



IBE

International Bureau
for Epilepsy

AFRICA REGION



2020
ANNUAL
REPORT

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Vice President STATEMENT



Greetings to all; As the Vice President of IBE Africa we want to thank you all for your continued support that you give our team as the African Regional Executive Committee as well as persons with epilepsy. Although in 2020 we were threatened by COVID-19, work continued, and we managed to reach more people together and form new partnerships. We really work so hard indeed to adapt new ways of doing work.

A special mention and vote of thanks to our team of Mr. Youssouf Noormamode C.S.K, and Madam Betty Barbara Nsachilwa who devoted all they could to ensure we remain afloat, despite the challenges and all our chapters who have been loyal to raise the flag of persons with epilepsy in Africa.

AREC has been working from home at times and working with members online. We are extremely proud of all our loyal members who have been learning new skills to join in. We endeavored to ensure that no person with epilepsy was left out. We are incredibly grateful for the continued support that we are receiving from Band Foundation and now we have three streams of funding to our chapters. New additional chapters than the traditional ones have started to access funding to support their work.

IBE-Africa has been doing lots of advocacy in the last year about Making Epilepsy a Health Priority and we will continue to do so in this coming year. We listened to people with epilepsy on what ought to be our focus and we will deliver more in this new operational year.

COVID-19 had impacted all chapter countries with 16 known deaths of persons with epilepsy. It is with sadness that we recorded deaths of some pillars in our work, notably among them Anthony Zimba (a man who supported and worked hard to establish many chapters in Africa.) He will be sadly missed by all in the epilepsy movement.

We wanted to thank you all for making sure that we stayed afloat despite all the challenges including economic challenges that the region faced.

Despite all this we scored remarkable achievements such as:-

- Expansion on Chapters (Mozambique, Gambia, Kenya) and discussion already at advanced stage with Botswana, Burundi, South Sudan and Madagascar.
- A special call for the endorsement of the WHA Resolution 68.20
- Youth Petition on WHA Resolution 73.11
- Participation on Global Initiatives including key WHO forums.
- Launching of Making Epilepsy a Health Priority in Africa + Promising Strategies projects.
- Development of Advocacy Toolkit.
- Partnerships: ILAE, WHO, African Union, Pan African Parliament.

We salute you all for unwavering support and we will continue to deliver despite the challenging environment that we all find ourselves in.

**Zikomo!!! Tatenda!!! Siyabonga!!!
Enkosi!!! Dankie!!! Thank You!!!
Merci!!! Asante Sana!!! Ke a Leboha!!!
Obrigado!!! Me daa si!!! Barka!!!
Webale!!! Murakoze!!! Tenkey!!!**

Action Amos
Vice President Africa



Message from Vice Chair



I am honored as Vice Chair of IBE Africa Regional Executive Committee to write down this short message as it is indeed a privilege to serve both the IBE Africa as a region and the people living in Africa impacted by epilepsy.

2020 has been another challenging year following the Covid-19 pandemic outbreak. The efforts of our highly committed team who constantly

put out that extra effort to ensure our programs are of real value to our affiliated chapters in Africa. Despite the numerous challenges we had to face, we keep struggling to regain momentum of our work on going for Africa and among the major key achievements remained the IBE Promising Strategies and the Making Epilepsy a Health Priority in Africa, under the generous support and funding from Band Foundation.

Mozambique joined the IBE movement and therefore expanded the epilepsy community organizations in Africa. The death of our beloved and most respected brother, Dr Anthony Mulenga Zimba was a huge loss for Africa, and I remembered the good memories of his visit to Mauritius and EDYCS Epilepsy Group.

Our Chair, Amos Action, Secretary Betty Nsachilwa, and I take great pride in what has been accomplished in 2020 even when the whole World, including Africa, was in lockdown. We look to more successes in the future as we leverage new and evolving social media to strengthen our members' communication and connection with one another.

I thank you for your support over the past year and invite you to take stock of our achievements in this Annual Report designed to shed light on our works, challenges, and future undertakings.

To end, let me congratulate both the Chair, Amos Action, and our Secretary, Betty Nsachilwa, for their relentless efforts in making things happen as regards to epilepsy matters in Africa.

Youssouf Noormamode
C.S.K

IBE Africa Regional
Executive Committee



Remarks by the Secretary



The year 2020, though full of anxiety, saw many strides in improving the stance of the IBE Chapters in Africa.

An opportunity to participate in two projects was opened to all, namely the Promising Strategies Grant (PSG) and Making Epilepsy a Health Priority in Africa (MEHPRI) programs, supported by Band Foundation. The PSG program started in April 2020 and five Chapters were awarded funds to carry out innovative projects that ranged from inclusive education, capacity building using technology and awareness projects. The MEHPRI

project commenced in May 2020, and the uniqueness of the 2020 projects was that even smaller organizations and Associate Chapters were privileged to receive funding if they met the set criteria.

Membership was increased with Mozambique added as a Chapter of the IBE, with discussions still in progress for Botswana and Angola.

The beginning of 2020 saw a gloomy beginning with the advent of the Corona Virus. Most of the activities planned by the IBE Africa Region Chapters needed some readjustment to suit the new normal. The outdoor activities came to a halt and a number of deaths owing to the disease were experienced in the region. The death of the one outstanding advisor and self-motivated leader, Late Mr. Anthony Mulenga Zimba, negatively affected the operations of the Epilepsy Association of Zambia and the epilepsy fraternity at large, as he was also the Treasurer of IBE.

This report gives an overview of what some of the Chapters in Africa did during the year under review. The Chapters were provided with a chance to give a summarized report on their activities and future endeavours.

I also take this opportunity to thank the 2017-2021 AREC team i.e. Vice Chairperson – Mr. Youssef Noormamode, Mauritius; other members Dr. Lisk Durodomi, Sierra Leone; Mr. Kenneth Nsom, Cameroon and Ms. Grace N. Moyo, Zimbabwe for their tireless effort to unite the IBE Africa Region Chapters.

Ms. Betty Barbara Nsachilwa,
Zambia





1.0 ACHIEVEMENTS

1.1 Advocacy

1.1.1 Petition from African Youths with Epilepsy, their friends and Political Will

On 20th October 2020, youths with epilepsy petitioned Ministers of Health and Parliamentary Committees of Health across Africa to support and endorse the World Health Assembly Resolution 68.20 on Global Action on Epilepsy and Its Synergies with Other Neurological Disorders during the 73rd WHA Assembly. The petition was signed by twenty-seven members with the hope of achieving at National Level the following:

1. Involvement of persons with epilepsy in the initial planning of programmes which affect our lives.
2. Creation and implementation of plans and programs which are tangible and can change in our lives.

3. As Governments, ensure that epilepsy is mainstreamed across all health and development initiatives and ensure implementation of policies that protect our rights.

To amplify the petition, AREC through the Vice President for IBE Africa region, Mr. Action Amos, engaged political figures to add to the voices calling on Ministers of Health and Parliamentary Committees on Health to act on WHA 68.20. Dr. Joyce Banda, former President of Malawi, issued a pre-recorded Statement urging all Governments in Africa to seriously consider the plight of people with epilepsy, as without their support the efforts of epilepsy advocates would amount to nothing.

1.1.2. Advocacy Toolkit

The drafting of an Advocacy Toolkit was commenced in 2020 with the assistance of a Consultant in South Africa and the Communications Committee.

2.0 COMMUNICATION

Improvement was shown in the longstanding issue of lack of feedback from the Chapters. In the past, it was observed that only a few members responded to calls for action, proposal writing or reporting on activities, mainly the southern and eastern sub-regions. The AREC team discussed ways to involve all Chapters by way of translating the information, which was usually transmitted in English, when there were several Francophone countries and one using Portuguese as the office language. The Vice Chairperson, Mr. Youssouf Noormamode offered to translate important information into French for the sake of Chapters in the French speaking countries. A special meeting was called inviting Chapters in the western and central sub-region.

Virtual Meetings, which included two Webinars, were held. The two Webinars were specifically held for Making Epilepsy a Priority in Africa Programme and included speakers from WHO, PAN Africa, African Union, and the Disability Organizations.

A Communications Assistant was engaged to continually improve networking in the African region. There were three applicants shortlisted; however, a youth by the name of Mbutfo Masuku of Eswatini, was selected to take up the position. The Communications Assistant would most importantly maintain the Africa region Website and organize the virtual meetings.

3.0 CAPACITY BUILDING

The AREC has always been interested in seeing continuity of the Epilepsy Program in Africa, and two areas identified as a need were skills in advocacy and proposal writing. The AREC announced the intended training session to be held virtually in 2021. The Chapters were requested to send two names of its members to participate and a little funding would be given to those Chapters to assist with payments for internet connection, venue, or refreshments.

4.0 2020 INTERNATIONAL EPILEPSY DAY

It was reported that fifteen African Countries participated in the year under review. The Day was commemorated in various ways, such as workshops, media interviews or awareness walks.

5.0 CHALLENGES

The challenges faced by the Chapters in the region are summarized as follows:

5.1 The COVID 19 effects:-

- Restrictions limited the activities of the AREC and the epilepsy society in Africa just like in other parts of the world.

- Most employees' services were terminated due to lack of business, thus leading to poverty and dependence.
- Reduced demand for services from Chapters owing to fear of contracting the corona virus at the facilities.
- Some countries experienced inflation.

5.2 Ministries of Health lack of interest in handling epilepsy issues.

5.3 Lack of steady funding to engage full time staff to run the Epilepsy Organization.

Action Amos
with Dr. Joyce Banda,
Former President of Malawi



ANNUAL REPORTS FROM CHAPTERS IN THE AFRICAN REGION

Parents Organization for Children with Epilepsy Tanzania (POCET)

Our Organization

The Parents Organization of Children with Epilepsy Tanzania (POCET) is also known in Swahili as “*Umoja wa Wazazi wa Watoto Wenye Kifafa Tanzania*” (UWAKITA). POCET is a non-governmental non-profit organization (NGO), developed based on self-help principles, which seeks to engage interested parties in providing for the needs of children with epilepsy. It was officially locally registered under the Ministry of Home Affairs on 15th of June 1992 and in the year of 2001, membership stood at 850. It was registered as a full member of IBE on 15th December 2005. POCET draws its members from all over Tanzania mainland and Zanzibar, is open to any parents, guardian, or care providers of a child with epilepsy and/or any person above 18 years.

Approach

What we did in 2020

In 2020 we managed to achieve the following: -

- Acquisition of a 56-acre farm in Kisemvule for vocational skills building for adolescents with related mental disabilities.
- Managed to increase community awareness on epilepsy through television programs, magazines, distribution of health learning booklets and drama programs.
- Success in advocating for the needs of children with epilepsy through sensitizing key political figures.

