



IBE International Bureau
for Epilepsy

2022-23

IBE Annual Report



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Letter from IBE President

2.

Dear friends,

Thank you for taking an interest in the work of IBE. It is our pleasure to bring you this report of our activities in 2022 and 2023. We have merged our reporting over this time period as 2022 was very much a year of transition for IBE, which laid the foundation for a growing programme of work that took root in 2023 and continues to flourish.

Back in 2022, as we began to emerge from the worst of the Covid-19 pandemic, the IBE management committee oversaw the appointment of a new CEO, the expansion of our staff team, and the launch of our new strategic plan. Indeed, the pandemic has shown us how precarious our very existence is and has profoundly changed social dynamics. In parallel, health systems continue to face dwindling resources, rising costs and the impact of chronic diseases – while huge inequalities in access to care, discrimination and human rights violations still plague vast regions of the world. This is all set against a backdrop of macro-economic issues such as climate change, conflict, energy crises, economic uncertainty, and so on; all combining to push healthcare policy down political agendas worldwide.

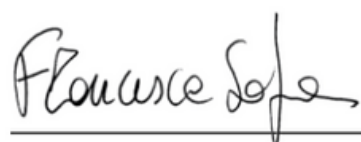
Nevertheless, we have chosen to serve the epilepsy community with the confidence that, many times, opportunities are hidden in the challenges. Our strategic review process, which led to the creation of our new strategic plan/direction, was based around uncovering such opportunities – many of which we have already seen come to fruition. For example, the unanimous adoption of WHO's 10-year Intersectoral Global Action Plan for Epilepsy and other Neurological Disorders, which is a major milestone for our community.

IBE's increased capacity to bring people and organizations together and build a collective global voice for epilepsy, and our efforts to empower and amplify the community of people with epilepsy and their caregivers is also giving us a real edge in engaging with key opinion leaders now embracing the concept of meaningful engagement of people with lived experience. And of course, advances in research and innovation continue apace and bring new promise to our field with new technologies going to trial or coming on stream regularly.

The outcome of this strategic planning process is more than a document; it is a compass that will guide IBE towards a transformational social change so badly needed by people with epilepsy around the world. It is said that progress only occurs when people work together towards a common goal. Therefore, I have no doubt that our plan is achievable because it is rooted in the commitment, synergy and shared purpose of our members and stakeholders.

As you will see throughout this report, we are already making great progress towards achieving our goals and we look forward to continuing on this journey with you in the months and years ahead.

I trust in your continued support and collaboration as IBE moves onwards and upwards!



DR FRANCESCA SOFIA
President, IBE

Governance

3.

International Executive Committee

The IBE International Executive committee is made up of three directly elected officers and out past-president (ex-officio member), as below:



Francesca Sofia



Professor Gus Baker



Graeme Shears

These officers, comprising the IBE management committee, are joined by our regional Vice-Presidents to form the full International Executive Committee.

Vice-Presidents elections

In 2023, new IBE VPs were selected across our regions. Therefore we said thank you and goodbye to the following regional VPs:

- Action Amos - Africa (who stays on as Coordinator for our African Region)
- Natela Okujava - Europe
- Tomas Mesa - Latin America
- Ding Ding - Western Pacific
- Hassan Hossny- Eastern Mediterranean
- Deirdre Floyd - North America (re-elected)
- Man Mohan Mehndiratta -South East Asia (returning as co-opted interim VP)

We welcomed the following new/returning VPs:

- Youssouf Noormamode - Africa
- Elvira Vacas Montero - Europe
- Alicia Bogacz- Latin America
- Anchor Hung - Western Pacific
- Chahnez Charfi Triki- Eastern Mediterranean
- Deirdre Floyd - North America (re-elected)
- Man Mohan Mehndiratta -South East Asia (returning as co-opted interim VP)

Youssef Noormamode

Founding President of EDYCS Epilepsy Group Mauritius, Youssef Noormamode has served as Chair and Vice-Chair of the IBE African Regional Committee for over a decade. Notable accomplishments include championing the ratification of IGAP in Africa, engaging in impactful policy dialogues, and contributing to the recognition of epilepsy in the African Union African Disability Protocol. As Chairperson of the Africa Disability Alliance Youssef advocates for the adoption and domestication of the Protocol on the Rights of Persons with Disabilities under the ARADI continental project, supported by EU/CBM.



Chahnez Charfi Triki

Chahnez Charfi Triki is a professor of neurology and head of the child neurology department at the Faculty of Medicine of Sfax. Since 1995, when she was elected chair of the Tunisian Association for Epilepsy Research, she has been committed to promoting epileptology. She was elected the ILAE-IBE Ambassador for Epilepsy in 2023 after serving as President, Secretary General, and past President of ILAE-EMR. She is a founding Member and President of Honor of the Ahmed Association for the Care of Children Suffering from Epilepsy and founding president of the Tunisian Association for the Development of Epileptology.

Elvira Vacas Montero

Elvira Vacas Montero has a criminology degree and an inquiring mind. She is finishing a degree in International Political Science and is passionate about social phenomena and people. In 2018, her son was diagnosed with an epileptic encephalopathy after encephalitis. It was the diagnostic delay, loneliness, lack of information and the idea that she would never give in to conformism and resignation that led her to chair the Spanish Epilepsy Federation (FEDE) and the Spanish Epileptic Encephalopathy Association POCS. She leads projects such as Epiforward and EpiAlliance and advocates for a European integration project that can face greater global challenges.





Alicia Bogacz

Alicia Bogacz has been an adult neurophysiologist, epileptologist, and a member of the Epilepsy Section at the Faculty of Medicine Hospital de Clinicas since 2000, as well as an honorary professor at the University of the Republic of Uruguay's Institute of Neurology. She established the Uruguayan chapter of the IBE, "Asociación Uruguaya Contra la Epilepsia" (AUCLE), and was the president of AUCLE from 2005 to 2017. In 2021, Alicia began her tenure as the Vice President of the IBE Latin American Committee.

Anchor Hung

Dr. Anchor Tak Fung Hung, a registered social worker in Hong Kong SAR, China, holds Master's degrees in Public Health and Disability Studies and a Doctorate in Business Administration. Currently, she is the Assistant Project Director at The University of Hong Kong's Department of Pharmacology and Pharmacy, leading an innovative community pharmacy project. With more than twenty years of significant experience, serving as an honorary advisor for the Hong Kong Epilepsy Association and the Epilepsy Foundation of Hong Kong, and as a co-founder and director of Hong Kong's Health and Social Exchange. She has contributed to many improvements for individuals with epilepsy. Her dedication also resulted in the successful redefinition of the term for epilepsy in Hong Kong's Chinese language, fostering greater comprehension of the condition. In 2023, Anchor was honoured as an IBE/ILAE Epilepsy Ambassador.



Deirdre Floyd

Diagnosed with epilepsy at 14, Deirdre has been an advocate both locally and nationally, serving as the local association's Vice Chair and President, the Canadian Epilepsy Alliance's President, and chairing the Purple Day for Epilepsy campaign. She has won many awards for her volunteer service over the years, including the Nova Scotia 'Women of Excellence' award, which recognises women who have helped people within their community achieve successful outcomes for charity work.

IBE Team

6.

Donna Walsh CEO (January 2022 -)

I joined the IBE as Chief Executive Officer in January 2022. Although my qualifications are in journalism, I have spent my whole career working in non-profit organisations, serving people living with neurological disorders. Directly prior to joining IBE, I worked as Executive Director for the European Federation of Neurological Associations, where I also served as a board member of the European Brain Council. Since joining IBE I have been actively involved in shaping and implementing our new strategic direction, with a focus on bringing lived experience to the centre of our organisation. With our growing team, I am excited about the new flagship projects and initiatives we are rolling-out to serve and support our chapters, and epilepsy advocates, worldwide. The role I now enjoy at IBE builds on my previous experience, but has offered new and exciting opportunities for me to connect with inspiring people from across the world, and to get involved in global awareness raising, capacity building and policy advocacy for epilepsy. I also continue to engage with the wider neurology community in my role as Chair of the OneNeurology Global Partnership; positioning IBE as a leader in this field.



Marie Ennis, Head of Communications (July 2022-)



I'm a communications professional with two decades of experience specialising in capacity building within the non-profit sector. Throughout my career, I have helped patient advocacy groups enhance their voice and visibility using digital capabilities to raise awareness of their cause, engage communities and advocate for policy changes. I have always had a passion for connecting people and ideas through digital platforms, and it's this passion that I bring to my role as IBE as Head of Communications. I joined IBE in July 2022, and lead on our annual awareness campaigns, #50MillionSteps and International Epilepsy Day. In addition, I am involved in the launch of IBE's new community platform the Knowledge Hub, and the Global Epilepsy Leader programme. I thrive in collaborative environments such as at IBE, where I can leverage my expertise to empower patient advocates and drive positive change.

