CareEpilepsy Ethiopia

SAVING LIVES | CHANGING PERCEPTIONS



2021 | ANNUAL REPORT













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Acronym

- 1. Anti-seizure medication (ASM)
- 2. CareEpilepsy Ethiopia (CEE)
- 3. People with Epilepsy (PWE)
- 4. Association of Ethiopian Neurologists (AEN)
- 5. National Epilepsy Week (NEW)
- 6. Ministry of Health (MOH)
- 7. Epilepsy Alliance Africa (EAA)
- 8. Patient Support Group Meeting (PSGM)

1. AN OVERVIEW OF CAREEPILEPSY ETHIOPIA

About Us

CareEpilepsy Ethiopia is the first non-governmental, non-religious epilepsy focused charitable organization in Ethiopia. We aim to improve the welfare of patients who have epilepsy, ease access to medical treatments, create more awareness in society, dispel negative perceptions of epilepsy, and enhance preventative measures against epilepsy at a national level.

Our People

We work for people with epilepsy, their families and anyone who is affected by epilepsy.

Vision

We envision a future when people with epilepsy are protected, respected, live free from discrimination and stigma and given the opportunity to realize their full potential.

Mission

We exist to radically improve the quality of life of people with epilepsy in Ethiopia and change perceptions of epilepsy in the community.

Values

Our moral compass for CareEpilepsy Ethiopia and our employees are compassionate care, integrity, accountability, innovation, inclusiveness, holistic approach to health and wellbeing based on the WHO guideline.

Beliefs

Our beliefs are derived from the principles outlined by the World Health Organisation "...the highest attainable standard of health as a fundamental right of every human being." We therefore believe:

- People with epilepsy have the human right to receive timely medical care and treatment.
- People with epilepsy deserve respect and dignity and equitable access to epilepsy care.
- Local leaders and local institutions are the best agents of change.
- Shared knowledge, skills, and experience are our most valuable tools.
- Culture-tailored communication is the most effective way to relay our message.
- Partnership is the only way to lasting change.

2. FROM THE DESK OF THE EXECUTIVE DIRECTOR

Reflecting on 2021 and our hopes for the year ahead, we reaffirm our commitment to serving anyone affected by epilepsy and creating a caring environment supporting our vulnerable women to have a sustainable life.

For our charity, 2021 has been a year with financial challenges that profoundly impact our program and staff. In addition, the Ethiopian government nationwide projects meant we received very little sponsorship for our program.

We had to prioritize essential programs in such circumstances, and some programs had to take a back seat. Despite this, we continued to deliver high-quality services to our clients with compassion and care. Despite the apparent challenges of 2021, we have so many reasons to be proud this year, and you will see these as you read through our report.

Our clinical service team has found innovative and safe ways to run clinical and psychological services. Our education team has delivered new content and run campaigns across digital, social and mainstream media.

Without exception, our team has shown resilience, agility and unity throughout 2021: I commend their dedication to ensuring service continuity and serving our beneficiaries while caring for loved ones. I have been inspired by the care and unity I have witnessed; the level of support and togetherness has been outstanding. On 28th August, we brought together our beneficiaries and volunteers to celebrate our successes and achievements.

CareEpilepsy Ethiopia has become significant epilepsy care and information provider throughout the country. It reflects our uniqueness and our growth. However, as I remind myself of 2021, the highlight is the culture here at CareEpilepsy Ethiopia. Our organizational culture, I am so pleased to shout about, is built on three simple core values: providing quality compassionate care, working with a quiet determination to consistently deliver our best, and pulling together when the demands placed on us are at their most challenging.

I want to thank our brilliant staff for their continued support in the last two unprecedented years. A special welcome also to new partners and volunteers with whom we have enjoyed working and made a difference in the lives of people with epilepsy. Your patience, adaptability and trust have helped us plot a safe and secure course through this turbulent year.

Once again, I want to thank all our colleagues and beneficiaries for their support and wish them the very best for 2022.

Focus on Epilepsy

Yours Sincerely,

Enat Yewnetu Founder and CEO

3. OUR OBJECTIVES AND STRATEGIC OBJECTIVES FOR 2021

3.1 General Objectives of Our Organisation

Our objective to achieve our mission is to close the gap between knowledge and action in medical care and treatment, build clinical care providers' capacity to treat epilepsy, enhance public awareness on epilepsy, and engage in partnership and advocacy work.

3.2 Strategic Objectives for 2021

Our Strategic Objectives for 2021 were to:-

SO1. Provide and facilitate early epilepsy diagnosis and treatment for patients.

The leading cause of disabilities is uncontrolled seizures. Lives will be saved if there was access to epilepsy care in health institutions, continuous supply of appropriate Anti-seizure medication (ASM) and diagnostic services like EEG and MRI.

- 1.1 Strengthening the consultation and referrals program to available epilepsy clinics, both government and private.
- 1.2 Strengthening the adult epilepsy clinic by recruiting more neurologists and adding two more clinics.
- 1.3 Further developing our child epilepsy service by recruiting neurologists to see more children.
- 1.4 Increasing supply and access to ASM (Drugs4epilepsy).
- 1.5 Increasing access to EEG services through developing CEE's EEG service and giving financial assistance for PWE who require urgent MRI examination. (Equipment4epilepsy)
- 1.6 Growing our 'Home Monitoring' service by using trained staff and volunteer epilepsy counselors.
- 1.7 Providing clinical training for nurses, health extension workers and health officers who are currently involved in epilepsy care at government health centers.

See Section 4. REVIEW OF PLANNED ACTIVITIES FOR 2021- SO1 page 11 for further details.

SO2. Increasing education for patients and the general population to promote medical seeking behaviour and inclusion and disassociate the undue stigma and exclusion placed on epilepsy patients;

The principal cause of stigma, rejection, and worsened health is the lack of knowledge about the causes of epilepsy as it is viewed to be supernatural, making spiritual healing and traditional medicine the chosen therapeutic modalities. Therefore, educational intervention is the only way to decrease disability, worsen health, and change the general population's attitude to improve patients' quality of life.

