



EPILEPSY AFRICA NEWS

Issue 22

January/February 2020

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



Cover Photo: Mr. Kenneth Nsom - AREC Member of Cameroon addressing school children during the International Epilepsy Day Commemoration

Contents

- 2020 International Epilepsy Day Reports from across Africa

About this newsletter: Editorial team: Action Amos; Youssef Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** bi-monthly **Distribution:** Email and other social media. **Email contributions to** ibeafrica@gmail.com or amos_action@yahoo.co.uk 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 associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrica@gmail.com. You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publication/s/regional-news/> and www.epilepsyafrika.org

CHAIRPERSON/ EDITOR'S MESSAGE

We are excited with developments that took place during this period. We had over 15 Chapters celebrate the Epilepsy Day across Africa. Chapters showed their capability in engaging and partnering policymakers, civil society organization and like-minded organization in spreading the message of friendship and inclusion. The message was spread in churches, schools, community gatherings and hospitals across the continent to show the diversity of where epilepsy gospel can be spread. Social media, radios, television. **We say BRAVO!!!!** to all persons with epilepsy, self-advocates and other stakeholders that devoted time on this special day to advocate for inclusion. In this article we will share with you some of the experiences of this years' Epilepsy Day.



We are also excited to inform you about the outcome of the World Health Organization Executive Board meeting that took place in Geneva, Switzerland in January, 2020. The Epilepsy Agenda item that mainly focused on states to create National Epilepsy Plans was supported by all 47 WHO Afro countries with Gabon taking the responsibility to present a paper indicating the Regional Support. Zambia and Swaziland are co-sponsoring the resolution together with Russia and China and other four countries spread across different continents. As we speak, efforts are now being made to work on the recommendations to have a synergy of epilepsy and other neurological conditions. It is expected that in May as promised by WHO another Resolution on Epilepsy and the synergy with other neurological disorders will be discussed. We want to thank the team that participated in the lobbying the Dr Samuel Wiebbe, Dr Guehkt (both from ILAE), together with Vice President of International Bureau of Epilepsy Action Amos and Mary Sacco the Secretary General for International Bureau of Epilepsy.

We also want to thank all Chapters that responded to the questionnaire on the Advocacy Toolkit. We are at an advanced stage of consultation and soon we will be sharing feedback with you all. This toolkit will enhance how we engage in our advocacy and lobbying work which are key if persons with epilepsy are to be included. There was also overwhelming response to Promising Strategies Call from many chapters and the shortlisting for the full proposals was done. We thank you all those that sent in your Letters of Intent. We endeavor to work with Band Foundation to raise more funds to support more Chapters with new initiatives as we strengthen our relationship between the African Regional Executive Committee (AREC).

In this edition, we do not feature Know Your Chapter and Leader of the Moment as we dedicate it to the Epilepsy Day. We are going to be having yet another Youth Section – Youth Shakers (You Sha!!!) which will feature efforts that youth with epilepsy are doing on the continent to change the face of epilepsy. Let me thank your continued support to Epilepsy in Africa and to the AREC. Relax and enjoy this edition and be **CORONA and Epilepsy Awake!!!!**

Action Amos
IBE Africa Vice President

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

ARTICLES OF INTEREST — Marina Clarke, SA

Most of the interesting issues marked the commemoration of the International Epilepsy Day in Africa. Only excerpts will be highlighted and the full story to be accessed through the links provided:

1. 2,000 people suffering from epilepsy in Kitgum

[The Independent](#) February 13, 2020 [Health](#), [News](#) [Leave a comment](#)



A mother with two of her children recovering from Nodding Syndrome in OdekSubcounty, Omoro District. **Kitgum, Uganda | THE INDEPENDENT** | At least some 2,076 people in Kitgum district are suffering from epilepsy, a neurological disorder characterized by recurrent epileptic seizures. The figure compiled since 2012 to 2019 indicates the disease burden is high among rural communities of LabongoAmida and LabongoAkwang sub-counties.

