

**MAKING EPILEPSY
A HEALTH PRIORITY IN AFRICA**
UTETEZI PROJECT PHASE 2



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BACKGROUND

The Utetezi Pilot Project, funded by the BAND Foundation in 2019, provided funding to five African countries to develop the groundwork to create national epilepsy task forces, the development and implementation of national epilepsy plans, and the introduction of educational initiatives to address the recommendations of WHO Resolution WHA68.20. The evaluation of the pilot project has provided direction and opportunities which will be harnessed in phase 2, where we will establish a communication plan, website and tool kit to share best practices. Phase 2 offers a small grants program to enable IBE chapters to develop plans at the national level and to work together to develop and disseminate a regional plan of action. This project is grounded in the core rallying principle of the 2030 Agenda for Sustainable Development – leaving no one behind. During its implementation, and in alignment with the commitment to sustainable development goals of regional governments, effort will be made to identify regional stakeholders to support the project cause. There will be the opportunity also to increase efficiencies and value for money through harmonized operations with the Promising Strategies Program, which are also supported by the BAND Foundation.

In addition, the project seeks to complement the efforts of state and other non-state actors and to empower persons with epilepsy, through capacity building, to influence society at large and policy makers to include epilepsy on national and regional health agendas. Other aspects of the project will be directed at capacity building of regional leadership in the development of well-equipped epilepsy initiatives. Interventions will be focused on both national and regional duty bearers with the aim of awareness raising, information sharing, and empowerment at all levels to break the barriers that hinder access to health services.

In response to the Corona virus threat, the project will also provide unique, innovative platforms for engagement using online platforms. This initiative recognizes the imperative to collaborate with people with epilepsy if a sustainable intervention is to be achieved. In doing so, we are confident that Epilepsy in Africa will have new face with the vision of contributing to barrier-free health systems.

OBJECTIVES

1. To improve the visibility of epilepsy initiatives in Africa
2. To strengthen the technical capacity of regional project management teams
3. To enhance the capacity of epilepsy organizations to influence health policies
4. To strengthen regional engagement and working relationship with WHO AFRO, the African Union (AU), ILAE Africa and the Pan African Parliament (PAP).

METHOD OF WORK

Structure

The IBE Project will be governed by a Steering Committee and supported by two standing committees - Advocacy and Communications. There will also be an External Advisory Team that will be part of the Steering Committee.

Steering Committee

The Project Steering Committee is a decision-making body within the project governance structure that provides, reviews and monitors strategic direction and policy guidance to the project coordinator and other stakeholders. The committee also provides recommendations on project approaches and participates in discussing general strategies and opportunities for project planning and implementation.



External Advisory Committee

The Advisory Committee will contribute ideas and offer advice on the overall strategy and direction of the project, particularly:

- Guidance to the Steering Committee.
- Guidance to the Project Coordinator.
- Broader strategic development for the project.
- Help in developing the project's position within networks locally, nationally and internationally.
- Act as a sounding board for new ideas and developments in the project.
- Provide appropriate and constructive support to the operation of the project and its Committees.
- Advise the Programme Coordinator on the overall development of the programme.

Communications Committee

The Communications Committee will be responsible for overseeing delivery of the project's strategic priority for Communications – Raising awareness through public engagement: to inspire and educate people about epilepsy, and allow them to make informed decisions which recognise the importance of making epilepsy a health priority.

The Communications Committee will provide communications advice and expertise on the development of a Communications Strategy and will be responsible for overseeing delivery of all communications activities.

MEMBERS OF THE STEERING COMMITTEE

IBE Management:

Ms Ann Little (IBE Executive Director)
Ms Mary Secco (IBE Secretary General)

African Regional Committee:

Mr Youssouf Noormande (Vice Chair IBE AREC)
Ms Betty Nsachilwa (Secretary IBE AREC)

BAND Foundation:

Ms Gardiner Lapham (Trustee)

Advocacy Committee

The Advocacy Committee will be responsible for:

- identifying advocacy needs and resources (i.e. toolkits, individuals, chapters) while working in conjunction with specific chapters
- providing specialized expertise/resources on any specific epilepsy issue/topic that might arise;
- facilitating networking and communication opportunities relating to advocacy;
- supporting national and regional relations strategies;
- communicating advocacy efforts to stakeholders.

MEETINGS AND RECORD-KEEPING

The project's business will be conducted through formally and appropriately constituted meetings – either meetings of all those involved in the project or meetings of the separate committees established to advise the project on various aspects of the project's business.

All meetings will be fully documented to include:

1. an agreed agenda;
2. necessary meeting papers and reports to aid decision taking by the Steering Committee, circulated to members sufficiently in advance for their full consideration;
3. accurate minutes recording discussion and decisions taken, to be approved by the relevant committee at its following meeting and maintained by the Project Coordinator.

MEMBER OF THE EXTERNAL ADVISORY COMMITTEE

- Dr Florence Baingana (World Health Organization AFRO Region)
- Prof Olawale Maiyegun (Africa Union)
- Ms Sarah Nekesa (Epilepsy Support Association of Uganda)
- Dr Symon Kariuki (Kenya Medical Research Institute)
- Dr Sammy Ohene (International League Against Epilepsy)
- Mr Action Amos (Secretary)

MEMBERS OF THE ADVOCACY COMMITTEE

- Ms Nina Mago (Young person with epilepsy - Uganda)
- Mr Max Bangura (Sierra Leone Epilepsy Association)
- Ms Marina Clarke (Epilepsy South Africa)
- Mr Action Amos (IBE-Africa) - Chair

MEMBERS OF THE COMMUNICATIONS COMMITTEE

- Ms Chantelle Kanyabutembo (Young person with epilepsy - Rwanda)
- Ms Comfort Mussa (West and Central Africa)
- Ms Angela Oketch (East Africa)
- Ms Sally Nyakanyaka (Southern Africa)
- Mr Action Amos – Chair (IBE)
- Ms Ann Little (IBE)