



Alliance Afrique pour l'épilepsie

تحالف الصرع الأفريقي

Epilepsia áfrica aliança

# Epilepsy Alliance Africa (EAA)

# **Annual Report 2020**

TOGETHER WE WILL MOVE MOUNTAINS



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#### President's message

It is with great honor and privilege that I welcome you to the first annual report of the Epilepsy Alliance Africa (EAA). Africa now, more than ever needs its citizen male, female, youth, and old to rise to the occasion and develop a homegrown solution to address the many challenges and situation we find our self in. The unavailability of affordable medication, lack of health professions in clinics and hospitals in most African countries is an issue of great concern. The COVID-19 pandemic has greatly affected our people and some have passed on.



According to the World Health Organization (WHO) estimates epilepsy affects over 10 million in Africa limited and poor resourced health system across the continent, stigma, myth and misconception further compound challenges faced by people with epilepsy and their families.

The Epilepsy Alliance Africa continues to grow and develop a home-grown solution by harmonizing all the regions of Africa, professionals, non-professional, member chapters, and individual contributing and participating on an equal level. Integration and coordination play a pivotal role of epilepsy programming and key in developing strategies to mobilizing resources and implementation for Africa. Creation of broadbased platforms that involve all participants willing to enhance and improve the lives of people with epilepsy in Africa. We have advanced telemedicine and publications.

As we move into the feature partnerships will need to be forged for the greater good of our people and Africa at large. Regional bodies in Africa, Africa Union, play a significant role in the success mitigation measures and reducing the treatment gaps. The Alliance will continue to develop practical means to capacitate and train professionals and non-professionals, to date the Alliance has conducted over 20 webinars on various subjects covering various tops presented by people with epilepsy, professional, advocates and non-professionals.

The landscape of Africa has changed and the Alliance will continue to provide technical support and training. The milestones the Alliance has achieved over the last 12 months can only be honored to our partners, men and women of the Alliance like Professor Kassani, Chantal Katyabutembo, Dr Jacob Mugumbate, Samuel Chigamba and many others in our Executive Council and membership who has supported immensely by hosting webinars, training of telemedicine. For those that I might have omitted, I acknowledge your support to the Epilepsy Alliance Africa This year the other highlight was the work of the EAA. I wish everyone a successful 2021.

Thank you, Taurai Kadzviti, EAA President

#### Secretary General's message

We welcome this first annual report.

Before, I start, on behalf of the council, I wish you a happy new year Please be safe from the COVID-19 pandemic! Unfortunately, we lost another Neurologist in East Africa, Dr Paul Kioy in the very beginning of 2021. In 2020, we lost Anthony Zimba. We dedicated a webinar to Anthony and we will dedicate another to Paul this year.

From 12 December 2019 up to the end of 2020 what did the council do in these 12 months?



This is what we achieved:

- We did several webinars and got many important guests for example Mr Kesamang from the African Union, Dr Angelina Kakooza from Uganda, Professor Emmanuel from Nigeria, Professor Nirmal from India, Dr Charlotte Baker from Lancashire University and Lorri Lorraine from Row Foundation.
- From such successful collaboration we managed to increase the members registration, now we do have 28 associations registered and members from 33 African countries including doctors and nurses.
- We partnered with the African and Middle East Epilepsy journal. We made several publications in 2020.
- We build committees for advocacy, awareness, fundraising and research.
- We did 8 webinars including a conference.

I want to thank everyone for a successful year and wish you another successful year. Together we will go far.

Thank you

Chantal Kanyabutembo, EAA Secretary General

#### **Vice-Presidents' messages**

**West Africa Report** 

by Gams Massi Daniel, MD V/P for West Africa

The year 2020 has been a special year for the West African region as it does throughout the world. The Covid-19 pandemic has spread very quickly, forcing states and health structures to adapt to new challenges. **Patients** suffering epilepsy have been greatly impacted by this new Coronavirus. They have been exposed to contamination, social distancing has increased stigma and isolation, and border closures have limited access to antiepileptic drugs which have been in short supply in some countries. There is also a sub-optimal follow-up in health centers because of the fear of being infected. Despite this difficult climate, associations



