



Alliance Afrique pour l'épilepsie

تحالف الصرع الأفريقي

Epilepsia áfrica aliança

Epilepsy Alliance Africa (EAA)

Annual Report 2021

CELEBRATING TWO YEARS OF GROWTH, INNOVATION AND SERVICE

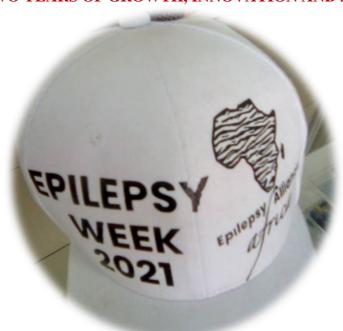




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Summary of our work and achievements in 2021

- We had our second epilepsy conference.
- We started stripes week/epilepsy week.
- We had 9 webinars organized in 2021 hosted by the following countries
 - O Webinar 9 Morocco
 - O Webinar 10 Kenya
 - Webinar 11 Association for the Fight Against Epilepsy Stigma in the DRC (ASLEK), The Defeating Epilepsy Foundation, USA
 - o Webinar 12 Nigeria
 - o Webinar 13 Ethiopia
 - Webinar 14 Burkina Faso
 - O Webinar 15 Zimbabwe
 - O Webinar 16 Malawi
 - O Webinar 17 Cameroon
- We started a tele-clinic.
- We increased our individual and association members.
- We had high level meetings, including with the AU and ECOWAS.
- We published 3 articles in peer reviewed academic journals.
- Our special media presence continues to grow on WhatsApp (over 120 members), Facebook and YouTube.

Welcoming our Executive Council for 2022 and 2023

Position		Name
President		Taurai Kadzviti, Zimbabwe
Regional	East Africa	Sarah Nekesa, Uganda
Vice-	Tanzania, Kenya, Uganda,	
Presidents	Rwanda, Burundi, and South Sudan	
	Southern Africa	Inácio Quembo, Mozambique
	Angola, Botswana, Lesotho,	
	Mozambique, Namibia, South	
	Africa, Eswatini, Zambia,	
	Zimbabwe	
	West Africa	Dr Daniel Gams Massi, Cameroon
	Benin, Burkina Faso, Cape Verde,	
	Côte D'Ivoire, Gambia, Ghana,	
	Guinea, Guinea-Bissau, Liberia,	
	Mali, Mauritania, Niger, Nigeria,	
	Senegal, Sierra Leone, and Togo.	
	Central Africa	Dr Prince Kazadi, DRC
	Angola, Cameroon, Central	
	African Republic, Chad, Congo	
	Republic - Brazzaville,	

	Democratic Republic of Congo,			
	Equatorial Guinea, Gabon, and			
	São Tomé & Principe.			
	North Africa		Professor Najib Kissani, Morocco	
	Algeria, Egypt, Li	bya, Morocco,		
	Sudan and Tunisi	a		
Secretary Gene	eral		Samuel Chigamba, Malawi	
Treasurer			Chantal Kanyabutembo, Rwanda	
Members of Co	ouncil	Dr Jacob Rugare	Mugumbate, Zimbabwe	
		Youssouf Noorn	namode, Mauritius	
		Epillose Musimb	oi, Kenya	
		Professor Athanase Millogo, Burkina Faso		
		Adam Janneh, The Gambia		
		Enat Yewnetu, Ethiopia		
		Professor Eeteda	al Ibrahim, Sudan	
		Dr Rabha Alsahl	ly, Libya	
		Bankole Murtala Olusola, Nigeria		
Directors		Director of Community Engagement and Programs: Enat Yewnetu, Ethiopia		
			-health and Public Education: Kissani, Morocco	
Director of Research and Training: Dr Rugar Mugumbate		arch and Training: Dr Rugare J.		

Congratulations to the new team. We wish the new executive a successful term in office and thank all members for taking part in the nominations and elections. As the organization grows, we have appointed 3 directors as shown in the table.

Condolences

In 2021, we lost some people who were playing crucial roles in improving the lives of people with epilepsy in their countries but also globally. May their souls rest in peace and may their families find comfort. These were:

- Professor Paul Kiouy, Kenya
- Mr Mbusoluni Mahlalela, Eswati
- Professor Emmanuel Sanya, Nigeria
- Mrs Mary Gowe, Zimbabwe

EAA Annual Awards 2021

We congratulate recipients of the EAA Annual Awards for 2021. The recipients are:

