



ANNUAL  
REPORT  
2019

CAREEPILEPSY  
ETHIOPIA

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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, ease access to medical treatments, create a more positive awareness in society, dispel negative thoughts and perceptions of epilepsy, and finally to 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, and 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 changing the perceptions of epilepsy through education, leadership and advocacy.

## ***Values***

Our core ethics which we abide by our 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 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.

## FROM THE DESK OF THE EXECUTIVE DIRECTOR

Like so many others, I find the lead up to writing an annual report time to reflect and share. What a fantastic year we've had! I'm so proud of our team who worked relentlessly to reach our goal and objectives in accomplishing our mandate and all the people who supported us truly impact the community we serve. 2019 was, indeed, a pivotal year. I also want to extend our sincerest thanks to you for choosing to partner with us during 2019. You enabled us to increase our impact in Ethiopia.

It gives me pleasure to let you know that your charity, CareEpilepsy Ethiopia, is making a vital difference in the lives of people with epilepsy in Ethiopia, for this and future generations. We want to do our part, and we will continue to collaborate and do our very best to support the government and other stakeholders in the unique work. We are thankful and pleased to be the initiators of the movement to change the perceptions of epilepsy in Ethiopia.

Just like the previous years, 2019 was a year full of change and progress for CareEpilepsy Ethiopia. During 2019, we encouraged patients and families to seek medical assistance for early epilepsy diagnosis and treatment using the media and health centres. We assisted 80 people with epilepsy to gain access to anti-epileptic medication. We helped many better understand epilepsy at school, in relationships with friends and family and conducted 12 teaching sessions to educate people about the clinical facts of epilepsy and the risks of untreated seizure.

We also worked to change public perceptions of epilepsy to end epilepsy stigma through education, training, and advocacy in Addis Ababa. It was unfortunate that we were not able to reach out to the regional cities due to the continued political unrest in the country. We managed to get sponsorship to use radio and TV time, and it was evident that the role of community radio stations in spreading information and creating awareness of epilepsy is enormous. We also celebrated the 4<sup>th</sup> National Epilepsy Week in Addis Ababa and raised awareness about epilepsy and the urgent need for improved treatment, better care, and more significant investment from the Ministry of Health and Regional Health Bureaus. The event was held between the 11th February - 17th February 2019, ending with a closing ceremony at Meskel Square on the 17th February 2019. We are delighted to announce that over 400 people attended the final programme. What made this year special was we joined the international effort of the WHO and its partners celebrating the International Epilepsy Day on the 11th February 2019.

We provided art and craft training for 8 women such as needlework and creative Christmas and other cards. We conducted 12 patient support group meetings in Addis Ababa, which resulted in improved social connectedness and more significant community ownership of our programme. A total of 493 people attended these support group meetings during 2019. 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 confidential epilepsy helpline continued to give help and support to people who are affected by epilepsy. Our trained counsellors listened to callers without judgement and helped them think through the problems they are facing, whether personal or professional, to find a way forwards and feel better.

CareEpilepsy Ethiopia continued to make progress with our partners, from government entities to the faith community which 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 epileptic patients in Ethiopia.

All charities are in challenging and transformational times. Government funding is shrinking, the donor base is ageing, and we are still working to identify ways to meet the expectations of our patients and their families. Big donors are increasingly funding

projects through government instead of funding charities. More than ever, Careepilepsy Ethiopia needs the tools and skills to directly engage individuals and cultivate a strong base of supporters to succeed in our projects.

This year would not have been successful had it not been for our volunteers. Doctors, nurses and youth volunteers have dedicated their time to support our projects by expanding access to medical care and treatment, raise epilepsy awareness and support our administrative office work. We raised a total of 1 million Birr in an in-kind donation. Thank you.

Our success is the community's success. With the ongoing support of our donors, partners, board members, and volunteers, CareEpilepsy Ethiopia is ready for the challenges and achievements ahead in 2020. We will continue to make a positive difference in the lives of people living with epilepsy in Ethiopia. Some of our priorities for 2020 include: strengthening the work of CareEpilepsy Ethiopia, continuing to develop and implement programmes, creating additional fundraiser activities, expanding our horizon for donors, networking with other international epilepsy charities, strengthening our current partnerships, both nationally and internationally, purchasing one EEG machine, and investing in staff development and leadership for epilepsy care to increase local nurses', health officers' and health extension workers' competence in the provision of adequate and sustainable epilepsy care.

Thank you for your unwavering support in helping us provide life-changing, essential services to those with epilepsy. We know that with your help, we'll be able to continue to respond to the needs of our community and remain in the fight to END THE STIGMA OF EPILEPSY!

Focus on Epilepsy



Enat Yewnetu  
Founder and CEO

## HIGHLIGHTS OF THE YEAR 2019 (PERFORMANCE AND ACHIEVEMENTS)

1. The most significant achievement of the year was to be able to increase the number of attendees of monthly peer-support group meetings. Our support group fulfilled many functions: educating patients/family about epilepsy, emotional and moral support for one another, sharing epilepsy experience, providing coping mechanisms to patients and families, raising public awareness, and improve their sense of belonging and connectedness.
2. The public education and awareness programme, which is intended to mobilise communities to help raise awareness and change social norms and perceptions of epilepsy and promote the inclusion of people with epilepsy in education, and the community, remained our primary pillar of intervention.
3. We celebrated the 4th National Epilepsy Week in Addis Ababa from the 11th February – 17th February 2019 with a motto "We have changed our Perceptions of Epilepsy, What About You?". The closing ceremony was on 17th February 2019 at Meskel Square. We had the privilege of having Dr Ashenafi Beza, Director General and Chief of Staff Federal Ministry of Health who spoke about the need and commitment to work on epilepsy, Dr Hana Demesie from Ethiopian Neurologist Association educated the public about the clinical facts of epilepsy and Mr Fekadu Soboka, Head of President Office gave the closing remarks.
4. Volunteers recorded a theme song for the 4<sup>th</sup> national epilepsy week, and the song was used during the entire week, and the walkers sang the theme song during the day of the closing ceremony.
5. 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.
6. Reviewed and worked on The community conversation, developing partnership strategies for epilepsy prevention, care and support.
7. Increased engagement from the current patient advocates (representatives), albeit commitment is not at the level required.
8. More than ever, we maximised the use of mass media (television, radio, print media, internet) which played a significant role in raising awareness of epilepsy and influencing public perceptions of epilepsy. This has created some pressure on the local policy actors indirectly.
9. More people used our face-to-face counselling service, which is dedicated for people with epilepsy and their families to provide practical advice and information about the importance of adherence to medical treatment and ways of living well with epilepsy.
10. We worked in partnership with the Ethiopian Neurologists Association in delivering clinical care and community education through TV interviews to explained the medical facts about epilepsy.

## OUR OBJECTIVES AND STRATEGIC OBJECTIVES FOR 2019

### 4.1 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.

### 4.2 Our Strategic Objectives for 2019 were to

#### **SO 1 - Facilitate access to medical care and anti-epileptic drugs. We do this by:**

- ♣ Organise consultation and referrals to available epilepsy clinics, both government and private.
- ♣ Develop our Child Epilepsy Service which is dedicated solely to the treatment and care of children with epilepsy.
- ♣ Continue to develop CareEpilepsy Ethiopia's Free Epilepsy Clinic adults.
- ♣ Increase supply and access to anti-epileptic drugs (Drugs4epilepsy)
- ♣ Give access to neuro-diagnostic service by importing modern diagnostic equipment such as an EEG machine. (Equipment4epilepsy)
- ♣ Home Monitoring
- ♣ Improve human capacity and leadership (Run Train-the-trainer (TOT) course in Epilepsy Basics) training and capacity building of those currently involved in epilepsy management for nurses, midwives, and health workers around epilepsy and precisely the needs of women and children living with epilepsy.

