IBE has a vision of the world where everywhere fear and ignorance about epilepsy are replaced by understanding and care. IBE exists to improve the social condition and quality of life of all people with epilepsy and those who care for them.

**Partners and Collaborators**
- 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)
- Board Member of the European Federation of Neurological Associations (EFNA)
- Associate Member of the European Patients’ Forum (EPF)
- Close working partnership with the International League Against Epilepsy (ILAE)
- Observer status on the PCWP Committee of the European Medicines Agency (EMA)

**Income sources**
- IBE’s activities are funded through membership subscriptions, congress income and grant funding from the pharmaceutical industry.
- IBE received industry-related income of US$47,560 from two pharma companies in 2021, amounting to 8% of total income:
  - Arvelle Therapeutics: $11,890
  - Sanofi: $35,670
- In 2021, non-industry income accounted to 92% of all income.
Dear friends,

I am pleased to write this short foreword to IBE’s 2021 annual report, reflecting on the first full year of my Presidency. 2021 was a year where continued disruption from the Covid-19 pandemic, frustratingly, impacted on the work programme of IBE.

Virtual meetings continued in place of face to face gatherings, but – having learned how to navigate this online world in 2020 – IBE continued to reap the benefits of connecting with our global community in a new way. Technology has helped us to bring people together from all corners of the globe and, as Covid-19 restrictions ease, we continue to embrace these innovative approaches.

2021 was also a year of transition at IBE. As the new Management Committee got down to work, our long-standing Executive Director, Ann Little, announced her impending retirement.

IBE will be forever indebted to Ann for work with IBE and the global epilepsy community, whom she has served with dedication and compassion for so long.

Losing Ann’s experience and expertise was always going to be a challenge for IBE, but the process to recruit a new CEO got underway quickly and Ann’s replacement – Donna Walsh – was appointed in late 2021.

Donna joined the Management Committee in working on the development of a new strategic plan for IBE. This built on a process that had been supported by KPMG Australia throughout 2021, and culminated in the launch of a new plan at the Annual General Meeting on December 10th.

In this plan IBE reasserts its vision of a transformational social change for people with epilepsy worldwide, and has committed to three goals:

• Making epilepsy a global public health priority
• Empowering and amplifying the voice of people with epilepsy
• Serving and supporting our chapters and committees in all regions

With these goals we can ensure that our work is focussed on adding value to our ‘customers’ – our chapters, but that everything we do is guided by the needs and perspectives of people with epilepsy.

We were heartened by the response of our chapters to the new direction of IBE, and we will be ensuring a major programme of engagement and outreach follows as we develop our workplans to reflect this new strategic direction.

It is important that IBE consolidates current partnerships but also continues to build our network of stakeholders with whom we can partner to ensure epilepsy is prioritised by those who order priorities worldwide.

Despite this work behind the scenes, many projects and activities continued apace. Throughout this report you will read more about the following initiatives:

• Women and Epilepsy
• Global Advocacy
• Making Epilepsy a Health Priority in Africa
• International Epilepsy Day
• 50 million steps campaign
• Congresses

As always, our doors at IBE remain open to all those interested in working with us in pursuance of a transformational social change for people with epilepsy worldwide.

Please do not hesitate to get in touch with us. Together we can make a difference.

Francesca Sofia
IBE President
Working for people with epilepsy and those who care for them across the globe

IBE has 158 chapters in 109 countries
With the world population estimated at 7.83 billion, 7.1 billion people or 91% of the world’s population live in countries served by an IBE chapter
Participation Around the World

International Epilepsy Day events were seen in 146 countries or regions around the world, making International Epilepsy Day 2021 the biggest yet!

A big THANK YOU! to all those who helped make the day a great success.

- Aruba
- Albania
- Angola
- Antigua and Barbuda
- Aruba
- Austria
- Australia
- Argentina
- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belize
- Belgium
- Bermuda
- Bhutan
- Bosnia and Herzegovina
- Botswana
- Bulgaria
- Burkina Faso
- Brazil
- Canada
- Cambodia
- Cameroon
- Chile
- China
- Colombia
- Congo
- Costa Rica
- Cote d’Ivoire
- Croatia
- Cyprus
- Czech Republic
- Denmark
- Dominican Republic
- Dubai
- Ecuador
- Egypt
- El Salvador
- Estonia
- Eswatini
- Ethiopia
- Fiji
- Finland
- France
- Gabon
- Gambia
- Georgia
- Guam
- Guatemala
- Guyana
- Ghana
- Greece
- Hungary
- Honduras
- Hong Kong
- Iceland
- India
- Indonesia
- Italy
- Iran
- Iraq
- Ireland
- Israel
- Jamaica
- Japan
- Jersey
- Jordan
- Kazakhstan
- Kenya
- Korea (Rep. of)
- Kuwait
- Lao
- Latvia
- Lebanon
- Lesotho
- Libya
- Lithuania
- Macedonia
- Malaysia
- Maldives
- Malta
- Martinique
- Mauritius
- Mexico
- Moldova (Rep. of)
- Mongolia
- Morocco
- Mozambique
- Myanmar
- Namibia
- New Zealand
- Nepal
- Nicaragua
- Niger
- Nigeria
- Norway
- Pakistan
- Panama
- Puerto Rico
- Peru
- Poland
- Portugal
- Qatar
- Romania
- Russia
- Rwanda
- Saint Lucia
- Saudi Arabia
- Scotland
- Serbia
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- Somalia
- South Africa
- Spain
- Sri Lanka
- Sudan
- Switzerland
- Sweden
- Syrian Arab Republic
- Taiwan
- Tanzania
- Thailand
- The Philippines
- Togo
- Tunisia
- Turkey
- Trinidad & Tobago
- UAE
- Uganda
- UK
- Ukraine
- Uruguay
- USA
- Uzbekistan
- Venezuela
- Vietnam
- Wales
- Yemen
- Zambia
- Zimbabwe
Launched in the European Parliament in 2015 by Carlos Moedas, EU Commissioner for Research, Science and Innovation, in 2021 International Epilepsy Day celebrated its 7th anniversary. Celebrated annually on the 2nd Monday of February, International Epilepsy Day it provides the platform for people with epilepsy to share their experiences and stories with a global audience and thereby to build a stronger epilepsy community.

Developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life, the objectives of the day are to:

- raise awareness of the disease at international and government level as well as in the general public
- strengthen the epilepsy movement by uniting epilepsy associations in a worldwide campaign
- raise visibility on epilepsy and encourage discussion about epilepsy
- provide epilepsy associations with a significant fundraising opportunity

IBE continues to promote the day using the dedicated website internationalepilepsyday.org which provides a toolkit of resources for chapters and other stakeholders wishing to celebrate the day.

