



EPILEPSY AFRICA NEWS

Issue 5

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

January 2018

Contents of this Newsletter

- New year messages from Chairperson & Secretary.
- Call for young person to join AREC
- Epilepsy day 2017 activities
- Welcome Lesotho
- Advocacy poster

Image (right): Flag of Lesotho. Lesotho Epilepsy association was approved as an Associate Member of the IBE recently. Welcome to the family.



Monday 12 February

International Epilepsy Day 2018. Visit <https://epilepsy.org/> for more details.

Apologies: In the December issue we indicated that the application form for the youth project was included with the newsletter yet it was not. We would like to inform you that the form will be made available at a later date but we encourage you to start thinking about and developing your proposals.

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.

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!

Letter to young people with epilepsy

Dear Member,

The call for a young person to apply for a position on the Africa Regional Executive Committee did not receive positive response, therefore, we wish to extend the application period for a month. This means that the deadline for application will be **19th February, 2018**.

We urge you to participate fully in order to hasten the progress of the already planned actions for the year. The success of the AREC depends largely on your collaboration.

Find attached the announcement with extended period and clear instructions on the application procedure.

Kind regards,

Betty Barbara Nsachilwa
Secretary

ANNOUNCEMENT



A CALL FOR YOUNG PERSONS WITH EPILEPSY TO APPLY TO BECOME A MEMBER OF THE AFRICA REGIONAL EXECUTIVE COMMITTEE

PERIOD: 2017 – 2021

ELIGIBLE CANDIDATE:

- Must be aged between 18 and 35 years.
- A person with epilepsy.
- An active Member of one IBE official affiliate Chapters.

DUTIES AND RESPONSIBILITIES:

Generally, this role enables you to make decisions about programs to improve the life of people with epilepsy in Africa, particularly young people with epilepsy. This is an unpaid role that is good for young people who want to develop their leadership skills.

APPLICATION PROCESS:

1. The applicant must give a brief statement about themselves (*a page or less is sufficient and a passport photo attached*)
2. Why they want to join the Committee
3. Send the statement to email: ibeafrika@gmail.com

DEADLINES:

1. All applications to be received by **2nd February, 2018**. If you are unable to meet this deadline, please let us know so that arrangements could be made.
2. Selection will take place between 3rd and 19th February.
3. Results will be announced in February 2018.

NB: Please note that the application process will take a whole month, therefore, you are requested to send your application statement by **2nd February, 2018, 17.00 hours**.

Welcome Epilepsy Lesotho

The letter of acceptance from IBE read as follows:-

Dear Ms Hlalele

I am pleased to write to you to inform you that your association has been approved as a Provisional Chapter of IBE by the International Executive Committee. Epilepsy Lesotho will remain as a Provisional Chapter until the next General Assembly, which will take place in 2019. Once the application is ratified by the assembly, Epilepsy Lesotho will then become a Full Chapter with voting rights. In the meantime, Epilepsy Lesotho will have all of the rights of membership, other than the right to nominate to the Regional or International Executive Committees or to vote.

I look forward to working with you and your association over the coming years. Can you confirm that you will be the contact person for all communications?

Kind regards

Ann

Ann Little

Executive Director

International Bureau for Epilepsy



New year message from Secretary

Dear Friends,

Hope you have planned well for 2018 and your plans include improving communication for local and international collaboration. I have a vision of developing community partners for the Epilepsy Association of Zambia by increasing access to effective community resources through ties with relevant agencies and organizations to obtain important services such as counseling or peer-support groups. Health care systems taking a partnership approach with community resources and organizations, and linking patients to those resources is key to self-management success.

Having short or long term goals for a certain period and being determined to achieve those goals, leads to success.

I wish you all a successful 2018 and keep dreaming on for future success!

Betty Barbara Nsachilwa
Secretary

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. Your local newsletter
2. Your 2017 report and plans for 2018
3. Questions
4. 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)

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

A big thank you to all those who participated in the photography competition. Good luck to you all.



Spotlight (#4): International Epilepsy Day 2017 in Africa

Photos: Epilepsy day 2017 in Kenya (bottom), Burkina Faso (right) and Swaziland.



Instead of focusing on one chapter in this newsletter, we are focusing on several chapters that reported their Social Work day activities for 2017. If other countries have reports, please feel free to email them to us.

Different activities took place in African countries to mark International Epilepsy Day that fell on February 13 this year. It is quite encouraging to see many associations being active and innovative using the little resources at their disposal.



In Swaziland, Swaziland Epilepsy Organisation (SEO) representatives met cabinet members who included the Prime Minister and Minister of Health (see photograph). This was a high level activity meant to improve visibility of needs of people with epilepsy. Commenting on the work being done in Swaziland, Mr Zimba, current President for Africa and IBE Treasurer – elect, said “If all of us were working like Mbuso, Epilepsy stigma would have been eradicated. Good work Mbuso” while Godfreda Bupanda said “Mbuso you are a selfless visionary. You make Swaziland proud. Keep up the good work.” Mbuso Mahlalela is the Director of SEO.

