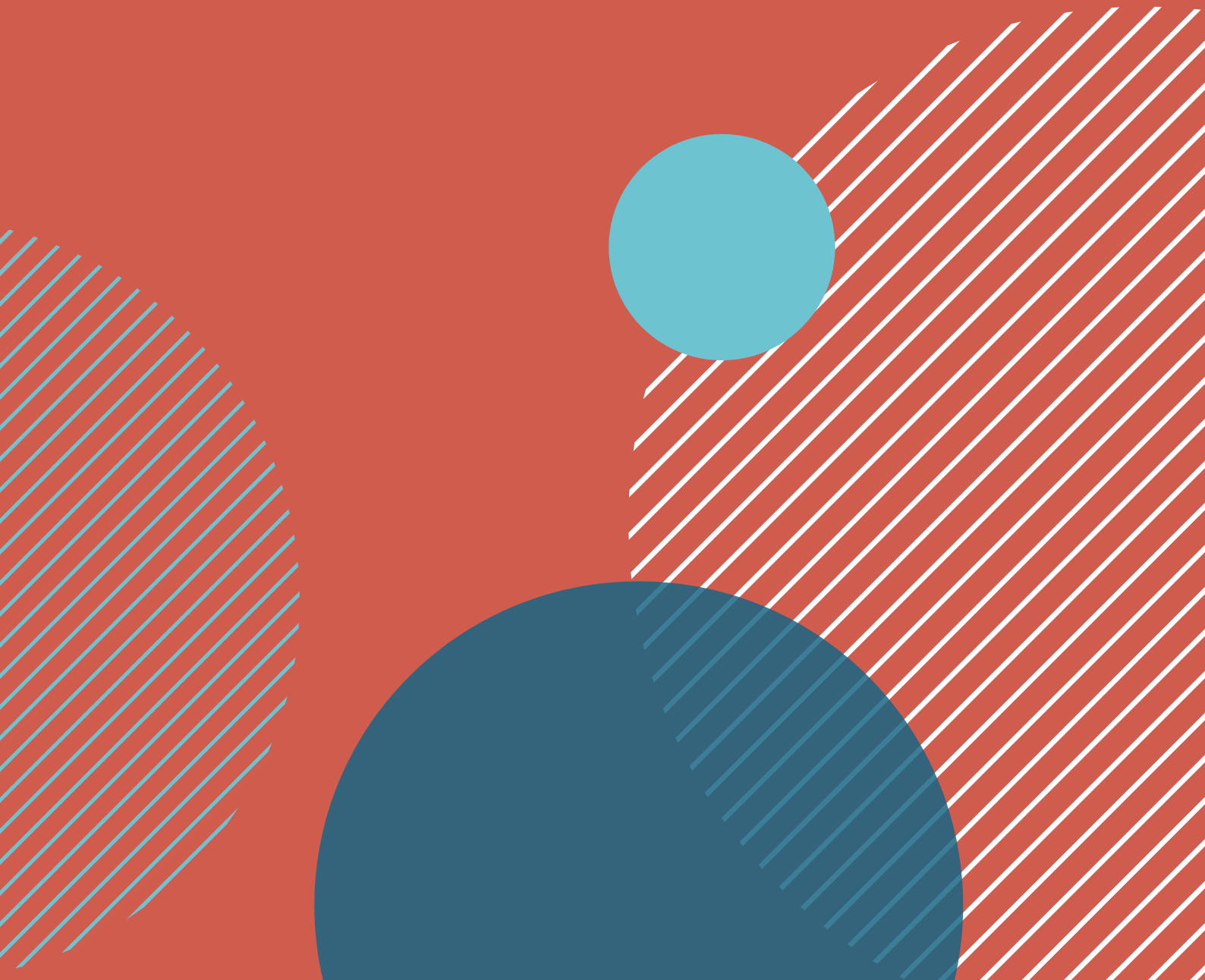


# CareEpilepsy Ethiopia

## ANNUAL REPORT 2017

Saving Lives | Changing Perceptions



## Table of Contents

An overview of CareEpilepsy .....	3
From the desk of the executive director.....	4
Epilepsy .....	6
Epilepsy .....	7
Highlights of the Year 2017 (Achievements and performance).....	8
Our Objectives and strategic objectives for 2017 .....	8
Review of planned activities for 2017 .....	10
Activities and Impacts of work in the community .....	13
Volunteering And Internship Development.....	26
Media and Communication.....	27
DEVELOPMENT PARTNERS .....	28
ORGANISATIONAL DEVELOPMENT AND CULTURE .....	29
Governance, Management, and Capacity Building .....	30
Significant Issues and Challenges we faced in 2017 and remain ahead of us are .....	32
Activities for the year 2018.....	35
OUR FINANCES .....	36
Acknowledgements & Thank You .....	38
Our other important information.....	38
Contact Us.....	<b>Error! Bookmark not defined.</b>

## **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, increase access to medical treatments, create a more positive awareness in society, dispel negative thoughts and perceptions of epilepsy, and finally advocate for 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

2017 was a year full of change and progress for CareEpilepsy Ethiopia. We welcomed new staff and new board members, moved offices, officially partner with CareEpilepsy USA, organised a trek in Ethiopia to raise funds for our work, established a plan to guide us, and have been building partnerships that which creates a lasting and positive impact on our project in Ethiopia. We continued to work to change public perceptions of epilepsy to end epilepsy stigma through education and training. This year saw us expand our service to the region of the Southern Nations, Nationalities and Peoples Region (one of the nine ethnically based regional states (kililoch) of Ethiopia) and Addis Ababa.

We are proud to be working with a wide range of dedicated caring individuals and organisations. From government entities to the faith community, 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.

CareEpilepsy Ethiopia have worked relentlessly over the past year to reach our goals in accomplishing CareEpilepsy's mandate which is providing a holistic care by improving access to medical care and treatment, ending stigma, economic empowerment, and advocacy and sharing what it is like to live with epilepsy. Helping everyone to understand the condition better can make a big difference – at school, work and in relationships with friends and family.

