



**ANNUAL
REPORT
2021**



IBE

International Bureau
for Epilepsy



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.



PRESIDENT'S REPORT

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

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.

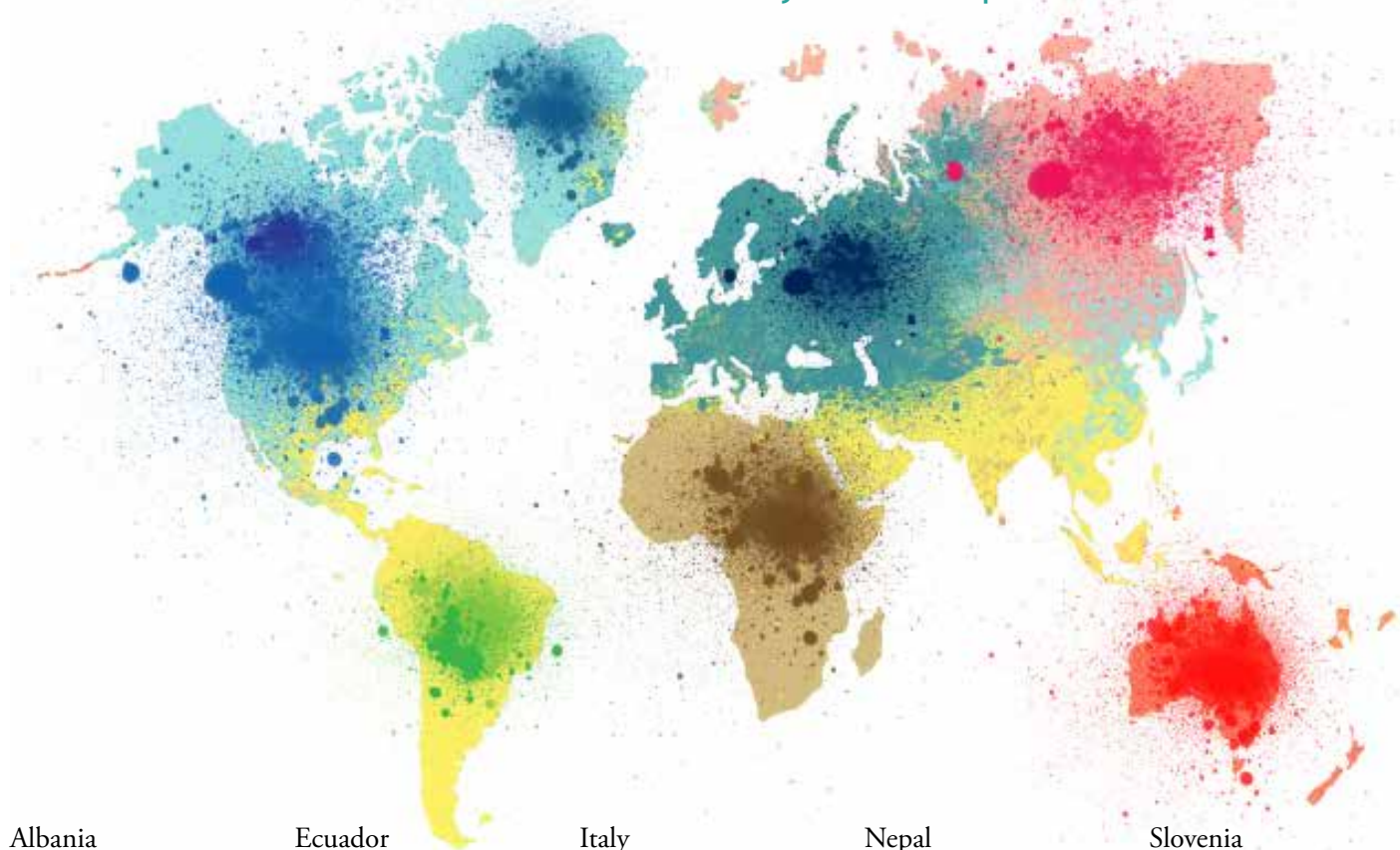
Losing Ann's experience and expertise was always going to be a challenge for IBE, but the process to recruit a new CEO got underway quickly and Ann's replacement – Donna Walsh – was appointed in late 2021.