#### **SO 2 - Reduce the epilepsy information gaps in the country. We do this by:**

Continue to educate the public and raise awareness of epilepsy using various tools.

- ♣ Revise the current epilepsy information leaflets and produce the information in a DVD format to be used for training.
- ♣ Organise the 4th National Epilepsy Week in joint partnership with the Federal Ministry of Health and Kirkos Sub-City. (Campagne4epilepsy)
- ♣ Epilepsy education at hospitals and health centres.
- ♣ Epilepsy education at schools (Seizure@school)
- ♣ Epilepsy education for employers (Seziure@work)

#### **SO 3 - Improve the wellbeing of people with epilepsy and empower them to be self-sufficient. We do this by:**

- ♣ Organise teaching sessions to educate people with epilepsy of the risks of untreated seizure, their care process and how to manage epilepsy and coexisting conditions to anyone affected by epilepsy (My Epilepsy Care).
- ♣ Improve our patients' life situations and overall wellness by providing them with services such as a Helpline, patient support group, coffee morning for epilepsy and counselling support.

- ♣ Facilitate increased skill training to empower people with epilepsy to be self-sufficient through craft training and farming and weaving in Bench Maji Zone so that they are not living in poverty. (Microenterprise Development)
- ♣ Eliminate preventable causes of injuries such as burns due to hazardous domestic environment like open fire cooking. (Wolafen)

***SO4 - Advocacy in partnership to influence public policy and organisational practice We do this by***

- ♣ Increase engagement in advocacy from patient representatives.
- ♣ Advocate and support the Ministry of Health 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. (Neurological division).
- ♣ Run joint programmes in partnership with stakeholders such as Ethiopia Neurology Association, initiate a new partnership with Kirkos sub-City to expand our services in Addis Ababa. Continue to work with our current partners such as Yeka Sub-City Health Office, Addis Ababa Health Bureau, Ministry of Health, and Region Health Bureau through initiation and implementation of joint projects of clinical care and awareness-raising. (Partner4epilepsy).
- ♣ Conduct needs assessment and clinical audit in Amhara region.
- ♣ Organise 2 workshops to address the problems of epilepsy and educate educators, employers, medical communities, faith leaders, traditional healers and other stakeholders and develop policies. (Community Conversation)

***SO5 Others***

- ♣ Grow our financial capacity through donors, sponsors and other fundraising activities, both nationally and internationally.
- ♣ Promote our volunteering and internship schemes, nationally and internationally.
- ♣ Design our organisational development through increased human resources, capacity building, governance and policy review.
- ♣ Introduce Social Media Activism to raise awareness in the social movement.

## Review of Planned Activities for 2019

<b>SO 1 - Facilitate access to medical care and anti-epileptic drugs through:</b>					
<b>Activities</b>		<b>Achieved</b>	<b>Not Achieved</b>	<b>In Progress</b>	<b>Remarks</b>
Activity 1.1.	<b>Organise consultation and referrals to available epilepsy clinics, both government and private</b>	✓			
Activity 1.2.	<b>Continue to develop CareEpilepsy Ethiopia's Free Epilepsy Clinic for adults.</b>	✓			
Activity 1.3.	<b>Develop our Child Epilepsy Service, which is dedicated solely to the treatment and care of children with epilepsy.</b>	✓			
Activity 1.4.	<b>Drugs4epilepsy</b>	✓			
Activity 1.5.	<b>Equipment4epilepsy</b>	✓			
Activity 1.6.	<b>Home Monitoring</b> (in order to alleviate the burden of the service, to make home monitoring via weekly telephone check-ups of people living with epilepsy).		x		The FMOH showed no commitment to engage in this project, and unfortunately, CEE did not manage to secure finance for this project.
Activity 1.7.	<b>Train-the-trainer (TOT)</b>	✓			Only 2 of the 4 scheduled training on "Basics of Epilepsy" for junior doctors, health extension workers and nurses were able to run due to lack of finance.
<b>SO 2 - Reduce the epilepsy information gaps in the country. We do this by:</b>					
Activity 2.1.	Epilepsy Information Leaflet and DVDs	✓	x		We were not able to produce DVDs due to lack of finance.
Activity 2.2.	<b>Campagne4epilepsy</b>	✓			
Activity 2.3.	Epilepsy Education at hospitals and health centres		x		

Activities		Achieved	Not Achieved	In Progress	Remarks
Activity 2.4.	Seizure@school	✓			
Activity 2.5.	Seizure@work			x	The project aimed to equip organisations to be able to help their employee with epilepsy and make the workplace a safer environment. This did not occur due to lack of interest from organisations.
<b>SO 3 - Improve the wellbeing of people with epilepsy and empower them to be self-sufficient. We do this by:</b>					
Activity 3.1.	<b>My Epilepsy Care</b>			✓	Although the booklet is completed, fund was not available to produce the booklet.
Activity 3.2.	<b>Helpline4epilepsy</b>	✓			
Activity 3.3.	<b>Connect4epilepsy</b> - Patient Support Group	✓			
Activity 3.4.	<b>Connect4epilepsy</b> - Coffee Morning for epilepsy	✓			
Activity 3.5.	<b>Counselling4epilepsy</b>	✓			
Activity 3.6.	<b>Microenterprise Development</b> - CareCraft			✓	Training on craftwork has been given, but on the development of a business plan, we were not able to facilitate microenterprise start-up financing.
Activity 3.7.	<b>Microenterprise Development</b> - Farming and Weaving in Bench Maji Zone		x		Lack of funding to start the project.
Activity 3.7.	<b>Wolafen</b>		x		Lack of funding to start the project

Activities		Achieved	Not Achieved	In Progress	Remarks
<b>S04 - Advocacy in partnership to influence public policy and organisational practice We do this by</b>					
Activity 4.1.	<b>Patient Representatives Committee</b>	✓			
Activity 4.2.	<b>Neurological Division at the Ministry of Health</b>		x		There is no sign of commitment from the Ministry of Health.
Activity 4.3.	<b>Partner4epilepsy</b>	✓			
Activity 4.4.	<b>Needs Assessment in Amhara region.</b>		x		This was not accomplished due to lack of partner and funding as well as political unrest.
Activity 4.5.	<b>Community Conversation (CC) Cluster workshops</b>		✓		Only 1 of the workshop was held due to a lack of funding.
<b>S05 – Others. We do this by</b>					
Activity 5.1.	<b>Financial Sustainability.</b>			✓	
Activity 5.2.	<b>Promote our Volunteering and Internship programme</b>			✓	
Activity 5.3.	<b>Organisational Development</b>			✓	
Activity 5.4.	<b>Media Activities.</b>			✓	

## ACTIVITIES AND IMPACTS OF WORK IN THE COMMUNITY

### Strategic Objective 1 - Facilitate access to medical care and anti-epileptic drugs in 2019

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

#### Activity 1.1. Free Community based epilepsy clinic

- ♣ 11 monthly free community clinics were held at Yeka Health Center on the last Sunday of each month.
- ♣ 7 neurologists and 1 specialist nurse were involved in running this clinic.
- ♣ 11 paediatric neurology clinic was given by Dr Kindu, a Pediatric Neurologist
- ♣ 11 clinical nurse care sessions were provided by Sister Kelemwork, a clinical nurse at the United Nations office.