In 2017, six teaching sessions were delivered to educate patients and families about the consequences of living with untreated seizure and encouraged them to seek medical assistance for early epilepsy diagnosis and treatment as a result 1,750 people with epilepsy gained access to anti-epileptic medication. We have been broadcast on 12 radio stations to raise public awareness, change perceptions, and increase the social acceptability of individuals who have epilepsy. We trained ten people with epilepsy in carpet-weaving intending to make them employable and self-sufficient. We conducted 12 patient support group meetings in Addis Ababa and supported 78 patients to do the same in Dire Dawa, which resulted in improved social connectedness and more significant community ownership of our programme. Our telephone helpline service provided help, information and advice on a variety of issues. Our face-to-face counselling service has been giving psychological therapy to help the mental and emotional health of patients to help them develop a positive sense of self-worth and empowered them to look after their health.

It was a joyous time to celebrate the 2<sup>nd</sup> National Epilepsy Week in Mizan Aman Town, Bench Maji Zone with great success. It is estimated that over 500 people attended the awareness walk on the day of the closing ceremony. We distributed over 50,000 informational leaflets and posters for people who live with epilepsy and involved in the care of a person living with epilepsy. These were distributed through hospitals, health centres, and on the street, both in Addis Ababa and Bench Maji Zone. We also further developed a successful community conversation workshop in Mizan town, which included health extension workers, nurses, health officers, and faith leaders.

We have, sadly, said goodbye to Tsion Agaji, our programme manager, after having worked with her for a year. We want to recognise and thank her for her excellent stewardship through our time of change.

This year would not have been successful had it not been for our volunteers. Our youth volunteers have dedicated their time to raise awareness and support our office

operational work. Our volunteers exhibited great passion, developed fresh ideas and showed a willingness to go above and beyond for epilepsy during 2016. 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 growth and exposure of our organisation.

We have been continuously growing, learning, and identifying partnership strategies through our involvement with other organisations such as Mizan Tepi University, Arba Minch University, Zone Bench Maji Zone Development Association.

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 2018. We plan to continue to make positive differences in the lives of people living with epilepsy in Ethiopia.