- 2.1 Update, print/produce and distribute epilepsy education materials such as Epilepsy Information Leaflet and posters in Amharic and Oromifa languages.
- 2.2 Organizing the 6th National Epilepsy Week (NEW) in joint partnership with the Federal Ministry of Health, Association of Ethiopian Neurologists (AEN), and a

chose sub-city. (Campagine4epilepsy)

- 2.3 Run community epilepsy education at hospitals and health centres.
- 2.4 Continue to run epilepsy education at schools for pupils and teachers and engage 12 more new government schools to join our program. (Seizure@school)
- 2.5 Identify 2 companies to run our 'seizure at work' program to educate employers and employees about epilepsy and seizure first aid (Seziure@work).
- 2.6 Produce Newsletter about epilepsy and our work.

See Section 4. REVIEW OF PLANNED ACTIVITIES FOR 2021 - SO2 - page 12 for further details.

SO3. Improve patients' emotional and social wellbeing and 5 family economic wellbeing of children and adults with epilepsy

Denied access to employment and lack of support and training is the primary cause of child neglect, poverty, emotional problems, drug abuse, and unaffordability to pay for medication and diagnostics. Therefore, our focus on wellbeing interventions should include counselling, group support and skills training to improve the psychosocial wellbeing of children and adults with epilepsy.

- 3.1 Organise teaching sessions to improve patients' knowledge, perceptions, attitudes and practices concerning epilepsy, enable them to understand the risks of untreated seizures, their care process and how to manage epilepsy and coexisting conditions. In addition, produce a booklet for patients about epilepsy and their care plan. (Patient Education)
- 3.2 Our confidential epilepsy helpline continues to give confidential and personal advice and support to people affected by epilepsy. (Helpline4epilepsy)
- 3.3 Continue to run the monthly 'patient support group meeting' (PSGM) the project.
 - Project staff to regularly meet with project beneficiaries.
 - Facilitate microenterprise start-up financing.
 - Identify new partners to support our women-run microenterprise business.
- 3.7 Farming and Weaving in Bench Maji Zone
- 3.8 Provide financial assistance for purchasing safe cooking stoves. (Wolafen project)

See Section 4. REVIEW OF PLANNED ACTIVITIES FOR 2021 - SO3 - page 14 for further details.

SO4. Increase our partner organizations and strengthen 'advocacy partnerships' to expand our impact and influence on policies that affect people with epilepsy

Unaddressed medical, social, environmental factors contributing to epilepsy cause poor health and lack of epilepsy awareness. Through a strong partnership with the ministry of health, other government agencies at the local, regional and federal

levels, and stakeholders, we can address the needs of people with epilepsy and raise awareness of epilepsy. In addition, through grassroots engagement and establishing a link and connecting with the local community and people with epilepsy, the stigma associated with epilepsy will be reduced.

- 4.1 Engage CareEpilepsy Ethiopia Patient Representatives Committee in advocacy work
 - Invite them to attend appropriate meetings and provide a platform to speak.
 - Arrange for them to visit patients in their homes.
 - Lead out in PSGMs.

4.2 Community Conversation

- Engage educators, employers, medical communities, faith leaders, traditional healers and other stakeholders to
- develop policies to raise awareness of epilepsy to eradicate the stigma of epilepsy.
- CEE will organize 4 1-day workshops (1 per quarter).

4.3 Faith Action

- Cluster workshops. CEE will organize workshops.
- Organize training for faith leaders to help them teach their congregation about epilepsy and how to deal with the social and cultural issues to reduce the stigma of epilepsy and increase social inclusion.
- Develop a 'Faith Advocacy Toolkit'

4.4 National Partners

- Continue to work with national partners such as Addis Ababa Health Bureau, Ministry of Health, and Region Health Bureau, Yeka, Kirkos, Arada and Bole subcities, tertiary referral hospitals to initiate and implement joint projects of clinical care and awareness-raising.
- Identify a national epilepsy ambassador.
- Continued discussion with Sanofi and Novartis (pharmaceutical companies) for ASMs imports and discounts.
- Discussion in progress with Cheshire Homes Ethiopia for collaboration work.
- Initiate a new collaboration with one new sub-City to expand our services in Addis Ababa.

4.5 International Partners

- Identify International Partners and register as a member.
- The international medical outreach team from the UK to come to Addis Ababa
- Register with the Epilepsy Alliance Africa (EAA) association as a member.
- Engage Ethiopian Diasporas.

4.6 Needs Assessment in the Amhara region.

Conduct needs assessment and clinical audit in Amhara region.

See Section 4. REVIEW OF PLANNED ACTIVITIES FOR 2021 - SO4 - page 16 for further details.

SO5 Others

5.1 Grow our financial capacity through donors, sponsors and other fundraising activities, both nationally and internationally.

- 5.2 Promote our volunteering and internship schemes, nationally and internationally Organizational Development.
- 5.3 Organizational development
 - increased human resources, capacity building, governance and policy review.
 - Acquire a new premise for an epilepsy rehabilitation center.
- 5.4 Media, Communications and IT

We believe in the power of the media to change lives therefore we work in partnership with the media and creative industry to give people with epilepsy a stronger voice.

See Section 4. REVIEW OF PLANNED ACTIVITIES FOR 2021 SO5 - page 18 for further details.

4. REVIEW OF PLANNED ACTIVITIES FOR 2021

SO1 - Facilitate access to medical care and anti-epileptic drugs through the followings are the various activities that we employ to accomplish our strategic objective 1

Note: AC = Activities; A = Achieved; Partially Achieved = PA; NA = Not Achieved; IP= In progress; CEE = CareEpilepsy Ethiopia

AC	Planned Programs/Activities	Objective	Α	PA	NA	ΙP	Remarks
1.1	 a) Organize consultation and referrals to available epilepsy clinics, both government and private. 	 Improve patients' ability to access medical care. 	√				a) 360 patients were seen by nurse led clinic.
1.2	a) Continue strengthening the monthly free neurologist led adult epilepsy clinic to be held at Yeka Health Center.	 Early diagnosis and administration of appropriate treatment of epilepsy. 	√				 a) 10 monthly free community clinics were held. b) 110 adult patients accessed medical care through our free community clinic.
1.3	 a) Further develop our child epilepsy clinic by recruiting pediatric neurologists to see more children with epilepsy. 	•					a) A total of 148 children were seen by pediatric neurologists through our free community clinic.
1.4	 a) Provide financial assistant to those who are economically unable to purchase anti-epileptic drugs b) Enroll 50 patients in the Tena Medhin (Health Insurance), a government health insurance, that will allow them to access free medication when available, program this year (Drugs4eilepsy) 	 Increase supply and access to AEDs. Uptake of AEDs Equitable access to a cost-effective, genuine and adequate supply of AED. 	√ √				a) For 225 PWE patients received financial support to purchase ASM. b) A total of 27 patients were registered and supported to purchases Tena Medhin.
1.5	 a) Develop CEE's EEG service. b) Support PEW financially to access MRI diagnostics. (Equipment4epilepsy). 	To get a confirmed diagnose of epilepsy due to increased resource of modern diagnostic equipment such as electroencephalogram (EEG)	✓				a) 40 PWE received EEG service . b) 21 PWE received MRI diagnostic service at Woudase diagnostic service center by the facilitation and covered the cost of CEE.

