

# ANNUAL REPORT 2020



**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.

### 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, philanthropic support and grant funding from the pharmaceutical industry.
- Industry funding amounted 18.75% of total income. IBE received industry-related income from one company in 2020 - UCB Pharma.
- Philanthropic support amounted to 56% of total income and was provided by BAND Foundation.
- In 2020, non-industry income accounted for 81.25% of all income.



Francesca Sofia, President

# INTERNATIONAL EXECUTIVE COMMITTEE 2021-2025



Gus Baker, Secretary General



Graeme Shears, Treasurer



Martin Brodie, 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 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



## MARTIN BRODIE

### PRESIDENT - September 2017 to September 2021

2020 will be remembered as the year when Covid-19 arrived; a pandemic that none of us was expecting, but which was to lead the world into a time of uncertainty, worry and fear. Our best laid plans were destroyed, as we learned to live with lockdowns and social distancing. However, despite the restrictions that saw so many activities move to the virtual world, there were benefits to be had from our necessary online operations and the work of IBE, by necessity, continued apace. While we had already begun to use Zoom for management committee meetings, this program was to provide opportunities to better communicate with our members that we had previously failed to recognise and take advantage of. This has been a major tool in all our activities since early 2020.

#### **EPILEPSYNEXT focus on youth**

EpilepsyNext, our work programme with young adults in mind, was severely affected by Covid, but one module, our Golden Lights Awards, did continue to grow and develop. These regional and international awards honour young people with epilepsy, recognising the fact that they should not be defined by their condition but, instead, embrace the longstanding call of IBE to 'bring epilepsy out of the shadows and into the light'. Each opportunity to bestow these awards provides the possibility to identify many more young people, who have the potential to become future leaders in their own communities and beyond.

#### **Our teams**

IBE is its people and chapters and, in line with our strategic plan, we recognise the need to place people with epilepsy and their care providers central to our decision making and

subsequent progression as a global organisation. Involving our stakeholders in all IBE's activities is vital if they are to become the motivators of tomorrow. Our objective is to see an expanded IBE board emerge over the next decade, whose membership consists of people with a wide range of knowledge, experience, expertise, and skills. The IBE Teams, introduced in 2020, represents a first step towards achieving this objective.

#### **IBE in Africa**

While IBE's structure comprises seven regions, some are more energetic than others for a variety of reasons. Over the past few years, our African region has been particularly active, thanks to the provision of substantial financial support from the BAND Foundation in the US. Over the past two years, an African Advocacy Toolkit has been developed, which is providing chapters and other groups in the region with the tools necessary to support their advocacy efforts, to encourage national health departments, and to create management plans for epilepsy across the continent.

Monthly webinars are an important tool in all this work, most of which have been attended by around 100 participants. Each of these has addressed a particular aspect of the current climate for people with epilepsy in Africa and the need for better care, easier access to medication, and improved public education to reduce stigma. Many of the activities that have been successful in Africa would be suitable for rollout in other regions with minor adjustments.

#### **Epilepsy and pregnancy**

Another initiative, being piloted in Europe, but with plans

to roll it out at an international level, is our “epilepsy and pregnancy” project. A working group has been developing this project since late 2020, comprising a number of young women from across Europe, as well as interested medical and other professionals. The goal is to develop a multifaceted toolkit as well as launching a dedicated website, first in English and later in other major languages. While this project is being developed with financial support from Sanofi, the company has no editorial influence over the content of the material.

### Global outreach

Twenty-four years ago in 1997, I took part in the ILAE/IBE/WHO Global Campaign Against Epilepsy ‘Out of the Shadows’ initiative, which was launched in Geneva and Dublin. In the intervening years, the working relationship of the three partners has remained strong, with the introduction of a number of initiatives and interventions. This momentum has continued thanks to the dedicated efforts of the global outreach group drawn from members of IBE and ILAE, which led to the production of a second resolution in November 2020 and the call for the development of an Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders to be ready for consideration by the World Health Association during its 75th session in 2022.

### International Epilepsy Day

International Epilepsy Day has been celebrated annually on the second Monday of February since 2015. It is a global event geared to promoting awareness of epilepsy around the world; a powerful opportunity to highlight the problems faced by people with epilepsy, their families and care providers; and a platform to advocate for appropriate legislation guaranteeing the human rights of people with epilepsy

in every corner of the world. This annual event grew in strength and reach during 2020 with more countries than ever before taking part.

