

IBE International Bureau for Epilepsy

AFRICA REGION

NEWSLETTER

MAY 2026

BAND FOUNDATION

Dear Friends,

Welcome to the First Edition of our 2026 Epilepsy Awareness Newsletter.

In this issue, we are proud to spotlight the remarkable progress and meaningful impact achieved by our chapters across the African region through the IBE–BAND Foundation sponsored projects for 2026.



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FROM THE DESK OF THE IBE AFRICA - COMMUNICATIONS OFFICER



WANCHIA CYNTHIA

Dear Friends,

Welcome to the first quarter edition of our 2026 newsletter.

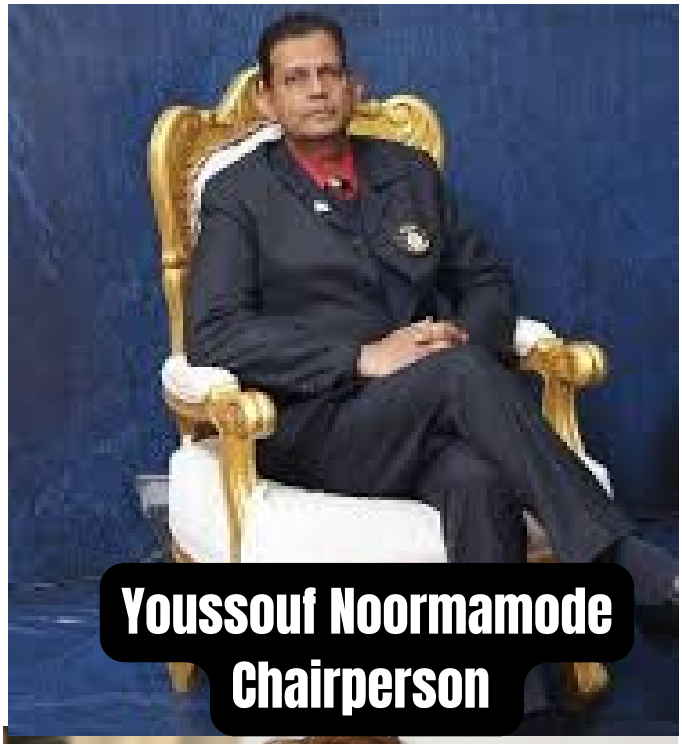
In this issue, we are pleased to bring you the significant progress made by our chapters across Africa through the IBE–BAND Foundation supported projects for 2025–2026. These efforts continue to drive meaningful change raising awareness, improving access to care, empowering communities, and strengthening advocacy across the region.

We invite you to explore these inspiring stories of impact and commitment as we work together toward a future where epilepsy is better understood, effectively treated, and fully supported.

I encourage you to remain engaged and be part of the conversation together, we can amplify our voices and make our collective advocacy even stronger and more impactful.

Happy Reading!!

MEET OUR NEW IBE - AFRICA REGIONAL EXECUTIVE COMMITTEE













IBE AFRICA 2026 REGIONAL UPDATE AND THE ROAD AHEAD FROM THE REGIONAL PROGRAMS COORDINATOR'S CORNER



Action Amos

The 2026 period has marked significant progress for the Africa region of the International Bureau for Epilepsy (IBE), with strengthened partnerships, expanded regional coordination, and growing momentum towards implementation of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP).
As part of strengthening regional leadership, IBE Africa welcomed:

Wanchia Nchang – Regional Communications Officer
Kur Ezekiel – Regional Secretary
Sharlene Cassell – Regional Vice Chairperson

Across the continent, 10 country grantees continued implementing activities under three key pillars:

- Policy Advocacy – including IGAP taskforces, leadership training, and policy dialogues with Ministries of Health and WHO;

- Health Systems Strengthening – through healthcare worker training, epilepsy manuals, EMR pilots, and community sensitisation;
- Education, Employment, and Inclusion – focusing on stigma reduction, economic empowerment, and strengthening community engagement.

Important lessons continue to emerge from the work. Government partnership remains critical for sustainability, lived experience voices are strengthening advocacy impact, and community awareness is contributing to increased treatment uptake.

At the aame time, challenges such as limited anti-seizure medication availability, insufficient funding, weak monitoring systems, and limited government ownership continue to affect progress.

