



ANNUAL REPORT



OUR VISION

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

OUR MISSION

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

International Executive Committee 2019-2021

President: Martin Brodie (Scotland), **Secretary General:** Mary Secco (Canada), **Treasurer:** Anthony Zimba (Zambia)

Vice Presidents:

VP Africa: Action Amos (Malawi), *VP Eastern Mediterranean:* Hassan Hosny (Egypt),

VP Europe: Natela Okujava (Georgia), *VP Latin America:* Tomás Mesa (Chile), *VP North America:* Philip Gattone (USA),

VP South East Asia: Man Mohan Mehndiratta (India), *VP Western Pacific:* Ding Ding (China)

Immediate Past President: Athanasios Covanis (Greece)

ILAE Ex Officio Members:

ILAE President: Sam Wiebe (Canada), *ILAE Secretary General:* Ed Bertram (USA), *ILAE Treasurer:* Helen Cross (UK)

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.
- Industry funding amounted 2.8% of total income. IBE received industry-related income from one company in 2019 - Shire Pharmaceuticals.
- In 2019, non-industry income accounted for 97.2% of all income.



MARTIN BRODIE PRESIDENT'S REPORT

Dear Friends

As I look back on IBE's agenda and achievements throughout 2019, it is difficult to remember how different life was less than 12 months ago. The year was filled with a range of diverse activities, most of which involved some element of travel – a very different place to the virtual world in which many of us have been struggling with since March 2020, if not before. Where did I go to represent of IBE in 2019? On flicking through my work diary, I see visits to India, Qatar, Morocco, Chile, England, Austria, Thailand, Belgium, Lebanon, Uganda, Jamaica, Italy, Spain, Japan, Ireland, and the USA. Those were the days!

Nevertheless, it is important to reflect on the successful initiatives that we undertook and the plans that we brought to fruition during 2019. Many laid the groundwork for our efforts in 2020. In no small measure, our first activity of the year provided the basis for much of which has happened since then. I am referring particularly to the executive committee meeting held in London in January 2019 to review and refresh IBE's Strategic Plan and to consider how it needed to be amended to be relevant to our continuing work and that of our chapters going forward into 2020.

In February, International Epilepsy Day celebrations took us to Strasbourg, France for a significant lunch event at the European Parliament. Hosted by Brian Hayes, President of Epilepsy Advocates Europe, the support group of Members of the European Parliament (MEP), a large number of MEPs from across Europe came to learn more about the difficulties faced by people living with epilepsy. I was also delighted to see that almost 140 countries around the world celebrated International Epilepsy Day in some way or another a day before.

May saw IBE and ILAE come together with WHO to arrange a meeting in Geneva to coincide with the World Health Assembly. This lunch side event welcomed more than 120 people, many of whom were national delegates to the assembly, where the soon to be published "Global Report on Epilepsy" was first introduced. This would lay the path for the inclusion of epilepsy on the WHO Executive Board meeting agenda for 2020.

In March together with ILAE, we held a successful regional meeting in Marrakech, Morocco. In June we were in Bangkok for the 33rd International Epilepsy Congress, at which IBE Golden Light awards were presented to eight exceptional young people from all seven IBE global regions. All spoke eloquently about living with epilepsy in their part of the world at a special forum that took place during the congress. Also, in Bangkok, we held our biennial General Assembly with a new format to ensure that your voices and those of your chapters, were heard loud and clear. I was delighted to meet many of you for the first time and to learn about the work of your associations.

August took me to Entebbe, Uganda, for the 4th African Regional Epilepsy Congress, where IBE provided bursaries to support our chapters from the region to attend. This gave us the excellent opportunity to host a number of meetings to discuss ongoing initiatives in Africa, such as the BAND funded Utetezi project, and to organise a full day programme relating to social topics relevant to the continent. I will long remember my visit to Uganda and the warmth with which I was greeted by everyone I met there. At the end of the month, I represented IBE at a regional meeting in Jamaica.

Dublin was the venue for the "Hear my Story" workshop for young adults from across Europe, who travelled to Ireland in October for this weekend event. This workshop provided a platform for participants to talk about the issues they faced from day to day and to provide them with some of the skills to become epilepsy advocates in partnership with IBE at an international level, as well as working with their national chapters. The success of the event was evident from the ongoing communication between those who attended and their continued collaboration and involvement with the IBE global agenda.

In closing, I would like to thank our executive committee, colleagues representing our regional committees and members of our commissions for their continued effort and support throughout 2019. Together we continue to work hard for IBE with the challenging goal of making a difference for people with epilepsy around the world!