<https://www.independent.co.ug/2000-people-suffering-from-epilepsy-in-kitgum>

2. Expert Tasks FG On Permanent Cure For Epilepsy

Published on February 12, 2020 By **The Tide**

A renowned Neurologist, Dr Ibrahim Wakama, yesterday, called on the Federal Government to make funds available for researchers to find permanent cure on epilepsy. Dr. Wakama made the call in an interview with newsmen in Abuja on the occasion of the International Epilepsy Day, celebrated annually on the second Monday of February. The day is an opportunity to raise awareness on epilepsy, what it is, how it can be treated, and what is needed to bring treatment to people who need it.

Dr. Wakama, who said that finding permanent cure for epilepsy would help to save lives of those suffering from the ailment, urged government to recognise the strength, resilience, and accomplishments of Nigerians living with the health challenge. He, however, added that "government cannot do it alone.

<http://www.thetidenewsonline.com/2020/02/12/expert-tasks-fg-on-permanent-cure-for-epilepsy/>

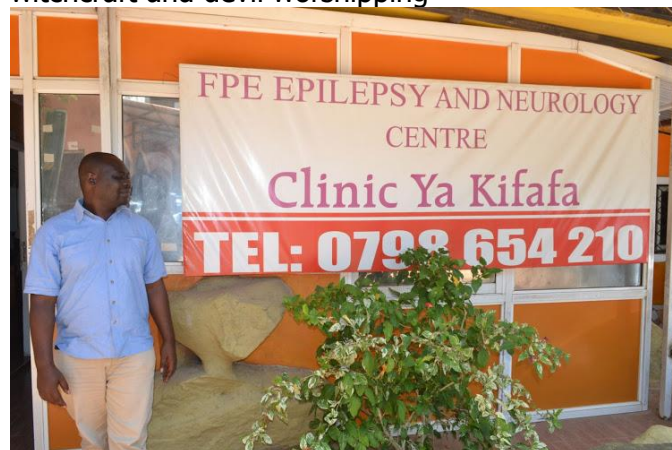
3. PARANOIA AND STIGMA

Bitter tales of epileptic patients

The world marked Epilepsy Day on February 10

In Summary

- Kenya has one million people who live with epilepsy, according to DrChengo
- There is widespread linking of the condition to witchcraft and devil worshipping



Dr Eddy Chengo of Epilepsy and Neurology Centre in Malindi, Kilifi county
Image:MALEMBA MKONGO

As the world marked Epilepsy Day last Monday, persons living with the condition told tales of how they had lost opportunities, suffered physical and mental injuries and been isolated and discriminated against. <https://www.the-star.co.ke/news/big-read/2020-03-01-bitter-tales-of-epileptic-patients/>

4. "Epilepsy is curable, stop seeking spiritual help,"-

Psychiatrist By Gideon Peprah, GNA

Kumasi, Feb 11, GNA – Dr Francis Oppong, a Psychiatric Specialist at the OkomfoAnokye Teaching Hospital (KATH), has admonished the public to seek professional help for epileptic patients rather than resorting to spiritual intervention at prayer camps.



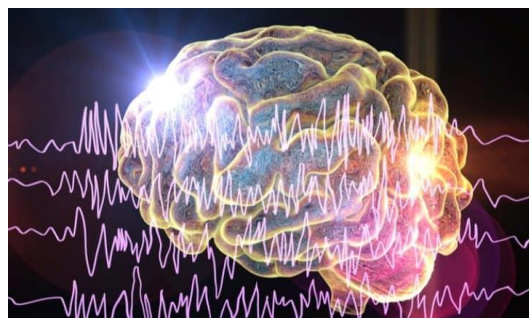
He said epilepsy was curable with medical treatment and cautioned against over reliance on spiritual treatment for the sickness.

He was speaking to the Ghana News Agency after a sensitization programme on epilepsy organized by the Psychiatric Unit of KATH, as part of activities to mark World Epilepsy Day on Monday.

<https://ghananewsagency.org/health/-epilepsy-is-curable-stop-seeking-spiritual-help-psychiatrist-163856>

Liberia – Growing Cohort of Epilepsy Patients Shows How Life-changing Treatment is Possible

Emmanuel Ballah | 4th March 2020 | GLOBAL REACH, NEUROLOGY |



Many of the patients that we see have serious problems from neglect and stigma, because people mistakenly believe that epilepsy is a contagious disease. This is especially true for patients who have convulsions throughout the day. Because of the continuous seizures, they are not able to do anything for themselves, they lack self-care, and family members fear them.

