



EPILEPSYAFRICA NEWS

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



Image: A conference in Cameroon. Report inside by Dr Daniel Massi.

Remember to prepare for International Epilepsy Day, 11 February 2019

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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. 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.

Chairperson & Editor's message

This newsletter has been published each month for a year now. It gives me great pleasure to dedicate my time to this publication. In this 12th edition of Epilepsy Africa news, you will find a report from Cameroon. The cover picture, taken by Dr Daniel Massi, shows participants of a conference in Cameroon. I wish to thank the team in Cameroon for the work that they are doing. In the same newsletter, you will also find information about projects that were submitted by young people with epilepsy, and a brief report of what is happening now. In the next issue, we will get short reports from the young people who were funded. You will find other exciting articles about epilepsy work being done in the region. I want to encourage you to contribute to this newsletter by sending an email to ibeafrika@gmail.com. Enjoy your reading. *Jacob*.



International Epilepsy Day in Douala, Cameroon

By Gams Massi Daniel, Email: danny.gamsmassi@gmail.com

As a prelude to the International Epilepsy Day, the Cameroonian League Against Epilepsy (CLAE) organized in association with the neurologists in the city of Douala grouped in the "Soirées Neurologiques de Douala", a training session for General Practitioners on different aspects of **Epilepsy on February 8th, 2018**.

Douala is the greatest city and the economic capital of Cameroon. About 3 million people live in this city with many social, cultural, ethnic, economic and educational disparities. It is a cosmopolitan city which represent a "small Cameroon". There are many health facilities and three main referral and teaching hospitals: Douala Laquintinie Hospital, Douala Gynecological and Obstetrical Hospital and Douala General Hospital. In term of health personnel, Douala counts thirteen (13) consultant neurologists, two (02) consultant psychiatrist and two (02) pediatric neurologists who are actively involved in the care for people with epilepsy.



Figure 1: The speakers: from the left to the right, Dr Dominique ENYAMA, Pr Yacouba MAPOURE, Pr Alfred NJAMNSHI, Pr Louis Richard NJOCK, Pr Callixte KUATE, Dr Clet Benjamin TCHALEU, Dr Jacques DOUMBE & Dr Caroline KENMEGNE.

The training session took place in the conference room of the Douala Laquintinie Hospital. The meeting was supported by SANOFI® and NOVARTIS® drug companies. The opening and closing ceremonies were done by the Douala Laquintinie Hospital director, Professor Louis Richard NJOCK.

Many topics were discussed during this meeting. Doctor Jacques DOUMBE introduced the talks with the definition and epidemiology of epilepsy. Pathophysiology and classifications were presented by Associate Professor Callixte KUATE. The talks on the diagnosis, the relationship between epilepsy and pregnancy as well as epilepsy in childhood were presented respectively by Doctors Caroline KENMEGNE, Clet Benjamin TCHALEU and Dominique ENYAMA. The closing talk on the management of epilepsy was presented by Associate Professor Yacouba MAPOURE and finally, Professor Alfred NJAMNSHI presented a short highlight on new perspectives in epilepsy research, focusing on the relationship between onchocerciasis and epilepsy in Cameroon. There were about two hundred (189) attendees from the whole city including medical doctors, medical students, nurses and social workers. To reach a larger audience and the public, were invited two major national TV channel who largely circulated the report of the training session before and during the world Epilepsy Day. The meeting was also presented on the television newscasts.



Figure 2: The conference room was full of audience.

In few words, this is how the International Epilepsy Day was celebrated in Douala-Cameroon.

Nurses And Village Health Workers Project in Zimbabwe

Presentation by Taurai Kadzviti, Advocacy Officer



OVERVIEW OF PROJECT

This project seeks to train nurses/village and community health workers (C/VHW) to:

- Aid diagnosis of epilepsy using national guidelines.
- Improve referring for secondary care treatment where appropriate
- To support treatment of pediatrics epilepsy.
- To enhance psychosocial issues such as adherence to medication.
- To improve access to medication and community education.

The project will also support the few doctors working in rural clinics who will be able to support the training of staff locally.

STAGES OF IMPLEMENTATION

1. Permission and clearance from MoH&CC, PMD and District
2. Workshop to consult and approve training module
3. Training of 40 Nurses Zvimba District on EM & ToT
4. Training 200 Village Health Workers in Zvimba District (Nurses)
5. Community Education & Awareness on Epilepsy (VHW)
5. Post training & Impact evaluation

TRAINING CONTENT

The module was co-authored by Dr Douglas Ball and Prof Jens Mielke was produced as part of the Zimbabwe demonstration Project of the Global Campaign Against Epilepsy - joint partnership of the International League Against Epilepsy, International Bureau for Epilepsy and the World Health Organisation.

- The causes of epilepsy
- Diagnosis of epilepsy
- The Medical treatment of Epilepsy
- Drugs Issues
- Psychosocial issues
- Traditional beliefs

EXPECTED OUTCOME OF THE PROJECT

1. 40 nurses trained Epilepsy Management and Training of Trainers (TOTs)
2. 200 C/VHW trained community education, identification and pre-counselling
3. Change in knowledge and attitudes of nurses and C/VHW
4. Change in community awareness and attitudes
5. Increase of diagnosed epilepsy
6. Increase of clients receiving treatment
7. Improved adherence to treatment
8. Increased referrals from CVHW to nurses
9. Reduced secondary care referrals

IBE educational and training scholarship for young people



BACKGROUND

The TEA Room (Teenage Epilepsy Agenda) recognises the value of peer support at the challenging teenage years in young people's lives. Already well-developed and successful, this project represents a safe online environment for teenagers with epilepsy to meet and discuss issues of relevance to them – not only those that might relate to epilepsy, but also their day to day activities and interests.

