



EPILEPSY AFRICA NEWS

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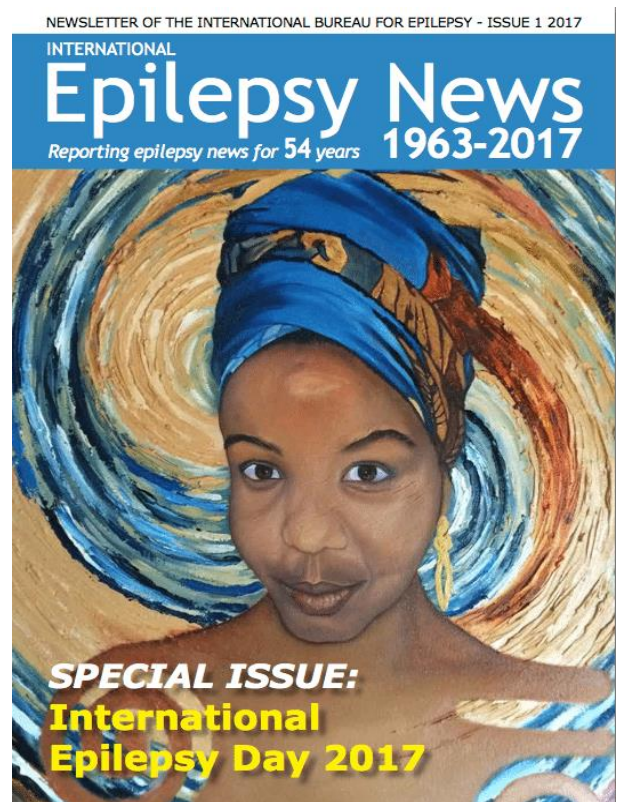
A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)

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Image (right)

The beauty of Epilepsy by Lungelo Dube of Swaziland. This is a success story of one by 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

- 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.

A Personal Report to Africa Region Members from Youssouf Noormamode, outgoing Chair IBE Africa Regional Committee



Dear Colleagues,

As my term in office comes to an end, I would like to offer you a personal account of what I have done over the past years and the goals that I have pursued, and hopefully, achieved. I would also like to thank you all, especially Marina Clark, Vice Chair, Harmiena Riphagen, Secretary, Anthony Zimba, outgoing Executive Vice President Africa and Ann Little, Executive Director for the support you have given me during this time. It has been a pleasure and an honour to serve as your Chair.

My report start with some general remarks and then focused on the specific activities that we have been able to undertake during the past years. I am grateful to the International Executive Committee members of the IBE for their collaboration and support on numerous occasions.

It is important to mention that despite the budget allocated by the IBE International Executive Committee for the Africa Regional Committee amounting USD 5,000; we have been struggling to make things happen and work within the allocated budget. Funding was among the major problematic issues which we used to deal with but forcibly to recognize that our efforts have not been in vain.

We have been in regular contact on major issues surrounding epilepsy thro emails and phone and at one time we used to have a teleconference so as to enable our team members to discuss on the regional agenda and coming plans.

When I took office of as Chair of the Africa Regional Committee, I had a clear strategy which set the priorities for our activities. Let me remind you briefly:

- that the IBE Africa Region becomes a vibrant and dynamic result oriented region;
- that the optimization of benefits by the African Chapters by partnering, networking and adopting the concept of new open clear cut collaboration is a reality;
- that the strengthening of the African Chapters through capacity building, autonomy and financial sustainability become our core priorities to enable the epilepsy promotion within the African region.

