt.

• The **Commission on Africa** has been very active in 2003; marked by the approval at the General Assembly of five new chapters in Africa - Tanzania, Zambia, Uganda, Algeria and Niger. The commission held well-attended sessions in Lisbon and has significant plans for future activities.

• An **Editor’s Network** was created and had its first meeting in Lisbon. The aims of this group are to provide a platform for editors of Chapter and Friend association newsletters to share editing and publishing experiences; to share ideas on becoming more creative in spreading the epilepsy message; and to see how members might share materials for best use of available resources.

• The **Public Education Commission** began researching the concept of an image database IDEA (Image Database Epilepsy Awareness). Images would be stored as “thumbnails” on a website managed by the Commission, with ownership and copyright remaining with the creator of the image.

• The **Asian Oceania Regional Committee** initiated plans for a regional Outstanding Person with Epilepsy Award.

• A **Reproduction Licence** was devised during the year by the IE News Editor. Renewable annually, the licence will allow unlimited reproduction of extracts from the IE News, subject to certain criteria being met.

• The **Latin American Regional Committee** facilitated the celebration of the annual Latin American Epilepsy Day on 9th September.
Throughout the world, Chapters and Friends worked tirelessly to support people with epilepsy in 2003 through a wide range of activities:

• **Epilepsy Canada** introduced a Community Grant Program to help epilepsy associations in Canada to develop new and innovative programs for people with epilepsy.

• Due to major cutbacks by health departments in Romania, the provision of AEDs to people with epilepsy was disrupted; **ANBER**, the IBE Romanian chapter, took positive action and was successful.

• Our Chapter in **Guatemala** was invited by the President of the Supreme Court in El Salvador to help implement epilepsy programs in that country.

• **AISPACE** in France began collaboration with autism associations to support those with autism who also have epilepsy.

• **POCET**, our chapter in Tanzania operated a drugs bank, to provide low cost AEDs to members.

• Registered nurses, psychologists, educators and communications professionals working with **Epilepsy Association** in Australia helped 25,000 people with epilepsy during 2003.

• **Spolecnost “E”** – Czech Epilepsy Association opened the first short-term hospital/epilepsy centre in the Czech Republic.

• **EYAL** in Israel provided subsidized tutoring for schoolchildren with epilepsy to help them achieve well at school and improve self-confidence.

• In the Netherlands, **SEIN**, continued work on a state-of-the-art residential complex at Heemstede; when completed it will offer accommodation to 90 people with epilepsy.

• **Singapore Epilepsy Foundation** continued to pursue its plans for a Centre to provide job opportunities for people with epilepsy.

• At **Epilepsy Hospital Bethel** in Japan, 270 people with epilepsy were assessed on an in-patient basis, amid concern at a recent governmental change in the Japanese medical system that pressurises an increase in the speed with which cases are dealt.

• The **Serbian-Montenegrin Society for Epilepsy** (formerly the Yugoslav Society for Epilepsy) established a non-profit, non-governmental organisation called “Episport” whose goal is to promote optimal quality of life for young people with epilepsy, through a range of social activities.

• **Dianalund Epilepsy Centre**, a Friend association in Denmark reopened a newly renovated ward for children with epilepsy.

• **Kenya Association for the Welfare of Epileptics (KAWE)** held 208 clinics and made 17,692 patient visits. The association aims to create a sustainable and integrated epilepsy care programme that is both accessible and affordable.

• **The National Centre for Young People with Epilepsy (NCYPE)** UK, raised funds required to endow Europe's first Chair in Childhood Epilepsy.
IBE works to promote the facts about epilepsy and to communicate its vision, mission and messages to the widest possible international audience.

- Our newsletter, International Epilepsy News, is distributed four times a year in 112 countries. During 2003 significant changes were made to format and content and by mid-2004 it is expected to publish in full colour.

- Our website is now used by many Chapters as their primary reference point for information from and about IBE. Emerging as an efficient and effective support facility for IBE’s administration, the creation of a Website Advisory Group will steer the site to even greater things in the coming years.

- Radical changes to our Annual Report have resulted in a publication that reflects a progressive organisation. Our report for 2003 also shows how the aims and activities of IBE are mirrored in many of the projects undertaken by our Chapters and Friends.

- During 2003 we carried out a major review of all our publications. We are now working to enable free downloading of almost everything we publish from the IBE website.