As always, social media messaging - Twitter, Facebook, Instagram and TikTok - played a lead role in celebrations with the hashtag #EpilepsyDay.

New for 2021 was our 50 Million Steps for Epilepsy initiative, which was even more successful than we could have hoped.

The most important roles on International Epilepsy Day are played by people with epilepsy and epilepsy associations around the globe, who use the day to highlight issues of particular relevance to them, while at the same time raising much needed funds.

In the years since its launch, the breadth and scale of the day has grown exponentially. In 2021, International Epilepsy Day was celebrated in no fewer than 146 countries around the world from Aruba to Zimbabwe, Australia to Venezuela. Despite the problems caused by Covid restrictions - social distancing, restricted movement and full lockdowns - suffice to say that effort and determination triumphed and you can see the results here in our photo gallery!
Players in Turkey wore purple glasses in a Look Awareness Campaign for Epilepsy

Young pupils at St Augustine’s College in Queensland, Australia learned more about epilepsy awareness

At the National Epilepsy Centre, Karachi, Pakistan

Bangalore Medical College in India lit the entrance in Purple and had special lectures on epilepsy for students

Kenya Association for the welfare of people with epilepsy

Samman Epilepsy Association, India
50 million
STEPS FOR EPILEPSY

We did it!
164,817,721
STEPS ACHIEVED

#50MILLIONSTEPS
50millionsteps.org
The 50 Million Steps for Epilepsy campaign was launched in the lead up to International Epilepsy Day 2021 as a novel opportunity for people around the world to highlight the impact of epilepsy on their lives while, at the same time, raising vital funds for the organisations that support them. The idea was to walk together to achieve a total count of 50 million steps, one step for each person in the world who has epilepsy (according to WHO figures). With the start date of Monday 4th January, in order to reach that goal, at least 500 people would need to walk 20,000 steps each week over the 5 weeks of the campaign. Was this achievable?

Setting out on Day One, we never imagined that we would reach the finish line within 3 weeks and complete more than 2 laps of honour before the campaign ended with a final step total of 164,817,721.

What is most remarkable about the campaign’s success, with participation from countries in all corners of the world, is that we reached more than triple our step goal just as countries worldwide locked down due to Covid with social contact and outdoor activity restrictions introduced. Despite the challenge that Covid brought, IBE chapters in every region of the world got involved and there was also participation by individuals, clinics, hospitals, companies and other stakeholders.

The dedicated campaign website 50millionsteps.org provided a stepcounter where participants were able to record their steps; a donate button allowed people to donate either to IBE or to the chapter of their choice; and when participants posted on Twitter, with the hashtag #50MillionSteps, their photo and its location appeared on a special interactive map.

This success and the tremendous feedback received has provided the impetus to see the campaign become an annual fixture around International Epilepsy Day.
Thanks to encouragement from IBE chapters, hundreds of buildings around the world ‘shone a light for epilepsy’ on 8th February with purple illumination. Thank you to everyone who played a part in having their local landmarks light up! Here are just a few:

1. The New Theater, Pilsen, Czech Republic
2. BC Place, British Columbia, Canada
3. Bangalore Medical College, India
4. UAP Old Mutual Tower, Nairobi, Kenya
5. Flanders, Belgium
6. Tower 42, London, United Kingdom
7. Novo Mesto, Slovenia
8. Bois-Guillaume, Normandy, France
9. Maison Demandols - Ministry for Finance and Employment, Valetta, Malta
10. Karachi, Pakistan
FOR EPILEPSY
Epilepsy & Pregnancy Project

womenandepilepsy.org
While the majority of women with epilepsy will have successful pregnancies, it is vital that women of childbearing age are fully informed on all issues relating to epilepsy and pregnancy. The use of anti-seizure drugs (ASDs) has been associated with an increased risk of birth defects such as cleft palate, spina bifida, autism spectrum disorders or a lower IQ. Nevertheless, seizure control during pregnancy is vital because the risks involved from having uncontrolled seizures can be greater than the risks from ASDs themselves. Informing women of child-bearing age about the problems that might arise in a pregnancy, due to their epilepsy, is vital for both the mother and her unborn child. Getting the right message, to the correct audience, in the most appropriate format, is vital.

A public hearing in 2017, hosted by the European Medicines Agency (EMA), reviewed the prescription of medicines containing sodium valproate for women and girls who are of childbearing age and also looked at the wider issues around epilepsy and pregnancy. At the hearing, IBE emphasised the need for improved public information and health education on all matters relevant to women of childbearing age and pregnancy, advancing advocacy and the exchange of international best practice. It was proposed that a well-organised education campaign was required to ensure that as wide an audience as possible was reached.

While a range of information resources had since been developed in a number of EU member states these were not reaching the right people at the right time. The distribution and use of these materials, as well as the acceptance of the need for change, had not happened as had been hoped. This problem was also raised by young adults attending an IBE EpilepsyNext workshop in Dublin in 2019.

The participants, from 12 different European countries, highlighted the lack of knowledge among many young people with active epilepsy around the issues of contraception, pregnancy and childbirth. They were particularly concerned that young people were often unaware of the associated risks for those with active seizures. The willingness of some doctors to discuss contraception, family planning and pregnancy, national legislation and religious teachings that impacted on safe family planning for people with epilepsy, and the need to support self-empowerment of people with epilepsy to be able to discuss these matters with their care providers were also discussed.

This discussion underpinned IBE’s concern around the knowledge gap on epilepsy and pregnancy with regard to control of seizures and issues relating to AEDs in pregnancy, not only in Europe but worldwide. In order to address this knowledge gap, IBE set up a task force involving young people with epilepsy and key professionals, including medical professionals, to establish where the problem lay and to develop a toolkit in a format most effective in closing the knowledge gap in the widest possible audience. The project would run as a pilot in Europe.

As a first step, a Europe-side survey was implemented to establish the current status in knowledge and understanding in women of childbearing age around the subject of anti-seizure medication and pregnancy. The survey results would inform the development of a toolkit that would act as a guide for advocacy planning and an aid to build capacity of the user.

The survey garnered 890 responses from 9 European countries with a wide variance across countries in respect of access to and provision of information and support. For instance, while 51% and 79% of responders reported that they had accessed, or been provided with, information about becoming pregnant with epilepsy, many reported that they did not receive information about the risks of pregnancy until after their first pregnancy. Between a third and two-thirds.