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.

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



- | | | | | |
|----------------|-----------|---------------|--------------|--------------|
| Albania | Ecuador | Italy | Nepal | Slovenia |
| Argentina | Egypt | Jamaica | Netherlands | South Africa |
| Australia | Estonia | Japan | New Zealand | South Sudan |
| Austria | Eswatini | Kazakhstan | Niger | Spain |
| Bangladesh | Ethiopia | Kenya | Nigeria | Sri Lanka |
| Belgium | Fiji | Korea | Norway | Sweden |
| Botswana | Finland | Lebanon | Pakistan | Switzerland |
| Brazil | France | Lesotho | Panama | Taiwan |
| Bulgaria | Gambia | Lithuania | Paraguay | Tanzania |
| Cameroon | Georgia | Luxembourg | Peru | Thailand |
| Canada | Germany | Macedonia FYR | Philippines | Togo |
| Chile | Ghana | Malawi | Poland | Tunisia |
| China | Greece | Malaysia | Portugal | Turkey |
| Colombia | Guatemala | Mali | Romania | Uganda |
| Congo, DR | Guyana | Malta | Russia | UK |
| Costa Rica | Honduras | Mauritius | Rwanda | Ukraine |
| Croatia | Iceland | Mexico | Scotland | USA |
| Cuba | India | Moldova | Senegal | Uruguay |
| Cyprus | Indonesia | Mongolia | Serbia | Venezuela |
| Czech Republic | Iran | Morocco | Sierra Leone | Zambia |
| Denmark | Ireland | Mozambique | Singapore | Zimbabwe |
| Dominican Rep | Israel | Namibia | Slovakia | |



International Epilepsy Day 2021

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!

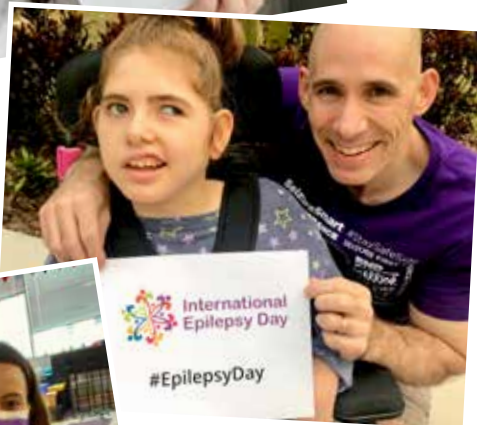
A big THANK YOU! to all those who helped make the day a great success.

- 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
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- Iraq
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- 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





International Epilepsy Day 2021



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 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 fund-raising 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!

Top Tweet earned 5,447 impressions

International **#EpilepsyDay** is a global event held annually on the second Monday in February to promote awareness of **#epilepsy** around the world. This year it takes place on Monday, February 8th. Find out more and learn how you can get involved at internationalepilepsyday.org pic.twitter.com/csHROQovqb



Players in Turkey wore purple glasses in a Look Awareness Campaign for Epilepsy



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



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



Kenya Association for the welfare of people with epilepsy



At the National Epilepsy Centre, Karachi, Pakistan



Samman Epilepsy Association, India

50 million

STEPS FOR EPILEPSY

We did it!

164,817,721

STEPS ACHIEVED





International Epilepsy Day

50 Million Steps for Epilepsy one step for every person living with epilepsy worldwide



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 track 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.

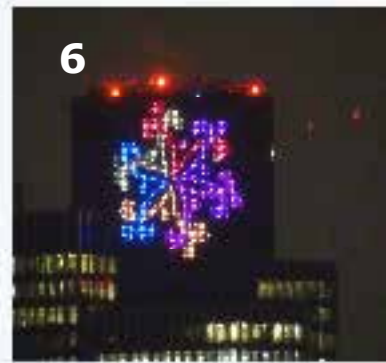
SHINING A LIGHT

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 gaps 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.