- The Latin American Regional Committee has published the first Spanish language book on epilepsy for doctors. There are now plans to translate the book into Portuguese.

- Every IBE activity involves communication; publications and newsletters, reports and promotional materials, General Assemblies, Congress Stand promotions, representation on other NGOs, and of course our website. A Communications Plan, commenced in 2003, will report on how best to facilitate the exchange of information, knowledge and experience about epilepsy between members and to ensure that IBE communicates effectively with all its identified audiences.

- The results of a survey carried out by the Commission on Risks & Insurability on insurance problems encountered by people with epilepsy in the UK was completed. The findings are now being written up and will shortly be submitted for publication. This commission also made a well-received presentation to the Australian Branch of the Life Underwriters and Claims Association.

- The Employment Commission, through its EYiE initiative, continues to maintain a weekly EYiE Chat Room.

- The Asia Oceania Regional Committee is producing a book on epilepsy for patients.

- The highlight for the year was undoubtedly the successful 25th International Epilepsy Congress, Lisbon. Large international meetings such as these provide an excellent opportunity to advertise the work of IBE. This we achieved through Commission Sessions, the IBE Stand, posters advertising our Commissions, Chapter Workshops, General Assembly, Open Business Meetings, Epilepsy Awareness Poster Competitions, as well as through media reporting during the congress.
Epilepsy still attracts stigma in every region of the world. IBE members continue to work for its reduction through the provision of appropriate information using all possible available media.

• **Epilepsialitto** in Finland dedicated 2003 as the Year for Children with Epilepsy and their Families. A range of new publications including Epilepsy ABC (a book for teachers) and Epilepsy and Children were published to mark the occasion.

• The **Iranian Epilepsy Association** provided 35,000 copies of books, brochures and posters to the public. The association also created a library of 300 volumes for members.

• **Deutsche Epilepsievereinigung e.V., Germany** produced a new newsletter “Denkzettel” providing information on health and social issues as well as events and opinions on epilepsy.

• The **Jamaican Epilepsy Association** hosted the 2nd Caribbean Congress on Epilepsy in Kingston in November.

• Mr Sven-Göran Eriksson, Manager of the English Football Team, became a member of the **Swedish Epilepsy Association** and provided an interview for its magazine.

• **Taiwan Epilepsy Association** produced a 20-minute video “Meeting People” with Chinese and English actors.

• The newly formed **epi-suisse** in Switzerland launched numerous information campaigns targeting the general public. Switzerland also celebrated the first National Epilepsy Day during 2003.

• **Epilepsy Support and Information Centre (ESIC)** in Saudi Arabia, continues to maintain a comprehensive Arabic language website: www.epilepsyinarabic.com

• **Epilepsy Association of South Australia and Northern Territory Inc.** established bus, television and radio community services promotions to get its message across.

• In **Cuba**, the IBE Chapter also used radio to spread its message. Radio Rebelde aired a programme on Epilepsy and Education.

• The **Danish Epilepsy Association** intensified efforts to provide information through meetings, a new website and a new publication.

• Still in its infancy, the **Hong Kong Epilepsy Association** encourages its members to produce an in-house magazine, helping to raise self-esteem while at the same time informing the public about epilepsy.

• **Epilepsy Foundation’s** Epilepsy Month campaign theme, Entitled to Respect, supported by radio messages targeted to African American teens and a Get the Word Out! contest on the meaning of respect, generated 164 million media impressions.
Increasing understanding and knowledge

Education forms a key element of our Long Term Strategy. Through a range of educational opportunities we can increase knowledge of epilepsy to both internal and external audiences. Through knowledge comes understanding.

- In response to positive feedback from Chapter and Friend associations, initial work on IBE’s Training Service Programme began, the first modules of which were a range of Chapter Workshops held during the Lisbon Congress. Since then, terms of reference for a Training Services Advisory Group have been drafted and were approved by the Executive Committee. The advisory group will provide the Bureau with an experienced team of people who will advise on various issues relating to its training services.

- In addition to the initiatives underway by the ILAE/IBE/WHO Global Campaign Against Epilepsy, many individual chapters around the world also used the campaign platform to launch educational initiatives relevant to their region and targeted audiences.