The survey report was promoted through social media, provided to IBE chapters and is available on womenandepilepsy.org (and the 8 translated sites) and on ibe-epilepsy.org. It’s findings, and the comments provided by those who responded to the survey, provided direction on the structure, focus and content of the WomenAndEpilepsy.org website.

Drafting of the English language website content became in early July 2021 and involved a high level of input and ongoing review by the young women with epilepsy and medical professionals who formed the project team. In planning content, close observation was taken of the survey findings and all stages in its development, the content was carefully checked to ensure that it was appropriate, medically accurate and comprehensive.

The website has four main sections:
1. Epilepsy in women
2. Epilepsy and pregnancy
3. Questions for your doctor
4. Information for medical professionals

The website launched in December 2021. In tandem with the launch, a second survey was opened to measure visitor satisfaction and to identify an information gap in the website content that could be addressed in the future.

Following the launch of the English language site, work on creating sites in a further eight European languages – Czech, French, Georgian, German, Italian, Russian, Polish and Spanish – began in early 2022. The work was completed in May 2022, with nine separate sites now operational.

It is hoped, with financial support, to widen the scope and content of this important initiative to address other issues that affect women with epilepsy, not just in Europe but worldwide.

The campaign was developed with financial support from Sanofi. Sanofi had no editorial control over the content of the materials.
GOLDEN LIGHTS 2021

Building confidence, recognising ability and supporting capacity in young adults, both at national and international levels, is an important element of the work of IBE.

There is wide recognition amongst IBE’s chapters that young adults are under-represented in their associations. This poses the risk of undermining the future potential of epilepsy associations or, at worst, putting their future in jeopardy. It is also felt that the issues facing young adults affected by epilepsy are not receiving the public or political attention they merit. Yet the diverse range of experience and the remarkable personal resilience that a large number of young adults with epilepsy demonstrate often goes unnoticed, because many feel ill-equipped to report on their achievements.

As part of IBE’s youth strategy, the Golden Light Awards, which are presented at the time of regional and international epilepsy congresses, provide three benefits:

1. they allow chapters to nominate young adults with epilepsy whom they believe deserve recognition;
2. they give those young adults nominate with the platform to share their stories;
3. in sharing their stories, other young adults can see that epilepsy is not always an insurmountable impediment to achieving ones dreams.

To be considered for an award, candidates must be between 18 and 35 years of age and be nominated by the IBE chapter in which they are involved. Selection of candidates to receive an award is then made based on the written submission provided by the nominee and a supporting message from their chapter. At the discretion of the IBE Management, further candidates may be selected if appropriate.

Everyone selected for a Regional or International Golden Light Award is presented with a trophy during the Congress Awards Ceremony. A lapel pin is also be presented, which it is hoped the awardees will wear with pride.

In 2021, the awards were presented at three congresses:

- 11th Latin American Epilepsy Congress
- 13th Asian & Oceanian Epilepsy Congress
- 34th International Epilepsy Congress

Since these congresses were held virtually, due to the Covid pandemic, the awards were also presented by video. On the following pages you can meet all 31 young adults who joined the ranks of IBE Golden Lights in 2021!

Nineteen young adults were awarded during the International Epilepsy Congress at which Lorraine Lally, then Co-Chair of the IBE Youth Team, spoke to ‘Empowering Youth to Raise their Voices’, acknowledging all people living with epilepsy and their importance. Many of the Golden Lights shared their stories, which were both powerful and well received. From this cohort of Golden Lights, Alison Kukla from the USA, Cassidy Megan from Canada and Vinay Jani from India went on to become core members of the IBE Global Youth Team.

OTHER YOUTH TEAM ACTIVITIES

During 2021, Lorraine Lally and Scarlett Paige also set up a Youth Team Facebook page for members to share events and information.

The IBE Global Youth Team held regular Zoom meetings across multiple time zones to accommodate all members. These meetings focussed on raising awareness of epilepsy, and growing the IBE Youth Team and Youth Programme. The team continues to grow in strength and looks forward to a busy and successful future.
Golden Lights at the
11th Latin American Epilepsy Congress
27 February - 1 March 2021

Matías Nicolás Páez, Argentina
Fernanda Bittencourt Hahl, Brazil
Debbie Salazar Zumbado, Costa Rica
Katherin Yuliety Gonzalez Cardozo, Colombia
Noemi Canales, Chile
Beatriz Clavel Helena Calvario Reyes, Mexico
Sonia María Sánchez Romero, El Salvador

Golden Lights at the
13th Asian & Oceanian Epilepsy Congress
10 - 13 June 2021

Chris Ang, Singapore
Dan Kumajai, Japan
Meng-Leo Chou, Taiwan
Salim Baredhwam, Malaysia
Divyasiny Sharma, India
Bin Wáng, China
International Golden Lights at the
34th International Epilepsy Congress
28 August - 1 September 2021

Lynna Hand,
Germany
Meng-Leo Chou,
Taiwan
Mohsen Fariborzi,
Iran
Luiza Gatto,
Brazil

Sophie Nabkenya,
Uganda
Mohan Dike
Nigeria
Praise Bessong,
Cameroon
Valentina Khan,
Chile

Veselka Šoštarić,
Croatia
Cassidy Megan,
Canada
Adi Vaknin-Aviram,
Israel
Bright Bwalya,
Zambia

Alison Kukla,
USA
Lai Siew Tim,
Malaysia
Emily (Ka Yan) Kwong,
Hong Kong
Vinay Jani,
India

Oliver Kilmartin,
Ireland
Fred Beuchi,
Kenya
Camila Herzberg Cuetu,
Cuba
Since 2019, the BAND Foundation has supported IBE’s initiative in Africa with the goal of ensuring that epilepsy becomes a health priority in in the region. During 2021, as part of Phase II of this initiative, the focus was on:

- Improving the visibility of epilepsy initiatives in Africa
- Strengthening the technical capacity of the regional project management team
- Enhancing the capacity of African epilepsy organizations to influence health policy

Fundamental to the success of Phase II was investing in the capacity of the African Regional team. IBE Africa has engaged and trained advocates, provided educational resources across the continent, built and grown a network of advocates and organizations, funded meaningful projects, and influenced policy makers.

A notable accomplishment was the development and implementation of the Advocate’s Toolkit ‘Making Epilepsy a Priority in Africa’.