Claire Nolan, Head of Engagement (August 2022-)

I joined the health charity sector in the UK in 2011 building a bowel cancer community awareness initiative, a research network of people affected by Parkinson's and a national Patient and Public Involvement (PPI) in research programme. After deciding to work as a freelancer, I worked with several UK and European patient organisations, the Charities Research Involvement Group (CRIG) in the UK and a patient centred research company, MediPaCe, developing my knowledge and expertise in supporting pharmaceutical companies, patient organisations and people affected by health conditions to work together to better design and deliver health-related research and initiatives. I joined IBE in August 2022 and now lead on our flagship initiatives, IBE INVOLVE; I work closely with our Community Council, developing the Global Epilepsy Leader programme, as well as delivery of our Global Epilepsy Needs Study.



Sebastian F. Winter, Head of Policy and Research, (September 2023-December 2024)



Sebastian, a physician-scientist, served as IBE's Head of Policy and Research from September 2023 to December 2024. During this time he crafted multifaceted person-centred and evidence-based policy advocacy initiatives, focused on prioritising epilepsy as a global public health issue, promoting global brain health, and fulfilling the strategic goals of the WHO-IGAP on Epilepsy and Other Neurological Disorders.

Eli Cripps, Engagement Officer (March 2024 -)



From my background in science communication, I've worked on bridging the gaps between scientists and the public through dialogue, accessibility, and public and patient involvement. One of my biggest drivers is the importance of involving people with lived experience in the research, laws, and initiatives that impact them. That led me to IBE's door: their commitment to amplifying the diverse voices of the global epilepsy community continues to advance initiatives for people with epilepsy and their caregivers, and I am excited to be part of its future. I love working on IBE INVOLVE with our brilliant and dynamic Global Youth Team, the Community Council, and the global chapters - working together and sharing ideas brings about such creative and impactful ways to improve the daily lives of people living with epilepsy around the world.

Niamh O'Neill, Communications Assistant (March 2024 -)

My background in anthropology has inspired a passion for exploring the ways in which cultures, societies, and politics influence individual and collective experiences. This led me to working as a journalist for three years, where I loved being able to write about the complexities of social experience and convey the diverse narratives of people's lives. At IBE, I have greatly enjoyed applying my skills in communication and creativity to amplify the voices of those affected by epilepsy and help to build greater understanding and support within the community. I've particularly enjoyed designing a promotional campaign for our upcoming Global Epilepsy Needs Study and I'm excited to help facilitate greater community connections on the Knowledge Hub.



Action Amos, Regional Coordinator, IBE Africa

I am a person with epilepsy, overseeing 28 affiliates across the African region, and a member of the Pan African Network for Persons with Psychosocial Disabilities (PANPDD). My qualifications include a Master's Degree in Mental Health for Children and Young People, a Master's in Leadership and Sustainability, and a BA in Development Studies. As part of my professional activities, I am a member of the International League Against Epilepsy (ILAE) Psychoeducation Task Force, WHO Topic Expert Group for the Mental Health Gap (mhGAP) Epilepsy Module, WHO Taskforce on IGAP Implementation Toolkit Development, and ICHOM Epilepsy Standard Outcomes Working Group. In addition, I advise the Kenya Medical Institute of Research on Epilepsy Pathway Innovation in Africa. With extensive experience in human rights, policy analysis, research, and technical implementation I am a member of the UN Spotlight Initiative Civil Society National Reference Group.



Moses Nderemani, Communications Officer, IBE Africa



I am a marketing and communications professional from Blantyre, Malawi, with over five years' of experience. I specialize in strategic communication, branding, and marketing development, including rebranding Mary Queen of Peace Catholic Institute and transforming the Beehive Centre for Social Enterprises. I am an Associate Chartered Marketer and a graduate of the University of Malawi with a degree in Public Relations. I am also a Young African Leaders Initiative (YALI) alumnus, Cohort 23, under the University of South Africa School of Business Leadership. I have served as a Communications Officer for the International Bureau of Epilepsy (IBE) Africa region since October 2022. I use my strategic communication skills to raise awareness about epilepsy across the continent, enhancing IBE's impact and driving social change.

New Chapters

10.

In 2023, IBE welcomed the below new members. We now have over 160 chapters in 110 countries worldwide.

Full Chapters:

- Association of Epilepsy Patients – ASPERO Romania
- Initiative for Epilepsy Awareness South Sudan
- Young Epilepsy Botswana Botswana

Associate Chapters:

- Epilepsie Empowerment Deutschland Germany
- Fuori dall’Ombra Italy
- Dravet Italia Onlus Italy
- Associazione Epilessia Italy
- Young Epilepsy United Kingdom
- Centar Against Epilepsy Bosnia
- Fundhemi Argentina
- Fundación Epilepsiyajuventud Chile Chile
- Espacio Epilepsia Argentina
- CareEpilepsy Ethiopia Ethiopia
- SHINE Epilepsy Support Kenya
- Tanzania Epilepsy Organisation Tanzania
- Global Health Mali Mali
- Youth on the Move Kenya
- Kiserem Epilepsy Kenya
- Pragya Epilepsy Wellness Society India

The full list of IBE chapters can be found here: <https://www.ibe-epilepsy.org/about/ibe-chapters/>

Other governance updates

In 2023, IBE launched a process of constitutional review to ensure its existing governance framework is fit for purpose; reflecting IBE’s new strategic direction and putting the foundations in place to ensure that IBE is working more closely with, and for, people with epilepsy and those who care for them.

The process will continue throughout 2024 and be completed in advance of the 2025 elections.

Read our strategic plan here

<https://www.ibe-epilepsy.org/wp-content/uploads/2022/04/IBE-Strategic-Plan-22-FINAL.pdf>

Engagement

Community Council

One of IBE's strategic impact goals is to empower and amplify the voice of people living with epilepsy. To achieve this goal, we want to ensure that stakeholders across the epilepsy community are working with people living with epilepsy. At IBE, we need to do the same – work in partnership with people living with epilepsy across the world – to ensure our strategy, projects and initiatives are relevant and meaningful to people with epilepsy and will have the most impact. Therefore, in 2023 we launched a new Community Council, made up of a diverse range of people living with epilepsy (including family members/carers) and representatives from our chapters across our different regions.

We are immensely proud of this initiative and excited to work with these inspiring advocates.

Role:

The responsibilities of the Community Council include:

- Provide leadership in community engagement and advocacy in co-designing IBE's annual work programme and its associated projects.
- Provide advice and input into community issues relating to IBE's strategic planning, policy, campaigns, program development and evaluation.
- Provide community input into IBE's resources, online content, publications and presentations.
- Provide advice/insights to IBE, relevant councils, commissions and taskforces, and to external partners of IBE with appropriate support and training.



Overview of 2023 activities

Update from Head of Engagement, Claire Nolan

Launching the IBE Community Council was a significant achievement for IBE in 2023. It was a privilege and a pleasure to meet so many people interested in joining this council. Members include people with epilepsy, caregivers and IBE chapter leaders. We have representation from 6 of IBE's regions, and a diverse range of views, experiences and expertise. In 2023, the council was focused on getting to know one another, on deepening their knowledge of IBE as an organisation and co-creating ways of working together. The Community Council contributed their views to the development of the IBE lexicon project, ensuring that the language we use and encourage others to use around epilepsy is appropriate and respectful. A number of members joined the ILAE Care Pathways taskforce, working together to map and improve the care pathways for people with epilepsy around the world. Finally, our Community Council selected two Co-Chairs to lead them.

In 2024, Community Council members will work with IBE across all of its projects and initiatives, including the Global Epilepsy Needs Study (GENS) and the IBE Knowledge Hub.

Meet our co-chairs

12.

Maria Marta Bertone

I am Maria Marta Bertone, mother of a child with a rare malformation called hemimegalencephaly who developed infantile spasms. This led me to advocate for people with epilepsy, especially those with early childhood onset. We live in Argentina.

I believe that the Community Council represents a significant step forward in IBE's commitment to developing a more agile and precise structure to represent the voices of people with epilepsy and their caregivers. This structure will ensure that their perspectives are heard in all IBE projects and initiatives. By the end of our term as co-chairs, along with Jessica, I hope we will have established a firm framework for this vision to become a reality. This will be an essential part of IBE's ongoing efforts to improve its advocacy practices for its chapters and for people with epilepsy and their families worldwide.



Jessica Veach



I am Jessica Veach. Diagnosed with epilepsy at the age of 19, I began my journey as a volunteer with the Epilepsy Foundation of America. Following successful brain surgery to control my seizures 12 years ago, I transitioned to a staff role within the Foundation. Today, I serve as the Executive Director of the Mountain West Region and live in Seattle, Washington, USA.