Some of our priorities for 2018 include: continuing to develop and implement programmes, strengthening our partnership with Bench Maji Zone health office, expanding our patient support group meetings within Addis Ababa and Dire Dawa, and opening a satellite in Bench Maji Zone, providing training for clinical staff, creating additional fundraiser activities, strengthening and building new partnerships, both nationally and internationally, and purchasing one EEG machine.

Focus on Epilepsy

*Enat Yewnetu*

Enat Yewnetu  
Founder and Chief Executive Officer



## 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

2

## WHAT IS EPILEPSY?

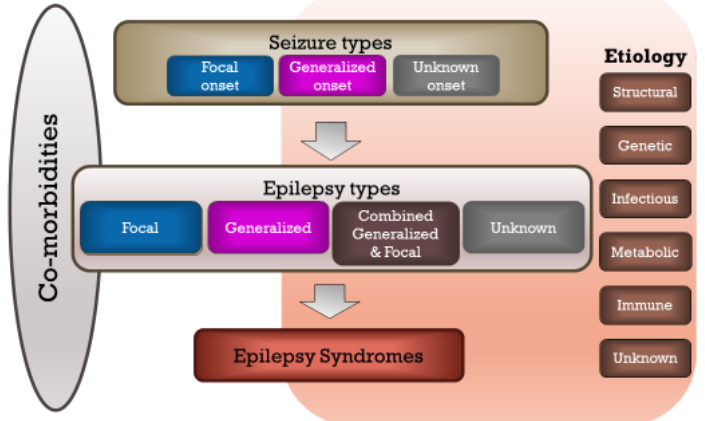


Epilepsy is a chronic neurological disorder characterized by a tendency to have recurrent seizures



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)

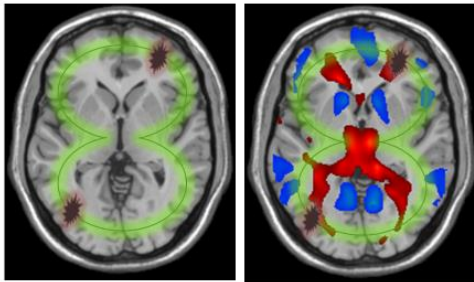
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# Epilepsy

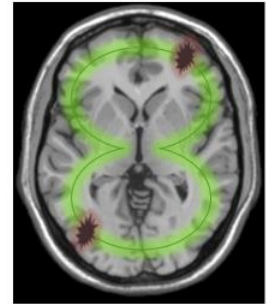
-  Awareness impaired/inability to respond
-  Often begins with blank dazed stare
-  **AUTOMATISMS** (repetitive purposeless movements)
-  Clumsy or disoriented movements, aimless walking, picking things up, nonsensical speech or lip smacking
-  Often lasts one to three minutes (1-3)
-  Often followed 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 2017 (ACHIEVEMENTS AND PERFORMANCE)

- The greatest achievement of the year was to be able to start and run six free epilepsy clinics in the community run by a pediatric neurologist and a clinical nurse for children with epilepsy. We provided financial support for patients to attend the free epilepsy clinic and the monthly peer-support group meetings.
- We strengthened the capacity of local epilepsy health care providers to be able to diagnose and treat epilepsy through training sessions on service delivery in Epilepsy. Among the attendees were clinical staff (nurses and health extension workers), decision-makers, faith leaders and university staff who were engaged in research.
- We produced epilepsy information leaflet (flyers, posters and banners) to decrease the gap of knowledge in epilepsy and change social norms and community perceptions of epilepsy.
- This year was our first experience to celebrate the national epilepsy week in the region of Bench Maji Zone, outside of Addis Ababa.
- We utilized mass media campaigns designed to raise awareness of epilepsy, promote medical seeking behaviour successfully.
- The peer-support group meetings remained the most effective way to help people with epilepsy and their families cope with their condition and improve their sense of belonging and connectedness.
- More patients attended our face-to-face counselling service on a regular basis.
- Our microenterprise project, CareCraft, run for half of the year.
- We were able to initiate a partnership with Yeka Sub-City Health Office, by them allowing us to use their clinic space and us helping their patient and others receive free epilepsy clinic and monthly patient support group meetings.
- We were able to do a presentation on the 30<sup>th</sup> June 2017 in UNOPS.
- This year was the first time we reached out to the Southern Nations, Nationalities, and Peoples' Region Health Bureau to celebrate the 2<sup>nd</sup> National Epilepsy Week in Bench Maji Zone and to organise the programme jointly.