IBE Global Youth Team and Golden Light Awards 2021

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



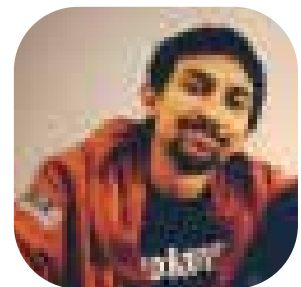
Chris Ang,
Singapore



Dan Kumajai,
Japan



Meng-Leo Chou,
Taiwan



Salim Baredhwam,
Malaysia



Divyasinny Sharma,
India



Bin Wang,
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 Nabukenya,
Uganda



Mohan Dike
Nigeria



Praise Bessong,
Cameroon



Valentina Khan,
Chile



Veselka Šoštarčić,
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



Making Epilepsy a Health Priority in Africa

Since 2019, the BAND Foundation has supported IBE's initiative in Africa with the goal of ensuring that epilepsy becomes a health priority 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
- Strengthening regional engagement with WHO African Region, the African Union and Pan African Parliament.

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.



COMMUNICATIONS


Overcoming the challenges of Covid 19

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 slowly 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.



Save the DATE

1 AND 3 SEPTEMBER

An invitation to mark your diaries for two important events in September!

Wednesday 1st September

IBE Day at the 34th International Epilepsy Congress

Three (3) two-hour virtual sessions on:

1. Making Epilepsy a National Health Priority - intersectoral collaboration
2. Empowering Youth to Raise their Voices
3. Best Practices to address the Psychosocial Impact of Epilepsy



Plus presentation of the International Golden Light Awards

Friday 3rd September

IBE General Assembly 2021

The IBE General Assembly will be held virtually this year. This is the opportunity for everyone to participate!

More information will be circulated in the coming weeks as arrangements are finalised.



IBE Epilepsy & Society Symposium
at the 13th Asian & Oceanian Epilepsy Congress

Join us for the IBE Epilepsy & Society Symposium
as part of the 13th AOEC congress programme
Date: Sunday 13th June 2021
Time: 09:00 - 17:30 Japan Standard Time

REGISTRATION NOW OPEN!

Topics include:
Epilepsy & Covid-19
Driving with Epilepsy
Golden Light Awards with personal testimonials
Review of the Special Art Exhibition

Delegate Registration Fees:

- High Income Countries: US\$30 up to 14th May, US\$45 from 15th May
- Upper Middle Income Countries: US\$20 to 14th May, US\$30 from 15th May
- Lower and Middle Income Countries: US\$15 to 14th May, US\$20 from 15th May

Links:

- Download the Epilepsy & Society Programme [here](#)
- Register for the symposium [here](#)
- Find out if you qualify for reduced registration [here](#)
- For any questions on registration, please email registration@iae.org
- For any general queries on the symposium, please email aoc@epilepsycongress.org

Organised by the IBE Regional Executive Committees Western Pacific and South East Asia.
All presentations and discussion will be in English.



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.



IBE International Bureau for Epilepsy
AFRICA REGION

WEBINAR INVITATION

Join us for our new monthly Webinar series
Making Epilepsy a Health Priority in Africa
Date: 20th October, 2020 Time: 2:00pm Pretoria Time
To register contact Action Areas: action_areas@epilepsy.org

Webinar Moderator: Action Areas, IBE Vice President African Region

Key Note Address: Epilepsy in Africa Today – WHO Perspective
Speaker: Dr Florence Bergasa – WHO Africa Regional Mental Health Policy and Planning Coordinator

The Role of Risk in Preventing Falls in Africa – Evidence from Disability Evidence
Speaker: Dr Elizabeth Duke – Director General Africa Disability Alliance and Chairperson Action for Disability and Development (ADD)

Best Practice in Engaging Governments – experience of Mozambique Global Project Phase 3
Speaker: Dr Yousouf Nourmand – Vice Chairperson IBE African Regional Executive Committee, Vice President African Disability Alliance and President CGDLS Group Mozambique

The International Bureau of Epilepsy Africa Region (IBE Africa) with 25 chapters in the region has been actively working towards...
Preventing Stigmatization Program and Making Epilepsy a Health Priority in Africa

