

REPORT ON THE IBE AFRICA REGIONAL EPILEPSY CONFERENCE HELD IN ADDIS ABABA – ETHIOPIA 20TH – 21ST NOVEMBER, 2023

amref health africa
ILAE International League Against Epilepsy
IBE International Bureau for Epilepsy
IBE International Bureau for Epilepsy AFRICA REGION
BAND FOUNDATION
World Health Organization
EPILEPSY PATHWAY INNOVATION IN AFRICA
The African Academy of Sciences

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BACKGROUND

The International Bureau of Epilepsy (IBE) partnering with the Ministry of Health of Ethiopia and the Ethiopian Human Rights Commission convened a conference in Ethiopia, with the aim of empowering persons with epilepsy to advocate for equal rights and full participation in society – leveraging global policy frameworks to drive action across the region.

For many years, IBE and its chapters have been working towards ensuring people with epilepsy benefit from international initiatives such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and the UN Sustainable Development Goals (SDGs) – ensuring that no one is left behind. Having a specific global instrument which aims to strengthen the public health approach to epilepsy, and which was unanimously approved by all member states of the World Health Organization, the World Health Organization's 10-year Intersectoral Global Action Plan on Epilepsy and Neurological Disorders 2022-31 (IGAP), many African governments are considering how IGAP can be domesticated and implemented in their countries. In line with this policy momentum, IBE has stepped up its advocacy efforts worldwide and is working to equip its organizations and advocates to ensure that IGAP can be used to drive a transformational social change for people with epilepsy everywhere, including in Africa.

Considering the above-mentioned factors, the International Bureau for Epilepsy Africa Region held a conference from the 20 – 21st of November 2023 in Addis Ababa, Ethiopia with the theme "Stamping out Stigma" and the activities carried out during the conference were in moderated sessions.



OPENING CEREMONY

The Conference on Day One, 20th November 2023, began with addresses from international and African experts on epilepsy and related sectors including the IBE president - Francesca Sofia, Vice President and IBE Africa Chairperson - Action Amos, IBE CEO – Donna Walsh, and, CEO of Care Ethiopia – Enat Yewnatu, the State Minister of Health and the Deputy Commissioner of Human Commission Rights Ethiopia.









DAY ONE – 20TH NOVEMBER
Honorable Guest Speech Highlights



The State Minister for Health Ethiopia said their government has prioritized epilepsy and for this reason they are committed to working with IBE, WHO, and the rest of the countries in Africa in implementing IGAP. He stressed that political engagement at the national and regional levels is imperative for the intersectoral Global Action Plan on epilepsy and other neurological disorders. He went on to lament that data on epilepsy in Africa is unavailable where chapters need it most for advocacy. He concluded his speech by citing some areas that IGAP can be implemented through such as the African Disability Protocol, SDGs, Universal Health Coverage and most importantly the Intersectoral Global Action Plan on Epilepsy And Other Neurological Disorders.



The Deputy Commissioner for Human Rights Ethiopia highlighted the work that the commission had done in the past year around epilepsy such engaging in the Epilepsy Day Commemoration and supporting the development of an epilepsy documentary. She also indicated that IBE and her chapters should take the implementation of IGAP as a Human Rights issue and not a charity issue. The commission committed to work with all partners to ensure that IGAP is domesticated and implemented in Ethiopia

DAY ONE – 20TH NOVEMBER

Session 1 : IBE & BAND: A Unique Partnership in Africa

After the addresses came time for presentations with a recorded presentation from BAND Foundation's representative, Gardiner Lapham, who thanked IBE chapters for the hard work they were carrying out in Africa. Next was the IBE CEO – Donna Walsh, who described the BAND Foundation as a unique partner in Africa and indicated that more funding partnerships were needed. She concluded that if more funding partners joined the fight against epilepsy it would lead to more scalability and sustainability of IGAP.





IGAP Defined & Simplified: Meeting Strategic Objective 5 in Africa - Strengthening the Public Health Panel: Chahnez Triki (Tunisia), Max Bangura (Sierra Leonne), Symon Kariuki (Kenya)

During the panel discussion featuring Dr. Chahnez Triki from Tunisia, Max from Sierra Leone, and Symon Kariuki from Kenya, several insightful perspectives were shared on leveraging IGAP to fortify public health strategies.

