15th-17th May 2025
Lusaka, Zambia

IBE International Bureau for Epilepsy

2nd IBE-Africa Chapter Convention

Advancing Epilepsy Advocacy in Africa: From Policy to People

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Day 1

Day 2

The IBE-Africa Chapter Convention was made possible thanks to a grant from the BAND Foundation'

GENS: WHAT ARE THE UNMET NEEDS OF PEOPLE WITH EPILEPSY IN AFRICA

Claire Nolan, Head of Engagement at IBE, presented the Global Epilepsy Needs Study (GENS), which gathers global data directly from people with epilepsy. The study identifies unmet needs across ten areas of life. GENS has 15 focus countries, including The Gambia and Uganda.

Research tools:

- A survey – completed by people with epilepsy over 18 years old, and caregivers of children (under 18 years old) and adults with epilepsy.
- Semi structured interviews – 5 people in each country took part in an hour-long interview on different aspects of life with epilepsy.

The survey yielded approximately 5300 responses across the 15 focus countries from a diverse range of individuals, and 76 semi-structured interviews took place.

Results:
The global unmet needs of people with epilepsy were grouped across five main areas:

Navigating uncertainty and redefining daily life
- Needs focused on addressing the unpredictability of epilepsy on a daily basis – and across the lifecourse - but also on supporting future planning.

Living with social judgement and misunderstanding
- Needs referred to tackling misconceptions and stigma of epilepsy which can impact interpersonal relationships and social participation.

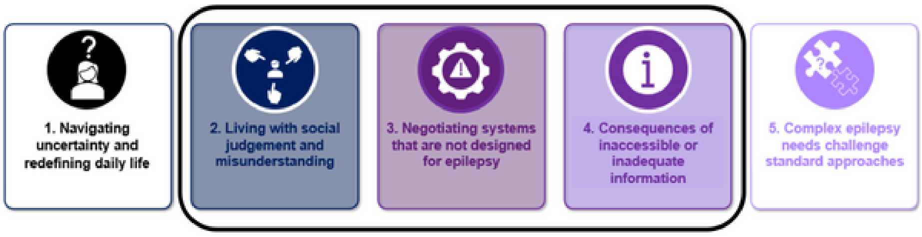
Negotiating systems that are not designed for epilepsy
- Needs expressed related to adapting societal systems (in healthcare, education employment, etc.) where lack of understanding and flexibility means they often do not adequately support inclusion and participation of people with epilepsy.

Consequences of inaccessible/inadequate information
- Needs here were based on the need for access to reliable information for individuals with epilepsy and their families, at community and wider societal levels - but also around better communication with healthcare professions

Standard approach inadequacies further exacerbated by rare/complex epilepsy.
- The additional needs of those with rare/complex epilepsy - including cognitive, behavioural and emotional needs - means that standard approaches are not sufficient to support those impacted.

GENS: WHAT ARE THE UNMET NEEDS OF PEOPLE WITH EPILEPSY IN AFRICA

There were significantly greater unmet needs in low-income countries (The Gambia & Uganda) compared to middle and high-income countries, particularly across the following areas, circled below:



Next steps for GENS

IBE will be working with MediPaCe, its research partner, to deliver focus groups exploring specific experiences and needs of different sub populations of people living with epilepsy [in both high and low income settings], including women (across the life course), people with lived experience of rare epilepsy, and the experiences and needs of caregivers.

Reflections on delivering GENS at national level

Adam Jallow Janneh, Foundation for Epilepsy & Stigma Support (FESS-Gam), The Gambia and Anita Mago, Purple Bench Initiative, Uganda, reflected on their experiences of delivering GENS on the ground in their respective countries.

In The Gambia, GENS represented the first national epilepsy study and was an opportunity to advocate for increased epilepsy care coverage across all regions. FESS-Gam partnered with the Ministry of Health and other stakeholders, which meant faster ethical approval, buy-in of senior management, and introduction to epilepsy clinics in rural district hospitals. GENS was extremely beneficial for FESS-Gam who will use the results to:

- Create online patient support groups
- Train healthcare workers by launching an online mentorship programme for physicians and nurses
- Deliver TV and radio programmes on epilepsy facts and misconceptions
- Launch a 'medication fund'
- Develop recommendations for national epilepsy policy guidelines

GENS: WHAT ARE THE UNMET NEEDS OF PEOPLE WITH EPILEPSY IN AFRICA

Reflections on delivering GENS at national level

In Uganda, Anita Mago and the team at Purple Bench Initiative worked closely with local councils, religious leaders, and cultural elders. They held sensitization meetings with the community prior to data collection which helped build trust and improved response rates. They experienced a lengthy and complex journey with ethics approval but, with perseverance, they gained approval. The team delivered the survey in Lugandan, simplifying any complex language and piloted in two locations before full launch. The team needed emotional resilience to listen to and record the experiences and needs of the families. For the Purple Bench Initiative, GENS results will inform future epilepsy education, advocacy, and programming and aid their fundraising efforts. They also plan to publish their field experiences as a case study.