The timing of the toolkit was ideal, since it aligned with a call to action from the WHO Director General to develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (WHA73.10). With funding from the BAND Foundation, the project coordinator worked with IBE chapters in the African region to develop an engagement strategy to enhance the capacity of people with epilepsy to influence health policy and to ensure that their voices were represented at every stage of the WHO consultation process. IBE chapters in Africa sent letters to their Ministries of Health and had meetings requesting the WHO Secretariat to implement a 90-80-70 cascade target for epilepsy:

- 90% of all people with epilepsy in Africa are aware of their diagnosis as a treatable brain disorder;
- 80% of people diagnosed with epilepsy in Africa will have access to appropriate, affordable, safe anti-seizure medicines; and
- 70% of those treated will achieve adequate seizure control through long term availability of treatment.

The IBE network in Africa secured written commitment for the proposed 90-80-70 target from 49 partners and stakeholders, including the Ministries of Health in Eswatini, Lesotho and Cameroon; endorsement of 14 IBE affiliates; and additional support from the Pan African Network for Persons with Psychosocial Disability and the South African NCD Alliance.

To improve the visibility of epilepsy initiatives in Africa, BAND Foundation funding was used to develop a communications strategy. Nine training webinars were organised, a YouTube Channel was established, and a health laws mapping report was published. The baseline data of existing legislation in 21 African countries, particularly in the areas of health, education, driving, employment, marriage, and social inclusion, will be used to address and amend clauses that discriminate against people with epilepsy. It is notable that WHO Geneva asked for permission to circulate this mapping report, recognising its significance.

Over the course of three months, the initiative was also able to train 40 journalists about epilepsy and the Intersectoral Global Action Plan, resulting in the publication of 12 impact stories.

Phase II monies were provided, through a competitive awards process, to six African nations to assist epilepsy organizations in implementing education and advocacy projects. Putting epilepsy policies and plans into action requires strong leadership and cross-cutting teamwork. Although the grassroots epilepsy movement has been mobilized and strengthened, thanks to BAND Foundation’s partnership, there is still work to be done to ensure that policymakers, WHO, and elected officials prioritize epilepsy as a public health priority in their budgets in the coming years.
On November 12, 2020, World Health Organization (WHO) Member States unanimously approved a resolution at the World Health Assembly (WHA) to develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (WHA73.10). In the months preceding the WHA, many IBE chapters engaged effectively with their governments to generate support for the resolution. This engagement made a huge impact and resulted in 38 countries co-sponsoring the resolution and many others voicing their public support.

The resolution built on successes and partnerships over the past 20 years but also created an unprecedented opportunity to ensure that epilepsy would be placed higher on governments’ agendas. It became the catalyst for ongoing engagement with our chapters in 2021 to ensure that the needs of people with epilepsy were firmly represented in the WHO consultations and in the final wording of the global action plan.

In March 2021, the WHO Secretariat published a Discussion paper related to WHA73.10. Member States, United Nations (UN) agencies and relevant non-State actors like IBE, ILAE, and the World Federation of Neurology (WFN) were invited to share their comments in response to the Discussion paper through virtual and web-based consultations.

In early April 2021, the IBE, ILAE, WFN and International Child Neurology Association (ICNA) submitted a joint letter with detailed comments in response to the Discussion paper circulated by the WHO. Prior to signing this joint letter, IBE sent a survey asking chapters from every region of the world to provide their feedback and to rank their priorities.

IBE chapters responded that they wanted the action plan to include an objective to address stigma and discrimination and to promote inclusion and equal opportunities for people with epilepsy. In addition, they felt that there was inadequate focus on the needs of children and on people with epilepsy living in low resource settings. These comments were officially sent to the WHO Brain Health Unit.

In May 2021, a Summary of consolidated comments received by WHO in the first round of the consultation was published on the WHO website. In June 2021, the first draft of the Intersectoral global action plan on epilepsy and other neurological disorders (IGAP) was developed based on the input received on the Discussion paper.

On July 16, 2021, IBE and ILAE hosted a virtual roundtable discussion. This event was a huge success with 160 attendees from 50 countries. At this virtual roundtable, IBE President-elect Francesca Sofia gave a heartfelt call for action as she expressed her hopes for the coming decade. She spoke about the urgent need for improved access to treatment,
GLOBAL ADVOCACY
the year in review

more investment in research and stronger approaches to address stigma and discrimination. International Golden Light Award Recipient Valentina Khan also spoke at the roundtable where she shared her personal experience of growing up with drug refractory epilepsy in Chile.

Between June and August 2021, web-based and virtual consultations were carried out by WHO to seek further comments from Member States, UN agencies and relevant non-State actors. This included a series of virtual consultations with people with lived experience. Many IBE advocates agreed to attend these consultations to ensure that the opinions and experiences of people with epilepsy was always present in the discussions.

WHO published feedback from 71 Member States and 75 relevant stakeholders in September 2021. Throughout this entire process, the IBE global advocacy team continued to seek input from chapter personnel and from people with epilepsy. We collated and consolidated the feedback which was used to create a position statement. This IBE position statement was a tool that our chapters used in their outreach with their governments.
Like so many other organisations, companies and groups around the world, normal communications became impossible during 2021, with planned congresses and meetings moving to web/video based events.

The 11th Latin American Epilepsy Congress, originally destined for Medellin, Colombia, became a virtual congress. Likewise, the 13th Asian & Oceanian Epilepsy Congress, due to take place in Fukuoko, Japan in October 2020 was moved to 2021 and was held online in June 2021; and the 34th International Epilepsy Congress, planned for Paris France, also became a virtual event.

In response to these challenges, the option of holding meetings online was embraced and, indeed, there were unexpected benefits. The cost savings on travel and accommodation, and the ease of attendance, meant that higher numbers of people attended the events planned by IBE around congresses. This allowed us to communicate more widely than ever before with our chapters, supporters and all stakeholders.

While the world is slowing beginning to revert to normal - or to a new normal - it is planned to continue to use webinars and online seminars as an important element of IBE communications.

COMMUNICATIONS
Overcoming the challenges of Covid 19
MAKING EPILEPSY A HEALTH PRIORITY IN AFRICA

As part of the African Region programme ‘Making Epilepsy a Health Priority in Africa’, nine webinars were organised during the year, each focussing on a specific aspect or challenge of living with epilepsy in the region. Up to 300 delegates attended each of these meetings with participant joining from both Africa and further afield.
IN MEMORIAM

Remembering those we lost in 2021, but whose legacies live on

ROSEMARY PANELLI
30 June 1952 - 27 April 2021

Rosey’s international career began in 2005 when she was involved in the production of “Sudden Unexpected Death in Epilepsy: A Global Conversation” with funding support from IBE. It contained inputs from 14 nations, giving voice to what both experts and ordinary people with lived experience knew about SUDEP and looking at the work that needed to be done. The book was hugely successful, leading to second and third editions.

