



EPILEPSY AFRICA NEWS

Issue 3

November 2017

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

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Image (right)

Petition letter being used by the association in Malawi to bring justice after a person with epilepsy was killed, accused of being a vampire or a witch. We support actions like this one and if you have any campaign you need us to support, please suggest it to us.

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 ibeafrika@gmail.com.

Death of a person with epilepsy in Chileka, Malawi

On 17 October 2017, Abdul Matola (a 19-year-old) who had epilepsy was burnt to death because he was suspected of being a vampire or bloodsucker. Eight more people died in related incidences. Abdul had a seizure and whilst he rested to recover people suspected him to be a bloodsucker. A mob dragged him to the nearby satellite police station, but police officers were overpowered. As a result the mob burnt Abdul to death. A young life was lost, and many more could be lost in future if the community is not educated about epilepsy. Epilepsy is a neurological condition treatable with medication, and people with epilepsy are not vampires, bloodsuckers or witches.

We support the petition set by the Federation of Disability Organisations in Malawi (FEDOMA) and the National Epilepsy Association of Malawi (NEAM) calling upon the government of Malawi to urgently develop and implement national plan for epilepsy management that includes:

- Epilepsy awareness campaign,
- Making treatment and anti-epilepsy medicines available,
- Changing laws that do not protect people with epilepsy, and
- Fully investigate incidences of violence including Abdul's death.

We thank the government for the efforts already in place to stop the killings and to bring justice but we want to stress that a long-term solution is desirable. **We call upon interested individuals and organisations to support this petition with statements and letters that FEDOMA/NEAM will deliver to the authorities.** Finally yet importantly, we extend our condolences to the families and friends affected by the ruthless killings.



Professor Martin J Brodie, President, International Bureau for Epilepsy

Jacob Mugumbate, Chairperson, IBE African Region

Action Amos, FEDOMA, Executive Director

Francina Gondwe, National Epilepsy Association, Director

Chapter spotlight: Swaziland Epilepsy Organization hosts epilepsy run/walk

The Swaziland Epilepsy Organization (SEO) under the Patronage of HRH Prince Bandzile host a number of events throughout the year aimed at promoting epilepsy awareness and raising funds for the organization to effectively carry out its mandate of taking care of the needs of people with epilepsy in Swaziland. These events include: Epi-Yellow Valentine's Day Dinner, Epi-Mother's Day Dinner, and the Epilepsy Golf Day. This year the organization added another event into the calendar dubbed “Epilepsy Run/Walk”.



ON YOUR MARKS! Some of the athletes at the starting point.

The organization hosted the event twice this year in April and August, respectively. Each time, over 200 athletes participated. Also in attendance was the Deputy Prime Minister (DPM) Paul Dlamini and the Minister of Sports, Culture and Youth Affairs David ‘Cruiser’ Ngcamphalala amongst other dignitaries. According to the National Director of the SEO Mbusomuni Mahlalela, the need for raising epilepsy awareness in the country still remained huge with a lot of responsibility left with the organization to spread the word about the condition.



R-L: Deputy Prime Minister Paul Dlamini and Minister of Sports, Culture and Youth Affairs running the 5 KM during the 2nd Edition of the Epilepsy Run.

The Director also expressed gratitude to the DPM, minister and all athletes for attending the event. “The event was great, the turnout was wonderful and most of all, I am thankful for the support

from the DPM and the Minister who are always there with us. It is also motivating to see that the awareness on Epilepsy is successfully being raised as more people now want to know more about the condition,” he said.

The overall objectives of the event is to promote epilepsy awareness as well presenting the organization with a fundraising opportunity.

The next newsletter will have a spotlight of Kenya. We thank both Kenya and Swaziland for submitting their articles on time. We want to encourage other associations to do the same too. If you do not have an association in your country, but still want to write about epilepsy in your country, please you are most welcome.