### Remembrance

I would like to remember those friends and colleagues who are now longer with us. They will forever remain in our memory, and we celebrate their efforts working with IBE to improve the quality of life of people with epilepsy around the world. May they rest in peace:

- Anthony Zimba: Treasurer 2017-2020
- Vinod Saxena: Vice President South East Asia 2009-2013
- Henry Stokes Brown: IBE Chapter in Guatemala

### Thank you

Having completed my four year term in early September 2020, I would like to take this opportunity to thank the many people that I have had the honour and pleasure to meet and work with over this challenging period. It has been a privilege to represent IBE during this interesting time and to use my skill and enthusiasm to introduce new activities to take our mission forward.

I would also like to congratulate Francesca Sofia, IBE’s new President. Francesca and her new team are already busy at work planning a ranges of initiatives that will underpin the objectives of a new strategic plan to ensure IBE’s future as the pre-eminent international organisation representing people with epilepsy and their care providers at a global level. I will continue to support our goals and activities to the best of my ability during her term of office.

With best wishes to all for the challenges ahead!

Martin Brodie  
Immediate Past President



**ANTHONY MULENGA ZIMBA**  
17 March 1954 - 9 August 2020

It was with great sadness that IBE learned of the death of its Treasurer, Anthony Mulenga Zimba, in August 2020. A victim of Covid-19, and with underlying medical issues that made his ability to recover much more difficult, Anthony passed away in hospital in Lusaka, Zambia after a short but hard fought battle.

Anthony had a long history of service to IBE. He was a member of the African Regional Committee from 2005 to 2009 before being elected to the position of Vice President - a position he held for two consecutive terms. He was elected as IBE Treasurer in 2017, a he still held at the time of his death.

Anthony worked tirelessly on behalf of people with epilepsy with a focus on his beloved Africa. He founded the Epilepsy Association of Zambia in 2001 and supported the development of other national associations that would become IBE chapters.

He worked as an Epilepsy Specialist at Levy Mwanawasa Hospital in Lusaka and established epilepsy clinics at health institutions in collaboration with the Ministry of Health. He also had a private practice - the Country Travellers’ Health Care Clinic - which specialised in psychiatry and epilepsy.

May he rest in peace.

# FINANCIAL REPORT

## Income and Expenditure Account

Year ended 31st December 2020  
With comparative totals for 2019

|                                      | 2020<br>US\$    | 2019<br>US\$     |
|--------------------------------------|-----------------|------------------|
| INCOME                               | 119,688         | 991,096          |
| EXPENDITURE                          | (131,729)       | (1,285,299)      |
| OPERATING (DEFICIT)/SURPLUS FOR YEAR | <u>(12,041)</u> | <u>(294,203)</u> |

## Balance Sheet

Year ended 31st December 2019  
With comparative totals for 2018

|  | 2020<br>US\$     | 2019<br>US\$     |
|--|------------------|------------------|
| CURRENT ASSETS   |                  |                  |
| Debtors  | 148,701          | 750,756          |
| Cash in hand and at bank                               | 2,002,731        | 1,804,699        |
| Amount held on behalf of the IBE/ILAE Joint Task Force |                  |                  |
|  | <u>2,151,432</u> | <u>2,555,455</u> |
| CREDITORS (Amounts falling due in one year)            | (295,063)        | (687,045)        |
| NET CURRENT ASSETS                                     | <u>1,856,369</u> | <u>1,868,410</u> |
| NET ASSETS   | <u>1,856,369</u> | <u>1,868,410</u> |
| CAPITAL AND RESERVES                                   |                  |                  |
| General Reserve  | 1,856,369        | 1,812,757        |
| Restricted and designated funds                        |                  | 55,653           |
|  | <u>1,856,369</u> | <u>1,868,410</u> |

The financial statements were approved on 20 October 2021 and signed by:  
Martin Brodie, Immediate Past President  
Ann Little, Executive Director