Max expounded upon the significance of awareness in bolstering public health initiatives, stressing the pivotal role of both governmental bodies and civil society in this endeavor. He illustrated this crucial point by citing a poignant example from Sierra Leone, where misconceptions surrounding epilepsy prevail. Max highlighted the prevalent belief attributing epilepsy to sin and ancestral associations, perpetuating the misconception that "epilepsy is contagious."

Symon Kariuki elaborated on Kenya's experiences collaborating with the government to fortify public health, particularly in an environment where health initiatives operate in a decentralized manner. He underscored the importance of targeted engagement with influential figures capable of effecting policy change. Symon emphasized the necessity of directing efforts towards individuals who wield the power to drive policy shifts.

Dr. Chahnez Triki emphasized the imperative of amplifying the voices of those directly impacted to actively participate in policy dialogues. She highlighted Tunisia's ongoing efforts to facilitate this involvement, emphasizing its sustainability and capacity-building impact on affected communities. Dr. Triki underscored the importance of inclusive policy dialogues, ensuring the representation of those affected by health policies.

Overall, the panelists' diverse insights underscored the criticality of raising awareness, targeted engagement with policy influencers, and the inclusion of affected voices in shaping sustainable and capacity-building public health policies



Closing the Treatment Gap - Partners in Africa - Meeting Global Target 5.2 in Africa 50% increase in epilepsy service coverage Speakers: Jacopo Rovarini (AMREF), Massimo Leone (SIN), Charles Newton (recorded)

During a collaborative effort among consortia of countries in 2023, unified initiatives were undertaken to implement Stigma Awareness programs. These initiatives were aimed at successfully executing projects aligned with the objectives outlined in the Integrated Global Action Plan (IGAP) 5.1. In a recent presentation, participating nations detailed their distinctive projects and efforts:

Shine Epilepsy (Kenya), Initiative for Epilepsy Awareness (South Sudan), Global Epilepsy Organisation (Rwanda) shared insights on their Stigma Benches, employing a Community Based Approach.

•**Key Achievement:** Establishment of Stigma Benches in these countries, coupled with active involvement of local chiefs in promoting and supporting these stigma benches.

Epilepsy Association of Zambia, National Epilepsy Association Malawi, Epilepsy Lesotho (LeMaZa) outlined their project centered on Eradicating Stigma in Schools across Sub-Saharan Africa.

•**Key Achievement:** Development of an engagement model involving teachers, parents, children with epilepsy, and those without epilepsy, supported by a newly devised teachers' guide.

Community Development and Epilepsy Foundation (Cameroon) presented their project aimed at Offering IGAP Opportunities through Stigma Elimination.

•**Key Achievement:** Successful implementation of a small funds project resulting in the establishment of an Epilepsy Anti-Stigma Awareness Working Group in Cameroon.

Purple Bench (Uganda) and Foundation for People with Epilepsy (Kenya) operating jointly as UGAKEN highlighted their project on Stakeholder Partnership for Stigma Reduction.

•**Key Achievement:** Inclusive integration of children with epilepsy into regular school settings.

Additionally, both countries initiated the development of an Epilepsy First Aid Training Tool specifically designed for teachers.

These presentations underscored the impactful efforts undertaken by these collaborative initiatives, showcasing their achievements in combatting epilepsy-related stigma through innovative and community-centric approaches across various countries

