

AFRICA REGION

MAKING EPILEPSY A HEALTH PRIORITY IN AFRICA – PHASE II: SUMMARY AND RENEWAL REQUEST – NOVEMBER 2021

The International Bureau for Epilepsy [IBE] has 135 chapters in 104 countries. These chapters are comprised of national epilepsy associations whose focus is to improve the social condition and quality of life of people with epilepsy and those who care for them. IBE helps these national organizations to achieve greater impact by developing and implementing programs; providing tools to enhance organizational effectiveness; and by investing in people with epilepsy allowing them to fulfill their full potential as community leaders and key drivers of systemic change.

IBE Chapters are grouped within seven regional structures following the WHO regional boundaries: Africa, Eastern Mediterranean, Europe, Latin America, North America, South East Asia and Western Pacific. IBE Africa Region consists of 24 chapters in 22 countries. This network is the voice of 10 million people with epilepsy in Africa. Over 75% of people in Africa with epilepsy live in rural and semi-urban areas where treatment is nearly non-existent and epilepsy is stigmatized, underfunded and ignored by the health care system.

Background & Phase II Summary

Since 2019, the BAND Foundation has generously supported the International Bureau for Epilepsy's Africa region with a goal of ensuring that epilepsy becomes a health priority in Africa. In phase II of this initiative, we focused on the following objectives:

1. Improving the visibility of epilepsy initiatives in Africa
2. Strengthening the technical capacity of the regional project management team
3. Enhancing the capacity of African epilepsy organizations to influence health policy
4. Strengthening the regional engagement and working relationship with WHO African Region, African Union (AU), ILAE Africa and Pan African Parliament (PAP)

Fundamental to the success of phase II was investing in the capacity of the African Regional team. Prior to the BAND grant, there were no funded staff persons to lead and carry out the work of IBE in Africa. (<https://epilepsyafrika.org/committee/>). Under the project leadership, IBE Africa has engaged and trained advocates, provided educational resources across the continent, built and grown a network of advocates and organizations, funded meaningful projects and influenced policy makers.



Action Amos and Betty Nsachilwa together with HRH Prince Bandazile of the Kingdom of Eswatini

A notable accomplishment in phase II was the development and implementation of the *Advocate's Toolkit for Making Epilepsy a Priority in Africa*. The engagement strategy used to design the tool kit (<https://epilepsyafrica.org/advocates-toolkit/>) and the implementation training helped to build knowledge and skills in 48 advocates. Additionally, the toolkit has been promoted on the website and through a webinar. Other regions of IBE have requested to modify the toolkit for their unique settings and for it to be translated in other languages. We are working with another possible donor to develop a similar resource for Latin America.

The timing of the tool kit training was ideal as it aligned with a call to action from the Director- General of the World Health Organization to develop a 10-year ***Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders*** (WHA73.10). The Brain Health Unit at the WHO sought public opinion and input on the first draft of this plan and invited civil society to identify achievable global targets. With funding from the BAND Foundation, the project coordinator worked with IBE Africa chapters to develop an engagement strategy to enhance the capacity of people with epilepsy to influence health policy and to ensure that their voice was represented at every stage of the WHO consultation process. People with epilepsy were encouraged to provide feedback on ways to strengthen service coverage and access to essential medicines. They were asked for recommendations to reduce stigma and discrimination. The project coordinator worked with the IBE Africa Regional Advisory Committee to develop written materials and letters for governments and Ministries of Health. IBE chapters in Africa sent letters to their Ministries of Health and had meetings requesting the WHO Secretariat implement a 90-80-70 cascade target for epilepsy: 90% of all people with epilepsy in Africa are aware of their diagnosis as a treatable brain disorder; 80% of people diagnosed with epilepsy in

Africa will have access to appropriate, affordable, safe anti-seizure medicines; and 70% of those treated will achieve adequate seizure control through long term availability of treatment. The IBE network in Africa was able to secure written commitments for the proposed 90-80-70 cascade target from 49 partners and stakeholders including the Ministries of Health in Eswatini, Lesotho and Cameroon. They received the endorsement of 14 IBE affiliates with additional support from two key networks namely the Pan African Network for Persons with Psychosocial Disability (PANPPD) and the South African NCD Alliance. The capacity that was built through our BAND Foundation partnership contributed significantly to this successful outcome.