## Statement of Income and Expenditure

Year ended 31st December 2020

With comparative totals for 2019

|  | 2020<br>US\$   | 2019US\$         |
|--|----------------|------------------|
| <b>INCOME</b>                                    |                |                  |
| Congress income received                         | 18,755         | 862,714          |
| IBE/ILAE JTF management fee                      | -              | 17,016           |
| IBE/ILAE JTF reimbursement of expenses (IBE 50%) | -              | 8,864            |
| Membership dues and solidarity fund              | 11,170         | 15,020           |
| Investment income                                | -              | 946              |
| Grant income receivable                          | 67,300         | 45,740           |
| Gifts and donations                              | 22,463         | 40,796           |
|  |                |                  |
| TOTAL INCOME                                     | <u>119,688</u> | <u>991,096</u>   |
|  |                |                  |
| <b>EXPENDITURE</b>                               |                |                  |
| Congress expenditure                             | 369            | 800,947          |
| Office expenses                                  | 12,591         | 14,740           |
| Travel   | 19,397         | 116,494          |
| Grant expenditure                                | 67,300         | 45,740           |
| Accountancy fees                                 | 6,042          | 5,449            |
| Audit fees                                       | 9,915          | 6,384            |
| Administrator costs                              | 11,432         | 10,629           |
| Staff costs                                      | 88,227         | 114,748          |
| Employer's PRSI                                  | 467            | 6,273            |
| Bank charges                                     | 515            | 587              |
| Rent   | 5,654          | 7,533            |
| Promising Strategies                             | 25,445         | 5,352            |
| Website costs                                    | 10,009         | 5,622            |
| IBE JTF expenditure                              | 561            | 8,863            |
| International Epilepsy Day                       | 5,012          | 7,796            |
| Legal and professional fees                      | 32,846         | 61,221           |
| Advertising and promotion                        | 1,601          | 3,181            |
| EpilepsyNext                                     | 584            | 23,845           |
| (Gain)/loss on exchange                          | (166,265)      | 39,895           |
|  |                |                  |
| TOTAL EXPENDITURE                                | <u>131,729</u> | <u>1,285,299</u> |

# FINANCIAL REPORT continued

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

### Epilepsy Alliance Europe - IBE/ILAE Joint Task Force

Epilepsy Alliance Europe, the IBE/ILAE Joint Task Force programme, is a joint 50:50 initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). Its aim is to raise the profile of epilepsy across Europe by undertaking new research and educational activities. The initiative received corporate sponsorship and the fund is jointly owned by IBE and ILAE. IBE administer the programme and the fund, and received a management fee of US\$NIL (2019: US\$17,016).

The debtor balance for the IBE/ILAE Joint Task Force is US\$18,142.

|                                 | 2020<br>US\$    | 2019<br>US\$    |
|---------------------------------|-----------------|-----------------|
| Opening balance                 | (18,142)        | 33,886          |
| Management fee                  | -               | (35,982)        |
| Gain/(loss) on foreign exchange | -               | (7,183)         |
| Expenditure incurred            | -               | (8,863)         |
| Closing balance                 | <u>(18,142)</u> | <u>(18,142)</u> |