In Zambia, Epilepsy Association of Zambia (EAZ) team visited the National Rehabilitation Center in Lusaka where they donated assorted items and had lunch with the children at there.

In Morocco Dr Najib Kissani reported that they had a celebration on 23 March in Marrakech that was shared with a second group in Fes City (500km north) by teleconference.

Judy Kariuki reported that in Kenya “...we put up an information stand at a popular shopping mall and created awareness. We also met county health officials and discussed how to scale up epilepsy care by opening more specialised centres in the capital”. She shared pictures of the event (see photographs).

From Malawi, Francina Ngodwe, Chief Executive Officer of Malawi Epilepsy Association, wished other associations a happy International Epilepsy Day and shared purple day messages promoting epilepsy awareness.

In Burkina Faso, Athanase Millogo reported that they postponed activities to 25 March. Athanase said, “We have had a 1km walk through the streets in Ouagadougou, with some sensitization messages with radio and TV interviews”. As the photographs from the event show, the march was quite successful in disseminating information.

Countries such as Democratic Republic of Congo (DRC) and Zimbabwe’s activities were affected by a lack of funding. In DRC, Dr Prince Kazadi reported that they had to cancel planned activities although they were able to organize a demonstration of purple day on March 26.

To further strengthen epilepsy work in Africa, and as a run up to International Epilepsy Day, the President, Mr Zimba initiated social media platforms including a WhatsApp group for professionals, a WhatsApp group for associations and a Facebook group for both professionals and associations. Epilepsy awareness information is being shared through these platforms. To join a relevant WhatsApp group, request via WhatsApp chat to Mr Zimba +260 97 7789042 and to join the Epilepsy Africa Forum facebook page follow this link:

<https://www.facebook.com/groups/1087643238013302/>

Youth Projects Funding is back again this year!

Youth project - we are going to seek funding for the youth project that the previous committee used to run. We will prioritise projects that promote epilepsy advocacy. Small but effective projects that we could trace, document and measure outcomes easily. For example, preparing a petition to Parliament or arranging a meeting with Health Minister or doing an epilepsy advocacy walk etc. keep checking this space for the application form. These projects were funded previously in 2016. We would be glad to hear from the young people who initiated these projects on their successes and challenges.

1. Cameroon received US\$ 246.00 for “Awesome Project” (Rabbit breeding project).



2. South Africa received US\$ 250.00 for “Epilepsy Awareness in Extreme Sport”.



3. Swaziland received US\$ 250.00 for “Out of the Shadow: Youth Enterprise”.



Did you enjoy reading our newsletters? Please give us some feedback: email ibeafrica@gmail.com



EPILEPSYAFRICA NEWS

Issue 2 October 2017
A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)

Contents of this Newsletter

- Message from Youssouf Noormande, outgoing Chairperson
- Message from Jacob Mugumbate, incoming Chairperson
- Know your new committee members
- Notes from the General Assembly
- Congress highlights
- Resources
- Social media contacts

Image (right)

The beauty of Epilepsy by Lungelo Dube of Swaziland. This is a success story of one of our chapters, the Swaziland Epilepsy Organisation. This photo won the IBE competition for 2016 and it is used to spread epilepsy awareness across the globe. Here, the picture was used as a cover for Epilepsy News. We hope to be able to feature Lungelo in future editions of Epilepsy Africa News.



We are on social media, join us today

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Epilepsy Africa News

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EPILEPSYAFRICA NEWS

Issue 3 November 2017
A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)

Contents of this Newsletter

- Introducing the Alliance for Right – Africa Disability Inclusion (ARADI)
- Swaziland Epilepsy Organisation hosts epilepsy run walk
- Minutes of a meeting of African delegates at the IEC in Barcelona
- Photos: Burkina Faso, Kenya, Mauritius & OAI 2017
- Resources and weblinks
- Poster-different names of epilepsy
- IBE Photo competition

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

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Death of a person with epilepsy in Chileka, Malawi

On 17 October 2017, Abdul Manda (a 39-year-old) who had epilepsy was burnt to death because he was suspected of being a vampire of bloodsucker. Eight more people died in related incidents. Abdul had a seizure and while he tried to recover people suspected him to be a bloodsucker. A mob dragged him to the nearby sundial 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 sent by the Federation of Disability Organizations 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 campaigns
- Making treatment and non-epilepsy medicines available
- Changing laws that do not protect people with epilepsy
- 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 its authorities. Finally we respectfully request our mutual confidence to the families and friends affected by the untimely killings.



Epilepsy Africa News

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EPILEPSYAFRICA NEWS

Issue 4 December 2017
A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)

Images (bottom): Epilepsy South Africa (ESA) celebrates 50 years of service to the community and some of the programs run by Epilepsy South Africa. See report inside.



Image (right): The new logo of Kenya Association for the Welfare of People with Epilepsy (KAWWE). See report inside.



Happy holidays

The holiday season is here. Our best wishes for Christmas day, Boxing Day, School holiday, Work holiday and the New year holiday.