For example, a patient has been abandoned by his relatives, is injured because of falling, and no one cares for him because they are afraid of catching his condition. This is something that we continually work on in explaining epilepsy to a person's family and community members.

In late January we had a community awareness event in the West Point township of Monrovia, with more than 50 community leaders, imams, pastors and school principals. Our health volunteers put on a drama to talk about what happens when someone has a seizure and other people are not willing to help them, because they are afraid.

<https://www.hippocraticpost.com/global-reach/liberia-growing-cohort-of-epilepsy-patients-shows-how-life-changing-treatment-is-possible/>

INTERNATIONAL EPILEPSY DAY 2020 HIGHLIGHTS

Swaziland Epilepsy Organization

Commemorated the Epilepsy Day in their usual fashion of holding a Yellow Valentine's Dinner. The support was extremely impressive and we believe its works are a spectacle to the community in Eswatini find out from the following briefing:

"The #Epilepsyday , #EpilepsyWeek and #YellowValentineDinner was a great success. We would like to thank and appreciate each and every individual, company or stakeholders who contributed to the success of these events. We hope we made enough people pay attention to epilepsy and now they understand how it needs immediate attention. We urge the public and stakeholders to continue to support us as there is still a long way to go in order to make Epilepsy a National Priority. Many Swazis suffer in silence because they are afraid of the stigma we still need to shed a light for those individuals to show them that they need to speak out and ask for help. As an organization we will continue to strongly advocate for persons living with Epilepsy and bring their issues to the forefront. Thank you, Thank you"

Noble Gesture:

HRH Prince Bandzile the Patron of EEO, who was represented by Senator Chief Mphatfwa, pledged to pay school fees for Nomphumelelo Dlamini until she completes her high school education. Nomphumelelo Dlamini a 17 year old doing Form 2, has been living with epilepsy for over ten years but due to fear of

stigmatizing she did not disclose her condition to her teachers.



For more photos, follow Facebook links:

[#YellowValentine2020](#) [#YellowEpilepsyWeek](#) [#Epilepsy](#) [#EpilepsyDay](#) [#Love](#)

[#YellowValentineDinner2020](#)
[#EpilepsyWeek](#) [#EpilepsyDay](#).

Uganda: Activists Unite To Inform, Dispel Myths about Epilepsy

A Ministry of Health survey has revealed that three percent of all Ugandans or about 1.3 million Ugandans suffer from Epilepsy.

The ailment is a neurological disorder, which leads to convulsions and loss of consciousness, associated with abnormal electric activity in the brain.

As Jjingo Francis reports, the findings have emphasised the call for more action, as the country joins the rest of the world in marking the international day for epilepsy.

[HTTPS://YOUTU.BE/BH-YKKYQ4LG](https://youtu.be/BH-YKKYQ4LG)

Ghana:

"Epilepsy care should be integrated into normal medical care" – Dr Akpalu



By Jesse Owusu Ampah/Christabella Arko, GNA

Accra, Feb. 11, GNA – Dr Albert Akpalu, a Neurologist and Epilepsy treatment expert, has called for Epilepsy care to be integrated into the normal medical treatment to improve access to medication and treatment for persons living with it.

Dr Akpalu, who is a Medical Doctor at the Korle-Bu Teaching Hospital, said the integration would increase the awareness, support and treatment of the disease just as other diseases such as HIV/AIDS, Malaria, among others.



He made this remark at an event organized by the Epilepsy Foundation Ghana (EFGH) to commemorate the celebration of the International Epilepsy Day on the theme, "Friendship and Inclusion."

He said there was inadequate ratio of patients to doctors, which required an increase in health professionals to be trained in treatment of the disease.

He said Epilepsy was not a psychiatric or contagious disease as people speculated, adding that, "people with Epilepsy also live normal lives".

Dr Akpalu said Epilepsy was a natural disease that could happen to anyone at any point in life.

"Epilepsy is not hereditary, and it is mostly caused by acts that affects the head and brain and caused a disorderly discharge of the brain cells".

Dr Akpalu said there were about 21 drugs for the disease of which five were available in the country at the moment but was not readily available to persons.

He said in treating victims whenever there were seizures, items such as spoons should not be put in their mouth, but advice that their heads should be cushioned well to avoid damages.