- Association of the year: Care Epilepsy Ethiopia for Stripes Week activities
- Youth Champion of the Year: Tashinga Alfreda Mubonderi, Zimbabwe
- Resilient Person of the Year: Ngonidzashe Mutamangira, Zimbabwe
- Innovation Award: Bright M Bwalya, Zambia who developed an epilepsy seizure detection application (www://seizureassistant.app)
- Awareness Awards individuals:
 - For sharing stories during Stripes Week: Lesley Donnelly,
 Chikhulupiliro Stanley Ng'ombe, Vallent Rachel Adhiambo, Banard
 Mbuya and Annastacia Kavemba.
 - o For webinar presentations: and Joan Kagema
- Awareness Awards associations:
 - o Epilepsy Support Association of Uganda for Stripes Week activities
 - Epilepsy Warriors Malawi for Stripes Week activities
- Medical Award: Professor Najib Kissani for weekly tele-health program free of charge
- Social Development Awards:
 - Foundation for Epilepsy and Stigma Support Gambia for continued growth and setting up EEG services
 - Chifundo Epilepsy Foundation for providing access to free antiepileptic drugs in rural areas to people with epilepsy in Malawi
- Tele-Health Award: Chantal Kanyabutembo, Rwanda for organizing telehealth clinics in Rwanda
- Leadership Award: Enat Yewnetu, Ethiopia for organizing and co-chairing 2nd epilepsy conference

Stripes Week Awards 2021

Epilepsy Week is an annual event promoted by the Epilepsy Alliance Africa (EAA) to be celebrated globally during the 3rd week of September each year. The first epilepsy week, popularly known as stripes week was held in September 2021. This will now be an annual event. During the week, several stories were shared and several activities took place in many countries. Stripes Week uses Zebra colours – white and black. Zebra stripes show belonging, oneness, strengths, shining and visibility. That is why they have been selected to represent epilepsy week. In Africa, where the epilepsy week idea originated from, zebras are well recognised and known for the qualities stated above. During the week, one can wear anything with stripes or zebra colours. A hat, scarf, headcover, shirt, dress, blouse, trousers, bag, belt, t-shirt and tie or cushion or hair.

We are glad to report that the following people were awarded for their courage in sharing their stories. The Stripes Week Awards 2021 were presented to:

- 1. Chikhulupiliro Stanley Ng'ombe
- 2. Ibrahim Mansary
- 3. Aubrey Chiumia
- 4. Ojijo Mbai Odhiambo
- 5. Vallent Rachel
- 6. Chantal Kanyabutembo
- 7. Evelyn Gadama
- 8. Banard Mbuya
- 9. Miriam Saka Ng'ombe
- 10.Simon Kaseko
- 11. Rufaro Nyamhenda
- 12.Lesley Donnelly
- 13. Evelyn Choto
- 14. Tafadzwa Hombarume
- 15. Dhliwayo Honest Simbarashe
- 16. Tashinga Alfreda Mubonderi
- 17. Francis Veliha
- 18. Gerald Hara
- 19.Enat Yewnetu
- 20. Epilepsy Association of Sierra Leone

Tele-health project

This year the telehealth project focused on two countries, and more will be added in 2022. These countries were Rwanda and Malawi. Our tele/online clinic offers free treatment, advice, support and education by experts every Wednesday online to people with epilepsy without access to this service because of unavailability of specialist doctors or because of lack of money to pay for the service. All clinics were attended by Professor Najib Kissani and his team of doctors of Morocco and doctors in Rwanda and Malawi. The Centre Coordinator for Malawi was Samuel Chigamba while in Rwanda it was Chantal Kanyabutembo. To participate in this amazing project in 2022 going forward, please send an email to epilepsyallianceafrica@gmail.com. Participation is free.

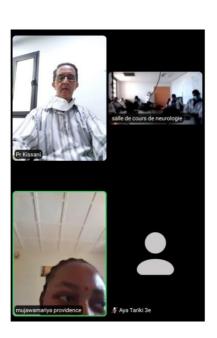


Photo: telehealth clinic in session

As numbers increase for the tele-health service, the following people have gladly offered themselves to provide free services:

Volunteer physicians

- Pr Najib Kissani, Morocco
- Dr Gams Massi, Cameroon
- Dr Olusola Talabi, Nigeria
- Pr Man Mohan Mahndiratta, India
- Dr Musa Watila, Nigeria

Volunteer nurses

- Millie Kumwenda, Malawi
- Joan Kagema, Kenya

Volunteer social worker

• Dr Jacob Mugumbate, Zimbabwe

Volunteer neuro-scientists and EEG workers

• Bankole Murtala Olusola, Nigeria

Volunteer mental health practitioner

• David Naboare, Ghana

Volunteer coordinators at country centres

- Samuel Chigamba, Malawi
- Chantal Kanyabutembo, Rwanda
- Bankole Murtala Olusola, Nigeria

President's message

Ladies and Gentlemen,

It is with honor and privilege that I welcome you to the 2021 report of the Epilepsy Alliance Africa. Despite the ever-growing challenges since the outbreak of the corona virus disease (COVID-19) with various mutation detected around the world, we have done very well an organization. Africa has not been spared from the deadly virus. Close members of the family, our close-friends and colleagues succumbed to COVID-19. These include Senator Rejoice Timire who was a person with a physical disability who stood not only for women with disabilities but also for



persons with epilepsy in Zimbabwe; Professor Paul Kiouy, Kenya; Mr Mbusoluni Mahlalela, Eswatini; Professor Emmanuel Sanya, Nigeria and Mrs Mary Gowe, Zimbabwe. May their soul rest in peace.