About this newsletter

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

Minutes of Africa Region Meeting held on 5th September, 2017 in Room D1, Palau Congressos, Barcelona

Agenda: a) Introductions b) Brief presentation incoming IBE Regional Executive Chairperson/Vice President-Africa (Jacob Mugumbate) c) Brief presentation incoming ILAE Commission of African Affairs (CAA), (Angelina Kakooza) d) Discussion (all delegates)

**This meeting was not an Africa Regional Executive (AREC) meeting. It was not possible to do an AREC meeting because AREC members were not able to attend the IEC in Barcelona. This meeting had delegates from both IBE and ILAE.*

Minutes:

1. Jacob Mugumbate said the incoming committee for Africa (IBE) will develop a program to increase advocacy, chapter development, and regional collaboration in research and fundraising. Jacob said the WHO Resolution on Epilepsy was an important advocacy tool will be used to encourage our governments to provide resources for its implementation.
2. Angelina Kakooza said the incoming commission for African affairs (ILAE) will spearhead awareness, telemedicine, nurse training (focus on PHC), and development of treatment guidelines, collaboration and supporting epilepsy champions. Angelina talked about the need for nurse training (especially at medical/nursing school level) to promote task shifting from specialists and other doctors to Primary Health Care level. Angelina highlighted the need for developing and improve epilepsy management guidelines in line with current research.
3. Osman Miyanji suggested that myths of epilepsy in the community that cause stigma and labelling and misunderstanding and myths of practice like the fact that epilepsy is no manageable without EEG or neurologist or that epilepsy treatment is costly must be addressed in Africa. Dr Miyanji said successful epilepsy management could be achieved without EEG or Neurologists. Although these were necessary for some cases, they are not readily available in Africa. KAWE has run a fairly successful epilepsy training program for more than 15 years for Primary Health Care **Workers**, who work at the grassroots.

4. Morris Scantlebury detailed the work he was doing in Canada and the Caribbean, noting that the challenges in Africa were not peculiar to the region.
5. Najib Kassim talked about the importance of telemedicine, saying that telemedicine (renamed e-solutions) need to be explored in Africa as a solution to limited resources and health personnel. Social media that is cheaper such as Whatsapp as well as Skype, Zoom Webex etc could be explored.
6. Anthony Zimba said there was need for training of treasurers and administrators of epilepsy associations in Africa. Anthony encouraged chapters to report finances accordingly and in a timely manner. Anthony suggested to have taskforces in Africa to deal with agreed tasks.
7. Martin Brodie encouraged development of programs that could attract funding in Africa, noting that epilepsy programs could be imbedded within HIV and AIDS projects that currently receive more funding. Need to identify key priority areas for epilepsy research in Africa and to develop a research agenda for the region.
8. Ann Little encouraged chapters to be active by communicating with IBE regularly, and submitting reports.
9. Osman Miyanji said Epilepsy Training should be included in the curriculum in the medical training colleges for all primary paramedical health workers. KAWE in Kenya is in contact with the relevant authorities to implement this.
10. Elie Mbonda said there was need for context specific interventions. For example, in Cameroon the Ministry of Health identifies an area and sends health workers to camp and do field work for about four days, while providing the necessary resources, similar to the Caravan project in Burkina Faso that Athanase talked about.
11. Athanase Millogo said there was need to focus attention on, and see what could be done about, 'traditional' methods of treatment since most people in Africa consult healers, prophets and use indigenous knowledge.
12. Osman Miyanji said phenobarbital remains the drug of choice in developing countries due to low cost. Research confirms this. KAWE has shown that the cost of treatment to the patient can be reduced to between KShs. 200 to 500. (i.e USD 2 to 5) per month (not year), by using basic generic AEDs. Phenytoin is also very useful. Martin said evidence supports the relevance of phenobarbital in settings like Africa.
13. Daniel Massi said there was need to put epilepsy high on the agenda in Africa at neurology congresses (such as Congress of Pan African Neurosciences and African Academy of Neurology), medical schools, nursing schools, regional organisations, governments etc. Neurology conferences should always have epileptology as part of the Scientific sessions
14. Symon Kariuki suggested that the IBE, ILAE and their regional committees should get very close to chapters, visiting them where necessary and communicating regularly.
15. It was suggested to find pathways to work with health and disability organisations in Africa such as the Alliance for Accelerating Health in Africa (AISA) (to check if this is correct name).
16. Members were encouraged to join social media groups (WhatsApp, Facebook and emailing list). It was agreed to have one WhatsApp group for professionals.
17. It was suggested to have combined IBE and ILAE meetings for the African region as often as possible.
18. Attendance (see list).