About this newsletter

Editorial team

Jacob Mugumbate

Youssouf Noormamode

Betty Barbara Nsachilwa

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ibeafrika@gmail.com

Enjoy your reading

Among the major activities carried out during my term in office is summarized below:

- Survey of IBE Africa member organisations and findings communicated to the IBE International Executive Committee through the IBE Vice President Africa;
- Coordination and organisation of the IBE 2nd Africa Epilepsy Congress in Cape Town May 2014
- Meeting of the IBE Africa Regional Committee during the IBE 2nd Africa Epilepsy Congress Cape Town
- Contribution to the Publication of the IBE International Epilepsy News Magazine

- Telephone Conference among IBE Africa Regional Committee members
- Facebook page created and maintained by Harmiena Riphagen, outgoing Secretary
- Development of electronic newsletters circulated by the outgoing Secretary covering activities held within the Africa region
- Affiliation to the World Society of Child Science – Journal Pediatric Medicines
- Attendance to the Annual General Meeting organized by the Africa Disability Alliance at Holiday Inn in South Africa
- Participation at the Third Round Table Workshop on the Communities of Practice in Disability Advocacy for Mainstreaming organized by the Africa Disability Alliance
- Projects call and funding of Africa Youth
- Participation and attendance at the Project launching Alliance for Right – Africa Disability Inclusion (ARADI) in Johannesburg, South Africa
- Support and collaboration to the 4th Epilepsy Africa Congress Dakar, Senegal despite my inability to attend at last minutes due to health problems;

I hope this short report will shed light on my humble contribution towards the IBE Africa Region and I re-iterate my support to the new incoming Chair newly elected for the Region.

Port Louis 31st August 2017

Statement by Jacob Mugumbate, incoming Chairperson



I would like to thank the outgoing committee for the work they did during their term in office. I am glad the availability of Youssouf in the incoming committee as Vice-Chairperson will help build continuity of programs. As Chairperson for the region, I am particularly interested in four issues:

1. Epilepsy advocates program meant to develop capacity of individuals interested in championing epilepsy. We are going to identify epilepsy advocates and seek resources to support them in their work. Advocates would be mainly young people with epilepsy.
2. Chapters' program meant to develop the capacity of associations for advocacy, fundraising, resource management and awareness.
3. National programs meant to develop the capacity of countries and advocating for increased recognition of epilepsy. We are going to advocate countries and adopt and implement the WHO Resolution on Epilepsy.
4. Regional program and regional advocacy meant to develop capacity of the African region for advocacy, fundraising and awareness. Regional advocacy will focus on the African Union and regional blocks such as ECOWAS, SADC and EAC.

Advocacy is an area of interest for me because the problems that we face in Africa are too huge to be solved by associations alone, there is need for making governments fund epilepsy programs and implement them on a larger scale. Because governments are not willing to do this, advocates and ambassadors would play a bigger role in highlighting the challenges that we face and making governments responsible. I have consulted widely, and I am happy to have included the input of many people in coming up with objectives for our term. Our program is going to be focused on the four objectives highlighted above and I will be sharing the program with you in the next newsletter that is coming in November.

Know your new committee members

Dear all,

Get to Know the Incoming Elected IBE Africa Regional Executive Committee. To hold office from 2017 to 2021



**Jacob Mugumbate, Zimbabwe
Chair**



**Youssouf Noormamode, Mauritius
Vice Chair**



**Betty Barbara Nsachilwa, Zambia
Secretary**

We are sincerely thankful to the Outgoing Committee Members, Marina Clarke who was Vice-Chairperson and Harmiena Riphagen who was Secretary. Job well done for all the successes made during your tenure of office.

We are in the process of identifying two members to join the committee. We are using this opportunity to bring in members from regions that are not represented – West and East Africa.

The inclusion of all IBE Chapters in coordinating activities for Africa, will show unity of purpose and collaboration. Africa is diverse and experience of life in a particular country may not be exactly as others are experiencing it in their area. We, therefore, feel that harmonization of ideas, plans and activities could lead to a fruitful culmination of all our objectives.

Notes of General Assembly held during the 32nd Epilepsy Congress, Barcelona - 6th September 2017

- 1) Rwanda now has a new chapter, the Global Epileptic Association that received its IBE membership at the Congress.
- 2) Chapters were encouraged to be active as follows:
 - a. Should communicate with IBE regularly.
 - b. Should communicate with regional committee regularly.
 - c. Should submit reports to IBE and regional committee.
 - d. Should report finances accordingly and in a timely manner.
 - e. To participate in regional activities such as surveys
- 3) Chapters need to support Epilepsy Day.
- 4) Chapters should promote the WHO resolution on epilepsy in their region. The WHO Resolution on Epilepsy is an important advocacy tool that we should encourage our governments to adopt and provide resources for its implementation.
- 5) Regional reports were presented.
- 6) Need for e-solutions, sometimes called telemedicine.