The Community Council is an important and exciting initiative for IBE, and I am very proud to be a part of it. Every time our members share their lived experiences, we provide valuable insights that help shape IBE's projects and initiatives. Together, we are creating programs and policies that better address the needs of individuals living with epilepsy around the world.

Along with my co-chair, Maria Marta, my hope is that at the end of our term, we will have built a strong foundation that unites advocates with diverse backgrounds and experiences related to epilepsy. I envision a global community where these advocates continuously come together to share their impactful stories and seamlessly integrate their insights into the work of IBE and beyond.

Meet our members

Africa Region

Youssef Noormamode (Mauritius)

Founding President of EDYCS Epilepsy Group Mauritius, Youssef has served as Chair and Vice-Chair of the IBE African Regional Committee for over a decade. Notable accomplishments include championing the ratification of IGAP in Africa, engaging in impactful policy dialogues, and contributing to the recognition of epilepsy in the African Union African Disability Protocol. As Chairperson of the Africa Disability Alliance Youssef advocates for the adoption and domestication of the Protocol on the Rights of Persons with Disabilities under the ARADI continental project, supported by EU/CBM.

Sharon Mbugua (Kenya)

Sharon, a person with epilepsy, is a member of the Kenya Association for the Welfare of People with Epilepsy (KAWE). She is a market researcher and behaviour evaluation specialist who brings a wealth of knowledge to her leadership of the Amethyst Consulting business team. Sharon has served as the Chairperson of the Mental Health Alliance of Kenya since 2021. Her notable achievements include being a panelist at the launch of the African IBE African Advocacy Toolkit in 2021, contributing to the dissemination of the ICHOM Epilepsy Set by the International Consortium for Health Outcomes Management in 2022, and serving as an advisory group member for the Anti Stigma Advocacy Toolkit. She has also participated in three media interviews aimed at raising awareness about epilepsy in the country.

Anita Mago (Uganda)

Serving as the Programme Director of Purple Bench Initiative, an organisation founded by her daughter Nina in Uganda, Anita draws on over 25 years of experience as an international development leader, specialising in grassroots community engagement. Anita holds an MSc in Extension for Natural Resource-based Livelihoods from the University of Reading, UK, and a BA in Mass Communication from Makerere University, Kampala, Uganda. She has also completed certifications in Rural Journalism from the University of Lagos, Nigeria, and Disability Rights in African Context from the University of Pretoria.

Action Amos (Malawi)

Action is a person with epilepsy, who has previously served as the Vice President for IBE Africa, overseeing 28 affiliates across the continent. He holds an MSc in Mental Health in Children and Young People from the University of Edinburgh, an MBA in Leadership and Sustainability from the UK, a BA in Development Studies from Ireland, and a Postgraduate Diploma in Disability and Rehabilitation Management. In addition to Action's role at the IBE, he is a member of the Pan African Network for Persons with Psychosocial Disabilities (PANPPD), founding Chairperson of the National Epilepsy Association, and serves on the Psychoeducation Task Force of the Psychiatry Commission. Action also contributes as a WHO Topic Expert Group (TEG) Member for the mental health gap (mhGAP) – Epilepsy Module and is part of the International Consortium for Health Outcomes Measurement Epilepsy Standard Outcomes Working Group.

South East Asia Region

14.

Naziya Ansari (India)

Diagnosed with epilepsy in 2006, Naziya has navigated life with epilepsy while establishing a successful career in banking. For the past nine years, she has dedicated her expertise to social work at the India Epilepsy Foundation, serving as the Public Relations Officer (PRO) and organizing activities at the rehabilitation center. In recognition of Naziya's outstanding contributions, she was honoured with the Asian Oceania Regional Golden Light Award in 2022.

Latin America Region

Maria Marta Bertone (Argentina)

Inspired by her experience of caring for her son who was born with hemimegalencephaly—a rare unilateral brain malformation causing hundreds of seizures daily - Maria Marta and her husband founded Fundación de Hemisferectomía in 2018 to support children facing similar challenges in Latin America and Spain. A passionate advocate, she regularly presents at national advocacy and medical conferences on topics such as inclusion, epilepsy surgery, cortical visual disability, and rare diseases. Currently, Maria Marta serves on the Argentine Federation of Rare Diseases (FADEPOF) steering committee and is a member of the board of directors for the Iberoamerican Alliance for Rare Diseases (ALIBER). She also represents FundHemi as part of the University of the Patient and the Family (UPF), contributing to patient-centered initiatives and support networks.

Gloria Quiero (Chile)

A lawyer and mother of four children, Gloria's daughter Michela, has had refractory epilepsy and seizures since the age of six. Gloria has tirelessly sought solutions, consulting numerous neurologists both locally and internationally, exploring treatments such as the ketogenic diet, vagal stimulator, and cannabis oil. She has also faced the difficulties of integrating Michela into society, navigating educational and employment challenges. In 2019, Gloria's advocacy efforts were recognised when she received the IBE Golden Lights Award, representing Latin America. Motivated by her daughter Michela's journey, Gloria volunteers with the Chilean League of Epilepsy, working alongside other professionals. She has shared her expertise on law and epilepsy at international congresses in Mexico and Costa Rica.

Mauricio Olave (Colombia)

Holding a master's degree in speech therapy and neuropsychology, Mauricio currently works at a neurological hospital and collaborates with the Secretary of Education of Cartagena. He serves as the IBE Latin America Secretary, contributing to regional efforts in epilepsy advocacy and education and is also a member of the expert committee on epilepsy in Colombia. Additionally Mauricio holds a position on the Executive Committee of the Colombian League Against Epilepsy. Recognised as a leader in his field, he has played a key role in the implementation of the 1414 Epilepsy Law of November 11th, 2010, aimed at protecting people with epilepsy. He has also organised prevention and promotion meetings, facilitated self-help groups, and developed educational materials and programmes on epilepsy for Colombia and Latin America. He has also been actively involved in epilepsy surgery programmes, focusing on pre- and post-surgical rehabilitation.

North America Region

Jessica Veach (USA)

Diagnosed with epilepsy at 19 years old, Jessica is currently the Community Operations Manager at the National Epilepsy Foundation of America. After undergoing successful brain surgery to manage seizures in 2012, she transitioned to a professional role within the Epilepsy Foundation as Volunteer Coordinator. Over the years, Jessica's responsibilities expanded, leading to roles such as Program & Outreach Manager in 2014 and assuming Communications and Marketing duties in 2018. In 2021, she assumed the role of Operations Manager for the West Region, overseeing programmes, events, Seizure First Aid training, social media initiatives, and advocacy efforts across 12 states in the western United States. In her current capacity as Community Operations Manager, Jessica continues to drive impactful programs and initiatives aimed at supporting individuals affected by epilepsy and raising awareness about the condition on a national scale.

Linda McClure (Canada)

Linda's journey with epilepsy began later in life when she received a diagnosis at 49 years old in 2015, followed by psychogenic non-epileptic seizures in 2019. Faced with challenges in accessing suitable care in British Columbia, she made the move to Calgary in 2019, where she continues to navigate her complex condition. Deeply involved in Calgary's epilepsy community, Linda co-facilitates Project UPLIFT sessions, which offer cognitive behaviour therapy and mindfulness skills to help individuals with epilepsy manage depression and anxiety. She actively participates in focus groups and research initiatives both locally and internationally. In 2023, Linda authored and published her memoir, "Battles of The Mind," aiming to raise awareness about epilepsy and psychogenic non-epileptic seizures while providing reassurance to others facing similar challenges that they are not alone.

Michael Bercovici (Canada)

With a professional background in finance and data science, Michael experienced his first seizures as an adult following bacterial meningitis that required intensive care. This experience led him to the epilepsy community through Epilepsy Toronto's support services, where he initially received assistance and now contributes as a volunteer. Michael raises awareness about epilepsy through public speaking engagements, facilitates group sessions, and advocates on community councils.

For more information on our community council and its members visit:

<https://www.ibe-epilepsy.org/initiatives/community-council/>

IBE Youth Programme



16.

Meet our Global Youth Team

- Melissa Chinyanta (Zambia, Africa)
- Ramadhan (Ramskie) Duevela (Kenya, Africa)
- Leonie Wollscheid (Germany, Europe)
- Stella Ponte (Croatia, Europe)
- Wayne O'Reilly (Ireland, Europe)
- Valentina Kahn (Chile, Latin America)
- Sonia Romero (El Salvador, Latin America)
- Cassidy Megan (Canada, North America)
- Maggie Loesch (US, North America)
- Cooper Sanchez-Skellet (Canada, N. America)
- Matisse McCullough (Australia, Western Pacific)
- Nina Mago (Uganda, Africa)
- Lorraine Lally (Ireland, Europe)
- Alison Kukla (US, North America)
- Liz Dueweke (US, North America)
- Vinay Jani (India, South East Asia)
- Godfrey Zaake (Uganda, Africa)



The IBE Global Youth Team achieved many great things over this period, including building a foundation and strategy for the IBE Youth Programme, recruiting new and exciting members from across the world, connecting young people, coming together to co-create projects focused on young people.