Looking ahead to 2027 and beyond, IBE Africa will focus on strengthening evidence-informed advocacy through initiatives such as:

Development of an African Epilepsy Barometer
Regional ASM monitoring frameworks
Advocacy for medication supply chain reform
Stronger engagement with AU, Africa CDC, and Pan-African Parliament
Expansion of policy dialogues and government engagement frameworks.

The region remains committed to advancing inclusive, evidence-driven epilepsy advocacy and ensuring that persons with epilepsy are meaningfully represented within health systems and policy spaces across Africa.
We encourage all chapters, partners, and stakeholders to read the full newsletter for detailed country updates, lessons learned, and strategic priorities shaping the future of epilepsy advocacy in Africa

Making Epilepsy a Health Priority in Africa Project

Ten (10) Country Grantees implementing project under 3-key pillars:



I. Policy Advocacy
II. Health Systems Strengthening
III. Education Employment & inclusion

CAMEROON

MALAWI

LESOTHO

ESWATINI

Ethiopia

MAURITIUS

South Africa

KENYA

THE GAMBIA

SOUTH SUDAN



Advancing IGAP in Eswatini: Strong Coordination, Public Awareness, and Advocacy

The **Eswatini Epilepsy Organization (EEO)** is actively supporting the Accelerated IGAP Implementation Project in Southern Africa through coordinated planning, public awareness efforts, and high-level advocacy on neurological conditions. A key milestone was the planning, coordination, and stakeholder mapping that led to the formation of the IGAP Task-force.

EEO identified and engaged institutions with shared objectives, including the Non-Communicable Diseases (NCD) Unit in the Ministry of Health, the NCD Alliance, and the Deputy Prime Minister's Office (DPMO) Social Welfare Department and Disability Unit. Community stakeholders working with persons with neurological and/or intellectual conditions and disabilities such as Autism Eswatini and Cheshire Homes of Eswatini also contributed to further mapping and Task-force development.

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Empowering Careers: Vocational Readiness and Digital Skills for People Living with Epilepsy in Mauritius

In Mauritius, the EDYCS Epilepsy Group continues to advance inclusive employment for people living with epilepsy through targeted, family-centered capacity-building. Building on the same initiative, two related one-day workshops were delivered to address persistent barriers to training, job readiness, and digital access.

Creating inclusive pathways to employment is essential for empowering people living with epilepsy. In this spirit, the EDYCS Epilepsy Group organized a one-day Career Guidance and Job Readiness Workshop, bringing together individuals with epilepsy, alongside parents, caregivers, and families. Complementing this initiative, the EDYCS Epilepsy Group hosted another Vocational Skills and Digital Literacy Workshop with 33 participants. This training aimed to enhance vocational readiness, digital inclusion, and independence.

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Cameroon: Epilepsy Screening & Education Brings Hope in Ntui Village

CODEF Cameroon carried out an epilepsy screening mission in Ntui village, Ntui Sub-Division, Yaoundé – Centre Region, Cameroon. The outreach created a strong sense of hope among families living with epilepsy. The day was not only about diagnosis it also included education and sensitization focused on anti-seizure medications (ASMs) adherence.

According to one staff member from the Catholic Health Center in Ntui, caregivers have gained confidence and found their footing in supporting people with epilepsy by understanding how to take medications consistently and follow guidance from health workers.

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Building Hope: Reducing Stigma and Improving Treatment Access in Mvolo-South Sudan

Between October 2025 and the present reporting period, the Change Beyond Knowledge Project 2025 implemented by the Initiative for Epilepsy Awareness (IFEA-South Sudan) has made meaningful progress in strengthening epilepsy awareness and improving linkage to treatment in Mvolo County, Western Equatoria State. With support from IBE Africa and Band Foundation, the project is designed to build on the successes of the previous Mvolo epilepsy awareness initiative while complementing the efforts of the county health department, Amref Health Africa, and SPEDP South Sudan.

So far, the project has reached 105 direct beneficiaries 59 females and 46 males and 525 indirect beneficiaries through stigma reduction and community dialogue activities conducted in five villages. A key outcome has been the strengthening of community resources.

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Progress in Education & Employment Inclusion for Young People Living With Epilepsy in Kenya

Kiserem Epilepsy Foundation and Youth on the Move Kenya collaborated on the Education and Employment Inclusion Pillar, working together to reduce stigma and expand opportunities for young people living with epilepsy in Kenya. Kiserem Foundation led the employment training component, using its established beauty and computer centers to deliver practical skills for economic empowerment. Youth on the Move led the education and stigma reduction activities through stigma benches conducted in Nairobi's informal settlements—Langata and Mathare.