Our Organizational Challenges

Our organization is facing the following challenges: -

- Delayed decisions to do with the fear, anxiety and hopelessness that

exist among our society regarding epilepsy.

- Lack of sufficient funds to run the organization and complete the legal registration for the fully acquisition of our 56-acre farm.

Our Ambition for 2021-22

In 2021-22 we have the following ambition: -

- Complete all the legal acquisition procedures of our 56-acre farm in Kisemvule.
- Complete the Architectural and construction mobilization process of the vocational skills building to be built in Kisemvule.
- To increase mass media awareness to the public regarding epilepsy in children.
- Create links with other support groups which can support our organization.





Our Organization

Epilepsy Lesotho is a Non-Governmental Organization registered in 2017. It has 10 Board Members and was founded with the aim of advocating on behalf of people with epilepsy. The Association is now run by 2 full-time employees (Board Members) and 2 pensioners; one is a volunteer and the other, is a member of the board.

Epilepsy Lesotho is currently operating from one district which is the capital city, Maseru, and we plan to expand to other districts as the organization grows by opening branches. The Association is not officially known as it has been dormant since its inception.

The Association does not, therefore, have a strategic plan. It has no clear direction as to where its heading,

except relying on what comes to its operators' mind at the time. It is our wish to have a direction and monitoring plan to measure how far we are towards achieving our goal.

Approach

We use a bottom-up approach that allows us to engage persons with epilepsy to inform how we work. Our plans are: -

- To reach out to the media and the community to raise epilepsy awareness to eliminate stigma, as people with epilepsy are being stigmatized against in their communities. We will approach the local radio stations, television, and newspapers for free health slots. We will also go to the villages and schools to raise

awareness as pupils with epilepsy are being stigmatized and end up leaving school.

- Community engagement - The Association will organize community forums through the village chief to address the community about the issues surrounding epilepsy.
- Fundraising - Epilepsy Lesotho will look for sponsorships to print epilepsy awareness materials which will be distributed during outreach programs.
- We will also provide trainings to epilepsy patients and their care givers. One other crucial approach which we should take as an Association is get the 'buy in' from our government by approaching the department of health so that they can consider epilepsy a health priority.



Our Organizational Challenges:

Our challenges are those related to infancy stage organizations as follows: -

- The Association does not have a strategic plan. This can lead to doing things haphazardly as and when they come to the minds of its members.
- As the Association, we have been faced with human resources challenges since the Association cannot employ its own full-time employees to do the work.
- The other main challenge is lack of funding. Due to this, the Association has not been able to do anything as it relies on donations.
- No financial assistance from the Government, i.e., our government does not seem to have any interest in epilepsy even after the Association approached them about the existence and the intention of the organization.

We are therefore relying on support to build capacity and put in structures for the organization. It is our hope that IBE and other

stakeholders will assist with these so that we identify sustainable partners to support our work towards persons with epilepsy.

Our Ambition for 2021-22

Due to lack of resources, the Association has not been able to undertake a lot of activities. The following were done in 2020: -

- Executive Strategic Planning meeting.
- Proposal Writing.
- Setting Governance Structure and opening bank account in progress.
- Mobilizing persons with epilepsy in Maseru to join the Association.
- IBE Africa webinar participation.





**EdyCS Epilepsy
Group**

EdyCS Group, Mauritius

Our Organization

EDYCS Epilepsy Group is the leading unique Non-Governmental Organisation founded on 24th December 1997 by a group of volunteers comprising of professionals, health specialists and persons with epilepsy whose aims are to assist people with epilepsy through advocacy, access to quality health care, training, campaigning, and research while also addressing the needs of Persons with Epilepsy and their families in the Republic of Mauritius. The prevalence of epilepsy is estimated at 1.5% of the population in Mauritius (which is an island country in the Indian Ocean, located off the eastern coast of Africa.) Physio-graphically, it is part of the Mascarene Islands. The capital is Port Louis. Our organization works to support both people with epilepsy and their families. The organization through the establishment of its

operating Centers is fully staffed and equipped to meet the needs of People with epilepsy in Mauritius and Rodrigues islands. (Rodrigues is an autonomous outer island of the Republic of Mauritius located 650 km east of Mauritius):-

- EDYCS Epilepsy Health Service Center (located 442 Boulevard Rivaltz Port Louis Mauritius)
- EDYCS Help to Grow SEN School (located 4 Boulevard Rivaltz Port Louis Mauritius)
- EDYCS Rodrigues Epilepsy Health Service Center (located la Ferme, Rodrigues)
- EDYCS Rodrigues Help to Grow SEN School (located Manick, la Ferme, Rodrigues)

The organization works cross sectors with partnership with key relevant authorities and ministries to advance the epilepsy agenda.

Our Approach

EDYCS Epilepsy Group sees continued opportunity in its strategic positioning as the leading NGO epilepsy professional organization. At the same time, the role of EDYCS Epilepsy Group is evolving with changes in health care, social programmes, pressures from the

decline in our sources of funding, covid-19 impact and changing expectations around professional development and education. To be well-positioned for these changes, EDYCS Epilepsy Group is proposing achievable plan to guide its work for the next four years. The revised Strategic approach is focused on: -

- WHO Resolution on the Global burden of epilepsy.
- WHO/ILAE/IBE Global Campaign against epilepsy.
- IBE Africa 'Making Epilepsy a Health Priority in Africa'.
- Inclusive Education and Employment Rights of PWE.
- Building new coalition and alliance with Regional and International Organisations to advance epilepsy.

What we did in 2020

Due to the Covid-19 pandemic and lockdown, the programs and services of EDYCS Epilepsy Group were heavily impacted. However, EDYCS Epilepsy Group managed to keep momentum of its work. The following key programs and services were organized and delivered: -

- Capacity Building Workshop for Government Officials and



DPOs in Alliance for Rights Africa towards Disability Inclusion under the financing EU/CBM/ADA.

- International Epilepsy Day Celebration 'Public Campaign' at Bambous Social Welfare Centre in collaboration with Lions Club Riviere Noire.
- Annual General Meeting EDYCS Epilepsy Group.
- Empowerment Program in Pastry and Small home businesses, targeting 10 Women with epilepsy supported by the SMEDA and Crans Co Ltd.
- Epilepsy Care, Psychological and Therapeutic services provided to PWE via EDYCS Epilepsy Health Center Mauritius and Rodrigues.
- Inclusive Education for children and young adolescents with learning disorders via EDYCS Help to Grow SEN Schools Mauritius and Rodrigues.
- Training of ECCEA Pre-Primary Schools Zone 1 & 2 Teachers in early childhood epilepsy under the financing of the IBE Promising Strategies /Band Foundation.

- Official signature of Memorandum of Agreement between EDYCS Epilepsy Group and Foodwise.
- Distribution of food packs and non-food packs to 150 needy families in vulnerable situation following Covid-19 lockdown.
- Collaborate with the Business Mauritius Covid-19 Solidarity Committee in a National Survey to identify the Covid-19 pandemic on our beneficiaries.
- Under the IBE/Band Foundation Utetezi Project financing, two Advocacy Seminars were organized namely for People with epilepsy and their families and the other one targeting Women federations and organizations registered under the Ministry of Gender Equality and the National Women Council.
- Two travel missions were held in Rodrigues (September & November) with key activities training of pre-primary schoolteachers, workshops with the RRA Commissions on the WHO Resolution, Capacity building of staff in organizational management and delivery of services).

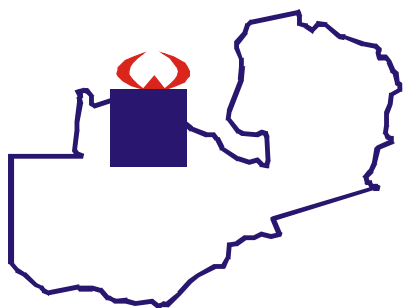
Our Organizational Challenges

- Cut in CSR funding following Covid-19 outbreak.
- Identification of adequate venues for implementation of planned workshops and trainings.
- Climatic change (sudden storm and torrential rain impacting on project and programs timeframe).
- Delay in the setting up of the Epilepsy Joint Working Committee as proposed by the Hon. Minister of Health & Wellness.

Our Ambition for 2021-22

- The Epilepsy Joint Working Committee (Ministry of Health & Wellness Mauritius & EDYCS Epilepsy Group) duly established and in operation.
- WHO Resolution in Epilepsy adopted and integrated into the Ministries of Health of the SADC countries health plans and working agendas.
- Raise additional funds to meet with planned programs and services.
- Become the Leading Champion organization in Epilepsy in Africa.





Epilepsy Association of Zambia

Our Organization

The Epilepsy Association of Zambia was formed on 22nd September 2001 and registered with the Registrar of Societies as a non-profit making organization. It has a paid-up membership of 650 but attends to all people with epilepsy country wide. The Association was founded by the Late Mr. Anthony Mulenga Zimba with seven (7) co-founders.

The last nineteen years has seen the Association grow in its quest to improve the livelihood of people with epilepsy. It mainly offers health care services which include EEG recording and dispensing of anti-seizure medication. The Association also supports school going children and adolescents with epilepsy. It partners with other organizations with similar objectives and interest in the care of people with epilepsy, like the Mental Health Association of Zambia, Cheshire Homes, Epilepsy Care Team of

Mazabuka, Neurological and Psychiatry Society of Zambia, Bauleni Special Needs School and the Zambia League Against Epilepsy.