- One of the most popular initiatives of our Commissions, the Epilepsy Youth in Europe (EYiE) Project of the Employment Commission, continues to encourage social development of young people and to provide youth leader training. Originally a Europe-based project, it has now spread its wings to other regions. In September 2003, 35 young people from 10 Chapters were involved in a youth exchange project in Malta. The next exchange will take place in Chile in 2004.

- The Psychological Approaches to Epilepsy Commission presented demonstrations on psychological approaches to seizure management in association with Epilepsy South Africa.

- The Latin American Regional Committee was involved, as part of a WHO programme team, in the compilation of clinical guidelines for primary health doctors.

- Plans for the development of educational programmes for specific target groups in Africa are being drafted by the African Commission.

- The European Regional Committee was involved in the production of the EUCARE Action Pack, in response to the European White on Epilepsy. The pack aims to equip Chapters and others with the skills to influence the future of epilepsy policy and services throughout Europe.

- As part of the Long Term Strategy Plan, an Education Plan was initiated. This will identify how best to integrate educational opportunities, research initiatives, published materials and database resources into a comprehensive and wide-ranging Education Programme.
During 2003 Chapter and Friend Associations successfully provided a high level of training and education services on a range of epilepsy-related topics for people with epilepsy and their carers, medical professionals, and the general public.

- The Chilean League Against Epilepsy, IBE’s chapter in Chile, held training courses for teachers and community workers.
- Caritas Malta Epilepsy Association hosted the EYiE of Horus Project of the Employment Commission. This event saw 35 young people from 10 countries meeting in Malta. The event was made possible by EU funding obtained by IBE’s Employment Commission.
- Epilepsy Association of Zambia celebrated two successful events in 2003 - the launch of the Global Campaign Zambia Programme and a Workshop on Management of Epilepsy at Primary Care level.
- For the past three years, the Centro Nacional de Epilepsia APNE, Ecuador, has been developing a programme of continuing education in Neurology and Psychomotricity, aimed at improving conditions for school-going children.
- Epilepsy Care Group (Singapore) set up “Opportunity!”, a one-stop charity shop providing hands-on retail training for unemployed people with epilepsy.
- The IBE Chapter in Cuba provided courses on the Internet and also ran workshops for families called “What everyone needs to know about epilepsy”.
- Epilepsy Society of Australia (ILAE Chapter) held its annual meeting in New Zealand, providing a rare opportunity for fieldworkers from Epilepsy New Zealand to meet with those undertaking similar work in Australia.
- POCET in Tanzania purchased a substantial plot of farmland. Plans are underway to develop training modules that will provide education in agriculture skills to adolescents with epilepsy.
Photo Gallery 2003

Clockwise from left: Ambassador Award winners Thanos Covannis (with his wife Lynn), Zenebe Damtie, Dragoslav Ercegovac, Mike Glynn, Susanne Lund, and Marshal Mo-Song Hsih; Dr Chi Wan Lai winner of the Social Accomplishment Award with his wife; Lisbon Congress banner; Caroline Morton at the IBE Stand in Lisbon; members of the EUCARE Management Group, Martin Brodie, Hanneke de Boer, Susanne Lund and Paul de Belder (UCB Pharma).
Clockwise from below: Members of the Editors Network at their first meeting during the congress in Lisbon; delegates to the Eastern Mediterranean Conference on “Epilepsy as A Public Health Concern in the Eastern Mediterranean Region”, Cairo, March 2003; members of the Employment Commission EYiE Group in Malta, September 2003; Finnish Poster – winner of the Public Awareness Poster Competitions in Lisbon; as part of a Global Campaign Against Epilepsy project in China, doctors man information desks in a Beijing Square to improve public awareness.
Advocacy and Awareness Raising

Lobbying and advocacy are now seen as standard tools in working to instigate change.

- Developing an expertise in making representations to government departments and health agencies is becoming a necessity as the importance of advocacy grows. Modules included in the EUCARE Action Pack demonstrating how some chapters in Europe have structured effective advocacy and awareness campaigns will provide examples that can be emulated by other epilepsy associations.

- At Parliament Level, the EUCARE Advocates for Epilepsy group, grew in strength in 2003. Led by John Bowis, MEP, who provided the Foreword for this report, it is expected that more Members of the European Parliament will join the group following European Union elections in 2004.

- Through membership of the European Federation of Neurological Associations (EFNA), IBE is forging strong links with other groups that have as their focus a range of neurological disorders. Such alliances lend strength and credence when making representation to appropriate European bodies.