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Contents of this Newsletter

- Chapters spotlight Kenya and South Africa
- Oncochoreo meeting report by Anthony Zaidi, IBE Treasurer
- Interviews with Lungelo Dube, Swaziland
- Opportunities and resources for associations
- Photos (please also tell us where you are)

Epilepsy Africa News

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EpilepsyAfrica News

A newsletter on epilepsy affairs in Africa

Issue 1 January-June 2010

Epilepsy in Africa: is there a sustainable way forward?

Editorial

From Dakar, Lome, Harare, Kampala to Cape Town, ideas have been shared on how to improve epilepsy management in Africa and how to better the quality of life of the more than 6 million people with epilepsy in Africa.

It is not now the time to concretize ideas! Now is the time to walk the talk, take these ideas with us and better the lives of people with epilepsy.

After we have started walking, we shall need to keep walking. Keeping walking may seem easy, but shall be very difficult when we get tired or old.

We need to put in place strategies for new players to take from us the button sticks for the race to continue. We need to set guidelines, sustained by a viable coordinating regional committee.

"I think we need a 3-pronged approach: stronger regional integration propelled by much stronger national associations and deeper networks with our grandest strategic partners, the IBE, ILAE and WHO"

But the question we all have is what is the most sustainable way forward?

We need to set up permanent structures to complement what the IBE is doing for us. This may include

plans to enhance unified fundraising, awareness, treatment, research, training and advocacy.

Our last option is to keep building the capacity of local associations. But donors now look for regional partners more than they do smaller organisations.

We need to weigh our options, including many others you know of and act for the best and the most sustainable way forward. I think we need a 3-pronged approach: stronger regional integration propelled by much stronger national associations and deeper networks with our grandest strategic partners, the IBE, ILAE and WHO"

J. MUGUMBATE, Harare

Mr. Zimba visits Zimbabwe during 20th National Epilepsy Awareness

September 21-25 2009 was Zimbabwe's National Epilepsy Awareness Week (NEAW).

This was the 20th edition of this event, spearheaded by the Epilepsy Support Foundation (ESF), a chapter of the IBE. Mr. Zimba, who is Vice President of IBE (Africa), Chairman Africa Region Executive Committee, Coor-

minator, Health Advisor to President and cabinet and visited hospitals. He had a lecture with about 100 doctors and attended to television and radio programmes. He visited the epilepsy centre and clinic run by the ESF. And was quite embraced by the work being done to uplift the life of PWE from

income generating projects (e.g. the peanut butter project supported by the IBE), youth programmes, women initiatives, computer training and rural projects, and non-government epilepsy programmes.

Photo: Mr. Kadavili of ESF and Mr. Zimba upon arrival. Story continued on page 2.

Right photo: poverty results in many people not seeking treatment in Africa. Burns and infections are some of the results. There is need for awareness.

Resources for both awareness and treatment are limited. Photos

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Advocacy project

Feedback was received and we improved the project. We will compile and report the feedback next month. Thank you all. What would you do to advocate for better epilepsy services in your country? Please see the poster on the next page for suggestions.

SUGGESTIONS FOR EPILEPSY ADVOCACY

To advocate is to talk about what should be done and is not being done. Advocacy is a powerful tool to ensure that government and other institutions provide much needed treatment, employment, education and many other services to people with epilepsy. Here are some suggestions to achieve this:-

Local level

- Ensure that local leaders recognise the needs of people with epilepsy.
- Ensure that all local institutions support epilepsy programs and have plans to deal with epilepsy.
- Educate people about the needs of people with epilepsy e.g. being accepted not stigmatised.

National level

- Ensure governments recognize needs of people with epilepsy and their families.
- Ensure that all government institutions like schools support epilepsy programs.
- Ensure that government has a national plan for epilepsy.

Regional level

- Ensure that Africa has a policy for epilepsy driven by the African Union.
- Ensure that all regional institutions like SADC, EAC and ECOWAS have epilepsy programs.

Global level

- Ensure global leaders understand needs of people with epilepsy and support epilepsy initiatives.
- Ensure that all global institutions support epilepsy programs.

How to achieve advocacy?

- Develop your own advocacy plan (goal to be achieved, message/problem to be solved, action to be taken and indicators of success).
- Write a letter to each leader in your area specifying challenges and solutions. Provide case studies of your members with epilepsy and their families. Use true stories.
- Provide them with a draft plan or policy or program that you develop or use the WHO Resolution on Epilepsy.
- Show them how inexpensive it is to manage epilepsy as a country, give examples.
- Attend meetings of leaders e.g. Parliament, local Chief court, etc and ask questions about epilepsy.
- Meet journalists and business people and tell them your story.
- Go to radio and TV stations and newspapers and social media and tell them your story.
- Ask people with epilepsy to share their experiences.
- Sing songs about epilepsy and encourage artists to do the same with positive messages.
- Work with related groups in disability, health, community development etc

Resource: get more information about advocacy here <http://www.pitt.edu/~super7/18011-19001/18351.ppt>

Do you have any other topics to suggest, please email us at ibeafrica@gmail.com.