fighting against epilepsy have spared no effort to raise awareness, advocate for better access to care, fight against stigma and socio-professional isolation and improve living conditions of people living with epilepsy. It is in this context that several associations have distinguished themselves such as: Epilepsy Foundation Nigeria, Epilepsy Association of Sierra Leone, Cameroonian League against Epilepsy, Foundation for Epilepsy and Stigma Support - Gambia, The Epilepsy Ambassadors Initiative, Burkinabe League for the fight against epilepsy and others (*pictures*). The year 2021 opens with new perspectives, in particular thanks to a better knowledge of Sars-Cov 2 responsible for Covid-19 and the arrival of several vaccines. We remain

hopeful that this pandemic will end soon. In the meantime, the West African region of the Epilepsy Africa Alliance will continue to work to move things forward, particularly with the telemedicine and teletraining program in partnership with all associations. Pictures: Top: A webinar organized by The Epilepsy Ambassadors Initiative (Nigeria)



Bottom: Training of general practitioners and nurses on the diagnosis and management of epilepsy in Bafoussam, Cameroon (in early February, before the first case of Covid-19)

#### **East African Region Report**

by Sarah Nekesa Vice-President, East Africa

The East African region covers 6 countries of Uganda, Kenya, Tanzania, Rwanda Burundi and recently South Sudan.

The year 2020 started well with so many programmatic ideas for people with epilepsy. In Uganda, ESAU was able to organize the international Epilepsy day which brought together people with epilepsy, their care takers, mental health workers, neurologists and representatives from ministry of health as the mother ministry.

This memory however deteriorated fast with the outbreak and upsurge of Covid 19 pandemic which has not left people with epilepsy in the region the same. Kenya was the first East African country to get the first case of corona Virus infection. The numbers have since continued to rise with immense loss of lives. Tanzania and South Sudan has been the only countries in the region that has not shown the rate of infections and deaths. Rwanda is still partially locked down because of the high infections and Ugandan education sector is still closed due to the fear of children and learners getting infected. The candidate classes however are allowed to school to complete the final exams

As a result, mental health departments in major hospitals have been used as Covid 19 treatment centres and most of the mental health workers now work on the Corona task forces. This has left PWEs in the region with very little support from public hospitals which are also faced with constant drug stock outs.

On the sad note, the region has in January 2021 lost two major players in the field of epilepsy. Prof. Paul Kioy, a renowned neurologist and founder of the National

Epilepsy Coordinating Committee in Kenya succumbed to Covid-19 8<sup>th</sup> January. Mr. Paul Spence who was the Finance Director at KAWE past on, on Sunday the 10<sup>th</sup>. May their souls rest in Peace.

The Chairperson BOD (in the middle) together with the ESAU staff and care taker of a person with epilepsy at the IED



#### **Central Africa Report**

by Dr Prince Kazadi EAA Vice-President for Central Africa

According to the UN definition, Central Africa includes the following 9 countries: Angola, Cameroon, Gabon, Equatorial Guinea, Central African Republic, Democratic Republic of Congo, Republic of Congo, Sao Tomé and Principe and Chad.

The year 2020 was marked by a covid-19 pandemic, which did not spare Central Africa, which hampered several operations of our institutions and the various projects and action plans of our Epilepsy Alliance Africa.

Despite the disruptions linked to this pandemic, some projects have been carried out by our ASLEK Epilepsy Association in DRC, we have brought within our EAA, our partners such as Row foundation, the defeating epilepsy Association... to be able to present in our webinar and to continue to disseminate until now the activities of EAA

in their respective platforms.

We connected 9 African countries member of EAA to Indian Epilepsy foundations with several projects in the near future, we were able to convince the Cameroonian epilepsy foundation CODEF of Mr. Kenneth to become a member of EAA.



The challenges to be met are much more, based on the fact that several Central African countries speak French and Portuguese and this constitutes a permanent barrier to being able to put all the countries together and I hope that this year 2021, we will put them strong strategies which will serve to convince all the countries of Central Africa to register in the EAA.