### **Activity 1.2. Anti-epileptic Medication (Drugs4epilepsy)**

- ♣ 30 Children and 50 adults received free anti-epileptic medication or financial support to purchase anti-epileptic medication.
- ♣ 15 patients were supported to buy Tena Medhin, a government health insurance, that will enable them to access free medication when available.
- ♣ We noticed increased adherence to prescribed anti-epileptic regimens by pharmacists/doctors.

### **Activity 1.3. Equipment4epilepsy**

We received a brand-new electroencephalogram (EEG) machine from CareEpilepsy USA as a donation.

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

2 clinical sessions training were provided to build the capacity of health officers to enable them to diagnose and treat people with epilepsy.

**Table 1 - Anti-Epileptic Medication Used**

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

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

<b>Reported Side effects of anti-epileptic medication (anticonvulsant)</b>
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 and Value of Work in Communities***

- ♣ 176 adult patients 110 pediatric epilepsy patients accessed medical care through our free community clinic
  - A total of 110 children were seen by a clinical nurse specialist and a pediatric neurologist through our free community clinic at the cost of 110,000 Birr.
  - During the months of (September – December) 2019, 176 adult patients accessed medical care through our free community clinic at the cost of 88,000 Birr.
- ♣ 30 children and 50 adults received free anti-epileptic medication or financial support to purchase anti-epileptic medication.
- ♣ 15 patients were supported to buy Tena Medhin, a government health insurance, that will allow them to access free medication when available.
- ♣ 3 children were financially supported to have an electroencephalogram (EEG) done, which is a noninvasive test that records electrical patterns of the brain.
- ♣ 150 attendees received knowledge about epilepsy and how to treat people with epilepsy

## **Strategic Objective 2 - Public Education and Awareness in 2019**

CareEpilepsy Ethiopia's awareness-raising campaigns are our organised communication activities which aim to create awareness on epilepsy, behavioural change as a result of social norms and perceptions among the general population and to improve the focus on better outcomes for epilepsy, higher patient's protection of their human rights, reduced early school leaving. Our awareness programme contributes towards stigma reduction to allow people with epilepsy access to education, the workplace, and the community. The practical strategies identified mainly concentrated on the individual and the community level. The followings are the various activities that we employ to accomplish our strategic objective 2.

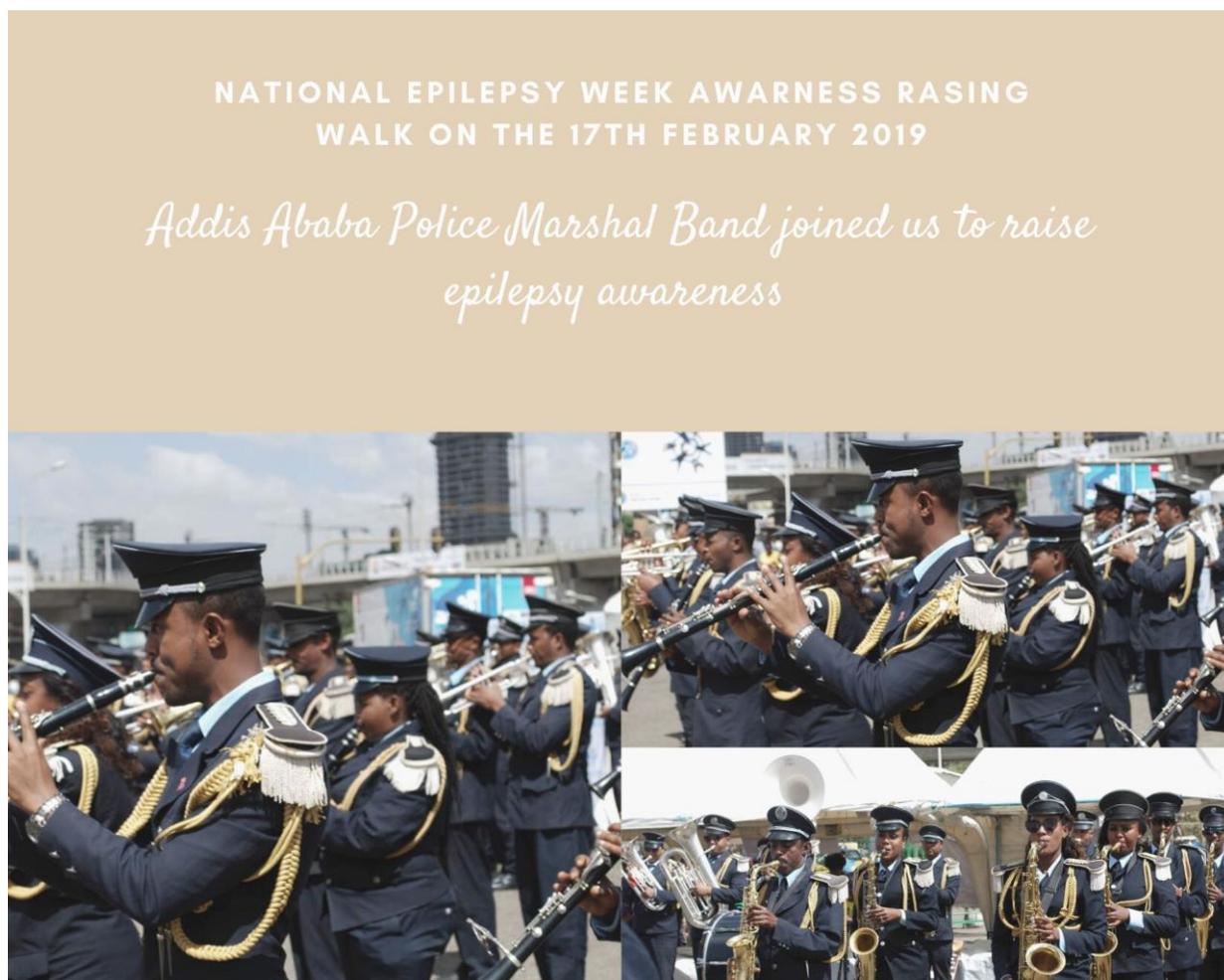
### ***Activity 2.1. Epilepsy Educational Materials***

- ♣ We revised the previous epilepsy education materials, and these were circulated to local health centres to tertiary referral hospitals, health centres, schools and on street campaigns to decrease the gap of knowledge in epilepsy within the community.

### ***Activity 2.2. Campaign4epilepsy***

- ♣ The 4<sup>th</sup> National Epilepsy Week in Addis Ababa from the 11<sup>th</sup> February – 17<sup>th</sup> February 2019 with a motto "We have changed our perceptions about epilepsy, what about you?" was planned to be held in Gondar however, due to political unrest the venue got changed to Addis Ababa, at Meskel Square.
- ♣ Mediums that we used include leaflets, public walks, local and national broadcast media such as radio and television.
- ♣ We invited to walk different stakeholders such as schools, clinics, hospitals, governmental and non-governmental organisations, health sectors, media like radio and television.
- ♣ Audio adverts and awareness-raising songs were played during the week and on the day of the walk.

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



### **Activity 2.3 Epilepsy Education at hospitals and health centres**

We gave community education for 35 health centres within Yeka, Kiroks, Bole and Kolfe Keranio sub-cities and 8 specialised hospitals received epilepsy education and seizure first-aid training for staff and patients.