The continued shortage of health professionals, antiepileptic medication and diagnostic equipment to manage epilepsy in Africa is a concern the Epilepsy Alliance Africa has taken note. We have good news to share with great results that have positive impact in some countries or regions of Africa. The world we leave in has changed in the last 2 years further worsening the already challenged health delivery systems in Africa. More than ever, we need regional coordination amongst the Alliance members in consolidating our efforts to improve and a responsive legislative health care system that will provide the best health care service for epilepsy management as per the WHA resolution on making epilepsy a health priority.

We acknowledge the positive strides our various governments have taken in addressing gaps, this also includes non-governmental organisation who have also supported our efforts in respective countries and regions. But Epilepsy remains one of the least funded conditions yet it has a prevalence of 10 million people in Africa according to WHO. Due to the invisibility of the condition very little attention is given in contrast to visible disabilities.

Noting the insurmountable predicament that we face, since inception the Alliance has continued to develop from strength to strength on programs such as webinars that have covered various subjects from medical to social aspects of epilepsy. Several countries have benefited from tele-education and tele-health targeting countries with limited health staff. We are grateful to Professor Kissani and team who have been spearheading the project including other executive council members. Further collaboration from various partners from around the global have been engaged from Asia, Europe and the Americas.

In 2021, we had our second epilepsy conference. The conference was held under the theme TOGETHER WE WILL DEFEAT EPILEPSY. co-chaired by Enat Yewnetu from Ethiopia and Samuel Chigamba from Malawi. There were 101 participants who joined during the Zoom conference and 20 presenters.

As we move into the new year and beyond the Alliance will focus on the following key points raised during the conference and regular consultations with members and partners:

- 1. Tele-health: Free weekly clinic for people with epilepsy from African country
- 2. Tele-education and training: Webinars for professionals, advocates and
- 3. people with epilepsy. We target 6 webinars in 2022.
- 4. Research and documentation: We will promote, support, carry out research and publish on epilepsy related topics. We target 4 publications.
- 5. Advocacy and policy: We will advocate for improved and new policies for
- 6. epilepsy on the African continent and help members achieve the same in their countries

- 7. Capacity building and coordination: We will support epilepsy association
- 8. in Africa to maximise their potential
- 9. Conference: we will do the 3rd annual conference this year

As we move collectively in our regions to build a more robust and responsive Alliance, we encourage more members, individuals, epilepsy organisations, funding agents to join our efforts in improving the quality of life of person with epilepsy in Africa. United we can conquer, only if each and everyone of us play their part and only can we build the Africa we want.

We have reached the top of the mountain but it's the bottom of another journey SLOW WE WILL GO FAR AND TOGETHER WE CAN GO FAR.

Thank you, Taurai Kadzviti, EAA President

Secretary General 's report

This year 2021 was a year of many challenges due to COVID-19. We thank the league of professional doctors, local associations members of the executive council who played merger role on driving this platform forwards, as a secretary I humble thanks all who contributed on our annual action plan as national webinar, stripe week event, the success telehealth run by Professor Najib Kissani, the research news we all contribute too as members of the executive council which played merger role to the EAA social affairs edition of Africa, and others! The 1st congress run by the epilepsy alliance Africa were very successful and we humble thanks all who presented on diplomatique side of each nation: the Ambassadors of Ethiopia, ministry of health of Zimbabwe, ambassador of Ghana, the Ecowas, the AU and the ILAE representative Dr Helen Cross, the scientist who share their knowledge we did learn more from Doctor Rory from Manchester University on generic and non-generic drugs and other Guest this congress took the all days but we host more than 250 guest thank you all for your contribution! I thank also many guest who help many association during the Pandemic specially Row Foundation regards their medical task forces and Dr Steve Coates for future planning to install a TeleEEG UK training in Africa, Stripe week organised by warrior foundation Malawi has played great role, the awareness club of patient share stories and celebrate the epilepsy day wearing a Zebra Print which impact on Africa culture awareness day, we thank you all youth able to play such sharing stories role and eliminate stigma in our national platform all together let fight united against stigma. The WHA resolution 73.10 is an essential for all national sector guideline and civil right law, we do expect as a pan African network to help the African Union and the disabilities federation worldwide, thank you all for such 2 years serving as a secretary I am now a treasurer from 2022-2024!