- The Commission on Risks and Insurability continues to focus on the insurance industry in its objective of improving insurance provision for people with epilepsy.

- Since pictures “paint a thousand words” one of the most effective ways of transmitting a message is with a powerful image. IBE’s Chapter Public Awareness Poster Competition in Lisbon provided inspiration to emerging chapters looking to increase awareness in their own regions.

- The number of countries involved in Global Campaign Against Epilepsy Demonstration Projects rose to 13 during 2003, and more are planned. For the second year, “epilepsy” appeared on the agenda of the annual WHO Regional Advisors for Mental Health meeting in Geneva with members of the Global Campaign Secretariat invited to attend.

- The Employers Forum initiative of the Employment Commission brings together employers and IBE chapters to develop equal opportunity policy statements for people with epilepsy. The Commission is also in contact with the International Labour Organisation which, with the UN and the World Bank, has a Youth Employment Network aimed at promoting youth and employment policies in Africa, South America and Asia.
Successful advocacy and awareness raising campaigns, targeting appropriate local audiences, were undertaken globally by members.

- **The Norwegian Epilepsy Association** celebrated the introduction of a government approved national treatment plan for people with epilepsy.
- **Hong Kong Epilepsy Association** undertook lobbying and advocacy work with transport companies and with the Equal Opportunities Commission.
- **During 2003, EDYS Epilepsy Group, Mauritius, encouraged by Government policy, broadened its base to become nationally focussed.**
- **Epilepsy South Africa** organised national Epilepsy Advocacy Action training workshops in Johannesburg.
- **Epilepsy Foundation, USA** held a Living Well II Conference, bringing together experts in treatment, epidemiology, self-management and quality of life, to make recommendations to the public health community.
- **Epilepsy Scotland** is assisting the government health body with new SIGN guidelines for children with epilepsy.
- The President of **Polskie Stowarzszenie Ludzi Cierpiacych na Padaczke**, Poland, was appointed to the National Consulting Board for Disabled Persons and to the Provisional Disabled Persons Social Affairs Board.
- **Epilepsy Support Association, Uganda**, networked with other NGOs in other disability movements and participated in the formation of the Disability Bill.
- **Bureau Francais de l’Epilepsie, France**, produced information leaflets to assist specialists in the area of disability employment to recognise specific difficulties faced by people with epilepsy.
- **Gravesend Epilepsy Network, UK**, was involved in setting up a South East Regional Neurological Alliance.
- **Les Amis de la Ligue Belge contre l’Epilepsie /De Vrienden van de Belgische Nationale Bond tegen Epilepsie** produced a video that was broadcast on TV to mark National Epilepsy Day.
- **Epilepsy Association of Western Australia (EAWA)**, a member of JECA, held their annual awareness and fundraising programme “World of Trivia”, involving almost 5,900 students.
- **In Ecuador, the Liga Tunguahuense de Control de la Epilepsia** continues to enjoy the patronage of the Archbishop of Cuenca, with help towards the provision of AEDs to members.
- **HALE, Hungary**, was represented on the National Council for Health and on the Social Council. Their EPHOUSE project was also discussed on two occasions in the Hungarian Parliament.
- **In Korea, the Korean Epilepsy Association** held a public forum to discuss the laws affecting people with epilepsy. The meeting was chaired by the Disabled Policy Making Committee of the Ministry of Health and Welfare.
- A public awareness campaign at one of the major shopping complexes in Kuala Lumpur was organised by **Persatuan Epilepsi Malaysia**. Plans are being made for a national epilepsy Awareness week in 2004.
- **National Epilepsy Fund (NEF)**, Netherlands, recruited a famous television personality and a former international footballer as ambassadors for the association.
- **AEAE, Spain**, took part in the “Mutual Assistance and Community Health” event in Madrid, with the opportunity to discuss experiences and ideas with other patient groups.
- **PERPEI, Indonesia** made representations to government regarding availability of reasonably priced AED’s, employment and salary equality for people with epilepsy. Support was also sought to host the 2006 Asian Oceania Regional Congress.
2003 was a particularly successful year for IBE with regard to epilepsy research with several new projects planned or initiated.

- The **Commission on Risks & Insurability** has continued work on amalgamating research evidence related to risks after a first seizure, risks of relapse following a period of remission, mortality risk and driving risk.