Final reflections

Professor Chahnez Triki, IBE Vice President, Eastern Mediterranean spoke about the importance of delivering GENS in Tunisia, but requested that the IBE expand its work regionally beyond the focus countries. Youssouf Noormamode, IBE Vice President, Africa finished the session by reflecting on the significance of GENS for the IBE community; providing data for policy makers and governments to use, increasing awareness on epilepsy in communities, as well as bringing about cross country collaborations.

WORLD CAFÉ

Six groups discussed GENS findings significant to the African region, during a facilitated table discussion. The themes were:

- Navigating uncertainty and redefining daily life
- Negotiating healthcare systems that are not designed for epilepsy
- Negotiating education and employment systems that are not designed for epilepsy
- Living with social judgement and misunderstanding
- Consequences of inaccessible/inadequate information for families and communities
- Consequences of inaccessible/inadequate information for, and from, health care professionals

Each group examined the GENS insights, discussing general reflections, examples of best practice in meeting needs, and IBE's role at global and regional levels.

1. Navigating uncertainty and redefining daily life

Living with epilepsy brings constant uncertainty — from unpredictable seizures to social stigma. Participants shared personal experiences showing how epilepsy is often misunderstood. Key themes included:

Stigma and misconceptions: Many noted that epilepsy is widely viewed as bad luck, leading to isolation and misunderstanding. There was strong agreement on the need for greater public awareness to challenge myths and promote acceptance.

Self-stigma and lack of awareness: Without proper education, people with epilepsy (PWE) may internalise negative beliefs, leading to low self-esteem and poor mental health, which can prevent them from seeking support or fully engaging in life.

Fears beyond seizures: Participants and caregivers spoke of fears beyond seizures—such as being judged, discriminated against, or losing independence. Parents often worry about unknown risks, sometimes becoming overprotective.

Overprotection and its impact: Well-meaning overprotection can restrict PWE from living a normal life by limiting independence, social development, and self-confidence.

Exaggerated risk perception: Risks are often overstated, increasing anxiety for both PWE and families. This can lead to unnecessary restrictions and missed opportunities.

Effects on career and life decisions: Epilepsy often influences career and life choices. Many feel held back by misconceptions or fear of workplace discrimination, limiting their options.

Employer engagement and legal protection
Educating employers on epilepsy and workers' rights is essential. Providing PWE with copies of the Employment Act (where relevant) and the national constitution empowers them to advocate for their rights and seek protection against discrimination.

Educational accommodations in schools
Introducing epilepsy-friendly school programmes can include accommodations such as extended exam times or exemption from certain assessments, allowing students with epilepsy equal opportunities to succeed.

Leveraging social media for awareness and support
Creating safe online spaces and awareness campaigns via social media can reach wider audiences, reduce stigma, and connect PWE with peer support networks.

Improved communication on medication side effects
Healthcare providers should provide clear, accessible, and thorough information on the potential side effects of anti-epileptic drugs. This transparency will help PWE make informed decisions, improve medication adherence, and reduce anxiety related to treatment.

Examples of good practice:

Eswatini created a project to promote work place equality: They shared an employment code of conduct and Employment Act to workers with epilepsy, and encouraged full disclosure of epilepsy to employers to ensure safety.

Tanzania led medical personnel training to overcome challenges of:

- Not presribing appropropriately (e.g. changing medications abruptly due to shortages)
- Not advising on the side-effects of medications.

Zambia empowers to teachers to create a safe place for students with epilepsy, and also runs WhatsApp support groups and community support for mothers of CWE.

Kenya provides peer to peer Whatsapp groups for caregivers and youths, reproductive health and emotional well-being counselling, and stigma benches as a safe space for all.

2. Living with social judgement and misunderstanding

The group felt that the main issue is lack of knowledge, which fuels stigma, discrimination, and poor care. Many, especially men who make family decisions, don't understand epilepsy. Families and caregivers often lack basic medical knowledge.