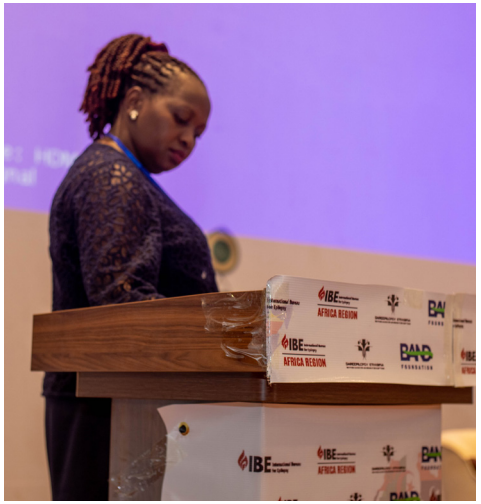
During the session addressing the imperative of achieving a 50% increase in epilepsy service coverage, three distinguished international experts contributed their insights. Among them, Prof. Massimo provided a concise overview of prevalent health challenges faced by individuals in Africa, particularly within Sub-Saharan Africa, focusing on the significant impact of HIV/AIDS. His discussion delved into the HIV/AIDS treatment model, underlining its relevance in the pursuit of achieving a 50% increase in epilepsy service coverage by the year 2031. Prof. Massimo emphasized the potential benefits of adopting or replicating this model, advocating its applicability for both the International Bureau for Epilepsy (IBE) and African nations.

Jacopo Rovarini, representing AMREF Africa, shared his extensive experience garnered from working in South Sudan. His insights likely provided a nuanced perspective on the challenges and strategies related to epilepsy service coverage in the region.

Additionally, the session included a recorded discourse by Charles Newton, which unfortunately encountered technical disruptions, preventing its completion. Nonetheless, the discourse was intended to revolve around “Education on IGAP for the New European Generation.” Despite the interruption, it was expected to offer valuable insights into the educational aspect of IGAP and its implications for the emerging European generation.

Overall, the contributions of these experts highlighted the critical need for innovative approaches, such as leveraging successful healthcare models like that of HIV/AIDS treatment, while also underscoring the importance of regional experiences and education for advancing the objectives of increasing epilepsy service coverage.









Closing the Inclusion Gap – Part 1: Meeting Global Target 5.1 in Africa-
Update on the fight against stigma in Africa - IBE Stigma Small Funds

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Closing the Inclusion Gap – Part 2: Meeting Global Target 5.1 in Africa
80% of countries updated discriminatory legislation - Uganda and Kenya

The findings revealed that individuals living with epilepsy often encounter self-stigma, leading them to opt for concealment rather than reporting injustices, driven by a belief that seeking justice would yield no favorable outcome due to perceived legal biases against them as victims. Participants in the discussion provided valuable advice:

Emphasized the necessity to empower and capacitate the youth, recognizing their potential to become a potent force in aiding epilepsy support groups.

Urged all conference-represented chapters to meticulously analyze the legislation in their respective countries. The focus should extend beyond identifying overtly discriminatory laws to uncovering latent legislation that may indirectly affect individuals with epilepsy.

Highlighted the importance of establishing an education pathway. This pathway would compel school authorities to accommodate children with epilepsy. For instance, in Sierra Leone, a protocol mandates school authorities to either allow children with epilepsy to attend school or not dismiss them without due consideration.

Advocated for the involvement of Human Rights defenders in addressing issues surrounding epilepsy-related discrimination and injustices.

Suggested an approach when engaging with Parliamentarians: initiate the dialogue by involving a single Member of Parliament initially before extending the engagement to the broader assembly. This strategic method ensures a more focused and potentially impactful interaction.

These recommendations collectively underscored the critical need for capacity-building, legal scrutiny, educational frameworks, involvement of Human Rights advocates, and strategic engagement with lawmakers. They aim to create a more supportive and inclusive environment for individuals affected by epilepsy, addressing the barriers perpetuated by self-stigma and discriminatory practices.



Building Intersectoral Alliances : Ensuring IGAP implementation is multi-sectoral, person-centred and evidence-informed.

During a panel discussion featuring representatives from CareEpilepsy Ethiopia, CDC Africa, and the WHO Ethiopia Office, critical insights were shared to guide the effective implementation of the Integrated Global Action Plan (IGAP) for Epilepsy.

The WHO representative underscored the significance of drawing lessons from the successful HIV model when executing IGAP. Highlighting the importance of sustainable funding over extended periods rather than short-term commitments, the representative emphasized the necessity of forging Memoranda of Understanding with Ministries, engaging in political advocacy, and adopting a strategic approach. Encouraging a focused strategy, the representative suggested prioritizing objectives that align with each Chapter's capabilities, initiating pilot projects, demonstrating unwavering commitment, and establishing robust mechanisms to attain IGAP goals.

