



EPILEPSYAFRICANEWS

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



About this newsletter

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Enjoy reading! How to join us:

WhatsApp group for people with epilepsy and significant others group for professionals interested in epilepsy: Epilepsy Africa Facebook group: Epilepsy-Africa-IBE; 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 the list, send an email to ibeafrika@gmail.com. You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publications/regional-news/> and www.epilepsyafrika.org

Cover photo

Mrs. Marie Richards at EDYCS Rodrigues Help to Grow Educational and Rehabilitation Centre

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Chairperson/Editor's Message

Dear Reader

Welcome to the 25th edition of Epilepsy Africa News. Epilepsy Africa News is a platform whereby persons with epilepsy, Epilepsy Organisations and Individuals are sharing their views on issues on epilepsy. This edition is covering news for the Month of August, 2020.

In this article we remember an epilepsy icon, Anthony Mulengaimba, through an obituary of his work in Zambia. Last month we produced a special dedication edition to his work in Africa. As we continue to remember him and mourn his departure we look ahead with hope to continue building on his legacy.

Investing in economic empowerment of persons with epilepsy has proven to be a path to reduce poverty. We think empowering persons with epilepsy to rise out of poverty is essential for the sustainable development of any country. Mauritius has developed a sustainable partnership worth replicating with Foodwise another Non-Governmental Organisation to ensure that the needs of persons with epilepsy are covered during the COVID-19 period and beyond. All organisations of persons with epilepsy have a leaf to borrow from the article covered in this issue. In Democratic Republic of Congo we profile the work of Aslek; an organisation working to alleviate the suffering people with epilepsy are facing in terms of abandonment, lack of support services and discrimination.

We are also giving tips on how to develop community-based partnerships to ensure that all organisations working with persons with epilepsy add value to their work across the region. It has been noted that organisations can effectively mobilise people to come out of the shadows but without effective and sustainable partnerships it is difficult to maintain created groups together. Persons with epilepsy do not only need medication, but they have other social needs that can be addressed through working with other organisations.

We are excited to announce that 6 countries (Mauritius, Zambia, Zimbabwe, Uganda, South Africa and Malawi) have received sub grants to carry out innovative projects in Africa to develop models that could be replicated across the region through our Promising Strategies Grant. In the next article we will share the outcome of the other four countries that will receive the Making Epilepsy a Health Priority Funding. We are excited that 16 countries applied for this funding. We want to thank the **Band Foundation** that has proved to be a **trusted friend** for epilepsy in Africa by supporting all our projects. In the next article we will be sharing with you new developments and prospects that are lying ahead, including the establishment of African Epilepsy Trust Fund. Let's all work together with IBE Africa to empower persons so that we can change the face of Epilepsy in Africa.

Action Amos IBE Africa
Vice President

If you have a story, you'd like us to consider for publication, please contact: ibeafrica@gmail.com, amos_action@yahoo.co.uk Also visit our website www.epilepsyafrika.org and our twitter page @EpilepsyAfrica



Chapter News: Epilepsy Association of Zambia



OBITUARY

ANTHONY MULENGA ZIMBA

March 17, 1954 – August 9, 2020

Epilepsy Association of Zambia is deeply saddened on the passing of its Chairman and Founder, Dr. Anthony Mulengaimba, on **Sunday, 9th August, 2020**. Anthony was born in Kawambwa District, Luapula Province of Zambia, and survived by a wife - Dr. Meamui Mumbela, four children and four grandchildren. He worked at the Levy Mwanawasa University Teaching Hospital as Epilepsy Specialist.

Having been a member of the Mental Health Association of Zambia, Anthony saw it fit to initiate the formation of the Association in 2001 and incorporated professionals from all walks of life to

legally register the Association with the Registrar of Societies. Given the many challenges faced by the epilepsy support group in Zambia, he led and guided the Association through difficult times, suggesting solutions to ensure tremendous progress. Though persistent and forthright, he was a hard worker, approachable, generous and willing to go out of his way for the benefit of others. An **Advocate** for what is right for people living with epilepsy.