FINANCIAL REPORT

Income and Expenditure Account

Year ended 31st December 2019
With comparative totals for 2018

	2019 US\$	2018 US\$
INCOME	991,096	571,550
EXPENDITURE	(1,285,299)	(1,066,484)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>(294,203)</u>	<u>(494,934)</u>

Balance Sheet

Year ended 31st December 2019
With comparative totals for 2018

	2019 US\$	2018 US\$
CURRENT ASSETS		
Debtors	750,756	603,112
Cash in hand and at bank	1,804,699	2,264,589
Amount held on behalf of the IBE/ILAE Joint Task Force		
	<u>2,555,455</u>	<u>2,867,701</u>
CREDITORS (Amounts falling due in one year)	(687,045)	(705,088)
NET CURRENT ASSETS	<u>1,868,410</u>	<u>2,162,613</u>
NET ASSETS	<u>1,868,410</u>	<u>2,162,613</u>
CAPITAL AND RESERVES		
General Reserve	1,812,757	2,016,960
Restricted and designated funds	55,653	55,653
	<u>1,868,410</u>	<u>2,162,613</u>

The financial statements were approved on 5 November 2020 and signed by:
Martin Brodie, President
Ann Little, Executive Director

Statement of Income and Expenditure

Year ended 31st December 2019

With comparative totals for 2018

	2019 US\$	2018 US\$
INCOME		
Congress income received	862,714	433,778
IBE/ILAE JTF management fee	17,016	17,548
IBE/ILAE JTF reimbursement of expenses (IBE 50%)	8,864	48,642
Membership dues and solidarity fund	15,020	11,606
Investment income	946	8,218
Grant income receivable	45,740	
Gifts and donations	40,796	51,758
TOTAL INCOME	<u>991,096</u>	<u>571,550</u>
EXPENDITURE		
Congress expenditure	800,947	655,316
Office expenses	14,740	13,414
Travel	116,494	90,178
Grant expenditure	45,740	
Accountancy fees	5,449	5,563
Audit fees	6,384	8,450
Administrator costs	10,629	12,556
Staff costs	114,748	118,996
Employer's PRSI	6,273	12,487
Bank charges	587	1,360
Rent	7,533	3,027
Promising Strategies	5,352	2,835
Website costs	5,622	5,283
IBE JTF expenditure	8,863	14,487
International Epilepsy Day	7,796	15,933
Legal and professional fees	61,221	26,531
Advertising and promotion	3,181	(9,528)
EpilepsyNext	23,845	
(Gain)/loss on exchange	39,895	89,596
TOTAL EXPENDITURE	<u>1,285,299</u>	<u>1,066,484</u>

FINANCIAL REPORT continued

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2019

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\$17,016 (2018: US\$17,548).

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

	2019 US\$	2018 US\$
Opening balance	33,886	66,618
Management fee	(35,982)	-
Gain/(loss) on foreign exchange	(7,183)	(12,249)
Expenditure incurred	(8,863)	(21,483)
Closing balance	<u>(18,142)</u>	<u>33,886</u>

Congress Financial Information

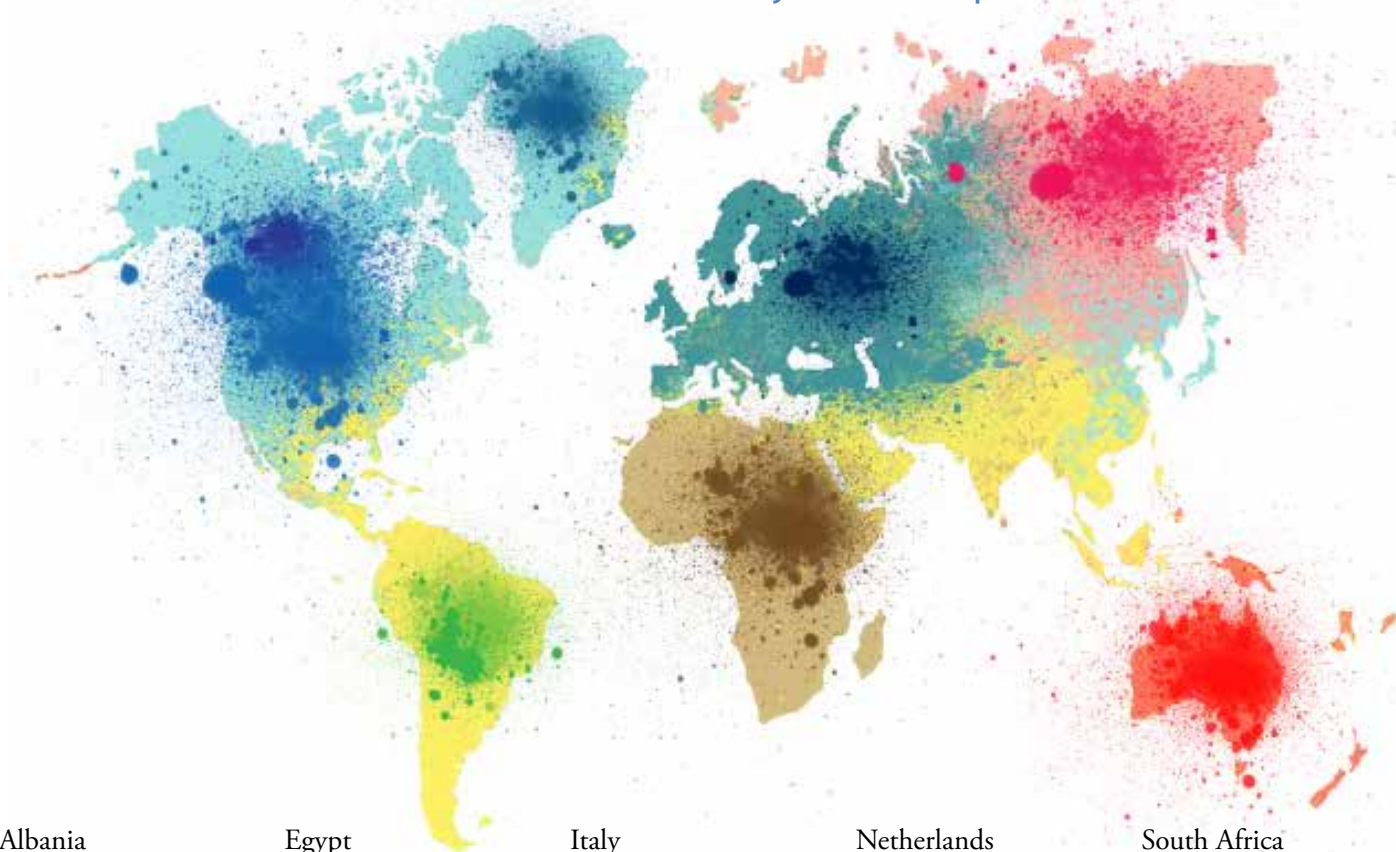
The International Bureau for Epilepsy and the International League Against Epilepsy (ILAE) engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 2 February 2016. The IDM is charged with the organisation of various European and International Congresses.