Our Approach

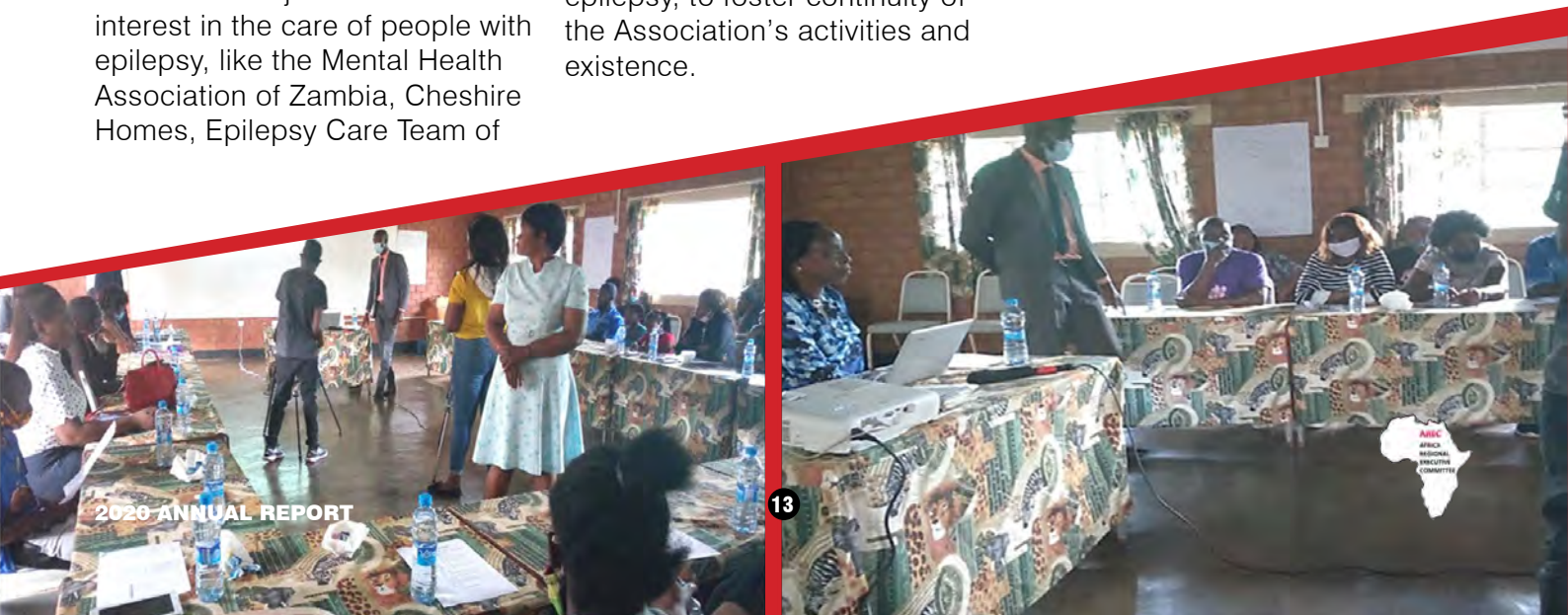
Using the high to low approach, the Association advocated for improved policy, healthcare, capacity building and social welfare of people with epilepsy while persuading the Health Authority to support the implementation of the WHA 68.20 Resolution of 2015.

We worked closely with governmental or private health care authorities and used the already existing government established institutions to accomplish the objects of the Association. Continued support to the health authority to make public awareness on epilepsy is a must and to educate on updated healthcare. Conducting special health care sessions helps to update other health providers on the latest treatment or diagnosis.

Training of youths in administrative and various avenues of care for people with epilepsy, to foster continuity of the Association's activities and existence.

What we did in 2020

- In 2020, the Epilepsy Association of Zambia was able to improve on diagnosis using an EEG as part of the investigations. Six health workers were trained in EEG Recording and a male nurse, Mr. Saidi Mbewe, has continued with EEG Recording for the Association clinic. Several patients, especially children and adolescents, were privileged to receive free medication through the Levetiracetam medication grant from Row Foundation.
- The Association commenced the Epilepsy and Education Survey aimed to assist children with epilepsy who are out of school to be enrolled into school. We were one of the beneficiaries of the Promising Strategies Projects funding from the Band Foundation through IBE.
- In December 2020, the Association held the seizure free day, a day





initiated by the Association in 2008, with the aim of encouraging people with epilepsy to take the prescription of anti-seizure medication seriously. The commemoration included a presentation on Management of Epilepsy.

- The Association also participated in the preparation and launch of the Zambia Non-communicable Diseases Alliance Strategic Plan for 2021-25.

Our Organizational Challenges

- Lack of permanent premises for day-to-day operations.
- COVID 19 restrictions reduced the activities of the Association to provision of health care only, as public events could not be held, and the Ministry of Health exclusively concentrated on communicable diseases.
- Inadequate resources to expand the activities countrywide or employ permanent staff.
- The demise of our leader had a negative impact on the operations of the Association, as most of the clients took long to come to terms with the fact that Mr. Zimba was not the only health care provider working with Association.

Our Ambition for 2021-22

- Ensure quality health care by improving accessibility to treatment by encouraging all district health offices to engage health personnel that can attend to people with epilepsy and improve supply of anti-seizure medication.
- To participate fully in the Non-Communicable Diseases activities as set out by the Zambia Non-Communicable Diseases Alliance.
- To partner with other Disability Organizations.
- Find a funder for full time operations of the Association and engage permanent staff.
- Advocacy training for both executive and general membership.
- To consider registering for Health Insurance Scheme for Association members, thus making it easier for members who are unable to buy expensive medication like sodium valproate.
- To work closely with Ministry of Health and participate in the drafting of the Epilepsy and other Neurological Disorders Action Plan in line with the WHA 73.11 resolution.



NGO GECO : GLOBAL EPILEPTIC CONNECTION

Our Organization

GLOBAL EPILEPTIC CONNECTION "GECO" is an NGO created in Rwanda, Western Province/ Rubavu District on 29th, October 2010 by different people of goodwill and willingness with the aim of fighting against stigma and discrimination perpetrated against people with epilepsy. GECO exists to promote, protect and improve the wellbeing and the rights of people with epilepsy, their families and/or their caretakers. In addition to this GECO ensures awareness and management of epilepsy across the Rwandan Society as well as advocacy in areas of health, psycho-social and legislative services, all in partnership with local and national entities involved in these domains.

Our Approach

For us to achieve on our goal, GECO has adapted several approaches such as:

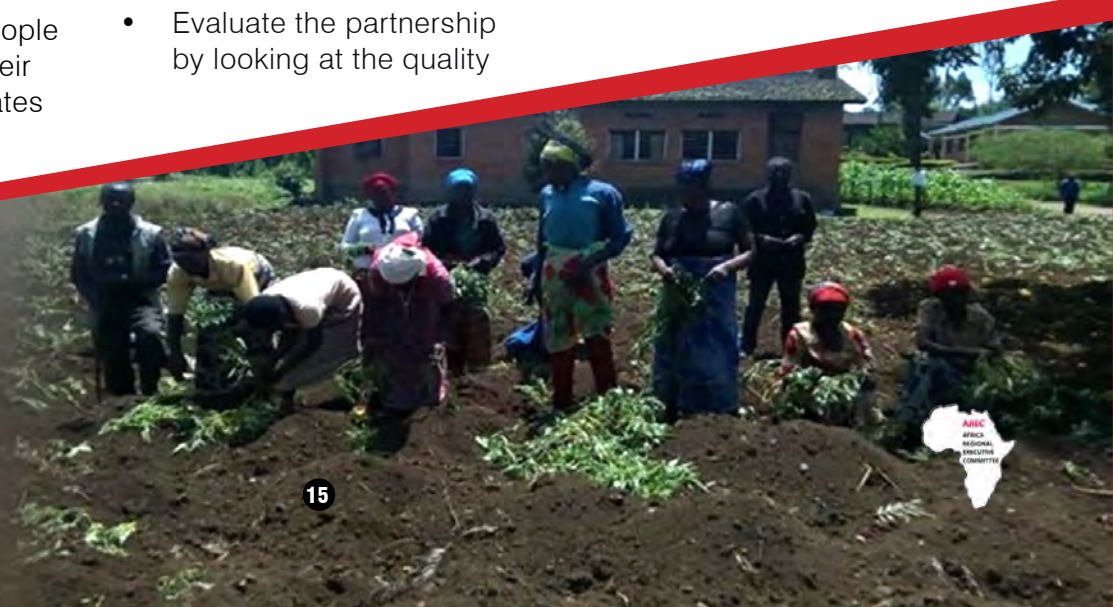
- Being composed of people with epilepsy and/or their family members facilitates and helps to make
- pertinent and convenient decisions both in all organizational organs.
- Working closely with Community Health Agents in mobilization, sensitization, identification and follow-ups of people with epilepsy
- Reach out to the communities by involving religious leaders, businesses, policy makers, media personalities, and others who have significant influence in the community.
- Ensure a constant flow of information by adopting formal communication strategies that allow for frequent, deliberate, and productive exchanges between partners.
- Designing both process and outcome evaluations and decide on the intervals at which each will be conducted
- Evaluate the partnership by looking at the quality

of the strategic plan, level of member participation, total number of actions implemented, and satisfaction of members and beneficiaries.

What we did in 2020

1. Reinforcement of the Groups of People with Epilepsy from Local Health Centers

As it is prescribed in the mission of Global Epileptic Connection (GECO), which is to fight against Epilepsy in various domains including health, psychosocial and legislative services, did several activities including regular visits and monitoring of 17 groups of people with epilepsy (GPE) composed of 336 persons from their respective health centers. The visits aimed at finding out the status of their health and social condition, and discussing together their challenges. One of the result for this activity is that advocacy was made to 29 patients who could not have access to drugs due





to not having health insurances. As for now their regularly taking medicines like others on due time.

GECO would also regularly visit GPE's income generating initiatives with aim to see their progression and impact both to members and their families as well. Most of these groups are involved in farming and agriculture in order to sustain themselves and their family members as well as telling the community people with epilepsy are as able as others.

2. Integration of children with epilepsy in the ECD program

For that reason, GECO with in partnership with Humanity & Inclusion (HI) organized training on integration of children with epilepsy in the ECD Program. These events took place at Byahi - Rubavu Sector and involved 21 participants comprised of ECD/ Rubavu District Officer, 2 Rubavu and Gisenyi Sectors' Social Affairs

As is often the case in the Rwandan Society, people with epilepsy are many times rejected, mistreated and

often denied of their rights. This is evident in different areas and even in schools. Therefore, in order to prevent this barrier, sensitization should be extended to ECD Centers so that caregivers can also have adequate and accurate information on epilepsy and how to provide basic care for someone in crisis, especially for children they usually take care of on a daily basis. In this workshop participants were shown how a child with epilepsy is a normal and capable child like anyone else and that epilepsy is a curable disease.

3. Distributing meals to people with epilepsy during COVID-19 lockdown

As a result of negative effects of the COVID-19 epidemic, GECO did advocacy and was able to provided food to 64 families of people with epilepsy composed of 336 persons.

This food was distributed on the basis of most vulnerable families. At least all groups of people with epilepsy within Rubavu District benefited from this assistance.

In order to ensure its suitable servicedelivery, operation and sustainability, GECO from

the very support of Handicap International / Humanity and Inclusion, has established a small maize flour factory. The project is designed that a certain amount of flour will directly go to the beneficiaries, organizational running coast as well as meeting other needs such medical insurances to most vulnerable families of having people with epilepsy.

The 17th new group preferred the breeding of pigs which they say to be so and quick productive and be reared easily, and they were given 6 intermediate pigs. These were 3 women and 3 men who were selected by their colleagues. In the agreement, once a pig had delivered, there is a number of piglets that will be given to other group members until the whole group got pigs.