Suggestion: some Central African countries do not have associations for the fight against epilepsy, it will be up to the EAA to create it in their countries if possible. We say thank you to the whole team who worked hand in hand, despite the difficulties related to covid-19 and in volunteering to finally improve, even slightly, the conditions of those suffering with epilepsy in Africa.

Together we will beat epilepsy.

Thank you

#### **North Africa Report**

by Professor Najib Kissani EAA Vice-President for North Africa

The region arranged several webinars in 2020 focusing on different topics for doctors and nurses but also people with epilepsy. The region led research and publications, and promoted the work on the Alliance. The EAA is now working with members of this region to develop the African and Middle East Epilepsy Journal (AMEEJ). The publications that were achieved are:

- 1. Epilepsy and COVID-19
- 2. Epilepsy and nurses
- 3. Epilepsy names in Africa
- 4. The role of the EAA in Africa

Another important development from this region was fundraising. The region facilitated a donation of trophies from a Moroccan company.

Thank you. Together we will move mountains

#### **Southern Africa Report**

by Samuel Chigamba EAA Vice-President for Southern Africa

The region worked very hard in 2020 to recruit members to the Alliance especially doctors. The region engaged the Disabled Women International (DIWA), a continental organization/network of women with disabilities in the African continent and consulted the Federation of Disability Organizations in Malawi on how best we can work with disability organizations in Southern Africa as well as the NCD Alliance. Work is ongoing to reach out to other continental and national level organizations in countries in our region. A lot of work happened in 2020. Unfortunately, we lost a senior epilepsy Mr Anthony Zimba from Zambia in 2020. May hos soul rest in peace. In 2021, we will carry on with the work of recruiting members and networking. We will also work with members in the region to host webinars.

Together we will beat epilepsy.

Thank you

#### **Treasurer's report**

#### Report by Chantal Kanyabutembo, Acting Treasurer

In 2020, we did not have many financial transactions since this was our first year. The income that we got was from membership fees although many members did not pay. Most of the work that we did was provided free of charge by our members and supporters. We want to thank them.

#### Income

From	Description	Amount (USD)
Epilepsy Resource Centre Zimbabwe	Membership 2020	20
GECO-Rwanda membership	Membership 2020	20
ESAU - Uganda	Membership 2020-2024	104
KAWE - Kenya	Membership 2020	*
Total		144
Expenditure		
		00
Balance		
At 14 January 2021		USD144-00

<sup>\*</sup>KAWE membership was paid but had not gone through by time of this report.

We would want to encourage our members to pay their dues for 2021 as soon as possible. We want to thank GECO for opening a bank account for the Alliance in Rwanda.

#### **History of the Epilepsy Alliance Africa**

The EAA was officially formed on 10 December 2019. It is a pan-African alliance of individuals, institutions, organisations, and groups interested in preventing and addressing challenges caused by epilepsy on the African continent. The Alliance started with 11 associations but now has 23 registered associations and individual members from 33 countries. Our rapid growth is proof that we are committed to the work that we are doing.

Before the Alliance was formed, there was a forum of professionals interested in epilepsy that was started by the professionals at the Epilepsy Congress in Barcelona, Spain in 2017. The first meeting was followed by other meetings in Bangkok, Thailand and Entebbe, Uganda in 2019. In all the meetings, those who attended encouraged each other to initiate African grown solutions to facilitate the fight against epilepsy. The meetings noted with concern that epilepsy programs in Africa were divided with professionals and patients not working together, and those in the North not working with those in the South. In Uganda, the forum launched a Call to Action to improve epilepsy services in Africa. To help move this Call to Action forward,

consultations were done and it was agreed to form an Africa-wide alliance to unite every association, every group and everyone working to defeat epilepsy in Africa. Consultations resulted in a constitution being tentatively agreed. This was followed membership applications and nominations for leadership positions. On 10 December 2019, the first Council for the Alliance started work for a two-year term.

#### Why was the Alliance formed?

- to engage the African Union (AU), WHO African Region and other regional institutions.
- to unite all forces working on epilepsy on the continent.
- to promote homegrown advocacy.
- to promote pan-African solutions.