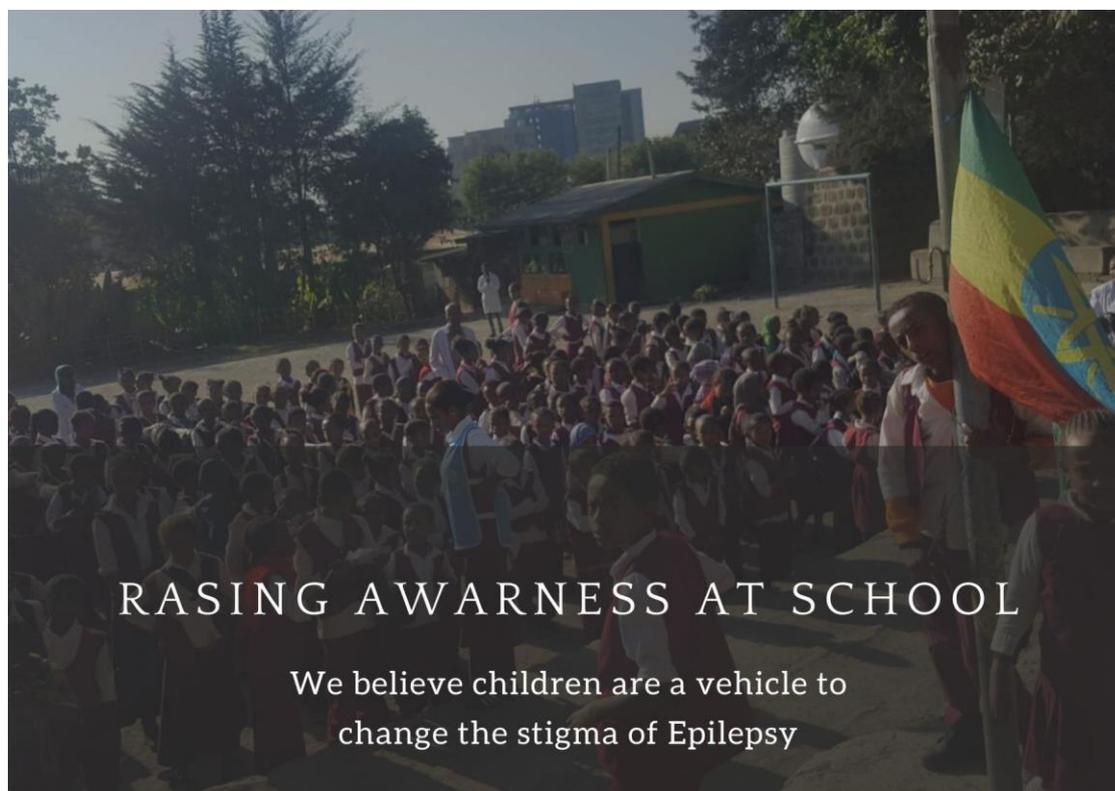
### **Activity 2.4. Seizure@school**

12 schools received epilepsy education and seizure first-aid response training to raise awareness and teach students and teachers about epilepsy and seizure first-aid at different schools. The training to pupils and teachers helped them understand that most pupils with epilepsy can participate in all school activities.

### **Impact and Value of Work in Communities**

- ♣ 7,800 pupils, 400 teachers received epilepsy education and seizure first-aid training.
- ♣ 400 people increased their knowledge of epilepsy by attending the closing ceremony of the 4<sup>th</sup> National Epilepsy Week.
- ♣ More than 1,750 received epilepsy education at Yeka, Kiroks, Bole and Kolfe Keranio health centres.

- ♣ More than 640 people received epilepsy education in 8 specialised hospitals.
- ♣ We distributed more than 25,000 leaflets and 5000 posters about epilepsy at tertiary referral hospitals, health centres, and schools and during our street campaigns.
- ♣ 4 days street campaigns covering all sub-cities in Addis Ababa were held during National Epilepsy Week.



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

When confronted by illness, patients seek professional help and advice from their doctors and also rely on support from family members, peers and fellow patients. Patients' living with epilepsy are no exception to this reality. They too face complexities and complications that require a network of professional support staff, family, and friends. Treatment involves more than a routine medical diagnosis, hospitalised care or even the prescription of drugs.

The aim of our programme is to improve our patients' life situations and overall wellness by providing them with epilepsy education and psychological support. The followings are the various activities that we employ to accomplish our strategic objective 3.

**Activity 3.1. My Epilepsy Care**

- ♣ 12 teaching sessions were arranged to educate people with epilepsy of the risks of untreated seizure, prevention, causes and consequence of epilepsy.
- ♣ 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 and wellbeing.

Seizure record sheet was designed for patients to record their seizure pattern to help 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.

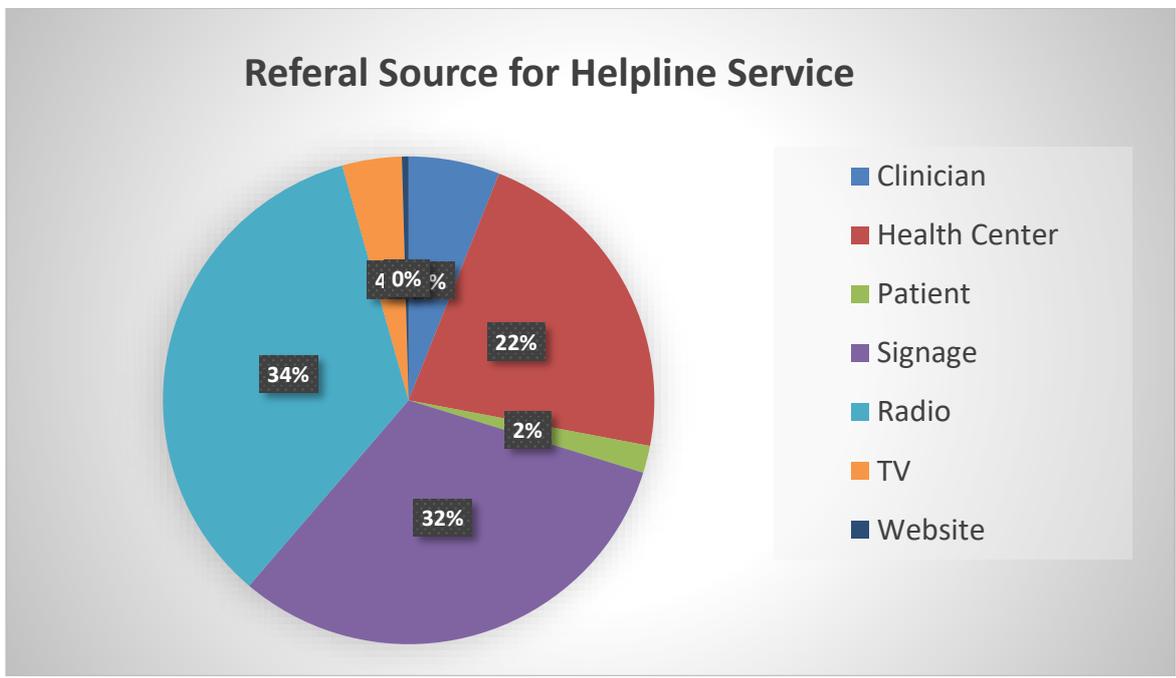
**Activity 3.2. Helpline4epilepsy**

- ♣ Our confidential epilepsy helpline, which run through the year, gave help and support to people who are affected by epilepsy. The most common requests we received are list out in Table 2.