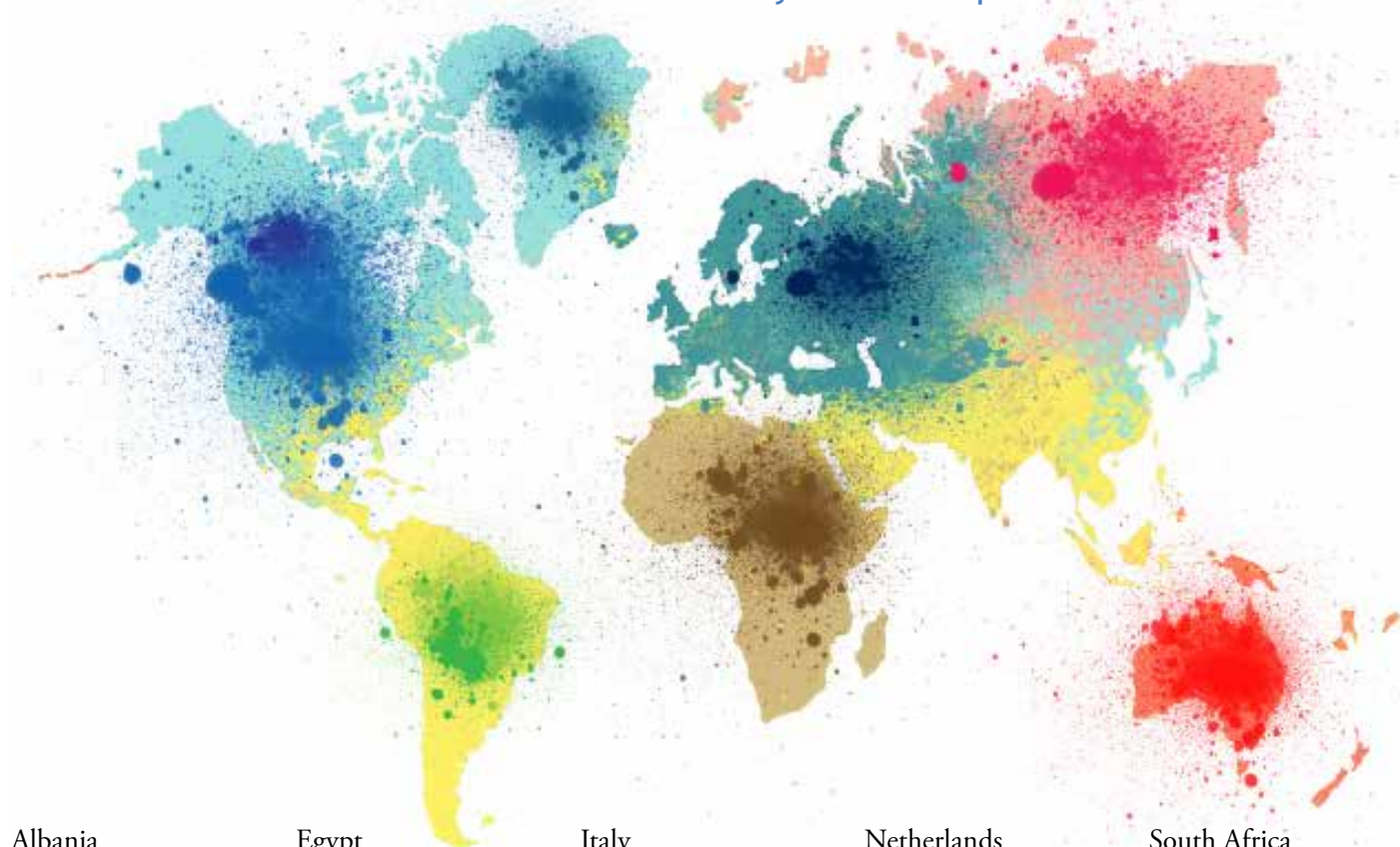
### Congress Financial Information

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 IBA and ILAE.

|                              | 2020<br>US\$ | 2019<br>US\$     |
|------------------------------|--------------|------------------|
| Cash at bank                 | -            | 32,5545          |
| Debtors and prepayments      | -            | 606,851          |
| Creditors                    | -            | (480,139)        |
| Bank overdraft               | -            | -                |
| Deferred income              | -            | -                |
| IDM-Congress income received | 18,755       | 862,714          |
| IDM-Congress expenses        | <u>(396)</u> | <u>(800,947)</u> |

# Working for people with epilepsy and those who care for them across the globe

In 2020, IBE had 137 chapters in 107 countries  
With the world population estimated at 7.7 billion,  
7.0 billion people or 90% of the world's population  
live in countries served by an IBE chapter



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



International  
Epilepsy Day

2020





# Participation Around the World

International Epilepsy Day events were seen in 142 countries or regions around the world, making International Epilepsy Day 2020 the biggest yet! A big THANK YOU! to all those who helped make the day a great success.