Mr Mike AmonKwafo, Founder and Convener of EFGh, said 308,000 of the population were living with Epilepsy, out of which 85 per cent were not under treatment.



He said Epilepsy was a natural disease as opposed to the various superstitions people alleged, calling on the public as well as religious bodies to lead the advocacy in the country against stigmatization of persons living with Epilepsy.

"People who do not understand the nature or cause of any human condition tend to explain it away by superstition, witchcraft or some other outlandish speculation.

"The Epilepsy Foundation of Ghana will like to emphasize to Ghanaians that Epilepsy is a known and understood condition or disorder in the brain," he said.

He said the commemoration was in realization of the Sustainable Development Goal Three on providing good health and wellbeing for all.

Mr Thomas Larbie, President, International Bureau of Epilepsy, Ghana Chapter, and a husband of an epileptic patient, appealed to families to be supportive to persons living with Epilepsy.

He also advice that families should not hide them from the public, saying, they should help bring the disease out of the shadow.

He said not only neurologists could assist a patient when he or she had a seizure but anyone at all with adequate training and education.

GNA

<https://ghananewsagency.org/health/-epilepsy-care-should-be-integrated-into-normal-medical-care-dr-akpalu-163857>

REPORT ON THE CELEBRATION OF THE INTERNATIONAL EPILEPSY DAY IN CAMEROON

The international epilepsy day in Cameroon was celebrated on the third (03rd) Monday of February 2020 which was the 17th of February 2020. This was contrary to the usual second (02nd) Monday of February earmarked by IBE for the International epilepsy day celebration which was to be on 10th February 2020 in Cameroon. Unfortunately, the day in Cameroon fell on the day just before the 11th February 2020 which was one day to our National Youth day. So CODEF had to postpone the activities planned for this day to the 03rd Monday which was 17th February 2020. Our main reason to change the day was because our planned activities this year 2020 was to be carried out in primary schools.

However, the activities were carried out after the National Youth Day in two primary schools in the Western region of Cameroon, Noun Division in Foubot Sub Division. The



schools were the Cameroon Baptist Convention Bilingual Primary and Nursery School Foubot (CBCBPNS) and the Elite Standard Bilingual Primary and Nursery School Foubot (ESBPNS).

We sensitized about **300 pupils** in CBCBPNS Foubot and **500 pupils** in ESBPNS Foubot on what epilepsy is, its causes, what to do when someone has seizures (fit), and on the ways of preventing epilepsy. Therefore, a total of about **800 school children** were sensitized on epilepsy. Emphases were laid on the none-stigmatization and discrimination of Persons with epilepsy (PWE) in schools and in communities.



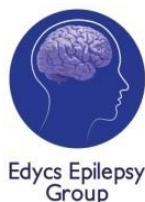
RESPONSE FROM SCHOOL CHILDREN AND SCHOOL MANagements



The school children and some teachers got so interested that their Head Teacher – Mrs. Ngong Charity had to request the CODEF staff to come the second day again for further education and for questions and answers from school children and some teachers. So the education and sensitization was carried out in CBCBPNS Foubot for two (02) consecutive days (17th – 18th) February 2020. Some school children were excited to go and read the information about epilepsy written on the charts or cardboard papers from CODEF. Some pupils were able to explain to the hearing of all their mates in school how they call PWE in pidgin English as “people were they di fall” and in their dialect and that just the phrases or words are stigmatizing. Other school

children asked questions like why is it not advisable to put anything in the mouth of someone when he/she is having the fits or seizures and would bite their teeth. Despite the fact that we told them that putting anything into their mouths will only help to wound the person’s mouth more was not so convincing enough to them and their teachers. They posed worries like the person can bite and cut his tongue partially or completely and it would add to the already existing problems of the person with epilepsy; and that of his family struggling to treat such a person. Other children and teachers ask why record time when someone has seizures? We explained that it will help the doctor know time and the frequency of seizures. What do you do if someone has seizures and falls in fire? Move the person from fire and ensure they are safe.





