



# EPILEPSYAFRICA NEWS

Issue 8

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

April 2018

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*Images (right top): Purple Day in the Democratic Republic of Congo (DRC). Bottom: Epilepsy day in Sierra Leone: Bangali tells his story in Sierra Leone during epilepsy week 2018.*



Bangali (25 years) said he first experienced seizure when he went to visit his girlfriend. It was not an easy episode but by the end my girlfriend took me home to my parents. When we reached home to my parents, they told me that I have been attacked by demon. I denied them and started to look out for medication until I came across the Epilepsy Clinic at Bo Government hospital. I suffered series of inconveniencies when I use to get seizure but now that my seizure is almost controlled, I thank God the stigma and discrimination is reduced.

## 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>

### 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:** [ibeafrika@gmail.com](mailto:ibeafrika@gmail.com). Enjoy your reading!

**Twitter:** [@EpilepsyAfrica](https://twitter.com/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](mailto:ibeafrika@gmail.com).

## Sierra Leone: International Epilepsy Day 2018.

*Report by Max Abu Bangura, [epilepsysl2014@gmail.com](mailto:epilepsysl2014@gmail.com)*

### **Report on the National Epilepsy Awareness-Raising Campaign Conducted by Epilepsy Association of Sierra Leone during the period of the 9<sup>th</sup> – 16 February 2018 in the Sierra Leone.**

#### **1. Introduction**

This year, the International Epilepsy Week took place on the 9<sup>th</sup> to 15<sup>th</sup> February, 2018. The goal of this celebration in Sierra Leone was to create a platform for people with epilepsy, their partners and service providers to share their experiences and stories with others thereby to build a stronger epilepsy community.

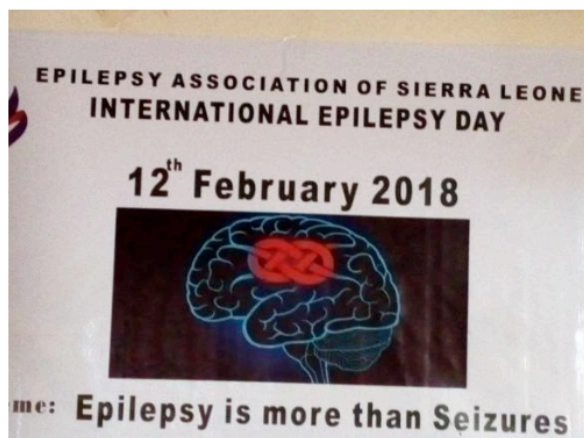
For Epilepsy Association of Sierra Leone (EASL), the theme of this year's celebration - 'Epilepsy is more than a Seizure' – is apt as we address more than the medical condition of our clients. Rather, we seek to address also the social and emotional aspects which often leads to isolation, exclusion and marginalization which in turn leads to poverty and poor life possibilities for persons living with epilepsy in Sierra Leone.

The celebrations of the International Epilepsy Week took the form of a national epilepsy awareness raising campaign conducted throughout the 3 main hubs that forms EASL's intervention areas in Sierra Leone

This report covers activities carried out in these 3 main hubs during the period of celebration



#### **Photos from Freetown Hub**



Freetown banner



Town hall participants

#### **Some speakers in Freetown town hall meeting**



Dr. Lisk (Neurologist)



Dr. Jalloh (Psychiatrist)



Dr. George (In charge of epilepsy and women in the project)



# **R** EPORT OF THE PURPLE DAY ORGANIZED BY THE ASSOCIATION IN THE FIGHT AGAINST THE STIGMA OF EPILEPSY BASED IN THE DEMOCRATIC REPUBLIC OF CONGO BY Dr PRINCE KAZADI, ERIC LUBOYA AND LEON KATANGA



The association against the stigmatization of epilepsy in the Democratic Republic of Congo organized on the occasion of the Purple day, an awareness campaign to fight against the stigmatization of epilepsy on all its forms, which constitutes our battlefield.

Report by Dr Prince KAZADI, Tel +243972253161, Email: princekazadi56@gmail.com



## **CONCLUSION**

The association fighting against the stigmatization of epilepsy based in the Democratic Republic of Congo, seized the purple day, a brilliant idea initiated by its founder Cassidy Megan and encouraged by the treasurer of the International Office of Epilepsy and President of Africa Epilepsy Forum Dr. Anthony Zimba and the Vice President of the African Epilepsy League Mr Jacob Mugumbate, to raise awareness about the stigmatization of epilepsy and the social, moral and other discriminations that afflict people suffering from epilepsy in the Democratic Republic of Congo in particular and in the world in general.

## **SUGGESTION**

We note that the anti-stigmatization association for epilepsy is a movement that brings together young physicians with the concerns and passion to help patients with epilepsy to help the general population to have perfect knowledge. and specifies on epilepsy.

We take this opportunity to send a shout of alarm to the international community and people of good will to help us in our struggle.

Several ideas are in place but we do not have the financial means to make the project a reality. Much remains to be done, the population not yet informed about epilepsy represents an estimate of 91% and our goal is to reach all sections of the Congolese, African and World population.

During our awareness campaign, we discovered 7 children with epilepsy but who are not on treatment and these children were recommended for appropriate examinations such as electroencephalogram and brain scan that we unfortunately do not have.

# Report from Mauritius

## Alliance for Rights Africa Towards Disability Inclusion

### Multi Stake Holders Workshop 12<sup>th</sup> April 2018



A multi stake holders workshop was organized by Edycs Epilepsy Group sub grantee of the Alliance for Rights Africa Towards Disability Inclusion, funded by the EU and CBM. The workshop was held on 12<sup>th</sup> April 2018 at the Chamarel Conference Room, Le Meridien Hotel, Pointe aux Piments and met with the participation of 52 participants from cross sectors.



Representatives were from the State Law Office,

World Health Organisation, National Human Rights Commission, National CSR Foundation, Ngo Trust Fund, SBM Foundation, Ministry of Social Security, Ministry of Education and DPOs/NGOs in the disability sector.

The Chief Guests at the official opening ceremony were:

- **His Excellency, P Vyapoory, Ag. President of the Republic of Mauritius**
- **Hon. R Rutna, MP and Deputy Government Chief Whip of the National Assembly Mauritius**
- **Mr. C Payaneandee, Barrister at Law, Vice Chairperson of UNCRDP, UN Expert**
- **Mrs. Nomvuyo Mabusela, Capacity Development Officer, CBM**
- **Ms. Catherine Van Staden, Head Finance CBM**
- **Ms. M Ndebele, Director of International Programme ADA.**
- **Mr. Mwewa Lufungolo, Grant Accountant ADA**

The workshop focused on the need for ratification of the Africa Disability Protocol endorsed by the Head of States of the African Union at its Summit held in January 2018 in Addis Ababa. Speakers at the workshop highlighted the disability mainstreaming in line with the Africa Disability Protocol and model disability law. **MORE NEWS FROM MAURITIUS IN THE NEXT NEWSLETTER**

## 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. Stories of members showing how they are overcoming epilepsy.
2. Your local newsletter
3. Your 2017 report and plans for 2018
4. Questions
5. 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](mailto:ibeafrica@gmail.com).
- Our Twitter account is here tweet to us: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica)

## Funding and fundraising in our region

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

**In the next issue, we will introduce Nsom Kenneth and Grace Moyo who recently joined the AREC. We will also talk about funding that has been made available for our advocacy project and donation of medicines to Kenya.**

**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](mailto: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

**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.**

1. URGES Member States:<sup>1</sup>

- (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;