1. Naluca Mwendaweli

nalucamimi@gmail.com

Zambia

2. Ngoungoure Halinaf. S.	siyi32000@yahoo.fr	Cameroon
3. Jacob Mugumbate	mugumbatej@gmail.com	Zimbabwe
4. Edward Kija	edwardkija@gmail.com	Tanzania
5. Angelina Kakooza	angelina_kakooza@yahoo.co.uk	Uganda
6. Tanya Spensley	tanyaspensley@btintemet.com	Gambia
7. Anthony M. Zimba	anthonymzmb@gmail.com	Zambia
8. Najib Kissani	najibkis@gmail.com	Morocco
9. Symon Kariuki	symonmkariuki@gmail.com	Kenya
10. Annick M. Maguerou	melanieannick@yahoo.fr	Cameroon
11. Sounga B. Prince	eliotprince2002@yahoo.fr	Congo
12. Daniel Gams Massi	danny.gamsmassi@gmail.com	Cameroon
13. Athanase Millogo	athanase.millogo@gmail.com	Burkina Faso
14. Morris Scantlebury	morris.scantlebury@ahs.ca	Canada
15. Osman Miyanji	omiyaji@yahoo.com	Kenya
16. Christelle Affognon	cadnelleaffognon@gmail.com	Senegal
17. Nadia Adotevi	kafuii@yahoo.com	Ghana
18. Marcellin Bugeme	marcellinbugeme@yahoo.fr	Senegal
19. Radcliffe D. Lisk	durodamil@yahoo.co.uk	Sierra Leone
20. Mbonda Elie	eliembondasn@yahoo.fr	Cameroon
21. Youssoufa Maiga	youssoufamaiga@hotmail.com	Mali
22. Martin Brodie	martin.brodie@glasgow.ac.uk	IBE
23. Ann Little	ibeexecdir@gmail.com	IBE

Apologies

1. Marina Clarke	nationaldirector.no@epilepsy.org.za	South Africa
2. Baba Aji	bm_aji@yahoo.com	Nigeria (based in UK)
3. Jo Wilmshurst	jo.wilmshurst@uct.ac.za	South Africa

We would like to thank all those who attended the meeting and we hope meetings such as this one will continue to happen.

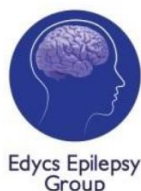
Introducing the Alliance for Right – Africa Disability Inclusion (ARADI)

By Youssouf Noormamode, President Edycs Epilepsy Group / Deputy Chair Africa Disability Alliance/Vice-Chair IBE Africa Region

The Africa Disability Alliance (ADA) is a disability led technical agency deriving its mandate from the African Continental Human Rights movement of organisations of persons with disabilities that constitute its membership. The ADA works on and utilizes a broad range of policy tools in disability programming and implementation processes. With the headquarters in Pretoria, South Africa, regional offices in Dakar, Senegal and Addis Ababa, ADA has been able to provide technical assistance on disability mainstreaming to the African Union Commission, the African Commission on Human and Peoples Rights in drafting of the Disability Protocol, the Pan African Parliament on the elaboration of the concept towards drafting a model law on disability in Africa.

The Alliances for Rights – Africa Towards Disability Inclusion is a continental disability oriented strategy that is aimed to support CSO's participation and contribution to African continental decision and policy making and standard setting. The ARADI project is to enable 13 Pan African Disability Federations (PADFs) and 14 Youth CSO to promote the importance of Disability Rights using AU's African Disability Protocol (ADP) and the Model Disability Law (MDL).

In the next issue of the newsletter, we are going to share with readers a report of a visit done by the ARADI team to Mauritius. We thank the Edycs group for hosting the visitors.



the
overseas
disability
charity

cbm
together we can do more



Please contribute to the newsletter

We are calling for chapters, their groups and members to contribute to the newsletter. Each month we are going to do a chapter spotlight. Be the first chapter to appear in our November issue of the Epilepsy Africa newsletter

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)

Life is Beautiful – Photography Competition to celebrate International Epilepsy Day 2018

To celebrate International Epilepsy Day 2018, IBE is delighted to announce an international photography competition for all ages with the theme 'Life is Beautiful' – that life is beautiful despite a diagnosis of epilepsy; that life is beautiful when enjoyed with family and friends; or that nature shows us how beautiful life is!

PRIZES Under 12 years 1st Prize of US\$500 5 runners up prizes of US\$100 each **Over 12 years** 1st Prize of US\$500 5 runners up prizes of US\$100 each. <https://epilepsy.org/life-beautiful-photography-competition-celebrate-international-epilepsy-day-2018/>



Photos

Awareness in Burkina Faso during epilepsy day 2017



Below: Awareness in Kenya as part of a Caravan outreach project.



The Caravan at a market centre in Bungoma County



At a market centre in Meru County

Below: Training workshop in Mauritius as part of ARADI project.



Read more information about these picture in the December and future editions. You can also submit your photos.