She was a member of a number of IBE commissions and working groups, most notably the IBE Research Commission. To recognise her contributions to epilepsy, she was awarded the IBE/ILAE Ambassador for Epilepsy Award in 2011. In 2016 she won the British Medical Journal (BMJ) community neurology award for “The SUDEP and Seizure Safety Checklist”.

JUDY COCHRANE
3 April 1940 - 14 June 2021

Judy’s long and successful career in epilepsy began in 1984 when she joined the Epilepsy Association of Scotland. From the beginning her belief that people with epilepsy should live a full and meaningful life, and have access to the same opportunities as everyone else, informed everything that she did and led to improved services for people with epilepsy in Scotland and beyond.

In 1993 she was elected Vice President of the International Bureau for Epilepsy and during her two terms in this role she chaired the IBE’s Public Education Commission, leading the global development of public awareness raising and epilepsy training programmes, and nurturing the Youth Commission for young adults with epilepsy. The impact of Judy’s work extended throughout Scotland, the UK and beyond. Her contribution was recognised with the Ambassador for Epilepsy Award in 1993.

Anastasia (Tata) Vassou
26 December 1956 - 25 June 2021

Tata (as she was known to everyone) began working as an EEG technician at the age of 24 years at the Children’s Hospital Aghia Sophia in Athens. She became an important figure in the organization of the annual Pan-Hellenic epilepsy congresses and workshops. The Greek IBE and ILAE chapters were her second family and she fought to inform and raise public awareness about epilepsy until her death.

Tata was well-loved by all who came to know her at IBE. Her first involvement was at the time of the Epilepsy & Society Conference held in Athens in 2020 where she played a large role in ensuring that everyone was well looked after. She would later serve on the IBE European Regional Executive Committee, becoming its Chair for the term 2013-2017. She was much loved by all who met her for her caring generous personality.
Join us for our 2023 challenge

Complete your steps
between Monday January 9 and Monday February 13 2023
and help us reach our goal
Find out more at
50MillionStepsForEpilepsy.org
FINANCIAL REPORT

Income and Expenditure Account
Year ended 31st December 2021
With comparative totals for 2020

<table>
<thead>
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<th></th>
<th>2021 US$</th>
<th>2020 US$</th>
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<td>EXPENDITURE</td>
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<td>(131,729)</td>
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<td>OPERATING (DEFICIT)/SURPLUS FOR YEAR</td>
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<td>(12,041)</td>
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Balance Sheet
Year ended 31st December 2021
With comparative totals for 2020

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<tr>
<th></th>
<th>2021 US$</th>
<th>2020 US$</th>
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<td>CURRENT ASSETS</td>
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<td>Debtors: amounts falling due within one year</td>
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<td>Bank and cash balances</td>
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<td></td>
<td>2,194,657</td>
<td>2,151,432</td>
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<tr>
<td>Creditors (Amounts falling due in one year)</td>
<td>(262,507)</td>
<td>(295,063)</td>
</tr>
<tr>
<td>NET CURRENT ASSETS</td>
<td>1,932,150</td>
<td>1,856,369</td>
</tr>
<tr>
<td>TOTAL ASSETS LESS CURRENT LIABILITIES</td>
<td>1,932,150</td>
<td>1,856,369</td>
</tr>
<tr>
<td>NET ASSETS</td>
<td>1,932,150</td>
<td>1,856,369</td>
</tr>
</tbody>
</table>

CAPITAL AND RESERVES

|                      |          |          |
| Other reserves       | -        | -        |
| Profit and loss account | 1,932,150 | 1,856,369 |

SHAREHOLDERS’ FUNDS

|                      |          |          |
| SHAREHOLDERS’ FUNDS  | 1,932,150 | 1,856,369 |

The financial statements were approved on 12 January 2023 and signed by:
Francesca Sofia, President and Graeme Shears, Treasurer
## Statement of Income and Expenditure

**Year ended 31st December 2021**

With comparative totals for 2020

<table>
<thead>
<tr>
<th></th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INCOME</strong></td>
<td>US$</td>
<td>US$</td>
</tr>
<tr>
<td>Congress income received</td>
<td>189,279</td>
<td>18,755</td>
</tr>
<tr>
<td>Membership dues and solidarity fund</td>
<td>19,926</td>
<td>11,170</td>
</tr>
<tr>
<td>Other income</td>
<td>172,437</td>
<td>67,300</td>
</tr>
<tr>
<td>Gifts and donations</td>
<td>49,244</td>
<td>22,463</td>
</tr>
<tr>
<td>ILAE support</td>
<td>128,592</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>559,478</strong></td>
<td><strong>119,688</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>EXPENDITURE</strong></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff costs</td>
<td>122,949</td>
<td>88,227</td>
</tr>
<tr>
<td>Employer’s PRSI</td>
<td>488</td>
<td>467</td>
</tr>
<tr>
<td>Administrator costs</td>
<td>-</td>
<td>11,432</td>
</tr>
<tr>
<td>Congress expenditure</td>
<td>-</td>
<td>396</td>
</tr>
<tr>
<td>Travel</td>
<td>(4,796)</td>
<td>19,397</td>
</tr>
<tr>
<td>Website costs</td>
<td>5,798</td>
<td>10,009</td>
</tr>
<tr>
<td>Office expenditure</td>
<td>15,315</td>
<td>12,591</td>
</tr>
<tr>
<td>Advertising and promotion</td>
<td>-</td>
<td>1,601</td>
</tr>
<tr>
<td>Legal and professional</td>
<td>34,553</td>
<td>32,846</td>
</tr>
<tr>
<td>Auditors’ remuneration</td>
<td>9,257</td>
<td>9,915</td>
</tr>
<tr>
<td>Accountancy fees</td>
<td>-</td>
<td>6,042</td>
</tr>
<tr>
<td>Bank charges</td>
<td>578</td>
<td>515</td>
</tr>
<tr>
<td>Rent</td>
<td>7,162</td>
<td>5,654</td>
</tr>
<tr>
<td>Grant expenditure</td>
<td>-</td>
<td>67,300</td>
</tr>
<tr>
<td>Promising strategies program</td>
<td>2,582</td>
<td>25,455</td>
</tr>
<tr>
<td>IBE/ILAE JTF expenditure</td>
<td>78</td>
<td>561</td>
</tr>
<tr>
<td>International Epilepsy Day</td>
<td>4,661</td>
<td>5,012</td>
</tr>
<tr>
<td>(Gain)/loss on exchange</td>
<td>168,294</td>
<td>(166,265)</td>
</tr>
<tr>
<td>EpilepsyNext</td>
<td>462</td>
<td>584</td>
</tr>
<tr>
<td>African advocacy project</td>
<td>93,246</td>
<td>-</td>
</tr>
<tr>
<td>Women and Epilepsy project</td>
<td>3,497</td>
<td>-</td>
</tr>
<tr>
<td>50 Million Steps campaign</td>
<td>254</td>
<td>-</td>
</tr>
<tr>
<td>Congress (awards)</td>
<td>19,320</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Expenditure</strong></td>
<td><strong>483,698</strong></td>
<td><strong>131,729</strong></td>
</tr>
</tbody>
</table>
NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