## OUR OBJECTIVES AND STRATEGIC OBJECTIVES FOR 2017

### - *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.

### - *Our Strategic Objectives for 2017 were to*

- a) Facilitate access to medical care and anti-epileptic medications
  - Establish a free epilepsy clinic
  - Increase access to anti-epileptic drugs
  - Strengthening existing epilepsy care providers through clinical training
- 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 2nd National Epilepsy Week in joint partnership with the Federal Ministry of Health, the Southern Nations, Nationalities and Peoples Region Health Bureau, specifically in Bench Maji Zone Health Office in in Mizan Aman.
- 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.
- Community conversation
  - To advocate and support the FMOH to put epilepsy high on it's 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.
  - Initiate partnership with the Addis Ababa Health Bureau, and further strengthen partnerships with 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.
  - Identify partners to establish new centre of excellence in neurology
- 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 2017

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

Objective	Activities		Achieved	Not Achieved	In Progress	Remarks
<b>Objective 2</b>	<b>Public Education and Awareness - to increase social acceptability. We do this by engaging in the following activities.</b>					
	<b>Activity 2.1.</b>	<b>Epilepsy Education Materials</b>	✓	No DVDs were produced		Lack of finance
	<b>Activity 2.2.</b>	<b>Epilepsy Education Program</b> - Establish educational program for children, youth and adults living with epilepsy.	✓	✓	✓	
	<b>Activity 2.3.</b>	<b>Raise awareness of epilepsy in the community</b> - <i>Epilepsy Education at hospitals and health centres</i> - <i>Campagne4epilepsy</i> Hold the 2nd National Epilepsy Week in Bench Maji Zone.	✓	✓	✓	
	<b>Activity 2.4.</b>	<b>Raise awareness of epilepsy in other professions</b> - 'School Epilepsy Champions' - <i>Seziure@school</i> - 'Employer Epilepsy Champions' - <i>Seziure@work</i>	✓	✓	✓	
<b>Objective 3</b>	<b>Improve the wellbeing of people with epilepsy by addressing the psychosocial factors affecting their lives. We do this by engaging in the following activities.</b>					
	<b>Activity 3.1.</b>	<b>CareEpilepsy Rehabilitation Center</b> - 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.	✓	✓	✓	
	<b>Activity 3.2.</b>	<b>Helpline4epilepsy</b> - Establish a telephone helpline and an Epilepsy Emergency Ambulance Service.	✓	✓	✓	
	<b>Activity 3.3.</b>	<b>Connect4epilepsy</b> - Establish peer support groups to provide counselling, social and recreational activities.	✓	✓	✓	

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.	✓	✓	✓	
	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.	✓	✓	✓	
<b>Objective 4</b>	<b>Advocacy in partnership to influence public policy and organizational practice. We do this by engaging in the following activities.</b>					
	Activity 4.1.	Patient Representative Committee	✓	✓	✓	
	Activity 4.2.	<b>Community Conversation</b> Involve the community to address pressing issues facing people with epilepsy and in supporting people with epilepsy and their families. - <i>Training Workshop</i> - <i>Faithaction4epilepsy</i> - <i>Online community forum</i>	✓	x	✓	<i>Lack of funding to start the project.</i>
	Activity 4.3.	<b>Partner4epilepsy</b> - Build partnerships with joint stakeholders develop partnership strategies for epilepsy prevention, care and support.	✓	✓	✓	<i>Lack of focus and engagement from partners.</i>
	Activity 4.4.	<b>Research4epilepsy</b> - Conduct clinical audit, epidemiological surveillance, research and develop best practice guidelines in collaboration with national and international experts.		x		<i>Lack of funding and partnership to start the project.</i>

## ACTIVITIES AND IMPACTS OF WORK IN THE COMMUNITY

### ***Strategic Objective 1 (SO1) – Facilitate access to medical care and anti-epileptic medication.***

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

#### ***Activity 1.1 Clinic-based Epilepsy Management***

- 6 paediatric neurology clinic was run Dr Kindu, a Pediatric Neurologist.
- 6 general health assessment clinic was given by Sister Kelemwork, a lead clinical nurse at the United.
- Yeka Sub-city allowed us to use their clinic room to see patients.
- Continued to organise consultation with and referrals to available epilepsy clinics, both government and private.
- Financial support to attend the free clinic and patient support group meetings.

