



EPILEPSY AFRICA NEWS

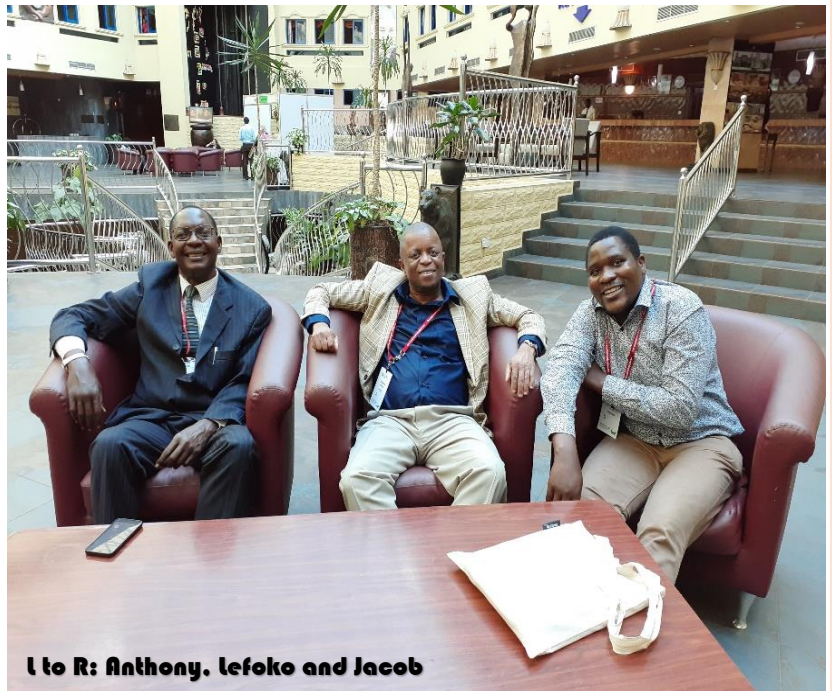
Issue 19

July - August 2019

A Newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)



L to R: Thelma and Tedi - KAWU



L to R: Anthony, Iefoko and Jacob

Cover Pictures: Some of the Delegates at the 4th Africa Epilepsy Congress in Entebbe, Uganda

Contents

- **Highlights on 4th African Epilepsy Congress held in Entebbe, Uganda from 22nd to 24th August, 2019.**

About this newsletter: Editorial team: Action Amos; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** Monthly **Distribution:** Email and other social media. **Email contributions to:** ibeafrika@gmail.com. Enjoy your reading!

How to join us:

WhatsApp group for people with epilepsy and significant others: +260977789042, group for professionals interested in epilepsy: +260977789042. Epilepsy Africa **Facebook** group: <https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts> **Twitter:** @EpilepsyAfrica. **Email list:** We have three email lists – for social issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrika@gmail.com. You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publications/regional-news/> and www.epilepsyafrica.org

CHAIRPERSON & EDITOR'S MESSAGE:



Welcome to this edition of Epilepsy Africa and very warm greetings to all readers of this important issue highlighting some of the features of the 4th African Epilepsy Congress held in Entebbe, Uganda from 22nd to 24th August, 2019.

The Congress hosted over 200 delegates and was considered to be interactive as more social issues were presented.

We wish to sincerely thank the Scientific and Organizing Committee for their tireless effort to ensure a successful programme for the Congress. The Committee comprised of (from left to right in picture) Prof. Agallo Diop, Ms. Mary Secco, Dr. Jacob Mugumbate, Dr. Angelina Kakooza-Mwesige, Ms. Helen Cross and Ms. Sarah



Nekesa, a combined team of members from ILAE and IBE. We would want to appreciate the contributions by all speakers and the effort done to ensure informative sessions and the support that was provided by the host IBE and ILAE Chapters.

It was a unique conference where medical research was challenged with social issues that cannot be addressed solely with medical treatments or knowledge of numbers. This will form basis of future social oriented research for Africa.

We look forward to a successful Fifth Session of an African Epilepsy Congress in 2021, subject to funding with the host nation to be announced.

Action Amos

IBE Africa Vice President

If you have a story you'd like us to consider for publication, please contact: ibeafrica@gmail.com, amos_action@yahoo.co.uk



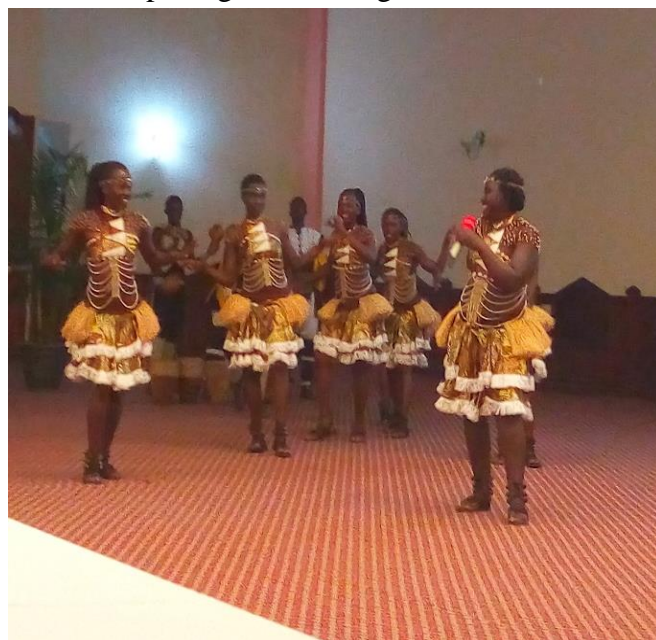
IBE Africa Meeting on 22nd August, 2019

The IBE African Region Meeting held on 22nd August, 2019 was attended by Kenya, Uganda, Malawi, South Africa, Zambia, Zimbabwe and Gambia represented by Ms. Tanya Spensley. The meeting received reports mainly on activities from each country. The Community on Development of Epilepsy Foundation (CODEF) of Cameroon sent a soft copy of their report.