DEBTORS

<table>
<thead>
<tr>
<th></th>
<th>2021 US$</th>
<th>2020 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trade debtors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balance of funds held on behalf of the IBE/ILAE Joint Task Force</td>
<td>18,142</td>
<td>18,142</td>
</tr>
<tr>
<td>Amounts held on behalf of the IBE/ILAE Joint Task Force</td>
<td>96,894</td>
<td>96,894</td>
</tr>
<tr>
<td>Other debtors</td>
<td>28,800</td>
<td>28,782</td>
</tr>
<tr>
<td>Prepayments</td>
<td></td>
<td>4,883</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>143,836</td>
<td>148,701</td>
</tr>
</tbody>
</table>

CREDITORS: Amounts falling due within one year

<table>
<thead>
<tr>
<th></th>
<th>2021 US$</th>
<th>2020 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congress creditors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IBE/ILAE Joint Task Force</td>
<td>96,894</td>
<td>96,894</td>
</tr>
<tr>
<td>Taxation and social insurance</td>
<td>230</td>
<td>2,992</td>
</tr>
<tr>
<td>Deferred grant</td>
<td>139,213</td>
<td>171,269</td>
</tr>
<tr>
<td>Creditors and Accruals</td>
<td>26,170</td>
<td>23,908</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>262,507</td>
<td>295,063</td>
</tr>
</tbody>
</table>

IBE/ILAE Joint Task Force

<table>
<thead>
<tr>
<th></th>
<th>2021 US$</th>
<th>2020 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening balance</td>
<td>(18,142)</td>
<td>(18,142)</td>
</tr>
<tr>
<td>Management fee</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closing balance</td>
<td>(18,142)</td>
<td>(18,142)</td>
</tr>
</tbody>
</table>

The IBE/ILAE Joint Task Force programme is a joint 50:50 initiative of the International Bureau for Epilepsy (IBE) and 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. The debtor balance for the IBE/ILAE Joint Task Force is US$18,142.

Congress Financial Information

Under an agreement dated 2 February 2010, which ended in December 2019, the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE) engaged the services of a contracted International Director of Meetings (IDM), who was charged with the organisation of various International and Regional Congresses. The financial statements for 2019 reflect the portion of assets, liabilities, net revenues and expenses held by IDM on behalf of the International Bureau for Epilepsy. Since January 2020, financial responsibility for congresses organised jointly by IBE and ILAE now rests solely with the ILAE as detailed in a Memorandum of Understanding signed jointly by IBE and ILAE.

<table>
<thead>
<tr>
<th></th>
<th>2021 US$</th>
<th>2020 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDM-Congress income received</td>
<td>189,279</td>
<td>18,755</td>
</tr>
<tr>
<td>IDM-Congress expenses</td>
<td></td>
<td>(396)</td>
</tr>
</tbody>
</table>

Approval of the financial statements

The board of Executive Committees approved these financial statements for issue on 12 January 2023

26 Annual Report 2021
CONTACT DIRECTORY

HEAD OFFICE

Donna Walsh
Chief Executive Officer
donnawalsh@ibe-epilepsy.org
T: +353 87 983 0816

OUR WEBSITES

womenandepilepsy.org
ibe-epilepsy.org
internationalepilepsyday.org
50millionsteps.org

OUR SOCIAL MEDIA

IBESocialMedia - Twitter
InternationalBureauForEpilepsy - Facebook
IBE LinkedIn account
international_epilepsy - Instagram
IBE YouTube channel
INTERNATIONAL EXECUTIVE COMMITTEE 2021-2025

Francesca Sofia
President

Gus Baker
Secretary General

Graeme Shears
Treasurer

Martin Brodie
Immediate Past President

Action Amos
VP Africa

Hassan Hosny
VP East Mediterranean

Natela Okujava
VP Europe

Tomás Mesa
VP Latin America

Deirdre Floyd
VP North America

Man Mohan Mehndiratta
VP South East Asia

Ding Ding
Western Pacific

Helen Cross
ILAE President

Ed Bertram
ILAE Secretary General

Alla Guekht
ILAE Treasurer

The term of the Regional Vice Presidents (VPs) ends in 2023.
Three members of the ILAE Executive Committee are ex-officio members of the IBE International Executive Committee with a reciprocal arrangement in place.
REGIONAL EXECUTIVE COMMITTEES
2021-2025

AFRICAN REGION

Action Amos, Malawi
VP/Chair

Youssouf Noormamode, Mauritius, Vice Chair

Betty Nsachilwa, Zambia
Secretary

EASTERN MEDITERRANEAN REGION

Hassan Hosny, Egypt
VP/Chair

Najib Kissani, Morocco
Vice Chair

Fatma Kamoun, Tunisia, Secretary

EUROPEAN REGION

Natela Okujava, Georgia, VP/Chair

Thomas Porschen, Germany, Vice Chair

Erin Davies, UK
Secretary

Claudine Aitken, Malta
Member

Ana Sruk, Croatia
Member
The term of the regional committees began on Friday 3rd September 2021 and runs until the time of the General Assembly in 2025. However, the term of the Vice President (VPs) will end in September 2023.