1.6	a) Develop home monitoring service which will run via weekly telephone check-ups of people living with epilepsy). (Home Monitoring)	Alleviate the burden of the government service,	√	a) For 400 PWE CEE continued to make telephone check-ups, especially as the regular clinic was suspended, patients' need for consultation grew.
1.7	a) Run 1-day Epilepsy Basics training course for those involved in epilepsy management such as nurses, midwives, and health workers. Run Train-the-trainer (TOT)	 Increased competency of nurses capable of effectively diagnosing and treating PWE. Provision of expert care and training from both national and international experts. 	√	a) 52 participants attended a 1-day "Basics of Epilepsy" training which was provided to health officers, general nurses, and psychiatry nurses working in health centers at the primary health care level.

SO2 - Increasing education for patients and the general population to promote medical seeking behavior and inclusion and disassociate the undue stigma and exclusion placed on epilepsy patients. The followings are the various activities that we employ to accomplish our strategic objective 2:

Note: AC = Activities; A = Achieved; Partially Achieved = PA; NA = Not Achieved; IP= In progress; CEE = CareEpilepsy Ethiopia

AC	Planned Activities	Objective/Aim	Α	PA	NA	ΙP	Remarks
2.1	 a) Update and print education materials (Epilepsy Information Leaflet and DVDs) to create awareness on epilepsy. b) Distribute teaching aid such as posters and leaflets written in Amharic and Oromifa languages 	Stigma reduction due to changed social norms and perceptions among the general population.	√				 a) Over 25,000 leaflet and 2000 posters were updated and printed. b) We delivered epilepsy education materials, which were disseminated to local health centers, tertiary referral hospitals, health centers, schools, and on-street campaigns in order to close the epilepsy awareness gap in the community.
2.2	a) Organize the 6 th NEW in joint partnership with the AEN and Gulele Sub-City from the 8 th – 14 th 2021, in Addis Ababa. Campagine4epilepsy	Stigma reduction due to behavioral change resulted from changing social norms and perceptions among the	√				a) The 6 th NEW was celebrated successfully in Addis Ababa in joint partnership with MOH, AEN, Bole and Arada Sub-City as planned with

		general population. Improved quality of life of PWE through increased acceptance and participation within the community.			a motto "I am a voice for Epilepsy". b) Three days of street campaigns were held in Addis Ababa. On the first day, we raise awareness with the collaboration of Bole sub-city and Arada sub-city in their compound. The second day of awareness-raising within Addis Ababa for different places. c) Mediums that we used include leaflets, street campaign, local and national broadcast media such as radio and television. d) Audio adverts and awareness-raising songs were played during the street campaign.
2.3.	a) Run community epilepsy education at hospitals and health centres.	Improve knowledge about epilepsy.	√		 a) 10 health centers and one hospital within Yeka, Kiroks, Arada, Bole sub-cities received epilepsy education and seizure first-aid training for staff, patients and Patient families during this education 468 people were address. b) Epilepsy awareness at different street during this education around 664 of people was addressed.
2.4.	 a) Run epilepsy education at schools. b) Engage 12 more government schools to join our program, which raises awareness for pupils and teachers. (Seizure@school) 	 Stigma reduction To allow children with epilepsy access education. Establish advocates to function as epilepsy resources in school and at work. 	√		a) 60 schools, a total of more than 31,399 students, and 1,825 teachers are received epilepsy education and seizure first-aid training.

2.5	 Engage 2 organizations to join our 'Employers Epilepsy Champions' initiatives, which raise awareness for staff and management. Seizure@work 	 To open access to employment for PWE so that they can be financially stable to lead their life without dependence on others. To equip management to make the workplace a safer environment for PWE. 		√		a) 1 organization was visited to give epilepsy awareness. Poor interest in organizations to be involved in this program.
2.6	Other campaigns: a) African Epilepsy Week b) Eyoha Exhibition Center		√ √			held from September 20-24/2021. We were educating the community on the street and at Ayer Tena bus station, Akaki bus station, Megenagna and Lamberet bus station by providing face to face teaching, brochures and audio. b) we acquired an exhibition booth at Eyoha Trade Exhibition center.
2.7	a) Produce a newsletter about epilepsy and Careepilepsy Ethiopia's work.	 To share information relating to every aspect of epilepsy, including the clinical, social and psychological impact of epilepsy. 	√		ē	a) Year End newsletter was distributed for the first time.

SO3. Improve patients' emotional and social wellbeing and 5 family economic wellbeing of children and adults with epilepsy. The followings are the various activities that we employ to accomplish our strategic objective 3:

Note: AC = Activities; A = Achieved; Partially Achieved = PA; NA = Not Achieved; IP= In progress; CEE = CareEpilepsy Ethiopia

AC	Planned Activities	Objective	Α	PA	NA	IP	Remarks
3.1.	 a) Organize teaching sessions for patients and family. b) produce a booklet for patients about epilepsy and their care plan. (Patient Education) 	 to improve patients' knowledge, perceptions, attitudes and practices concerning epilepsy enable them to understand the risks of untreated seizure, their care process and how to manage epilepsy and coexisting conditions. PWE empowered to look after their health and make informed choices and participate in their care. 	✓		√		 a) 12 teaching sessions were arranged to educate people with epilepsy of the risks of untreated seizure, causes and consequence of epilepsy. b) We designed epilepsy information leaflet to help patients and their family learn more about epilepsy, work with healthcare professionals to identify the treatment they need and set goals and action plans to assist them with their epilepsy care wellbeing. Seizure record sheet was designed for patients to record their seizure pattern to help doctors to prescribe the right dosage of medication. c) "My epilepsy care" booklet providing knowledge about epilepsy, and care planning for people with epilepsy is designed but not printed due to lack of funding.