The 2019 financial statements reflect the portion of assets, liabilities, net revenues and expenses held by the International Director of Meetings on behalf of the International Bureau for Epilepsy. An analysis of the proportion of congress assets, liabilities, income and expenses applicable to the Bureau is as follows:

	2019 US\$	2018 US\$
Cash at bank	32,5545	146,055
Debtors and prepayments	606,851	495,594
Creditors	(480,139)	(504,361)
Bank overdraft	-	(16,045)
Deferred income	-	(41,597)
IDM-Congress income received	862,714	433,778
IDM-Congress expenses	<u>(800,947)</u>	<u>(655,316)</u>

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

In 2019, 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 | |



LOOKING FORWARD

IBE reviewed its Strategic Plan

In this modern fast-changing world, where innovation is key and where no idea remains new for long, the need to adapt is key to providing the support and services that IBE chapters deserve. Recognising the importance of regular reviewing where we are, and where we need to be, is vital. With this in mind, in January 2019, IBE held a meeting in London to review the strategic plan already in place and to consider the changes needed to ensure that its future direction continued to be in line with its core mission.

The meeting was attended by a number of invited stakeholders representing people with epilepsy and their care-givers, along with the members of the International Executive Committee. It was generally agreed that the current Strategic Plan (2016-2019) was still relevant but required an implementation plan. The current plan identifies goals but does not include the 'who, how, when' nor does it identify a budget to achieve the goals.

It was proposed that the board identify 'working groups' and that board members be encouraged to join a working group or appoint people from their region to a working

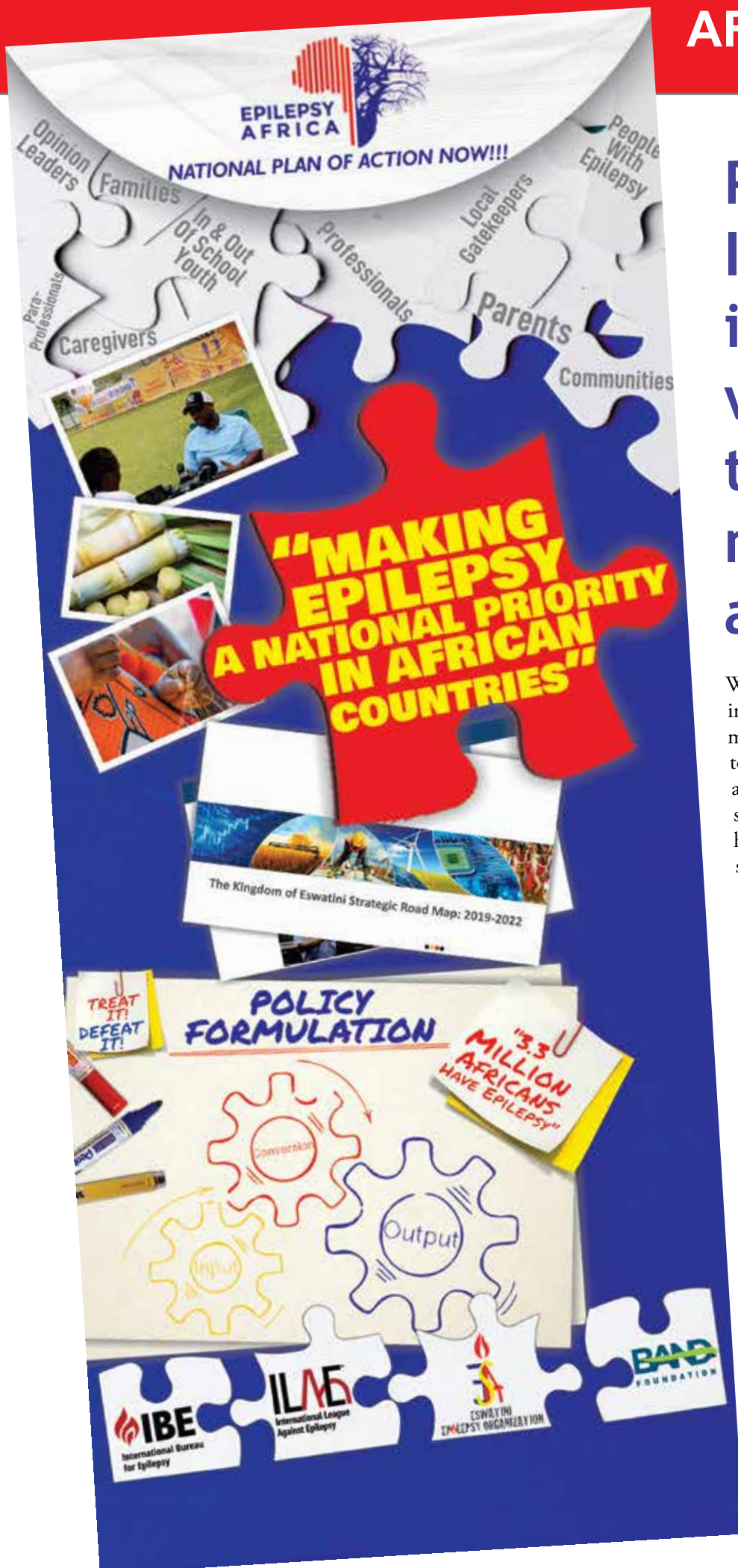
group. Four groups were proposed: Stakeholder Engagement, Sustainability, Capacity Building and Communication. It was also suggested that Youth Engagement be made a priority.

