



CAREEPILEPSY ETHIOPIA
SAVING LIVES | CHANGING PERCEPTIONS

ANNUAL REPORT 2018



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An overview of CareEpilepsy

ABOUT US

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

OUR PEOPLE

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

VISION

Our vision is to see people affected by epilepsy and associated disabilities receive the quality medical care they need, the public respect, fairness and understanding they deserve so that they can live a healthy productive life, free from discrimination and stigma, and have opportunity to realise their full potential.

MISSION

Our mission is to save the lives of people with epilepsy by facilitating epilepsy care through proper diagnostic tests and treatment options, strengthening the role of primary health care providers to enable the delivery of quality epilepsy services and change the perceptions of epilepsy through education, leadership and advocacy.

VALUES

Our core ethics which we abide by are compassionate care, dignity, integrity, partnership, accountability, innovation and inclusiveness

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 and equitable access to medical care and treatment.
- 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.

From the Desk Of The Executive Director

Dear friends and partners,

This year is our third full year of operation, and it has been busy with successes and a good deal of learning. We have been through an evolutionary stage during the past year, and instead of a fledgeling charity, we are now young with some rapid development and growth ahead.

In 2018, our programmes focus remained on improving the quality of life and relieving emotional suffering of people with epilepsy. Our operational emphasis was on building infrastructure, training volunteers, gaining new partners, recruiting staff, strengthening the work of the national advisory board.

I am proud to say that we renewed our charitable status in Ethiopia, relocated office, welcomed new staff, volunteers, and new Board members. Our communities are benefiting from our work in the form of increased access to medical care, anti-epileptic medications and psychosocial support.

During 2018 we assisted 54 people with epilepsy to gain access to clinical care and anti-epileptic medication. Our experience has shown to us that when confronted by an illness such as epilepsy, it not only affect the physical but also it touches the emotional, social, and spiritual wellbeing of those living with epilepsy and their families. Consequently, we believe epilepsy treatment must involve more than routine medical diagnosis and treatment. In order to support the wellbeing of our beneficiaries, we carried out 12 patient support group meetings in Addis Ababa, and 3 in Dire Dawa and a total of 225 and 78 people attended these support group meetings in Addis Ababa and Dire Dawa consecutively, which strengthen meaning, value, resilience, and dignity to patients. Our "Coffee Morning for Epilepsy Education" activity remained to be the favourite programme of our patients, where they come and chat over coffee and snakes developing friendship while doing their craftwork. We provided art and craft training for 15 women and men such as needlework and creative Christmas cards. Our Telephone Helpline continued to provide information and support. Our face-to-face counselling service empowered patients to look after their health and develop a definite sense of self-worth.

Our awareness-raising activities also continued to expand, and we hold various events to raise awareness to change the social norms and community perceptions about epilepsy. We were reported on eleven radio stations and three TV stations. We distributed over 20,000 leaflets and posters about epilepsy at tertiary referral hospitals, health centres, and schools and during our street campaigns. Our seizure@school programme continued to progress, and we provided epilepsy education to six schools for them to understand epilepsy better. We ran a summer school programme where children under the age of 16 with epilepsy and other disadvantaged children received tutorials to help them catch up academically, raise aspirations and knowledge about epilepsy. We also celebrated the 3rd National Epilepsy Week in Addis Ababa from the 12th-18th February 2018, ending with a walk on the 18th February 2018 were more 350 people were expected to have participated.

CareEpilepsy Ethiopia maintained to make significant progress with our advocacy work where our members elected a network of 5 empowered people with epilepsy, and one community member to become their advocates.

CareEpilepsy continued to make progress by heightening our sense of urgency, proposing meaningful action, and sparking essential conversations around epilepsy and its impact. Our partners, from government entities to the faith community has made us believe that there is a genuine groundswell of support for putting an end to epilepsy stigma and lack of access to medical care and drugs for people with epilepsy in Ethiopia.

As always, our youth volunteers have dedicated their time to raise awareness and support our office operational work. They exhibited great passion, developed fresh ideas and showed a willingness to go above and beyond for epilepsy during 2018. None of the achievements highlighted in this report would have been possible without our volunteers' commitment and dedication, and it is to them that we owe the continued progress of CareEpilepsy Ethiopia.

We have worked relentlessly over the past year to reach our goal and objectives in accomplishing CareEpilepsy Ethiopia's mandate. When we see patients and families share what it is like to live with epilepsy or care for someone with epilepsy, it is a job well done for us. Our success is the community's success. With the ongoing support of our donors, partners, board members, and volunteers, CareEpilepsy is ready for the challenges and achievements ahead in 2019. We aim to continue to make a positive difference in the lives of people living with epilepsy in Ethiopia.

Some of our priorities for 2019 include: strengthening the work of CareEpilepsy Ethiopia, continuing to develop and implement programmes, creating additional fundraiser activities, establishing a network of Epilepsy Charites in Africa, enhancing our current partnerships, both nationally and internationally, purchasing one EEG machine, and improving human capacity and leadership for epilepsy care to strengthen local nurses', health officers' and health extension workers' competence in the provision of adequate and sustainable epilepsy care.

CareEpilepsy Ethiopia looks forward to continuing their work to ensure that 2019 is another year of success.

Focus on Epilepsy



Enat Yewnetu
Founder and CEO

Epilepsy

NEURONS



- The brain is comprised of thousands of neurons – cells that process and transmit information by interacting with each other.
- In most brains, neuron interactions occur in a chaotic but balanced, orderly fashion with few disruptions.
- When multiple cells misfire at the same time it causes muscle twitches and spasms. This is a seizure.



WHAT IS A SEIZURE?

A seizure is defined as a sudden, a brief, excessive discharge of electrical activity in the brain that alters one or more of the following:

- Movement
- Sensation
- Behavior
- Awareness

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WHAT IS EPILEPSY?

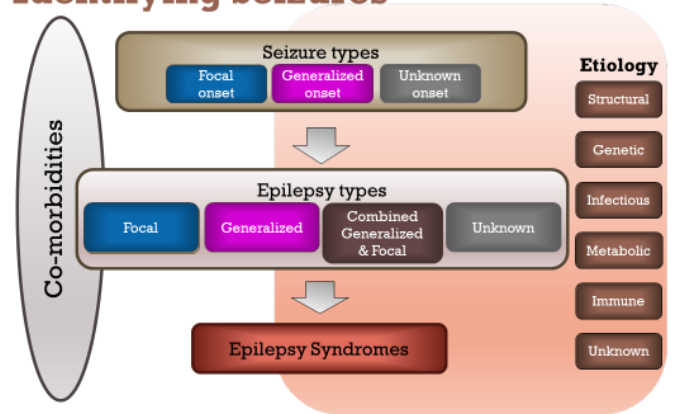


Epilepsy is a chronic neurological disorder characterized by a tendency to have recurrent seizures



Epilepsy is also known as a "seizure disorder"

Identifying Seizures



3

Focal seizures

- Originate within networks limited to one hemisphere
- May be discretely localized or more widely distributed....











