



EPILEPSY AFRICA NEWS

Issue 24

May/June 2020

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



ABOUT THIS NEWSLETTER

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Frequency: bi-monthly
Distribution: Email and other social media.
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Enjoy reading!

How to join us:
WhatsApp group for people with epilepsy and significant others group for professionals interested in epilepsy: +260977789042, +260977789042.
Epilepsy Africa Facebook group: Epilepsy-Africa-IBE Twitter: @EpilepsyAfrica.

Email list:
We have three email lists - for social issues, for professionals and 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/publication`s/regional-news/](https://www.ibe-epilepsy.org/publication/s/regional-news/) and www.epilepsyafrika.org

COVER PHOTO

GECO Rwanda community work (third from left on the bench, Ms. Chantal)

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Chairperson/Editor's Message

Dear Reader,

It is with excitement that we engage you in this trying time of COVID19 challenges were our work has been slowed down by the pandemic that has hit all African Countries. It is with sadness that to inform you that some of our chapter in Rwanda and Democratic Republic of Congo has been hit hard with some reported deaths of persons with epilepsy in these countries. In this edition we share you some of the exciting work that our chapters have been carrying out in Rwanda, Uganda and Eswatini despite the challenges we are facing. In addition we share you a report on the quarterly meeting we had with our chapters and plans that lie ahead of us in the coming months.

As a region we are also excited to report the commencement of two projects that are supported by Band Foundation namely the Promising Strategies Grant (PSG) and Making Epilepsy A Health Priority in Africa (MEHPRI) programs. The PSG program started earnestly in April 2020 with five Chapters been awarded to carry out innovative project that range from inclusive education, capacity building through to use of technology to bring out epilepsy out of the shadows of remote areas. It is with excitement that these countries have started on a high note of working on the deliverables.

MEHPRI project commenced well in May, 2020 with zeal and determination to deliver on its objectives.

By the end of the reporting period, there were engagements with International Bureau of Epilepsy Chapters filling in key roles of the project structures. Twelve (12) chapters are now in the Steering, Advocacy and Communications Committees. This will allow the project to tap from the experiences of these position holders to influence the direction of the project and ultimately contribute to the main goal of ensuring "Epilepsy is on the Health Agenda in Africa". In support of these three Committees there is a team of eight (8) Advisory Team drawn from different partner organizations such World Health Organization (WHO), Africa Union (AU), Kenya Medical Research Institute (KEMRI), International League Against Epilepsy (ILAE) and Band Foundation. During this quarter the main advocacy priority was working on the development of the advocacy toolkit with the appointed Consultants firm.

It is with no doubt that Epilepsy in Africa will not be the same in the coming months as chapters are gearing for a change!!!!!! Enjoy your reading and Stay Safe!!!!!!!!!!

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



QUARTERLY UPDATE MEETING with Chapters and Key Stakeholders

The first quarterly update Meeting with Chapters and Key Stakeholders was held on Friday, May 8th, 2020 with seventeen (17) participants, including the IBE President, Prof. Martin Brodie.

Mr. Action Amos VP and Chairman, IBE Africa Region informed the participants of the region's 2020 - 2021 Action Plan and gave an update on the progress of activities, especially on the key resolution concerning the Global Epilepsy Plan. There was progress to develop an Epilepsy Toolkit, aimed at helping Chapters to speak one voice and focus at how they could advocate at national level. The Vice President informed all that the BAND Foundation, sponsor of the Advocacy Projects in six African countries would fund more countries in the Second Phase of the Project on Making Epilepsy a Health Priority. All Chapters were encouraged to apply including those that participated in the first phase. Intends to hold training on Advocacy and engage research organizations. To come up with a Disability Trust Fund. Two countries with offer of land to develop Epilepsy Development Centre.

Mr. Youssouf Noormamode, Vice Chairperson spoke on Resource Mobilisation for Epilepsy Chapters,

that there were many NGOs in the world. Africa may have its own fundraising plan or policy but to work on a long-term plan may take two or more years. It was important to have a sustainable plan for African Chapters and training for the leadership. The Vice Chair was already in touch with the African Union and PAN African Parliament.