In 2023, the Global Youth Team delivered on a number of firsts:

- The first Global Youth Team publication, focused on highlighting the experiences of families of young people with epilepsy.
- The first Global Youth in Epilepsy webinar, hearing from a panel of Global Youth Team members across the world, sharing their experiences and achievements and celebrating the 2023 Golden Light award winners.
- The first Global Epilepsy Youth Summit, which took place at the International Epilepsy Congress in Dublin in September.

Thank you to all Global Youth Team members for their energy, insights and commitment. And a particular heartfelt thanks to the members who have now stepped down from their roles as Global Youth Team members, Scarlett, Lorraine, Nina, Vinay, Alison and Liz.

Message from Scarlett Paige, Global Youth Team Co-Chair



I'm Scarlett Paige from Tasmania, Australia and a proud person living with epilepsy. I'm even prouder to be able to use my voice and status to speak up for, and support, those living with or affected by epilepsy. It's not as easy as people think. There is still so much stigma and judgement around epilepsy.

I first became involved with the IBE in 2019. At the International Epilepsy Congress in Bangkok that year, I received the Golden Light Award for my voluntary commitment to supporting those with epilepsy within the Western Pacific Region.

During the congress it was clear that there needed to be more youth from around the world, working together and learning from one another, to better support those with epilepsy and reduce stigma.

Move forward to 2020 and the IBE's Global Youth Team [GYT] was born! This team gives IBE an insight into what living with epilepsy looks like in each corner of the world from the perspective of young people. It shows just how powerful youth can be, and it brings change in a positive way.

The IBE is here for people living with epilepsy and the IBE, with entities such as the GYT, is people with epilepsy!

I have been asked to write about my highlights during 2022 and 2023. There are many - with new members, the family day report and the youth webinar.

But how could I, or the other team members, look past the Global Youth Summit at the International Epilepsy Congress in Dublin during September 2023. IBE brought outstanding young advocates together to share and expand their knowledge, and true understanding, on epilepsy in a confident and comfortable way. This was something I'd been dreaming of since I was first diagnosed in my dark early days and, finally, here it was: the youth of today taking on the world and showing we are our own experts!

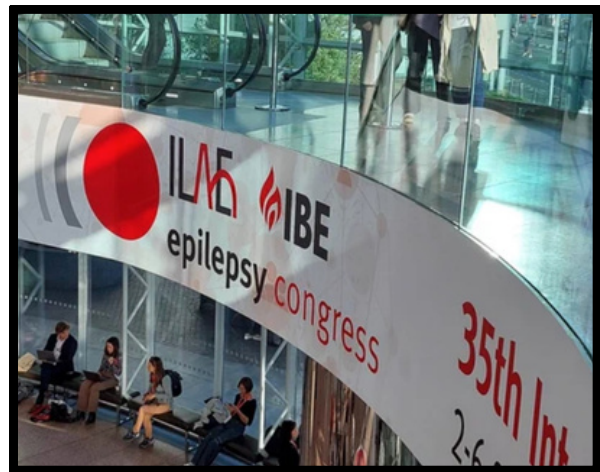
Knowing I have left the GYT in safe strong hands, that it is equipped with the resources to push to new heights and continue building on its foundations, gives me great joy and pride.

As most of you are aware, Lorraine Lally from Ireland started as my Co-Chair in the early days, putting the foundations in place and continuing to stay involved as a much loved and respected member. Thank you Lorraine!

The Global Youth Team means so much, not only myself, but to all those who have come across it and been a part of it. Never underestimate the power of youth!

Global Youth Summit at the IEC 2023

In September 2023, IBE, in collaboration with Epilepsy Ireland, Young Epilepsy (UK), and Epilepsy Connections (Scotland, UK), organised a Global Epilepsy Youth Summit in Dublin, Ireland. This event, part of the 35th International Epilepsy Congress (IEC), brought together 27 young people with epilepsy from ten countries and provided a platform for young people with epilepsy to connect, learn, share their experiences, discuss challenges, and propose solutions.



The participants took part in interactive workshops, discussions, and networking events, exploring issues like healthcare access, education, employment, and social inclusion. They also attended sessions focused on the importance of self care in epilepsy, and training on how researchers and people affected by epilepsy can work together to improve epilepsy research.



Understanding challenges faced by young people with epilepsy

Understanding the specific challenges faced by young people with epilepsy is essential for ensuring we can better meet the needs of young people and shape treatment and care. Ahead of the summit, IBE developed a questionnaire to gather information on prevalent challenges experienced by young people with epilepsy. These challenges were prioritised and discussed during the summit, including social challenges, mental health, information and support, employment and stigma.

Attendees proposed several solutions to help overcome challenges, including increased support and information for families at diagnosis, public education to address stigma, enhanced mental health support after diagnosis and more information on medication side effects.

The summit also included discussions on personal challenges such as employment, dating and driving. Attendees discussed the difficulties of disclosing epilepsy to employers and the associated stigma and shared experiences of potential partners' reactions to epilepsy and the impact of not being able to drive on independence.



The unique challenges faced by young men with epilepsy were additionally a focal point of discussion. Discussions highlighted how traditional notions of masculinity can hinder young men from seeking help and sharing their experiences.

Summit report

If you would like to read more about the Youth Summit, please download our report detailing the event. The release of this report not only documents the outcomes of the summit but also serves as a catalyst for action and change. It calls upon stakeholders to heed the voices of young people with epilepsy, engage them as partners in decision-making processes, and work towards building a more inclusive and supportive society for all.



Download the Report: [2023-Global-Youth-Summit-Report-IEC.pdf \(ibe-epilepsy.org\)](#)

Marking Global Awareness Days

International Day of Families 2023

For young people with epilepsy, the role of family is crucial to support their development and allow them to reach their true potential.

Ahead of the UN International Day of Families, the IBE Global Youth Team asked their families about their experiences supporting loved ones with epilepsy.

Youth Team members then produced a report outlining their findings and making some important recommendations for the epilepsy community and beyond.

The [report is available to download](#) in English and Spanish.

International Youth Day 2023

IBE, along with our Global Youth Team, held a webinar to celebrate young people with epilepsy in advance of International Youth Day 2023.

The event – available in English and Spanish - offered a platform for young people with epilepsy to learn from one another, foster connections, and, and most importantly, have their voice heard!

Inspiring members of IBE's Global Youth Team shared their epilepsy stories and their journeys to become active advocates in the field, and our 2023 International Golden Light Award winners were announced.

Golden Light Awards

In 2023, we selected three inspiring young people – from Brazil, Tanzania and Ireland – to receive our International Golden Light awards. These awards are an opportunity to recognise and reward outstanding young people who live with epilepsy or care for a person with epilepsy.



There are so many young people with epilepsy globally who are working to improve the quality of life of others through activities such as advocacy, awareness raising, information sharing, fundraising and so much more,' said IBE Secretary-General, Prof. Gus Baker, who was part of the 2023 judging panel.



'Although we could only choose three winners, we also highly commend the work of all those nominated who are a real inspiration for other young people around the world. Their efforts will help us to achieve IBE's vision of a transformational social change for young people with epilepsy worldwide.'

These three inspiring young people were selected to receive IBE's 2023 Golden Light Awards during the opening ceremony of the 35th International Epilepsy Congress in Dublin, Ireland:

Walter Fiuza (Brazil)

A diagnosis of epilepsy at 14 years old didn't stop Walter from becoming a medical doctor. While studying in Paraguay, he founded an academic organisation to raise epilepsy awareness in Argentina and Brazil. This work escalated to advocacy with local authorities and legislators, which was recognised by the Brazilian Federation of Epilepsy (EpiBrasil). He was recently elected as President after playing a leading role in driving national initiatives.



Fides Uiso (Tanzania)

Fides' firsthand experience with epilepsy stigma, as a mother of a child with severe epilepsy, inspired her to become a dedicated parent advocate and establish the Tanzania Epilepsy Organization (TEO), where she serves as CEO. Certified in seizure recognition and first-aid by the Epilepsy Foundation of America, Fides develops school training programs to improve public awareness of epilepsy in Tanzania.



Wayne O'Reilly

Wayne is a volunteer with Epilepsy Ireland, where he shares his personal journey with epilepsy across their social media platforms, at national conferences, and with the media. He has notably led two of Epilepsy Ireland's highly successful #EpilepsyDay campaigns. Wayne's efforts have significantly heightened epilepsy awareness throughout Ireland and have inspired others to share their stories and participate in advocacy efforts.