Traditional healers are often the first consulted, but they can spread harmful myths. This leads to dangerous practices, especially for children. In one case, a father raped his daughter on a witch doctor's advice to "cure" her seizures. Herbal treatments are often preferred over prescribed medicine, and many don't understand the need for ongoing medical care.

In Mauritius, treatment is free and accessible, but over 30% still hold negative views, leading to exclusion.

Even where care has improved, stigma and misunderstanding still cause harm. Education and cultural awareness are essential for safety, dignity, and inclusion.

Examples of good practice:

Mauritius has developed strong relationships with the government, due to diverse professionals in its board, which supports legislative efforts to protect PWE.

Kenya (Kawe) has a number of initiatives:

- Networking with NCD bodies for more recognition of epilepsy
- An anti-stigma documentary (The Curse of Stigma) to raise awareness of epilepsy and associated stigma
- Community 'stigma benches', inviting people from the community to talk and learn of epilepsy to dispel myths, foster understanding and inclusion.

Cameroon (CODEF) has formed awareness-raising peer-support groups for PWE to increase individual, family and wider understanding of epilepsy.

Zambia has focused on anchoring epilepsy needs into the national budget to support activities around awareness; breaking down stigma associated with epilepsy

3. Negotiating healthcare systems that are not designed for epilepsy

The group acknowledged that the GENS report resonates with the realities on the ground in their respective countries. It accurately highlights systemic gaps and reflects persistent challenges across the region.

The group felt GENS would benefit from considering the diversity of environments in the region, particularly countries facing crisis situations such as armed conflict, natural disasters (floods, droughts), and volcanic threats; all of which severely disrupt health services and care continuity.

Two areas worth further exploration included:
- 'Treatment fatigue': long-term use of anti-seizure medication without change, often coupled with side effects and limited psychosocial support, which is leading to non-adherence.
- SUDEP (Sudden Unexpected Death in Epilepsy): This major concern is often absent from public health discussions and national epilepsy strategies.

Examples of good practice:

Zambia introduced awareness programmes in schools and developed a Teachers' Guide to support early identification and stigma reduction.

Rwanda launched an economic empowerment initiative for persons with epilepsy, along with a medication access programme supported by UCB.

South Africa implemented a bottom-up awareness campaign guided by research evidence, contributed to the South African Intersectoral National Action Plan (SAINAP) process, and collaborated with the Department of Youth, Women, and Persons with Disabilities to develop a Patients' Charter.

Zimbabwe prioritised training for faith-based and community leaders to foster inclusive messaging and reduce stigma, while advocating for free medication supply. The local IBE chapter also actively supplements public healthcare facilities by directly supplying medicines in the community.

4. Consequences of inadequate or inaccurate information about epilepsy - Healthcare professionals (HCPs)

The group agreed that many HCPs in Africa lack a deep understanding of epilepsy and its impact. Training is limited, appointments are short, and real issues are often missed.

Other conditions like TB and HIV/AIDS get more focus, so HCPs often know more about them. Pharmaceutical training rarely covers epilepsy. Medical education is mostly theoretical and not standardised. There's little awareness of what good epilepsy care involves, including managing side effects, mental health, and other related issues. Training should also reach community-level workers like nurses and health officers.

Helping people with epilepsy and their families understand and remember what they hear during appointments is also key.

Training needs to be standardised, ongoing, and supported. Existing guidance should be updated with input from epilepsy experts and adapted for each country.

Examples of good practice include:

WHO offers mhGAP training and a toolkit to build basic skills for healthcare providers.

Kenya (KAWE) provides epilepsy counsellors-who have epilepsy themselves to support patients after appointments, improving understanding and treatment adherence. A Health Promotion Programme supports self-care, and mhGAP has helped develop national epilepsy guidelines, involving traditional healers.

Ethiopia trains HCPs through in-person sessions and monthly webinars with Ethiopian experts abroad. A 180-member WhatsApp/Telegram group provides peer support. They also offer clinic visit guides for people with epilepsy and their families.

Tunisia has a peer to peer programme which supports parents in educating other parents.

Zambia has a network of volunteers trained by clinical officers.

5. Consequences of inadequate or inaccurate information about epilepsy – people with epilepsy, families and communities

The group identified lack of information as a major issue for people with epilepsy. It affects access to care and prevents epilepsy from being recognised as a health priority.

For families, this can lead to self-stigma and isolation - including absenses from education and employment, which limits future opportunities. Parents - usually mothers - may face blame or conflict, and may become sole caregivers.

In communities, limited awareness means people don’t know how to respond to seizures, putting lives at risk and increasing vulnerability to abuse.