Ms. Betty Barbara Nsachilwa, Secretary on Enhanced Advocacy & Communication in Face of Covid-19 presented three strategies to advocate online as:

- i. **Get creative and cut through the online platform** by communicating digitally on sustainable organizational issues. We are encouraged to use virtual advocacy with a bottom-up approach that mobilizes a groundswell of voices and cuts through the online noise. Thus, opening up the possibility for more creative strategies that reach intended audiences through volume and frequency rather than the precision of direct in-person appeals. These smart switches enable organizations to keep their advocacy relevant and timely, while harnessing the power of global audiences to continue to achieve their objectives.
- ii. **Pay Close attention to communication channels** Engaging with the most influential policymakers in the virtual lobby of the World Wide Web, then, requires paying close attention to the ways in which they communicate as well, it

could be through Facebook, Twitter or LinkedIn.

- iii. **Give a platform to those whose lives are impacted** Humanize digital communications as much as possible. At in-person events, the message is as powerful as the messenger, who can deploy charm, wit, and rhetoric to make their case directly to their intended recipient. However, communicating virtually often involves using open forums, which means online advocacy must factor in broader public perceptions around key issues.

Plenary with Chapters & Stakeholders:

- IBE President, Prof. Brodie, acknowledged the disastrous time and was willing to assist in any way possible.
- Mr. Arjune Sen, one of the stakeholders, revealed his intention to work with the IBE Africa Region and was in the process of circulating a survey on the impact of COVID 19 on people with epilepsy, their carers and health providers.
- Ms. Chantal Kanyabutembo of Rwanda mentioned the need to look into the poverty affecting people with epilepsy during the COVID 19 Era to avoid loss of life and thinking about simple fundraising for IBE Africa.
- Mr. Anthony M. Zimba commended the efforts of the AREC to hold such a meeting, but advised to handle projects one at a time for sustainable progress.





Ambassador Bernadette Olowo addressing participants

Purple Bench Initiative – Uganda

While the rest of the World celebrates International Awareness on Epilepsy Day every second Monday of February every year, in Uganda the year 2020 was the very first time this day was marked, thanks to the Purple Bench Initiative, a patient led organization. It was an opportunity to join the rest of the world to declare Epilepsy as a Health Imperative. The day was marked with a series of activities that were planned amidst apprehension since epilepsy is still highly stigmatized in this country. However, under the guidance of the Ministry of Health, led by the Health Minister, Dr Jane Ruth Aceng and her team, the Purple Bench Initiative (PBI), founded by Nina Mago, a trail blazing non-governmental organization, spearheaded organizing this awareness activities to mark Epilepsy Day, with support from the World Health Organization and USAID - American Center and the media organizations.

As evidenced from the activities that took place, it was quick to note that epilepsy awareness could be integrated in activities

that touch people's everyday life activities. For instance, Ugandans have adapted a health-conscious lifestyle so a marathon by Epilepsy fraternity to raise awareness was well placed on a weekend. One may say that it is not easy to reach those in the world of corporates who are busy in the day with hardly any time to spare. PBIL organized quiz nights about Epilepsy at three venues frequented by the corporate class. The American Club is a popular spot for the urban youth who are hungry for information. Here they were addressed on issues pertaining

to epilepsy and dental care and more about myths and facts about epilepsy. At this point the airwaves of popular radio stations and TV stations were busy playing messages about reducing stigma and discrimination.

The D-day, the second Monday of February attracted stakeholders from various parts of the country. Indeed, 2020 International Awareness on Epilepsy did bring hope to persons living with epilepsy in Uganda that there is light at the end of the tunnel for meaningful dignified and productive lives.



Support for a Person with Epilepsy – Eswatini

Eswatini Epilepsy Association reported on a young man living with epilepsy from Mahlalini in the Shiselweni Region of Eswatini.



Bongikhosi Malindzisa is a 29-year-old orphaned male who was diagnosed with epilepsy while staying at the SOS Children's Village, where they care for orphaned and vulnerable children. He then had to leave the village, came back home and lived in a stick and mud house. Unfortunately, there was disaster when the dilapidated stick and mud house fell, nearly killing Bonginkosi who was asleep inside.

On the 5th of June he was presented with a proper house, as seen on the picture, by the SOS Children's Village. Eswatini Epilepsy Organization on the day expressed their utmost appreciation to SOS for the construction of the house as they show that they care for people living with epilepsy. Mr. Abraham Ntshalintshali who represented the National Director Mr. Mbusomuni Mahlalela pledged to donate 5 bags of maize as the young man expressed that he desperately needs food assistance mostly.

The entire community also came out to show support and witness this special day for the young man. We continue to applaud stakeholders who assist us in caring for people living with epilepsy.



A section of the people listening to EEO's representative



Bonginkhosi Malindzisa (standing second from right) preparing to enter into his newly built house.