#### ***Activity 1.2 Anti-epileptic Medication***

- As a result of our campaign during the 2<sup>nd</sup> National Epilepsy week, the Bench Maji Zone Health Office took an audit to identify the number of people with epilepsy within the Bench Maji zone.
- The audit indicated that many patients living with epilepsy in Guraferda woreda had never received clinical care and treatment. We are happy to report that the Bench Maji Zone Health Office arranged clinical consultation and were put on anti-epileptic drugs.
- Facilitated for patients to receive “the poorest of the poor identification card” (a government system to identify the poor as beneficiaries) which enables them to receive their anti-epileptic medication free of charge.

**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 drug (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



### **Activity 1.3 Neuro-diagnostic service**

Although CareEpilepsy Ethiopia was not able to purchase its electroencephalogram (EEG), we paid for patients to receive the service.

### **Activity 1.4 Improve Human Capacity and Leadership**

We provided training to clinical staff (health officers, nurses and health extension workers), decision-makers and Mizan Tepi university staff who were engaged in research to improve epilepsy service delivery within the Zone.



### **Impact of our strategic activities to achieve Objective 2**

- 30 children with epilepsy received epilepsy care by attending our free community clinic for the first time.
- 30 children with epilepsy received general health assessment by attending our free community clinic for the first time.
- 10 people received financial assistance in acquiring anti-epileptic medication in Addis Ababa.
- 1,750 individuals with epilepsy, gained access to antiepileptic medication at Bench Maji Zone.
- 4 Children underwent a free electroencephalogram (EEG) neuro-diagnostic assessment.

- 150 nurses and health extension workers received training about epilepsy.
  - 92% of people knew more about epilepsy and its impact on an individual life after the clinical training (130 out of 150 attendees).

## ***Strategic Objective 2 (SO2) – Public Education and Awareness during 2017***

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. We initiate campaigns to raise general awareness and understanding of epilepsy to eradicate stigma and discrimination. The followings are the various activities that we employ to accomplish our strategic objective 2.

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

CareEpilepsy Ethiopia continued to upgrade and produced epilepsy information leaflet and posters for educational purpose, and this was distributed in Addis Ababa and among regions.

### ***Activity 2.2. Epilepsy Education Program***

Establish educational program for children, youth and adults living with epilepsy and learn the risks of untreated seizure, prevention, causes and consequences of epilepsy.

- We have started to gather information and design "My epilepsy care" booklet providing knowledge about epilepsy, and care planning for people with epilepsy.
- 12 teaching sessions were organized to educate people with epilepsy of the risks of untreated seizure, prevention, causes and consequence of epilepsy.
- Engaged people with epilepsy to be self-motivated to access and receive epilepsy care by attending a hospital for the first time.

### ***Activity 2.3. Raise awareness of epilepsy in the community***

- **Epilepsy Education at hospitals and health centres**  
We run 6 sessions of community education in Yeka health centre in Addis Ababa.
- **Campaign4epilepsy**  
The national epilepsy week was an educational event that provided a fun and exciting way to raise awareness about epilepsy, teach the correct seizure first aid response in the case of a tonic-clonic seizure, and connect with others living with epilepsy. Our target audiences were people living with epilepsy, their families, and the public at large. Radio adverts and the theme song were played during the week and on the day of the walk sung by the walkers. Hold the 2nd National Epilepsy Week in Bench Maji Zone.
- **National Epilepsy Week in Addis Ababa**

The 2nd National Epilepsy Week, was celebrated by teaching around schools and hospitals. We distributed printed epilepsy information leaflet and posters via epilepsy clinics in five government hospitals and four private hospitals, and seven



schools. We also used social media such as Facebook, and our website to raise awareness about epilepsy.