Our Organizational Challenges

- Epilepsy is not among the Rwanda Government prioritized diseases, for that reason GECO can't get any financial support from national health channel.
- Operating only in one district of the country out of 30 districts due to financial means limitations

- It's very hard for GECHO to satisfy health and other socio-economic needs of people with epilepsy. The desire was to do strong and sustainable projects for sustainable solutions to these challenges
- It is difficult to GECHO to hire staff and/or even getting an incentive and transport fee to its volunteering members.
- People with epilepsy who don't have permanent residential places due to various reasons.
- Make advocacy to find the necessary funds for the construction of a special center to take care of people with epilepsy.
- Organizing trainings on this disease as well as making available the various documentations on epilepsy disease and train people with epilepsy and / or some of their relatives/ caregivers in arts and vocational & professional trades. We invite everyone who can help us achieve this good deed to agree to release and provide their strengths funds and advice.

Our Ambition for 2021-22

FORECAST AND PLANS OF GECHO FOR YEAR 2021 - 2022:

- Expand our operations from Rubavu to other Districts and operate at least in other 5 districts of Western Province
- : Nyabihu, Rutsiro, Karongi, Ngororero and Muhanga.

For this, we invite all stakeholders; institutions, organizations, finance agents and other donors and supporters to help us for implementation of this plan.



Foundation for Epilepsy and Stigma Support – The Gambia

Our Organization

Foundation for Epilepsy and Stigma Support was registered as an NGO in November 2020, and successfully launched virtually on the 11th December 2020 with the support of The Ministry of Health of The Gambia, Edward Francis Small Teaching Hospital, Provost of The University of The Gambia, Medical Research Council (MRC) Gambia, ROW foundation, TeleEEG and Pretola Global Health Consulting.

Our executive team consists of 12 members in the Capacity of a Strategic and Fund-Raising Team, Outreach Team and Research Team with also a Legal Advisor. Mrs Adam Jallow Janneh and Dr John Jabang are President and Vice President of the Foundation respectively, as well as the Co-Founders. The foundation can be contacted by email at fessgambia@gmail.com and our contact numbers are +220 2445301, +220 2226004 and on WhatsApp +44 7958717530. We are also on Facebook, Twitter, Instagram, and LinkedIn @FESSGAM.

Our Approach

Our aim is to improve quality of life lived by people with Epilepsy in The Gambia through health promotion and prevention strategies, advocacy to reduce stigmatisation and raise awareness, Research, Social and Mental Health Support and Government Policies. We also aim to partner with Traditional healers since

they are the first point of contact in most cases and also play a key role in patient's decision to use conventional medicine.

What we did in 2020

After registering FESS as an NGO, we opened a bank account for the Foundation and a post box. We opened social media pages on Facebook, Twitter, Instagram, and our website is under construction. Following our successful virtual launching we have enrolled 8 health personnel onto an Epilepsy Assessment and Management course and the same group are also training on how to use an EEG machine in collaboration with TeleEEG. We have also opened an epilepsy patient forum where people living with epilepsy can network and share their stories and inspire others to join the group and support one another.

Four schools have also agreed to partner with FESS to raise awareness about epilepsy and train students and teachers on Seizure First Aid. All expenses of the foundation are currently being paid for by members and courses are being sponsored by few individuals and mainly by The Draman Foundation.

Our Organizational Challenges

1. COVID restrictions.
2. Inadequate facilities and Diagnostic tools.
3. Availability of cost-effective AED's.
4. Lack of specialists, doctors and nurses.
5. Lack of Funds.
6. Absence of Reliable Database.

Our Ambition for 2021-22

1. Treatment: Start a Multi-Disciplinary Epilepsy Clinic for the first time in The Gambia. Collaborate with the Ministry of Health of The Gambia for the availability of AED's in all the main hospitals in the country, together with the use of cost-effective AED's like levetiracetam or Keppra.
2. Capacity Building: Conclude the initiated partnership with TeleEEG for the donation of an EEG machine and training of our doctors and nurses on how to use an EEG machine and same Group of trainees to complete an epilepsy assessment and management course.
3. Outreach efforts: Conduct school assemblies where Epilepsy and Seizure first aid will be discussed. Quarterly radio awareness shows in partnership with the MOH across all the 5 regions of The Gambia.
4. 50million Steps Campaign and International Epilepsy Day: Walk and add steps to the count down. Facebook live program about Epilepsy and support available in all the major languages spoken in The Gambia.
5. Fundraising: Reach out to companies who share our dream of improving the lives of people living with epilepsy for donations.





**Kenya Association for Welfare
of People with Epilepsy**

Our Organization

KAWE is a not-for-profit organization that was founded in 1982 and has a strong organization structure with a voluntary board of 5 members, supported by various documented policies and procedures including the KAWE constitution, a five-year strategic plan that is periodically reviewed, the personnel and finance policies, among others. We are transparent in our undertakings, handling finances in a compliant way ensuring all our donations are put into good use and audited every year and NGO returns filed with the government every 31st of March.

**Our Vision: People with epilepsy
living their lives to full potential.**

**Our Mission: To facilitate
improved quality of life for
people with epilepsy.**

KAWE is able to accomplish its mission by engaging key stakeholders both in the public

and private sectors to meet the needs and challenges of PWE by providing information about epilepsy, reducing the treatment gap by training primary health care workers in proper diagnosis, treatment and management of epilepsy, facilitating access to quality healthcare, increasing treatment referral points, training community health workers, providing psychosocial support and opportunities. KAWE seeks to act as a voice for People with Epilepsy (PWE).

Our Approach

At KAWE we believe that people with Epilepsy have a right to quality care, inclusion and equal opportunities. We strive to replace fear and ignorance about epilepsy with understanding and care. We do this by providing information and advice about epilepsy through trainings and awareness, facilitating access to quality health care through a community-based model that is sustainable and affordable.

We conduct awareness and trainings at the community level targeting various groups such as the Community Health Workers (CHWs), schools, churches and conduct Continuous Medical Education sessions (CME) for primary healthcare workers at the county levels (PHCWs).

KAWE also engages use of mass and social media and technology to demystify the condition. Epilepsy is viewed as a curse and with the community and families shunning PWE, we provide psychosocial support through support groups. These provide safe spaces to address diversified patient's needs e.g., provision of food and hygiene equipment to vulnerable patients was distributed during the COVID-19 pandemic, digital trainings, and other opportunities.

KAWE is guided by the following ideals that shape how we create value and relate with other stakeholders, Compassion, commitment, teamwork, integrity and intelligence.

What we did in 2020

The highlights for the year's activities have been the implementation of livelihoods projects for our beneficiaries, awareness creation and trainings of primary healthcare workers in partnership with the Kenyan Ministry of Health (MOH), issuance of NCPWD cards and getting approval from the Nairobi Metropolitan Services (NMS) for placement of a refurbished container at Huruma Lions Health Centre.



Despite the pandemic and healthcare workers strike, KAWE was able to undertake trainings and awareness to over 246 primary healthcare workers across three counties of Nairobi, Kiambu and Kajiado, a feat not achieved recently. We were able to reach over 3 million people from our mainstream media interviews and social media. A special attention was given to November epilepsy awareness month and the global week for actions on NCDs: Epilepsy focus.

KAWE recorded 341 new patients in addition to about 16,000 registered patients in its 3 epi-care clinics at Riruta, Huruma Lions and Karen Health Centers. We were also able to upload 10,571 patients' files into the EMR out of an estimate of 16,000 patients.

Three caregivers' support group meetings were held; two of them were physical while one was online. A total of fifty people were reached.

KAWE conducted medical trainings on epilepsy to persons in the medical field (CMEs) and sensitization to Community Health Workers (CHWs) in Nairobi County-138, Kiambu county-58 and Kajiado county-50.

KAWE was also able to sign a Memorandum of Understanding with the Non-Communicable Disease Alliance of Kenya (NCDAK) for the Fafanuka platform, a USSD messaging platform for creating awareness (*215#)

We supported patients through livelihood activities to enable them to have some source of income. Due to the covid19 pandemic, most of the beneficiaries lost their jobs while others were not able to keep their businesses running. This has had far reaching effects on families' disposable income.

KAWE was able to enroll 22 patients for a week duration digital training with Ajira digital where they were taught how to market their products online and reach a wide range of people. The attendees went on with Google classes on further teaching on the application of the skills learnt for the following week and were later awarded certificates of completion at the end of the training.

KAWE was represented at EPIInA workshop at the KEMRI Kilifi which was about combating stigmatization in Sub-Saharan Africa and the use of technology in diagnosing the condition.

KAWE also had a chance to participate at the National Epilepsy Coordination Committee (NECC) AGM at Malindi.

KAWE issued 108 patients with the cards from the National Council for People with Disability (NCPWD) during the International Epilepsy Day (IED) and they will be able to enjoy the listed benefits.

We partnered with various partners who include Kenya Community Development Foundation (KCDF), Visa Oshwal Community and the Cheshire Disability Society of Kenya (CDSK) for post covid recovery intervention to our patients and provided food and hygiene packages. We reached several (31) households equivalent to 137 individuals.

Our Organizational Challenges

- Closure of the Riruta Health Centre for two weeks in August due to confirmed Covid19 cases.
- Covid19 travel restrictions; patients were not able to visit the clinic on time for appointments and prescription refills.
- Increase in costs of medicines due to increased cost of raw materials and the Kenya Shilling fluctuation against the US Dollar.
- Due to health workers' strike nationally, the normal operations were affected and, in some instances,

increased number of patients to the clinics not initially anticipated.

- Working from home/online had its own challenges since most of the 2020 planned activities had not provided for non-physical meetings.

Our Ambition for 2021-22

- Primary Health Care Workers (PHCW) training at Tharaka Nithi.
- Community Health Care Workers (CHW) sensitization at Tharaka Nithi.
- PHCW training at Kasarani.
- CHW sensitization at Kasarani.
- Media interviews and public awareness on Purple Day.
- PHCW training at Kakamega.
- CHW sensitization at Kakamega.
- PHCW training in Kiambu county.
- CHW sensitization in Kiambu county.
- PHCW training at Embakasi.
- CHW sensitization at Embakasi.
- PHCW training in Kisumu.
- CHW sensitization in Kisumu.
- PHCW training and CHW sensitization at Kibwezi.
- Affiliate clinics meetings.
- Launch the 3rd EpiCare Facility at Huruma Lions Health Centre.
- Register persons to access social protection benefits.
- Fully automate epilepsy services at 3 health facilities.

epilepsy

SOUTH AFRICA



Our Organization

Epilepsy South Africa is the only national organization in the country focusing on the needs, challenges, and aspirations of persons with and affected by epilepsy. The organization was established in 1967 as the South African National Epilepsy League (SANEL) and changed our name to Epilepsy South Africa in 2002.