The group reviewed each of the goals of the current strategic plan to identify how they aligned with the proposed leadership groups. There were 3 goals that need to be revised by the executive committee:

- Promote the prevention of epilepsy
- Promote access to currently available treatments
- Promote the value of research and new therapies to stop seizures and cure epilepsy.

It was proposed that by 2023, a minimum of 50% of the board should be stakeholders (persons with epilepsy (PWE), care providers, staff of not for profit epilepsy organisations). A high priority was that people living with epilepsy need to have access to becoming an active board member.

It was also agreed that IBE should develop advocacy training. This needed three separate approaches for chapters in high-, middle- and low-income countries and tailored as needed.



Providing IBE chapters in Africa with tools to develop national action plans

Work on this important initiative, involving the African Regional Executive Committee, began in mid-2018 with a call to the chapters in the region to express an interest in the project. Following the submission expressions of interest from a high number of chapters, a final short list of six chapters was selected to be involved in a first pilot programme.

The overarching goal of the project, which has been made possible thanks to funding from the BAND Foundation, is to reduce the epilepsy treatment gap and to improve epilepsy knowledge throughout Africa. This goal is being achieved by providing IBE chapters in Africa with the tools to develop and execute country-specific national action plans and thereby implement the WHO Epilepsy Resolution (WHA68.20).

Work on developing national projects began with a workshop, which took place in Nairobi in early 2019. The 4th African Epilepsy Congress that took place in Entebbe, Uganda from August 2019 provided the opportunity to review progress to date.

Since then, the African project has received additional funding from the BAND Foundation that is supporting further work on this important initiative.

INTERNATIONAL EPILEPSY DAY



International Epilepsy Day

Celebrated across the world in 139 countries on Monday 11th January 2019

Our Social Media activity:

TWITTER

@IntEpilepsyDay Account performance, February 2019:

Tweet impressions: 25.1K
Profile visits: 2,848
Mentions: 309
New followers: +355
Total followers: 1,902



25K+ impressions



INSTAGRAM

@IntEpilepsyDay Account performance, February 2019:

Total followers: 1,003
New followers: +423

1,125
#EpilepsyDay posts



FACEBOOK

International Epilepsy Day Page performance, February 2019:

Page engagements: 6,587
Reach: 87,478
Top post reach: 27,851
New followers: +739
Total followers: 7,573



Top influencer...

THE WORLD HEALTH ORGANISATION

The World Health Organisation (WHO) were Twitter's top Health Influencer during the period, with 4.7 million followers. For the third consecutive year, the most popular health-related URL in a tweet during the period was WHO's epilepsy factsheet <http://www.who.int/mediacentre/factsheets/fs999/en/>, shared over 1,000 times.

As well as featuring International Epilepsy Day on the WHO epilepsy page, the organisation shared three feature stories: 'Pilot studies help close the epilepsy treatment gap', 'The Fight against epilepsy in Ghana' and 'Scaling up epilepsy care in Myanmar'.



TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

Important event took place in the European Parliament to celebrate International Epilepsy Day



A successful lunch meeting took place in the European Parliament in Strasbourg on Tuesday 12 February 2019, the day after International Epilepsy Day attended by 12 Members of the European Parliament (MEPs), from Czech Republic, France, Germany, Ireland, Finland, Luxembourg, Romania and Slovenia, who voiced their support for the 6 million people living with epilepsy in Europe. In turn, the MEPs heard from speakers about the continued unmet needs of people living with epilepsy and the need for improved services, novel new treatments and actions designed to educate the public about epilepsy and, thereby, reduce discrimination.