#### **Our members**

Within just a year after formation, we currently have 24 associations and individual members from 33 African countries and we are still growing. Members who had completed their membership enrolment by end of 2020. Our members are committed to improving the lives of people with epilepsy in their countries. Some use their individual and family resources, their energy and time. The table below lists our members, their objectives and some of their needs their needs. If you want to know more about each organisation, or you want to support them, please feel free to ask for their contact details from us.

Name of member and	Aims/Objectives	Needs
contact person  Mauritius  Edycs Epilepsy Group  Youssouf Noormamode	<ul> <li>Promote epilepsy awareness and education;</li> <li>Provide inclusive education to children and adults with epilepsy and learning disability;</li> <li>Advocate for the rights of Persons with epilepsy;</li> <li>Rehabilitate and provide epilepsy care support to PWE</li> </ul>	<ul> <li>Professional training in epilepsy and early childhood</li> <li>Additional funding for programs and services</li> </ul>
The Gambia/Gambie The Gambia Epilepsy Support Society (GESS) Dr John Jabang and Adam Janneh	<ul> <li>Health promotion: Routinely conduct an awareness campaign of what Epilepsy is.</li> <li>Advocacy: To advocate for funding from International Organizations, Businesses, individuals and governments in a bid to support the initiative in The Gambia and beyond.</li> <li>Research: Provision of evidence-based guidelines for the care of people living with Epilepsy.</li> <li>Support: Serves as a principal support group for families and communities of people living with Epilepsy including financial support, treatment of the disease and management of its complications.</li> <li>Policy: Engage the ministry of Health and Government of The Gambia with regards to the availability of Anti-epileptic Drugs (AEDs).</li> </ul>	<ul> <li>Initially we would like funding towards compiling a national database on epilepsy and people living with the condition.</li> <li>Fundings on projects that would help reduce the treatment gap between Africa in this case The Gambia and the more developed world.</li> <li>Fundings on community awareness projects on the Social stigmas associated with the condition.</li> </ul>
Zimbabwe Zimbabwe League Against Epilepsy (ZLAE) Country: Zimbabwe Dr Gift Ngwende	Started in the year 2000, the ZLAE's aim is to provide expertise to epilepsy treatment and services in Zimbabwe; cooperate with local, regional and international partners and research.	Needs: Funding for research, training and administration.
Uganda Epilepsy Support Association Uganda (ESAU) Sarah Nekesa	<ul> <li>Awareness Raising in communities and schools Advocating for the rights of PWE, Provide psycho social support,</li> <li>Fundraising and creating epilepsy self-help groups throughout the country.</li> </ul>	More support in funds to further the school awareness program in the country
Rwanda Geco Rwanda (Global Epilepsy Connection Rwanda) Chantal Kanyabutembo	Geco Rwanda has been established since 2010 his aim is to improve the social welfare of patients under seizure and work on prevention of the disease through counselling; maternity infants; advocacy and capacity build programs in enhance the social security welfare.	Support of professional's health care; funding for education programs and capacity build; improve network of patient with other affiliation.
Malawi Epilepsy Warriors Foundation Samuel Chigamba	<ul> <li>Enhance the quality of life of people with epilepsy.</li> <li>Form and maintain effective relationships with different stakeholders both national and internationally through partnerships, affiliation, collaboration, communication and offering technical advice.</li> <li>Improve community understanding</li> <li>and response to Epilepsy.</li> <li>Provide Epilepsy related guidance, education and support services.</li> </ul>	<ul> <li>Funding for programs and projects</li> <li>Professional training in Epilepsy</li> <li>Capacity building trainings</li> </ul>