Thank you

Chantal Kanyabutembo, EAA Secretary General 2020 and 2021

Vice-Presidents' Reports and Messages

West Africa Report

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

Unlike the year 2020 which was a period of great constraint, the year 2021 was marked by the hope of getting out of this pandemic with the avenue of anti-Sars Cov 2 vaccines. However, the inequalities in the access to these vaccines and the occurrence of many variants of this virus has helped to dampen the enthusiasm. The West African region was one of the first regions in Africa to obtain vaccines through the WHO COVAX system, thus enabling millions of people to be vaccinated to date. Associations fighting against epilepsy have contributed to this fight by encouraging patients to be vaccinated before scientific evidence demonstrates the effectiveness

and harmlessness of these vaccines. Even if resistance to vaccination is numerous. EAA West Africa region will continue to work to encourage as many people as possible to be vaccinated. Despite this difficult context. the various associations carried awareness-raising, training and information activities



on epilepsy by using in addition to social networks and e-learning platform. It is here to congratulate all those who have worked for the fight against epilepsy and the protection of patients suffering from this disease. The year 2022 opens up new perspectives and we hope to strengthen activities and progress in advocacy for free care for patients living with epilepsy and their socio-professional integration.





Left figure A webinar organized by The Epilepsy Ambassadors Initiative (Nigeria) Right figure: 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).

The region has these countries:

Benin	

2. Burkina Faso

3. Cape Verde

4. Côte D'Ivoire,

5. Gambia

6. Ghana

7. Guine

8. Guinea-Bissau

9. Liberia

10.Mali

11.Mauritania

12.Niger

13.Nigeria

14.Senegal

15. Sierra Leone

16.Togo

East African Region Report

by Sarah Nekesa Vice-President, East Africa Executive Director, Epilepsy Support Association Uganda

In addition to the 6 countries that make up the East African Region, I am happy to report that Ethiopia now is a member of the EAA East African region with Enat Yewnetu as a major participant in that country. Like in 2020, 2021 has not been a very easy year for the East African region. The Covid 19 pandemic continued to affect service delivery for everybody especially to persons with epilepsy. However, organizations in the region remained resolute to addressing challenges being faced by people with epilepsy and will continue doing so in 2021. Countries in the region commemorated Stripes Week notably Uganda, Ethiopia, Kenya and Rwanda.

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

There are 6 countries in the region. The region has these countries:

- 1. Algeria
- 2. Egypt
- 3. Libya
- 4. Morocco
- 5. Sudan
- 6. Tunisia

Morocco was the first country to join the alliance from the region, followed by Libya and Sudan this year. There are no contacts at the moment with Algeria, Tunisia and Egypt. In Morocco, telemedicine is the top priority working with partners in the country, in Africa and internationally. We run many scientific activities, webinars and research. Morocco hosted the 9th webinar of EAA and it was international. We have created big WhatsApp groups for patients in Morocco and provide medication for free. We work with universities and hospitals. The African and Middle East Epilepsy Journal is doing well and is now associated with the EAA. The VP will continue working with all countries in the region.

Southern Africa Report

by Samuel Chigamba

A lot of work happened in 2021, the region worked tirelessly to recruit members to the Alliance especially persons with epilepsy. With Covid 29 restrictions and the number of people receiving treatment declining organizations and persons with epilepsy in the region were fortunate enough to have access to EAA's Tele health services. Through EAA's Tele-health persons with epilepsy in the region received treatment and epilepsy related advice/information through EAA's weekly Tele-health. Organizations in the region participated in the first launch of Stripes week 20-24September 2021, an initiative of the Epilepsy Alliance Africa launched with the aim of raising Epilepsy awareness annually. During Stripes week youth advocates from Zimbabwe used radio and social media to raise epilepsy awareness. Epilepsy Warriors Foundation an NGO based in Blantyre, Malawi launched a Stripes week stories initiative 17 stories were shared with the aim show the different achievements made by persons with epilepsy as one way of showing the different achievements made by persons with epilepsy. The region attended webinars organized by the Alliance every month from January 2021. Unfortunately, we lost Mr. Mbusolini Mahlalela who up to his passing was the founder and executive director of Eswatini Epilepsy Organization in 2021. May his soul rest in peace. In 2022, we will carry on with the work of recruiting members and networking. We will also work with members in the region to host webinars. Thank you.