To improve the visibility of epilepsy initiatives in Africa, BAND Foundation funding was used to develop a communications strategy and to hire a communications support person. The communications support person maintained the www.epilepsyafrika.org website and organized 9 training webinars. These webinars were attended by 413 people representing countries across the continent. In addition, the communications support person established a YouTube Channel that was viewed by 373 people; and used Facebook, Twitter and Instagram to reach an audience of 1000+.

IBE Africa published a **health laws mapping report** (<https://www.ibe-epilepsy.org/wp-content/uploads/2021/06/IBE-Africa-Report-on-the-21-States-copy.pdf>) with legislation reviewed in 21 countries. This baseline data of existing legislation, particularly in the areas of health, education, driving, employment, marriage, and social inclusion, will be used to address and amend clauses that discriminate against people with epilepsy. It is notable that WHO Geneva asked for permission to circulate this mapping report.

In phase II, \$50,000 was distributed to 6 countries through a competitive grants process. The goal of this small grants fund was to help epilepsy organizations implement education and advocacy projects. This table provides brief project descriptions.

Country Name	Project Goal	Project Outcome
Mauritius – Edycs Epilepsy Group	Training of ECCEA Pre-School Teachers in Epilepsy and Seizure Disorder	150 Preschool teachers trained and using training tools and knowledge to support parents and other school staff
Eswatini Epilepsy Organization	To lobby and advocate for the development of epilepsy national plan	Draft Plan under review with the Ministry of Justice
Zambia – Epilepsy Association of	Education Survey in Lusaka	40 stakeholders and authorities engaged to support education for

Uganda- Purple Bench	Create epilepsy smart communities in sub-counties of Kyanamukaaka and Butego in Masaka	20 local government leaders trained in one-day workshop in August 2020 by epilepsy experts
Malawi – National Epilepsy Association of Malawi	Fighting Epilepsy Silence in Rural Malawi Using Technology	6 Volunteers trained to use drug audit/availability check tool on using a mobile phone
South Africa – Epilepsy South Africa	Using WHA68.20 Resolution to make epilepsy a public health priority	Establishment of a National Epilepsy Taskforce
Zimbabwe – Individual Youth Grant	Epilepsy Campaign Video	Developed musical video to teach others about epilepsy
Epilepsy Association of Zimbabwe	To develop a National Epilepsy Plan	Not successful 90% funds retained

In addition, Cameroon, Eswatini, Lesotho, Malawi, Mauritius, Sierra Leone, Tanzania, Uganda, and Zambia received small grants (~\$700 per country) to engage people with epilepsy to participate in the 50 million steps challenge, an IBE global epilepsy awareness initiative.



A photo of Edycs Epilepsy Group in Mauritius

KEY OBJECTIVES AND RATIONALE PHASE III 2022

We have learned in phase I and phase II that implementation of policies and plans for epilepsy requires strong leadership and inter-sectoral collaboration. The grassroots epilepsy movement that has been mobilized and strengthened through the partnership with the BAND Foundation has yielded so many positive outcomes but there is still work that needs to be done to ensure that policy makers, the WHO, and elected officials prioritize epilepsy as a public health priority in their 2022+ budgets and work plans.

In many countries, laws impacting the lives of people with epilepsy are outdated and fail to protect and promote their human rights. Legislation for epilepsy, where it exists, sometimes actively violate the rights of people with epilepsy. This leads to unmet needs in the areas of education, employment, residential and community services, and access to appropriate and affordable health care. Left untreated, people with epilepsy face devastating consequences.

In phase III, IBE Africa will continue to provide infrastructure support to IBE chapters and skills training to people with epilepsy. We will prioritize three key areas that we believe will narrow the epilepsy knowledge gaps and improve the social condition of people with epilepsy in Africa.