Right: 1st International Workshop on Onchocerciasis – Associated Epilepsy (Oae2017), held on 12-14th October 2017, Antwerp, Belgium



Resources

- Killing of person in Malawi-<https://www.nyasatimes.com/malawi-mob-torch-death-epilepsy-sufferer-another-stoned-death-accused-bloodsuckers/>
- IBe Life is Beautiful photo competition <https://epilepsy.org/life-beautiful-photography-competition-celebrate-international-epilepsy-day-2018/>
- WHO resolution on epilepsy: <https://www.ibe-epilepsy.org/who-resolution-on-epilepsy-approved-at-world-health-assembly/> or <https://www.ibe-epilepsy.org/wp-content/uploads/2015/05/NewResolutionText.pdf>
- African chapters: <https://www.ibe-epilepsy.org/about/ibe-chapters/africa/>

Did you rate yourself, share with others your results!

Last month we asked you to rate yourself. How did it go? We will be glad to get your feedback.

In the next and future issues

In the next issue we are going to talk about

- Message from Anthony Zimba, IBE Treasurer.
- Interview with Lungelo
- Information about IBE Taskforces.
- Information about IBE's exciting Epilepsy Next project.
- Chapter spotlight Kenya (If your chapter or country is willing to appear in the next newsletter, please email Betty).
- Understanding epilepsy in local languages.
- Pictures (please tell us what is happening where you are).

Call for new committee members

Last month we said we were in the process of identifying two members to join the committee. The good news is we already have one. We still need another one. We are using this opportunity to bring in members from regions that are not represented – West and East Africa.

Until the next issue, happy happy everyone! Please print the poster on the next page and share with your members.

Are you an active association – a self-assessment tool?

We have developed this tool to help associations rate their level of activity. This follows reports from the previous committee and the IBE that some chapters are not active. Use the table below to answer. Just try to be as truthful as possible.

Name of Chapter:	Rating					
Activity	0	1	2	3	4	5
1. We submitted all reports and information required by the IBE?						
2. We had activities for International Epilepsy Day?						
3. We completed the survey run by the Africa Regional Executive Committee.						
4. We applied for Promising Strategies?						
5. We submitted an article to the IBE Newsletter?						
6. We participated in the IBE photo competition?						
7. We applied for Solidarity Funding?						
8. We have been following up the WHO Resolution on epilepsy and we have a plan for its implementation.						
9. We are active on social media						
10. At least one of our members applied for conference funding from IBE/ILAE						
11. We collaborate with our local League						
12. (Choose an activity of your choice and rate it).....						
MARKS OBTAINED						
TOTAL MARKS						

Key to grades

45-60 marks means your chapter is **Very Active**, well done, keep it up, ****

30-44 means your chapter is **Active**, but aim higher, ***

15-29 means your chapter is **Somehow Active**, please do more, **

0-14 means your chapter is **Not Active**, please start doing something, *

NAMES GIVEN TO EPILEPSY (LANGUAGE & COUNTRY)

Epilepsy is found in all communities of the world. It affects both males and females, blacks and whites, children and adults, rich and poor, educated or not. Below you can see some 20 names given to epilepsy.

1. **Akwukwu na-adọ**-Igbo-Nigeria
2. **Apasmāra/ Miragī/ Mirgī**-Hindi-India
3. **Chipumputu/Khunyu/Chitutwane**- Bemba-Zambia
4. **Dikotlo/Motlotlwane**-Setswana-Botswana
5. **Epilepsie**-Afrikaans-South Africa
6. **Épilepsie**-French
7. **Epilepsy** -English
8. **Isithuthwane/Sokuwa**-Zulu-South Africa
9. **Izifafa/Izithuthwane**-Ndebele-Zimbabwe
10. **Kasuntu**-Tonga-Zambia
11. **Khunyu/Wakhunyu**-Chichewa-Malawi
12. **Kifafa**- Kiswahili-Kenya
13. **Kifafa**-Swahili-Tanzania
14. **Njirijiri**-Nyanja-Zambia
15. **Pfari/Zvipusha/Nhuta/Tsviyo**-Shona-Zimbabwe
16. **Sifo sekuwa**-Swaziland
17. **Warapa**-Yoruba-Nigeria
18. **Xián 癲/Diānxián 癲**-Chinese
19. **Yemīt'ili/ የሚጥል**-Amharic-Ethiopia
20. **صرع/الصرع داء**-Arabic

**Do you know any other names, please email us at
ibeafrika@gmail.com.**