GECO Rwanda in Lock down COVID19

By Chantal Kanyabutembo

HOW PATIENTS MAY MANAGE SEIZURE IN THIS COVID19 LOCK DOWN?

**SPECIAL POINTS OF INTEREST:
HOW TO MANAGE A SEIZURE
THROUGH COVID LOCK DOWN?**

GECO provided 5 tonnes of foodstuff to the western province Rubavu in 12 health centers for 200 patients and 1.6 tones donated to other provinces Rutsiro, Gakenge, Kinyinya, Gikondo, Bugesera hospitals covered 100 patients in food allowance

Geco Rwanda, were established since end 2010 to care after patient's victim of the brain disease epilepsy known as IGICURI in our local language!

In this epic center covid19 lock down, more patients are victims of hunger disease & patients re facing a high risk of sudden death due to consumption of heavy drugs AEDs (anti-epileptic drugs) under lower nutriment on daily basic. Hunger disease emerge, in fact we did experience 5 cases of sudden deaths due to lower nutriment and abandoned of AEDS (anti-epileptic drugs)

We do have 5% of the population affected by seizure: 600000 patients (ref 2016 booklet MOH), and epilepsy represent 54.7% of mental disease in Rwanda, then we

need to make epilepsy as a public health imperative in improving livelihood of our patients, amongst youths and adults unemployed in this lock down.

Geco makes this initiative as a scheme for foods crisis rising grant on behalf of patients from rural area very poor, and we thank our donors for giving Geco, 6.6 tonnes of foods (beans, rice, flour, oil and sugar) but the challenge we face is that we are less funded to reach every single poor individual under AEDS in government universal free health, who faces poverty In Rwanda!

As a social worker, this country presents a high rate of mental disease due to the history of the Rwanda 1994 Genocide against Tutsi because more adults



experienced brain injuries in a masse slough, and we still have cases of new infant with seizure up till now despite prevention measures established in hospital maternity infant national health care through innovation technology as telemedicine, and the social security well fare of our patients!

GECO did raise a local Grant on behalf of patients i.e. 6.6 tonnes (beans, rice, flour, oil, sugar) as so far, we covered 12 health centers and provided relief to 200 patients in western province Rubavu where Geco supervises 12 district hospitals in Maternity infants, advocacy, and social capacity!

Currently, we need more innovation path on telemedicine and increase capacity build programs in creating income scheme generating for patients in decrease poverty and improve awareness in fighting against stigma.

GECO Rwanda granted on 28th May to 2nd June 2020, 200 patient foods (15 kg maize, 15 beans, and kg. sugar, oil), then we started another scheme in another region of Rwanda despite being less funded and supplied 1.6 tonnes of foods in Kinyinya, Bugesera Districts, the ADEPR Hospital and in Gikondo, Rutsiro and hospitals, in totals 100 patients from other provinces.

I am calling for any corporate firms or institutions able to assist us or other association in Africa to help victim of the brain disease under heavy drug AEDS consumption to reduce the rate of Drugs abandon, self-harms, suicide anxiety, stigma, and we do make sure they follow the guidance of the OMS through COVID19. We need to decrease mortality in maternity units, miscarriage from women under AEDS drugs, from the consequence



Epilepsy girl since birth and is now in Senior 5 Secondary School. A great result of counselling and AEDs

of global recession, jobless, lack of income & lower nutriment!
Epilepsy girl since birth and is now in Senior 5 Secondary School. A great result of counselling and AEDs

This story is about a young lady suffering for seizure in Kinyinya district, she is a victim seizure since birth, and she faced a fatal incident at young age, get his head burn in hot oil then despite such injuries and her challenge through seizure, and social life,

she is taking Depakine and get two (2) episodes every six (6) months. As at now, she pursues her studies in GCSE economy in secondary school, it may be brave to see such positive story from a baby born under AEDS drugs and still productive with a positive outcome result story despite her injuries, this is an example of a free universal health AEDS, and the health coach counselling orientation in their future success career thank you all for your help!

GECO Rwanda – Community Activities



Contributing 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
3. Questions on epilepsy care
4. Photographs

Did you enjoy reading our newsletter?

Please give us some feedback:

Email: ibeafrika@gmail.com

If you have any other topics to suggest, please email us at ibeafrika@gmail.com by 20th of each month.

Next Issue to feature:

- Reports from Malawi and Mauritius
- Association fighting stigma epilepsy in the Democratic Republic of Congo (DRC)-ASLEK
- Promising Strategy Projects
- Making Epilepsy a Health Priority in Africa - Phase II