Dr. Adelard Kakunze from the Africa CDC urged all International Bureau for Epilepsy (IBE) Chapters to elevate awareness regarding epilepsy while concurrently fostering alliances. Stressing the significance of coordinated alliances, Dr. Kakunze highlighted the pivotal role of these collaborations in guiding advocacy efforts, providing direction, and offering comprehensive support throughout the advocacy process. He emphasized the need for multisectoral, person-centered, and evidence-informed implementation of IGAP. Additionally, he emphasized the crucial collaboration with the Ministry of Health, being the pivotal entity mandated to oversee IGAP implementation.

Furthermore, the Care Epilepsy Ethiopia representative shared valuable insights into CareEpilepsy's experiences and successful endeavors in implementing IGAP. Their contributions likely offered practical and context-specific examples of initiatives that aligned with IGAP objectives, serving as valuable case studies for effective implementation strategies



Building Intersectoral Alliances : Ensuring IGAP implementation is multi-sectoral, person-centred and evidence-informed.

Epilepsy South Africa showcased remarkable accomplishments as a pioneering entity during their project, highlighting the establishment of a civil task force, comprehensive training on Integrated Global Action Plan (IGAP) across six branches of Epilepsy SA, and the publication of a localized booklet on IGAP. Amidst their achievements, the organization encountered challenges, successfully surmounting some but not all.

Key Achievements: Epilepsy South Africa submitted a preliminary draft for a national plan encompassing epilepsy and related neurological conditions to the Department of Disability for Persons with Disabilities in South Africa. Notably, they authored and disseminated the first-ever IGAP book, widely shared across various social media platforms and key stakeholders. Additionally, the organization conducted three webinars and produced three episodes on IGAP, shared through accessible mediums like YouTube.

Epilepsy Eswatini reported enthusiastic results, particularly through the signing of multiple Memoranda of Understanding (MOUs) with the Eswatini government and educational institutions, including universities. Their endeavors were supported by the upper House of Parliament in Eswatini.

Key Achievement: Eswatini Epilepsy Organization successfully advocated for policy and legislative changes detrimental to persons with epilepsy and neurological disorders (PWEND). Their advocacy resulted in waivers on laws obstructing the issuance of Birth Registration Certificates and National Identity Documents. Over a hundred PWEND have been registered, now eligible for disability grants, financial inclusion programs, and other essential benefits. This partnership significantly contributed to achieving IGAP objective 1.2, focusing on national policy updates. Notably, partnerships were strengthened with crucial ministries like the Ministry of Home Affairs and the Deputy Prime Minister's Office, fostering supportive mechanisms for PWEND lacking familial support.

The CEO and founder President of EDYCS Mauritius underscored the significance of nurturing robust personal relationships for achieving collaborative successes. The presentation stressed the pivotal role of engaging the business sector in epilepsy initiatives and IGAP implementation, fostering opportunities analogous to those in the business realm.

Key Achievement: EDYCS Mauritius highlighted achievements such as sensitizing sixty-two Members of Parliament, including key ministers, on IGAP. The initiative successfully integrated IGAP onto the agenda of the National Assembly's parliamentary questions session. Collaborative workshops with medical professionals, educators, and parastatal bodies led to constructive inputs for domesticating IGAP. Additionally, an agreement was reached with the Ministry of Health to establish an IGAP working committee for further exploration.

Kenya Association for Welfare of People with Epilepsy emphasized their close collaboration with the Kenya Ministry of Health. Their efforts focused on demystifying epilepsy in communities and establishing epilepsy care in health centers across counties.

Key Achievement: The Association managed to sign two Memorandum of Agreements with two counties on domestication of IGAP. They also secured high level political will from the Presidium bu appointing the Second Lady of Kenya as the IBE Epilepsy Ambassador.











DAY TWO – 21ST NOVEMBER
Opening Session



The final day of the conference began with opening remarks from Nsom Kenneth of Cameroon. After the opening remarks and the recap of the first day by getting comments from all participants.