Many healthcare professionals lack proper training, leading to poor advice; including treating epilepsy as a mental health issue.

This widespread lack of understanding means epilepsy is often ignored by policymakers, resulting in underfunded services and support.

Examples of good practice include:

Teacher training/schools programme – almost all chapters in the region have this type of programme.

Gambia engages the Ministry of Education in its work around epilepsy at school.

Uganda was successful in securing children with epilepsy additional time during exams.

Kenya, and some other countries, provide 'training' to parents to ensure they can best support the child with epilepsy. It is often not the schools who exclude the children, but the families who fear disclosing the epilepsy diagnosis.

Concern was expressed about how such initiatives/programmes only reach limited numbers and there is a need for governmental support and wider societal campaigns.

6. Negotiating systems not designed for epilepsy – education & employment

The group focused on school rather than jobs, noting that high unemployment in many African countries makes work hard to find for everyone.

They said teachers often lack knowledge about epilepsy and don't always know how to support students emotionally. Cultural beliefs, like thinking epilepsy is contagious or caused by witchcraft, make things worse. These beliefs hurt both educational and employment prospects.

Stigma in families can lead parents to keep children home, afraid they'll be bullied or harmed. Some parents hide the diagnosis, hoping to protect their child.

Everyone agreed that teachers can help or hinder inclusion. They need training to support learning, memory, and behaviour. Separating students with epilepsy or excluding them from activities, like sports, holds them back. The group felt teacher training was more urgent than changing policies.

They also noted that epilepsy isn't seen as a disability in every country, and student needs differ based on seizure severity.

Transport was another barrier, as special schools are often far away.

Examples of good practice:

South Africa created school programs, learning resources, fact sheets, and videos to support children with epilepsy and train teachers.

Lesotho, Malawi, and Zambia co-developed a teacher's guide with epilepsy information, seizure first aid, and social inclusion tips. Local volunteers visit schools when parents ask.

Uganda uses parent-requested volunteer visits to teach students and support teachers, but this isn't sustainable without a paid coordinator.

Mauritius provides training materials and a school protocol to help teachers manage seizures in class.

Prioritising Key Action Areas

After identifying challenges, each group proposed actions IBE can take, then another group prioritised which would have the most impact. The results are listed below.

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1. Navigating uncertainty and redefining daily life

National level support:

- Train medical personnel to better support people with epilepsy (PWE).
- Advocate for a dedicated epilepsy resource person at health centres.

Regional/global support:

- Mobilise resources for policy advocacy using IBE toolkits.
- Provide technical and financial support for peer networks and support groups.

2. Living with social judgement and misunderstanding

National level support:

- Support chapters to engage governments and learn from other advocacy movements (e.g., HIV, NCDs).
- Promote standardised information sharing; encouraging Knowledge Hub use.
- Organise/support annual conferences and shared messaging.
- Develop partnerships and provide funding for stigma-reduction efforts.

Regional/global support:

- **Convene regional stigma taskforces and improve Knowledge Hub engagement.**
- Fund stigma-reduction projects and promote a unified message.
- Engage Ministries of Health, WHO, and the AU.
- Collaborate with NCD alliances and host regional learning events.

3. Negotiating health systems not designed for epilepsy

National level support:

- Share tools and good practices across chapters.
- Provide small grants/seed funding for local advocacy and services.
- Organise training and mentorship to build chapter capacity.

Regional/global support:

- **Conduct and share regional research for advocacy.**
- Develop tools to track healthcare access and IGAP alignment.
- Create a legislative toolkit to support national advocacy.

Prioritising Key Action Areas

4. Education and employment systems not designed for epilepsy

National level support:

- Provide webinars and tools to help chapters build school action plans.
- Train PWE and caregivers to engage with schools.
- Fund local training sessions for parents, teachers, and policymakers.
- Develop multi-pronged strategies for schools and communities.

Regional/global support:

- **Create a regional teacher training portal and education programme.**
- Partner with teacher unions/colleges to reach educators.
- Develop regional resources and advocacy materials.
- Support volunteer training across countries.

5. Inadequate information – healthcare professionals (HCPs)

National level support:

- Provide endorsement letters for chapters to use with Ministries of Health.
- Support collaboration with WHO and ILAE.
- Share adaptable information templates and build regional networks.

Regional/global support:

- **Work with professional organisations to train HCPs, using adaptable resources.**
- Promote CME-endorsed training on epilepsy care and rights.
- Share tools and best practices from other chapters.