PUBLIC CONFERENCE

Monday 10th February 2020 – Venue: Bambous Social Welfare Centre Time: 10h30 – 13h30

(Official Sponsor – Lions Club Riviere Noire)

Edycs Epilepsy Group, the unique leading Non-Governmental Organisation working with epilepsy sufferers in Mauritius and Rodrigues islands organised a Public Conference on Monday 10th February 2020 at the Bambous Social Welfare Centre to celebrate the International Epilepsy Day. The event was graced by the Honourable Alan Gannoo, Minister of Transport and



Light Rail, Dr. Ori, Representative, Ministry of Health and Wellness, Mr. Kevin Boodhoo, President Lions Club de Riviere Noire, Dr. Anishta Gunese, President Health Commission Lions Club de Riviere Noire in the presence of Edycs board members, staffs, Persons with Epilepsy and their families and the public at large. The event was largely covered by the Mauritius Broadcasting Corporation National TV, Cool FM Radio, Radio One, Best FM Radio and the press. In addition, the National TV produced a short film on Edycs Epilepsy Group more particularly

its operating Health Service Center providing support to PWE and Families. The film was broadcasted on 10th February 2020 during the News.



The Honourable Alan Gannoo spoke on the need for an invalid pension for people living with epilepsy. Youssouf Noormamode, Founder & President Edycs Epilepsy Group spoke on the role of Edycs as an Ngo with a view to promoting education and awareness of PWE Rights, empowering patients and creating increased independency. He further elaborated on the Human Rights issues for people with epilepsy in the context of the Africa Disability Protocol and informed that a “**Joint Working**

Committee in Epilepsy” will soon be established by the Ministry of Health & Wellness. This decision was taken by the Minister of Health & Wellness, Hon. Dr. Kailesh Jagutpal during a meeting session with Edycs representatives held at the ministry of last 13 January 2020.



Dr. Ori from the Ministry of Health & Wellness and Yasheer Soohun, Occupational Therapist spoke on the epilepsy disorder and its medical consequences. Many issues and questions relevant to epilepsy were addressed to the key speakers. All the participants were invited to visit the **Exhibition booth** in epilepsy at the closure of the Conference. The event was co-sponsored by the Lions Club de Riviere Noire.

PROGRAMME

Official Opening Ceremony

(Moderator Mokshada Toolsee, Edycs Programme Officer)

10.00 Arrival of Guests and Families

10.15 Arrival of Chief Guests

Hon. Mr. Alan Gannoo, Minister of Land Transport and Light Rail

Dr. Ori, Representative, Ministry of Health & Wellness

Mr. Kevin Boodhoo, President Lions Club de Riviere Noire & Dr. Anishta Gunese, PhD, President Health Commission Lions Club de Riviere Noire

10.25 Presentation of Welcome Bouquets to Chief Guests (M. Toolsee & I. Roubinah)

10.30 Welcome address – Mokshada Toolsee, Edycs Programme Officer

10.35 **Speech** – Youssouf Noormamode CSK, President Founder Edycs Epilepsy Group & Vice Chairman IBE Regional Committee Africa & Council Member Epilepsy Alliance Africa

10.45 **Speech** – Mr. Kevin Boodhoo, President Lions Club de Riviere Noire

10.55 **Speech** – Dr. Ori, Representative, Ministry of Health & Wellness

11.05 **Speech** – Hon. Mr. Alan Gannoo, Minister of Land Transport and Light Rail

11.15 Pause Refreshments & Departure of Chief Guests

PLENARY SESSION: (Moderator Mokshada Toolsee, Edycs Programme Officer)

11.30 **Epilepsy and Seizures – Video & Presentation** (Speaker Yasheer Soohun, Edycs Epilepsy Group)

12.00 **WHO Resolution 'Global burden of epilepsy and the need for coordinated action at the country level. To address its health, social and public knowledge implications** (Speaker Paramasiva Chengan, Edycs Deputy President & Project Lead IBE AREC Band Foundation)

12.15 **Epilepsy a Healthcare Imperative & Human Rights** (Speaker Youssouf Noormamode CSK, President Founder Edycs Epilepsy Group)

12.30 Questions and discussions

13.00 Closing of Conference, **Visiting Exhibition booth & Distribution of T-shirts**

13.30 Departure of Guests (**Collaboration Bambous Social Welfare Centre**)





Dr. Prince Kazadi of Democratic Republic of Congo (second from left) visited Zambia in February, 2020.

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 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:

- **More International Epilepsy Day Reports**
- **Fundraising Campaign**
- **Know Your Chapter**
- **Leader of the Moment**
- **Youth Shakers**