**LATIN AMERICAN REGION**

Tomás Mesa, Chile  
VP/Chair

Alicia Bogacz  
Uruguay, Vice Chair

Mauricio Olave  
Colombia, Secretary

**NORTH AMERICAN REGION**

Deirdre Floyd, Canada  
VP/Chair

Vice Chair  
to be announced

Secretary  
to be announced

**SOUTH EAST ASIAN REGION**

Man Mohan Mehndiratta  
India, VP/Chair

Muzharul Mannan  
Bangladesh, Vice Chair

Secretary  
to be announced

**WESTERN PACIFIC REGION**

Ding Ding, China  
VP/Chair

Anchor Hung, Hong Kong SAR, Vice Chair

Chris Dougherty  
Australia, Secretary
CHAPTER CONTACT DETAILS
Listed by region

AFRICA

BOTSWANA
Young Epilepsy Botswana
Contact: Ms Naledi

CAMEROON
Association Camerounaise contre l'Epilepsie
s/c Coordination Diocésale de la Santé, Bafia, Cameroon.
ASSOCIATE CHAPTER
Community Development and Epilepsy Foundation (CODEF)
c/o CODEF Board Chair,
Mr David Mtsauhu,
PO Box 45 Bamenda, NWR,
Cameroon.
Contact: Mr Nsou Kenneh Ninying

CONGO, DR
ASSOCIATE CHAPTER
MHCD Centre for Prevention and Treatment of Epilepsy
Luwungi General Hospital, Itara/Luwungi, Utara Territory,
DR Congo.
www.mhcdafrique.com
Contact: Dr Luc Mulimbakima -Masururu

ASSOCIATE CHAPTER
Association Against the Stigmatisation of Epilepsy in Democratic Republic of Congo (ASLEK)
Av. Capitaine Mukena,
N°24, C/Lubumbashi,
Q/Golf Meteo, DRC,
Lubumbashi City,
DR Congo.
www.aslek.org
Contact: Dr Prince Kazadi

ESWATINI
Eswatini Epilepsy Organisation
DPMs Premises, Gwamile Street,
PO Box 7220,
Mbabane H100,
ESWATINI
Contact: Mr Abraham Ntsalini

ETHIOPIA
Epilepsy Support Association of Ethiopia
PO Box 25516,
Code 1000
Addis Ababa,
Ethiopia.
Contact: Dr Zenebe Damtie

ASSOCIATE CHAPTER
Epilepsy Care
Contact: Enat Ewnetu

THE GAMBIA
Gambia Epilepsy Association
PO Box 2230, Serrekunda, Gambia.
Contact: Dr David Seys and Dr Paul Colley
ASSOCIATE CHAPTER
Foundation for Epilepsy & Stigma Support
10 Street East,
Fajara M Section,
Kanifing Municipal Council,
Contact: Ms Adam Jallow and Mr John Jabang

GHANA
Ghana Epilepsy Association
c/o Box M230, Accra, or Box SD233, Stadium, Accra, Ghana.
Contact: Mr Paul Ayisu and Mr Leonard Agbley

KENYA
Kenya Association for the Welfare of People with Epilepsy (KAWE)
PO Box 60790 00200
Nairobi, Kenya.
www.kahe-kenya.org
Contact: Dr Osman Miyani and Mr Patrick Ng'echu
ASSOCIATE CHAPTERS
Foundation for People with Epilepsy (FPE)
PO Box 817 - 80108, Kilifi, Kenya.
Contact: Mr Frederick Beuchi
Shine Epilepsy Support
Contact: Anastacia Kavembu
LESOTHO
Epilepsy Lesotho
PO Box 13081, Maseru 100,
Lesotho.
Contact: Ms Nthabeleng Hlalele
MALAWI
Malawi Epilepsy Association
PO Box E681, Postdornet,
Blantyre, Malawi.
Contact: Mrs Francina Gondwe
MALI
Global Health Mali
Contact: Zainab Kone
MAURITIUS
Edys Epilepsy Group
442 State Land Boulevard Rivaltz,
Port Louis, Mauritius.
http://edysepilepsy.imnet.mv
Contact: Mr Youssouf Noahamode

MOZAMBIQUE
Associação Moçambicana de Apoio a Pessoas com Epilepsia - AMAPE
Rua/Ave. da Resistência No. 1.75,
Maputo, Mozambique.
Contact: Mr Rogerio Manjate

NAMIBIA
Epilepsy Namibia
PO Box, 11822 Klein Windhoek, Namibia.
www.epilepsynamibia.org
Contact: Mrs Harmiena Riphagen

NIGER
LNECMNMC
Service de Psychiatrie,
Hôpital National de Naimy,
BP238 Niamey, Niger.
Contact: Dr Djibo Douma

NIGERIA
Epilepsy Association of Nigeria
No 2 Weeks Road,
by 84 Asa Road Aba,
Abia State,Nigeria.
Contact: Dr SE Nwakwue

RWANDA
Global Epileptic Connection (GECO)
25 Kibuye, Western Province,
Rubavu District, Rwanda.
www.gecorwanda.org
Contact: Mr Vedaste Rusagara and Mr Philip Benimana

SENEGAL
Ligue Senegalaize contre l’Epilepsie
Clinique Neurologique, Centre Hospitalo-Universitaire de Fann,
BP 5035, Dakar-Fann, Senegal.
Contact: Prof Moustapha Ndiaye

SIERRA LEONE
Epilepsy Association Sierra Leone
8 Mansaray Street, Rokupa,
PO Box 38, Freetown,
Sierra Leone.
www.epilepsyassocsl.org
Contact: Mr Max Bangura

SOUTH AFRICA
Epilepsy South Africa
Postnet Suite #131
Private Bag X3,
Blouberggrant, 7443, Republic of South Africa.
www.epilepsy.org.za
Contact: Mrs Sharlene Cassel

SOUTH SUDAN
Initiative For Epilepsy Awareness
Contact: Kur Ezekiel

TANZANIA, UNITED REPUBLIC OF POCKET
PO Box 65293, Dar Es Salaam
Tanzania.
Contact: Mrs Asia Matowo Mrema
ASSOCIATE CHAPTER
Tanzania Epilepsy Organisation
Contact: Eides Uiso

UGANDA
Epilepsy Support Association Uganda (ESAU)
Plot 695 Gombe B,
Off Kayunga-Kinoni-Wakiso Rd,
Wakiso Town Council,
PO Box 16260,
Wandegeya, Kampala,
Uganda.
www.epilepsy.org.ug
Contact: Ms Sarah Nekesa

ASSOCIATE CHAPTER
Purple Bench Initiative
Plot 25, Kampala Road, Masaka,
and PO Box 1240 Masaka / PO Box 8310 Kampala,
Uganda.
www.purplebenchug.org
Contact: Ms Anita Mago

ZAMBIA
Epilepsy Association of Zambia
Amanda Ethu Building,
Kalundwe Road,
PO Box 3243,
Lusaka, Zambia.
Contact: Ms Betty Nzachilwa

ZIMBABWE
Epilepsy Support Foundation
43 St. David Road,
Hatfield, Harare,
Zimbabwe.
www.esf.org
Contact: Ms Rutendo Gwatinyanya

Annual Report 2021 31
EGYPT
Egyption Epilepsy Association
40 Safeya Zaghlol Street, Alexandria 21111, Egypt.
Contact: Dr Hassan Housny