6. Inadequate information – PWE, families, and communities

National level support:

- Campaign for epilepsy to be covered in the school curriculum.
- Train HCPs and improve outreach to policymakers.
- Improve communication around epilepsy's social and health impacts.

Regional/global support:

- Advocate with global data (e.g., GENS) to support national efforts.
- Fund awareness campaigns and scale up chapter work.
- Share best practices and develop accessible information resources.
- **Rank countries on epilepsy care in collaboration with WHO, MoH, and AU.**

Donna Walsh shared the results of the World Café prioritisation exercise. Each group was then asked to take the top-voted action and outline how it could be implemented, using the SMART framework (Specific, Measurable, Achievable, Relevant, Timely) from the Advocates' Toolkit. A summary of their plans is provided below:

GENS Priority area – Living with social judgement & misunderstanding

Activity: Convene stigma taskforce and use IBE Knowledge Hub to facilitate chapter shared learning
Specific: Expand the utilisation of the stigma toolkit through the thematic taskforce
Measurable: +50% from baseline of chapters to use effectively
Achievable: Giving progress reports on cases that have improved
Relevant: Target specific marginalised groups
Time bound: Taskforce could be formed within 3 months

GENS Priority area: Negotiating systems that are not designed for epilepsy – health systems

Activity: Conduct, or collate, and share regional research for advocacy.
Specific: Translate and consolidate existing data, reflect and identify gaps
Measurable: 60% of African chapters should contribute to the research data
Achievable: Policy brief developed, regional bodies engaged: WHO, Pan-African Parliament & African Union
Relevant: Credible statistical data on prevalence & the treatment gap
Time bound: 12-18 months

GENS priority area – Negotiating systems that are not designed for epilepsy – education & employment

Activity: Develop a 'regional' teacher training portal
Specific: Build an online portal each region in chapter commits to
Measurable: Targets based on how many chapters commit, how many teachers per region register and do the programme
Achievable: Chapters work together to write modules
Relevant: Educational resources are online, IBE partnering closer with chapters, chapters enabling upskilling of teachers, multilingual
Time bound – teacher has 6 months to complete, platform takes 1 year to develop

GENS priority area – Consequences of inaccessible or inadequate information - HCPs

Activity: Partner with professional organisations to deliver standardised epilepsy training for healthcare providers, using existing materials adapted to local needs
Specific: Create national training materials for primary care providers and set up a Technical Working Group led by IBE, including people with epilepsy
Measurable: Update the mhGAP epilepsy module, develop national guidelines, and track the number of working group meetings
Achievable: Use existing training materials and build collaboration through a task force with technical support and lived experience input
Relevant: Improve the quality of care and ensures the voices of people with epilepsy are included
Time bound: To be developed over 2 years, with work starting within 6 months.

GENS priority area – Consequences of inaccessible or inadequate information - people with epilepsy, families and communities

Activity: Rank and rate countries in their care and support of PWE, in partnership with key policy making institutions incl. WHO, MoH, AU
Specific: National Epilepsy Guidelines – to ensure no one is left behind
Measurable: Backed up with policy
Achievable: Achievable set up of technical task force incl. lived experience
Relevant: Linked to IGAP, SDGs, ILAE, IBE targets – human rights context
Timebound: 2 years with quarterly reviews

HOW DO WE ADDRESS THE UNMET NEEDS OF PEOPLE WITH EPILEPSY IN AFRICA VIA POLICY ADVOCACY?

IGAP Implementation in Africa: Where is Epilepsy?

Presenter: Dr Chido Rwafa Madzvamutse, WHO-AFRO

Dr. Chido Rwafa from WHO-AFRO presented the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP). WHO is conducting a Global Neurology Status Report to assess where countries are with IGAP implementation. This has been more difficult in some African countries where there has been a limited response to the WHO survey; meaning that there are gaps – or lack of engagement – in terms of knowledge and understanding on progress in the region.

She emphasised the need for a dedicated budget line to be awarded by national governments to work on epilepsy. Otherwise, she said, epilepsy may be directly - or indirectly - listed as a priority area, but without financing there will be no impact.

Capacity building/training tools like mhGAP, the emergency humanitarian guides, and quality rights training can be used by IBE chapters in communities for IGAP implementation. WHO has also developed an epilepsy technical brief and IGAP implementation toolkit.

Epilepsy, along with Parkinson's disease, is listed as a 'tracer condition' by WHO in its work on Access to Medicines. The report on this topic is available to download from the WHO website. Recent funds were approved for a two-year project on Access to Medicine in Zambia and epilepsy will be a central focus. The Epilepsy Association of Zambia is involved via the WHO country office. Work is also happening in Ethiopia and Cote D'Ivoire.