- ✓ Full awareness maintained
- 🧑 Rhythmic movements (isolated twitching of arms, face, legs)
- 😬 Sensory symptoms (tingling, weakness, sounds, smells, tastes, feeling of upset stomach, visual distortions)
- 😬 Psychic symptoms (déjà vu, hallucinations, feeling of fear or anxiety, or a feeling they can't explain)
- 🕒 Usually lasts less than one minute
- 🧑 May be confused with: acting out, mystical experience, psychosomatic illness

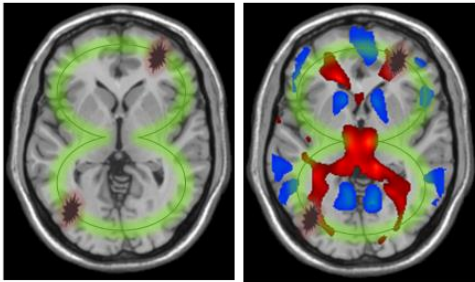
SIMPLE PARTIAL SEIZURES (FOCAL ONSET AWARE SEIZURES)

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Epilepsy

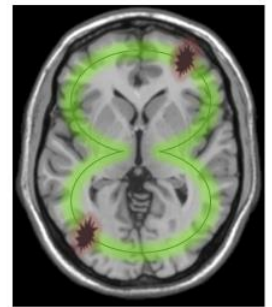
-  Awareness impaired/inability to respond
-  Often begins with blank dazed stare
-  **AUTOMATISMS** (repetitive purposeless movements)
-  Clumsy or disoriented movements, aimless walking, picking things up, nonsensical speech or lip smacking
-  Often lasts one to three minutes (1-3)
-  Often followed by tiredness, headache or nausea
-  May become combative if restrained
-  May be confused with: Drunkenness or drug abuse
Aggressive behavior







COMPLEX PARTIAL SEIZURES (FOCAL ONSET IMPAIRED AWARENESS SEIZURES)



GENERALIZED SEIZURES

- Originate at some point within and rapidly engage bilaterally distributed networks
- Can include cortical and subcortical structures but not necessarily the entire cortex



-  Atonic means a loss of muscle tone. In an atonic seizure, a person suddenly loses muscle tone so their head or body may go limp.
-  They are also known as drop attacks.
-  In some children, only their head drops suddenly.
-  Atonic seizures can begin in one area or side of the brain (focal onset) or both sides of the brain (generalized onset).
-  1-4 seconds
-  May involve head-nodding or sagging at knees

GENERALIZED –ATONIC (MOTOR)

Anything that disrupts the brain's natural circuitry can cause epilepsy, such as:

- Brain injury at birth
- Infections of the brain (e.g. meningitis, encephalitis, measles, malaria)
- Neonatal Seizures from Infection
- endemic parasitic diseases such as tapeworm.
- Brain trauma e.g. road traffic accidents.
- Brain lesions (e.g. tumours)
- Genetics
- For seventy percent (70%) of people with epilepsy the cause is unknown

THE CAUSES OF EPILEPSY IN ETHIOPIA

-  **DO NOT** put anything in the person's mouth during a seizure
-  **DO NOT** hold down or restrain
-  **DO NOT** attempt to give oral medications, food or drink during a seizure

DANGEROUS FIRST AID!!!

Highlights of the Year 2018 (Achievements and performance)

The highlights of our key activities from the year 2018 include:

a) *Free Community Clinic*

- 12 monthly free epilepsy community clinics were held by a neurologist at Yeka Health Center on the last Saturday of each month.
- 12 monthly free general health assessment clinics were held by a clinical nurse at Yeka Health Center on the last Saturday of each month.
- 1 neurologist, 2 psychiatrists and 1 specialist nurse were involved in running this clinic.
- We have gained commitment from Yeka Sub-City health centre to enable us to run a free epilepsy community clinic.

b) *Neuro-diagnostic service*

- 6 children received a free electroencephalogram (EEG) neurodiagnostic assessment.

c) *Anti-epileptic medication*

- Children and adults received free anti-epileptic medication or financial support to purchase anti-epileptic medication.
- The number of people adhering to the prescribing regimens by pharmacists/doctors has also increased through awareness-raising programmes that target people with epilepsy and their families.

d) *Epilepsy Education materials*

- We updated and revised our epilepsy educational materials, and these were distributed to local health centres to tertiary referral hospitals, health centres, schools and on street campaigns.

e) *Seizure4school*

- Awareness-raising, and Epilepsy First Aid training sessions were provided to students in 6 government secondary schools. CareEpilepsy delivered training to pupils and teachers to bridge the gap of education in epilepsy and show that most pupils with epilepsy can participate in all school activities.
- Children with epilepsy were given a seven-week summer class tutorial that aimed at educating them not only about epilepsy but also other subjects that would help them improve their academic performance.
- The summer was a very successful time for our organisation as we planned seven weeks, involving 29 volunteers, school education tutorial program for children with epilepsy and underprivileged children in Yeka sub-city.

f) *National Epilepsy Week*

- On February 12, 2018, about 350 people attended the 3rd National Walk for Epilepsy in Addis Ababa, starting from the Diaspora square and proceeding to the British Embassy. "The motto for the year was "Our Perception on Epilepsy has changed, How about yours?"
- Although this programme was planned to be held in one of the regions, it was unfortunate that we were not able to reach out to the regional cities due to political unrest in the country.
- This event has helped increase awareness of the attendees and the public through media coverages of the event.
- Epilepsy first aid was taught to the attendees on the day of the walk.
- Audio adverts and songs were played during the week and on the day of the walk.
- The week was a yearly educational event that provided a fun and exciting way to raise awareness in the community about epilepsy through the mass media and the public walk.

g) *Health Service Providers*

- We gave community education about epilepsy at health centres and specialised hospitals.

h) Street Campaign

- 3 days of street campaigns were held in Addis Ababa using audio education and printed materials.

i) Psychological Support

- As one of our objectives is to reduce epilepsy-related stigma and discrimination, we used a patient-centred approach, which started with interventions targeting the intrapersonal level, to empower affected patients and families. We gave a face to face counselling, and psychotherapy sessions to people with epilepsy and their families.

j) Patient Support Group meeting

- 12 monthly support group meetings were held where participants learned clinical facts about epilepsy, safety issues, and ways to live positively with epilepsy.
- People with epilepsy and their families were educated about the importance of achieving seizure-control through anti-epileptic medication, safety issues around the house and what and how they communicate with people around them and who may offer them help when needed.
- 3 psychologists who attended the meetings provided psychological support to the participants and taught them skills for better living; shared experiences and discussed ways of coping with stress.
- The Medical Director and Nurse Specialist of the Yeka Sub-City attended 2 meetings and listened to patients' concerns and challenges with their services. They provided patients with information on how to access medication and access to care for epilepsy from the Woreda Health Office.

k) Coffee Morning for epilepsy

"Coffee Morning for Epilepsy Education" was rolled out based in the CareEpilepsy office in Addis Ababa, where patients have a chat and share their experiences of living with epilepsy over a cup of coffee or tea. The programme is held on a bi-weekly basis. When people feel relaxed and comfortable, they are more likely to talk about their challenges and to listen!

l) CareCraft

38 sessions of CareCraft programme were held, and CareEpilepsy Ethiopia provided material for doing different crafts such as table mat, coffee mat, needles, thread, and cards and craft beads.

m) Helpline

Anyone affected by epilepsy was offered emotional support (counselling), action plan support (coaching), assisted with long term referrals, and connect them to our services via our telephone Helpline throughout the year.

n) Patient representatives

- 12 Patient representative meetings were held, and more than ever, there seems to be a commitment from members to engage in raising awareness and putting forward the concerns of people with epilepsy.
- The patient representatives themselves also led our patient support group meetings.
- 1in-house epilepsy training sessions were given to representatives.

o) Advocacy

- In collaboration with the Addis Ababa University, research was conducted that addressed the availability and access to anti-epilepsy medication.
- We were able to continue to develop our partnership with Yeka Sub-City Health Office, specifically through monthly patient support group meeting and the organization of National Epilepsy Week.
- We worked to expand our horizon to attract new partners in our project for epilepsy prevention, care and support. We were delighted to be able to engage Bole Sub-City, which is an addition to the current sub-city that we assist.
- We continued to strengthen partnerships with Addis Ababa Health Bureau, Federal Ministry of Health, and the Southern Nations, Nationalities, and Peoples' Region Health Bureau,

through initiation and implementation of joint projects and dissemination of epilepsy information through health offices.