The event was hosted by Brian Hayes, MEP, President of Epilepsy Advocacy Europe, the group of MEPs supporting epilepsy in the European Parliament. Notable achievements in which the group had been supportive included the Written Declaration on Epilepsy 22/2011, signed by 459 MEPs, that had resulted in major funding for epilepsy research in

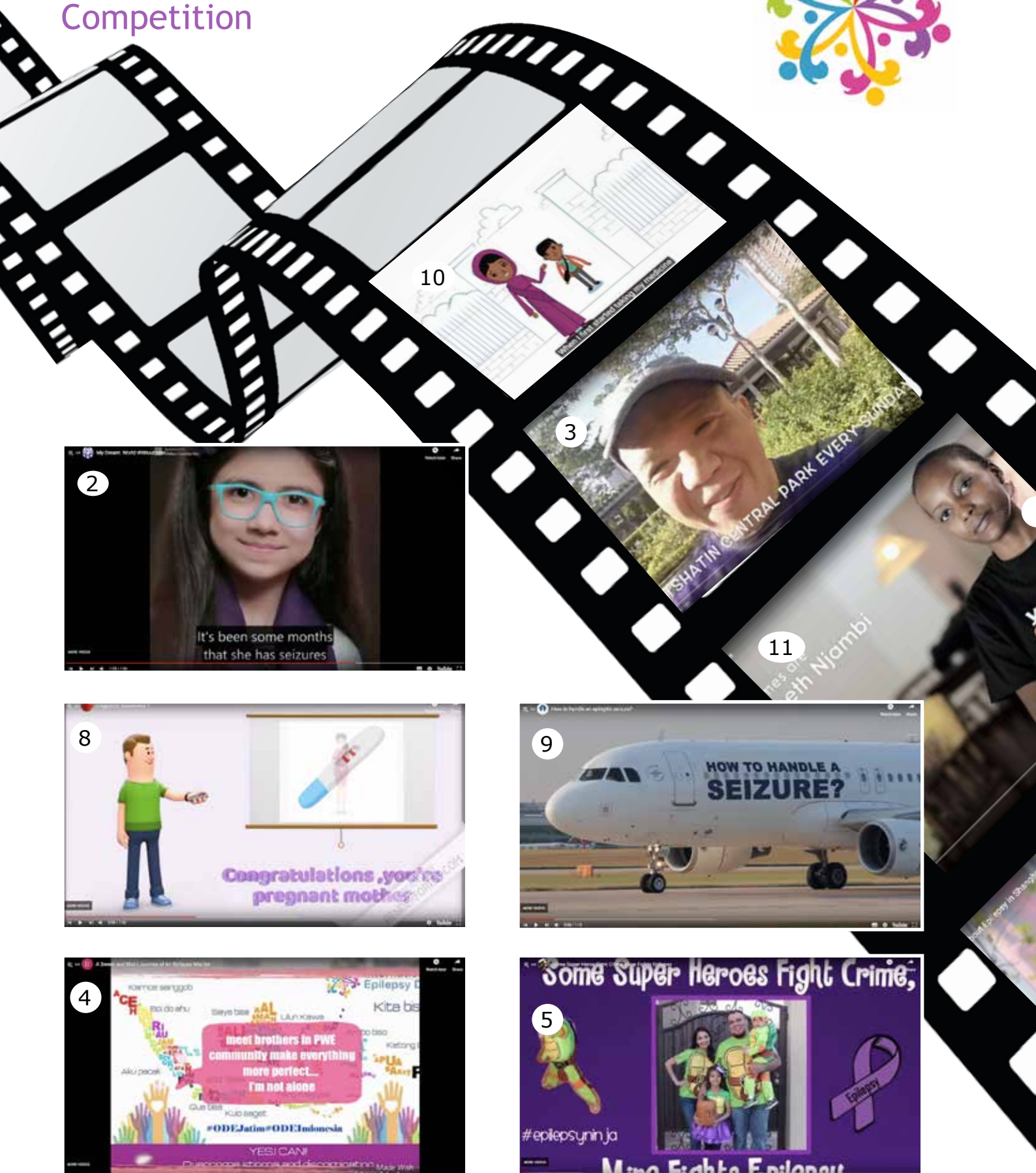
the Framework Programme 7 (FP7). The meeting discussed the need for a global focus on epilepsy research if progress is to be made in identifying new and novel treatments for the 30 – 35% of people with epilepsy whose seizures currently are not controlled by existing treatments. There were new opportunities for such global research initiatives through the European Brain Research Area (EBRA). An issue for concern was the lack of support in Europe for the WHA Resolution on Epilepsy, approved by the World Health Assembly in 2015. The argument was that epilepsy was too narrow a topic. However, the counter arguments were that epilepsy encompassed several hundred diseases; was sufficiently wide to have been selected for an EU-funded European Reference Network (ERN); 50 million people worldwide had been diagnosed with epilepsy; and it ranked second in the league of years of life lost. Speakers included Martin Brodie, Philippe Ryvlin, Francesca Sofia and Fred Destrebecq.



From left: Brian Hayes MEP; Martin Brodie, IBE President and co-chair Epilepsy Alliance Europe; Francesca Sofia, IBE European Regional Committee and Member of Epilepsy Alliance Europe; Fred Destrebecq, European Brain Council; and Philippe Ryvlin, co-chair Epilepsy Alliance Europe

INTERNATIONAL EPILEPSY DAY

And the Oscars go to....!
International Epilepsy Day Video
Competition



10

3

2

11

8

9

4

5

It's been some months
that she has seizures

SHAT IN CENTRAL PARK EVERY SUNDAY

eth Njambi

Congratulations ,you're
pregnant mother

HOW TO HANDLE A
SEIZURE?

meet brothers in PWE
community make everything
more perfect...
I'm not alone
#ODEJatim#ODEIndonesia
YES! CAN!