A shared slide deck has been made available to all attendees, and includes the full WHO presentation.

PANEL DISCUSSION

Initiating National Policy Dialogues

Action Amos, Coordinator, IBE-Africa - *in conversation with:*
South Africa, Ethiopia and Tanzania.

The panel, moderated by Action Amos, began with agreement among all speakers that to move epilepsy advocacy forward, we must use existing policy opportunities, even if they're not ideal.

Enat Yewnetu from CareEpilepsy Ethiopia explained that in her country, epilepsy falls under 'mental health'. While not perfect, pushing for reclassification isn't the best use of resources. Instead, advocates should work within existing frameworks.
In South Africa, progress first came through the Ministry of Disability, Youth and Women —before the Ministry of Health got involved.

Speakers stressed the value of collaboration beyond epilepsy. Epilepsy South Africa has built a coalition of organisations working on neurological conditions, disability, and NCDs. Together, they formed a National Civil Society Taskforce to support IGAP implementation and broader advocacy.
Abraham Ntshalintshali from Eswatini shared similar work, partnering with groups focused on autism and other brain conditions.

A bottom-up approach was seen as key. Building local relationships and identifying community champions helps scale efforts nationally. Chahnez Charfi Triki, IBE VP for the Eastern Mediterranean, noted that in countries without IBE chapters, it's vital to engage healthcare professionals as allies.

Patrick Ngechu from Kenya highlighted the need to work with regional governments, since advocacy can't always be centralised.
Sharlene Cassel added that a one-size-fits-all approach doesn't work; Epilepsy SA relies on regional branches, while in Ethiopia, CareEpilepsy involves both national and local policymakers in events.

Youssouf Noormamode, IBE VP for Africa, emphasised combining local action with regional collaboration. Shared data can strengthen awareness campaigns, capacity building, and research, leading to stronger policy impact.

Panellists acknowledged that change takes time. Success comes from persistence, building political support, and generating relevant data. Sharlene Cassel underlined the importance of tracking progress and aligning with government priorities.
All panellists had achieved significant results with support from IBE grants:

- CareEpilepsy Ethiopia leads a technical IGAP working group with the Ministry of Health
- Epilepsy SA developed SAINAP, a national action plan soon to be adopted by government
- POCET (Tanzania) secured an epilepsy desk at the Ministry of Health, staffed by a person with epilepsy

IGAP ADVOCACY UNDER PRESSURE

Survey insights from Action Amos

The last presentation of the day was from Action Amos, Coordinator, IBE-Africa. It was entitled 'IGAP advocacy under pressure'. He started off with a proverb: 'If you try to sit on two stools you will split your trousers'.

Where does epilepsy belong?
Action invited participants to share where epilepsy is housed in their national health systems. Responses varied widely:

- Mental Health
- Noncommunicable Diseases (NCDs)
- Disability
- Neurology/Brain Health

This variety, he said, places epilepsy at a crossroads—reflecting a lack of consistency that can hinder coordinated action.

Insights from the IBE pre-meeting survey
A survey conducted across 17 IBE chapters revealed key insights:

- Inconsistent classification: Epilepsy is managed under different departments in different countries—commonly Mental Health, NCDs, or Neurology.
- Variable IGAP awareness: Some governments are actively collaborating with IBE chapters; others are not yet engaged.
- Common advocacy partnerships: Most chapters reported working with groups such as ILAE, WHO, Ministries of Health, and drug regulators.

A need for change in framing
Dr Chido Rwafa of WHO-AFRO explained that epilepsy currently sits under Mental Health, which itself is part of the NCD Department, there. She noted this was due to historical legacy, and suggested renaming the department to Mental Health and Neurology, or Brain Health, to better reflect its scope.

Top challenges to IGAP implementation
Chapters identified the main barriers to progress as:

- Low political will and weak government commitment
- Limited prioritisation of epilepsy in national agendas
- Lack of resources and funding

Skills needed for advocacy success
To move IGAP forward, respondents said they need more training and support in:

- Policy advocacy and lobbying
- Communication and storytelling
- Community mobilisation and empowerment

These findings highlight the urgent need to strengthen advocacy capacity across the continent. This includes training, better access to funding, and more effective partnerships with policymakers to ensure epilepsy is no longer overlooked in national health planning.