In addition, the following received Highly Commended recognition:

- Maning Ghislain Maning (Cameroon)
- Chifundo R Zamadunga (Malawi)
- Jim Owen Tenywa (Uganda)
- Princess Ubani (Nigeria)
- Yahya Njie (Gambia)
- Gunocean Singh Bedi (India)
- Shraddha Chaurasia (India)
- Emeline Vandaela (Holland)
- CHANG, PIN-HSUAN (Taiwan)
- Janet Lee Jia Hwei (Malaysia) (in memory)
- Bin WANG (China)
- Gail Simpson (Jamaica)
- Sol Roberts (Argentina)
- Sadie Kline (Canada)

In 2022, three worthy candidates, nominated by their chapters, were honoured as Regional Golden Light Award Winners during the Epilepsy & Society Symposium at the 14th Asian & Oceanian Epilepsy Congress which took place 19th November 2022.

Naziya Ansari (India). Naziya's involvement in The Epilepsy Foundation India has been instrumental in driving her advocacy efforts, taking her to camps in remote and rural parts of Maharashtra to raise awareness about epilepsy.

Jae Shin Shim (Korea). Jae Shin Shim founded “Warm Eye”, a group for epilepsy patients aimed at raising awareness. Additionally, he has written a book “Child Walking in the Mist”, an autobiographical tale about coping with epilepsy and anxiety. For contributions to revitalizing the youth community, Jae Shin Shim received the Chairman's Citation from the Daegu Metropolitan Council and the Excellence Award from the Minister of Public Administration and Security.

Lee May Yoong (Malaysia) Lee May's involvement in epilepsy programs and activities organized by the Malaysian Society for Epilepsy (PEM) includes delivering talks, distributing informational pamphlets, and sharing her personal experience with epilepsy.

Highly Commended

- Wilson Yung King Ho (Hong Kong)
- Hsiu-Wen Hu (Taiwan)
- Yawen Pang (China)
- Aditya Mehta (Mumbai)
- Orla Stark (Singapore)

Awareness Raising

Flagship Campaigns 2022

#50MillionSteps

The #50MillionSteps campaign, launched in 2021, returned in 2022 with the ambitious goal of taking a step for every person living with epilepsy worldwide. The campaign ran from January 10th to February 14th (International Epilepsy Day), aiming to raise awareness, improve visibility, and increase understanding of epilepsy. The campaign exceeded its target of 50 million steps, with a remarkable 122,009,748 steps achieved!



International Epilepsy Day

International Epilepsy Day 2022 was held on February 14th and the theme was "Love," aligning with Valentine's Day and emphasising the importance of love, support, and understanding for individuals living with epilepsy and their families.

Key Initiatives

- **Social media campaign:** Organisations and individuals used hashtags #EpilepsyDay and #LoveEpilepsy to share stories, information, and messages of support.
- **Educational events:** Webinars, workshops, and public lectures were organised to educate the public about epilepsy, its causes, symptoms, and available treatments.
- **Video messages:** Presidents of both ILAE (Helen Cross) and IBE (Francesca Sofia) shared videos, as did a number of IBE's past Golden Light award winners.
- **Global illumination:** Iconic buildings and landmarks around the world were lit up in purple, the internationally recognised colour for epilepsy awareness.



Flagship Campaigns 2023

In 2023, IBE spearheaded two interconnected campaigns united under the overarching theme of stigma reduction: #EpilepsyDay and #50MillionSteps. By disseminating evidence-based information and encouraging global participation, the IBE aimed to challenge harmful stereotypes and myths about epilepsy.

Key Initiatives

- **Social media toolkit:** A comprehensive toolkit with campaign resources for social media was developed and translated into multiple languages.
- **Video messages:** The IBE and ILAE Presidents and Vice Presidents shared video messages on the theme of stigma, which were widely disseminated on social media.
- **Virtual art exhibition and personal stories:** The #EpilepsyDay website featured a virtual art exhibition and personal stories on the theme of stigma.



Impact

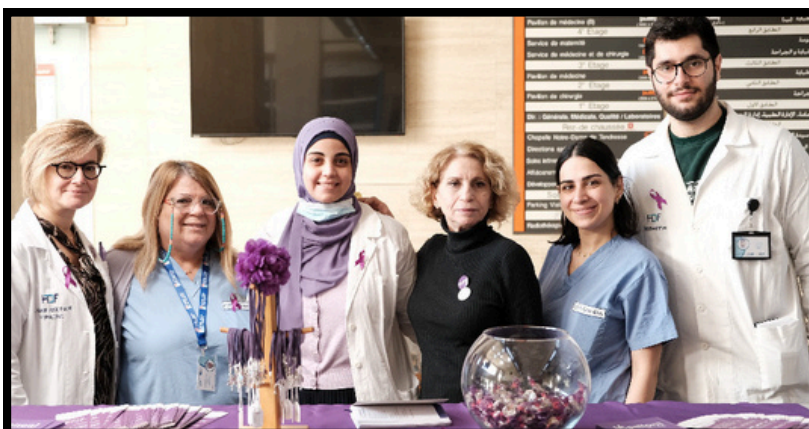
Increased awareness: The campaigns reached a significantly wider audience with accurate information about epilepsy, contributing to a more informed public discourse.

Empowered the community: By sharing real stories and experiences, the campaigns empowered people with epilepsy and their families to speak out and advocate for themselves.

Fostered global solidarity: The #50MillionSteps campaign united people worldwide in support of the epilepsy community, demonstrating the power of collective action.

Record-breaking step count: The #50MillionSteps campaign achieved a record-breaking step count of over 185 million steps in 2023.

View full reports at: internationalepilepsyday.org/international-epilepsy-day-reports



Awareness Days: Amplifying Key Messages

In 2023, the IBE recognized the power of awareness days as opportunities to amplify key messages about epilepsy and connect with new audiences who may not have been previously engaged with epilepsy issues. We made a concerted effort to participate in the following events:

- **International Women's Day:** Highlighting the unique challenges faced by women with epilepsy, and directing traffic to Women and Epilepsy website.
- **Brain Awareness Week:** Raising awareness of epilepsy as a neurological condition, sharing information about brain health, and advocating for research funding.
- **World Health Day:** Emphasizing the importance of epilepsy care and prevention, advocating for access to quality healthcare for all, and promoting healthy lifestyles.
- **International Volunteer Day:** Celebrating the invaluable contributions of our Global Youth Team volunteers in supporting people with epilepsy and advancing the IBE's mission.
- **International Day of Persons with Disabilities:** Promoting the rights and inclusion of people with epilepsy, challenging stigma, and advocating for accessible healthcare and services.
- **International Day of Families:** Recognizing the vital role of families in supporting individuals with epilepsy with the publication of Family Day report.

Social Media Performance and Growth

The IBE's social media channels have seen continued growth and engagement throughout 2022/2023. We increased our followers across platforms by 65% demonstrating a growing interest in epilepsy information and advocacy. This period also saw a 85% increase in post interactions (likes, comments, shares).

Refining IBE's Organizational Identity: A Focus on Consistent Communication

In 2023, the IBE undertook a strategic initiative to refine and strengthen its organisational identity. Recognising the importance of consistent communication in maintaining a professional image and distinguishing ourselves from similar organisations, we are prioritising the development of clear guidelines and frameworks for internal and external messaging.

We refreshed our visual identity to create a more impactful look. This update included:

- **Colour Palette:** A rich palette featuring dark purple, light purple, medium purple, maroon red, and black.
- **Typography:** A clean, modern sans-serif typeface selection, primarily using Calibri, Arial, Montserrat, and Lato for optimal readability and accessibility.
- **Imagery:** A mix of graphics and stock images, with a strong focus on diversity and inclusivity. We are committed to building a library of "real people" imagery that reflects the diverse experiences of the epilepsy community.

Impact:

Increased clarity: Our messaging is now clearer and more consistent. Enhanced brand recognition: Our updated visual identity has increased brand recognition and memorability. Professional image: Consistent messaging across all channels has bolstered our professional image and helped us stand out amongst similar organisations. Inclusive representation: Our focus on diverse imagery demonstrates our commitment to representing and including all members of the epilepsy community.

We are developing comprehensive guidelines to ensure that the tone, lexicon, and key messages used in every communication touchpoint (both online and offline) remain consistent across IBE, our chapters, and partners. These guidelines will provide a framework for all internal and external communications, ensuring a unified and impactful voice for the IBE.

Lexicon Project

We recognise that the words we choose have a profound impact on how we connect with and support the epilepsy community. In 2023, we initiated the development of a lexicon that outlines key terms and language to be used by IBE, its chapters and its partners. This dictionary will serve as a valuable resource to ensure person-first language, (prioritising the individual over their condition) avoiding stigmatising terms and focusing on abilities rather than limitations.