3.2.	a) Our confidential epilepsy helpline to continue to give help and support to people who are affected by epilepsy. (Helpline4epilepsy)	answer questions about epilepsy and seizures and provide patients with help, hope, support, guidance, referral line and access to national and local resources to people who are affected by epilepsy.	✓		a)More than 2,793 people received the service.
3.3.	a) Continue to run the monthly PSGMs (Patient Support Group)	To support the wellbeing of our beneficiaries and help PWE cope with their condition better and improve their sense of belonging and connectedness so they feel less isolated.	✓		a) 12 monthly PSGMs were held. b) 580 people participated in the program.
3.4.	a) Encourage new patients to join `coffee morning for epilepsy' program. (Connect4epilepsy)	For patients to have a chat and share their experiences of living with epilepsy over a cup of coffee or tea and develop friendship and support.		√	a)221 people participated in the 'coffee morning' program. b)44 sessions were held.

AC	Planned Activities	Objective	Α	РА	NA	ΙP	Remarks
3.5.	Continue to provide counseling and psychotherapy service for our beneficiaries. (Counselling4epilepsy).	To help PWE cope with their condition better to by providing emotional support through counseling and psychotherapy services.	√				 a) 264 people with epilepsy and their families got access to counseling support by CEE staff. b) 8 people with epilepsy and their families got access to psychiatric support at Black Lion Hospital.
	a) run microenterprise development training to empower 20 women with epilepsy to be financially stable through the program. b) Develop microenterprise business plans. c) Provide monitoring and ongoing support for those who will be involved in the project. d) Project staff to regularly meet with project beneficiaries. e) Facilitate microenterprise start-up financing. f) Identify new partners to support our women run microenterprise business.	 Facilitate increased skill training to empower people with epilepsy to be self-sufficient through craft training. We have provided patients with raw materials such as needles, threads, plastic mats for table mat, coffee mat, and cards to continue learning and doing craftworks. Microenterprise Development - CareCraft 	✓ ✓		✓		 a) 44 sessions of Care Craft program were held, and CEE provided patients with raw materials such as needles, threads, plastic mats for table mat, coffee mat, and cards to continue learning and doing craftworks. However, due to a lack of funding, we could not open a shop for them b) Our Craft trainer and patient-therapist continued to meet regularly with patients and give support and monitoring. c) 3 single mothers with a child with epilepsy were enrolled in our income generating program's. d) Ongoing monitoring and support have been given to the women. e) Regular meetings were held to identify the business venture and monitor and weed out problems. f) Still looking for partners to

	S O				support our work.
3.7.	Microenterprise Development - Farming and Weaving in Bench Maji Zone			√	Due to political instability, shortages of funds, we did not venture to start the farming and weaving project.
3.8	Provide financial assistance for purchasing safe cooking stoves. (Wolafen project)	 Eliminate preventable causes of seizure- related burn injuries whilst due to hazardous domestic environment like open fire cooking. 		√	Due to lack of funds this was not scaled up as planned.

SO4- Advocacy in partnership to influence public policy and organizational practice. The followings are the various activities that we employ to accomplish our strategic objective 4:

AC	Planned Activities	Objective	Α	PA	NA	ΙP	Remarks
4.1.	 Engage CareEpilepsy Ethiopia Patient Representatives Committee in advocacy work a) invite them to attend appropriate meetings and provide a platform to speak. b) Arrange for them to visit patients in their homes. c) lead out in PSGMs. 	Increase engagement in advocacy from patient representatives.	√ √ √				Patient representatives: a) attended 11 meetings, and they continued to engage in raising awareness and expressing the needs of people with epilepsy. b) continued to take the lead role in leading our PSGMs. c) received 1 in-house epilepsy training session. d) Visited 10 PWE together with CEE staff.

4.2	•	To initiate community	√			a) CEE made every effort to partner
	 a) Engage educators, employers, medical communities, faith leaders, traditional healers and other stakeholders to develop policies to raise awareness of epilepsy to eradicate the stigma of epilepsy. b) CEE will organize 4 1-day workshops (1 per quarter). 	 conversation and involvement in preventing epilepsy and support for people with epilepsy and their families Connected and collaborative community leaders committed to change the stigma of epilepsy. Increased collaboration between multiple sectors, professions, regions, and cultures. 		✓		the communities indicated but no tangible action took place. b) Only 1 of the workshop held
4.3	 a) Organize training for faith leaders to help them teach their congregation about epilepsy and how to deal with the social and cultural issues to reduce the stigma of epilepsy and increase social inclusion. b) Develop a 'Faith Advocacy Toolkit' 	To engage faith leaders to come up with solutions about providing emotional care in churches and mosques.			1	a) We did not organize training for faith leaders as planned b) Faith Advocacy Toolkit was not done due to lack of time.
4.4.	 National Partners a) Continue to work with national partners such as - Addis Ababa Health Bureau, MOH, AEN and Region Health Bureau, Yeka, Kirkos, Arada and Bole sub-cities, tertiary referral hospitals to initiate and implement joint projects of clinical care and awareness-raising. b) Identify a national epilepsy ambassador. c) Continued discussion with Sanofi and Novartis (pharmaceutical companies) for AEDs imports and discount. d) Discussion in progress with Cheshire 	the MOH to put epilepsy high on its agendas as a public health issue and develop the neurological division that coordinate epilepsy affairs with proper short term or long-term plans, and plan funding.	V	√		a) Continued to work with the national partners identified, although no progress was made with the involvement of neurologists within the MOH under the Mental, Neurological and Substance abuse directorate. On a positive note, AEN was involved in leading the clinical training and joint in awareness-raising walk during the 6th NEW. More collaboration is sought. b) We are happy to accept Habiba Faris as epilepsy ambassador. c) Discussion in progress with Sanofi

	Homes Ethiopia for collaboration work. e) Initiate a new collaboration with one new sub-City to expand our services in Addis Ababa.			✓		and Novartis. d) In the final stage of signing an MOU with Cheshire Home Ethiopia, a UK charity that provides orthopedic and social rehabilitation services for children and young people with disabilities in Ethiopia. We plan to provide services for children with epilepsy, and they will allow us to use their facilities etc. e) Slow engagement from government offices.
4.5	 International Partners a) International medical outreach team from the UK to come to Addis Ababa b) Register with the EAA association as a member. c) Engage Ethiopian Diasporas. 		√		√	 a) International outreach team program did not go ahead due to various obstacles. b) Registered with EAA. c) Gained increased engagement of Ethiopia Diasporas.
4.6	Needs Assessment in Amhara region. a) Conduct needs assessment and clinical audit in Amhara region.	The purpose of needs assessment in health care is to gather the information required to bring about change beneficial to the population's health.			√	a) Unaccomplished lack of funds and political unrest.