DAY 2: IDEAS EXCHANGE FORUM

Moderator: Sharlene Cassel, Epilepsy SA

Kur Ezekiel, South Sudan (via recording)
Presented a community-led project with AMREF to challenge epilepsy stigma through:

- Talks with religious leaders and media (radio show reaching 15,000)
- School workshops and community sessions in 7 villages (250+ people)
- “Stigma benches” to spark dialogue
- Survey showed increased awareness, reduced stigma and violence towards PWE
- Jacopo Rovarini (AMREF) shared plans to launch an epilepsy clinic and offered to share the project’s impact survey with IBE chapters

Chifundo Zamadunga, Malawi & Abraham Ntshalintshali, Eswatini
Presented a law enforcement training project to protect legal rights of people with epilepsy.

- Trained 200+ officers and 160 recruits; now part of police academy curriculum
- Officers reported past harm caused by misinformation
- Abraham called for justice system-wide reform and acknowledged that many cases still go unaddressed
- Discussions highlighted police mistrust, cost of legal action, and challenges accessing justice

Group Discussion Summary

- Many epilepsy organisations feel “passed from pillar to post”
- Ministries often decide classification despite advocacy
- Consensus: epilepsy should be placed where the most progress is possible (e.g. under disability in South Africa)
- Action Amos advised using the health law mapping report to understand each country’s current classification

Mary Secco, Canada
Presented a school-based epilepsy education programme, co-designed with families and teachers:

- Grade 5 (ages 9–11): 45-minute lesson on bullying, empathy, seizure first aid
- Grade 12 (ages 17–18): Biology-focused lessons with teacher toolkits on epilepsy
- Parents help develop care plans with teachers
- Data showed reduced bullying and increased knowledge
- The programme was approved by curriculum officials after extensive stakeholder consultation

Nthabeleng Hlalele, Lesotho & Cameroon
Presented two national projects highlighting increased epilepsy visibility in policy-making:

- IGAP integrated into Cameroon’s district health workplans
- In Lesotho, a national event led to an MoU with the Ministry of Health
- Epilepsy moved under NCDs in Lesotho
- Discussions followed about inconsistent placement of epilepsy (NCD, mental health, disability)
- Dr Chido Rwafa (WHO) urged caution: Reclassification can reduce stigma, but might also lead to loss of benefits. She advised advocates to weigh gains and losses carefully and tailor their strategy to local realities

Patrick Ngechu, Kenya
Shared KAWE’s media campaign using The Curse of Stigma documentary.

- Combined TV, radio, social media, and community events (e.g. stigma benches)
- Weekly posts encouraged real-time public engagement
- Results: 70% increase in awareness, 120+ new epilepsy cases identified and referred

RESOURCE MOBILISATION WORKSHOP

PANEL AND INTERACTIVE TABLE DISCUSSION

Building a fundable strategy, Enat Yewnetu, Ethiopia

Key Takeaways:

- Ensure the right people are in place, trained in epilepsy, and understand community needs.
- Involve young people through awareness campaigns and support their access to certifications.
- Engage trusted family members for help with finance tasks like auditing.
- Research funders early and understand your financial needs and their funding priorities.
- Build a reliable Board of Directors - select people who share your mission and offer constructive challenge.
- Report regularly to funders to maintain trust.
- Use what you have - don’t let limitations hold you back.
- Always check backgrounds of collaborators, especially public figures, to avoid reputational risk.
- Celebrate small wins to maintain motivation.
- Be creative and network widely to uncover opportunities.
- Make auditing part of your fundraising for transparency.
- Understand what’s already happening in the community and use those insights to appeal to funders.
- Start small; small steps can lead to big impact.

Considerations when writing project proposals, Patrick Ngechu, Kenya

Key Takeaways:

- Lack of awareness and visibility of epilepsy among funders and in broader health agendas is a major challenge.
- It's possible to align epilepsy with popular funding themes like youth, gender, or disability but there is confusion about where it ‘fits’ (mental health, NCDs, brain health).
- Organisations should choose funders based on where they can make the strongest case and where funding exists.
- Building and maintaining strong relationships with funders is essential.
- Accept both in-kind and cash donations or sponsorships.
- List what you need and approach businesses that provide similar products or services.
- Small organisations can attract large funders by aligning with the funders priorities and showing clear evidence of impact.
- Funders are more likely to support projects that use data and evidence matching their goals.
- When funders are unfamiliar with epilepsy, link it to broader issues they care about (e.g. education, poverty, disability).
- Real-life stories and making a clear economic case can strengthen your appeal.