The project has enrolled 25 young people in coding, covering skills from basic computer orientation, web development, HTML and CSS, and progressing into Java and GitHub. Eight stigma benches were conducted, reaching 2,500 people.

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Ethiopia: Building Readiness, Strengthening Partnerships, and Empowering Health Extension Workers to Advance Epilepsy care



To support ethical research and service delivery, epilepsy prevalence survey tools have been drafted and are currently in preparation for validation and rollout. This work is conducted in partnership with Jimma University to strengthen survey logistics and community field engagement.

During the early months of implementation, CareEpilepsy project in Bench Maji Zone focused on preparation, partnership building, and technical readiness to ensure activities are delivered effectively, ethically, and to high-quality standards.

Fous shifted towards, strengthening coordination with the Ministry of Health, EPHI (Ethiopian Public Health Institute), and Gerar Bet Tehadso Mahiber (GTM) to clarify roles and align plans, while also working closely with the Bench Maji Zonal Health Office to facilitate field access, mobilize Extension Workers (HEWs), and co-lead community engagement.

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Voices for Change: South Africa's Community-Led Push to End Epilepsy Stigma

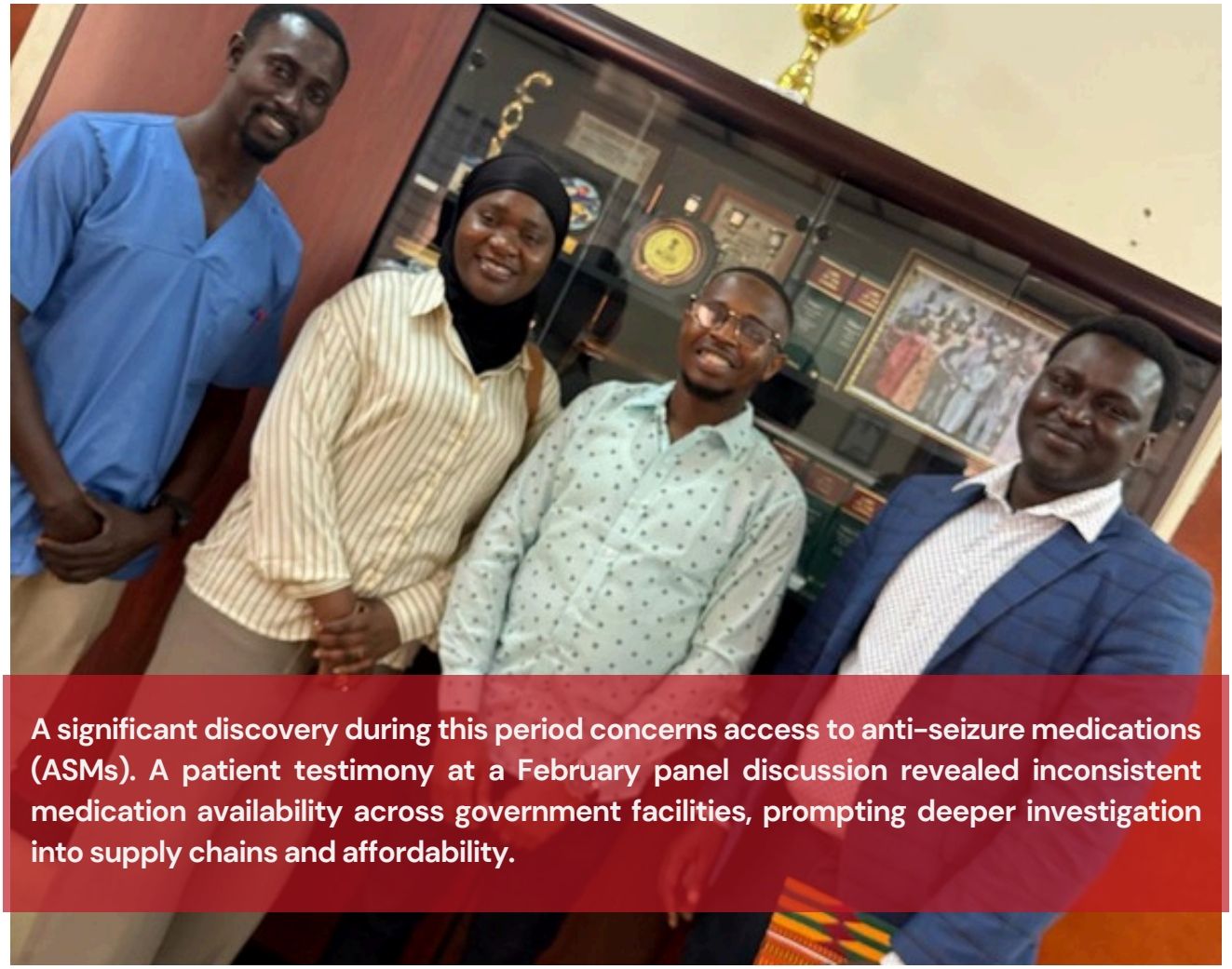


Epilepsy South Africa is making significant strides in its national campaign to reduce stigma and generate evidence on the lived experience of people with epilepsy. The "Voices for Change" project, supported by an IBE Small Fund grant, has reached its midpoint with strong results across both of its core components.

The Epilepsy SA Development Hub has delivered stigma reduction workshops across multiple provinces, reaching approximately 100 participants — surpassing the original target of 80. Four facilitators have been trained, including two people with epilepsy, embedding peer-led delivery at the heart of the programme. Workshops cover themes including understanding stigma, language and representation, and self-advocacy, using participatory methods adapted to participants' needs. Early findings reveal that internalised stigma is a dominant experience, prompting facilitators to place greater emphasis on practical self-advocacy tools.

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Epilepsy Care in The Gambia: Building Foundations for Change



A significant discovery during this period concerns access to anti-seizure medications (ASMs). A patient testimony at a February panel discussion revealed inconsistent medication availability across government facilities, prompting deeper investigation into supply chains and affordability.

A community-led project to strengthen epilepsy care across The Gambia is showing promising results after five months of implementation. The IBE Small Funds Project, delivered in partnership with FESSGam (Epilepsy and Stigma Support), is working to build primary healthcare capacity across five regions of the country.