- Funding for a research prize has been obtained from Novartis by the Research Commission. The **Novartis Research Prize** will award research into the understanding of social and psychological consequences of epilepsy and ameliorating its impact. The prize will be presented during the 26th International Epilepsy Congress, Paris 2005.

- The Commissions on Risks & Insurability and Research, working with the Global Campaign and the WHO, have secured significant funding from the National Institutes of Health (USA) to develop research capacity into the stigma of epilepsy. Work on this project has already begun in Vietnam and China.

- The **Commission on Psychological Approaches to Epilepsy** continues work on two major projects to investigate the impact of psychological interventions for people with drug resistant epilepsy. The aim of the study is to evaluate the Acceptance and Commitment (ACT) approach and the use of Yoga versus supportive therapy to improve quality of life and reduce seizure frequency. Studies are ongoing in South Africa and India.

- Preparations for Phase 2 of **EUCARE** were ongoing during much of 2003. The new programme, funded by UCB Pharma, will include a major research project “An observational study of pharmacological outcomes and lifestyle consequences of newly diagnosed epilepsy in different countries in Europe”. More that 100 centres will be recruited who diagnose, investigate, manage and follow-up such patients. The aim of the programme will be to link patient outcomes with a range of educational, scientific and public policy projects that will be designed and led by members of the EUCARE Scientific Advisory Board.

- The **Global Campaign Against Epilepsy** has been researching national epilepsy resources by way of a questionnaire to IBE and ILAE chapters. To date 130 completed questionnaires have been submitted and entered into a database. Collection of data is ongoing. The Global Campaign has also been working with the WHO to develop evidence based guidelines on the treatment of epilepsy in childhood and adolescence.

- The **Employment Commission** carried out a survey of sheltered work facilities and supported employment initiatives for people with epilepsy with help from the Latin American Regional Committee and the African Commission, the results of which were presented in Lisbon. The objective of the survey is to create a network of people around the world who are involved in providing sheltered and supported services.

Young members of AISPACE, France in happy mood
IBE Chapters and Friends are well aware that research, on social or medical aspects of epilepsy, helps to focus on and target specific difficulties faced by people with epilepsy and those who care for them.

- **Associacao Brasileira de Epilepsia**, Brazil, created commissions on Quality of Life, Neuropsychology, Publications and Communications to validate recognised international scales for the impact of epilepsy in Portuguese.

- The **Danish Epilepsy Association** was involved in the establishment of a working party to prepare new National Clinical Guidelines for Epilepsy Treatment.

- The **Portuguese League Against Epilepsy** presented the findings of research on attitude and knowledge of epilepsy to the general public.

- The **Epilepsy Association of Sri Lanka** set up a clinic to gather information on patients learning problems and employment difficulties. The clinic will also assess patients for neurosurgery and treatment.

- The **Swiss Epilepsy Centre** continues to host the EPI-Info Centre. The centre maintains a unique collection of materials and information on epilepsy, including the IBE video collection and materials donated by Chapter and Friend associations.

- The **Serbian-Montenegrin Society for Epilepsy** has completed a five-year project “Epilepsy—what we know and learn”.

- Member organisations of **JECA**, our new Australian chapter, will research the state of epilepsy services in Australia and negotiate with the Australian Government on issues relating to these services.

- **Epilepsie Euro Services**, France, continued its research project “Epilepsy – its presence and perception in the workplace”. First results were presented at the Epilepsy & Society conference in Malta in March 2004.

- In Senegal, the **Ligue Sénégalaise Contre l’Epilepsie** held several meetings to address the Pikine Test, which is the prelude to the Global Campaign Against Epilepsy project.

- The **Taiwan Epilepsy Association (TEA)** website was voted one of the best medical sites by the Department of Health.