Generating Evidence and IBE Global Needs Survey

The second day of the conference unfolded with a series of significant sessions, each addressing critical aspects of epilepsy advocacy and research. Among these sessions, one featured Prof. Gus A Baker, who delivered insights on "Generating Evidence."
Prof. Baker elucidated on the process of generating evidence, touching upon key strategies including the identification of areas requiring attention, the establishment of effective methodologies, potential barriers to research, challenges inherent in conducting studies, and offering comprehensive conclusions. As the Secretary General of the International Bureau for Epilepsy (IBE), Prof. Gus Baker underscored the paramount importance of data collection in the context of policy advocacy, emphasizing its role in shaping informed policies and practices.

Additionally, Dr. Sebastian, serving as the IBE Head of Policy and Research, delivered a presentation remotely, shedding light on the GENS (Global Epilepsy Needs Survey) initiated by the IBE. Dr. Sebastian detailed the objectives and outcomes of this comprehensive survey, showcasing its significance in understanding and addressing the diverse needs within the global epilepsy community. The presentation could have outlined the methodology employed, key findings, and the anticipated impact of the survey in informing targeted policies and interventions to better support individuals affected by epilepsy worldwide.

The session continued with Donna Walsh, the CEO of the International Bureau for Epilepsy (IBE), focusing on the upcoming 2024 International Epilepsy Day (IED). Donna Walsh communicated to IBE chapters the designated theme for the 2024 IED, which is "My Epilepsy Journey." She emphasized the importance of IBE chapters across Africa leveraging hashtags such as #MyepilepsyJourney or #EpilepsyDay during the International Epilepsy Day.

Furthermore, Donna Walsh elaborated on ways for IBE Chapters and individuals living with epilepsy to actively engage in the month leading up to the IED. Suggestions included sharing personal stories through written narratives or videos, submitting various forms of artistic expression such as drawings, organizing events, and participating in online discussions.

Highlighting the significance of social media engagement, she concluded by encouraging the posting of selfies related to all activities during the IED and the preceding month. Her directives aimed to inspire widespread participation, encouraging individuals, chapters, and communities to actively contribute to the 2024 International Epilepsy Day, fostering a collective celebration and awareness of “My Epilepsy Journey.”









Making Epilepsy a Health Priority in Africa 2024

During a presentation by the IBE Chairperson and Vice President for the Africa Region, the 2024 work plan titled "Making Epilepsy A Health Priority in Africa" was introduced. The comprehensive plan for the year centered on three fundamental pillars: Awareness Raising, Policy Dialogue, and Capacity Building.

Highlighting the Awareness Raising pillar, the emphasis was placed on planning and executing a pilot anti-stigma working group/team in Kenya. Additionally, a commitment was made to continue the small funds program, offering support to IBE chapters for implementing anti-stigma interventions and adopting stigma benches as an initial step toward Integrated Global Action Plan (IGAP) integration.

The Capacity Building pillar aimed to cultivate a diverse group of advocates and fortify IBE Chapters. To achieve this objective, there was a focus on enhancing essential leadership skills within the IBE chapters.

The third pillar, Policy Advocacy and Action, centered on advocating for the implementation of IGAP recommendations as part of the call to action aimed at eradicating epilepsy stigma in Africa. Amos Action, the IBE Vice President for the region, emphasized that support would be extended exclusively to countries or IBE chapters exhibiting a proactive involvement in high-level meetings and IGAP workshops. They stressed the importance of cross-cutting pillars and showcased a high level of commitment towards fulfilling the objectives outlined in the Intersectoral Global Action Plan for epilepsy and other neurological disorders (IGAP).



Call to Action Launch

The subsequent segment of the session was dedicated to the Call to Action, which engaged participants in group sessions aimed at providing insights and contributions to the proposed Call to Action. Following these group discussions, a plenary session facilitated general discussions and further inputs. Subsequently, a dedicated team involving the IBE CEO, Donna Walsh, and Amos Action reviewed and refined the Call to Action based on the collective feedback.