Our vision:

Epilepsy South Africa Igniting the flame of potential.

Our mission:

Epilepsy South Africa promotes human rights and an inclusive society for persons with disabilities, primarily persons with epilepsy.

Our organization is coordinated by a virtual National Office with services provided by six Branches located in Cape Town, Knysna, East London, Springs, Dullstroom and Parys.

Our services include social development (e.g., counseling and support groups), residential care (six facilities, including independent living), skills development (e.g., training programmes and learnerships) and economic development (e.g., open labor market, protective workshops, and entrepreneurial development). However, our core focus is on awareness, advocacy, and education about epilepsy, including the development of self-representation and self-advocacy.

Our Approach

While Epilepsy South Africa grew from a social work perspective, our focus is on epilepsy and disability as a human rights issue. Our work is based in the philosophy and prescriptions of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) as South Africa was one of the first countries to ratify the Convention in November 2007.

We contributed to the development of the African Disability Protocol and specifically the South African White Paper on the Rights of Persons with Disabilities (WPRPD).

Epilepsy SA believes that the stigmatization of persons with epilepsy can be changed through creating awareness and education about the condition. New

knowledge counteracts community fears, myths and misconceptions and creates understanding, acceptance and (ultimately) inclusion. This approach is reflected in the organizational logo which features the “flame of knowledge”. Our mascot (Flame) supports this approach while our annual Flame of Courage award recognizes the achievements of persons with epilepsy.

What we did in 2020

In addition to the ongoing services provided at Branch level, 2020 brought new and exciting challenges and opportunities – this despite the impact of the Covid-19 pandemic and accompanying lockdown in South Africa.

At national level we focused on (a) improving organizational functioning and service delivery; (b) national/international coordination, liaison, and representation; (c) marketing and public relations; (d) implementation of WHA Resolution 68.20; and (e) coordinating national information services and education/awareness programmes.

As one of our focal areas related to much-needed research we conducted a survey on the social, health and economic challenges of persons with epilepsy. This research would form the basis of



the anticipated National Epilepsy Plan in support of the WHA Resolutions.

We also established a partnership with the University of Venda and the GladAfrica Foundation for a four-year research project on the effects of epilepsy with a view to developing an awareness programme, cultural congruent intervention programme and epilepsy life skills manual for primary and secondary school in Limpopo and Mpumalanga. We also entered into an agreement with research partners in Canada, Haiti, and Vietnam for a seven-year project on Engendering Disability-Inclusive Development (EDID) focused on women and girls with disabilities.

In support of the development of an Independent Monitoring Mechanism (IMM) required in terms of the UN CRPD we participated in a study tour to Ireland, Spain, Belgium, and the European Union in partnership with the South African Human Rights Commission (SAHRC).

Our media campaigns (including social media) were highly active, resulting in media coverage to the value of USD396,367.

Epinews is our biannual newsletter compiled by people with epilepsy for people with epilepsy and offers a platform to share experiences and stories of inspiration. We

are pleased that our Editorial Panel now comprises five people which will enable a regular health column.

A key highlight of the year was our WHA Project which formed part of the IBE Africa Utetezi initiative. Our Project is managed by a person with epilepsy (Gresham Africa) and aims to (i) establish a National Epilepsy Task Force responsible for (ii) the development of a National Epilepsy Plan. Other objectives include (iii) education and awareness about epilepsy and (iv) maintaining the WHA Resolutions on the international agenda.

The Epilepsy SA Educational Trust provides bursaries to students with epilepsy for tertiary education. In the 2020 academic year we supported eight students with bursaries to the value of USD10,250

Our Organizational Challenges

- Financial sustainability given fundraising constraints and re-allocation of funding to the pandemic.
- Closing the treatment gap (particularly medication shortages and access to neurological services)
- Addressing the lack of knowledge and understanding about epilepsy from healthcare

workers (particularly in the public healthcare sector) impacting on the way persons with epilepsy are treated.

- Succession planning (especially at senior management level).

Our Ambition for 2021-22

2020 marked the beginning of a new three-year strategic plan focused on seven goals: -

1. Representing the voice of persons with and affected by epilepsy through growing organizational membership.
2. Increasing knowledge about epilepsy through organizational capacity development.
3. Promoting independent living as a realistic and feasible choice for persons with epilepsy.
4. Ensuring implementation of WHA Resolutions 68.20 and 73.10 in South Africa, including ratification by our Parliament.
5. Ensuring adequate organizational funding through diversified and innovative income streams.
6. Ensuring appropriate succession planning.
7. Formalizing employee wellness.





NATIONAL EPILEPSY ASSOCIATION MALAWI

Our Organization

The National Epilepsy Association of Malawi (NEAM) is a non-governmental organization registered with the Council of Non-Governmental Organization in Malawi (CONGOMA) and affiliated to the Federation of Disability Association of Malawi (FEDOMA). NEAM was founded in 2006 with the primary objective of putting epilepsy on the national agenda.

OUR VISION

“Putting Epilepsy on the Agenda”

OUR MISSION

To promote the rights of persons with epilepsy in Malawi and to work for equality of rights and opportunities for persons living with epilepsy.

OBJECTIVES

- To promote and coordinate development efforts and self-help projects among persons with epilepsy.
- To facilitate the full participation of people living with epilepsy in the design, formulation,

implementation and evaluation of policies, programs, and services for their needs and to monitor, evaluate and review such services.

- To facilitate the exchange of information in the field of epilepsy health, through research, civic education programs and seminars.
- To affiliate and cooperate with other regional, national, and international organizations that work in epilepsy care, support and advocacy.

Our Approach

National epilepsy uses user friendly technology to collect and gather information concerning people with epilepsy. Volunteers were recruited and trained to use phones to gather information which is sent to the central district data base to make a collective summary and identify the challenges facing people with epilepsy and lobby for solutions as a nation using the right channels.

The information also helps the association to identify the areas that need more attention and intervention. The volunteers use

support groups to answer the questions hence a collective answer is given on each question. This allows for a collective opinion to be reached.

What we did in 2020

- Baseline survey on the total number of people with epilepsy and the challenges they face in the project district. This was done to have a comparison at the end of the project to measure the outcomes of our intervention to map the way forward about assisting people living with epilepsy.
- Piloting the project. The Geopoll people piloted the project technology tool by putting the necessary questions in phones which were to be given to the volunteers after training.
- Recruitment of volunteers. The project was to be carried out in 12 health centers in the project district hence 6 volunteers were selected based on their proximity to the health center. The medical staff responsible for attending to epilepsy patients, were



involved in the identification of these volunteers. These volunteers were deliberately selected to make the task of data collection and support groups creation easy because of the fact they could access medical assistance from the health center closer to them.

- Kick off meeting. After recruitment of the volunteers, they had to undergo training on how to use the technology provided, hence they were given a line and a phone that had the questions that they were to be answering every month of the project time. They were to report on the challenges that people living with epilepsy face in their community. The feedback would guide us as an association and a country on how we could solve the challenges identified.
- Capacity building. This was done with the aim of training people with epilepsy (project volunteers) on how to form support groups and the importance of such groups. The participants were trained in the following area, (a) identifying epilepsy, (b) referrals, (c) the importance of support groups, (d) the importance of medication adherence and (e)

the importance of community inclusion.

- Monitoring and data collection. The activity is done every month to see how the monitors are doing their work and to see the impact of the project on the community. The district monitoring is done through meetings at the health centers or through phones calls for easy communication since health center visit dates are different.
- Training of community and health personnel. The strategy was to ensure that the community health workers (CHW) would eventually work with the project volunteers in the community. The participants were oriented on the following: project objectives, epilepsy in Malawi, training on the formation of support groups, working with volunteers and referrals.
- Formation of support groups in order to make a significant impact on this technology-based project. The volunteers created support groups in the two healthy centers where they are working

and meet the respective group members two or three times a month so that they can encourage each other in taking medication and discuss the benefits thereof and solve some of the problems that they face as a group. The groups are also created to help in discussing and answering the survey questions. The groups' formation is a continuous process because the people meet at different times in some health centers.

- National epilepsy plan meeting. This was attended by different stakeholders that work in the mental and neurological diseases sector. The agenda of the meeting was as follows:
 - (a) to discuss on the development of the National Epilepsy Plan, (b) to discuss the road map on developing the National Plan and to develop terms of reference for a national task force. According to what was discussed at the meeting the road map was to develop by the task force of 13 people that was selected comprising of different stakeholders.





NATIONAL EPILEPSY

National Epilepsy Association of Malawi was to develop the terms of reference for the task force. The action plan was to take three to six months in developing and some of the thrust areas to be added in the plan include awareness, availability of medication, training of health personnel and funding to the Ministry of Health.

- Supporting upcoming Epilepsy organization such as Epilepsy Movers.
- Networking with other health advocacy groups.
- Lack of transport has affected the organization's officers to reach all the project areas.

Our Ambition for 2021-22

- Formation of district epilepsy fora
- Advocacy and awareness raising meetings.
- Monitoring.
- National epilepsy task force meeting.
- 50 million steps challenge.
- International Epilepsy Day.
- Formation of support groups.
- Data collection.
- Policy dialogue (National Plan) and dissemination of current SA report and publication.
- Monitoring and evaluation.
- Establishment of an Epilepsy Academy training.
- Establishment of an economic empowerment program for persons with epilepsy.
- Holding a national conference on epilepsy.

Our Organizational Challenges

- The volunteers were not conversant with the idea of virtual training; as such it proved difficult to train them remotely.
- Covid 19 which has restricted the movement and in person meetings.
- The suspension of mobile clinic services has delayed data collection processes.



PURPLE BENCH INITIATIVE

Our Organization

Purple Bench Initiative was incorporated in 2018. Our main work is centered on awareness creation to reduce stigma and discrimination and support the sustainability of caregivers. Our vision is: "A society where people living with epilepsy live a dignified, meaningful and highly impactful life". We take the rights-based approach to advocate for people with epilepsy and provide psychosocial support to individuals with epilepsy. We are physically located in Masaka city in Masaka Sub - region and Kampala city in Central region. We have virtual presence on social media where individuals and organization with epilepsy concerns reach us; on social media we interact with public within Uganda and beyond.

Our Approach

Our approach is firstly demystifying epilepsy since there is a lack of awareness through the various levels of our population. We test the levels of the audience's knowledge and give facts about epilepsy; the causes; the triggers; and how to handle a seizure attack.

Before getting into communities, we first address ourselves to the local leadership of an area. Here we have District Chairperson, Department Heads, and village Councils in their hierarchy. This approach gives us a secure entry into communities whereby we avoid our intentions in the communities to be misunderstood.

Outreach audiences comprise schools, Tertiary Institutions, other NGOs, corporate entities and general public in community spaces. We also reach out to specific audiences like women groups and caregivers.