Key Area One: Legislative and Policy Framework

Aim: Strengthen the capacity of chapters to influence health policy makers to adopt and implement WHO IGAP

The adoption of WHA68.20 in 2015 drew attention to the need for coordinated action for epilepsy at the country level. WHA68.20 opened doors for people with epilepsy in every region of the world giving them a reason to meet with policy makers. It was also the catalyst for the development of the 10-year intersectoral global action plan (IGAP) on epilepsy and other neurological disorders (WHA73.10). In May 2022, at the World Health Assembly in Geneva, member states will be asked to ratify WHA73.10 which includes Strategic Objective 5.0 which commits signatories to strengthen their public health response to epilepsy. Ratification of WHA73.10 will become the most powerful weapon in the arsenal for people with epilepsy in Africa. After ratification, member states will be asked by the WHO Secretariat to take concrete action at the country level to reduce the treatment gap; to improve access to safe and affordable medicines and to protect the rights of people with epilepsy in national legislation.

In phase III, it will be critical for IBE chapters to support people with epilepsy who will need to advocate for ratification of this resolution and once ratified to monitor progress of its domestication. It will be incumbent upon people with epilepsy to work with policy makers to create opportunities to strengthen the public health response to epilepsy at the country level.

In this phase III we are requesting funds to support the IBE chapters in Mauritius, Eswatini and South Africa allowing them to dedicate a staff person to the legislative and policy

framework project. Funds will be used to partially offset their wages, to allow them to attend face-to-face meetings with the MOH and to recruit Intersectoral partners and collaborators. These 3 chapters will work with the project coordinator to set up a regional advisory group. They will develop an IGAP monitoring and evaluation tool and an exchange hub to share best practices. These chapters were selected because they have each developed a strong connection to policy makers at the national level. They also have the professionalism that is necessary to develop a formal partnership with their Ministries of Health. To build on the work of the lawyer network group, they will develop materials to promote proactive laws and policies that are aligned to WHO IGAP.

- Maintain Steering Committee and External Advisory Committee to provide project oversight and best practice guidance.
- Work with other NGO's (AMREF, NCD Alliance, ILAE African Region, PANPPD, African Medicines Agency, African Lawyers Network for Epilepsy, UNICEF, etc.) to establish Intersectoral collaborations.
- Set up a regional advisory group (Ministries of Health; IBE advocates, people with epilepsy, and other key stakeholders) to develop a plan of action to monitor the progress towards implementation of the WHO IGAP in Africa. Terms of Reference will be developed by the Project Coordinator, African Regional Executive Committee and IBE HQ.
- Set up an IGAP monitoring and evaluation tool and an IGAP exchange hub to share best practices.

Key Area Two: IBE Academy

Aim: Address the disparities in access to authoritative, culturally relevant epilepsy information

One of the key priorities of the incoming IBE management team is the development of the IBE Academy to improve access to authoritative, culturally relevant epilepsy information. The Academy will be the first accredited global training program for people with epilepsy. IBE HQ is currently meeting with potential donors but has committed to investing \$100,000 in 2022 to hire a project coordinator and to develop training modules for the Academy. Many Academy modules will be condition specific: counselling people with epilepsy; diagnosing and treating epilepsy; assessing risk; staying safe and active; epilepsy across the lifespan (children, youth, men, women, older adults); and identifying and managing comorbidities. These condition specific modules will be developed by IBE HQ for use in all IBE world regions.

Two modules, one related to stigma and the other to health diplomacy will be developed with content specific to the African Region. These modules will be highly interactive using instructor led facilitation to small groups (6-8 participants per session). Having instructor led modules will allow facilitators to evaluate health literacy and to engage group discussion. It is expected that these African Region modules will include testimonials, video clips, expert panels, group discussion and regional case scenarios. Stigma is a

significant contributor to poor physical and mental health in people with epilepsy. Stigma can delay appropriate health care seeking, access to care, health financing and availability of treatment. The Africa Academy stigma module will be developed to identify cultural aspects of stigma and regional strategies and plans to reduce discrimination.