- We signed an MOU with Addis Ababa Health Bureau, and Bureau of Finance and Economic Development (BoFED).
- We developed a 'Faith Advocacy Toolkit' for the faith and community leaders to teach their congregation about epilepsy and how to deal with the social and cultural issues (Train-the-trainer course concept) and to strengthen their advocacy to reduce the stigma of epilepsy and increase social inclusion.

Our Objectives and Strategic Objectives for 2018

1. General Objectives of our organisation

Our goal is to close the gap between knowledge and action in medical care and treatment, build clinical care providers' capacity to treat epilepsy, enhance the public awareness on epilepsy and associated disabilities, patient education, and engage in partnership and advocacy work.

2. Our Strategic Objectives for 2018 were to

- a) Facilitate access to medical care and anti-epileptic medications
 - Continue to develop the service of free epilepsy clinic.
 - Increase access to anti-epileptic drugs
 - Strengthening existing epilepsy care providers through clinical training
 - Identify partners to establish new centre of excellence in neurology
- b) Continue to educate the public and raise awareness of epilepsy
 - Reduce the epilepsy information gaps in the country.
 - Continue to give seizure first-aid response training for patients, pupils, and teachers.
 - Organise the 3rd National Epilepsy Week in joint partnership with the Federal Ministry of Health, and Yeka Sub-City.
- c) Improve the wellbeing of people with epilepsy by addressing the psychosocial factors affecting their lives.
 - Improve our patients' life situations and overall wellness by providing them with epilepsy education and psychological support
 - 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.
- d) Promote epilepsy and the needs of people with epilepsy through advocacy and partnership with key partners and stakeholders.
 - Establish a patient representative committee.
 - Hold Community conversations.
 - To advocate and support the FMOH 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.
 - Strengthen our relationship with Yeka Sub-City Health Office by engaging them in our monthly free clinic; using them as a referral centre for patients to receive counselling and psychological support, and participating in the yearly national epilepsy awareness week programme.
 - Initiate a new partnership with Bole sub-City to expand CareEpilepsy Ethiopia's services.
 - Strengthen partnerships with Addis Ababa Health Bureau, Federal Ministry of Health, and Region Health Bureau through initiation and implementation of joint projects of awareness-raising through National Epilepsy Week and dissemination of epilepsy information through health offices.

e) Financial Sustainability

- :- Increase financial capability through donors, sponsors and other fundraising activities, both nationally and internationally.
- :- Continue to develop the financial planning and management of our projects.

f) Develop both national and international volunteering and internship schemes.

g) Organisational Development through increased human resources, capacity building, governance and policy review.

Review of Planned Activities For 2018

Objective	Activities	Achieved	Not Achieved	In Progress	Remarks
Objective 1	Facilitate access to medical care and anti-epileptic medications. We do this by engaging in the following activities.				
	Activity 1.1. Clinic-based epilepsy management <i>- Organise consultation and referrals to available epilepsy clinics, both government and private</i> <i>- Establish CareEpilepsy Ethiopia's Free Epilepsy Clinic</i> <i>- Establish a Child Epilepsy Service.</i>	✓ ✓			
	Activity 1.2. Anti-epileptic Drugs (Drugs4epilepsy) <i>- Supply and maintain cost-effective and adequate supplies of anti-epileptic drugs of proven quality.</i>	✓			
	Activity 1.3. Neuro-diagnostic service (Equipment4epilepsy) <i>- Building up an adequate resource of modern diagnostic equipment.</i>			✓	
	Activity 1.4. Improve Human Capacity and Leadership (Clinical Training/TOT) <i>- Face-to-face training</i> <i>- Epilepsy-On-the-Net Training Programme</i>	✓		✓	
	Activity 1.5. Mobile Epilepsy Service <i>- Build a mobile epilepsy service for diagnosis, treatment and on-going management of epilepsy in rural communities.</i>		x		<i>Due to priority of project based on funding.</i>
	Activity 1.6. Telemedicine <i>- Run a Telemedicine program via the Internet using videoconferencing to enable nurses and doctors to develop expertise where they face challenges in diagnosis and treatment.</i>		x		<i>Due to priority of project based on funding.</i>

Objective	Activities	Achieved	Not Achieved	In Progress	Remarks
Objective 2	Public Education and Awareness - to increase social acceptability. We do this by engaging in the following activities.				
	Activity 2.1. Epilepsy Education Materials	✓			<i>No DVDs were produced due to Lack of funding.</i>
	Activity 2.2. Epilepsy Education Program <i>- Establish educational program for children, youth and adults living with epilepsy.</i>	✓			
	Activity 2.3. Raise awareness of epilepsy in the community <i>- Epilepsy Education at hospitals and health centres</i> <i>- Campagine4epilepsy</i> <i>Hold the 2nd National Epilepsy Week in Bench Maji Zone.</i>	✓			
	Activity 2.4. Raise awareness of epilepsy in other professions <i>- 'School Epilepsy Champions' - Seziure@school</i> <i>- 'Employer Epilepsy Champions' - Seziure@work</i>	✓	x		<i>Lack of focus and engagement from partners.</i>
Objective 3	Improve the wellbeing of people with epilepsy by addressing the psychosocial factors affecting their lives. We do this by engaging in the following activities.				
	Activity 3.1. <i>CareEpilepsy Rehabilitation Center</i> <i>- Establish a CareEpilepsy rehabilitation centre to provide training in life skills, vocational skills, and self-management skills, and to house modern diagnostic facilities to improved quality of life.</i>	✓			
	Activity 3.2. <i>Helpline4epilepsy</i> <i>- Establish a telephone helpline and an Epilepsy Emergency Ambulance Service.</i>	✓			
	Activity 3.3. <i>Connect4epilepsy</i> <i>- Establish peer support groups to provide counselling, social and recreational activities.</i>	✓			

Objective	Activities		Achieved	Not Achieved	In Progress	Remarks
	Activity 3.4.	<i>Counselling4epilepsy</i>	✓			
	Activity 3.5.	<i>Wolafen</i> - Provide financial assistance for improvement of domestic environments such as building safe cooking stove.		x		<i>Due to priorities of projects and lack of sponsors.</i>
	Activity 3.6.	<i>Income Generating Activities (IGA) - CareCraft</i> - Design Income Generation Programs. This aims to provide PWE with opportunities for both social and economic development.	✓			
Objective 4	Advocacy in partnership to influence public policy and organizational practice. We do this by engaging in the following activities.					
	Activity 4.1.	<i>Patient Representative Committee</i>	✓			
	Activity 4.2.	<i>Community Conversation</i> <i>Involve the community to address pressing issues facing people with epilepsy and in supporting people with epilepsy and their families.</i> - <i>Training Workshop</i> - <i>Faithaction4epilepsy</i> - <i>Online community forum</i>	✓	x	x	<i>Lack of funding to start the project.</i>
	Activity 4.3.	<i>Partner4epilepsy</i> - <i>Build partnerships with joint stakeholders develop partnership strategies for epilepsy prevention, care and support.</i>			✓	
	Activity 4.4.	<i>Research4epilepsy</i> <i>Conduct clinical audit, epidemiological surveillance, research to provide evidence-based service and develop best practice guidelines in collaboration with national and international experts.</i>		x		<i>Lack of interest from the MOH and funding to start the project.</i>

Activities and Impact of Work in Communities

Strategic Objective 1: *Facilitating access to medical care and anti-epileptic medication in 2018*

The followings are the various activities that we employ to accomplish our strategic objective 1.

Activity 1.1 Epilepsy clinic

- 12 paediatric neurology clinic was given by Dr Kindu, a Pediatric Neurologist
- 12 clinical nurse care was given by Sister Kelemwork, a clinical nurse at the United Nations office. Further follow-up appointments are scheduled for them.
- Continued to organise consultation with and referrals to available epilepsy clinics, both government and private.