RESOURCE MOBILISATION WORKSHOP

PANEL AND INTERACTIVE TABLE DISCUSSION

Sustaining Donor Engagement, Sharlene Cassel, South Africa

Key Takeaways:

- In South Africa, private companies contribute to a disability fund to which disability-focused organisations can apply. Similar opportunities may exist elsewhere.
- Non-profits must have key documents in place: registration, operating certificates, MOUs, data protection policies, annual and audited financial reports, etc.
- Align with your country's social investment framework. Epilepsy SA tracks demographics (e.g. race, gender) to match funder priorities.
- Acknowledge donors meaningfully—at events, in newsletters, on websites/social media — but only if they were involved in the activity.
- Use written agreements with donors to define roles, expectations, and how they want to be recognised.
- Explore multiple funding sources: membership fees, government grants, corporate and foundation support, events, and individual donations.
- Use technology and social media to raise awareness - consider involving youth volunteers to manage accounts.
- IBE could support chapters by offering standardised governance training - especially helpful for start-up or volunteer-led groups.

PANEL DISCUSSION ON SUSTAINABLE FUNDRAISING

Moderator: Donna Walsh (CEO, IBE)
Panellists:

- Lisa Brown (ROW Foundation)
- Gardiner Lapham (BAND Foundation)
- Cristina Bautista (UCB)

Key Takeaways:

- Each organisation shared its mission and funding approach in epilepsy care.
- Funding is increasingly difficult to secure in the current financial climate.
- Strong alignment between funder priorities and project goals is essential.
- Collaboration and innovation are key to successful resource mobilisation.
- Institutions value impact data and evidence of effective implementation.
- Building long-term relationships with funders is crucial.

FINAL CONCLUSIONS

Closing Reflections

Claire Nolan invited participants to reflect on their experience at the convention. Highlights shared by delegates:

- Joy in meeting face-to-face and connecting across chapters
- Inspiration from shared ideas and initiatives
- Renewed motivation to prioritise the future of IBE in Africa and beyond
- Appreciation for the host country and team, especially Betty Nsachilwa

Youssouf Noormamode, IBE Vice President (Africa), presented Betty Nsachilwa with a commemorative plaque to thank her for her leadership and dedication.

Final remarks from Action Amos

A total of 60 participants attended the convention, including representatives from the local Epilepsy Association of Zambia, contributing to engaging discussions and knowledge exchange. The event provided a platform for collaboration, strategy development, and a renewed commitment to improving epilepsy care across the continent.

With the momentum gained from these engagements, the IBE-Africa Chapter Convention continues to serve as a vital space for fostering partnerships, strengthening advocacy efforts, and advancing epilepsy-related policies within Africa. It is, therefore, hoped that such convening is held regularly.

IBE will use the outputs from the meeting to shape a regional strategy in which chapters will play an active role.

APPENDIX

Prior to the IBE-Africa Chapter Convention, meetings took place with the Ministry of Health and the WHO Country Office. Here are the reports:

Also on May 15th, the group met with Ministry of Health officials, including Minister Dr. Elijah Muchima. They discussed, again, strengthening epilepsy care and public health initiatives in Zambia. The meeting, also, focused on implementing the Intersectoral Global Action Plan (IGAP); fostering coordinated partnerships, building capacity through training of healthcare professionals, and addressing stigma and discrimination to uphold patients' rights. The discussion highlighted the importance of research collaborations, including potential work with the Tropical Diseases Research Centre in Ndola, and emphasized treating epilepsy as a public health priority via universal healthcare care. The engagement reaffirmed the Ministry's commitment to advancing IGAP implementation and coordinated national epilepsy programs and provided a platform for further local engagement.

On May 15th 2025, the IBE, IBE Africa, and local Zambian epilepsy associations — the Epilepsy Association of Zambia and Zambia League Against Epilepsy — met with Dr. Freddie Masaninga, NCD Coordinator at WHO Zambia. The group discussed strengthening epilepsy care and public health initiatives in Zambia. The discussion focused on implementing the Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders, integrating epilepsy care within broader neurological programmes, and promoting a data-driven approach to IGAP implementation; using the IGAP Implementation Toolkit and One Health resource. Training for health workers, including community-level personnel, was highlighted, and WHO Africa Region's approval of a project on "Access to Medicine" for neurological conditions in Zambia was noted; with a stakeholders virtual meeting pending. The WHO AFRO annual meeting in Zambia in August was identified as an opportunity to engage local neurologists. The meeting concluded with a call for enhanced coordination and communication to ensure effective implementation and monitoring of national epilepsy programs.