	<ul> <li>Undertake research or promote research into understanding of Epilepsy models of care</li> </ul>	
Democratic Republic of Congo ASLEK Dr PrinceKazadi	<ul> <li>Aslek was founded by Dr Prince Kazadi to provide support to people and families living with Epilepsy in the DRC. We are a non-profit charity that offers support, treatment, awareness and community services.</li> <li>We work at ground level, face-to-face with the Epilepsy Community and some of the most disadvantaged people in our country.</li> </ul>	Funding to deal with problems that occur in DRC relating to Epilepsy: be it health care, education, work, social isolation, abuse and violence or other factors.
Cameroon Cameroonian League Against Epilepsy DOUALA Prof. Callixte KUATE	Awareness and training	Funding for awareness and training
Zimbabwe Epilepsy Resource Centre of Zimbabwe (ERCZ) Dr Jacob Mugumbate	<ul> <li>Create a forum for organisations, support groups and people with epilepsy to share ideas</li> <li>Provide resources to people affected by epilepsy to enable them to overcome challenges associated with the condition;</li> <li>Advocacy.</li> </ul>	Information on epilepsy in local languages and support for meetings, seminars and conferences.
Malawi Chifundo Epilepsy Awareness Foundation Chifundo Petro	<ul> <li>To reach and give health care services and support to the people affected with epilepsy.</li> <li>Educate guardians and all others who have people with epilepsy on how to take good care of them.</li> <li>Bring about awareness campaigns to the public so much so that those with epilepsy should not be discriminated be it in schools or community and any other places.</li> </ul>	Support of funding for education programs throughout epilepsy center and capacity build.
Morocco Youssef Ben Tachfine Association Professor Najib Kissani	Awareness, research and training	Funding for awareness, research and training
Gambia Epilepsy Footprint and Gambia Epilepsy Association Tanya Spensley	Awareness and training	Funding for awareness and training
Kenya BANARD EPILEPSY AWARENESS FOUNDATION (BEAFK) Banard Mbuya Vallent Rachel Adhiambo Dr Vincent Orimba	<ul> <li>Educate the people of Nyanza Region of Kenya the truth about Epilepsy and hence get rid of the myths and misconceptions</li> <li>Refer persons living with Epilepsy to the hospital for review treatment.</li> <li>Improve the quality life of People living with Epilepsy in the Nyanza of KenyaPromote the rights of people living with Epilepsy in Nyanza Region of Kenya</li> <li>Promote social integration of People living with Epilepsy in Nyanza Region of Kenya</li> <li>We also work in collaboration with all the players in Epilepsy Awareness, advocacy and management.</li> </ul>	<ul> <li>Funding for our         Awareness Program         throughout the Nyanza         Region of Kenya</li> <li>Funding for setting up         resource center for the         persons living with         Epilepsy the Nyanza         Region of Kenya</li> <li>Funding to start         apprenticeship         program for the         persons living with         Epilepsy</li> </ul>
Mozambique	Improve the quality life of People living with Epilepsy in Mozambique	Funding for Trainings     on Epilepsy

Mozambique Epilepsy Support Association- AMAPE Rogério Manjate	<ul> <li>Promote the human rights of people living with Epilepsy</li> <li>Promote social integration of People living with Epilepsy in Mozambique</li> <li>Health promotion through Awareness raising Campaign on Epilepsy issues</li> <li>Advocate by engaging the Government (Ministry of Health) for policy on availability of AEDs.</li> </ul>	<ul> <li>National database on people living with Epilepsy and care</li> <li>Funding for communities Awareness raising projects</li> <li>Countrywide Research on the provision of evidence-based guidelines for People with Epilepsy care.</li> </ul>
Cameroon Massi Gams Foundation Dr Gams Massi	The Foundation is non-political and non-profit association which aims to contribute to local development and raise awareness of disease among vulnerable population. The non-profit has a department for epilepsy care because Cameroon has one of the highest prevalence of epilepsy in the world.	<ul> <li>Support with resources for awareness and treatment</li> <li>Training</li> </ul>
Zimbabwe Epilepsy Support Foundation Taurai Kadzviti	The Epilepsy Support Foundation envisions a better quality of life for all persons living with and affected by epilepsy in Zimbabwe. This is achieved through awareness, counselling, treatment, advocacy and income generating projects.	<ul> <li>Funding medicines</li> <li>Funding for awareness</li> <li>Administration costs</li> </ul>
Sierra Leone The Epilepsy Association of Sierra Leone (EASL) Max A Bangura	<ul><li>Awareness</li><li>Lobbying</li><li>Training</li></ul>	Funds for lobbying, awareness education and research
Kenya Youth on the Move Epillose Musimbi	<ul><li>Awareness</li><li>Lobbying</li><li>Training</li></ul>	Funds for lobbying, awareness education and research
Burkina Faso Burkinabe League against Epilepsy Athanase MILLOGO	<ul><li>Awareness</li><li>Lobbying</li><li>Training</li></ul>	Funds for lobbying, awareness education and research
Cameroon GBM Foundation for Epilepsy and Mental Wellbeing ABANGA MARIE ANGELE	To contribute to research, and the fight against taboo, stigma, unawareness, rejection and outright abuse of epileptics and mentally challenged in our society, guided by empathy, respect, inclusiveness and justice for the vulnerable and persons with disabilities.	Funds for awareness, training and research
Cameroon Community Development and Epilepsy Foundation- CODEF Cameroon Nsom Kenneth	<ul> <li>To identify, educate and sensitize the population about epilepsy, combat stigma and abandonment, raise awareness about epilepsy.</li> <li>To lobby, advocate and network with communities affected and health institutions</li> <li>To carry out research on the causes and prevention of epilepsy, support victim and their families, and empower persons with epilepsy</li> </ul>	Funds for lobbying, awareness education and research

