



EPILEPSY AFRICA NEWS

Issue 7

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

March 2018

Contents of this Newsletter

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- Funding and fundraising for the region
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Images (right top): Epilepsy day in Swaziland. Bottom: Purple day in DRC. We thank Mr Mbuso Mahlalela and Dr Prince Kazadi for the hard work in their countries. Full reports will be available in the next issue of the newsletter.

MEDIA LAUNCH



LAUNCH: Swaziland Epilepsy Organization National Director Mbusomuni Mahlalela addressing the media during the Epilepsy Week launch at Pot and Garden – Swazi Plaza.

Join us today

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 ibeafrica@gmail.com.



About this newsletter

Editorial team: Jacob Mugumbate; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** Monthly **Distribution:** Email and other social media. **Email contributions to:** ibeafrica@gmail.com. Enjoy your reading!

Epilepsy Association of Zambia 2018 International Epilepsy Day Activities



Given the wet weather conditions during the month of February in Zambia, it has been difficult to have outdoor activities to commemorate the International Epilepsy Day. However, this year the Association participated in sensitizing the Community on Epilepsy through interviews and health talks.

INTERVIEWS:

The highlighted interview was held on Saturday, 10th February, 2018, where Mr. Anthony Mulenga Zimba, Chairman of the Association, appeared on the national Radio Station phone-in programme at the Zambia National Broadcasting Services to announce the activities lined up for the epilepsy week and answer questions from listeners. It was encouraging to hear callers from all parts of the country participating and expressing their gratitude for a talk on epilepsy.



HEALTH TALK:

A sensitization talk which was supposed to be held on 6th February, 2018 at Ministry of Home Affairs, was held on Wednesday, 14th February in conjunction with the Zambia Agency for Persons with Disabilities (ZAPD). The theme was centered on 'Common Disabilities and their myths'. Mr. Zimba began with topics on epilepsy, followed by Mrs. Emmah Kaputo Phiri from ZAPD who gave a presentation on various disabilities and urged all to treat people with disabilities with the respect they deserve. Not to overly feel pity but interact with them normally.

More than forty workers in attendance appreciated the presentations. Most of those in attendance felt enlightened and the misconceptions they held earlier were dispelled. The Ministry of Home Affairs was targeted because it handles issues of internal security and correctional services. Under the Correctional Service, there are a number of epilepsy clients incarcerated for committing crimes such as arson and



murder. It was, therefore, prudent to discuss issues related to epilepsy to aid understanding the causes, dispelling myths and also encourage seeking treatment from qualified medical personnel at earliest stage of the condition. The audience were glad the important message was delivered and requested for more talks on the topic as some had relatives or friends living with epilepsy. Others even requested for consultation appointments with Mr. Zimba.

Though we have in the past been accustomed to holding outdoor awareness activities and had challenges organizing indoor events, the Association realizes that the Epilepsy Day could be celebrated in any way possible. The health talk was a success and we thank the Ministry of Home Affairs Management for affording us the opportunity and providing lunch for all in attendance. Looking forward to holding similar events in the near future.

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Please contribute to the newsletter

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 2017 report and plans for 2018
3. Questions
4. Photographs

We are on social media, join us today

You are encouraged to join these social media groups, and participate, follow, like posts, and comment regularly:

- WhatsApp Group for people with epilepsy and significant others: +260977789042
- WhatsApp Group for professionals interested in epilepsy: +260977789042
- Epilepsy Africa Facebook group: <https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts>

- 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 ibeafrica@gmail.com.
- Our Twitter account is here tweet to us: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica)

Funding and fundraising in our region

Our region is looking for funding for these needs of our chapters:

- Increasing the number of projects and amount of funding for young people.
- Funding for chapters that are struggling to remain afloat.
- Funding for new chapters.
- Funding for visits to chapters by AREC members.
- Travel bursaries to congresses, workshops and meetings.
- Fundraising for the region.
- Funding more advocacy initiatives.
- Funding income generating initiatives.
- Capacity building of chapters through training of treasurers and administrators.

The regional committee needs funding for:

- AREC meeting (face-to-face, once in 2 years) and online (twice a year).
- Regional Committee Meeting – face to face (all chapters, once in 2 years, usually at AEC).
- Fundraising for the region.
- Communication with struggling and new chapters (every year).
- Advocacy activities for each chapter (every year).
- Youth projects (every year).
- Visit to chapters (at least one chapter per year).
- Regional project - promoting WHO Resolution (every year).
- Regional project - promoting International Epilepsy Day (every year).
- Supporting and promoting attendance of member chapters to Africa Regional Congress 2019 and 2021 and International Epilepsy Congress 2019 and 2021.

These are some future large-scale projects suggested by members

- Income generating and employment projects.
- Research projects.
- Training projects.
- Infrastructure projects.
- Treatment projects.
- Fundraising consultant.

List of potential sponsors

As part of this budget statement, we are developing a list of potential sponsors for AREC. Could you please add to the list if you have suggestions? Provide as much detail as you can.

Name of potential sponsor	What they/may fund	Contact email, telephone, address etc

PLEASE SEE AND USE THE POSTER ON THE NEXT PAGE.

Do you have any other topics to suggest for a poster, please email us at ibeafrica@gmail.com

THREE SIMPLE STEPS TO IMPLEMENT THE WHO RESOLUTION ON EPILEPSY

Every government is obliged to implement the WHO resolution on epilepsy. There are THREE simple steps that the government of each country should take:

136th session
Agenda item 6.6

EB136.R8
2 February 2015

Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications

ONE: Forming a national taskforce that includes epilepsy associations, local League, Ministry of Health, local WHO office and other stakeholders.

TWO: Developing a national action plan for epilepsy that includes activities and funding for:

- a. Awareness
- b. Training of health and social care workers
- c. Research
- d. Medicines

1. URGES Member States:¹

- (1) to strengthen effective leadership and governance, for policies on general health, mental health and noncommunicable diseases that include consideration of the specific needs of people with epilepsy, and make the financial, human and other resources available that have been identified, as necessary, to implement evidence-based plans and actions;
- (2) to introduce and implement, where necessary and in accordance with international human rights norms and standards, national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services, paying special attention to people with epilepsy living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public health care services, and training local human resources with proper techniques;
- (3) to integrate epilepsy management, including health and social care, particularly community-based services, within the context of universal health coverage, including community-based rehabilitation, into primary health care, where appropriate, in order to help to reduce the epilepsy treatment gap, by training non-specialist health care providers to provide them with basic knowledge for the management of epilepsy so that epilepsy can be diagnosed, treated and followed up as much as possible, in primary health care settings, as well as by empowering people with epilepsy and their carers for greater use of specified self and home care programmes, by ensuring a strong and functional referral system and by strengthening health information and surveillance systems to routinely collect, report, analyse and evaluate trends on epilepsy management;
- (4) to support the establishment and implementation of strategies for the management of epilepsy, particularly to improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines and include essential antiepileptic medicines into national lists of essential medicines;
- (5) to ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions;
- (6) to promote actions to prevent causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health;
- (7) to improve investment in epilepsy research and increase research capacity;
- (8) to engage with civil society and other partners in the actions referred to in subparagraphs 1(1) to 1(7) above;

THREE: Implementing the national action plan

Where to start? Take a copy of the Resolution and meet the officials responsible for epilepsy in your country. Inform them about the three simple steps and ask them what they think about implementing the Resolution in your country.