What we did in 2020

1. This was a challenging year for us due to COVID 19. However, despite the odds - we completed "The Promising Strategies" project which fed into our Smart Communities project. Band Foundation funded this. (Sensitization of local District leadership and youth awareness) B – The "Susan" project for a vulnerable family under which we constructed a 30,000 underground water tank, a protected cooking stove, kitchen gardens and dwelling improvement. (Many village

of Kyanamukaaka Sub-county, Masaka District) C – Carried out a food distribution exercise to support people with epilepsy in the outskirts of Kampala and Masaka Districts. (We served 85 families). D. Trained 16 community VHT volunteers, E – carried out five Community Children's awareness sessions

Our Organizational Challenges

- Outstanding rent for our office space.
- Payment of utilities.
- Facilitation of staff to enable them to perform efficiently. Currently all staff are on voluntary basis which makes it optional for them to participate in our activities since they need to sustain their families.
- Establishing an acceptable new normal to reach our clients.
- Transport and communication – Our vehicle bought eight years ago has become a liability.
- Computers and stationery.



PURPLE BENCH INITIATIVE

Our Ambition for 2021-22

- Establish the entire Greater Masaka area as an “Epilepsy Smart” region.
- Plans for 2021 – Participation in International Epilepsy Day activities.
- 50 Million Steps challenge – working with 120 active participants.
- Participate in “Lets Shine a light on Epilepsy” challenge – On 8th February lighting the Jinja Nile Bridge; Protea Hotel Kampala Skyz on Naguru Hill in Kampala and Pearl of Africa Hotel on Nakasero Hill.
- Participate in marking PURPLE Day.
- Engage PLWE in advocacy projects to better their lives.
- Increasing on our partnership base (to at least 60).
- Resume the school program to reach 200 schools.
- Finalize training guidelines.
- Train in 60 corporate entities in epilepsy awareness and seizure management.
- Increase on awareness area of coverage and outreach to entire MasakaK Sub region.
- Implement 30 caregiver projects.
- Participate in International Epilepsy Day celebrations 2021/2022.





Kingdom of Eswatini

Our Organization

The Eswatini Epilepsy Organization [EEO], formed in 2004 and legally incorporated in 2010 (Eswatini Companies Act). A registered Non-Governmental Organization recognized by the Ministry of Health with a sole mandate of addressing epilepsy challenges.

Our main achievement is from 0 to about 25 000 persons living with epilepsy enroll in epilepsy treatment.

One of the fundamental reasons for forming the Organisation was to ensure that the rights and social protection issues of people living with Epilepsy are properly addressed.

In order to ensure that people with epilepsy are given an opportunity to improve well-being and status as citizens of Eswatini, EEO embarks on various health and poverty alleviation initiatives that are enshrined in the organization's Strategic Framework (SF) 2021 – 2023. The SF is an extended strategic plan emanating

from the 1014-2018 Strategic Plan; which is a practical action-oriented guide, based on an examination of internal and external factors, aiming to direct goal-setting and resource allocation for achievement meaningful results.

Our Approach

Our organization operates around its 7 Key Strategic Focus Areas (KSFA)

1. Advocacy & Awareness - To increase epilepsy awareness among influential groups and the public while influencing an improved policy environment.
2. Resource Mobilization - To build a sustainable base of resources for epilepsy programmes and projects, ensuring availability of adequate resources to execute planned activities
3. Impact Mitigation – To minimize and remedy the adverse impacts of epilepsy among PLWED and those with epilepsy ties, ensuring that the residual effects are within acceptable standards.
4. Capacity Building – to build capacity within the organization and among other actors at household, community, up to national level
5. Capital Projects – to make available requisite physical infrastructure including equipment that are necessary for execution of epilepsy programmes and activities

6. Research – to ensure evidence based planning through continuous examination and study of epilepsy trends and situations
7. Monitoring & Evaluation - ensure continuous and systematic assessment of project implementation based on targets set and activities planned, in order to promote efficiency in use of inputs, infrastructure, and services.

What we did in 2020

2020 was a very challenging year for our organization just like many other organizations. At the beginning of 2020 we managed to:

1. Hosting the Yellow Epilepsy Week – We usually host a week long events and in 2020 we hosted the International Epilepsy Day which was graced by various members to society including Ministry of Health Representative, WHO Representative, Ministry of Education representative and may others. We also hosted the Yellow Epilepsy Valentines Fundraising Dinner, where we mobilize resources while raising awareness about epilepsy. Sadly, due to the coronavirus we had to cancel the Yellow Epilepsy Charity Half-Marathon. We were also not able to host the Yellow Golf Tournament.





2. The organization through its Patron, His Royal Highness Prince Bandzile facilitated a donation of the EEG Machine to the Ministry of Health.
3. Due to the effects of the Coronavirus (COVID-19) we had to scale up our impact mitigation efforts as we made a number of donations to close to a 100 people in the Ndangu Community, which did not benefit those living with epilepsy alone but also the elderly and needy. We assisted a number of clients to access anti-epileptic medications as the country was slowly running out.
4. Our organization was invited to sit on a number of meetings aimed at addressing human rights issues especially during the pandemic. This was very beneficial as we managed to establish working relations with many other organizations in the Social Protection Cluster formed by government, Civil Society Organizations and the private sector.
5. Since we could not do community outreach, we have taken advantage to the good working relationship we have with the various media houses in the country to raise awareness about epilepsy and communicate with persons living with epilepsy. A

video was produced which spoke specifically to persons living with epilepsy and precautions they should take. Radio jingles were produced sung traditionally with epilepsy messages and aired on the national radio. We published weekly articles targeting the different sectors in the country in one of the widely read newspapers of the country i.e. The Eswatini Observer Sunday.

6. We also had the opportunity to work on our Strategic Framework which now has seven Key Strategic Areas of Focus, having added two to the previous five. The new ones are Research and M&E.
7. We conducted an Epilepsy Situational Analysis in the country, which will be a great tool for us and others to address the gaps in epilepsy management.

Our Organizational Challenges

For us the CORONAVIRUS (COVID-19) really crippled us as about 70% of our plans/programs had to be halted.

- One of the main challenge we are faced with is we cannot host meetings yet most of our work requires us to meet people in groups and face to face. The country since early June 2020 has experienced a number of lockdowns and travel curfews.
- Our country donors and partners have expressed that they have also suffered

from the pandemic. We could not host any of our resource mobilization activities. This stance resulted in a remarkable decrease in our financial resources leading to low input and output performance.

Our Ambition for 2021-22

2021-22 is supposed to be a big year for epilepsy, we still have to assess COVID-19 situation and we have explored other ways to operate under the given condition. We plan to:

- Finish the Epilepsy National Plan of Action
- Engage government and relevant stakeholders in the Epilepsy Country Situational Analysis.
- Raise more awareness about epilepsy and promote the World Health Assembly Resolution 68:20 & 73:11.
- Begin and complete the first phase of construction of the Epilepsy Center at Sikhuphe. A center which will be for people living with epilepsy.
- Continue to provide relief assistance to our clients.

On the 5th of June Bongikhosi Malindzisa, 29 year old, was presented with a proper house, as seen on the picture, by the SOS Children's Village in conjunction with the Eswatini Epilepsy Organization.





ASSOCIAÇÃO MOÇAMBICANA DE APOIO A PESSOAS COM EPILEPSIA

Rua de Malhangalene, Nr. 1175, FAMOD- Maputo, Moçambique

Our Organization:-

Mozambique Support Association of/for People with Epilepsy (AMAPE) is a nationwide association that works in the social and health realm, whose aim is to advocate for improving the quality of life of people living with epilepsy in Mozambique. Its mission is to educate the society about epilepsy, protect people living with epilepsy and empower them to overcome the adversities imposed by stigma and discrimination. Currently our officially registered membership is of 40 people, and 150 people with epilepsy in Nampula province waiting to be confirmed as our Association members to effectively join the Organization.

Our Approach:-

AMAPE is an Organization that privileges a holistic approach to support people with epilepsy reinforcing social and medical intervention, by educating the society about epilepsy to reduce

stigma and discrimination against people living with epilepsy and accede to treatment. We do this through:-

1. Awareness and community education on epilepsy.
2. Advocacy to improve legislation on epilepsy, including medical treatment and assistance for people living with epilepsy.
3. Institutional development and partnership with different stakeholders such as Ministry of Health, Community based organizations (CBOs) including traditional healers, churches and community leaders.

What we did in 2020:-

- Organized and celebrated the first (1st) International Epilepsy Day as an Association which brought together people with epilepsy, their care takers, mental health workers, neurologists, and

representatives from the Ministry of health as the mother ministry including Mr Paul Saveca, a respected figure (MD) from the Ministry of Health of Mozambique.

- From the above activity AMAPE managed to convince some important people to join us and together fight against Epilepsy in Mozambique, especially doctors and nurses from the Mozambique health system.
- We got a partnership paper from the Ministry of Health that allows AMAPE to present itself as a serious, trustworthy, and unique Organization that pursues relevant objectives to support people living with epilepsy in Mozambique.
- Approached World Health Organization in Mozambique to seek a possible partnership. A preliminary meeting was set forth. Unfortunately, the same week that the meeting was scheduled the Covid-19 pandemic broke out and the meeting was cancelled. A new meeting is still to be arranged in 2021.



- Also, we approached the French Embassy to seek for a partnership. The Embassy was open enough and in 2021 AMAPE will submit a proposal for sponsorship.
- Together with other professionals including people living with epilepsy in the region we created and founded the Epilepsy AFRICA Alliance.
- After nearly 5 years trying to be part of IBE, finally we got a positive answer from IBE in mid, 2020.

Our Organizational Challenges:-

- Low capacity of members in Advocacy skills to fully advocate for the rights and better-quality life of people living with epilepsy in Mozambique.
- Limited skills of the members including leadership in fundraising issues.
- The unavailability of affordable medication in the health system in Mozambique.
- Lack of health professionals in clinics and hospitals in most parts of the country, which is an issue of great concern.

- The COVID-19 pandemic has greatly affected our members and people living with epilepsy and some have passed on.
- The fact that most AMAPE leadership members only speak Portuguese, limits our Association to fully and actively participate in many meetings including webinars arranged by IBE and EAA. This constitutes a major barrier to engage our members in other international fora.

Our Ambition for 2021-22:-

For 2021, as we move forward, we intend to enhance partnerships that will need to be forged for the greater good of our people living with epilepsy in Mozambique. Epilepsy regional bodies in Africa such as IBE and EAA will play a significant role in advancing and forging support to mitigating the challenges faced by people living with epilepsy particularly in Mozambique and in Africa in general. Thus, we intend to:

- Approach the World Health Organization in Mozambique for support on the production of awareness raising material on Epilepsy issues and foster our first meeting in 2021, as well

as a request for support to mitigation measures and reducing the treatment gaps.