Don't miss the next Webinar!
21st October, 2020 @ 2:00pm Pretoria Time
Key Note Address: Contribution of the African Union to mainstreaming epilepsy in the African health agenda
Guest Speaker: Mr. Ibrahim Choukri-Bachem, Director African Union – Social Affairs and Health Division
Visit our website www.epilepsyafrika.org

Reported to a panel with the IBE President

IBE International Bureau for Epilepsy
AFRICA REGION

WEBINAR INVITATION

Join us for our monthly Webinar series
Making Epilepsy a Health Priority in Africa - WHA Resolutions 68:20
Youths with Epilepsy across Africa Speak Out!
Date: 20th October, 2020 Time: 2:00pm Pretoria Time – 1:00pm Pretoria Time
Moderator: Action Areas, Vice President Africa, International Bureau for Epilepsy
To register and receive a webinar link email: action_areas@epilepsy.org

Key Note Address: Why are governments in Africa having a difficult time meeting
Speaker: Dr Wanda Wilson – Disability Rights Watch Africa
Zambian Human Rights Commission

Global Youth Issues in the WHO
Resolution 68:20
Speaker: Mr. Mwanuzi
BE Global Youth Award Winner
Pepes South Uganda

Meeting the WHO Resolution 68:20 on SDG Targets
Speaker: Mr. Mwanuzi
Epilepsy Line Mozambique
Epilepsy Line Mozambique

Panel Discussion (30 mins): Why the Global Epilepsy Plan matters for Youths with Epilepsy in Africa?
Moderator: Corneil Muna, Co-Chair, IBE Epilepsy Executive Board Member 2014

Panelists:
• Corneil Muna, WHO Regional Coordinator, Epilepsy South Africa
• Shalini Nair, Board Member, Epilepsy Support Association, Uganda (ESAU)
• Mwanuzi Mwanuzi, Executive Director for the Welfare of People with Epilepsy (EWEP)

Panelists (20 mins): Youths with Epilepsy Politics in 24 Minutes of Health and Parliamentary Health Committees in Africa to support the World Health Assembly (WHA) Resolution 68:20

Panelists:
• Corneil Muna, Co-Chair, IBE Epilepsy Executive Board Member 2014
• Mwanuzi Mwanuzi, Executive Director for the Welfare of People with Epilepsy (EWEP)

The International Bureau of Epilepsy Africa Region (IBE Africa) with 25 chapters in the region has been actively working towards...
Preventing Stigmatization Program and Making Epilepsy a Health Priority in Africa

Visit our website www.epilepsyafrika.org

Reported to a panel with the IBE President

IBE International Bureau for Epilepsy
AFRICA REGION

WEBINAR INVITATION

Guest speaker: Dr. Tarek Daa
Head of Brain Health Unit
Department of Mental Health and Substance Use, WHO Geneva

Join us for our monthly Webinar series
MAKING EPILEPSY A HEALTH PRIORITY IN AFRICA
Double Celebration with WHA Resolutions 68:20, now WHA 73
+ International Disability Day
Date: 2nd December, 2020 Time: 1:00pm Pretoria Time
[2:00pm GMT, +1hr WAT, +1hr EAT, +2hrs Mauritius/Seychelles]
Moderator: Corneil Muna, Co-Chair, IBE Vice President Africa
To register and receive a webinar link email: action_areas@epilepsy.org

Panelists:
• Abdourahmouh Ndoumou – Executive Epilepsy Coordinator
• Shalini Nair – Epilepsy South Africa
• Dr. Yousouf Nourmand – IBE Vice President African Region
• Remy Beuchet – Epilepsy Support Association, Zimbabwe
• Tarek Daa – Epilepsy Support Association, Zimbabwe

Session 1: Epilepsy work in Africa in light of World Health Assembly Resolution 73 (WHA73)
Moderator: Dr Tarek Daa, Geneva and
Dr. Daa is Head of the Brain Health Unit in the Department of Mental Health and Substance Use at WHO Headquarters. The aim of the unit is to promote optimal brain development, cognitive health and wellbeing and prevent and manage neurological disorders across the life course. She leads the WHO work on epilepsy and other neurological conditions, including development of guidance and other resources and advocacy support.