Kenya Kenya Association for the Welfare of People With Epilepsy (KAWE) Dr Osman Miyanji	<ul> <li>Health care: To reduce the existing epilepsy treatment gap by facilitating universal access to affordable, sustainable and comprehensive quality health care;</li> <li>Knowledge management: Aims at generating and sharing knowledge on epilepsy by being at the forefront of research, as well as to offer expert advice, training and information to raise people's awareness, remove stigma/ discrimination</li> <li>Influencing and partnerships: Through this pillar, KAWE intends to facilitate voice, inclusion and equal opportunities for people with epilepsy.</li> </ul>	Funds for healthcare, awareness, advocacy and institutional development.
Cameroon Epilepsy Awareness and Aid Foundation (EAAF) Dr. Mundih Noelar Njohjam	<ul> <li>To raise awareness on epilepsy and epilepsy-related issues.</li> <li>To assist people living with epilepsy to get adequate care and follow-up.</li> <li>To advocate for the enactment of better health policies for epilepsy</li> </ul>	Funds for healthcare, awareness, advocacy and institutional development.
Ethiopia Care Epilepsy Ethiopia Enat Yewnetu	Our objective is to facilitate access to medical care and treatment, enhance the public awareness on epilepsy and associated disabilities, build the wellbeing and the capacities of people living with epilepsy and associated disabilities to be self-sufficient, engage in advocacy work to address the medical, social, environmental factors contributing to epilepsy problems in Ethiopia.	Funds for healthcare, awareness, advocacy and institutional development.
Nigeria The Epilepsy Ambassadors Initiative Bankole Murtala Olusola	<ul> <li>To wipe out stigma around epilepsy especially in underdeveloped countries where epilepsy is considered as some sort of witchcraft or devilish possession.</li> <li>To create medical awareness of Epilepsy as it is a controllable disease if treated.</li> <li>Assist individuals living with epilepsy who are incapable financial to keep up with the treatment and follow-up.</li> </ul>	Funds for healthcare, awareness, advocacy and institutional development.
Kenya Shine Epilepsy Support Annastacia Kavemba	<ul> <li>To close the gap of the plight of people with epilepsy; improve how people with epilepsy are perceived, accepted and valued in our society; as well as to ensure together with their families have access to full life experiences.</li> </ul>	Funds for healthcare, awareness, advocacy and institutional development.
Zambia Kabemba Mwale Epilepsy Foundation Kabemba Mwale	<ul><li>Awareness</li><li>Lobbying</li></ul>	Funds for lobbying, awareness education and research
Ghana  David Naboare  Foundation  David Naboare	<ul><li>Awareness</li><li>Lobbying</li></ul>	Funds for lobbying, awareness education and research

We welcome new members including associations of people with epilepsy; professional association of doctors, nurses, or others; individual advocate or

supporter; an international organisation; a service provider; a funder; a supplier; a government department; or a research institute.