- Submit a proposal for support and first sponsorship to the French Embassy and seek strong partnership on Epilepsy matters for Mozambique.
- Seek funding opportunities for AMAPE activities and raise funds.
- Approach the Ministry of Health in Mozambique to strengthen our partnership.
- Seek partnership with media (TV stations and radio) for awareness raising on epilepsy in Mozambique to fight against stigma and discrimination.
- Increase membership for our Association and expand AMAPE activities to other provinces.



Our Organization

Community Development and Epilepsy Foundation - CODEF Cameroon is a legally registered organization or Association Numbers: 001/E.29/1111/Vol.8/ APPB and 0124/L/MINAS/DRAS/ NW/CB/BDA.

Our mission is to improve the health, human rights, and socio-cultural and economic status of PWE in Cameroon. CODEF is governed by a board made up of 10 members.

Some of our major activities include lobbying/advocacy, epilepsy, health education, awareness raising, disabilities, income generation activities (IGA).

For details about our work browse www.codefcameroon.wordpress.com

Our Approach

CODEF uses the following as ways of dealing with epilepsy in Cameroon: Awareness raising, health education, lobbying and advocacy, income generation, psychosocial support, and research on ways of epilepsy prevention.

What we did in 2020

CODEF carried out sensitization and awareness raising on epilepsy in Foubot Subdivision, Noun Division in the Western region of Cameroon. Home visits were carried out in Bamemnda II Subdivision for families of persons with epilepsy internally displaced from Batibo health district to safe sites due to the North West/South West crisis in Cameroon.

We also carried out the International Epilepsy Day (IED) in the Elite Standard Bilingual Nursery and Primary school Foubot and the Cameroon Baptist Convention Bilingual Nursery and Primary School Foubot. The school children/pupils and teachers at such schools were sensitized on epilepsy and awareness raised on the signs and first aid measures.

Our Organizational Challenges: -

- Lack of funds to intensify field activities.
- Capacity building needed for staff and volunteers.
- Lack of office stationery.
- No salaried staff is present in CODEF.

Our Ambition for 2021-22:-

- Lobbying and advocating for the implementation of the WHA resolutions 68.20 and 73.11 on epilepsy at local country level on epilepsy and global level respectively at the National health level.
- Advocating for these resolutions at the regional levels.
- Increasing epilepsy awareness both regionally and with communities especially with great focus at earmarked institutions where stigmatization and discrimination are prominent.

Epilepsy Association of Nigeria

Our Organisation:

The Epilepsy Association of Nigeria is a non-profit and a non-governmental organization which was founded in 2002.

The organization collaborates with International Bureau for Epilepsy to fight against epilepsy, learn about epilepsy, increase awareness and understanding about epilepsy.

We are dedicated to render specialised and comprehensive services to people living with epilepsy and other disabilities, including education and economic empowerment through job creation and entrepreneurship- and skills training suited to almost any level of development. We are dedicated to enhancing the quality of life of people living with and affected by epilepsy as well as other disabilities.

Our Organizational Challenges:

- Availability of funds to implement activities
- Sustainability and nationwide rollout of epilepsy programs.
- Gaining government advocacy
- Lack of basic infrastructure for adequate management.
- High levels of stigma and low community awareness of epilepsy.
- Highest incidence and prevalence of active epilepsy compared to that of all other countries.

Our Ambition for 2021-22

- Promote research into the causes of and treatments for epilepsy.
- Collect and process statistical data and information on a national and regional basis.
- Promote and encourage the setting up of Centres for the diagnosis and treatment of patients with epilepsy.
- Establish and maintain relations with the IBE and with national Associations and Entities dealing with the treatment and assistance of people with epilepsy.
- Collect contributions and donations and organise fundraising for the purpose of achieving the statutory objectives.
- Promote and encourage research concerning epilepsy.





Introduction

Epilepsy Support Foundation plays a vital role to support people with epilepsy to live a productive life. The Foundation works to raise awareness of epilepsy and to ensure clients are treated fairly and with respect. Covid -19 has had some effects on 2020 programming, however we managed to adopt and adapt to the new norm and continued with programming. The first lockdown did have some effect in the way the foundation provides its services. Staff during lockdown rapidly took to providing services via phone and email. Membership has increased to 2,163. While we absolutely value our members, our priority is supporting our entire epilepsy community. The Epilepsy Support Foundation is also a member of Epilepsy Africa Alliance.

What we did:

1. **Clinic** - continued providing care and support through person centered approach to the provision of some of

the clinical, intellectual and emotional needs of a person affected by epilepsy to improve their quality of life.

2. **Medication** – with continued support from the National Foods, the organization received carbamazepine, phenobarbitone and sodium valproate. Beginning of 2020 there was an increase in number of clients coming to get medication from Harare Hospital Children's rehabilitation unit. This was attributed to the unavailability of epilepsy medication from government hospitals, the increases in the prices of medication and pharmacies' charging in United States Dollars. This is beyond reach for many clients which has led clients to defaulting if they do not get medication at the Foundation. Clients were also referred to Rokpa Foundation to get financial assistance for required prescribed medicines. Rokpa Foundation

is a humanitarian organisation serving those in need in the fields of education, medication, medical care, poverty relief, self-help and ecology. Members received vouchers worth US\$15 which they redeemed at Greenwood pharmacies. The Foundation also dispensed medication four times this year to Tose Respite Care home. This is a welfare organisation that caters for people with multiple disabilities. Medication was also dispensed to Gutu support Group, Rusape and Zvimba support Group through local persons.

3. Collaboration with Jairos Jiri

The Foundation collaborated with Jairos Jiri Association Zimbabwe, developed IEC materials on COVIDS 19, conducted radio interviews with National FM & Classic 263, and a documentary on the effects of COVID 19 on people with disabilities.

4. Information giving and counselling:

The department continued with information giving and education to new and old clients.



5. Home visits

The foundation visited two clients in January and March. One client had reported that her house had been gutted by fire and needed urgent assistance, when the situation was not as described. The second client had defaulted medication. Both clients were assisted with medication. In June, the Advocacy Officer together with Dr Chidovi a member of the Zimbabwe League Against Epilepsy visited actor Marabha who was experiencing seizures, after making an appeal on ZTV. The Foundation dispensed medication and also distributed donated groceries sourced by Dr Chidovi to the actor.

6. EEG Training

The president of Global Organisation of Health Education was due to come to Zimbabwe in May to train two staff members to carryout EEG. The visit was postponed to a time when it's safe to travel due to the Covid-19 pandemic. The President of GOHE has committed to training the staff members online.

7. Advocacy Department

Advocacy has been active in ensuring that the voice of epilepsy is now being heard from hidden disability. We have been able to amplify concerns raised by our members and ensure that action by public authorities was followed.

8. International Epilepsy Day

A belated International Epilepsy Day was commemorated on the 27th of February 2020. This is a powerful opportunity to highlight the problems faced by people with epilepsy. The event was graced by Ministry of Health and Child Care Department of Mental Health, Epidemiology, Safe Guard and Tszun Chi Foundation. Safe Guard donated two computers to be used for data capturing at the Foundation and Tszun Chi Foundation distributed over 500 bags of rice to members. Clothes donations from DSV were also distributed to members.

9. Advocacy tool kit development

The Foundation also participated on a survey for the

development of an advocacy toolkit by International Bureau for Epilepsy. The aim of the toolkit is to assist chapters in advocacy and lobbying work.

10. Capacity Building of bookkeeper

The bookkeeper attended a capacity workshop hosted by FODPZ. The aim of the workshop was to equip organisations with skills to effectively and efficiently advance the organisations mission. Having proper accounting system in places is very important.

11. National Epilepsy Awareness Week

This year we hosted a virtual National Epilepsy Awareness Week with presenters from around the world presenting on various topics.

12. International Disability Day

The organisation participated in International Disability Day on the 3rd of December

2020 hosted by the Ministry of Labour and Social Welfare under the theme 'Building back better: towards an inclusive, accessible and sustainable post COVID-19 world by, for and persons with disabilities'. The event was commemorated at Ruwa Rehabilitation Centre with Provincial Minister of Mashonaland East as the Guest of Honour. Members from the Foundation were also invited and received hygiene buckets.

- The COVID-19 pandemic increased challenges faced by people with epilepsy in 2020. The challenges included loss of employment as most people with epilepsy work in the informal sector due to lockdown, access to basic needs, medication and medical checkups, clearance letters to travel to seek medical attention. This led to clients defaulting medication as they faced travel restrictions to come and get medication.

Challenges:

- Doctors Reviews
Appeals were made to recruit a volunteer doctor. However we did not manage to get a volunteer doctor. A volunteer doctor is needed at the Foundation to make provisional diagnosis in new patients, providing appropriate initial information and regular structured reviews. The primary care needs of people with epilepsy include a structured regular review, as is common with other chronic conditions. Clients were referred to Sally Mugabe and Parirenyatwa Hospitals for further management.

Ambitions for 2021-22

- The Foundation is in the process of recruiting volunteers to revive programs in the two provinces.
- The Foundation is in the process of recruiting a nurse, following the retirement of Nursing Officer Sister Makoni in December, 2020.
- The Foundation is to work with FODPZ in reviewing the training manual for health workers.



EPILEPSY SUPPORT ASSOCIATION UGANDA (ESAU)

1.0 INTRODUCTION

Epilepsy Support Association Uganda (ESAU) is an indigenous NGO that brings together people with epilepsy, their families to work towards eliminating the social stigma attached to epilepsy, create an environment where epilepsy is better understood among communities in Uganda and the diaspora; so, people with epilepsy can reach their full potential and enjoy equal rights. The association exists to empower people with epilepsy use the challenge of epilepsy as an opportunity, come out of the shadows, and contribute to development processes in their respective communities while also supporting them to lobby development partners and their local and central governments improve service delivery to persons with epilepsy.

The association is democratically governed by the members who elect a local executive committee at sub-county and district levels.

Each district branch sends two delegates to a national assembly that elects a national board. At the helm of the association is the board which is the policy making organ of the association.