Activity 1.2. Drugs for epilepsy

- Financial aid to purchase anti-epileptic medication was given out to patients who were economically unable to do.

Activity 1.3. Equipment for epilepsy

- Although we were not able to procure our own an electroencephalogram (EEG), we paid for our patients to receive the service at a different place.

Activity 1.4. Clinical Training

- Due to lack of funding, we were not able to run any training course.

Table 1 - Anti-Epileptic Medication Used

Anti-Epileptic Medication Used
Phenobarbital
Phenytoin
Sodium valproate/Epilim
Carbamazepine/Tegretol
lamotrigine

Table 2 - Reported Side effects of anti-epileptic medication (anticonvulsant)

Reported Side effects of anti-epileptic medication (anticonvulsant)
Hyperactivity/Aggression/Irritability
Dizziness/Unsteadiness
Drowsiness/sedation/fatigue
Loss of memory or concentration
Headache
Skin rash
Trouble sleeping
Depression/Anxiety
Weight gain/weight loss

Impact

- 35 people with epilepsy to be self-motivated to access and receive epilepsy care by attending the hospital for the first time. Out of these, 30 were adults, and 5 were children.
- 2 people acquired due to our intervention the 'poorest of the poor' card given by the government indicative of their poverty status, which allows them to access medication and care for free.
- Yeka Sub-City Health Office has grown their orders for anti-epileptic medication so that patients can have access to medication.
- 120 children were seen by a paediatric neurologist and by a clinical nurse specialist
- 12 children were given free anti-epileptic medication, and 6 were supported financially to buy their medication.
- 6 children received a free an EEG neuro-diagnostic service.
- 12 people with epilepsy were helped to become self-motivated to access and receive epilepsy care by attending hospital for the first time in Addis Ababa.

Strategic Objective 2: Public Education and Awareness in 2018

The public education and awareness programme remains our primary pillar of intervention, and it aims at promoting the inclusion of people with epilepsy in education, the workplace, and the community. Our awareness programs aim to mobilize communities to help decrease the gap of knowledge and change social norms and community perceptions of epilepsy. The followings are the various activities that we employ to accomplish our strategic objective 2.

Activity 2.1. Epilepsy Information Leaflet

- Epilepsy educational materials such as leaflets, posters and banners were produced to increase knowledge of epilepsy in the community. This is available in Oromo language and Tigrinya.
- Seizure record sheet was also incorporated in this for patients to keep a record of their seizure frequency to assist doctors to prescribe the right dosage of medication.

Activity 2.2. Campaign4epilepsy

We marked the 3rd National Epilepsy Week from the 12th February – 18th February 2018 in Addis Ababa. The walk and closing ceremony were carried out on February, 18th 2018 about 350 people attended the 3rd National Walk for Epilepsy in Addis Ababa, starting from the Diaspora square and proceeding to the British Embassy, an event that has helped increase awareness of the attendees and the public through media coverage such as the mainstream media, social webs and the CareEpilepsy website, Epilepsy information leaflets, flyers and posters both in Amharic and Oromifa of the event. Epilepsy first aid was taught to the attendees on the day of the walk. Audio adverts and songs were played during the week and on the day of the walk. The week was a yearly educational event that provided a fun and exciting way to raise awareness in the community about epilepsy through the mass media and the public walk. The guest speaker was the Director of Yeka Sub-city Health Office.



DIASPORA
SQUARE,
MEGENAGNA
ADDIS ABEBA

18th February 2018



Activity 2.3 Seizure@school

Our 'School Epilepsy Champions' initiative grew more than last year. CareEpilepsy Ethiopia delivered training about epilepsy and seizure first-aid response to pupils and teachers at Ethio Parents Private School, Nazareth School, School of Tomorrow, Saint Joseph School, Young Roots, Vision Academy. This initiative is expected to bridge the gap of knowledge in epilepsy, reduce the stigma faced by children and open doors for children with epilepsy to receive education and participate in all school activities. The activity directed to teachers to equip them to support their students with epilepsy and make the school a safer environment. Although we continued to teach at line up sessions in the morning, it has been difficult to secure sufficient time for education.

It was our first time to run a 7 weeks summer school tutorial program for children with epilepsy and underprivileged children.



CAREEPILEPSY ETHIOPIA RIASING AWARENESS OF EPILEPSY •
KOKEBE TSIBAH SECONDARY AND PREPARATORY SCHOOL.
2018



Activity 2.4. Epilepsy Education at hospitals and health centres

We run 12 sessions of community education in Yeka health centre and 12 sessions at Yekatit 12 teaching hospital.

Impact

- We disseminated over 30,000 leaflets and 5000 posters for epilepsy education in tertiary referral hospitals, health centres, and schools and during our street campaigns.
- 4200 pupils 120 teachers received epilepsy education and seizure first-aid training.
- More than 350 people increased their knowledge of epilepsy by attending the closing ceremony of the 3rd National Epilepsy Week.
- More than 600 members of the community who received treatment at Yeka health centre gained knowledge about epilepsy knowledge at Yeka health centre.
- More than 480 families of children with epilepsy received epilepsy education at epilepsy children clinic at Yekatit 12 teaching hospital.
- Around 4.8 million people reached through talk show and radio interviews in Addis Ababa.
- Around 20 million people reached through electronic media during the celebration of the 3rd National Epilepsy Week

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

The followings are the various activities that we employ to accomplish our strategic objective 3.

Activity 3.1. My Epilepsy Care

- 11 teaching sessions were organised to educate people with epilepsy of the risks of untreated seizure, prevention, causes and consequence of epilepsy.
- CareEpilepsy Ethiopia designed epilepsy information leaflet to benefit 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 and wellbeing. Seizure record sheet was designed for patients to record their seizure pattern to assist doctors to prescribe the right dosage of medication.
- "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.

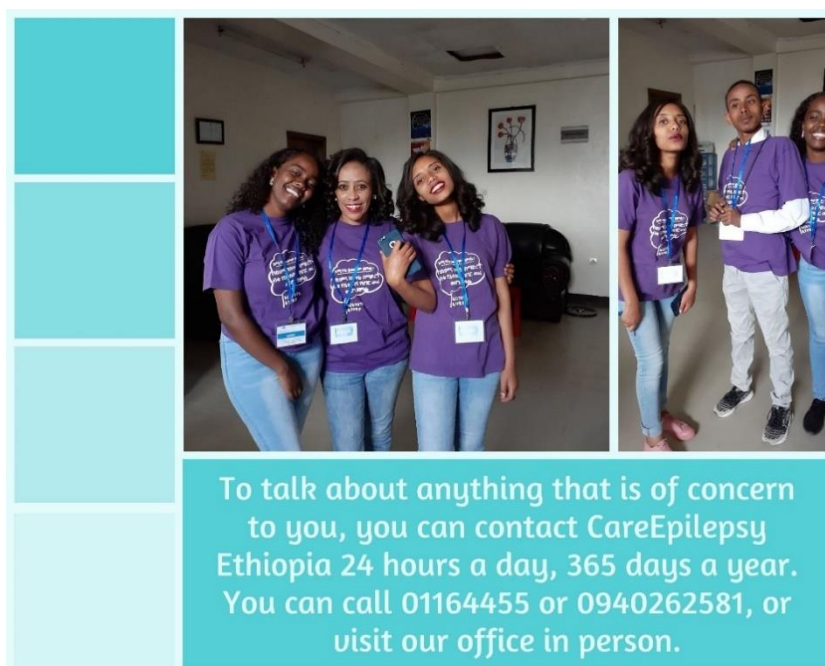
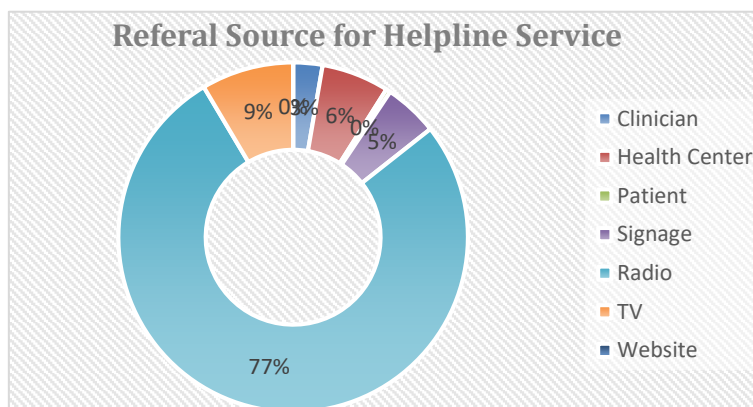
Activity 3.2. Helpline4epilepsy