SO5 -Others. The followings are the various activities that we employ to accomplish our strategic objective 5:

AC		Plan	A	PA	NA	ΙP	Remarks
5.1.	Financial Sustainability.	To continue to provide our service.			√		We were able to find some sponsors but not as many as we
	Grow our financial capacity through donors, sponsors and other fundraising activities, both						planned for. Again, COVID and national programs played a role

	nationally and internationally.			in this.	
5.2.	a) Promote our volunteering and internship schemes, nationally and internationally	 To inspire our youth and other professionals to make a difference in their community. Get the organization work done for free. Internships provide training and skills development for participants. 	│	a) 21 neurologists were involvin our community clinic during 2021. b) 142 new volunteers activel engaged in supporting the activities of CEE.	ly
5.3.	a) increased human resources b) capacity building c) governance and policy review. d) Acquire a new premise for an epilepsy rehabilitation center.	To build a competent workforce who are in proportional ratio to the need of our activities.	✓	a) A community outreach worker has joined the tea b) No training was given to staff. c) CEE policies were reviewe d) There was no fund to acquire a new premise for an epilepsy rehabilitation center.	
5.4	Media, Communications and IT work in partnership with the media and creative industry to give people with epilepsy a stronger voice.	 Discuss epilepsy on the national broadcast media such as radio and television Introduce Social Media Activism to raise awareness in the social movement. Good media engagement for public education as well as social media such as Facebook and Twitter. promote medical seeking behavior and adherence to anti-epileptic drugs. media4epilepsy 	√	a) Excellent media engagement for public education as well as so media such as Faceboo and Twitter. b) We had 10 TV presentations and 4 rad presentations. c) TV like Fana, EBC,Addis Tv, Amhara, Walta, OB EBS, Asham, Ahadu an ArtsTv. d) Radio Ahadu, FM 105.3, Sheger(102.1), 96.3	ocial ok dio s BN,

5. IMPACTS OF WORK IN THE COMMUNITY

Strategic Objective 1 - Facilitate access to medical care and anti-epileptic drugs in 2021

- a) New patients attended epilepsy clinic.
- b) We observed increased knowledge about epilepsy among patients and family as well as adherence to ASM regimens prescribed by doctors.





Dr Kindu and Dr. Behailu seeing children with epilepsy at our free community clinic

Activity 1.2. Anti-Seizure Medication (Drugs4eilepsy)





Provide Anti-Seizure Medication for People with Epilepsy

Activity 1.3. Diagnostic Service

61 patients had a confirmed epilepsy diagnosis assisted by EEG and MRI tests instead of word of mouth.





EEG Diagnostic service

Activity 1.4. Epilepsy Clinical Training (Train-the-trainer)

One clinical session training was provided to build the capacity of health officers to enable them to diagnose and treat people with epilepsy.





Clinical training at Ethiopian Public Health Institute

Strategic Objective 2 - Public Education and Awareness in 2021

CEE's awareness-raising campaigns are planned communication activities with the goal of raising awareness about epilepsy, changing behavior as a result of social norms and perceptions in the general population, and improving the focus on better outcomes for epilepsy, higher patient protection of their human rights, and reduced early school dropout. Our awareness campaign contributes to stigma reduction, allowing people with epilepsy to participate in education, the workplace, and the community.

Activity 2.2. Campagine4epilepsy







 6^{th} National Epilepsy Week 2021 Epilepsy awareness at Street



African Epilepsy Week September 2021, Epilepsy Awareness at Bus station

Activity 2.4. Epilepsy Education at Schools (Seizure@school)

The training to pupils and teachers helped them understand that most pupils with epilepsy can participate in all school activities.







Epilepsy Awareness at school

Activity 2.5. Epilepsy Education at Work Place (Seizure@work)

Management and staff increased their knowledge of epilepsy and felt equipped to deal with anyone having a seizure at work.





Epilepsy Awareness at work place

Strategic Objective 3 – Improve the wellbeing of people with epilepsy by addressing the psychosocial factors affecting their lives.

Patients seek clinical care and guidance from their physicians when they are sick and support from family members, friends, and fellow patients. Patients suffering from epilepsy are not immune to this fact. They, too, face complexities and problems that necessitate the assistance of a network of professionals, relatives, and friends. In addition, treatment entails more than just a routine medical diagnosis, hospitalization, or drug prescription.

- a) Our program improved our patients' lives and overall wellbeing by providing them with epilepsy education and psychological support.
- b) Our confidential epilepsy helpline gives help and support to people who are affected by epilepsy. Epilepsy Helpline runs throughout the year. The most common requests were inaccessibility of medication, clinic information where they could receive epilepsy care, financial support.
- c) participants learned clinical facts about epilepsy, safety issues, and ways to live positively with epilepsy, and we reimbursed the attendees' transportation cost.



Patient Support Group Meeting

Activity 3.6. Income Generating Activities (Microenterprise Development)







Impact and Value of Work in Communities

- a) access to psychological support through our face to face counselling services made them feel confident to deal with their epilepsy which improved their wellbeing.
- b) developed a friendship and felt more connected with each other.
- c) Those affected with epilepsy received information that increased access to clinical care.
- d) people were able to attend programs as CEE covered the transportation cost to participate in the meetings.

Strategic Objective 4 - Advocacy to influence public policy and organizational practice.

Impact and Value of Work in Communities

Community members received a platform of conversation to discuss and investigate the lack of clinical service and stigma issues associated with epilepsy.