With sixteen in attendance, the meeting successfully discussed the achievements and future endeavours of the AREC. Encouraging all to engage in fundraising ventures and advocacy projects more than ever before.

Entertainment

The wonderful occasion did not lack entertainment. The young Ugandan dance troupe entertained the delegates during the official opening of the Congress.



Presentations:



Mr. Taurai Kadzviti boldly spoke at the Congress, giving testimony of his experience with epilepsy and the care received from the local epilepsy support, the Epilepsy Support Foundation of Zimbabwe. He proudly thanked the Foundation for assisting him to discover his potential as a capable person who could achieve his desires despite being a person with epilepsy.

Global Epilepsy Report 2019

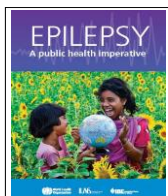


IBE Secretary General, Mary Secco, announced the release of the Global Epilepsy Report 2019 produced by WHO and key partners, IBE and ILAE.

The report highlights the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels.

This report was a call for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination in all parts of the world. It is time to highlight epilepsy as a public health imperative, to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

The report is a guiding tool to all seeking to reduce the disease burden as part of the universal health coverage agenda. The delegates were encouraged to read the Report, especially online, since there were only a few hard copies for distribution at the Congress.



https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/

Africa Union Representation

Another exciting feature during the Congress, was a presentation by Mr. Lefhoko Kesamang from the African Commission on Human and People's Rights - Africa Union. The congress delegates were assured of AU's commitment to



ensuring promotion of human rights for people with disabilities, which includes people with epilepsy, and the elderly. Mr. Kesamang informed the congress that a Protocol was drafted on disability rights and awaited signing from member states. It should be noted that the African Disability Rights Protocol will only become effective once it has been formally accepted ('ratified') by 15 of the 55 AU member states. At the time of the Congress, only five countries had signed for ratification of the said Protocol.

He urged all present as representatives of their countries to take interest in promoting rights for people with disabilities, particularly PWE in this case through legislature.

IBE Symposium:

The symposium was held after the official closure of the Congress, and was Co-chaired by Mr. Action Amos of Malawi (IBE Africa Vice President) and Ms. Sarah Nekesa of Uganda.



The presenters were Ms. Nina Mago (Uganda and Africa winner of the Golden Lights Award 2019), Ms. Betty Barbara Nsachilwa (Zambia and IBE AREC Secretary), Ms. Marina Clarke (National Director of Epilepsy South Africa). There was also a discussion with panelists being Mr. Anthony Mulenga Zimba (Zambia and

IBE Treasurer), Dr. Osman Miyanji (Kenya and KAWE Board Member), Mr. Mbusomuni Mahlalela (Director Eswatini Epilepsy Organization) and Mr. Max Bangura (Sierra Leone).

Nina and Betty narrated experiences and challenges common to a person with epilepsy. With one experiencing stigma and discrimination while the other faced overprotection from parents. On the way forward, they both encouraged the audience to be knowledgeable about their condition, to be agents of change by demanding for better health care services and to be fully involved in the work of the existing support groups in their countries. Ms. Clarke also gave the successful activities of the Epilepsy South

Africa, how it is sustained through fundraising and its collaboration with Disability Organizations.

Ms. Justine Engole, Project Coordinator of the African Epilepsy Advocacy (Utetezi) Project was given a chance to inform the participants on **Developing a Plan of Action: Lessons from the Advocacy Project.**

This was followed by Group discussions on Addressing Stigma in Africa: The Way Forward. There were four groups and presentations were on:



Group 1 – Stigma in rural areas

Group 2 – Stigma in Urban Areas



Group 3: Stigma among children and young people

Group 4 – Treatment as a Strategy to address Stigma









EPILEPSY SOCIETY UGANDA & EPILEPSY SUPPORT ASSOCIATION
4TH AFRICAN EPILEPSY CONGRESS IN UGANDA
 HELD AT IMPERIAL RESORT BEACH HOTEL ENTEBBE-UGANDA **22ND - 24TH AUG, 2019**

Your contribution to the newsletter means continuity:

We are calling for chapters, their groups and members to contribute to the newsletter. You could share this with us:

1. Your local Newsletter
2. Your plans for 2020
3. Questions on epilepsy care
4. Photographs

Did you enjoy reading our newsletter? Please give us some feedback: Email - ibeafrica@gmail.com
 If you have any other topics to suggest, please email us at ibeafrica@gmail.com by 20th of each month

Next Issue to feature: National Epilepsy Purple Week – Rwanda – Local Newsletter
 New Features: Know Your Chapter
 Leader of the Month