Our confidential Helpline, open 24 hours a day, 7 days a week, 365 days a year, has trained information specialists standing by to answer callers' questions about epilepsy and seizures and provide support, guidance, and access to national and local resources to people who are affected by epilepsy.

Table 3 - Referral sources for Helpline Service

Referral Source	Number of patients
Clinician	78
Health Center	120
Patient	0
Signage	114
Radio	560
TV	70
Website	18

Figure 1



Activity 3.3. Connect4epilepsy

a) Patient Support Group

Our peer-support group meeting continued to flourish. 12 monthly peer-support group sessions were run, and we covered the attendees' transportation cost. Our support group fulfilled many functions: educating patients/family about epilepsy, emotional and moral support for one another, sharing epilepsy experience, providing a coping mechanism to patients and families, raising public awareness, and improve their sense of belonging and connectedness.



CAREEPILEPSY ETHIOPIA

PATIENT SUPPORT GROUP MEETING

@ Yeka Sub-City center

b) Coffee Morning for epilepsy

Our bi-weekly 'coffee morning for epilepsy' project is where people with epilepsy share experiences in a smaller setting while doing craftwork. Although the people who attended the coffee club programme are enthusiastic about it, it has proven challenging to involve more participants.

Activity 3.4. Counselling4epilepsy

Our counselling service provided practical advice and information about living with epilepsy.

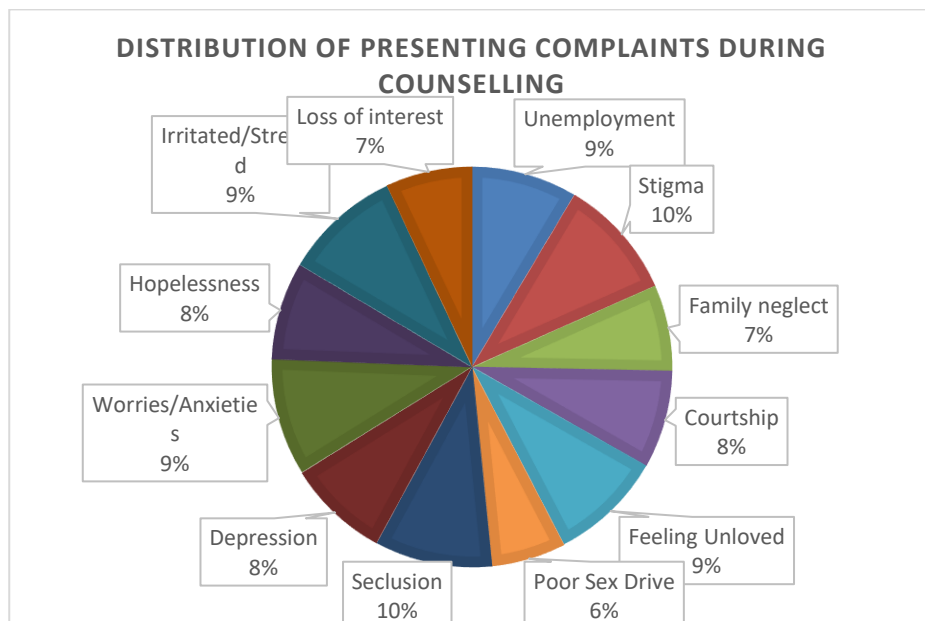
Table 4 – Beneficiaries who received counselling and psychotherapy

Beneficiaries who received Counselling During 2018	
Male	Female
20	48

Table 5 - Distribution of Presenting Complaints During Counselling

Distribution of Presenting Complaints During Counselling		
	Female	Male
Unemployment	39	18
Stigma	48	20
Family neglect	40	12
Courtship	42	10
Feeling Unloved	47	16
Poor Sex Drive	14	16
Seclusion	40	19
Depression	48	18
Worries/Anxieties	47	20
Hopelessness	44	15
Irritated/Stressed	24	13
Loss of interest	22	16

Figure 2



Activity 3.5. Microenterprise identification.

a) CareCraft (Microenterprise Development)

We continued with our CareCraft programme where women advanced to weave carpet as an income-generating project. CareEpilepsy Ethiopia provided tools and raw materials for their practical work. This is a platform where people with epilepsy receive training for life skills, vocational skills, and self-management skills, which addresses the psycho-social and economic issues which they face. We continued to provide breakfast, lunch and transportation of patients.

b) Develop business plans.

A business plan for microenterprise development training is compiled and looking for funds to start the project.

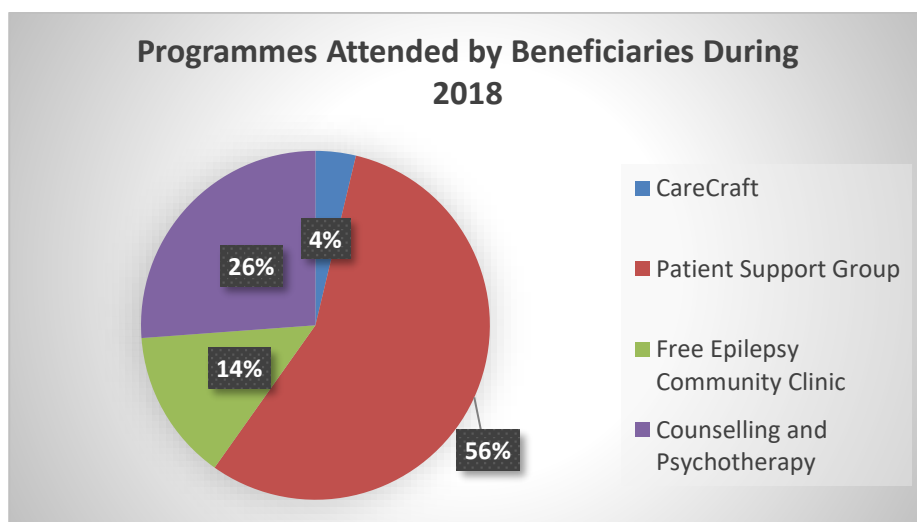
c) Monitoring and Ongoing Support

Business mentors and project staff met regularly to provide monitoring and ongoing support for our project beneficiaries.