Community Workshop on Epilepsy 2021





Patient representatives and CareEpilepsy staff doing home visit

6. VOLUNTEERING AND INTERNSHIP

CareEpilepsy Ethiopia provides volunteer opportunities and internships for professionals and those who are in education. As a by-product of this work, we help our volunteer team learn life skills for their future, like leadership, teamwork, communication, accountability, and the satisfaction of doing well in the community.

6.1 Volunteering

Neurologists, nurses, and youth volunteers continued to significantly impact clinical care and awareness-raising program through their engagement with CEE.

Working with youth volunteering is one of the program we run tapping into the time and experiences of young volunteers. During 2021, we have recruited 142 youth volunteers consisting of high school pupils and university students from different backgrounds with a passion for raising awareness of epilepsy in the community. By using younger and fresher minds, we found creative ways of boosting awareness and raising money.

They were mainly involved in:-

- a) Raising awareness in the community by teaching at health centres and hospitals
- b) Distributed epilepsy information materials to clinics, hospitals, health posts, and schools
- c) Provided support in organizing and supporting training for clinical professionals
- d) The organization and participation of the 6th NEW
- e) Involved in fundraisers activities

Impact and Value of Work in Communities

- a) 12,780 hours were given to us by volunteers to help us complete our objective for the year
- b) 142 new volunteers actively engaged in supporting the activities of CareEpilepsy

- Ethiopia,
- c) 142 volunteers received a one-day in-house training session on epilepsy and epilepsy first aid
- d) 92% of CareEpilepsy Ethiopia volunteers who attended our in-house training acquired new knowledge on epilepsy and stated its impact on their individual life (131 out of 142 attendees)
- e) Another six half-day in-house epilepsy and epilepsy first-aid training programs were held for 6th NEW, school campaign, and summer volunteers.
- f) 70 volunteers performed the epilepsy response and recovery position on the streets of Addis Ababa during the National Walk on Epilepsy day.
- g) 20 volunteers performed the epilepsy response and recovery position on the school campaign of six sub-cities.
- h) 48 summer volunteers performed the epilepsy response and recovery position African epilepsy week, and they were work fundraising at exhibition center.







Some members of CareEpilepsy Volunteers of 2021

6.2 Internship

Due to political instability and the global COVID-19 restrictions, the planned internship program did not go ahead.

7. MEDIA AND COMMUNICATION

We believe in the power of the media to change lives. We have used various means of communication such as broadcasting, publishing and the internet for our mass communication program to educate the public about epilepsy.

7.1 Media Engagement

 Epilepsy was raised and discussed through talk shows and interviews through the mainstream TV programmes that have popular viewers such as EBS, Arts, Fana, EBC, Addis Tv, Amhara Tv, Walta, OBN, Asham, Ahadu and radio stations that have a significant number of listeners such as Sheger, Ahadu to raise awareness.

7.2 Communication

a) Website

- Our website was an avenue of communication to give education about epilepsy and show the progress of CEE's work.
- Due to having no dedicated person to do the work, there has been a time lag in updating the website.

b) Social Media Activism: Raising Awareness in Social Movement

 CEE believes social media activism is a useful tool to raise awareness and visibility for epilepsy and related issues by using various tools sites like Facebook, Twitter, YouTube, Telegram, Instagram. Due to having no dedicated person for the job we did not maximize the use of social media due to a lack of funding to employ a dedicated person for the job



Press conference on International Epilepsy Day with Dr. Hanna Demissie (Assistant Professor in neurology), Dr Ebba (Director General, Ethiopian Public Health Institute) and Abiy Asrat (Deputy Manager CareEpilepsy Ethiopia) at Ethiopian Public Health Institute

c) Speaking Engagements

No speaking engagement due to the national COVID-19 restrictions.

Impact and Value of our work in the community

Mass media campaigns designed to raise awareness of epilepsy have shown immediate and significant effects in promoting medical seeking behavior and voluntary counseling and adherence to ASM.

8. DEVELOPMENT PARTNERS

The solutions to epilepsy problems in Ethiopia are too complex to be solved by an individual organization. Therefore, CareEpilepsy Ethiopia is aware of developing partners' importance to help us incubate new ideas and come up with proven solutions. Consequently, we aim to encourage community involvement in medical, social and environmental factors contributing to epilepsy such as poverty, female and child health, mental health, communicable diseases, education and employment.

Our partners for 2021 included:-

- **National:** neurologists, nurses, sub-city health offices, government ministerial offices, business organizations and other local non-governmental organizations
- **International:** CareEpilepsy UK, CareEpilepsy USA During 2021, our partners provided essential funding and support in the form of cash and in-kind to complete our programs and initiatives.

National Policy influence

- As a regulator, we are putting pressure on the Ministry of Labor and Social Affairs to enforce equal opportunity law so that people with epilepsy are not denied employment.
- In discussion with the Ministry of Education and the Ethiopian Teachers' Association to provide equal access to education for children with epilepsy
- We have identified new partners such as Kirkos Sub-City, Bole Sub-city, Gefersa Mental Health Rehabilitation Center and Ethiopian Mental Service Users' Association.
- Working together with the AEN in training and clinical care.

Impact and Value of our work in the community

• This year, Ethiotelecom has offered a one-year short dialing number (9610) and Tele birr fundraising number (5262) for free to Care Epilepsy Ethiopia.





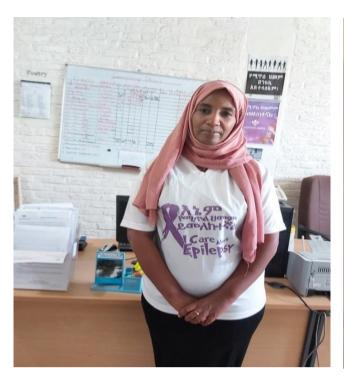
Partnership with Ethio-Telcom





Partner's Visiting CareEpilepsy Ethiopia office, Addis Ababa







CareEpilepsy is delighted to announce that Mrs Habiba Faris, Deputy Chief Executive Officer of the Ethiopian Broadcasting Corporation, will be an ambassador for Epilepsy in Ethiopia. She has already visited our office and met patients and their families to better understand the challenges they face. We look forward to working with her to raise awareness about epilepsy and make life better for people with epilepsy.