The health diplomacy module will reinforce the tools found in the *Advocates Toolkit* and will include instruction related to health diplomacy and health negotiation, the role of the WHO, elected officials and policy makers.

The development of these modules will include strategies and case studies that are relevant to regional challenges: stigma in the family, community, school and workplace; understanding barriers to access safe and affordable anti-seizure medicines, working with traditional healers, the role of the media, negotiating with health policy makers, training health care providers. The methodology for the development of these two African Academy modules will be similar to the Geneva Global tool kit development where IBE established a small advisory group, worked closely with the consultant, engaged chapter personnel to solicit input and asked stakeholders to provide feedback on the final content and design. With funds from BAND Foundation, we would like to hire a consultant with a proven track record of working in Africa to develop interventions. Our timeline includes developing the two African modules and piloting them in 5 countries by the end of 2022.

Key Area Three: Capacity Building

Aim: Increase opportunities for knowledge sharing, networking, partnering, and advocating for the creation of national epilepsy plans

At the end of phase II, the project coordinator and the Africa Regional Executive Committee (AREC) surveyed small grant recipients. These recipients reiterated that receiving dedicated funds allowed them to increase their visibility with their health and government stakeholders. They identified that small grants have provided them with the capacity to dedicate time and personnel to advocating for improvements in care. They acknowledged that without these funds, advocacy is reactive not proactive. In phase III we will announce a small grant competition in January and issue a request for proposals. The competition is open to all countries. There are however countries that are primed for small grants: Cameroon, Lesotho, Ghana, South Sudan and Sierra Leone. Cameroon and Lesotho have signed a formal partnership agreement with their Ministry of Health. To be eligible for a small grant, a country will need to show evidence that they have used a tool kit template to develop a plan of action. Grants will be announced in March.

In phase III, IBE Africa Regional Executive Committee (AREC) is requesting funds to develop materials and messaging to support International Epilepsy Day. The funds will be used to develop campaign materials in English, French and Portuguese and a social media campaign with unified African messaging.

In addition, AREC would like to launch a Champions Bursary Fund to empower individual community advocates. AREC would like to be in the position to offer small bursaries for

women and/or youth who demonstrate that they can effectively influence and advance progress towards social inclusion of people with epilepsy in their community. These individuals may be youth with epilepsy, nurses, teachers, journalists, film makers, social workers, students and/or IBE Golden Lights Recipients. The applicants for these small bursaries will be asked to share their project idea using a manageable one-page application. The benefit of a bursary is that it will attract people who are not formally engaged with IBE chapters but who have a personal motivation to support change at the community level.

- Launch round three of a small grant's advocacy fund
- Develop February 2022 International Epilepsy Day Campaign
- Establish 'Champion' Bursary Fund to individuals
- Host media training webinar for French language countries
- Hire a consultant to develop a regional fundraising and sustainability plan

In phase II, the project management team appointed an External Advisory Committee which included a Trustee from the BAND Foundation and appointees from WHO Afro Regional Office, African Union, African Disability Alliance, IBE HQ, ILAE and Kenya Medical Research Institute. His Royal Highness Prince Bandazile of the Kingdom of Eswatini and Dr. Joyce Banda, the Former President of Malawi were appointed Honorary Patrons.



Dr. Joyce Banda – Former President of Malawi

MONITORING AND EVALUATION

- A full monitoring and evaluation plan will be developed in consultation with BAND Foundation.
- The IBE Academy will be piloted in Africa. The development of the Academy modules and the curriculum is being supported by an expert advisory group who have been appointed to design and implement the program evaluation.
- The External Advisory Committee will be maintained with appointments of new members to fill any identified gaps.
- IBE Africa Regional Executive Committee (AREC) will continue to provide project oversight and will continue to provide monthly written progress reports.
- IBE HQ will provide governance, guidance, supervision and fiscal oversight to IBE Africa Region.
- IBE HQ will work with AREC to develop a regional fundraising and sustainability plan.