...continued

- 7) Need to capacitate youths with skills. Need to capacitate youth with epilepsy with education, leadership skills, economic opportunities etc. The Epilepsy Next project of the IBE seeks to achieve these objectives.
- 8) Need to develop and strengthen associations in Africa through improving fundraising, training of administrators and treasurers.
- 9) Regions should build their capacity to fundraise, research, advocate and implement regional epilepsy programs.
- 10) Taskforces were set as follows: Research Telemedicine/e-solutions and Education. We are represented by Harmiena, Augustine Mugarura and respectively in these taskforces.
- 11) Training of chapters in managing funds, fundraising etc. was recommended.

Congress highlights

1. We had two meetings attended by 18 and 22 delegates from Africa respectively. Suggestions from the two meetings
 - a. Need for IBE and League members to work together in Africa, both at country and regional level.
 - b. Need to develop and strengthen associations in Africa through improving fundraising, training of administrators and treasurers.
 - c. Need for research, publishing and utilisation of existing research.
 - d. Need to increase attendance of delegates from Africa at Congresses.
 - e. Need for collaboration, networking and communication of professionals working in the area of epilepsy in Africa to be achieved through social media, emailing lists, etc.
2. The WHO Resolution on Epilepsy is an important advocacy tool that we should encourage our governments to adopt and provide resources for its implementation.
3. Epilepsy advocates or champions (people with epilepsy who are trained and resourced to play this role) could play an important role to promote recognition of the needs of people with epilepsy and to increase awareness of epilepsy as a treatable condition.
4. Need to capacitate youth with epilepsy with education, leadership skills, economic opportunities etc. The Epilepsy Next project of the IBE seeks to achieve these objectives.
5. Telemedicine (or 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. Need for nurse training (especially at medical/nursing school level) to promote task shifting from specialists and other doctors to Primary Health Care level. This is necessary and it has been proven to work in several countries that had demonstration projects under the Global Campaign Against Epilepsy.
7. Epilepsy training programs should be part of curriculum in colleges for nurses, clinical officers and medical assistants.
8. Need to develop and improve epilepsy management guidelines in line with current research.
9. Need for context specific interventions. For example, in Cameroon the ministry identifies an area and sends health workers to camp and do field work for about four days, while providing the necessary resources.
10. Need to focus attention on 'traditional' methods of treatment since most people in Africa consult healers, prophets and use indigenous knowledge. *...continued*

11. Phenobarbital remains the drug of choice in developing countries due to low cost. Research confirms this.
12. Regions should build their capacity to fundraise, research, advocate and implement regional epilepsy programs.
13. Need to identify key priority areas for epilepsy research in Africa and to develop a research agenda for the region.
14. There is 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

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

Resources

- This newsletter carries over from our 2010 publication which was discontinued. View our 2010 newsletter here: <https://www.ibe-epilepsy.org/downloads/Newsletter%20January%20to%20June%202010.pdf>
- WHO resolution on epilepsy: <https://www.ibe-epilepsy.org/who-resolution-on-epilepsy-approved-at-world-health-assembly/>
- WHO resolution on epilepsy: <https://www.ibe-epilepsy.org/wp-content/uploads/2015/05/NewResolutionText.pdf>
- African chapters: <https://www.ibe-epilepsy.org/about/ibe-chapters/africa/>

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 coming soon!

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: Activity	Rating					
	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, *

In the next and future issues

In the next issue we are going to talk about

- Message from Anthony Zimba, IBE Treasurer.
- Information about IBE Taskforces.
- Information about IBE's exciting Epilepsy Next project.
- Chapter spotlight (If your chapter is willing to appear in the next newsletter, please email Betty).
- Minutes of Africa Region delegates held during the Congress in Barcelona.
- Introducing the Alliance for Right – Africa Disability Inclusion (ARADI).
- Understanding epilepsy in local languages.

Until the next issue, happy happy everyone!