- Albania
- Angola
- Antigua and Barbuda
- Armenia
- Aruba
- Austria
- Australia
- Argentina
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Bermuda
- Bolivia
- Bosnia and Herzegovina
- Botswana
- Bulgaria
- Brazil
- Brunei
- Darussalam
- Burkina Faso
- Canada
- Cambodia
- Cameroon
- Cayman Islands
- Chile
- China
- Colombia
- Congo
- Costa Rica
- Cote d'Ivoire
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Dominican Rep
- Ecuador
- Egypt
- El Salvador
- England
- Estonia
- Fiji
- Finland
- France
- Gabon
- Georgia
- Guatemala
- Guyana
- Ghana
- Greece
- Hungary
- Honduras
- Hong Kong, SAR
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Israel
- Italy
- Jamaica
- Japan
- Jordan
- Kazakhstan
- Kenya
- Korea (Rep of)
- Kuwait
- Latvia
- Lebanon
- Lesotho
- Liberia
- Lithuania
- Luxembourg
- Macedonia
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Mauritius
- Mexico
- Moldova (Rep of)
- Mongolia
- Morocco
- Myanmar
- Namibia
- New Zealand
- Nepal
- Nicaragua
- Niger
- Nigeria
- Norway
- Northern Ireland
- Oman
- Pakistan
- Panama
- Puerto Rico
- Peru
- Poland
- Portugal
- Qatar
- Romania
- Russian Federation
- Rwanda
- Saudi Arabia
- Scotland
- Serbia
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- South Africa
- Spain
- Sri Lanka
- Suriname
- Swaziland
- Switzerland
- Sweden
- Syrian Arab Rep
- Taiwan, China
- Tanzania
- Thailand
- The Philippines
- Togo
- Tunisia
- Turkey
- Turkmenistan
- Trinidad & Tobago
- UAE (United Arab Emirates)
- Uganda
- Ukraine
- Uruguay
- USA
- Uzbekistan
- Venezuela
- Vietnam
- Wales
- Yemen
- Zambia
- Zimbabwe

# International Epilepsy Day Events

Once again, events were held around the world this year to mark International Epilepsy Day 2020, raising awareness of and educating the public about epilepsy as well as providing support to members of the epilepsy community. Below are a selection of images to illustrate the variety of events that took place. You can find out more by visiting [www.internationalepilepsyday.org/events](http://www.internationalepilepsyday.org/events).



Association "AHMED" D'aide Aux Enfants Avec Epilepsie, celebrate the day in Tunisia.



CODEF marked International Epilepsy Day by raising awareness among students and teachers in schools in the Western region of Cameroon.



International Epilepsy Day is celebrated in Lagos, Nigeria.



Epilepsy Liga (Belgium) brought a giant brain to the Central Station in Antwerp, showing passers-by how our brains work and what types of epilepsy exist!



Colourful celebrations again this year in Sendai Japan at the Epilepsy Hospital BETHEL



Vida Saei celebrates International Epilepsy Day in Tehran with the Iranian Epilepsy Association.





## TURNING PURPLE!

A highlight of International Epilepsy Day 2020 was seeing a number of landmarks and buildings around the world turn purple to mark the day!

The Lega Italiana Contro de l'Epilessia (LICE) coordinated events in Italy that included having the Colosseum in Rome (above) and a fountain in Trieste (below) lit up in purple to raise awareness.

Tower 42, the fifth tallest skyscraper in London, projected the international epilepsy Day logo from the top of the building as well as raising awareness among all inside the building through electronic posters and signage in lifts.

We hope to see more landmarks lit up to mark International epilepsy Day in 2021!







# GLOBAL OUTREACH

## Developing a Global Plan on Epilepsy

*Photo right: Action Amos, Sam Wiebe (then ILAE President), and Alla Guekht, (then ILAE Vice President), at WHO Headquarters in Geneva*





In February 2020, the need for a Global Plan on Epilepsy was discussed by the WHO Executive Board at its annual meeting in Geneva. IBE was represented at the board meeting by Action Amos, Vice President Africa, who delivered a statement on IBE's behalf.

As IBE Vice President for the African region, and as a person living with epilepsy, Action Amos was well-placed to seek out meetings with country representatives from his region and to present his case. In this he was highly successful, meeting with representatives from eight African countries, all of whom promised their support when the agenda item came up for discussion. In addition to these face to face meetings, the WHO AFRO Region held a meeting where it discussed the Epilepsy Agenda Item EB146/11 and unanimously agreed to support the development of a Global Action Plan. The Cameroon and Eswatini Missions (Geneva), as Coordinator and Secretary respectively of the African countries, volunteered to support engagements on epilepsy in Geneva if their support was needed in the future.

The agenda item was discussed by the Executive Board on 7 February with a tremendous level of support by country members and non-members alike. Ten countries agreed to act as co-sponsors (including Germany which was also representing the other 26 EU member states) and 13 countries spoke in support (including Finland on behalf of 8 Nordic countries, Gabon on behalf of 47 AFRO countries and Tu-

nisia on behalf of 22 EMRO countries). The decision taken was to request the WHO and Member States to develop a document (WHO Technical Policy Brief) on epilepsy and its comorbidities and to develop and present a new Resolution "Epilepsy and Other Neurological Disorders" at the World Health Assembly in May.