Session 2: Resolutions from the Panel – Best Practices in Epilepsy

Panelists:
• Abdourahmouh Ndoumou – Executive Epilepsy Coordinator
• Shalini Nair – Epilepsy South Africa
• Dr. Yousouf Nourmand – IBE Vice President African Region
• Remy Beuchet – Epilepsy Support Association, Zimbabwe
• Tarek Daa – Epilepsy Support Association, Zimbabwe

The International Bureau of Epilepsy Africa Region (IBE Africa) with 25 chapters in the region has been actively working towards...
Preventing Stigmatization Program and Making Epilepsy a Health Priority in Africa

Visit our website www.epilepsyafrika.org

Reported to a panel with the IBE President

IBE International Bureau for Epilepsy
AFRICA REGION

WEBINAR INVITATION

State of Epilepsy Health Laws in Africa: webinar no. 6
Date: 19th May, 2021 Time: 2:00pm Pretoria Time
(-2hrs GMT, -1hr WAT, +1hr EAT, +2hrs Mauritius/Seychelles)
To register and receive a webinar link email: action_areas@epilepsy.org

Twenty-one African States are engaged in this project through their international commitments and the humanity of their national laws as they relate to epilepsy. Despite several African States consenting to international treaties concerning the universal right to health and the protection of the rights of persons with specific health needs, there is still a dearth of antiepileptic drug policies and laws, as well as accompanying monitoring and enforcement mechanisms. This webinar report reflects on how health laws may be used to strengthen the prohibition of epilepsy in resource-restricted settings, specifically in the African context.

GUEST PRESENTER:
Advocate Nkandiso Nkandiso, South African High Court
Adv. Nkandiso Nkandiso, from Zambia, is a lawyer, writer, researcher and human rights activist. She has worked on human rights, international human rights, international law and forced migration studies. She has a special interest in epilepsy advocacy and is supporting the International Bureau for Epilepsy Africa. She has worked for the United Nations, intergovernmental and non-governmental organizations (NGOs) at both national (South Africa) and international levels.
A member of the International Law Association and International Bar Association, she holds an LL.B. degree and International Certificate in Human Rights from the University of Pretoria as well as an LL.M. degree (cum laude) from the University of South Africa. Furthermore, Nkandiso has a certification in Human Rights Protection, Response and Management. She is currently a Director of Law students at the University of South Africa in the Department of Public, Constitutional and International Law.
Between her academic assignments and legal practice, Nkandiso shows great interest and academic awareness in gender equality and women's reproductive health services to HIV/AIDS within the Kalisno Foundation, which she maintains in 2019.

Co-Chair: Yousouf Nourmand, Vice Chair, IBE African Regional Executive Committee

Moderator: Corneil Muna, IBE Africa Communications

Visit our website www.epilepsyafrika.org

Reported to a panel with the IBE President

IN MEMORIAM

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

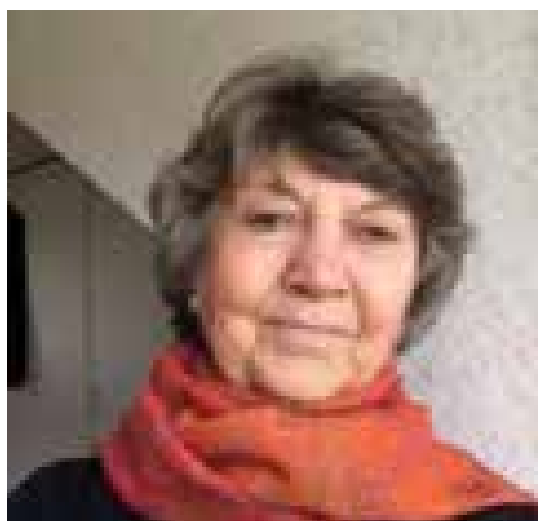


ROSEMARY PANELLI

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.