Upon its refinement, the finalized Call to Action was formally launched and signed. This momentous occasion was led by the Deputy Minister for Health in Ethiopia, symbolizing a significant endorsement and commitment to the cause. Subsequently, the Ethiopian Human Rights Commission also lent its support by signing the Call to Action, solidifying a collaborative and multi-stakeholder commitment toward addressing the objectives outlined within it.









Advancing implementation of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) in Africa

Esteemed Policymakers and Development Partners,

Your steadfast commitment is urgently sought to advance the implementation of the globally endorsed WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 -2023 [IGAP].

On November 20th to 21st 2023, the International Bureau for Epilepsy [IBE] held its inaugural Epilepsy in Africa conference, themed: 'Stamp Epilepsy Stigma out of Africa'.

There, advocates from 20 African countries, acknowledged the importance of the ratification of IGAP by all African Member States, committing to achieve 10 country-level targets by 2031 and aligned on a set of recommendations which have been encapsulated in this Call to Action.

Consequently, we implore all policymakers and decision-makers to:

1.Co-produce IGAP domestication and implementation roadmaps or plans by 2025, fostering meaningful engagement of individuals with lived experiences, underpinned by intersectoral collaboration.

2.Ensure these roadmaps align with past resolutions on epilepsy and are synchronized with global and regional commitments such the United Nations Sustainable Development Goals and the United Nations Convention on the Rights of People with Disabilities.

These roadmaps must encompass the priority thematic areas highlighted during the conference, deemed essential prerequisites to fulfil IGAP's objectives in the region:

•Close the prioritization gap by creating national plans or strategies on epilepsy and other neurological disorders, and/or integrating epilepsy and other neurological disorders in intersectoral national plans or strategies of relevance; aiming to provide a comprehensive framework in which the wider unmet needs of all persons with epilepsy and neurological disorders across the life course, and within all parts of our society, are addressed.

•Close the inclusion gap by taking a human rights-based approach to addressing the stigma, discrimination and social exclusion of people with epilepsy, increasing knowledge of epilepsy and other neurological disorders through the roll-out of national awareness campaigns, and designing social inclusion programs to ensure active participation of people with epilepsy and other neurological disorders in our societies.

•Close the treatment gap by defining healthcare pathways, improving access to diagnosis, treatment and care by addressing shortages of essential medicines for epilepsy and other neurological disorders – including at times of crisis – and building health workforce capacity with a focus on primary healthcare services.

•Close the data gap by ongoingly collecting regional data on the burden of epilepsy, monitoring and evaluating the cost-effectiveness of existing and new interventions and allocating sufficient resources to the implementation of evidence-based approaches to care.

Your support and proactive engagement in this imperative endeavour are vital to foster meaningful change in the landscape of neurological health in Africa.

Alongside the International Bureau for Epilepsy and its chapters across the African region, the following organisations have shown their support for this Call to Action:

The success of our recent conference was significantly bolstered by the invaluable contributions and steadfast support of our esteemed partners. We express our profound gratitude to Dr. Simon Kariuki of KEMRI Kenya, Dr. Charles Newton, Dr. Chahnez Triki of Tunisia, Jacopo Rovarini from AMREF, Prof. Massimo Leone (SIN), Dr. Tobela from AAS, and Dr. Kone from ILAE, who graciously participated both online and in person as distinguished panelists. Their expertise, diverse perspectives, and active engagement enriched our discussions, elevating the depth and breadth of our discourse on epilepsy and neurological disorders. Their invaluable insights and unwavering commitment significantly contributed to the success of the conference, leaving an indelible mark on our collective mission. We extend our heartfelt appreciation for their pivotal role in ensuring the conference's success and look forward to continued collaboration in advancing our shared objectives.

DAY TWO – 21ST NOVEMBER
Clossing Session

The Epilepsy Congress concluded at 4:50 PM Ethiopia time, marked by a vote of thanks delivered by the Vice President of IBE Action, Amos. Following the congress, participants had the opportunity to visit both the Care Epilepsy Ethiopia center and the Ethiopian Cultural Centre.







DAY TWO – 21ST NOVEMBER

Social Event - Visit to Care Epilepsy