The TEA Room is managed and moderated by Scottish Epilepsy Initiative, a registered charity based in Glasgow, Scotland (Scottish Charity Number SC034354). TheTea-Room.com <http://www.thetearoom.org.uk>.

The TEA Room project was initiated in 2011 and has grown to be a worldwide site available to anyone, anywhere, aged between 13 and 19 years. Communicating with peers in a safe and comfortable environment is the ideal starting point to build confidence in young people allowing them to speak freely without fear of discrimination about how it is to live with a diagnosis of epilepsy. Discussions, among its many users, however, include a wide range of topics from sitting a driving test to going to a concert. More than 800 people are currently accessing the website from more than 20 different countries.

Now, under the umbrella of the IBE EpilepsyNext program, the plan is to extend the remit of the TEA Room initiative through the provision of funding support to provide education and training opportunities for some of the young users of the platform across the world on a competitive basis. The program includes funding for schooling, college and university fees, developing sporting expertise and support for training opportunities and apprenticeships.

REQUIREMENTS

To be considered, an applicant must:

- be aged between 16 and 23 years
- provide a typed essay (400 – 500 words) entitled “What the scholarship would mean to me”
- include a statement signed by the candidate or mentor (parent, guardian, teacher) stating that the essay:
 - is entirely the work of the candidate with no material copied from existing sources, or
 - has been written with assistance provided by a third party (the name of the third party and their connection to the candidate, as well as the type assistance provided, to be stated)
- complete the application form
- meet all the other conditions as laid out in this document.

Selection of candidates to receive funding, will be decided by the IBE International Executive Committee whose decision will be final.

ABOUT IBE

The International Bureau for Epilepsy (IBE) is an international network organisation of national epilepsy associations, which was founded in Rome in 1961.

IBE exists to improve the social condition and quality of life of people with epilepsy and those who care for them by increasing awareness, understanding and knowledge of epilepsy.

IBE currently has a membership of 137 epilepsy associations (chapters), based in 103 countries worldwide.

CONTACT

Ann Little, Executive Director, 7 Priory Office Park, Stillorgan Road, Blackrock, Dublin A94 FN26, Ireland
annlittle@ibe-epilepsy.org www.ibe-epilepsy.org

IBE is a US registered not for profit organisation with tax exempt status 501(c)(3). EID: 59:2606654

Funded projects: Young people with Epilepsy Support (YES) project

Currently, the young people who were funded are getting their payments processed by the IBE. Please make sure you submit all information requested to avoid delays. While you wait for your funds, please start preparing so that when the money arrives you implement and finish the projects this year. Meanwhile, we would like to hear how you are doing with the preparations. Please email Betty telling us what you are doing now, and what you are expecting to get out of this project. Tell us about your excitement and challenges if any. We will publish your short reports in the next issue.



Africa Epilepsy Advocacy (AEA) Project

Call for expressions of interest for the advocacy project had a huge response. The following countries applied. At the moment, selected countries have been asked to submit applications.

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: Stories of members showing how they are overcoming epilepsy, Your local newsletter, Questions and 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 ibeafrika@gmail.com.
- Our Twitter account is here tweet to us: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica)

In the next issues of the newsletter, we will talk about the advocacy project, human rights project in Mauritius, donation of medicines to Kenya and IBE Golden Awards. We will also have articles about other issues.



AS PART OF OUR INTERNATIONAL EPILEPSY DAY CELEBRATIONS FOR 2019, WE INVITE YOU TO ENTER OUR VIDEO COMPETITION WITH CASH PRIZES FOR THE WINNING ENTRIES!


The winning videos will be selected based on their success in telling an inspiring personal story or in using a novel means of increasing knowledge and awareness of epilepsy. In each category, there will be one 1st Prize of US\$500 and five Runners' Up prizes of US\$100.

CATEGORY ONE:
My Personal Story
People with epilepsy, their families, friends and carers, can create non-professional individual short videos, using a smart phone or personal camera, to inspire others or to highlight problems faced.

CATEGORY TWO:
Educational Video
Open to organisations and support groups who have developed professionally produced videos to educate the public, policy-makers, and people with epilepsy themselves, about epilepsy during the past 3 years.

VISIT WWW.INTERNATIONALEPILEPSYDAY.ORG FOR MORE

Increasing public awareness and understanding of epilepsy and thereby reducing the stigma and discrimination that is caused by ignorance and lack of knowledge is crucial to improving the quality of life of people with epilepsy. With social media now playing a major role in the dissemination of information, short videos are an extremely effective means of telling a story, whether the video is made using a personal smart phone or as a professional production.



CONDITIONS OF ENTRY

Category 1:
My personal story, applicants must submit a video filmed on their own smart phone or other device and must run for no longer than 2 minutes, including title and end credits.

Category 2:
A video must run for no longer than 2 minutes, including title and end credits.

Categories 1 and 2:
1. One entrant may submit a maximum of three entries in total to the competition. A separate entry form must be completed for each video submitted to the competition.

IN BOTH CATEGORIES, THE VIDEO MUST RUN FOR NO LONGER THAN TWO MINUTES AND MUST BE UPLOADED TO YOUTUBE OR YOUKU (CHINA). ENTRIES MUST ALSO BE ACCOMPANIED BY A SHORT DESCRIPTIVE TEXT OF NO MORE THAN 100 WORDS