In November, at a meeting held virtually because of Covid-19, countries from around the world requested WHO to develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (iGAP).

These countries stated that the 10-year plan should address the current significant gaps in promotion of physical and mental health, prevention, early detection, care, treatment and rehabilitation as well as the social, economic and educational needs of persons with epilepsy and other neurological disorders. The plan is to include ambitious, but achievable, global targets on reducing preventable cases and avoidable deaths from epilepsy and other neurological disorders; strengthening service coverage and access to essential medicines; improved data collection on the incidence at the country level; and critical research in addressing discrimination and stigma.

Since November 2020, work has been ongoing in drafting the iGAP plan of action.

# PROMISING STRATEGIES 2020

Fourteen years after the first round of the Promising Strategies Program in 2005, we took time out to reflect on the many successful outcomes: those projects that had continued to run successfully when funding support ended or which had grown and adapted into other initiatives. We also considered those projects that disappointed, by falling short of expectations.

One of the biggest issues was the level of funding provided to each project. In our efforts to support as many as possible, the thin spread of funds prevented us from adequately evaluating why some projects were so successful and why others failed to deliver fully on their promise. We decided to address this by selecting a lower number of projects, with a narrower focus in terms of the issues to be addressed, thus allowing an increase in funding for those chosen for support. We were delighted, also, to receive a grant from the BAND Foundation

We realised also that, for the future, we needed to take on board the new technologies that have revolutionised communications. These technologies provide cost-effective means of equipping both young and old with the training, information and self-confidence to play active roles in their society.

Equally important is the changing role of the patient in

decisions made on their care and treatment. The call of the World Health Organization, the European Union, and social and political scientists, for a redistribution of power between patients, experts and specialists in policy and decision-making that concerns them, is also a huge step in the right direction.

The 2020 round of the Promising Strategy Program, which focused on the African continent, funded projects aimed at equipping people affected by epilepsy with the expertise needed to be equal partners in all aspects of their healthcare, education, employment opportunities, legal rights and in issues related to stigma reduction. Many African patient organisations are motivated to change epilepsy understanding on their country. Unfortunately, the capacity of these chapters is limited, yet there is a strong desire to build their infrastructure in order to narrow the knowledge gap and reduce the stigma and discrimination that people with epilepsy face in the region and which often leads to inhumane treatment by society and even by their families.

Five projects were selected and, although work was delayed due to Covid-19 restrictions, most have now successfully completed. While the latest Promising Strategies projects were based in Africa, they were chosen on their suitability to become a template for roll out in other regions of the world.



Supported by a grant from Band Foundation

## MALAWI

Fighting Epilepsy Silence in Rural Malawi using Technology



Persons with epilepsy face many forms of stigma and discrimination in Malawi, as well as barriers to access health services ranging from inaccessible health systems to non-existent services in some remote areas. Non commitment by the government to address these barriers creates a serious treatment gap. Persons with epilepsy now have a high risk of non-adherence to medication, leading to recurrence of seizures which forces many not to participate or be included in society on an equal basis with others.

The project aims to improve the quality of service to persons with epilepsy by providing real time evidence of gaps in service using a tracking system. Using mobile phones, persons with epilepsy will work as monitors capturing data that will be analysed and used to generated evidence of the treatment gap and social exclusion.

## MAURITIUS

Training preschool teachers about epilepsy



In Mauritius, preschool teachers supervise children up to six years of age. Research undertaken by Edycs Epilepsy Group through direct conversation with 15 teachers from different preschools concluded they had no understanding or knowledge about epilepsy and seizures. Parents reported that their children were bullied while preschool teachers were frightened when witnessing seizures in class, not knowing what to do. It was also evident that preschool teachers did not have sufficient knowledge on how to manage and work with children with epilepsy in the preschool setting.

The project aimed to equip preschool teachers with adequate and relevant tools to help them identify children with epilepsy in early years, and at the same time to help those children in class, so that no child is left behind.

## SOUTH AFRICA



Epilepsy South Africa was provided with funding to continue the work it began during Phase 1 of the Utezezi advocacy program, focused on the World Health Assembly Resolution WHA 68:20, that finished earlier in 2020. The Promising Strategies funds would support:

- Establishment of a National Epilepsy Task Force;
- Development and implementation of a National Epilepsy Plan;
- Epilepsy awareness and education; and
- Supporting international initiatives to ensure that the Resolution remains on the WHO agenda.