International
Epilepsy Day

50 million
Steps Against Stigma

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

	2021 US\$	2020 US\$
INCOME	559,478	119,688
EXPENDITURE	(483,698)	(131,729)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>75,780</u>	<u>(12,041)</u>

Balance Sheet

Year ended 31st December 2021
With comparative totals for 2020

	2021 US\$	2020 US\$
CURRENT ASSETS		
Debtors: amounts falling due within one year	143,836	148,701
Bank and cash balances	2,050,821	2,002,731
	<u>2,194,657</u>	<u>2,151,432</u>
Creditors (Amounts falling due in one year)	(262,507)	(295,063)
NET CURRENT ASSETS	<u>1,932,150</u>	<u>1,856,369</u>
TOTAL ASSETS LESS CURRENT LIABILITIES	<u>1,932,150</u>	<u>1,856,369</u>
NET ASSETS	<u>1,932,150</u>	<u>1,856,369</u>
CAPITAL AND RESERVES		
Other reserves	-	-
Profit and loss account	1,932,150	1,856,369
SHAREHOLDERS' FUNDS	<u>1,932,150</u>	<u>1,856,369</u>

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

	2021 US\$	2020 US\$
INCOME		
Congress income received	189,279	18,755
Membership dues and solidarity fund	19,926	11,170
Other income	172,437	67,300
Gifts and donations	49,244	22,463
ILAE support	128,592	-
	<u>559,478</u>	<u>119,688</u>
EXPENDITURE		
Staff costs	122,949	88,227
Employer's PRSI	488	467
Administrator costs	-	11,432
Congress expenditure	-	396
Travel	(4,796)	19,397
Website costs	5,798	10,009
Office expenditure	15,315	12,591
Advertising and promotion	-	1,601
Legal and professional	34,553	32,846
Auditors' remuneration	9,257	9,915
Accountancy fees	-	6,042
Bank charges	578	515
Rent	7,162	5,654
Grant expenditure	-	67,300
Promising strategies program	2,582	25,455
IBE/ILAE JTF expenditure	78	561
International Epilepsy Day	4,661	5,012
(Gain)/loss on exchange	168,294	(166,265)
EpilepsyNext	462	584
African advocacy project	93,246	-
Women and Epilepsy project	3,497	-
50 Million Steps campaign	254	-
Congress (awards)	19,320	-
	<u>483,698</u>	<u>131,729</u>

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

DEBTORS

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

CREDITORS: Amounts falling due within one year

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

IBE/ILAE Joint Task Force

	2021 US\$	2020 US\$
Opening balance	(18,142)	(18,142)
Management fee	-	-
Closing balance	<u>(18,142)</u>	<u>(18,142)</u>

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.

	2021 US\$	2020 US\$
IDM-Congress income received	189,279	18,755
IDM-Congress expenses	-	(396)

Approval of the financial statements

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



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](https://www.instagram.com/international_epilepsy) - Instagram
IBE YouTube channel



Francesca Sofia
President

INTERNATIONAL EXECUTIVE COMMITTEE 2021-2025



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



Youssef 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 Sruck, 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 Diocésaine de la Santé, Bafia, Cameroon.

ASSOCIATE CHAPTER

Community Development and Epilepsy Foundation (CODEF)

c/o CODEF Board Chair,

Mr David Ntuchu,

PO Box 45 Bamenda, NWR,

Cameroon.

Contact: Mr Nsom Kenneth Ninying

CONGO, DR

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Luvungi General Hospital,

Itara/Luvungi, Uvira Territory,

DR Congo.

www.mhcdafrika.com

Contact: Dr Luc Mulimbalimba

-Masururu

ASSOCIATE CHAPTER

Association Against the Stigmatisation of Epilepsy in Democratic Republic of Congo (ASLEK)

Av. Capitaine Mukena,

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Q/Golf Meteo, DRC,

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www.aslek.org

Contact: Dr Prince Kazadi

ESWATINI

Eswatini Epilepsy Organisation

DPMs Premises, Gwamile Street,

PO Box 7220,

Mbabane H100,

Eswatini.

www.epilepsy.org.sz

Contact: Mr Abraham Ntshalintshal

ETHIOPIA

Epilepsy Support Association of Ethiopia

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Contact: Dr Zenebe Damtie

ASSOCIATE CHAPTER

Ethiopia Epilepsy Care

Contact: Enat Ewnetu

THE GAMBIA

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PO Box 2230, Serrekunda, Gambia.