Some Super Heroes Fight Crime,
Mine Fights Epilepsy
#epilepsyninja

Personal Story Video

First Prize:

- Linda Cambell (Scotland):
Zoned Out (1)

Runners up:

- Farah (Fatemeh) Abbasi Siar (Iran):
My Dream is a world without war (2)
- Ng, Wai Hung (Hong Kong):
A Big Boy Story (3)
- Delyma Asnydar SS (Indonesia):
A Sweet And Short Journey of An Epilepsy Warrior (4)
- Yvette Barrera-Molina (USA):
Some Super Heros Fight Crime, Mine Fights Epilepsy (5)
- Jess McCallum (Australia):
Jess McCallum She Beast (6)

The Video Competition for International Epilepsy Day saw some excellent videos submitted for judging.

You can view all 'Personal Story' entries here: <https://www.youtube.com/playlist?list=PLDtaVe7olIXygWvY7fb9nRk-dcsS9uRbg>.

You can view all 'Educational Video' entries here: https://www.youtube.com/playlist?list=PLDtaVe7o-IIXzgS_uzzsnN2xe-7Flp-4diq.

Educational Video

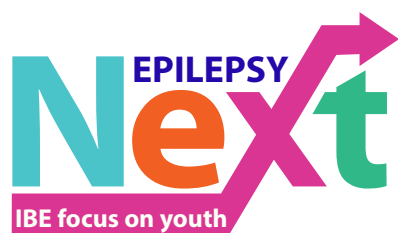
1st Prize:

- Epilepsy Foundation (USA):
Taking Charge of the Storm Jr. (7)

Runners up:

- Cairo University Epilepsy Unit (Egypt):
Pregnancy Awareness (8)
- Norsk Epilepsiforbund (Norway):
How to handle an epileptic seizure (9)
- Epilepsy Action (UK):
Ali's story: taking my medicine (10)
- Youth on the Move (Kenya):
Njambi's Tonic Seizure (11)
- China Bureau of Epilepsy (China):
2018 Street Interview About Epilepsy in Shanghai (12)





HEAR MY STORY

Communications workshop for young people

There is wide recognition amongst IBE's chapters that young people are currently under-represented in their associations. This poses the risk of undermining the future potential of epilepsy associations. It is also felt that the issues facing young people affected by epilepsy are not getting the public or political attention they should. Yet the diverse range of experience and the remarkable personal resilience that a large number of young people with epilepsy already demonstrate is going unnoticed, because many feel ill-equipped to report on their achievements.

Recognising this and in line with IBE's goal 'to provide resources for people with epilepsy and their families to maximise quality of life', a workshop took place in Dublin for young adults. Under the banner of the IBE EpilepsyNext programme, the aims of the workshop, supported by Shire, were:

- To offer a platform for young people to voice the issues they face and raise awareness of these issues;
- To provide young adults with epilepsy with the skills to become epilepsy advocates, in partnership with IBE's chapters in Europe;
- To hear how young people with epilepsy perceive patient organisations and how IBE, together with its chapters, can better adapt its operations to embrace the views and expectations of these young people;
- To harness the outcomes of the workshop towards building a political campaign that could be brought to national policy makers as well as those at EU level;

- To encourage the group to channel their results into a campaign for International Epilepsy Day 2020.

We were delighted to welcome participants from Austria, Croatia, Cyprus, Denmark, England, Finland, Germany, Ireland, Italy, Norway, Scotland and Slovenia.

The workshop, which took place in Dublin in early October, was led by Evaldas Rupkus, an experienced facilitator from Germany, an associate with People Dialogue & Change, which has a strong track record in supporting organisations to train and support a generation of young patient activists.

It was hoped that one of the primary outcomes of this workshop would be the development of a programme that would assist young adults living with epilepsy to become epilepsy advocates, with the added potential to be replicated at a national level through IBE's chapters and with the possibility of adaption for use in other IBE regions. Unquestionably, this was achieved.

The success of the project is still evident in the continued active engagement of the young people in their interest in further evolving the group. It was inspirational to witness how this group of young people felt that their capabilities and skills as advocates had improved as a result of the workshop. Each one returned home with the strong belief and confidence that they could make a difference.

We now look to rolling out the initiative in other regions with the possibility of engaging the young adults from the Dublin workshop in our future endeavours.



Golden Light Awards 2019



The Golden Light Awards programme is one of the modules of EpilepsyNext and honours young people with epilepsy who have been a 'shining light' for others and deserving of recognition. Each bestowing of awards provides IBE with new opportunities to identify young people who have the potential to become future leaders in their own communities and as members of the IBE Youth Team.

The award recognises the contributions of people affected by epilepsy in their community and those who care for them and were first presented in 2004, with the title 'Outstanding Person with Epilepsy Award'. They have been given every two years at each Asian & Oceanian Epilepsy Congress since then.

The title of the award was changed to Golden Light Awards in 2016, to reflect the fact that people with epilepsy should not be defined by their condition, thereby embracing the call of the International Bureau for Epilepsy to 'bring epilepsy out of the shadows and into the light'.

To be considered for an award in 2019, candidates must be between 18 and 35 years of age on 1st January in the year in which the award is presented. The candidate must be nominated by the IBE chapter in which they are involved (as a member, volunteer, board or staff member). Each IBE chapter (full, associate and provisional) is entitled to nominate one person to be considered for the award.