Treasurer's report

Report by Chantal Kanyabutembo, Treasurer

In 2021, 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)
Amount carried over from 2020	Memberships	124
Epilepsy Resource Centre Zimbabwe	Membership 2021 and	40
	2022	
ESAU - Uganda	Membership 2021	20
Total income		184
Expenditure		00
Balance		
As at 04 January 2022		USD184-00

We would want to encourage our members to pay their dues for 2022 as soon as possible. We want to thank GECO for opening a bank account for the Alliance in Rwanda.

Membership report

Within just a year after formation, we currently have 30 associations and individual members from 33 African countries and we are still growing. 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	 Promote epilepsy awareness and education; Provide inclusive education to children and adults with epilepsy and learning disability; Advocate for the rights of Persons with epilepsy; Rehabilitate and provide epilepsy care support to PWE 	 Professional training in epilepsy and early childhood Additional funding for programs and services
The Gambia/Gambie Foundation for Epilepsy and Stigma Support - Gambia	 Health promotion: Routinely conduct an awareness campaign of what Epilepsy is. Advocacy: To advocate for funding from International Organizations, Businesses, individuals and governments in a bid to support the initiative in The Gambia and beyond. Research: Provision of evidence-based guidelines for the care of people living with Epilepsy. 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. 	 Initially we would like funding towards compiling a national database on epilepsy and people living with the condition. Fundings on projects that would help reduce the treatment gap between Africa in this case The Gambia and the more developed world. Fundings on community awareness projects on the Social stigmas

	Policy: Engage the ministry of Health and Government of The Gambia with regards to the availability of Anti-epileptic Drugs (AEDs).	associated with the condition.
Zimbabwe Zimbabwe League Against Epilepsy (ZLAE)	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)	 Awareness Raising in communities and schools Advocating for the rights of PWE, Provide psychosocial support, Fundraising and creating epilepsy self-help groups throughout the country. 	More support in funds to further the school awareness program in the country
Rwanda Geco Rwanda (Global Epilepsy Connection Rwanda)	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	 Enhance the quality of life of people with epilepsy. Form and maintain effective relationships with different stakeholders both national and internationally through partnerships, affiliation, collaboration, communication and offering technical advice. Improve community understanding and response to Epilepsy. Provide Epilepsy related guidance, education and support services. Undertake research or promote research into understanding of Epilepsy models of care 	 Funding for programs and projects Professional training in Epilepsy Capacity building trainings
Democratic Republic of Congo ASLEK	 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. We work at ground level, face-to-face with the Epilepsy Community and some of the most disadvantaged people in our country. 	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	Awareness and training	Funding for awareness and training
Zimbabwe Epilepsy Resource Centre of Zimbabwe (ERCZ)	 Create a forum for organisations, support groups and people with epilepsy to share ideas Provide resources to people affected by epilepsy to enable them to overcome challenges associated with the condition; Advocacy. 	• Information on epilepsy in local languages and support for meetings, seminars and conferences.
Malawi Chifundo Epilepsy Awareness Foundation	 To reach and give health care services and support to the people affected with epilepsy. Educate guardians and all others who have people with epilepsy on how to take good care of them. Bring about awareness campaigns to the public so much so that those with epilepsy 	Support of funding for education programs throughout epilepsy center and capacity build.

	should not be discriminated be it in schools or community and any other places.	
Morocco Youssef Ben Tachfine Association	Awareness, research and training	Funding for awareness, research and training
Gambia Epilepsy Footprint and Gambia Epilepsy Association	Awareness and training	Funding for awareness and training
Kenya Banard Epilepsy Awareness Foundation (BEAFK)	 Educate the people of Nyanza Region of Kenya the truth about Epilepsy and hence get rid of the myths and misconceptions Refer persons living with Epilepsy to the hospital for review treatment. 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 Promote social integration of People living with Epilepsy in Nyanza Region of Kenya We also work in collaboration with all the players in Epilepsy Awareness, advocacy and management. 	 Funding for our Awareness Program throughout the Nyanza Region of Kenya Funding for setting up resource center for the persons living with Epilepsy the Nyanza Region of Kenya Funding to start apprenticeship program for the persons living with Epilepsy
Mozambique Mozambique Epilepsy Support Association- AMAPE	 Improve the quality life of People living with Epilepsy in Mozambique Promote the human rights of people living with Epilepsy Promote social integration of People living with Epilepsy in Mozambique Health promotion through Awareness raising Campaign on Epilepsy issues Advocate by engaging the Government (Ministry of Health) for policy on availability of AEDs. 	 Funding for Trainings on Epilepsy National database on people living with Epilepsy and care Funding for communities Awareness raising projects Countrywide Research on the provision of evidence-based guidelines for People with Epilepsy care.
Cameroon Massi Gams Foundation	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.	 Support with resources for awareness and treatment Training
Zimbabwe Epilepsy Support Foundation	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.	 Funding medicines Funding for awareness Administration costs
Sierra Leone The Epilepsy Association of Sierra Leone (EASL)	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research