- 6 awareness and information days held by our volunteers in Addis Ababa.
- National Epilepsy Week in the region
  - The 2nd National Epilepsy Week, which was held from the 12th -18 June 2017 in Bench Maji Zone Mizan Aman Town, was a joint initiative between CareEpilepsy Ethiopia, Federal Ministry of Health and the Southern Nations and Nationalities People Region Health Bureau under the leadership of CareEpilepsy.
  - Our awareness-raising campaigns are recognised as the most efficient and effective means of communicating information about epilepsy to the general public.
  - We invited various stakeholders such as schools, hospitals, governmental and non-governmental organisations, health sectors to join our walk and raise awareness.



## **Activity 2.4. Raise awareness of epilepsy in other professions**

### **- 'School Epilepsy Champions' - Seziure@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 various schools. 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.



### **- 'Employer Epilepsy Champions' - Seziure@work**

It has been a challenge to find an organisation to partner with us. We will continue to work on this activity in 2018.

## **Impact of our strategic activities to achieve objective 2**

- More than 600 members of the community who received treatment at Yeka health centre gained knowledge about epilepsy education.
- More than 350 people increased their knowledge of epilepsy by attending the closing ceremony of the 2<sup>nd</sup> National Epilepsy Week in the administrative town of Mizan Tepi.
- 5,000 epilepsy information leaflets were given to Bench Maji Zone to be distributed within their 11 woredas.



- 25 million people are estimated to have been reached through talk show and radio interviews in Addis Ababa and the Southern Region during the 2<sup>nd</sup> National Epilepsy Week.
- We provided 10,000 epilepsy educational leaflets to the Southern Nations Nationalities and Peoples regional Health Bureau to be distributed to 14 zones within the region.
- 200 university students who study at Mizan Tepi University received information about epilepsy.
- 2 schools (1200 pupils) received a seizure response and first aid training.
- More than 480 families of children with epilepsy received epilepsy education at epilepsy children clinic at Yekatit 12 teaching sessions hospital during June – August 2017.
- We provided training for teachers in epilepsy and seizure first-aid to equip them to support children with epilepsy.

***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. CareEpilepsy Rehabilitation Center***

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.

***Activity 3.2. Helpline4epilepsy***

- We continued to expand our epilepsy telephone helpline service, a confidential helpline where we offer counselling and up-to-date information about epilepsy care provider hospitals and clinics and pharmacy list, which hold antiepileptic drugs.
- The most common requests were inaccessibility of medication, clinic information where they could receive epilepsy care, financial support.

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

<b>Referral Source</b>	<b>Number of patients</b>	<b>% of Patients</b>
Clinician	13	3
Health Center	30	6
Patient	2	0
Signage	24	5
Radio	370	77
TV	41	9
Website	0	0

○



### **Activity 3.3. Connect4epilepsy**

Our peer-support group meetings continued to flourish and provide counselling, social and recreational activities. We held 12 monthly support group meetings in Addis Ababa and established one group in Dire Dawa for people living with epilepsy and their families to share their experiences. We had 9 guest speakers to teach about epilepsy which increased the knowledge of patients and families to deal with the condition.



## **PATIENT SUPPORT GROUP MEETINGS IN 2017**



### **Activity 3.4. Counselling4epilepsy**

CareEpilepsy Ethiopia continued to provide face to face individual counselling service which aims to

- help patients find understanding, ways to cope, or to feel more in control about their epilepsy and to develop healthy thoughts about life with epilepsy;
- provide practical advice and information for families how to take care of their family member with epilepsy;
- provide practical advice and information about adherence to anti-epileptic drugs, living with epilepsy and in general keeping wellbeing.