The lexicon project serves several critical purposes:

- 1. Understand perceptions:** Gain insights into how people with epilepsy perceive the language commonly used to describe their experiences.
- 2. Identify accurate terminology:** Determine which words accurately and respectfully describe the lived experience of epilepsy and which might hinder communication or perpetuate stigma.
- 3. Standardise terminology:** Establish a clear and consistent set of terms to be used in all IBE communications and materials, ensuring a unified and person-centric approach to discussing epilepsy.
- 4. Guide partners:** Provide a resource for our partners and collaborators to understand and adopt the standardised terminology in their own communications and interactions, fostering a cohesive message within the wider epilepsy community.

To gather feedback from the epilepsy community, we conducted a survey asking individuals to rate the appropriateness of common words and phrases used to describe epilepsy. The results of this survey will inform the development of our lexicon, ensuring it is directly informed by the experiences and preferences of our community.

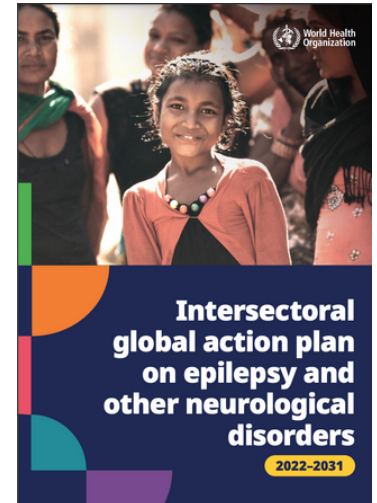
Advocacy

30.

On 27 May 2022, World Health Organization Member States approved the [Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders](#) (IGAP) at the 75th World Health Assembly in Geneva, Switzerland.

Four international organisations – including IBE – and 116 Member States spoke in support of the plan, which passed unanimously. IGAP will address the challenges and gaps in providing care and services for people with epilepsy and other neurological disorders that exist worldwide and ensure a comprehensive, coordinated response across sectors.

This is the culmination of many years of advocacy led by IBE and its partners. Our focus now must move from advocating for adoption, to accelerating implementation. Below you will find information on how IBE has begun to position itself as a key implementing partner across 2022/2023, setting the groundwork for efforts in the years to come.



2022

In 2022, IBE focused its efforts on lobbying policy and decision-makers at national, regional and global level to adopt the proposed Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders [IGAP], maintaining the specific strategic objective of strengthening the public health approach to epilepsy.

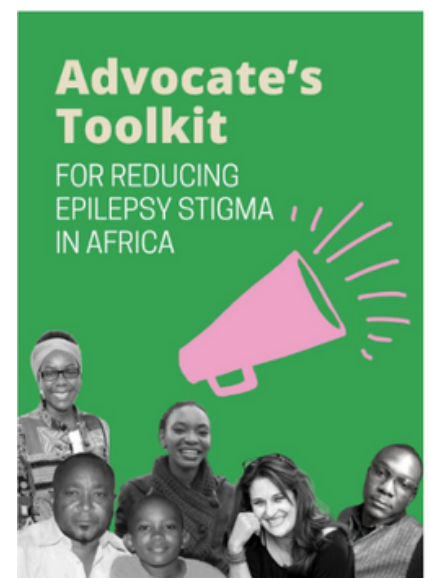
These efforts proved successful and IBE set about planning our advocacy strategy for 2023 onwards by appointing to a new role: Head of Policy and Research.

The below initiatives were also rolled out in 2022...

IBE's [Advocate's Toolkit for Making Epilepsy a Priority in Africa](#) (2022) is a guide designed to help recognise and address different kinds of stigma. It provides practical information, real-life examples, case studies, and templates to help advocates effectively reduce stigma. This toolkit goes along with other IBE resources focused on making epilepsy a health priority in Africa.

The toolkit was created with input from people with epilepsy and their families to make sure it meets their needs. This approach highlights the value of including people with epilepsy in designing effective ways to tackle stigma.

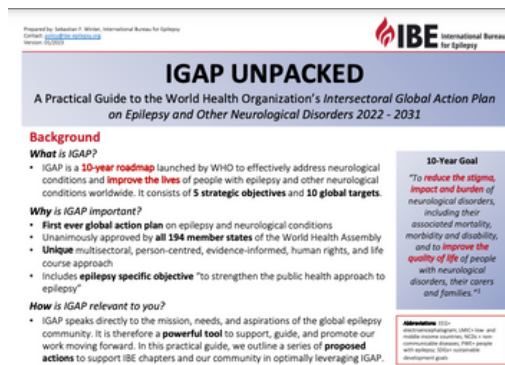
Consultant Mary Secco, an Epilepsy Ambassador and former Secretary-General of IBE, led this project and developed a related training webinar on creating stigma reduction programs.



IBE's Head of Policy and Research, Dr Sebastian Winter, led an impactful programme of advocacy activities which we have summarised below.

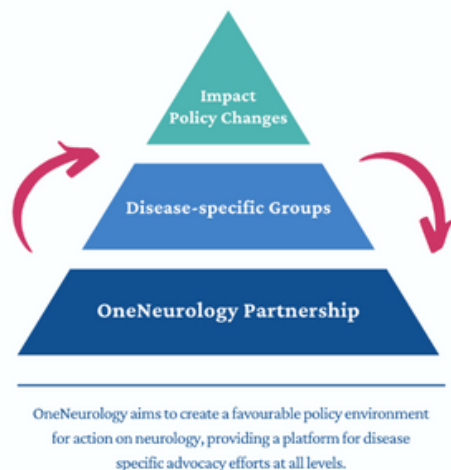
Global IGAP-directed Policy Advocacy Activities, Publications, Technical Reports:

- IBE's WHO-IGAP UNPACKED Guide (2023) was created to help national and local organisations better understand IGAP and its importance to the global epilepsy community. It explains what IGAP is, how it can be used to make epilepsy a public health priority, and provides specific recommendations for using IGAP in policy advocacy and actions. The guide also includes key facts, statistics on epilepsy, and links to useful resources. It is available in English, Spanish, French, and German.



- IBE launched an eLearning Series on Health Diplomacy (2023) consisting of five modules to help learners gain a stronger understanding of health diplomacy for epilepsy advocacy. The modules cover topics like health diplomacy, policy advocacy, the role of organisations like WHO and IBE, and how to effectively use policy frameworks such as WHO's IGAP, the UN Sustainable Development Goals, and the WHO Epilepsy Technical Brief. Those who complete the course and pass a quiz will earn an official IBE Health Diplomacy Certificate. The modules are available in English and Spanish.

- IBE has joined the OneNeurology Partnership, with IBE CEO Donna Walsh elected as Chair. This partnership unites top organisations in neurology to work toward a shared goal: improving the lives of people with neurological conditions and making neurology a global health priority. This collaboration is a key chance to highlight epilepsy alongside other neurological disorders and to show how epilepsy can lead the way for broader action on neurological health. For more about the OneNeurology Partnership, visit: <https://oneneurology.net/partnership/>



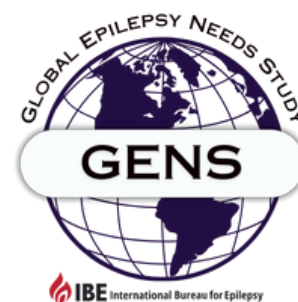
- IBE published an editorial *The WHO intersectoral global action plan and epilepsy cascade target: Towards a roadmap for implementation* (Winter, Walsh, et al. *Seizure: European Journal of Epilepsy*, Dec 2022) to raise awareness on IGAP and present the extended ILAE-IBE Epilepsy Cascade Target.



- IBE led a multi-stakeholder publication on IGAP titled *Uniting for global brain health: Where advocacy meets awareness* (Winter, Walsh, et al., *Epilepsy & Behavior*, Aug 2023), together with representatives of the global brain health community including ILAE, EFNA, OneNeurology, WFN, ICNA, EBC.
- As part of the OneNeurology Partnership, IBE led the creation of a major health policy paper titled 'National Plans and Awareness Campaigns as Priorities for Achieving Global Brain Health'. This paper lays out six key strategies to help countries meet important IGAP goals quickly and effectively.
- IBE provided technical review and feedback to several official WHO documents:
 - [WHO's Epilepsy Technical Brief \(2022\)](#)
 - [WHO's framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. \(2023\)](#)
 - WHO's IGAP Implementation Toolkit (in development)

THE LANCET Neurology

- IBE's efforts to reduce stigma around epilepsy were featured in The Lancet Neurology. The editorial, *Time to end the stigma of epilepsy* (April 2023) showcases IBE's flagship projects and resources, such as the Advocate's Toolkit for Stigma Reduction in Africa, our new WHO-IGAP UNPACKED Guide, the EpilepsyPOWER Project, the IBE-ILAE Statement for IED 2023, our International Epilepsy Day Website and Campaign.
- In 2024, IBE is launching its Global Epilepsy Needs Study (GENS), a groundbreaking initiative that will be co-designed by individuals with lived experience of epilepsy and backed by a multi-stakeholder expert advisory group. This global study will result in a scientific publication and a policy report identifying the unmet daily needs of people with epilepsy worldwide.