- The **National Society for Epilepsy (NSE)** concluded a fundraising campaign for a 3T MRI scanner which, when operational in mid-2004, will underpin the NSE’s research programme.
## BALANCE SHEET

**Year ended 31st December 2003**

With comparative totals for 2002

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<td>50,744</td>
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<tr>
<td></td>
<td>193,266</td>
<td>147,733</td>
</tr>
</tbody>
</table>

These figures are extracted from the IBE accounts for the year ended 31st December 2003 audited by Deloitte & Touche
# STATEMENT OF INCOME AND EXPENDITURE

Year ended 31st December 2003  
With comparative totals for 2002

<table>
<thead>
<tr>
<th></th>
<th>2003</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>US$</td>
<td>US$</td>
</tr>
<tr>
<td><strong>INCOME</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>International congresses and symposia</td>
<td>225,589</td>
<td>337,771</td>
</tr>
<tr>
<td>Commerce and industry</td>
<td>22,500</td>
<td>11,250</td>
</tr>
<tr>
<td>Membership dues</td>
<td>27,263</td>
<td>27,955</td>
</tr>
<tr>
<td>Society contributions</td>
<td>6,163</td>
<td>3,719</td>
</tr>
<tr>
<td>Investment income</td>
<td>359</td>
<td>810</td>
</tr>
<tr>
<td>Sale of materials</td>
<td>293</td>
<td>1,021</td>
</tr>
<tr>
<td>Other grants</td>
<td>107,249</td>
<td>66,560</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td>389,416</td>
<td>449,086</td>
</tr>
<tr>
<td><strong>EXPENDITURE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salary costs</td>
<td>78,756</td>
<td>62,678</td>
</tr>
<tr>
<td>Office expenses</td>
<td>9,132</td>
<td>7,765</td>
</tr>
<tr>
<td>Printing and postage</td>
<td>12,846</td>
<td>9,666</td>
</tr>
<tr>
<td>Printing and postage - International Epilepsy News</td>
<td>29,939</td>
<td>23,124</td>
</tr>
<tr>
<td>Travel</td>
<td>66,076</td>
<td>60,454</td>
</tr>
<tr>
<td>Global Campaign costs</td>
<td>(169)</td>
<td>35,550</td>
</tr>
<tr>
<td>Accountancy services</td>
<td>15,000</td>
<td>15,000</td>
</tr>
<tr>
<td>Bank charges</td>
<td>833</td>
<td>849</td>
</tr>
<tr>
<td>Rent</td>
<td>5,885</td>
<td>4,529</td>
</tr>
<tr>
<td>Subscriptions</td>
<td>355</td>
<td>274</td>
</tr>
<tr>
<td>Depreciation</td>
<td>1,367</td>
<td>1,142</td>
</tr>
<tr>
<td>International Resource Centre costs</td>
<td>-</td>
<td>10,122</td>
</tr>
<tr>
<td>International Director of Meetings costs</td>
<td>121,337</td>
<td>171,843</td>
</tr>
<tr>
<td>Website costs</td>
<td>4,056</td>
<td>16</td>
</tr>
<tr>
<td>Management fees</td>
<td>17,829</td>
<td>-</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>(19,356)</td>
<td>(23,023)</td>
</tr>
<tr>
<td><strong>Total Expenditure</strong></td>
<td>343,886</td>
<td>379,989</td>
</tr>
<tr>
<td><strong>Operating Surplus for year</strong></td>
<td>45,530</td>
<td>69,097</td>
</tr>
</tbody>
</table>
IBE has 106 member associations, working for people with epilepsy, in 77 countries around the world.

ALGERIA
Chapter: Association d’Entraide aux Malades Epileptiques, 4, Bd Didouche, Mourad, SIG 29300, T: +213 4584 9775, F: +213 4584 0555, E: amel_epilepsy@yahoo.fr

ARGENTINA
Chapter: Asociacion de Lucha contra la Epilepsia, Tucuman 3261, 1189 Buenos Aires, T/F: +54 114 8620 440, E: gonzalezgartland@aol.com

AUSTRALIA
Chapter: Joint Epilepsy Council of Australia Ltd, 818 Burke Road, Camberwell, Victoria 3124, T: +613 9805 9111, F: +613 9882 7159, E: rjp@bigpond.net.au
Friend: Epilepsy Association (ACT) Inc, 27 Muley Street, Holder, ACT 2611, T/F: +61 026287 4555, E: epilepsyact@bigpond.com
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Friend: Epilepsy Association of Western Australia (Inc), Centre for Neurological Support, The Niche, Suite B, 11 Aberdare Road, Nedlands WA 6009, T: +61 89436 7699, F: +61 89436 7696, E: epilepsy@cnswa.com

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Friend: Dr Hans Berger Kliniek, Gelderseweg 81, Postbus 1098, 4800 RA Breda, T: +31 7656 08287, E: info@shbk.nl
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