## UGANDA

Epilepsy Smart Communities



A project of Purple Bench Initiatives to:

- Create understanding of epilepsy among government officials to support policies that favour people living with epilepsy
- Establish working relations with other NGOs to promote programs geared towards reduction of stigma and discrimination
- Train trainers to create continuity and to change the mindset of school communities to be epilepsy smart
- Respond to the call to action for Sustainable Development Goals through the pledge to “Leave No One Behind” in efforts to ensure that all people enjoy peace and prosperity by 2030.

## ZAMBIA



The Epilepsy Association of Zambia planned to carry out a survey to establish the number of children with epilepsy not attending school; to establish why high numbers of children are not attending school (it is believed this is due to the consequences of the disease, which include overprotection, stigma or lack of self-confidence); and help them and their parents or guardians, to make informed decisions regarding school attendance despite living with epilepsy.

Following the formulation of the 2015 national policy on disability, the vision of the Zambian government is to see that all people with disabilities enjoy equal rights, including the right to an education.



# SUPPORTING EPILEPSY ADVOCACY EFFORTS IN AFRICA

## Launch of the Advocate's Toolkit manual

The epilepsy advocacy toolkit was created in response to increasing interest and requests from persons with epilepsy and their representative organizations from across Africa.

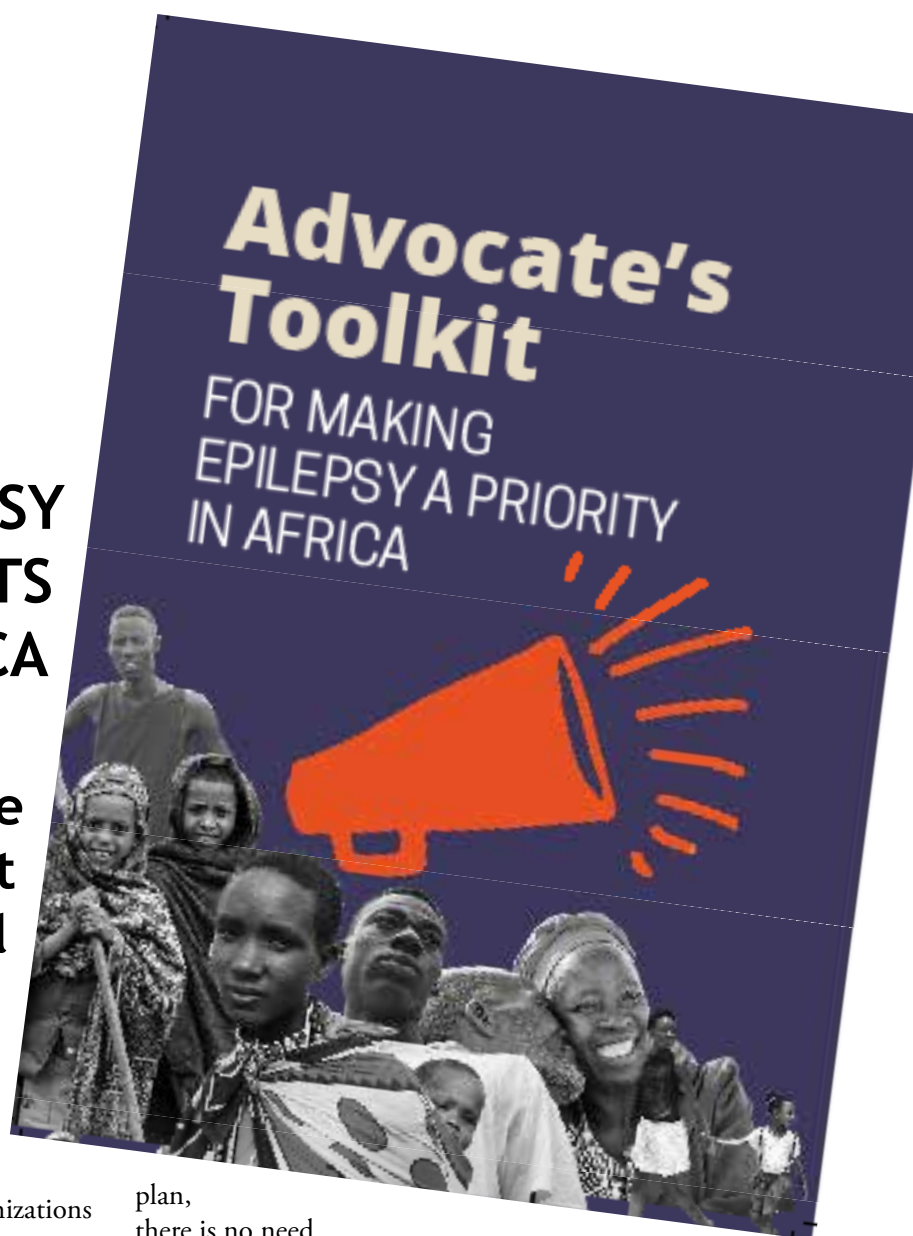
The aim of this toolkit is to contribute to the growing regional and global dialogue on the importance of engagement on issues that affect persons with epilepsy. Specifically, the toolkit will show how to engage, and win, with easy-to-use but effective tools and methods and effective use of evidence-based advocacy to influence policy and decision-makers. Coincidentally, this toolkit comes at a time when the epilepsy movement is celebrating the endorsement of the World Health Assembly Resolution 73.11 on a Global Plan for Epilepsy and Other Neurological Disorders.