Mrs Habiba Faris, Epilepsy Ambassador visiting CareEpilepsy Ethiopia's office

9. ORGANISATIONAL DEVELOPMENT

9.1 Organisation Policy and Procedures

CareEpilepsy Ethiopia Staff Plan in 2020 set the following organizational development and culture goals:

- Building organizational systems that align to realize a workforce with the capability to perform in a complex environment and to adapt to change
- Developing a culture of staff who recognize and value different perspectives, work together well and engage with others to create desired outcomes
- Creating a staff development and training plan

9.2 Recruitment and Selection

- Two staff were given notice of termination of contracts due to financial shortages.
- We managed the shortage of staff within the existing team by cross-training them.
- Staff worked for three months for half of their contracted salary

• Our recruitment and selection plan needed no revision

9.3 Staff Training and Development

We did not provide any external training for staff due to lack of finances; however, internal training and cross-training were given to improve their work level and quality. As a result, the time taken shows a high return on investment due as shown by a workforce with renewed motivation, new skills and strengthened morale.

Achievements During 2021

- A review of the standard operating procedures system was completed. This work will continue as part of ongoing system development
- 8 staff in house training sessions were provided, these include: #
 - Epilepsy and epilepsy first aid (x2)
 - Compassionate care
 - Communication skills
 - Teamwork
 - Presentation skills
 - Leadership skills
 - Time management
 - Customer Service Skills
 - o CareEpilepsy Ethiopia

Impact and Value of our work

- Staff felt valued and appreciated.
- Increased quality of work and productivity level across the board
- Gave staff great motivation to do their job well
- Staff have increased knowledge about the various topics of training
- This has, to some extent, helped to free up the time of the chief executive officer and other members of staff
- Help build relationships amongst staff

10. GOVERNANCE AND MANAGEMENT

We are dedicated to enhancing our leadership continuously. During 2021, we focused on building our national advisory board with people of experts as good governance, which is key to the growth and sustainability of Careepilepsy Ethiopia. In addition, we spent hours discussing with our governing Body on building strategic thinking and oversight characterize the board's leadership role.

10.1 Governance

- a) Board of Directors
 - CareEpilepsy Ethiopia functions with Boards of Directors in the UK and National Advisory Board in Ethiopia
 - We have seen productive engagement from the National Advisory Board both in program activities and fundraising

b) Patient Representative Committee

The Patient Representative Committee

- Regularly gives feedback to the operational team on programmes and issues raised by beneficiaries.
- Supports the work of CareEpilepsy and promotes their rights as they navigate through the epilepsy care system

Achievements

- We have put in place structures for reporting, accounting and evaluation so that we build the confidence of our funders.
- National reports, organizational policies, staffing policies, sources of finance and auditing and evaluation arrangements are all put into place.

10.2 Operational and Project Management

- a) Operational Management
- The CEO provided the overall direction in which CEE moves, as well as managing the day-to-day activities
- The Administrative and Finance Manager was responsible for the financial management of projects and accounts, keeping track of spending against CEE's annual budget, training, supervising our volunteers.
- b) Project Management
- A task force (paid staff and volunteers) was founded with the assignment to organize the organization's various activities.
- Although the group was disbanded after their task was completed, we found this to be extraordinarily productive and reduced the stress of the general staff.

11. SIGNIFICANT ISSUES/CHALLENGES FACING CAREEPILEPSY IN 2021 AND BEYOND

The followings are an overview of significant current issues facing CareEpilepsy.

In order of impact	Challenges/ Issues	Challenges/Issues Explained	Proposed Solutions
11.1	Financial sustainability	 Financial constraints are still a problem limiting our engagement and the number of people with epilepsy we could reach out to. In addition, it affects our ability to meet the medication needs of patients and to cover essential administration costs. Lack of a named person with real experience or skill in donors/grant pursuits/searches causes loss of opportunity. 	 Diversify funding sources Identify donors with a focus on corporate partnerships to help them achieve their social responsibilities Paid grant writer Paid fundraisers
11.2	Workforce/staff	 CEO covering the project management and the operational work while adhering to the requirement of CareEpilepsy UK has proven to be a great challenge Shortage of expert workforce within our team and this lack of expertise has a drawback on the CEO engagement in the UK and grant searching. We still rely heavily on our volunteers due to the shortage of paid staff The amount of workload has affected the efficiency of our staff 	 Employ a full-time program manager in Ethiopia. Generate revenue to finance the justifiable, affordable and minimum level of staff Increase expertise through in-house and external training and partnership with higher education institution

11.3	Premises	 The frequent move of office in search of cheaper rental office causes loss of patients and stable engagement with communities We need to acquire our facility to run the clinic as the current arrangement proved to make us insecure about running the program 	 Fundraise to pay for a center Receive land to build an epilepsy center from the government
11.4	Patients Expectations	Patients are putting increasing demands on CareEpilepsy Ethiopia to provide financial support to purchase medication, pay for diagnostic tests, and general support with their life. In the absence of this support, patients lack the interest to involve in other programs.	Continue to advocate for the Ministry of Health to provide sustainable AEDs at affordable price and free
11.5	Stigma	 Stigma about epilepsy is still a challenge affecting the involvement/ engagement of patients and their families in our activities CareEpilepsy Ethiopia faced a great deal of stigma in comparison with other charities because of the nature of our work 	 Build on the work that has been achieved so far Continue to work with the media and engage with national and regional government offices and community leaders Approach recognized members of the community and personalities such as celebrities to serve as goodwill ambassadors
11.6	External Factors	 Attitude and policy of the national and regional government offices towards charities have a crippling effect on our finances The public is skeptical of in general charities' work Political instability 	 The impact of policy change towards charities looks hopeful Keep track of any regulatory and statutory changes and where possible, adopt the legal and compliance changes to our favor

11.7	Lack of proper networking	 Inadequate network in the UK We need more neurologists to engage in our program Sustainable volunteering support 	 Board members and CEO to look into their network to gain interest CEE to become a member of Consortium of Christian Relief & Development Associations (CCRDA) which is a Consortium of Ethiopian Resident and Foreign Charities
11.8	Engagements of partners	 Commitment from government health authorities and health facilities to make required practice changes is slow coming. Commitment from neurologists and doctors to provide training in slow coming 	 Encouraging government health authorities and health facilities to take ownership of our program and invest in training and practice changes Encourage neurologists and doctors to provide training through PR incentives for their association