Table 6 - Programmes Attended by Beneficiaries During 2018

CareCraft	Coffee Club	Patient Support Group	Free Epilepsy Community Clinic	Counselling and Psychotherapy	Helpline
15	15	225	120	68	960

Figure 3



Impact

- 22 families taught the risk of non-adherence to anti-epileptic medication and encouraged to assist their children to continue with their clinical care and treatment consistently.
- 960 people with epilepsy and their families gained access to a dedicated confidential 24/7 Helpline service that provides them with necessary clinical information, counselling and support.
- 12 Patient Support Group Meetings were organised, and 225 people living with epilepsy and their families attended the programme. Transportation cost, for the patients, to attend the meeting was covered.
 - 93% of patients felt less isolated and part of a broader community of people with epilepsy (210 out of 225).
 - 84% of patients felt more confident in discussing epilepsy with healthcare professionals (190 out of 225).
 - 46% of patients felt more confident being open about their epilepsy (105 out of 225).
- 15 people with epilepsy involved in coffee morning programme and attended 46 session.
- Through CareCraft,
 - o the women learned to engage in group discussions and learnt the skill of self-management.
 - o The women formed a friendship with other members.
 - o 15 women completed for 6-month self-management and carpet weaving training.
 - o 100% of women who were included in CareCraft training felt empowered, and their self-esteem increased.
- 68 people benefited from our face-to-face counselling services felt they have the confidence, knowledge, skill, and support they need to manage their epilepsy effectively.

Strategic Objective 4 - Advocacy and partnership to influence public policy and organisational practice to address the medical, social, environmental factors contributing to epilepsy. We do this by

The followings are the various activities that we employ to accomplish our strategic objective 4.

Activity 4.1. Patient and Family Advocacy Group

- Epilepsy advocacy group is an effective way of pushing the epilepsy agenda and putting pressure on national governments to observe the right to health. The group's primary interests are improving epilepsy awareness and understanding and access to care and treatment.

Activities:

Established patient representatives to give the beneficiaries a voice about their concerns.



Impact

A network of 5 empowered people with epilepsy and 1 community member formed a group as patient representatives and advocates. They support the work of CareEpilepsy Ethiopia and promote their rights as they navigate through the epilepsy care system.

Activity 4.2 Community Conversation

Our community conversations are an intervention method through which local people work with a facilitator to collectively identify local strengths and challenges and brainstorm potential strategies for solving epilepsy problems in the community. Community conversations have the potential to strengthen positive responses to epilepsy stigma reduction and increase the knowledge gap.

- Training Workshop

Due to lack of finance we were not able to run a workshop however, we initiated community conversation with various groups of society to find way forward to reduce the stigma of epilepsy and support for people with epilepsy and their families in Addis Ababa.

Activity 4.3 Partnership for epilepsy

1. Public Policy Change

Advocacy is an essential means of raising awareness on epilepsy issues and ensuring that epilepsy is on the national agenda of the government. Through our advocacy work, we engaged in discussions with various sectors of the government legislators, voluntary agencies, line ministries (Labour, Women's and Children's Affairs), that can lead to improvements in policy, legislation and service development.

2. Disability and Discrimination

Safeguarding disability rights of people with epilepsy. Under Ethiopian law, organisations are not allowed to discriminate, harass or victimise anyone with a disability.

Activities:

It has proven to be a challenge to get the interest of organisations to engage in this programme.

1. Establish Ethiopian Epilepsy Association

It will take time for patients to understand the need for organized association therefore, we have moved this activity for the year 2017.

Activities:

Discussion is in progress with the Ministry of Education and the Ethiopian Teachers' Association to provide equal access to education for children with epilepsy and train teachers in epilepsy and seizure first-aid to equip them to support children with epilepsy.

Activity 4.4 Research for evidence-based care

- ❖ The promotion of research to gain a better understanding of the current prevalence and incidence of epilepsy in Ethiopia, the aetiology of epilepsy, and, ultimately, provide evidence-based care and decrease the prevalence and incidence of epilepsy in Ethiopia.

Activities:

Steps for research is being discussed and working on securing government funding for epilepsy programs, research and treatments at institutions including the Federal Ministry of Health, Ethiopian Public Health Institute, and Ethiopian Food and Drug Administration in collaboration with CareEpilepsy Ethiopia and international funding.

Impact of our strategic activities to achieve objective 4

- ❖ The Federal Ministry of Health acknowledged the knowledge gap of epilepsy in the community as such agreed to cover paid the printing cost for epilepsy information leaflets for patients and families.
- ❖ In discussion with the Labor and Social Affairs Ministry to enforce the law and require organisations to give equal opportunity for people with epilepsy in employment. As a regulator, we are putting pressure on the Ministry to take the equal opportunity seriously so that people with epilepsy are not denied employment.

Volunteering and Internship

7.1 Volunteering

Youth4Epilepsy Ethiopia volunteers continued to make an impact through their engagement Activity fwith CareEpilepsy Ethiopia. We managed to recruited 110 volunteers and they had a notable impact on our awareness-raising program. Our volunteers played a role in the organization and participation of the National Epilepsy Week and distributed epilepsy information materials to clinics, hospitals, health posts, and schools. All volunteers have received a half-day in-house training on facts about epilepsy, and Epilepsy First Aid. The course delivered medical and statistical information and knowledge about the resources CareEpilepsy can provide in the form of leaflets, posters and DVDs During 2018.

7.2 Internship

Hlina Sirak was our intern at CareEpilepsy Ethiopia from Washington DC, the USA during July. She had the opportunity to learn about epilepsy and engage with people with epilepsy.

Impact

- ❖ 74 volunteers actively engaged in advancing the activities of CareEpilepsy donating a total of 6400 hours.
 - 95% of CareEpilepsy Ethiopia volunteers who attended our in-house training acquired new knowledge about epilepsy and stated its impact on their individual life (70 out of 74 attendees).
- ❖ 3 street campaigns covering Arada, Yeka, Bole, Gullele, Lideta Sub-Cities were held during National Epilepsy Week.
- ❖ 36 volunteers taught Math, English, Science and life skills for 350 students attending the summer course in the year.

Media and Communication

8.1 Media Engagement

- a) A press conference was given by the CEO of CareEpilepsy and Yeka Sub-City Health Office Director regarding the impact of the 3rd National Epilepsy Week on the community.
- b) Epilepsy was raised and discussed through talk shows and interviews through the mainstream TV programmes that have popular viewers such as AfriHealth, ETV, EBS, JTV, and Fana.
- c) Radio stations that have a significant number of listeners such as Sheger, Zami, FM 90.7, Fana, and FM Addis were used.

8.2 Communication

a) Website

Our website was an avenue of communication to give education about epilepsy and show the progress of the work of CareEpilepsy Ethiopia.

b) Social Media Activism: Raising Awareness in Social Movement

We believe 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 offer, such as posting, liking, sharing info, news and photos, reblogging, commenting and sparking discussions and debates as our online communication channels. Unfortunately, during 2017 we did not maximise the use of social media due to a lack of funding to employ a dedicated person for the job.

c) Speaking Engagements

We had speaking opportunities at the Federal Ministry of Health's Health Strategy Setting meeting in Nazareth and various government schools to raise awareness about epilepsy.

Impact

Mass media campaigns designed to raise awareness of epilepsy have shown immediate and significant effects in the promotion of medical seeking behaviour and voluntary counselling and adherence to anti-epileptic medications.

Development Partners

The solutions to epilepsy problems in Ethiopia are too complex to be solved by an individual organisation. Therefore, CareEpilepsy Ethiopia is aware of the importance of developing partners to help us incubate new ideas and allowed proven solutions to be scaled up. Therefore, 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, employment. During 2018, our partners provided essential funding and support in the form of cash and in-kind assistance which strengthen our impact by channelling resources to initiatives that improve the lives of people with epilepsy. Our partners for 2018, that engaged in our work, were neurologists, general practitioners, sub-cities, and Ethiopian Neurologist Associations.

This activity directed at developing partnership strategies for epilepsy prevention, care and support.