- IBE, in partnership with the Thomson Reuters Foundation (TrustLaw), is mapping epilepsy-related laws in 10 jurisdictions in the Americas and 6 in South Asia. The project aims to identify and address discriminatory laws, supporting advocacy to protect the rights of people with epilepsy.

2023 Regional Policy Advocacy and IGAP Implementation:

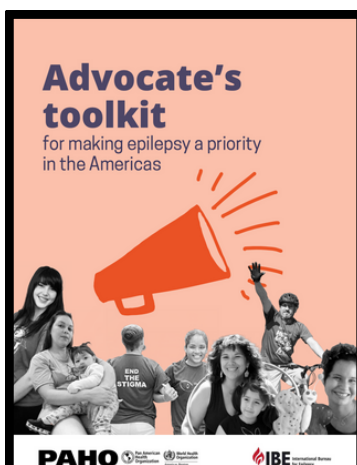
The Americas

- In April 2023, IBE made history in Santiago, Chile, by hosting the first-ever PAHO-IBE Workshop on "Leveraging Policy Frameworks for Epilepsy Advocacy Action." The event, organised with the Chilean League against Epilepsy, brought together people with epilepsy, their families, caregivers, healthcare professionals, civil society groups, WHO/PAHO representatives, and policymakers from the Chilean Ministry of Health.

Participants discussed how the WHO-IGAP and UN Sustainable Development Goals could benefit people with epilepsy, exploring key needs, challenges, and opportunities for Chile and the region. The workshop's outcomes were published and shared at the 2023 American Epilepsy Society congress.



- IBE participated in the XII Simposio Internacional de Epilepsia, Santiago, Chile, (April 2023) with contributions from IBE Secretary General Prof. Gus Baker, IBE President Dr Francesca Sofia, and Dr Sebastian F. Winter. Presentation topics included IBE's policy advocacy and WHO-IGAP implementation plans for the region, IBE's work on stigma reduction, and the importance of leveraging technology to foster epilepsy awareness and advocacy.



- In May 2023, IBE began co-creating the Advocate's Toolkit for Making Epilepsy a Priority in the Americas. The Pan American Health Organization (PAHO) is a key partner and co-author of the project. The expert steering group includes people with epilepsy, their families and caregivers, advocates, IBE Community Council members, regional IBE Chapters, and representatives, as well as leading experts from ILAE, PAHO/WHO, and PAHO/WHO Collaborating Centres.

South East Asia

IBE held the first-ever IBE-IEA-IES multi-stakeholder symposium and IGAP workshop in South Asia, titled *Epilepsy & Society in the Era of IGAP: Realities and Prospects*. The event took place as part of the 2023 IEA/ IES ECON Conference in Jaipur, India, on July 22 and 23.

The aim of the event was to promote intercultural exchange, cross-country collaboration, person-centred approaches, and strong partnerships for regional IGAP implementation.

Over 40 key stakeholders from the epilepsy community across South East Asia and the Western Pacific Regions participated, including:

- People with epilepsy, caregivers, and families
- Healthcare providers, researchers, and advocates
- Non-state actor representatives and policymakers



IBE Multi-stakeholder IGAP Symposium & Workshop, Jaipur, India, July 2023

Participants shared global, regional, and national views on addressing gaps in inclusion, treatment, research, and prevention of epilepsy.

Institutional representatives included senior leadership from:

- IBE, IEA, IES, the International League Against Epilepsy (ILAE)
- The International Child Neurology Association (ICNA)
- The OneNeurology Partnership
- WHO SEARO Regional Office and the Indian Ministry of Health

The proceedings of the symposium and workshop will be used to develop regional policy advocacy tools and a call to action with key policy recommendations to improve the lives of people with epilepsy in the region.

Africa

In the African Region, with support from the BAND Foundation, IBE is expanding its work on implementing the WHO-IGAP through our Trendsetters, Champions, and Small Funds initiatives. These projects include dedicated resources for initiatives focused on youth and women.

In collaboration with IBE Africa (led by VP Action Amos), Care Epilepsy Ethiopia, and in partnership with the Ministry of Health Ethiopia, the African Union, and WHO Regional Office (WHO AFRO), IBE organised the IBE Africa Conference 2023.

- The conference took place in Addis Ababa, Ethiopia, in November 2023. It brought together people with epilepsy, advocates, IBE chapters, ILAE and WHO AFRO representatives, policymakers, and other epilepsy stakeholders.
- The main focus of the conference was to advocate for equal rights and full participation in society for people with epilepsy, using global policy frameworks to drive action across the region.

IBE participated in a WHO AFRO expert group focused on adapting the IGAP for the African region. The group carried out an analysis of key neurological conditions in Africa and is working on creating important policy recommendations for the region, which will be shared soon.



IBE Africa Conference, Addis Ababba, November 2023

To read more about the work happening in the region, you can access the impact reports here: <https://epilepsyafrika.org/wp-content/uploads/2023-IBE-WORK-IN-AFRICA-REGIONAL-REPORT-.pdf>

Congresses

36.

International Epilepsy Congress

Here are some memorable highlights from this year's event:

New hashtag created: To amplify the voices of people with lived experience of epilepsy during IEC, we registered the hashtag #EpilepsyVoices with Symplur's Healthcare Hashtag Project. This will be used alongside the official #IEC2023 hashtag. We will continue using #EpilepsyVoices on our social media to share personal stories and encourage you to do the same.

Golden Light Awards: Three inspiring young people – from Brazil, Tanzania and Ireland – were selected to receive this year's award, from over 20 nominations received from across the world. The Awards are an opportunity to recognise and reward outstanding young people who live with epilepsy or care for a person with epilepsy. See Page 19.

Citizen journalists: This innovative addition infused IEC 2023 with fresh perspectives. The participation of citizen journalists brought the voice of the people with direct experience of epilepsy to the forefront. Thanks to Anita Mago, Jessie Nyirenda, Preston Kukla and Deirdre Floyd!

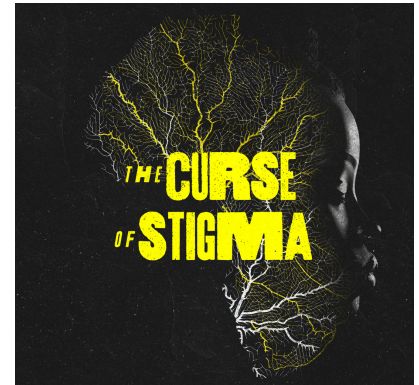
Youth summit: A group of young people (18-35) living with epilepsy came to Dublin to participate in our first-ever Epilepsy Youth Summit. The aim was to connect young people living with epilepsy to share their experiences and explore common challenges. Sessions also focused on building leadership skills, learning more about epilepsy research, engaging in personal development activities, and networking with each other and other stakeholders. The feedback was overwhelmingly positive, with many attendees declaring it to be a life-changing experience! See Page 16-17.

Public sessions: Organised by our colleagues at Epilepsy Ireland, a special public programme was held over two evenings. The programme included talks by well-known epilepsy experts, who shared their research and findings in a way that was easy for everyone to understand.

Lived experience speakers: A key focus of this year's Congress was the inclusion of speakers with lived experience, who shared real-life stories that reminded attendees that every data point represents a person, a family, and a unique journey.

Social Accomplishment Award: This is awarded to an individual to recognise his or her outstanding personal contribution to activities that have resulted in a significant advance in the social well-being and/ or quality of life of people with epilepsy. This year the Award was given to 24-year-old Cassidy Megan, from Nova Scotia, Canada. Cassidy is the founder of Purple Day, an epilepsy awareness day that is recognised and celebrated globally every year on March 26. Cassidy is also a member of IBE's Global Youth Team and played an active part in the Youth Summit at IEC.

The Curse of Stigma Preview Screening: We hosted the first screening of an exclusive preview of the documentary film *The Curse of Stigma* – a powerful and intimate documentary film that tells the story of a group of African women living with or caring for someone with epilepsy and the pain, isolation, and harm they have suffered because of discrimination and deeply embedded cultural beliefs. Their ultimate understanding of epilepsy as a treatable condition leads them to better health and brighter futures. By telling their truth, and the truth about epilepsy, they overcome shame – the ultimate curse of epilepsy stigma.