Anthony, held positions as Secretary for International Bureau for Epilepsy (IBE) - Africa Regional Executive Committee for four (4) years, Vice Chairperson for four (4) years, Vice President for Africa Region for four (4) years and concurrently as a member of the Board of Directors for the Africa Epilepsy Alliance for eight (8) years. He was also a member of the Executive Committee of the Zambia Non-Communicable Diseases Alliance and currently held the position of Treasurer for the IBE Executive Committee since 2017 until his passing. The African Epilepsy fraternity regarded him as one of the elders, who guided and counselled the younger leaders.

Anthony had a good sense of humour, and was determined to uplift the spirits of his colleagues. He adopted vulnerable children and adolescents living with epilepsy, paying for their education and caring for other social needs. He surely had a distinguished service rendered to the people with epilepsy in Zambia and Africa as a whole, leaving a legacy we are proud to continue.



Chapter News: EDYCS Epilepsy Group of Mauritius

Collaboration and Partnership – Edycs and Foodwise

A strong collaboration and partnership established with Edycs Epilepsy Group by Foodwise, a Non-Governmental Organisation regarding food distributions to needy and vulnerable families. On 25th June 2020, a meeting was held with Akena at the seat of Edycs Epilepsy Health Centre.

The following food distributions have been organized:

- April 2020 – During the COVID-19 lockdown, 10 families were reached.
- June 2020 – The public was invited to make food donations at Winners. Following this, 20 needy families were reached.



Donation of School Materials

EDYCS Rodrigues Help to Grow Educational and Rehabilitation Centre received donation of school materials through Mrs J. Marie Richard.



Epilepsy Organizations Developing Community Partnerships - what do you need to know?

Increasing access to effective community resources through ties with relevant agencies and organizations is a cost-effective way 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. Patients live, work, and play in social and physical environments outside the health care system. Look for community resources and support networks. Linking patients to these resources is critical for long-term results.

Definition:

Community is defined broadly as the places people live, learn, work, worship and play.

Community partnerships may:

- Be traditional services that can extend a health system's patient care
- Help patients who have special needs (e.g., blindness) or limited resources (e.g. no transportation)
- Be very non-traditional, yet supportive:
 - Beauty and barber shops may have access to hard-to-reach populations
 - Shoe stores may partner to raise foot care awareness
 - Faith-based organizations can offer

support group opportunities.

Community Partnerships: Nine Steps

By following these 9 steps, you can develop important partnerships with other organizations, agencies and businesses in

your community to provide support and resources for patients.



1. Identify community-based team members

In addition to creating linkages to community-based services, there should be a mechanism for relevant community members.

2. Identify needs and align with resources already available in your area for patients, their families, and medical staff:

Identify your country's community resources and financial support.

3. Create new partnerships to create new resources.

Conduct a brainstorming session with your healthcare team: what are your needs now? What might you need in the future? Are there any gaps in available community services or resources? Assess the situation using data collected about your patient population, identify community resources to fulfill your needs, and update your assessment as you learn more.



4. **Make the resources accessible.**

Don't just hand patients a list – work with the health system to coordinate planning and referrals. Link patients to community resources via a designated staff person (e.g., nurse case manager). Develop supportive programs and policies with community organizations so they contact patients, and know how to refer back to the health care system when problems are identified. Formalize a policy to be sure it survives staff turnover.

- Lay health workers (e.g. parish nurses, community health workers, peer educators) may offer a liaison between health care services and community resources, and can provide effective self-management support.

5. **Periodically review your community partnerships.**

Are there new partnerships that can be developed to fill the gaps in needed services?

- Who are the leaders in local ethnic minority communities? Share your concerns about patient needs – they may already have information and resources to help with epilepsy care. Team up with high profile community members for advanced advocacy.

6. **Think broadly: partner on a local, international and national level.**

Don't miss an opportunity. Contact local officials about your needs. Local officials may include the mayor, district health officers, health departments, legislative officials, Epilepsy Organizations or pharmaceutical industry.