- Continued dialogue with Addis Ababa Health Bureau, Federal Ministry of Health, and the Southern Nations through initiation and implementation of joint projects and dissemination of epilepsy information through health offices.
- Initiate a new partnership with Bole Sub-City to extend care epilepsy services.
- There is a dim light of acknowledgement from the Federal Ministry of Health and regional governments about epilepsy being a public health issue and should be one of the health priorities.
- Discussion is continued with the Ethiopian Midwives Association (EMA) to achieve best practice for people with epilepsy.
- Discussion is underway with the Federal Ministry of Health, the Ethiopian Midwives Association (EMwA), Gonder University, Jimma University, and Addis Ababa University to achieve best practice for people with epilepsy.
- As a regulator, we are putting pressure on the Ministry of Labor and Social Affairs to enforce the law of equal opportunity 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 were able to continue to develop our partnership with Yeka Sub-City Health Office, specifically through monthly patient support group meeting and the organization of National Epilepsy Week. We worked to expand our horizon to attract new partners in our project for epilepsy prevention, care and support.

Impact

We provided training for teachers in epilepsy and seizure first-aid to equip them to support children with epilepsy.

Organisational Development

a) Organisation Policy and Procedures

A 'Policy' is a predetermined course of action, which is established as a direct link between our vision, mission and objectives and our day-to-day operations. Our policies help us identify the key activities and provide a general strategy to decision-makers on how to handle issues as they arise.

Our ultimate goal of our 'procedure' is to provide the reader with a clear and easily understood plan of action required to carry out or implement a policy. A well-written procedure will also help eliminate common misunderstandings by identifying job responsibilities and establishing boundaries for the jobholders.

- CareEpilepsy Ethiopia Staff Planned in 2016 set the following organisational development and culture goals:
- Building organisational systems that align to realise a workforce with the capability to perform in a complex environment and to adapt to change.
- Develop organisational policy such as human resources, finance, recruitment and selection and communication policy.
- Developing a culture of staff who recognise and value different perspectives, work together well and engage with others to create desired outcomes.
- Staff development and training plan was created.

b) Recruitment and Selection

We believe recruitment along with financial and material resources, contribute to the accomplishment of our objectives. Our recruitment processes and procedures is developed in a way which all applicants must pass through; that all applicants must all be treated equally, and that what constitute qualification and merit must be well spelt out to include applicant ability to “deliver” and not just ‘paper’ qualification.

Achievements During 2018

- :- New recruitment, selection and appointment policy were completed.
- :- Work continued aligning planning, performance reporting, capability and roles.
- :- The new remuneration system was fully implemented.
- :- A review of the standard operating procedures system was completed. This work will continue as part of ongoing system development.

c) Staff Training and Development

CareEpilepsy Ethiopia has not been successful to give external training for our staff due to lack of finances, however internal training to improve the level and quality of their work was given. Staff also received cross training where they can do other jobs within the orgnsiation. The time taken show a high return on investment due to a workforce with renewed motivation, new skills, and strengthened morale.

Achievements During 2018

We hold 8 staff training sessions where staff had the opportunity to ask questions and receive resources for detailed reading. The one-day in-house training include:

- epilepsy and epilepsy first aid (x2)
- compassionate care
- communication skills
- team work
- presentation skills
- conflict resolution
- leadership skills
- time management
- CareEpilepsy Ethiopia

Impact

- :- Staff increased their knowledge about epilepsy and epilepsy first aid, communication skills, compassionate care, and team work.
- :- The dedicated time taken to train our staff and improve their skills has shown to give them great motivation to do their job well as well as feeling valued and appreciate.
- :- This has, to some extent, helped to free up the time of the chief executive officer and other members of staff and allowed them to become more independent in the workplace.
- :- Increased productivity levels across the board, meaning more work is being performed.
- :- Cross training proved to help employees better do their primary jobs. They also gained skills that they can apply to their tasks. And, help them know what to expect from co-workers in other positions.
- :- We managed the shortage of staff within the existing staff by crosss train them.
- :- Cross training allivated the burden of shortage of staff during the year.
- :- Help build relationships amongst staff.

Governance and Management

CareEpilepsy regularly consults with people with lived experience, both nationally and internationally, to help develop long-term strategy as well as services, projects, and

campaigns. As an organisation, during 2019, we made a focus to build good governance which is key to the growth and sustainability of Careepilepsy Ethiopia. We spent hours of discussions with our governing Body on building strategic thinking and oversight characterize the board's leadership role.

We have put in place structures for reporting, accounting, evaluation so that people so that we build the confidence of our funders.

We have strengthened our self-regulation through norms of corporate governance such as the timing of reports, issues to be publicly disclosed, staffing policies, sources of finance and auditing and evaluation arrangements.

10.1 Governance

a) Board of Directors

CareEpilepsy functions with Boards of Directors and Advisory Boards in the UK and Ethiopia. The Boards play an active role in forming all elements of CareEpilepsy's strategy and helping develop work programmes that are now in place.

National Advisory Board meeting quarterly but also provide expert advise in interim and reviews both physical and financial reports. We used national board members' skills and expertise (i.e., a board member with financial experience supported us on financial matters. Understanding the clients' needs serves on the program committee

More than ever before, the national advisory board members are aware of all of the organization's activities and encourage inappropriate participation activities in the community. During 2019, the board seeks opportunities to enhance the public image of the organization.

b) Patient Representative Committee

Patient Representatives Committee meetings on a month by basis and follow-up programmes and activities Providing opportunities to become involved and serve the organization.

10.2 Management

a) Management

- The chief executive director was responsible for the overall direction in which CEE moves, and the day-to-day activities of CareEpilepsy Ethiopia.
- The Administrative Manager and Finance Manager managed financial and administration work and teams to achieve our financial goals. Their job involved supervising financial management of projects and accounts; implementing and controlling the accounting management; keeping track of spending against CareEpilepsy Ethiopia's annual budget; training, supervising administrative clerks who come for work experience and volunteers in general.

b) Project Management

All project assignments were completed with the current staff and volunteers.

Significant Issues/Challenges facing CareEpilepsy in 2018 and beyond

In order of impact	Challenges/Issues	Challenges/Issues Explained	Proposed Solutions
1	Financial sustainability	Financial constraints are still a problem limiting our engagement, and the number of people with epilepsy we could reach out the to.- Frequent move of office in search of cheaper rental office causes loss of patients and stable engagement with communities	<ul style="list-style-type: none"> - Diversify funding sources - Identify donors with a focus on corporate partnerships to help them achieve their social mission.
2	Manpower/staff	CEO covering the two offices is a challenge. We still rely on our volunteers as our office has got only 3 full time and 1 part-time member. The amount of workload has affected the efficiency of our staff. The lack of expertise has a drawback on our engagement.	<ul style="list-style-type: none"> - Increasing expertise at the national level through training and partnership with higher education institutions. - Develop strategies to generate revenue to finance the justifiable, affordable and minimum level of staff.
3	Patients Expectations	Due to financial constraints, CareEpilepsy Ethiopia is not able to satisfy the medication needs of patients. On the other hand, patients are putting increasing demands on CareEpilepsy Ethiopia to provide medication or financial support to buy medication. This has also affected the other programmes of CareEpilepsy as they lack interest in the awareness-raising programs without the provision of free medication.	<ul style="list-style-type: none"> - Engage with government authorities, politicians, community leaders and other partner organisations to realise affordable or free medication.
4	Stigma	Although some encouraging progress has been made, stigma about epilepsy is still a challenge affecting the involvement/ engagement of patients and their families in our activities. CareEpilepsy Ethiopia, as an organisation, faces a great deal of stigma in comparison with other charities because of the nature of our work.	<ul style="list-style-type: none"> - Building on the work that has been done so far - Engage more with national and regional government offices, community leaders, the media - Approach recognised members of the community and personalities such as celebrities to serve as goodwill ambassadors
5	External Factors	Attitude and policy of the national and regional government offices	The impact of political change in the country

		towards charities have a crippling effect on our finances. As an international charity, we are not allowed, as a matter of law, to accept financial support nationally. The government, as well as the public, is sceptical of charities work.	looks hopeful, and we need to work to get the regulation that the government put in place in the past lifted
6	Expand our network	Inadequate network which is also caused by the limited workforce with expertise.	Expand our network by attending meetings where we can connect with new organisations and critical people.