Contacts: Dr David Seyes and Dr

Paul Colley

ASSOCIATE CHAPTER

Foundation for Epilepsy & Stigma Support

10 Street East,

Fajara M Section,

Kanifing Municipal Council,

Banjul, The Gambia.

Contact: Ms Adam Jallow and Mr

John Jabang

GHANA

Ghana Epilepsy Association

c/o Box M230, Accra, or Box

SD233, Stadium, Accra, Ghana.

Contacts: 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.kawe-kenya.org

Contacts: Dr Osman Miyanji and

Mr Patrick Ngechu

ASSOCIATE CHAPTERS

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Contact: Mr Frederick Beuchi

Shine Epilepsy Support

Contact: Anastacia Kavemba

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Epilepsy Lesotho

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Contact: Ms Nthabeleng Hlalele

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MALI

Global Health Mali

Contact: Zainab Kone

MAURITIUS

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442 State Land Boulevard Rivaltz,

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http://edycs epilepsy.intnet.mu

Contact: Mr Youssouf Noormamode

MOZAMBIQUE

Associação Moçambicana de Apoio a Pessoas com Epilepsia - AMAPE

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Maputo, Mozambique.

Contact: Mr Rogerio Manjate

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Epilepsy Namibia

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www.epilepsynamibia.org

Contact: Mrs Harmiena Riphagen

NIGER

LNCEMNMC

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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 Senegalaise contre l'Epilepsie

Clinique Neurologique, Centre

Hospital-Universitaire de Fann,

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SIERRA LEONE

Epilepsy Association Sierra Leone

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Sierra Leone.

www.epilepsyassocsl.org

Contact: Mr Max Bangura

SOUTH AFRICA

Epilepsy South Africa

Postnet Suite #131

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South Africa.

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Contact: Mrs Sharlene Cassel

SOUTH SUDAN

Initiative For Epilepsy Awareness

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TANZANIA, UNITED REPUBLIC OF

POCET

PO Box 65293, Dar Es Salaam

Tanzania.

Contact: Mrs Aisia Matowo Mrema

ASSOCIATE CHAPTER

Tanzania Epilepsy Organisation

Contact: Fides Uiso

TOGO

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and PO Box 1240 Masaka / PO

Box 8310 Kamapala,

Uganda.

www.purplebenchug.org

Contact: Ms Anita Mago

ZAMBIA

Epilepsy Association of Zambia

Amanda Ethu Building,

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Lusaka, Zambia.

Contact: Ms Betty Nsachilwa

ZIMBABWE

Epilepsy Support Foundation

43 St. David Road

Hatfield, Harare, Zimbabwe.

www.esf.org

Contact: Ms Rutendo Gwatinyanya

EASTERN MEDITERRANEAN

EGYPT

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40 Safeya Zaghlol Street,
Alexandria 21111,
Egypt.
Contact: Dr Hassan Hosny

IRAN

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

LEBANON

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40080 Marrakech, Morocco.
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Chaker 3029 Sfax, Tunisia.
Contact: Dr Chahnez Triki

ASSOCIATE CHAPTER

Association 'Ahmed' d'aide aux enfants avec Epilepsie, Route el
Ain Km 2.5, 3000 Sfax, Tunisia.
Contact: Mrs Nadia Fourati

EUROPE

ALBANIA

Shoqata "Epilepsia"
Sherbimi I Neurologjise,
QSUT "Nene Tereza", Tirana,
Albania.
www.epialbania@live.com
Contact: Prof Ilirjana Zekja

AUSTRIA

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1170 Wien, Austria.
www.epilepsie.at
Contacts: Mrs Liselotte Kastl-Soldan
or Mr Michael Alexa

BELGIUM

Belgian League Against Epilepsy (Flemish and French Division)
Epilepsie Liga,
Beleidsmedewerker Epilepsie Liga,
C. Heymanslaan,
10 - 9000 Gent, Belgium.
www.epilepsieliga.be
Contact: Ms Barbara Eichperger

BULGARIA

Association of Parents of Children with Epilepsy
Triadica district, Strelbishte Bl 10,
entr. G floor 7 ap 67,
Sofia 1408, Bulgaria.
www.frde.org
Contact: Mrs Veska Sabeva