Kenya Youth on the Move	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research
Burkina Faso Burkinabe League against Epilepsy	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research
Cameroon GBM Foundation for Epilepsy and Mental Wellbeing	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	 To identify, educate and sensitize the population about epilepsy, combat stigma and abandonment, raise awareness about epilepsy. To lobby, advocate and network with communities affected and health institutions To carry out research on the causes and prevention of epilepsy, support victim and their families, and empower persons with epilepsy 	Funds for lobbying, awareness education and research
Kenya Kenya Association for the Welfare of People With Epilepsy (KAWE)	 Health care: To reduce the existing epilepsy treatment gap by facilitating universal access to affordable, sustainable and comprehensive quality health care; 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 Influencing and partnerships: Through this pillar, KAWE intends to facilitate voice, inclusion and equal opportunities for people with epilepsy. 	Funds for healthcare, awareness, advocacy and institutional development.
Cameroon Epilepsy Awareness and Aid Foundation (EAAF)	 To raise awareness on epilepsy and epilepsy-related issues. To assist people living with epilepsy to get adequate care and follow-up. To advocate for the enactment of better health policies for epilepsy 	Funds for healthcare, awareness, advocacy and institutional development.
Ethiopia Care Epilepsy Ethiopia	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	To wipe out stigma around epilepsy especially in underdeveloped countries where epilepsy is considered as some sort of witchcraft or devilish possession.	Funds for healthcare, awareness, advocacy and institutional development.

Kenya Shine Epilepsy Support	 To create medical awareness of Epilepsy as it is a controllable disease if treated. Assist individuals living with epilepsy who are incapable financial to keep up with the treatment and follow-up. 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 	• Funds for healthcare, awareness, advocacy and institutional development.
Zambia Kabemba Mwale Epilepsy Foundation	experiences. • Awareness • Lobbying	Funds for lobbying, awareness education and research
Ghana David Naboare Foundation	AwarenessLobbying	Funds for lobbying, awareness education and research
Zambia Zambia League Against Epilepsy	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research
Libya	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research
Sudan	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research
Kenya GENO - Epilepsy Center for Empowerment	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research
Kenya Pambazuka Elimisha Kifafa	AwarenessLobbyingTraining	Funds for lobbying, awareness education and research

Reports from members

Epilepsy Resource Centre Zimbabwe (ERCZ)

In 2021, the ERCZ had two major activities. These were training and hosting the Stripes Week webinar. The training was a basic course on epilepsy covering topics like What is epilepsy?, First aid for epilepsy, Basics about epilepsy diagnosis and treatment including EEG and How to raise awareness. The webinar was hosted in collaboration with the Epilepsy Support Foundation and EpiAction their youth group. In 2022, we intend to do more awareness, community work and training of health and social care and development workers.



Epilepsy Support Association of Uganda (ESAU)

In Uganda, a second lock down was imposed with strict standard operating procedures which among others included closure of public transport. Persons with epilepsy were forced to walk long distances looking for care and proper management of their condition. This was coupled with was lack of anti-epileptic drugs in major health centres for a period of 5 months across the country and as a result, we recorded 15 deaths of persons with epilepsy. The International Epilepsy Day was celebrated amidst lockdown restrictions. A special media conference was conducted with representatives from Makerere University medical teaching school, World Health Organisation, The Buganda Kingdom and the Ministry of Health. In their book, Kenya National Guidelines for the Management of Epilepsy, The Ministry of Health, Kenya developed a practical guide for health workers in 2016. This has supported the health workers in different health centres to manage epilepsy patients effectively. ESAU together with the Ministry of Health, Uganda, have learned lessons from Kenya and are working in conjunction with the Duke University and the Disability Rights Fund to develop a treatment guide for epilepsy care and management for Uganda. This will bridge the gap that has been evident in the care and management of persons with epilepsy in the country. Picture: A health camp conducted by ESAU, raising awareness on epilepsy, management and care, breast and cervical cancer screening.