7. **Think collaboratively.**



- Link with large and small self-management support programs.
- Partner with other local organizations with similar objectives e.g. International League Against Epilepsy Local Chapter, Neurological support group or Non-Communicable Diseases network.

8. **Support your community:** Volunteer as a guest lecturer, visit a school health program, or participate in a community event. These actions can go a long way to show your support of community activities.

9. **Pursue public policy to support healthy lifestyles.**

Health policies, insurance benefits, civil rights laws for persons with disabilities, and other health-related regulations play a critical role in chronic illness care.

Epilepsy in Democratic Republic of Congo

ASLEK is a non-profit charity organisation run by CEO & Founder Dr. Prince Kazadi. ASLEK provides support, awareness and community services. Provides support to people with Epilepsy and their families in the DRC. The Association fighting stigma epilepsy in the Democratic Republic of Congo (DRC), abbreviated as ASLEK, reports that the fight against the stigmatization of epilepsy in the DRC has been their battle song and the general public know very little about epilepsy. People with epilepsy are isolated, victims of social discrimination and face challenges in attaining education more especially children.

People suffering with epilepsy are almost abandoned to their plight and often victims of social discrimination, educational blocks, professional discrimination and ESPECIALLY children. All this leads to consequences of a life lacking fairness or opportunity.

The burden of epilepsy is unbearable in that country because people with epilepsy are unable study or work and the disease is dogged by myths - religious & social - being considered as a curse or bad luck. The few children with epilepsy they have tried to support are quite a load to the team, and have not had much luck gaining school supplies so far. ASLEK as an IBE Africa member wants to change the situation in DRC.



Making Epilepsy a Health Priority in Africa – Phase 2

Phase 2 offers a small grants program to enable IBE chapters to develop plans at the national level and to work together to develop and disseminate a regional plan of action. This project is grounded in the core rallying principle of the 2030 Agenda for Sustainable Development – leaving no one behind. During its implementation, and in alignment with the commitment to sustainable development goals of regional governments, effort will be made to identify regional stakeholders to support the project cause. There will be the opportunity also to increase efficiencies and value for money through harmonized operations with the Promising Strategies Program, which are also supported by the BAND Foundation. In addition, the project seeks to complement the efforts of state and other non-state actors and to empower persons with epilepsy, through capacity building, to influence society at large and policy makers to include epilepsy on national and regional health agendas. Other aspects of the project will be directed at capacity building of regional leadership in the development of well-equipped epilepsy initiatives. Interventions will be focused on both national and regional duty bearers with the aim of awareness raising, information sharing, and empowerment at all break the barriers that hinder access to health services.

16 countries have applied for funding and in the next article we will cover those new projects that will be successful.

Promising Strategies Program 2020

The latest round of the Promising Strategy Program, which focuses on the African continent, is funding projects aimed at equipping people affected by epilepsy with the expertise needed to be equal partners in all aspects of their healthcare, education, employment opportunities, legal rights and, in particular, in issues related to stigma reduction. Many African patient organisations are motivated to change epilepsy understanding on their continent. Unfortunately, the capacity of such chapters in Africa is limited, yet there is a strong desire by these member chapters to build their infrastructure in order to narrow the knowledge gap and to reduce the stigma and discrimination that people with epilepsy face in Africa and which often leads to inhumane treatment by society and even by their families.

Participating Countries:

Malawi
Zimbabwe
Mauritius
Zambia
South Africa
Uganda

Contributing to the newsletter means continuity

We are calling for chapters, their groups, researchers and members to contribute to the newsletter. You could share this with us:

1. Epilepsy work
2. Your plans and work
3. Questions on Epilepsy Care

Did you enjoy reading our newsletter?

Please give us some feedback –

Email: ibeafrica@gmail.com

Or whatsapp +265 998 138 134 or +260 955 559 629

next issue to feature:

- Global Action Plan on Epilepsy and its Synergies with other Neurological Disorders
- Local Chapter News
- African Epilepsy Trust Fund