To dive deeper into these highlights and explore the congress in greater detail, we invite you to download our full report, which provides insights, quotes, and an array of images of the event's key moments: https://www.ibe-epilepsy.org/wp-content/uploads/2023/09/2023_International-Epilepsy-Congress-Report-.pdf

Regional Congresses

Two of our regional congresses took place in virtually in 2022:

- 2nd North American Epilepsy Congress [NAEC], May 5th to 8th
- Asian Oceanic Epilepsy Congress [AOEC], November 17th to 19th
- At the AOEC, IBE coordinated a full-day online Epilepsy and Society Symposium giving our chapters, advocates and partners in the region an opportunity to meet, share and learn from one another. Topics such as improving access to health and social care, as well as effective advocacy and awareness raising were discussed amongst participants in an inspiring session.
- Anchor Hung, representing IBE's chapter in Hong Kong SAR China and member of the regional executive committee for Western Pacific, acted as co-chair of the Scientific and Organising Committee for the congress.
- At NAEC, IBE led a special session to present its current work and future strategy to address the needs of people with epilepsy worldwide. Deirdre Floyd, representing IBE's chapter in Canada and Vice-President for the North American Region, acted as co-chair of the Scientific and Organising Programme.

In 2022, one regional congress was held in person:

LAEC 2022 – October 1st to 4th, Medellín, Colombia

Here, IBE was well represented on the Scientific Organising Committee by our Vice-President for the Latin American Region, Tomas Mesa, as well as representatives from our chapters in Colombia and Costa Rica.

The congress featured several key IBE events, including the IBE Public Day, the IBE Chapter Convention, the IBE IGAP Workshop, the Latin American Youth Summit, and special sessions on Epilepsy & Law, jointly organised by IBE, ILAE, and PAHO.

Reporte LAEC 2022. Medellín - Colombia

Mauricio Olave

El XII Congreso Latinoamericano de Epilepsia se llevó a cabo en Medellín, Colombia, conocida por su innovación, resiliencia y movilidad sostenible. Esta ciudad acogió a participantes de toda América Latina y otros países, ofreciendo una experiencia enriquecedora tanto a nivel académico como social, permitiendo el intercambio de iniciativas exitosas en epilepsia.

Entre los momentos destacados estuvieron los premios Latin America Golden Light Awards, que reconocieron a jóvenes con epilepsia por su trabajo social. Las presentaciones de líderes del IBE, como Francesca Sofia, Gus Baker y Mary Secco, sobre el futuro del IBE, epilepsia y embarazo, y los Objetivos de Desarrollo Sostenible, fueron bien recibidas.

El Día del IBE superó las expectativas, con una agenda centrada en la epilepsia a nivel local, regional e internacional, y temas como epilepsia y sexualidad, embarazo y juventud. El día concluyó con la premiación, intercambio de experiencias y debates que promovieron la visibilidad y el empoderamiento de las personas con epilepsia.

La asamblea de capítulos del IBE para América Latina fue un espacio valioso donde cada representante compartió avances y retos. Se presentó el material educativo creado por los miembros, resaltando el trabajo colaborativo en la región. Talleres importantes, como epilepsia y ley, destacaron medidas de protección como la Ley 1414 en Colombia.

El congreso mostró la unión de los capítulos de América Latina y su compromiso activo en impulsar un cambio social, posicionar la epilepsia como prioridad en salud pública y apoyar iniciativas clave como Epilepsia Next, Mujer y Epilepsia, y la implementación del IGAP según los lineamientos de la OMS/IBE. Este evento promovió el aprendizaje, la unidad y el empoderamiento, alzando la voz de las personas con epilepsia en la lucha contra el estigma y la discriminación.

Other Projects

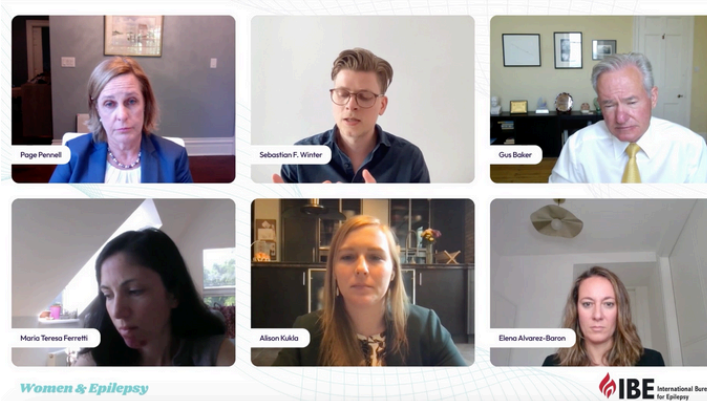
Women and Epilepsy

Following on from the launch of IBE's new website: www.womenandepilepsy.org; now available in eight languages, IBE began an outreach programme to raise awareness of the challenges facing women with epilepsy.

This included social media outreach and a virtual conference that took place on June 2nd 2023.

The recording of this event can be watched in English and Spanish.

- English version - vimeo.com/840438195
- Spanish version - vimeo.com/840483317



In Part 1 of the virtual conference, we heard from world leading expert, Dr Page Pennell, about the latest research and clinical best practice in the field, as well as hearing the experiences of women with epilepsy directly.

Part 2 focussed on the social impact of epilepsy on women affected, and discussed intersectoral solutions – ranging from policy interventions to psycho-social support.

Epilepsy and Employment

IBE is part of an ERASMUS+ EU-funded project, EpilepsyPOWER, aimed at improving employment opportunities for people with epilepsy and encouraging employers and educational institutions to create epilepsy-friendly environments. The project involves six partners from five countries: Italy, Germany, Bulgaria, Ireland, and France.

In 2022, IBE conducted a survey and literature review to assess employers' and educators' knowledge of epilepsy and the support available to people with epilepsy. In 2023, IBE, through Epilepsy Alliance Europe, hosted a partner meeting in Dublin to plan 14 learning modules for people with epilepsy, employers, and educators.

The next phase includes collaborative labs to present and refine the learning platform with stakeholders. IBE/EAE will lead Ireland's lab in 2024.

Finance and Funding

40.

Accounts 2022/2023

ANNUAL ACCOUNTS - Profit & Loss 2022 and 2023

Income	2023 \$	2022 \$
Congress income received	96,894	0
Membership dues and solidarity fund	12,747	8,717
Administration fees	0	2,988
Sponsorship Income	306,649	103,757
ILAE Support	108,000	104,930
EU Project	0	16,540
Foundations	156,058	132,800
Returned project grants	0	17,935
Corporate Council Fees	32,181	0
Total Income	712,529	387,667
Expenditure		
Unallocated Staff costs	112,351	183,117
Employer's PRSI	16,865	14,019
Administration costs	4,595	14,722
Website costs	4,469	7,893
Office expenditure	1,483	2,137
Advertising and promotion	3,022	1,105
Legal and professional	21,915	33,300
Auditors' remuneration	6,150	6,650
Membership fees	579	438
External Representation	9,366	27,727
Bank charges 37 1,754	37	1,754
(Gain)/loss on exchange	-65,178	135,223
African Utetezi project costs	167,005	175,662
Unallocated project costs	337,579	48,872
Congress other - 96,894	0	96,894
Total Expenditure	620,238	749,513
Annual Surplus/Deficit	92,291	-361,846

Balance Sheet 2022/2023

BALANCE SHEET		
AS AT 31 DECEMBER 2023		
	2023	2022
	\$	\$
CURRENT ASSETS		
Debtors: amounts falling due within one year	86,699	64,726
Bank and cash balances	<u>1,835,423</u>	<u>1,646,251</u>
	1,922,122	1,710,977
Creditors: amounts falling due within one year	<u>-259,527</u>	<u>-140,673</u>
NET CURRENT ASSETS	<u>1,662,595</u>	1,570,304
TOTAL ASSETS LESS CURRENT LIABILITIES	<u>1,662,595</u>	1,570,304
NET ASSETS	<u>1,662,595</u>	1,570,304
CAPITAL AND RESERVES		
Other reserves	0	0
Profit and loss account	<u>1,662,595</u>	1,570,304
SHAREHOLDERS' FUNDS	<u>1,662,595</u>	1,570,304

**Full audited accounts are available for download from the IBE website.
Project based accounts are also available on request.**

IBE would like to thank the following for their financial support this year: BAND Foundation, Green Park Foundation, Whitten-Newman Foundation, International League Against Epilepsy, Angelini, Jazz, Sanofi, Takeda and UCB.

Corporate Council

In 2022, IBE began work on creating a Corporate Council.

The Council is a unique partnership opportunity – showcasing commitment to collaboratively identify and address the needs of people with epilepsy globally.

The Council is composed of a select group of leading companies committed to the cause of epilepsy; by meaningfully engaging with people with epilepsy and their representatives. Members in 2022/2023 are:



Angelini
Pharma

sanofi



Jazz Pharmaceuticals®



Membership is by invitation only, but expressions of interest can be submitted.

Find out more at: www.ibe-epilepsy.org/initiatives/corporate-council



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