Epilepsy Warriors Foundation, Malawi (EWF)

Report submitted by Samuel Chigamba

2021 has been a remarkable year for EWF with the foundation achieving so much despite facing a number of challenges. This is what we managed to achieve in 2021:

- 1. For the first time the foundation started renting an office space
- 2. EWF secured funding for its second project ever since its inception with financial support from the Disability Rights Fund, the project is being run by persons with epilepsy and later got approved by Blantyre District Executive Committee to implement the project in the District.
- 3. Sponsored a nurse based at Queen Elizabeth Central hospital to attend and Epilepsy Assessment and management course with support from EWF supporters both based locally and international.
- 4. Attended a national NCDI & MH stakeholders interface meeting organized by the ministry of health.
- 5. Conducted 4 epilepsy orientation meetings targeting learners.
- 6. Referred 5 Clients with epilepsy to to Dream Centre to receive treatment.
- 7. Launched stripes week stories initiative, EWF called for and shared stories of persons with epilepsy in a bid to raise epilepsy awareness and celebrate the achievements of ordinary heroes, this was done during stripes week.
- 8. Hosted a webinar in October under the umbrella of epilepsy Alliance Africa, the webinar was titled a collaborative approach on the fight against epilepsy, the foundation, a neurologist based at Queen Elizabeth Central hospital, the acting executive director of the federation of disability organizations in Malawi and a doctor based at Dream centre presented during the webinar.
- 9. Conducted one engagement meeting with the ministry of health to advocate for the inclusion of anti-epileptic drugs as essential drugs found at every District hospital including Health Centres with financial support from the Disability Rights fund.
- 10.Identified, documented two disability related cases, cases were handled successfully by one stop center in Blantyre.
- 11. Sponsored a young boy with epilepsy to attend Learn and Play nursery school with Montisori syllabus based in Thyolo District with support from Learn and play
- 12.EWF was trained in managing Difficult epilepsy by epilepsy Scotland and later conducted training of trainers targeting National Initiative for Civic education volunteers based in Lunzu, persons with epilepsy and staff of Mzuzu Disability organization in Mzuzu District, Persons with epilepsy from Lilongwe District with financial support from Epilepsy Scotland.
- 13.EWF attended an epilepsy assessment and management course for non-medical participants in May 2021 offered by Pretola Health Global.



Picture: An engagement meeting with the ministry of health advocating for the inclusion of anti-epileptic drugs as an essential drugs found at every District Hospital including health 've tries with support from the Disability rights fund.

Shine Epilepsy Support Organization

Shine Epilepsy Support Organization, Kenya, https://shineepilepsysupport.org/home/
National Epilepsy Awareness Month, which was held from November 1st to 30th, 2021, teaches others what a seizure is, and is not. Let us dare to imagine a society free of stigma, fear, isolation, discrimination and seizures; a community that is safe, supportive and accommodating of those living with epilepsy. Throughout the month, the Shine Epilepsy Support Organization worked to spread awareness across our regions through community events, local partnerships, social media campaigns to declare November National Epilepsy Awareness Month. In observance of National Epilepsy Awareness Month, we organised a hike to Mt. Kilimambogoon the 11th of December 2021. The mission of the hike was to increase awareness and raise funds to alleviate the suffering of those living with epilepsy as well as to increase public appreciation for and responsible use of wilderness trails. We were able to raise an additional kshs. 13,000.00 in charity from the participants at the event. We are in the process of giving all this money towards the noble cause of paying annual National Hospital Insurance Fund (NHIF) contributions for 2 people with epilepsy.

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 2022 plans are:

- 1. Epilepsy walk in March
- 2. Tree planting in May
- 3. Family camping in August
- 4. Medical clinic/camp in October
- 5. Epilepsy hike in November



GENO - Epilepsy Center for Empowerment

2021 was a very successful year for Geno since it's the year we were registered and got a registration certificate, we then organised the first Epilepsy event in the whole of South Nyanza and that's global Epilepsy day in February and we got 40new clients, we also managed to launch a monthly Epilepsy clinic where we have clients come to see a neurologist and review, we have also been creating awareness in different schools and churches and have even partnered with other like-minded organisations to shout out Epilepsy. We have approximately 100 Epilepsy clients who attend our monthly Epilepsy clinic and that's a very big achievement to us.

CareEpilepsy Ethiopia

As the new year begins, we are busy making plans for 2022 and looking back at what we have achieved this year. This year, our activities were centred around increasing access to medical care, treatment, training, awareness, the improvement

in the wellbeing of people with epilepsy, and advocacy for issues related to epilepsy. I am delighted to share that 2021 has seen an increase in the number of neurologists volunteering at our clinic and providing our "Epilepsy Basics" training course. Our telephone helpline and monthly patient support group meetings continued to provide assistance, hope, support, guidance, and access to both national and local



resources. Our work in 2022 aims to:

- 1. provide and facilitate access to medical care and anti-epileptic drugs for 500 patients
- 2. launch a telemedicine program for rural areas to support epilepsy management
- 3. provide epilepsy training sessions
- 4. expand our EEG service to its total capacity
- 5. move into a safe, comfortable, convenient, and affordable premises to use as our rehabilitation centre where we will run our programs (clinic, diagnostics, counseling, support group, children activities, and income-generating activities)
- 6. continue to educate the public and raise awareness
- 7. continue to offer information on how to access help, available treatments and support for 5000 people
- 8. provide skill training and capital to empower people with epilepsy to be self-sufficient
- 9. increase our financial capacity to achieve our goal