**Table 3 - Referral sources for Helpline Service**

Referral Source	Number of patients
Clinician	150
Health Center	550
Patient	45
Signage	786
Radio	860
TV	98
Website	11

**Figure 1**



**Activity 3.3. Connect4epilepsy - Patient Support Group**

- ♣ 12 monthly support group meetings were held where participants learned clinical facts about epilepsy, safety issues, and ways to live positively with epilepsy, share their worries and experiences and we reimburse the attendees' transportation cost.

- ♣ We provided financial support for 493 people to attend the meetings by covering their transportation cost.

### **Activity 3.4. Connect4epilepsy - Coffee Morning for epilepsy**

46 sessions of “Coffee Morning for Epilepsy” were held where they have a chat and share their experiences of living with epilepsy over a cup of coffee or tea. Our coffee morning for epilepsy programme has proved itself to be the favourite programme of the year. Although the people who attended the coffee club programme are enthusiastic about it, it has proven challenging to involve more participants.

### **Activity 3.5. Counselling4epilepsy**

- ♣ 46 sessions of face-to-face counselling was given, and the programme has been utilised exceptionally well; however, the volunteer will no longer work voluntarily in the year 2020—a cause for great concern.
- ♣ The most common requests were inaccessibility of medication, clinic information where they could receive epilepsy care, financial support.

Table 4 – Beneficiaries who received counselling and psychotherapy

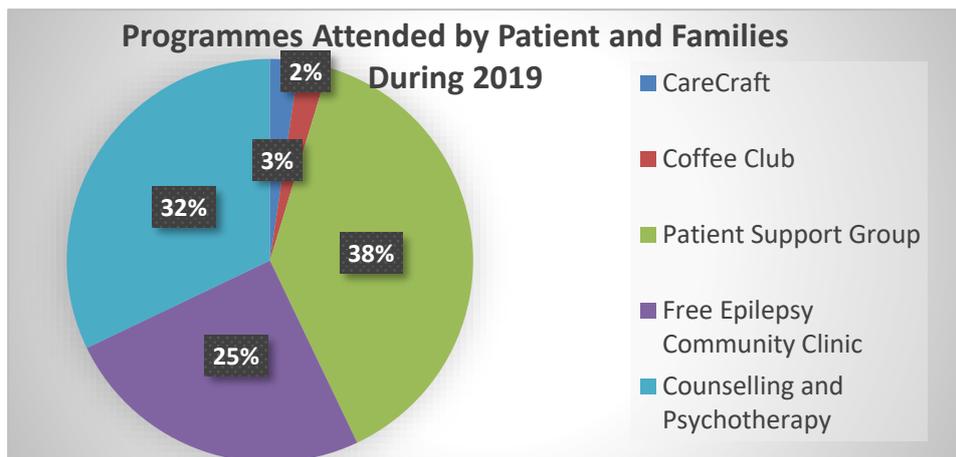
Beneficiaries who received psychological support during 2019	
Male	Female
180	234

Distribution of Presenting Complaints by the gender of the patients during counselling and psychotherapy sessions. The gender distributions of presenting complaint about are illustrated below.

**Table 5 - Distribution of Presenting Complaints During Counselling**

Distribution of Presenting Complaints During Counselling in 2019		
	Female	Male
Unemployment	120	180
Stigma	300	114
Family neglect	250	100
Courtship	80	90
Feeling Unloved	40	79
Poor Sex Drive	70	55
Seclusion from social activity	67	120
Depression	57	89
Worries/Anxieties	44	70
Hopelessness	67	52
Irritated or stressed	57	57
Loss of interest	22	41

**Figure 2**



**Table 6 – Programme Attended by Patient and Families During 2019**

Programmes Attended by Patient and Families During 2019				
CareCraft	Coffee Club	Patient Support Group	Free Epilepsy Community Clinic	Counselling and Psychotherapy
30	30	493	321	414

**Figure 3 - % of Patients and Families attended Programmes.**

**Activity 3.6. Microenterprise Development**

- 38 sessions of CareCraft programme were held, and CareEpilepsy Ethiopia provided patients with raw materials such as needles, threads, plastic mats for table mat, coffee mat and cards for them to continue to learn and do craftworks. However, due to lack of funding, we were not able to open a shop for them.
- The farming and weaving project for Bench Maji Zone did not materialise due to lack of funding. We continued to negotiate with other partners who can get involved in this project.
- Our Craft trainer and patient-therapist continued to meet regularly with patients and give support and monitoring.



**CAREEPILEPSY REHABILITATION CENTRE**

**Our patients working on Sheraton Addis order for invitation cards and table mats they designed.**

October 2019

## ***Impact and Value of Work in Communities***

- ♣ 414 people with epilepsy and their families got access to psychological support through our face to face counselling services.
- ♣ 493 people attended patient support group meetings out of these, 321 were patients, and 172 were family members. They increased knowledge about epilepsy and felt more connected with each other.
- ♣ 30 patients who participated in the Coffee Morning for Epilepsy programme feel connected and developed friendship.
- ♣ 30 people with epilepsy were engaged in CareCraft project
  - We raised 12,500 Birr through selling New Year card for Ethiopian New Year to Jupiter International Hotel and SaroMaria Hotel. The card was designed and decorated by patients and volunteers.
  - 9,000 Birr was received from Sheraton Addis for the purchase of their order of invitation cards.
- ♣ More than 2,500 people with epilepsy and their families got access to a dedicated 24/7 Helpline service that provides them with necessary information such as a list of care providers and pharmacies.
- ♣ 100% of patient support group attendees felt less isolated and part of a broader community of people with epilepsy (493 out of 493).
- ♣ 83% of patient support group attendees felt more confident discussing epilepsy with healthcare professionals (407 out of 493).
- ♣ 56% (275 out of 225) of patient support group attendees felt more confident being open about their epilepsy.
- ♣ 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.
- ♣ 68 people who used our counselling services felt they have the confidence, knowledge, skill, and support they need to manage their epilepsy effectively.

## **Strategic Objective 4 - Advocacy to influence public policy and organisational practice.**

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

### ***Activity 4.1. Patient Representatives Committee***

- ♣ 12 Patient representative meetings were held, and members continue to engage in raising awareness and expressing the needs of people with epilepsy.
- ♣ The patient representatives themselves continue to take the lead role in leading our patient support group meetings.
- ♣ 1in-house epilepsy training sessions were delivered to representatives.

### ***Activity 4.2. Community Conversation Cluster workshops***



**PATIENTS EXPRESSING  
THEIR CHALLENGES OF  
LIVING WITH EPILEPSY**



- ♣ Our Community Conversation is an interactive process which brings together members of the community, village or kebele and encourages them to think, discuss and explore the leading causes and stigma issues behind epilepsy and finding a solutions to the problems people with epilepsy and their families face.



*CareEpilepsy Ethiopia  
Teaching and Discussion the  
issues of Epilepsy*



**SELASE  
EDER**

**COMMUNITY  
CONVERSATION IN 2019**



## ***Impact and Value of Work in Communities***

- ♣ 85 new volunteers actively engaged in supporting the activities of CareEpilepsy Ethiopia.
- ♣ 85 volunteers received one-day in-house training course on epilepsy
- ♣ CareEpilepsy Ethiopia invited to join the Ministry of Health Mental Health Technical Working Group set up by the Federal Ministry of Health.
- ♣ Established conversation and future partnership plan with the Gefersa Mental Health Rehabilitation Center (GMHF) near Addis Ababa offers professional psychiatric treatment, boarding and rehabilitative occupational therapy.
- ♣ Working together with Ethiopian Mental Service Users' Association as a partner.

## **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 to learn life-skills for their future, like leadership, teamwork, communication, accountability and the satisfaction that comes from doing good in the community.