CROATIA

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

CYPRUS

Cyprus Association of Support for People with Epilepsy
8 Epidavrou Str,
2114 Nicosia, Cyprus.
Contact: Mrs A Kallimachou

CZECH REPUBLIC

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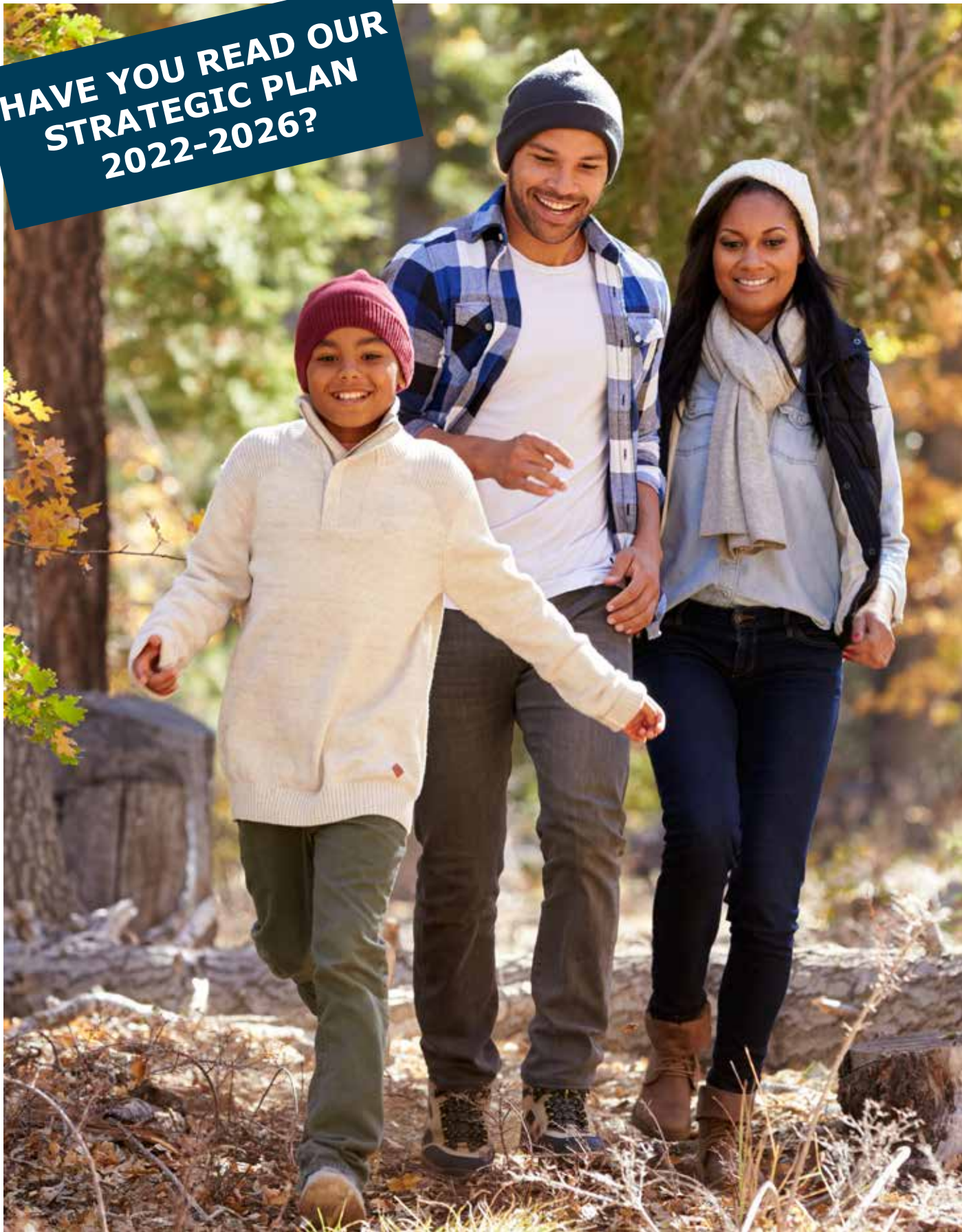
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