IRAN
Iranian Epilepsy Association
No 1352, Resalat Exp, Tehran, Iran.
Contact: Dr Gharagozli

LEBANON
Avance School & Association for Epilepsy and Special Needs
Lebanon - Baabda, Old Road, Le Rez, Lebanon.
Contact: Mrs Arlette Honein

ASSOCIATE CHAPTER
ECAL
Shams Building, Qayy’a al wosta, Saida, Lebanon.
Contact: Mrs Manar Sawwan

MOOROCCO
Association Marocaine contre l’Epilepsie,
BP 7010 Sidi Abbad, 40080 Marrakech, Morocco.
Contact: Prof Najib Kissani

TUNISIA
Tunisian Epilepsy Association
Child Neurology Dept., EPS Hedi Chaker 3029 Sfax, Tunisia.
Contact: Dr Chahnez Triki

ASSOCIATE CHAPTER
Association ‘Ahmed’ d’aide aux enfants avec Epilepsie,
Route el Ain Km 2, 3000 Sfax, Tunisia.
Contact: Mrs Nadia Fournati

ALBANIA
Shqot “Epilepsia”
www.epialbania@live.com
Contact: Dr Mirada Haliti

ASSOCIATE CHAPTER
ECAL
Shams Building, Qayy’a al wosta, Saida, Lebanon.
Contact: Mrs Manar Sawwan

BELGIUM
Belgian League Against Epilepsy (Flemish and French Division)
Epilepsie Liga, Beleidsmedewerker Epilepsie Liga, C. Heymanslaan, 8, 1170 Wien, Austria.
www.epilepsie-online.de
Contact: Dr Michael Mueller

BELGIUM
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Epilepsie Liga, Beleidsmedewerker Epilepsie Liga, C. Heymanslaan, 8, 1170 Wien, Austria.
www.epilepsie-online.de
Contact: Dr Michael Mueller

BULGARIA
Association of Parents of Children with Epilepsy
Triadica district, Strelbishte Bl 10, 00700 Republic of Kazakhstan.
www.spolecnost-e.cz
Contact: Mrs Alena Červenková

CROATIA
Croatian Association for Epilepsy
General Hospital “Sveti Duh”, Sveti Duh 64, 10000 Zagreb, Croatia.
www.epilepsija.hr
Contact: Prof Ilirjana Zekja

DENMARK
Danish Epilepsy Organisation
Store Grøndrestraße 10, 1, DK-5000 Odense C, Denmark.
www.epilepsie-organisætionen.dk
Contact: Prof Ilirjana Zekja

ENGLAND
United Kingdom
249 Crumlin Road, Dublin 12, 249 Crumlin Road, Dublin 12, 40080 Marrakech, Morocco.
Contact: Dr Michael Mueller

FINLAND
Epilepsy Environment Association of Georgia
33 Chavchavadze Ave. S. Khechinashvili University Hospital, Epilepsy and Sleep Centre, 0179 Tbilisi, Georgia.
Contact: Dr Natela Okujava

GEOURGI
Georgia Society of Young Epileptologists
Institute of Neurology & Neuropsychology, 85 Vaja Phavela Str, Tbilisi, Georgia.
Contact: Dr Irina Toidze

GERMANY
Deutsche Epilepsievereinigung eV
Zillestrasse 102, D-10585 Berlin, Germany.
www.epilepsie-vereinigung.de
Contact: Ms Frida Bragadottir

ICELAND
LAUF - Icelandic Epilepsy Assoc
Hatun 10, 105 Reykjavik, Iceland.
www.lauf.is
Contact: Mr Peter Murphy

ISRAEL
Israel Epilepsy Association
4 Avotd Yisrael, Box 1598, Jerusalem 91014, Israel.
www.epilepsy.org.il
Contact: Mr Karen Tress

ITALY
Associazione Italiana contro l’Epilessia (AICE)
Via Garavaglia No 5, 40127, Bologna (BO), Italy.
www.aice-epilessia.it
Contact: Dr Giovanni B Pesce

IRAN
Iranian Epilepsy Association
No 1352, Resalat Exp, Tehran, Iran.
Contact: Mrs Alena Červenková

JERUSALEM
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www.spolecnost-e.cz
Contact: Mrs Alena Červenková

CROATIA
Croatian Association for Epilepsy
General Hospital “Sveti Duh”, Sveti Duh 64, 10000 Zagreb, Croatia.
www.epilepsija.hr
Contact: Dr Ana Sruk or Dr Latica Friedrich

CYPRUS
Cyprus Association of Support for People with Epilepsy
8 Epivdavrou Str, 2114 Nicosia, Cyprus.
Contact: Mrs A Kallimachiou

CZECH REPUBLIC
Spolecnost “E”
Liskova 959/3 14200, Prague 4, Czech Republic.
www.spolecnost-e.cz
Contact: Mrs Alena Červenková
LUXEMBOURG
Association d’aide aux Personnes Epileptiques - AAPE
17 rue Charlemagne L-1328, Luxembourg.
Contact: Mrs Maryse Ardent
MALTA
Caritas Malta Epilepsy Association
5, Lion Street, Floriana FRN 1514, Malta.
www.caritmalta.org/epilepsy
Contact: Mr Frank Portelli or Ms Robin Pinkston
MOLDOVA
Association Supporting Children with Special Needs
1-A, Constantin Stere str, Chisinau MD-2009, Rep of Moldova.
www.ascs.md/en
Contact: Dr Antonina Gavajuc
NETHERLANDS
Epilepsie Vereniging Nederland-EVN
Postbus 8105, 6710 AC Ede, The Netherlands.
www.epilepsievereniging.nl
Contact: Office
ASSOCIATE CHAPTERS
Epilepsiefonds Dr Molen 35, 3994 Da Houten, Netherlands.
www.epilepsiefonds.nl
Contact: Ms Marissa Piso
SEIN
Postbus 540, 2130 AM Hoofddorp, Netherlands.
www.sein.nl/en
Contact: Mr Jean Willem Barzilay
NORWAY
Norwegian Epilepsy Association
Karl Johans Gate 7, 0154 Oslo, Norway.
www.epilepsi.no
Contact: Ms Sissel Karin Haavaag
POLAND
Polish Association for People Suffering from Epilepsy
Ul Fabryczna 57, 15-482 Bielskost, Poland.
www.padaaczka.bialystok.pl
Contact: Mr Tadeusz Zarebski
ROMANIA
Association of Epilepsy Patients from Romania – ASPERO
1, Aleea Circului Street, Romania.
www.aspe.ro
Contact: Mr Ileana Stefan
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