### **7.1 Volunteering**

#### ***a) Professional Volunteers***

Neurologists, nurses and youth volunteers continued to make a significant impact in clinical care and awareness-raising programme through their engagement with CareEpilepsy Ethiopia.

#### ***b) Youth Volunteers***

Youth4Epilepsy Ethiopia is one of the programmes we run tapping into the time and experiences of young volunteers. We have recruited 85 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.

During 2019, our volunteers helped prepare the 4<sup>th</sup> National Epilepsy Week; they covered the information booths on the promotion day, they answered the telephone helpline and talked to visitors to the office and during the awareness walk.

- ♣ 85 volunteers received a one-day in-house training on epilepsy and epilepsy first aid.
- ♣ 98% of CareEpilepsy Ethiopia volunteers who attended our in-house training acquired new knowledge about epilepsy and stated its impact on their individual life (83 out of 85 attendees).
- ♣ 8 half-day in-house training on epilepsy and epilepsy first aid response were given.
- ♣ 12 volunteers performed the epilepsy response and recovery position in the street of Addis Ababa on National Walk for Epilepsy day.

**Table 6 – Volunteers Age Distribution**

<b>Volunteers Age Distribution</b>				
14-18	19-24	25-34	35-44	45+
75	10	0	0	0

## 7.2 Internship

The planned internship programme did not go ahead due to political instability.

### *Impact and Value of our work in the Community*

- 16,672 hours were given volunteering to help us complete our objective for the year.
- 85 new volunteers actively engaged in supporting the activities of CareEpilepsy Ethiopia. They were mainly involved in
  - o Raising awareness in the community by teaching at health centres and hospitals.
  - o Involved in fundraising
  - o Provided support in organising and supporting training for clinical professionals.
  - o The organisation and participation of the 4<sup>th</sup> National Epilepsy Week.
  - o Distributed epilepsy information materials to clinics, hospitals, health posts, and schools.

## **MEDIA AND COMMUNICATION**

We have used various means of communication such as broadcasting, publishing and the internet for our mass communication programme to educate the public about epilepsy.

### **8.1 Media Engagement**

- ♣ 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 and radio stations that have a significant number of listeners such as Sheger, FM 90.7, Fana, Bisrat 101.1, Ethio FM 107.8, Ahadu Radio 104.3, and FM Addis to raise awareness.
- ♣ The chief executive officer of CareEpilepsy Ethiopia gave a press conference, the president of Ethiopian Neurologists Association and the CEO of MCM general hospital (Korean) with regards to International Epilepsy Day and the 4<sup>th</sup> National Epilepsy Week at MCM general hospital (Korean).

### **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 2019 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

- ♣ Guest speaker at the 21st Health Sector Annual Review Meeting on mental health on the 15<sup>th</sup> October 2019 at Addis Abeba, Skylight Hotel.
- ♣ Provided epilepsy training at the German Church School which is a social project of the Protestant German Speaking Congregation in the Ethiopian capital of Addis Ababa.
- ♣ Various fundraising events organised by CareEpilepsy USA in Chino Hills (California), Atlanta, and DC.
- ♣ The 4th African Epilepsy Congress organised by International League Against Epilepsy (ILAE), International Bureau for Epilepsy (IBE) held from Aug 22 - 24, 2019 at Imperial Resort Beach Hotel, Entebbe, Central, Uganda.
- ♣ Selase Edir, a traditional Ethiopian association, established among neighbours or workers to raise funds that will be used during emergencies, such as death.
- ♣ The Federal Ministry of Health's 5 year National Health Communication Strategy steering committee meeting in Adama.
- ♣ The yearly Global Customer Appreciation Week of the Sheraton Addis and The Marriott Executive Hotel Apartments.



**CareEpilepsy Ethiopia Team giving a presentation to the Marriott Executive Apartments and Sheraton Addis Management Team At our centre in November 2019**

- ♣ Established partnership with other African non-governmental organisation that works on epilepsy to work together on epilepsy issues in Africa, share experiences and educational materials.

### ***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 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 2019, 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 2019, that engaged in our work, were neurologists, general practitioners, sub-cities, and Ethiopian Neurologist Associations.

- ♣ 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.
- ♣ Discussion is continued with the Ethiopian Midwives Association (EMA) 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.
- ♣ It has been slow progress to gain the interest and commitment of Addis Ababa Health Bureau (AAHB), and the Federal Ministry of Health (FMOH), to get involved in projects to improve the service of epilepsy in Ethiopia.
- ♣ We have made progress in identifying new partners such as Kirkos Sub-City, Bole Sub-city, Gefersa Mental Health Rehabilitation Center (GMHF) and Ethiopian Mental Service Users' Association.

- ♣ Working together with the Ethiopian Neurology association to raise awareness of epilepsy and provide free clinic.



### ***Impact and Value of our work in the Community***

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

## **ORGANISATIONAL DEVELOPMENT**

### **10.1 Organisation Policy and Procedures**

CareEpilepsy Ethiopia Staff Planned in 2019 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.
- ♣ Developing a culture of staff who recognise and value different perspectives, work together well and engage with others to create desired outcomes.
- ♣ Creating a staff development and training plan.

## 10.2 Recruitment and Selection

Create a successful recruitment plan for CareEpilepsy Ethiopia.

## 10.3 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 Organisation. The time taken show a high return on investment due to a workforce with renewed motivation, new skills, and strengthened morale.

### ***Achievements During 2019***

- ♣ A review of the standard operating procedures system was completed. This work will continue as part of ongoing system development.
- ♣ We employed an epilepsy specialist nurse.
- ♣ 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
  - :- teamwork
  - :- presentation skills
  - :- ethics
  - :- conflict resolution
  - :- leadership skills
  - :- time management
  - :- CareEpilepsy Ethiopia
  - :- Problem-solving skills
  - :- Emotional Intelligence
  - :- Time management
  - :- Microsoft Office Version Upgrades
  - :- Customer Service Skills
  - :- CareEpilepsy Ethiopia

### ***Impact and Value of our work***

- ♣ Patients and their family received clinical care utilising the skills and expertise of the epilepsy specialist nurse.
- ♣ Staff increased their knowledge about epilepsy and epilepsy first aid, communication skills, compassionate care, and teamwork.
- ♣ The dedicated time taken to train our staff and improve their skills has shown to give them great motivation to do their job thoroughly as well as feeling valued and appreciated.
- ♣ 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 team by cross-train them.
- ♣ Cross-training alleviated the burden of a shortage of staff during the year.
- ♣ Help build relationships amongst staff.

## **GOVERNANCE AND MANAGEMENT**

We are dedicated to enhancing our leadership continuously. As an organisation, during 2019, we made a focus to build our national advisory board with people of an expert as 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 characterise the board's leadership role.

### 11.1 Governance

#### *a) Board of Directors*

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

#### *b) Patient Representative Committee*

We continued to get regular feedback from our patient representatives on how to manage programmes and identify the support the patients need. The group support the work of CareEpilepsy and promote their rights as they navigate through the epilepsy care system.

### **Achievements**

- ♣ 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.

### 11.2 Operational and Project Management

#### *a) Operational Management*

- ♣ The chief executive director provided the overall direction in which CareEpilepsy Ethiopia 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; 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*

We founded a Task Force with the assignment to organise the 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.

### ***Impact***

- ♣ Staff felt valued and appreciated.
- ♣ Increased productivity level and quality of work.
- ♣ Gave them great motivation to do their job well.
- ♣ Gained confidence to manage oppositions by expressing their feelings with accuracy, diplomacy and flexibility.