Key milestones have already been reached. Preparations are underway to train Community Health Workers (CHWs) in Brikama, following productive meetings with regional health directors. An Electronic Medical Records (EMR) pilot has been initiated at the Edward Francis Small Teaching Hospital (EFSTH), laying the groundwork for a potential national epilepsy database. Awareness videos have been produced in English and two local languages, with more languages planned to reflect the country's diverse communities.

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Commemorating International Epilepsy Day Febraury 09, 2026.

Highlights from Africa!!



IBE Africa commemorated the International Epilepsy Day by joining the launch of "The Epilepsy Pledge Campaign a global initiative to convert awareness into concrete actions & we committed to continue raising awareness about epilepsy related issues via our social media platforms. Our chapters engaged in different activities ranging from the #50Million steps, symposiums, online campaigns, workshops, sports walk amongst others.

Observed on the 2nd Monday of February each year and first created in 2015, International Epilepsy Day was launched by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). In 2026, it falls on February 9. The day plays a pivotal role in raising awareness about epilepsy, promoting compassion, and encouraging better understanding of the condition.

The annual event provides a platform for people with epilepsy to share their experiences and advocate for human rights, inclusive policies, and legislation that supports full participation in society. It also highlights the need for improved treatment, care, and increased investment in epilepsy research.

Despite epilepsy being one of the oldest medical conditions, fear, stigma, and misinformation still affect many individuals often making discrimination harder to overcome than seizures themselves. By bringing together communities, healthcare professionals, and policymakers, International Epilepsy Day strengthens support systems and reinforces that epilepsy can be managed with the right resources..

Click on the video link to watch highlights of our chapters commemorating IED 2026

WATCH NOW

UPCOMING !!

IBE AFRICA 3-Part Regional Webinar!



IBE Africa in partnership with Partners Against Mortality in Epilepsy (PAME) will host a Three-Part Regional Webinar Series in;

📅 June, July & August

Theme: SUDEP, Epilepsy Safety, Survival & Comorbidities in Africa.
This series brings together key voices and practical insights to deepen understanding, improve awareness, and help strengthen responses to epilepsy across the region.

REGISTER NOW!

📩 A participation link will be shared with you ONLY after registration.
You can't afford to miss this opportunity.

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