Pambazuka Elimisha Kifafa

Report by Rosslyn Kiragu

November 2021 was the launch of the Pambazuka Elimisha Kifafa organization. This is an organization based in Kenya that seeks to reduce stigma associated with epilepsy and work with other stakeholders in creating awareness about epilepsy. Pambazuka is a terminology in Swahili that is indirectly translated to mean rise up while elimisha is a Swahili terminology directly translated to mean educate. Pambazuka Elimisha Kifafa means after one has a seizure one should rise up and educate others about Kifafa (Epilepsy). On the 26th November Pambazuka

Elimisha Kifafa had a workshop with children in grade four and five at a private primary school. Prior to the commencement of the workshop, questionnaires were distributed to their teachers and the children as well. Before the workshop started, the children's scale of knowledge was low scaling at 1-4! After the workshop, the children's knowledge scale was rated at 8-10. In the workshop, Children together with



their teachers learnt what epilepsy is and the causes that lead somebody to have epilepsy. I shared my life as a person living with epilepsy. Through the workshop, children were able to understand the epilepsy condition. At the end of the workshop there was a cake cutting ceremony.

Second annual epilepsy conference

In 2021, we had our second epilepsy conference. The conference was held under the theme TOGETHER WE WILL DEFEAT EPILEPSY. The conference committee was co-chaired by Enat Yewnetu from Ethiopia and Samuel Chigamba from Malawi. There were 101 participants who joined during the Zoom conference and 20 presenters. All presentations were recorded and can be accessed from EAA
YouTube channel. Themes that came out of the discussion are shared below.

Theme 1 Medicines, treatment and facilities

- Reduce treatment gap
- Increase access to health services
- Supply of drugs is low
- Address side effects
- Shortage of facilities or infrastructure

Theme 2 Social stigma, myths & marginalisation

- Awareness needed
- School awareness
- Correct terminology needed
- Ethical use of social media
- Social cultural beliefs

Theme 3 Research and Publishing

• Statistics & data missing

Theme 4 Collaborating and empowering PWE

- Employment skills for young people
- Tertiary education
- Self-employment
- Strategies to reduce poverty
- Reduce social and environmental barriers
- Women with epilepsy issues

Theme 5 Training and Education

• Training nurses, primary care doctors

Theme 6 Policy, treaties, legal instruments and advocacy

- Laws
- Driving
- Marriage
- Action Plans for each country
- Transport
- Reduce exclusion

Theme 7 Collaboration and Funding

- Engage the AU & WHO Africa engage governments as policy & decision makers
- Engage funders and charities form partnerships
- Supporting countries that have no epilepsy programs
- Training on how to get funding, ethical fundraising
- Collaborate with governments, complement not compete work within national frameworks

EAA Plans for 2022

- **Tele-health**: Free weekly clinic for people with epilepsy from any African country
- **Tele-education and training**: Webinars for professionals, advocates and people with epilepsy. We target 6 webinars in 2022.
- **Research and documentation**: We will promote, support, carry out research and publish on epilepsy related topics. We target 4 publications.
- Advocacy and policy: We will advocate for improved and new policies for epilepsy on the African continent and help members achieve the same in their countries
- Capacity building and coordination: We will support epilepsy association in Africa to maximise their potential
- **Conference**: we will do the 3rd annual conference this year
- **Awareness**: we will do second annual epilepsy awareness week (stripes week) in the 3rd week of September
- **Voice Indaba** we will hold this symposium 2 times a year to recognise the voices of people with epilepsy and providers of care. It will be organised by people with epilepsy.

How you can you help or work with us

- Email us to find out about our membership options.
- Email us to find out about our partnership options.
- Join our monthly webinars or host a webinar.
- 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.
- Initiate Stripes Week event.
- If you have lived experience of epilepsy, host an Indaba (symposium of 30 minutes to 1 hour).

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2022 Events

Please add these important events to your diary

Voice Indaba

Thursday, 24 February 2022.

The second Indaba for the year will be announced later.

What is an Indaba – this is a meeting where people get an equal chance to participate. The meeting is owned by participants. The purpose is to amplify the voice of people with epilepsy. Key to achieving this is to provide space where people feel valued and safe.

3rd Epilepsy Conference 2022 (EAAC3)

Friday, 24 June 2022

If you want to share a story or presentation, please send an email to epilepsyallianceafrica@gmail.com

Africa Epilepsy Week 2022, EpiWeek2022

Mon to Friday, 19-23 September 2022 (yearly every 3rd week of September)

United Against Seizures & Stigma in Africa