## SIGNIFICANT ISSUES/CHALLENGES FACING CAREEPILEPSY IN 2019 AND BEYOND

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

In order of impact	Challenges/ Issues	Challenges/Issues Explained	Proposed Solutions
1	Financial sustainability	<ul style="list-style-type: none"> <li>♣ Financial constraints are still a problem limiting our engagement and the number of people with epilepsy we could reach out the to.</li> <li>♣ Due to financial constraints, we were not able to satisfy the medication needs of patients.</li> <li>♣ 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.</li> <li>♣ Lack of a named person with real experience or skill in donors/grant pursuits/searches causing loss of opportunity.</li> </ul>	<ul style="list-style-type: none"> <li>- Diversify funding sources</li> <li>- Identify donors with a focus on corporate partnerships to help them achieve their social mission.</li> <li>- Targeted fundraising and financial management.</li> </ul>
2	Workforce/ staff	<ul style="list-style-type: none"> <li>♣ Chief Executive Officer covering the project management and the operational work has proven to be a great challenge and affected productivity.</li> <li>♣ We still rely heavily on our volunteers due to the shortage of paid staff.</li> <li>♣ The amount of workload has affected the efficiency of our staff.</li> <li>♣ Shortage of expert workforce within our team and this lack of expertise has a drawback on our engagement.</li> </ul>	<ul style="list-style-type: none"> <li>- Identify professional volunteers to work as an assistant for work experience.</li> <li>- Develop strategies to generate revenue to finance the justifiable, affordable and minimum level of staff.</li> <li>- Increase expertise through in-house and external training and partnership with higher education institutions.</li> </ul>
3	Premises	<ul style="list-style-type: none"> <li>♣ The frequent move of office in search of cheaper rental office causes loss of patients and stable engagement with communities.</li> <li>♣ We need to acquire our facility to run the clinic as the current arrangement proved to make us insecure about running the</li> </ul>	<ul style="list-style-type: none"> <li>- Discussions need to start to get support from the government.</li> </ul>

		programme.	
4	Patients Expectations	<ul style="list-style-type: none"> <li>♣ 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 programmes.</li> </ul>	<ul style="list-style-type: none"> <li>- Engage with government authorities, politicians, community leaders and other partner organisations to realise affordable or free medication.</li> </ul>
5	Stigma	<ul style="list-style-type: none"> <li>♣ Stigma about epilepsy is still a challenge affecting the involvement/engagement of patients and their families in our activities.</li> <li>♣ CareEpilepsy Ethiopia faced a great deal of stigma in comparison with other charities because of the nature of our work.</li> </ul>	<ul style="list-style-type: none"> <li>- Build on the work that has been achieved so far.</li> <li>- Continue to work with the media and engage with national and regional government offices and community leaders.</li> <li>- Approach recognised members of the community and personalities such as celebrities to serve as goodwill ambassadors.</li> </ul>
6	External Factors	<ul style="list-style-type: none"> <li>♣ Attitude and policy of the national and regional government offices towards charities have a crippling effect on our finances.</li> <li>♣ The public is sceptical of charities' work.</li> <li>♣ Political instability.</li> <li>♣ It has proven to be extremely difficult to secure Tena Medhin insurance for our patients due to the chronic nature of epilepsy which require extensive financial resources. Furthermore, the insurance could only be purchased via sub-cities which excluded those living on the street without any identification card.</li> </ul>	<ul style="list-style-type: none"> <li>- The impact of political change in the country looks hopeful.</li> <li>- Keep track of any regulatory and statutory changes and where possible, adopt the legal and compliance changes.</li> </ul>
7	Lack of proper networking	<ul style="list-style-type: none"> <li>♣ The inadequate network which is also caused by the limited workforce with expertise.</li> <li>♣ We need more adult neurologists to engage in our free clinic work.</li> <li>♣ We have not been able to increase the number of members of Youth4Epilepsy Ethiopia volunteers to 1000 as planned; instead, we only gained 85 new volunteers. We will need to do more promotion in 2020.</li> </ul>	<ul style="list-style-type: none"> <li>- Expand our network by attending meetings where we can connect with new organisations and critical people.</li> <li>- Become a member of Consortium of Christian Relief &amp; Development Associations (CCRDA) which is a Consortium of Ethiopian Resident and Foreign Charities.</li> </ul>
8	Engagements of	<ul style="list-style-type: none"> <li>♣ It has been difficult to secure sufficient time for epilepsy education in</li> </ul>	<ul style="list-style-type: none"> <li>- Encouraging government health</li> </ul>

	partners	<p>schools. We have only been allowed to teach at line up sessions in the morning.</p> <ul style="list-style-type: none"> <li>♣ Commitment from government health authorities and health facilities to making required practice changes is minimal.</li> <li>♣ Commitment from neurologists and doctors to provide training is slow coming.</li> </ul>	<p>authorities and health facilities to take ownership of our programme and invest in training and practice changes.</p> <ul style="list-style-type: none"> <li>- Encouraging neurologists and doctors to provide training through PR incentives for their association.</li> </ul>
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## ACTIVITIES AHEAD FOR NEXT YEAR (JANUARY 2020 – DECEMBER 2020)

In order of Priority	Activities	Strategies
1	Facilitate access to medical care and anti-epileptic drugs.	<ul style="list-style-type: none"> <li>♣ Clinic-based epilepsy management through our free community epilepsy clinic</li> <li>♣ Increase access to anti-epileptic medication by purchasing Tena Medhin for 200 people with epilepsy.</li> <li>♣ Training and capacity building of those currently involved in epilepsy management using national and international experts.</li> <li>♣ Establish an online 'Train the Trainer' course to improve human capacity and leadership for epilepsy care.</li> <li>♣ Run a workshop on "Patient-Centred Service For Epilepsy".</li> <li>♣ A medical outreach programme from the United Kingdom "Team GB" to Addis Ababa for a week of clinical consultation and training in November 2020.</li> <li>♣ Develop and produce clinical training manual and policy guideline for epilepsy.</li> </ul>
2	Public education and awareness	<ul style="list-style-type: none"> <li>♣ Continue to educate the public and raise awareness of epilepsy using various tools.</li> <li>♣ Continue to give seizure first-aid response training for pupils, teachers and at workplaces.</li> <li>♣ Organise campaigns to raise general awareness and understanding of epilepsy and the service CareEpilepsy provides.</li> <li>♣ Celebrate International Epilepsy Day, on the 10th February 2020 during the 5th National Epilepsy Week from 10th February – 16th February 2020 in Addis Ababa in partnership with Ethiopian Public Health Institution.</li> <li>♣ Organise 4 workshops to provide information and education to educators, employers, medical communities, faith leaders, traditional healers and other stakeholders.</li> <li>♣ Onsite epilepsy education in schools and companies.</li> </ul>
3	Improve the wellbeing of people with epilepsy and empower them to be self-sufficient.	<ul style="list-style-type: none"> <li>♣ Schedule 12 teaching sessions (monthly) to educate people with epilepsy of the risks of untreated seizure, their care process and how to manage epilepsy and coexisting conditions to anyone affected by epilepsy and produce "My Epilepsy Care booklet" where patients could write their medical information and follow-ups. (My Epilepsy Care).</li> <li>♣ Continue to offer information on how to access help, available treatments and support, assist with long term referrals, provide emotional support (counselling), action plan support (coaching). (Helpline4epilepsy).</li> <li>♣ Maintain patient support group meetings to improve social connectedness and more significant community ownership of our programme.(peer support group).</li> <li>♣ Continue to give emotional and psychosocial support for epilepsy and coexisting conditions to anyone affected by epilepsy (Counselling4epilepsy).</li> <li>♣ 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.</li> <li>♣ Identify funding sources to run the planned income-generating projects.</li> </ul>