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

In order of impact	Challenges/Issues	Challenges/Issues Explained	Proposed Solutions
1	Financial sustainability	<ul style="list-style-type: none"> - Financial constraints are still a problem limiting our engagement and the number of people with epilepsy we could reach out to. - Difficulty in securing funding to cover essential administration cost. Donors often desire to see results only in the defined project activities, and as such, they forbid or limit the use of funds for organisational overheads administration or development. - Lack of epilepsy specific grants on the international level. - Lack of a named person with real experience or skill in donors/grant pursuits/searches causing loss of opportunity. 	<ul style="list-style-type: none"> - Diversify funding sources - Identify donors with a focus on corporate partnerships to help them achieve their social mission. - Encouraging government health authorities and health facilities to take ownership of our programme and invest in training and practice changes.

2	Workforce/ staff	<ul style="list-style-type: none"> - The Chief Executive Officer covering most of the work due to lack of finance has proven to be a great challenge and affected productivity. - We still rely on our volunteers as our office has got only 1 full time and 2 part-time member. - The amount of workload has affected the efficiency of our staff. - The lack of expertise in project management has a drawback on our engagement. 	<ul style="list-style-type: none"> - Investing in staff development. - Identify volunteers to work as an assistant in the UK office as work experience. - Encouraging neurologists and doctors to provide training through financial incentives. - Develop strategies to generate revenue to finance the justifiable, affordable and minimum level of staff. - Increase expertise at the national level through training and partnership with higher education institutions.
3	Premises	<ul style="list-style-type: none"> - The frequent move of office in search of cheaper rental office causes loss of patients and stable engagement with communities. 	<ul style="list-style-type: none"> - Discussions need to start to get support from the government.
4	Patients Expectations	<ul style="list-style-type: none"> - Patients are putting increasing demands on us 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 programmes. 	<ul style="list-style-type: none"> - Engage with government authorities, politicians, community leaders and other partner organizations to realize affordable or free medication.
5	Stigma	<ul style="list-style-type: none"> - Stigma about epilepsy is still a challenge affecting the involvement/engagement of patients and their families in our activities. - As an organisation, we faced a great deal of stigma in comparison with other charities due to the nature of our work. 	<ul style="list-style-type: none"> - Build on the work that has been done so far - Engage more with national and regional government offices, community leaders, the media - Approach recognised members of the community and personalities such as celebrities to serve as goodwill ambassadors.
6	External Factors	<ul style="list-style-type: none"> - Attitude and policy of the national and regional government offices 	<ul style="list-style-type: none"> - The impact of political change in the

		<p>towards charities have a crippling effect on our finances. As an international charity, we are not allowed, as a matter of law, to accept financial support nationally.</p> <ul style="list-style-type: none"> - The government, as well as the public, is sceptical of charities work. - Delayed input and feedback from Directors and institutions. 	<p>country looks hopeful, and we need to work to get the regulation that the government put in place in the past lifted.</p> <ul style="list-style-type: none"> - Keep track of any regulatory and statutory changes and where possible, adopt the legal and compliance changes.
7	Lack of proper networking	The inadequate network which is also caused by the limited workforce with expertise.	<ul style="list-style-type: none"> - Expand our network by attending meetings where we can connect with new organizations and critical people.

Activities Ahead for Next Year – 2019

In order of Priority	Activities	Strategies
1	Increase access to anti-epileptic medication for 200 people with epilepsy.	<ul style="list-style-type: none"> - Use the Tena Medhin (Health Insurance) system run by the Ethiopian Health Insurance Agency to promote the country's community-based health insurance program. We aim to enrol 200 patients in the program this year (375 Birr per person for a year) doing so will improve patients' ability to access medical care and afford anti-epileptic medication.
2	Continue raising awareness of epilepsy	<ul style="list-style-type: none"> - Celebrate International Epilepsy Day, 11th February 2019 during the 4th National Epilepsy Week from 11th February – 17th February 2019 in Addis Ababa. - Run a workshop for community and faith leaders. - Engage more schools to "Schools4Epilepsy" programme
3	Increase human resource capacity to treat epilepsy	<ul style="list-style-type: none"> - Establish an online 'Train the Trainer' course to improve human capacity and leadership for epilepsy care. The online training will be designed in partnership with GPs and neurologists in the United Kingdom. - A medical outreach programme by "Team GB" to Addis Ababa for a week of clinical consultation and training in November 2019. - Run a workshop on "Patient-Centred Service" during the 4th National Epilepsy Week.
4	Foster and facilitate regional and international collaborations	<ul style="list-style-type: none"> - Search for potential partnership not just as a money-making scheme, but as an opportunity to gain access to new skills and networks, and to further the goals of CareEpilepsy.
5	Empower people with epilepsy to be financially stable.	<ul style="list-style-type: none"> - Provide financial tools and training for people with epilepsy to build businesses/ cooperatives, and become self-sufficient. - Activities include food drying, preparation and marketing of dairy products, agricultural production, establishment and improvement of livestock and poultry raising, handicrafts, rugs, shopkeeper activities.

Our Finances

CareEpilepsy Ethiopia is in the process of identifying international donors to build financial capacity and publicity.

13.1 Treasure's Report

Year-end accounts for the 31-Dec-2018 for CareEpilepsy Ethiopia is attached as Annex 1.

13.2 Fundraising Success

CareEpilepsy UK and Epilepsy and Psychogenic Seizures Association (EPSA) of Isle of Man (joint initiative) trek the Ras Dashen Mountain to raise awareness about epilepsy and raise funds for CareEpilepsy Ethiopia's projects.



CAREEPILEPSY UK AND EPSA ISLE OF MAN

TREKKING RAS DASHEN FOR EPILEPSY - INSIDE ETHIOPIA'S WORLD HERITAGE SITE

7-25 November 2018

13.3 Funding Sources

CareEpilepsy is financially supported by donations from sponsorships, fundraising activities and friends. During 2018, financial support came in the form of donations from sponsorships, fundraising activities and friends. We received

- 529,214.00 from our head office, CareEpilepsy UK.
- 30,000.00 Birr from the Ras Dashen Trek Team.
- 13,000.00 Birr from Mrs Tegest Lema.
- In-kind donations of service worth more than 500,000.00 Birr.
- Yeka Sub-city covered major costs of the closing ceremony for the National Epilepsy Walk.

13.4 Auditors Report

As CareEpilepsy's income was below the threshold of £10,000, we were not required to present an external audit report.

Acknowledgements and Thank you

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

- CareEpilepsy UK
- Ras Dashen Trekking Team
- Yeka Sub-City
- Our volunteers
- Tegeest Lema

Other Important Information

How you can help CareEpilepsy to achieve its goals?

Become a member

- Membership of CareEpilepsy Ethiopia is open to any individual with epilepsy, or organisation and individuals working, or that has an interest in the field of epilepsy.
- Join our Speak Up Speak Out advocacy network and help us raise awareness with public officials about the public policy issues relevant to the epilepsy community.

Volunteer your time

CareEpilepsy provides both long-term and short-term volunteering opportunity. 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 benefit to the volunteer 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 programmes 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. Our account details include:



CONTACT US

CareEpilepsy Ethiopia

Company address: Bole Sub-City, Addis Ababa

Phone: +251 11 669 4455

mobile: +251940262581

Website: www.care-epilepsyethiopia.org

Email: helpcareepilepsyethiopia@gmail.com

Social media: Facebook/Careepilepsy

"let's do something amazing."