Selection of candidates to receive an International Golden Light award is made on a regional basis with nominations judged by members of the local Regional Executive Committee. One candidate from each region is chosen to receive an award. The first of the International Golden Lights Awards were presented at the 33rd International Epilepsy Congress in Bangkok in June, 2019.

As part of the nomination process for the 2019 awards, candidates were required to submit a written article, between 500 and 800 words in length, telling the story about their life with epilepsy. The successful candidates were then invited to present these stories during a special forum as part of the official programme of the congress in Bangkok. This was a very successful initiative and the presentations made by the Golden Lights were awe-inspiring.

The Golden Lights were presented with their award trophies at the Opening Ceremony of the congress and their travel and accommodation expenses to attend the congress formed part of their prize.

Photo: *Golden Light awardees at the Opening Ceremony of the 33rd International Epilepsy Congress, Bangkok. From left: Scarlett Paige, Australia; Mohammad Agus Rahmatulloh, Indonesia; Elizabeth Dueweke, USA; Rebecca McGhee, Scotland; Martin Brodie, IBE President; Emma Lovise Larsen, Norway; Amirsoheyl Pirayeshfar, Iran; and Nina Mago, Uganda*



Young Epilepsy Advocates Hub

A third initiative, under the banner of EpilepsyNext was launched during 2019.

YEAH (Young Epilepsy Advocates Hub) recognises the value of peer support for young people with epilepsy. The project represents a safe online environment for these young people to meet and discuss issues of relevance to them – not only those that might relate to epilepsy, but also their day to day activities and interests.

The upper age limit is 30 years.

YEAH replaces the TEA Room, an initiative set up as an online forum for those in their teenage years by the Scottish Epilepsy Initiative (SEI) and which SEI has kindly provided to IBE.

YEAH now operates through Facebook:

(<https://www.facebook.com/YEAHepilepsy/>)

For member discussions there is an additional link

(<https://www.facebook.com/groups/YEAHepilepsy>)

BRINGING THE EPILEPSY MESSAGE TO THE 72nd WORLD HEALTH ASSEMBLY



EPILEPSY

A public health priority

Wednesday 22 May 2019, 12.30-14.00
Palais des Nations, Room XXIV

Co-hosted by:

the Russian Federation, China, Colombia, Croatia, Kazakhstan, Mexico, Slovenia, Tunisia and Zambia with contributions from the ILAE, IBE and the WFN

Epilepsy affects over 50 million people worldwide. Among neurological diseases, it accounts for the highest disability life year rates and carries a high risk of premature mortality. Persons with epilepsy are stigmatized in all societies, with the consequences of prejudice and discrimination adding to the medical burden of the disease.

Epilepsy affects people of all ages, genders, race and income levels, but poor populations and those living in vulnerable situations, in particular in low- and middle-income countries, bear a disproportionate burden, posing a threat to public health and economic and social development.

Epilepsy is the only severe and disabling neurological disease that is fully treatable in the majority of cases. About two thirds of persons with epilepsy achieve complete seizure control with inexpensive medications.

This event will bring together policy makers, NGOs, patients, health care leaders and Member States to develop next steps for the implementation of WHA68.20. The Global Epilepsy Report will be presented and key directions of the Epilepsy Action Plan will be identified.



**Refreshments and a light lunch will be served
Interpretation from/to Russian and English provided**

Contact: Dr Alexey NOVOZHILOV, Health Attaché
The Permanent Mission of the Russian Federation
Phone: +41227331870 (O), +41766408703 (M)
E-mail: novozhilov.av@gmail.com

Photo: Sujan Sarkar, India
Used with consent of IBE



An epilepsy side event took place at the 72 WHA (72 World Health Assembly) on 22nd May 2019, at which Dr Svetlana Akselrod, NCD Assistant Director General, WHO participated in person and with WHO Director-General, Dr Tedros attending by video. The Executive Summary of the Global Epilepsy Report, which would be launched later in the year, at the 33rd International Epilepsy Congress in Bangkok, was presented.

It was strategically important for IBE and ILAE chapters to ask their national healthcare authorities, representing their country at the 72 World Health Assembly, to send a delegate to the side event. Attendance by Member States was vital for its success and played a very significant role in raising the profile of epilepsy as a public health priority.

The support of IBE (and ILAE) proved to be extremely successful with more than 120 people attending the event in May. This augured extremely well for the efforts that were to come later to have epilepsy included on the WHO Executive Board agenda for its meeting in February 2020.

The application for the official side event “Epilepsy - a public health priority” was submitted by the Russian Federation, co-sponsored by China, Colombia, Croatia, Kazakhstan, Mexico, Slovenia, Tunisia and Zambia, and supported by the ILAE, IBE, WFN (World Federation of Neurology).

MAKING EPILEPSY A PUBLIC HEALTH IMPERATIVE

First global report on epilepsy published

Epilepsy: a public health imperative is the first global report on epilepsy summarizing the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels. The report was published in June 2019 and launched at a special event held during the 33rd International Epilepsy Congress, Bangkok. It was produced by WHO in collaboration with IBE and ILAE.

The report is a call for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination in all parts of the world. It demonstrates that it is time to highlight epilepsy as a public health imperative, to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

Evidence in the report highlights that the risk of premature death in people with epilepsy is up to three times higher than for the general population. In low- and middle-income countries, early death among people with epilepsy is

significantly higher than in high-income countries. Reasons for this premature mortality in low- and middle-income countries are likely associated with lack of access to health facilities when seizures are long-lasting or occur close together without recovery in between, and preventable causes such as drowning, head injuries and burns.