Table 4 – Beneficiaries who received counselling and psychotherapy

Beneficiaries who received psychological support during 2017	
Male	Female
25	31

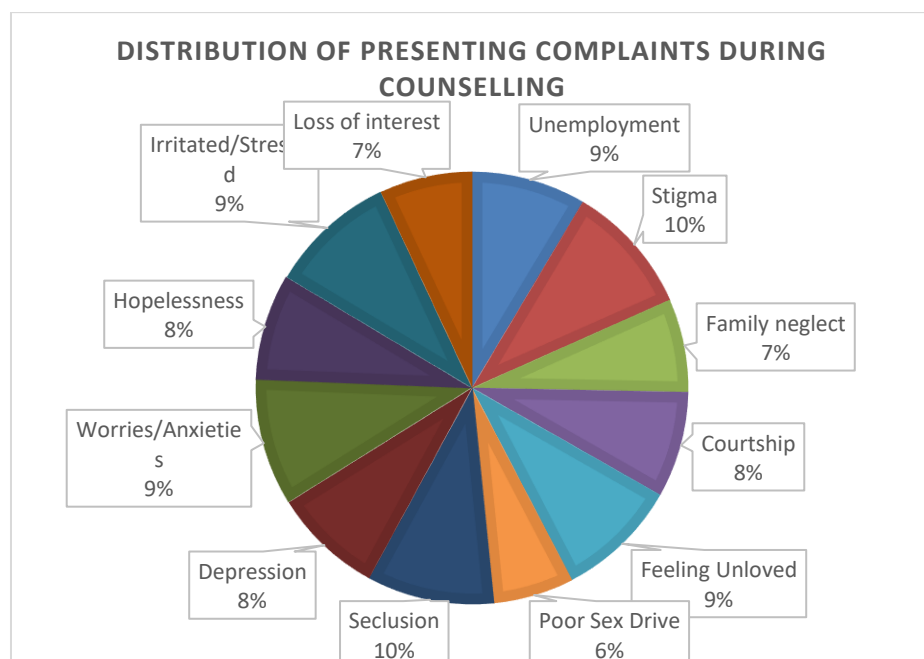
**Table 5 - Distribution of Presenting Complaints by sex patient**

Below illustrated are the gender distribution of presenting complaints by the gender of the patients during counselling and psychotherapy sessions.

Distribution of Presenting Complaints by Gender during Face-to-Face Counselling		
	Female	Male
<b>Unemployment</b>	27	24
<b>Stigma</b>	31	25
<b>Family neglect</b>	22	10
<b>Courtship</b>	25	10
<b>Feeling Unloved</b>	29	17
<b>Poor Sex Drive</b>	19	20
<b>Seclusion</b>	30	21
<b>Depression</b>	26	14
<b>Worries/Anxieties</b>	30	23
<b>Hopelessness</b>	25	12
<b>Irritated/Stressed</b>	30	25
<b>Loss of interest</b>	22	13

**Figure 3 - Distribution of Presenting Complaints by sex patient**

These are some of the most common side-effects of medication: significant medication complaints.



### **Activity 3.5. Wolafen**

Provide financial assistance for improvement of domestic environments such as building safe cooking stove to reduce morbidity, mortality and disability as a result of burns among people with epilepsy, especially women.

### **Activity 3.6. Income Generating Activities (IGA) - CareCraft**

This programme aims to provide people with epilepsy with opportunities for both social and economic development.

#### **- CareCraft**

The first cohort of the programme, 8 women with epilepsy, continued to be trained in carpet weaving for 6 more months and completed their training during the first half of 2017. CareEpilepsy Ethiopia organised a graduation party and gave out certificates of completion to the participants. While engaging in the training, we continued to provide tools and raw materials for their practical work as well as breakfast and lunch and transportation costs. Business mentors and project staff met regularly to provide supervision and ongoing support for our project beneficiaries.