BACKGROUND TO THE ANNUAL REPORT

2020 started well but saw most countries in the world suffer one of the most deadliest pandemics - The COVID- 19 pandemic. Nevertheless the association kept afloat and ESAU ran a number of projects with support of numerous donors. These funders included Danish Epilepsy Association (DEA) through Disabled People's Organization of Denmark, The Disability Rights Fund, The Aga khan Foundation, Light for the World, Uganda National Action on Physical Disability (UNAPID), Light for the World and The International Bureau for Epilepsy

2.0 ESAU ACTIVITIES CARRIED OUT IN 2020

ESAU activities were carried out under the following themes of: -

2.1 AWARENESS RAISING

2.1.1 Demystifying epilepsy

- A. Supporting awareness raising in schools through E-Clubs establishment
- B. Production and distribution of information and educational materials
- C. Media conferences
- D. Participation in international and national events
- E. Partnership meetings
- F. Website and social media updates
- G. The Ushahidi Platform to regularly communicate with ESAU membership
- H. Radio talk shows and Spot messages

2.2 Advocacy and lobbying

ESAU was awarded a grant from the disability rights fund in 2019 for a period of one year. The overall objective of this grant was to support the advocacy and lobbying function to improve health service delivery at local government level in 2 districts of Gomba and Jinja. Intermediate objectives of the grant included:

- ❖ To mobilize People with epilepsy into psycho-socio support groups to better advocate for themselves.
- ❖ To empower PWEs & their leaders to advocate for themselves.
- ❖ To lobby duty bearers and decision makers better understand PWEs so they include them in programming & budgeting processes at district level.

3.0 CAPACITY BUILDING

With support from the Disabled People's Organization of Demark, ESAU focused on sustainability theme whose main objective was to ensure that the capacities of key members in the organization was built in a sustainable way. This function was supported by Disability Rights Fund, Uganda National Action for physical

disability among other players. Activities carried out under this thematic area included:

- a) Staff training & BOD training in fundraising & website upload and design
- b) Training regional TOTs
- c) Training of health workers
- d) 4 Regional meetings held for women

2.4 Monitoring and support Supervision

National BOD meetings -ESAU has held 2 board meetings during the implementing period. The BOD met to approve work plans and discuss programs to be implemented for the association. Monitoring Visits to West Nile: These have been held with support from the Aga Khan foundation.

Support Supervision: 2 support supervision visits were held by the in charges of the mental health units form Adjumani and Moyo hospitals. Mentoring and coaching and support supervision provided to clinical officers at the not-for-profit Health centers.

2.5 Networking

Membership to International, National bodies and Corporate.

Partnership meetings: This year ESAU staff have attended 24 partnership meetings hosted by different partners in health, education, disability among others and showcased epilepsy, sensitized partners about epilepsy, supported partners in development of their strategic plans, and development of position paper, among others.

International Celebrations: The association participated in the international Disability Day celebrations. This year's International Disability Day celebrations started with a disability symposium that took place on 2.12.2020 at Imperial Royale Hotel.

International Patients Alliance Day: ESAU sensitized communities in Uganda about epilepsy, management of epilepsy, gaps in care realized during the COVID -19 lockdown and strategies to combat these gaps on 2 national and 5 local radios. The association reached approximately 4million Ugandans with this information. 33 calls to the association secretariat were made to the secretariat after the media campaigns ran for 2 weeks.



Partnership with Network of Public Interest Lawyers (NEPTIL): In partnership

with NEPTIL and Mental Health Uganda, ESAU was privileged to have a legal officer placed in their organization for a period of 6 months.

Pig rearing project in Gomba district

ESAU was awarded a 2 time grant from Uganda National Action on Physical Disability. The grant was to the tune of UGX 7,000,000. Main objective of the grant was to skill PWEs in Piggery rearing; provide them with pigs to supplement their income. The second grant was to support the function of learning and documentation of best practices from various project implemented by partners.

Outputs:

- ❖ 20 PWEs skilled in piggery rearing in Gomba district.
- ❖ 20 PWEs access pigs for a revolving piggery project.
- ❖ Improved collaboration between ESAU members and district community services & Veterinary department staff.

- ❖ Improved welfare and dignity of PWEs in Gomba District.

Making epilepsy a priority among grassroots communities in Uganda.

ESAU received a one year grant from the International Bureau for Epilepsy to the tune of UGX 36,500,000. The main objective of this grant was to engage with local government in two districts to ensure adequate and regular medication access for PWEs.

COVID-19 Response grant - LFW

The association was awarded a COVID-19 response grant for people with epilepsy in Jinja in the four sub counties of Butagaya, Bugembe, Buwenge and Mafubira by Light for the World. The grant award was UGX 9,996,400.

Beneficiaries of cashouts in Buwenge & Mafubira

Outcomes

- 100 PWEs accessed cash out support from light for the world.
- 15 women and girls with epilepsy supported in soap making and start up soap making components. The women and girls were able

to make up to 100 litres of soap and sell to support their families.

4.0 ACHIEVEMENTS

- ESAU managed to develop 8 National Project proposals and submitted all of them. Three were granted, three still waiting for response while two were not funded.
- Successfully conducted a National Advocacy Epilepsy Conference that brought to light the plight of PWE.
- Developed a 5 year strategic plan.
- Increased membership to the association. More people have joined the association as a result of increased awareness raising compared to last year (2011).
- 28 Counseling and guidance services were provided as a result, parents and clients were happy due to reduced negative attitudes in their communities.
- 6 district branches were supported by the secretariat to develop and submit applications for their respective branches for funding.



- ESAU continued supporting 8 faith based health centers to run community drug banks and this enabled PWE to access regular and cheap epilepsy medications.

5.0 CHALLENGES

- Limited and untimely disbursement of medicine (AEDs) at health centers as well as long distances travelled by some of the Persons with epilepsy, still poses a challenge to the association especially as the numbers are increasing.
- ESAU still has to mobilize funds to fully implement her activities throughout her districts of operation. With the creation of new districts, there have been more branches formed. However, some of these branches are not facilitated and there are no sufficient funds to cover such areas.

Start a cultivation drive for supporters of ESAU.

- Engage new donors and write more grant proposals to international and bi-lateral donors.
- ESAU plans to continue mobilising persons with epilepsy and sensitising communities so as to increase membership to the association.
- Continued awareness raising, among district officials in the districts of operation, civil society leaders on issues concerning epilepsy.
- Continued advocacy and lobbying at national, district and sub county level.
- Improving fundraising strategies and thereby make Esau's activities more sustainable; proposals for funding as one of the alternative funding resources as well as from membership.

6.0 FUTURE PLANS FOR THE ASSOCIATION

- fundraising plans in place for this year's fundraising efforts and

COMMITTEE MEMBERS



**Vice-President,
IBE Africa**

**Action Amos,
Malawi**

Mr. Amos Action, a person with epilepsy, is the Vice President of the International Bureau of Epilepsy Africa Region. He possesses an MSc in Leadership and Sustainability, a Postgraduate Diploma in Disability Management and Rehabilitation and a BA in Development Studies. He is also a Director for the African Disability Alliance. Amos volunteers as a Technical Advisor for the National Epilepsy Association of Malawi. He is also a Researcher attached to the University of Edinburgh.



**Vice-
Chairperson**

**Youssouf
Noormamode,
Mauritius**

Youssouf is the head of the epilepsy chapter in Mauritius. He has a Higher School Certificate from University of Cambridge and professional qualifications ILO Diploma in Project Management and Diploma in Legal Studies awarded by the American Legal School Scranton.



Secretary

**Betty B. Nsachilwa,
Zambia**

Betty is proud to be one of the founding members of the Epilepsy Association of Zambia (2001). Betty is a Personal Secretary with qualifications in Personnel Management and Industrial Relations. She works for the Government of Zambia.



Member

**Dr. Radcliffe D. Lisk,
Sierra Leone**

Dr. Lisk heads the epilepsy program in Sierra Leone. He is the Chairman of the Sierra Leone Chapter and Vice President of the College. He is presently a visiting professor at the College of medicine (COMAHS) at the University of Sierra Leone and has served as a Consultant neurologist at Basildon University Hospital in Essex, England where he started the first Epilepsy clinic in 2004.



Member

**Kenneth Nsom,
Cameroon**

Nsom Kenneth Ninying, is the chapter head for epilepsy in Cameroon. He has lots of knowledge on epilepsy and its management and has been quite instrumental in supporting the visibility of epilepsy in his country. Kenneth has a Diploma (Hons) in Community Health Nursing and has worked with a number of health institutions. He is from a family of persons living with epilepsy, a caregiver of 2 people living with epilepsy and a founder of an epilepsy organization in Cameroon. Kenneth has worked as a field a Project Coordinator for Community Development Volunteers for Technical Assistance (CDVTA) – an elderly persons organization. Currently he is the Project Initiator and Developer for the Cornerstone Enrichment Services (CES), an organization for delinquent children and youth.



Member

**Grace N. Moyo,
Zimbabwe**

Grace Nkazana Moyo is a young person living with epilepsy and a strong advocate for epilepsy in her country, Zimbabwe. She holds a Bachelor of Science Honors Degree in Sociology for the University of Zimbabwe. She also has an Executive Certificate in Projects and Programs Monitoring and Evaluation again from the University of Zimbabwe. Grace has a strong passion in Disability Advocacy especially issues related to Epilepsy. She envisions a society that is free of stigma, discrimination and marginalization. Currently, Grace works as an Assistant Projects Officer for the Federation of Organizations of Disabled People in Zimbabwe (FODPZ) and volunteers at the Epilepsy Support Foundation of Zimbabwe.

OUR PARTNERS



The BAND Foundation is a US-based private family foundation that makes grants in support of nature conservation and epilepsy care. We strive to back visionary individuals and institutions, promote science-based solutions, catalyze additional funding and operate in a collaborative, adaptive and risk-tolerant manner.



The WHO Regional Office for Africa is one of WHO's 6 regional offices around the world. It serves the WHO African Region, which comprises 47 Member States with the Regional Office in Brazzaville, Republic of Congo. As the lead health authority within the United Nations (UN) system, WHO works with the Member States in the African Region and with development partners to improve the health and well-being of people.



The Commission on African Affairs is an arm of the International League Against Epilepsy (ILAE), coordinating the Organization's work in the Continent to reduce the scourge of epilepsy in Africa at large. It is made up of local chapters in the various countries in the continent helping in epilepsy care. We work in relation with doctors that are specialists in this field in different parts of the continent. For a start, we have made a tremendous achievement in chapters like Cameroon, Ghana, Libya, Somalia and Burundi.



The ADA's vision is that An African continent where people with disabilities enjoy their human rights. The mission is to be an African knowledge-based organisation that works in partnership with the AU, UN, African governments, CSOs, Academia and DPOs to promote inclusive development and human rights for persons with disabilities.



The African Union (AU) is a continental body consisting of the 55 member states that make up the countries of the African Continent. It was officially launched in 2002 as a successor to the Organisation of African Unity (OAU, 1963-1999).

We welcome your support

How can you help?

We welcome support for our work provided by donations of money, goods and services as well as the time put in by volunteers with any of our affiliates.

Please contact us if you would like to contribute in any of these ways

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