#### Our work and achievements in 2021

- We started monthly online meetings in February 2020.
- In March 2020 Morocco was selected to host the website of the Alliance.
- In April 2020, Rwanda was selected to host the office and back account of the Alliance.
- In April, we produced and shared information on COVID and epilepsy through a statement and a poster.
- In May 2020 we started monthly webinars with the first one focusing on Corona virus disease and epilepsy.
- We publish a regular email newsletter that gives updates about our work.
- Individual members in 33 countries and 28 registered associations
- Tele-health: Free weekly clinic available to people with epilepsy from any African country
- Created partnerships and working arrangements with organizations in Africa and beyond, including the African Union and the University Hospital Mohamed VI, Marrakech, Morocco

#### **Our Executive Council**

Our Executive Council started work in December 2019. In 2020, the Council had 8 meetings. All meetings were done through Zoom but a few were through WhatsApp. The current members of the Council are:

Leadership of the Alliance December 2019-December 2021

Position		Name
President		Taurai Kadzviti, Zimbabwe
Regional Vice-	East Africa	Sarah Nekesa, Uganda
Presidents	Southern Africa	Samuel Chigamba, Malawi
	West Africa	Dr Daniel Gams Massi, Cameroon
	Central Africa	Dr Prince Kazadi, DRC
	North Africa	Professor Najib Kissani, Morocco
Secretary Genera	al	Chantal Kanyabutembo, Rwanda
<b>Members of Cou</b>	ncil	Dr Jacob Mugumbate, Zimbabwe
		Rogerio Manjate, Mozambique
		Youssouf Noormamode, Mauritius
		Dr John Jabang, Gambia

The Council's term is two years. This means that there will be elections later this year.

#### Our taskforces/committees

In 2020, we formed committees to improve the work of the Alliance. These committees are:

Name of Committee	Members	
Fundraising and Marketing	Chantal Kanyabutembo; Samuel Chigamba,	
Committee	Epillose Musimbi; Dr Daniel Massi, Adam Janneh	
	and Dr Najib Kissani	
Research Committee	Dr Jacob Mugumbate; Chantal Kanyabutembo; Dr	
	Najib Kissani; Dr Prince Kazadi; Dr Daniel Massi;	
	Dr Athanase Millogo; Dr John Jabang and Dr Musa	
	Watila; Dr Najib Kissani.	
Media and Awareness	Banard Mbuya; Petro Chifundo; Ester; Mesheke S	
Committee	M	
Youth Committee	Chantal Kanyabutembo; Ester, Epillose Musimbi;	
	Frederic Beuchi; Kamleu Balbine; Meshek M M and	
	Samuel Chigamba	

#### **Webinars**

Sharing information on epilepsy is very important for professionals, people with epilepsy, advocates and family members. It is very difficult to meet face to face because people are in different countries. This is even more difficult because of COVID. However, tele-education services provide an opportunity to address these challenges. As such, we had 8 webinars in 2020. This is one of our success stories. We could have done more, but we appreciate the challenges our members face with data to connect to the internet. To address this challenge, we made our webinars short (1 hour to 1 hour 30 minutes). We also recorded and shared on YouTube with those who failed to attend. We intend to keep on with the webinars in 2021, and we will have countries hosting to allow for experience transfer.





#### First conference



In 2020, we had our first conference. With 15 speakers, this conference was a success. It set our stage for future conferences. Our second conference will be held in 2021 and further details will be provided.

## Tribute Anthony Mulenga Zimba 17 March 1954 – 9 August 2020

Anthony Mulenga Zimba was born on 17 March 1954 and died on 9 August 2020. Zimba was a father, husband and a family Elder. His untimely death was a huge blow to his immediate and larger family, and it surprised and saddened many. Anthony was active at both country, continental and global level. In Zambia, he led his government's epilepsy program as epilepsy specialist and in Africa he visited several

countries to learn about what they were doing and to encourage them. His participation at international level was motivated by a desire to create opportunities for Africa to genuinely collaborate, partner and participate. His strongest view was that our international partners should respectfully work with us not to work for us. This is the message he left the IBE, where he was Treasurer. He was also mindful of the fact that global activities at times take away local creativity and self-reliance, hence he always encouraged us to go for Africa driven initiatives. In 2010 he showed us how to do this by organising a successful conference in Zambia that was attended by delegates from several countries. His last email message to the Epilepsy Africa Alliance (EAA), a collection of associations and activists from over 30 African countries was TOGETHER WE WILL MOVE MOUNTAINS