		<ul style="list-style-type: none"> <li>♣ To move into a safe, comfortable, convenient and affordable premises for our rehabilitation centre.</li> </ul>
4	Advocacy to influence public policy and organisational practice.	<ul style="list-style-type: none"> <li>♣ Establish Patient Representatives Committee to be the first point of call for patients and to be actively involved in raising awareness and advocating for policy change for epilepsy.</li> <li>♣ Advocate and support the Ministry of Health to develop the neurological division that coordinate epilepsy affairs with proper short term or long term plans, and plan funding.</li> <li>♣ Initiate a new partnership with Gulele sub-City to expand our services in Addis Ababa.</li> <li>♣ Conduct four 1-day workshops (1 per cluster) to initiating community conversation and involvement in the prevention of epilepsy and eradication of stigma.</li> <li>♣ Conduct needs assessment and clinical audit in Amhara or Oromia region to design evidence-based practice to the delivery of epilepsy care that integrates the best evidence from studies and patient care data with clinician expertise and patient preferences and values.</li> </ul>
5	Increase financial capability Raise funds and aid local fundraisers who support CareEpilepsy Ethiopia	<ul style="list-style-type: none"> <li>♣ Hold 1 national and 1 international fundraising dinner.</li> <li>♣ Continue to search for donors and partners.</li> <li>♣ Explore corporates who take action to fulfil their obligation of corporate social responsibilities.</li> <li>♣ Improve our financial capacity through membership fees, alternative self-financing means, donors, corporate sponsorship and other fundraising activities, both nationally and internationally.</li> <li>♣ Social Media Activism: Raising Awareness in Social Movement.</li> </ul>
6	Volunteering and Internship	<ul style="list-style-type: none"> <li>♣ Promote our volunteering and internship schemes, both nationally and internationally.</li> </ul>
8	Organisation Development:	<ul style="list-style-type: none"> <li>♣ Hold 12 one-day in-house training sessions</li> <li>♣ Assigned appropriate staff to 2 external trainings</li> <li>♣ Review our organisational policy to adapt to change.</li> <li>♣ Increase office essentials such as office furniture and equipment, desktop computer and accessories and monitor.</li> <li>♣ Review staff development and training plan to align a workforce with the capability to perform in a complex environment and to adapt to change.</li> </ul>
9	Engagements of partners and networking	<ul style="list-style-type: none"> <li>♣ Encouraging government health authorities and health facilities to take ownership of our programme and invest in training and practice changes.</li> <li>♣ Encouraging neurologists and doctors to provide training through PR incentives for their association.</li> <li>♣ Expand network with government officials, local and international NGOs and pursue new alliances/partners to effect change successfully.</li> </ul>
10	Volunteering and Internship	<ul style="list-style-type: none"> <li>♣ Promote both national and international volunteering schemes and internship projects.</li> </ul>

## OUR FINANCES

CareEpilepsy Ethiopia is in the process of identifying international donors to build financial capacity and publicity. We completed the year 2019 by complying with the Ethiopian government policy of charities finance guideline "30/70", where 70% of our project income is used on direct project cost, and only 30% of our project income can be used to fund core organisational costs or capacity building.

### a) *Treasure's Report*

Year-end accounts for the 31-Dec-2019 for CareEpilepsy is attached as Annex 1.

### b) *Funding Sources*

Despite our efforts, funding to fight epilepsy remains limited. There are insufficient government, philanthropic, and commercial resources available to achieve our mission. During 2019, financial support came in the form of donations from sponsorships, fundraising activities and friends.

- ♣ 392,805.00 was received from our head office, CareEpilepsy UK.
- ♣ The Marriott Executive Hotel Apartments purchased a photocopier machine worth 34,000 Birr and donated to us.
- ♣ CareEpilepsy USA purchased an EEG machine for us worth 500,000 Birr.
- ♣ In-kind donations of service worth more than 1 million Birr.
- ♣ CareEpilepsy Ethiopia advertised an open call for sponsorship and hand-delivered 47 invitation letters to various organisations. These included private businesses, banks, private health care providers and medical professionals. We were grateful to receive 100,000.00 Birr from BGI Ethiopia PLC, 10,000 Birr from Enat Bank, 10,000.00 Yehulushet Clinic 10,000 Birr DSTV, 5000, Tamesol Communications.
- ♣ Individual donors include Kibrom Yirgalem and Kelemework Tesfaye 70,000.00 Birr each.

### c) *Fundraising Success*

#### a) *National*

- We were not able to make a fundraising dinner nationally.

#### b) *International*

- ♣ We were not able to make a fundraising dinner internationally.
- ♣ USA Fundraising
  - Nava Yewnetu, Dr Hirut Woldemedhin, Mr Yonas Tilahun helped to raise funds by hosting a fundraiser in Chino Hills, California, Virginia, and Washington, DC consecutively in April 2019. During this event, we raised awareness about the disease and how it affected Ethiopians as well as educated participants about the remarkable efforts of CareEpilepsy. Not to mention, raised 153,760 Birr!

### d) 14.4 Auditors Report

2019 Audit report is attached as Annex 2.

## ACKNOWLEDGEMENTS & THANK YOU

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

- :- CareEpilepsy UK.
- :- The Marriott Executive Hotel Apartments
- :- CareEpilepsy USA
- :- BGI Ethiopia PLC
- :- Enat Bank
- :- Yehulushet Clinic
- :- DSTV
- :- Tamesol Communications.
- :- Our volunteers for their in-kind donations of service
- :- Individual donors include Kibrom Yirgalem and Kelemework Tesfaye

## OTHER IMPORTANT INFORMATION

- ♣ Today, more than 1.5 million kids and adults in Ethiopia live with epilepsy.
- ♣ Existing treatments too often have debilitating side effects.
- ♣ Not enough funds are available at the local level to fully support people with epilepsy and families impacted by epilepsy daily through local services.
- ♣ Epilepsy is not discussed by the general public.
- ♣ Finding a cure for epilepsy has not attracted a level of philanthropic support commensurate with the unmet medical need.
- ♣ We have no data to show us how many people will die as a result of Sudden Unexpected Death in Epilepsy (SUDEP).

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 organisation 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 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.

CareEpilepsy Ethiopia  
Commercial Bank of Ethiopia  
Account Number: 1000161849166  
Finfine Branch  
IBAN NO. ET0010252  
+ Our account number  
SWIFT CODE: CBETETAFFIN  
Address: P.O.BOX 5656, Addis Ababa

*Thank you  
for caring .*

CAREPILEPSY ETHIOPIA  
AWASH INTERNATIONAL BANK  
ACCOUNT NUMBER: 01308052022900  
AIRPORT BRANCH  
SWIFT CODE: AWINETAA  
Address: P.O.BOX 12638, Addis Ababa

*Thank you!*

With appreciation from  
CareEpilepsy Ethiopia

## CONTACT US

### CareEpilepsy Ethiopia

Company address: Bole Sub-City, Addis Ababa  
Phone: +251 11 669 4455  
mobile: +251940262581

Website: [www.care-epilepsyethiopia.org](http://www.care-epilepsyethiopia.org)  
Email: [helpcareepilepsyethiopia@gmail.com](mailto:helpcareepilepsyethiopia@gmail.com)  
Social media: Facebook/Careepilepsy

*"let's do something amazing."*