The toolkit highlights four particular aspects of the advocacy journey, starting with creating the bigger picture, planning your advocacy, taking action and expanding your reach. The bigger picture helps us to understand the real situation for persons with epilepsy, to identify gaps that are not addressed through policies and to provide examples of success. The second aspect highlights how advocates can have a systematic plan to effectively engage. With a trusted

plan, there is no need to hesitate to take action! Lastly, there is a need to ensure that advocates expand their reach and work with others who are like-minded and those who would be influencers. The toolkit also includes a number of case studies in which organisations of person with epilepsy and stakeholders in Africa have been working.

In conclusion, there is no excuse for failing to develop an epilepsy advocacy plan or for excluding key stakeholders in advocacy efforts. Persons with epilepsy and their representative organizations are the experts on issues affecting them and are generating community- and evidence-based information that will complement official data.

With the guidance of the toolkit, persons with epilepsy and their representative organizations can respond in a highly professional manner to advocacy needs. Please help us distribute this to all those who need it to help us in Making Epilepsy a Health Priority in Africa!



**For additional information or to download the toolkit, please use this link:**

<https://epilepsyafrika.org/wp-content/uploads/Advocates-Toolkit-Epilepsy-Africa.pdf>

Supported by a grant from Band Foundation





# IBE GLOBAL TEAMS

## An invitation to find out more!

IBE recognises the importance of engaging people with epilepsy and their care providers in our decision making. Involving these stakeholders in all our activities is vital if they are to become the motivators of tomorrow. Our aim is to see an expanded IBE board emerge over the next decade whose membership consists of people with a wide range of knowledge, experience, expertise and skills. As a first step, a new series of working 'Teams' was created in 2020, each one focusing on a specific issue related to epilepsy and with membership invitations.

The **Research Team** is focussing on the scientific, medical and psychosocial research occurring in all regions and areas of IBE activity. The goal is to

- take an active role in developing research programmes;
- to promote opportunities to participate in research and learn to be part of the leadership team;
- to promote opportunities to participate in research and help bring research advances back to the community.

The **Youth Team** is working with young people from around the world interested in being involved in a range of

epilepsy initiatives and, potentially, training them to be the next leaders of IBE. The aim is to:

- increase participation of young people affected by epilepsy in decision-making processes within IBE;
- seek out advocacy opportunities so that young people can be actively involved in our global remit;
- support capacity building in young people to help them make a difference in society.

The **Professional Development Team** will link, support and educate staff, volunteers and those responsible for the governance of IBE chapters globally. It aims to enable chapters better meet their missions to support and represent people with epilepsy in their countries. It will do this by:

- enabling the sharing of good ideas and good practice;
- connecting individuals and teams from IBE chapters to identify areas of common interest and encouraging collaboration;
- identifying opportunities for joint learning and development and facilitating capacity-building within IBE chapters.



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MONDAY, 14 FEBRUARY, 2022



### Do you love someone with epilepsy?

This year, International Epilepsy Day falls on Valentine's Day!  
Show your love by sharing a message with the **#EpilepsyDay** hashtag.

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