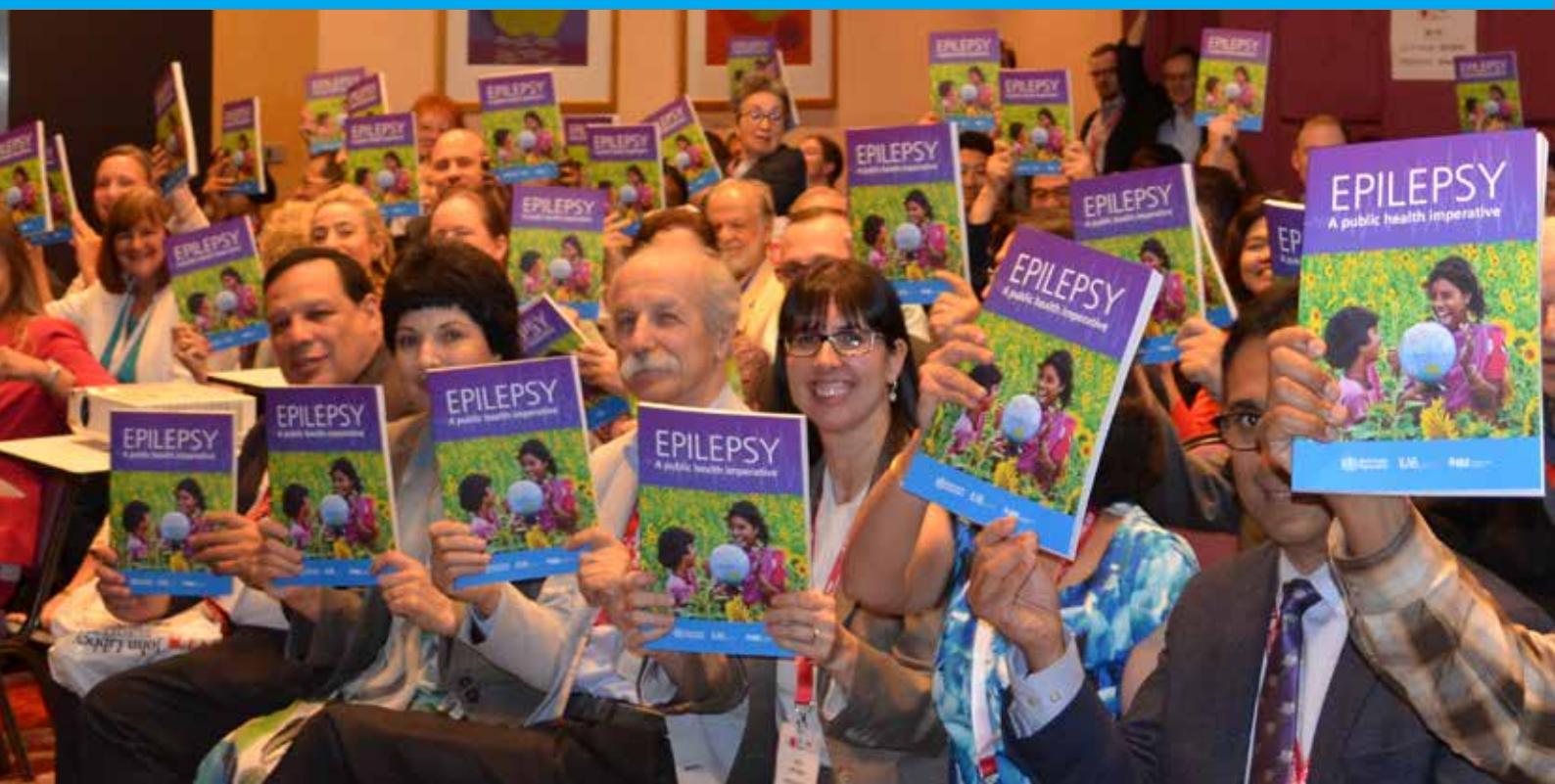
The report also shows that when the political will exists, the diagnosis of, and treatment for, epilepsy can be successfully integrated into primary health services and that cost effective and sustainable strategies exist to treat and defeat epilepsy. Pilot programmes have led to a considerable increase in access, such that 6.5 million more people have access to treatment for epilepsy should they need it.

The final chapter of the report is the 'Way Forward' which is a call to action with details of next steps. This chapter reinforces that everyone has a role to play if we are to treat and defeat epilepsy.

To read the report please go to our website: ibe-epilepsy.org. Summaries of the report are available in six languages: Arabic, Chinese, English, French, Russian and Spanish.

"I encourage all WHO Member States and partners to build on the findings and recommendations of this report and to share it widely."

Dr Ren Minghui, Assistant Director-General for Universal Health Coverage/ Communicable and Noncommunicable Diseases World Health Organization



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EPILEPSY IS



MORE THAN SEIZURES



MONDAY, 8 FEB 2021



Epilepsy is more than seizures, and so are we!
On International Epilepsy Day we're asking everyone to raise awareness by sharing a photo with the **#EpilepsyDay** hashtag.

www.internationalepilepsyday.com

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