#### **Africa Epilepsy Awards 2020**

- 1. Leadership Award/Trophy: commendable work as Secretary General of EAA, Mrs Chantal Kanyabutembo (Rwanda)
- 2. Leadership Award/Trophy: commendable work as President, Mr Taurai Kadzviti
- 3. Innovation Award/Trophy: for starting and leading tele-clinic; Prof. Najib Kissani (Morocco)
- 4. Awareness Award/Trophy: for riding Mt Kilimanjaro for epilepsy awareness; F Beuchi (Kenya)
- 5. Awareness Award: for epilepsy awareness, E. Musimbi (Kenya)
- 6. Awareness Award: for epilepsy awareness in Malawi, S. Chigamba (Malawi)
- 7. Medical Award: Dr Prince Kazadi for treatment programmes in DRC
- 8. Social Development Award: for mobilizing people to start the Alliance and for webinars; Dr Jacob Rugare Mugumbate (Zimbabwe)



## **Certificates of appreciation**

The certificate below was presented to Miss Deaf Africa, for supporting the EAA in 2020. Many other people were appreciated. These were:

Dr Angelina Kakooza, Uganda
Dr Emmanuel Sanya, Nigeria
Mr Lefhoko Kesamang, African Union
Mr Peter Nyette, Kenya
Joan Kagema (2 certificates), Kenya
Dr Charlotte Baker, UK
Professor Durodami Lisk, Sierra Leone
Dr Mussa Watila, Nigeria
Dr Nirmal, India



Dr Gams Massi, Cameroon Dr Najib Kissani, Morocco Dr Jacob Mugumbate, Zimbabwe Fred Beuchi, Kenya
Natalie, Boehm, USA
Lori Hairrel, ROW Foundation, USA
Tim Ulmer, USA
Adam Janneh, The Gambia
Tolu Olaniyan, Nigeria/UK
Bankole Olusola, Nigeria

James Zimba, Zambia
Musimbi Epillose, Kenya
Chimwemwe Kamkwanda, Mrs Deaf,
Africa, Malawi
IM Alliance, Morocco
Martin Luther Kintu, Afripeans Sueden

#### What you can do? How can you help?

- Email us to find out about our membership options.
- Email us to find out about our partnership options.
  - Join our monthly webinars.
- Share resources that we have on our web page and social media platforms.
  - Support our weekly clinic
  - Support our training program for nurses and other professionals

#### Our contact details

Email: epilepsyallianceafrica@gmail.com

Website: www.eaa.neuromarrakech.com

Facebook: Epilepsy Alliance Africa https://www.facebook.com/Epilepsy-Alliance-Africa-105086551211552/

Instagram: epilepsyallianceafric https://www.instagram.com/p/CAQ2Rz5pHwK/?igshid=6svzj334wj76

YouTube: Epilepsy Alliance Africa EAA https://www.youtube.com/channel/UCRZOkz\_8OKLY2eWpUSfSJqg

Twitter: AfricaEpilepsy https://twitter.com/AfricaEpilepsy?s=09

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#### **Final Message**

The Executive Council of the EAA would like to thank our members and partners for their support during our first year of operation. As an executive, we are quite happy about our achievements. We achieved beyond expectations. We now face another year, our second year. The year did not start very well because of COVID but we are ready to face it. We want this year to be a year of developing and growing effective partnerships. We will be reaching out to our members and partners to talk about how this could be achieved. We remain committed to addressing epilepsy in Africa. The first institution that we will talk with, in line with our pan-African agenda, is the African Union. Meetings are already lined up, and we look ahead to meeting the AU. We want to wish everyone the best and success in 2021.

# United Against Seizures & Stigma in Africa