12. PROGRAM ACTIVITIES AHEAD FOR NEXT YEAR 2022

	Activities	Strategies
12.1	Facilitate access to medical care and anti-epileptic drugs	 a) Providing and facilitating early epilepsy diagnosis and treatment for 700 adults with epilepsy b) Providing and facilitating early epilepsy diagnosis and treatment for 300 children with epilepsy c) 300 patients to receive the benefit of nurse led clinical service d) Increasing supply and access to anti-epileptic drugs for 350 patients e) Increasing access to EEG services for 384 patients f) Provide 'Home Monitoring' service for 480 family
12.2	Clinical Training	 a) Providing clinical training to increase the number of nurses and health officers to treat epilepsy by 200 at the primary health care level.
12.3	Increasing education for patients and the general population to promote medical seeking behavior and inclusion and disassociate the undue stigma and exclusion placed on epilepsy patients;	 a) Educate the public through 30 radio programs and 5 TV programs b) Continue to give seizure first-aid response training for pupils, teachers and at workplaces c) Celebrate International Epilepsy Day in February 2023 d) Celebrate the 7th NEW and identify partners to work with us. e) Run 120 onsite epilepsy education in schools f) Run 20 onsite epilepsy education in companies
12.4	Improve 1000 patients' emotional and social wellbeing and 30 family economic wellbeing;	 a) Printing 'My Epilepsy Care' booklets for patients, the booklet provides information on epilepsy as well as a seizure monitoring diary (My Epilepsy Care). b) Continue to offer information on how to access help, available treatments and support and assist with long term referrals, c) provide emotional support through counselling and psychotherapy for 100 patients d) Schedule 12 PSGMs. e) Facilitate increased skill training to empower people with epilepsy to be self-sufficient through craft training and trading so that they are not living in poverty f) To move into safe, comfortable, convenient and affordable premises for our rehabilitation center g) 30 family to be supported through income generating activity to be self-sufficient.
12.5	Increase our partner organizations by 10 to expand our impact and influence on policies that affect people with epilepsy	 a) Use Patient Representatives Committee for advocating for policy change for epilepsy b) Advocate and support health care providers and our partners c) Increase our partner organizations by 10 d) Conduct 2 1-day workshops to initiate community conversation e) Hold 1 webinar where international partners are involved f) Encourage government health authorities and health

		facilities to take ownership of our program and invest in training and practice changes. g) Encourage neurologists and doctors to provide training through PR incentives for their association. h) Expand network with government officials, local and international NGOs and purse new alliances/partners to effect change successfully.
12.6	Increase financial capability	a) Continue to search for donors and partnersb) Explore corporates who take action to fulfil their obligation of corporate social responsibilities.
12.7	Volunteering and Internship	a) Gain 1 internb) Grow our professional volunteering team by 10c) Grow our youth volunteering team by 30
12.8	Organisation Development:	 Hold 8 half-day in-house training sessions Assign appropriate staff to 2 external trainings Review our organizational policy to adapt to change. Review staff development and training plan to align a workforce with the capability to perform in a complex environment and to adapt to change. Team Building Activity

13. OUR FINANCES

- a) CareEpilepsy Ethiopia is in the process of identifying international donors to build financial capacity and publicity;
- b) We completed the year 2021 by complying with the Ethiopian government policy of charities finance guideline "30/70" (Remarks: "30/70" means 70% of our project income is used on direct project cost, and only 30% of our project income can be used to fund core organizational costs or capacity building). Our final output was 80/20 (where 80 percent of the financial income both in cash and kind was used on direct project cost).

c) Funding Sources

Despite our efforts, funding for epilepsy remains limited. There are insufficient government, philanthropic, and commercial resources available to achieve our mission. During 2021, financial support came in the form of donations from sponsorships, fundraising activities and friends.

d) Auditors Report

2021 Audit report is submitted as Annex 1.

14. ACKNOWLEDGEMENTS & THANK YOU

CareEpilepsy Ethiopia wishes to thank the following organizations and individuals for their generous donation, hard work, time and patients.

14.1 National 44

- a) Our national youth and professional volunteers for their in-kind donations of service and other governmental and private organizations
- b) Association of Ethiopian Neurologists for their in-kind donations of service
- c) CareEpilepsy Ethiopia Advisory Board Members
- d) Yeka sub city
- e) Gulele sub city
- f) Awash Bank
- g) BGI Ethiopia PLC

14.2 International

- a) CareEpilepsy UK
- b) CareEpilepsy USA
- c) Friends of CareEpilepsy in Atlanta
- d) Selam Sisters, California
- e) William Grant & Sons

15. SUPPORT OUR WORK

- a) Today, more than 5 million children and adults and their family are affected by epilepsy
- b) Existing treatments are few and apart and too often have debilitating side effects
- Not enough funds are available at the national nor local level to fully support people with epilepsy and families impacted by epilepsy daily through local services
- d) Epilepsy is not discussed by the general public
- e) The social implication of epilepsy has not attracted a level of philanthropic support
- f) We have no data to show us how many people will die as a result of Sudden Unexpected Death in Epilepsy (SUDEP) in Ethiopia

We need your support to bring a laser-focused spotlight on epilepsy. Your investment will change lives by bringing much-needed resources to people impacted by epilepsy.

Become a member

Membership of CareEpilepsy is open to any individual with epilepsy, or organization and individuals working, or that has an interest in the field of epilepsy.

Volunteer your time

CareEpilepsy provides both long-term and short-term volunteering opportunities. We take volunteers from all walks of life, doctors, nurses, teachers, musicians, artists, counsellors, artisans. For international volunteers, there are clear benefits that overseas volunteering brings to Africa countries; however, the volunteer's benefit is equally priceless.

Become a corporate partner

CareEpilepsy's corporate partnership is a mutually beneficial arrangement where we gain funding, support and increased visibility; and the corporate gain good PR and the chance to "make a difference."

Donate

Our programs and effort to save lives and change perception of epilepsy cannot take effect unless we have financial support. Any amount you donate will be much appreciated.

16. CONTACT US