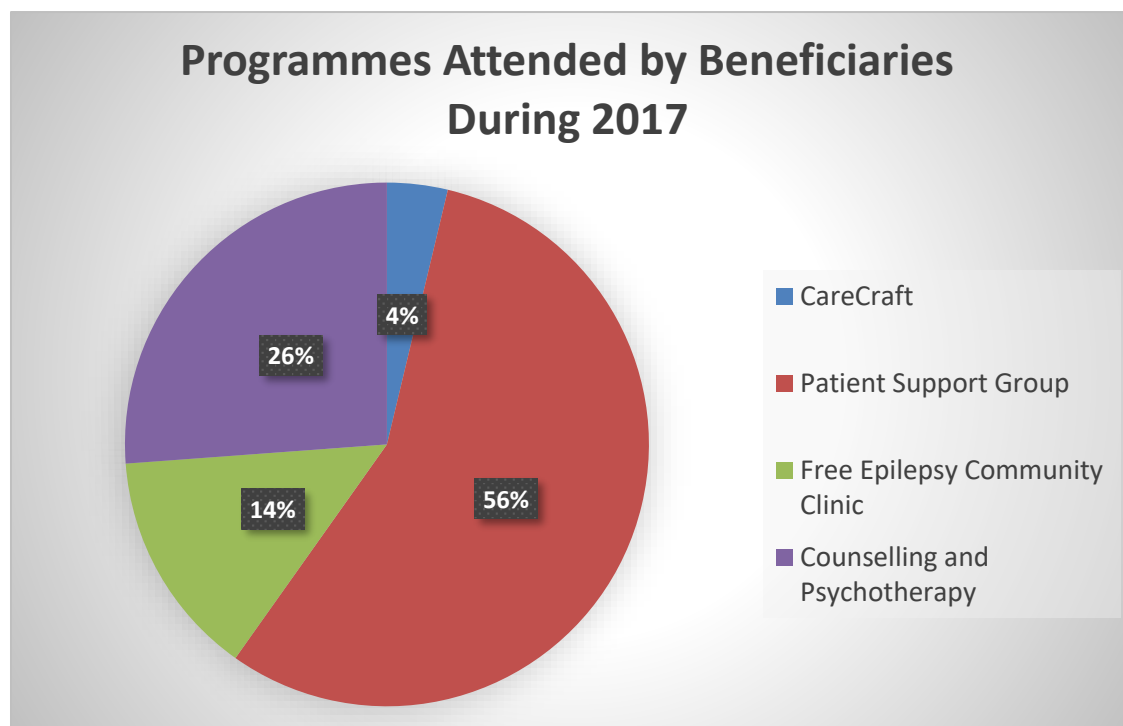




**Table 6 – Total Number of Attendees of our Programmes During 2017**

Free Epilepsy Community Clinic	Help Line	Patient Support Group	Counselling and Psychotherapy (face-to-face)	CareCraft
30	480	120	56	8

Figure 4



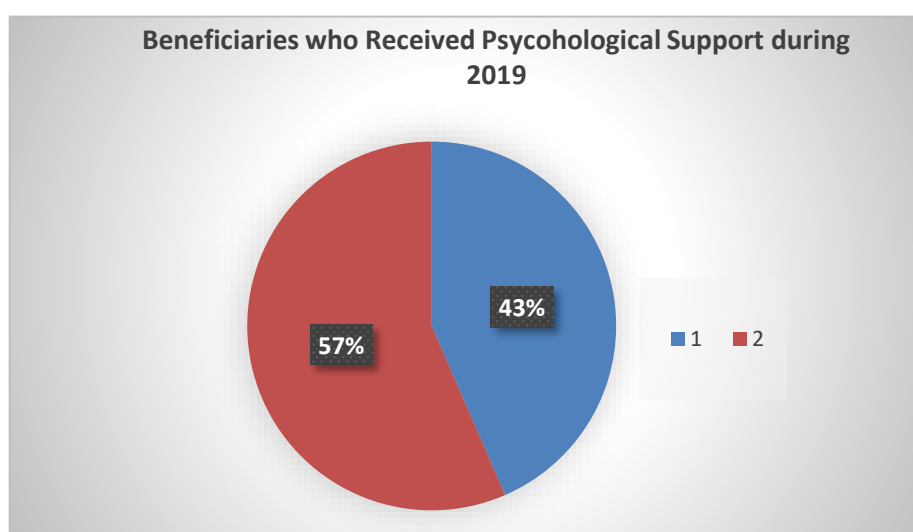
### ***Impact of our strategic activities to achieve objective 3***

1. 12 Patient Support Group meetings were held (which covered 48 hours of discussion) in Addis Ababa, and 120 people attended patient support group meetings.
2. 480 people received clinical information about epilepsy through our dedicated 24/7 Helpline. Out of these 78 were new patients.
3. 12 Patient Support Group meetings were held (which covered 48 hours of discussion) in Addis Ababa, and 120 people attended patient support group meetings
  - 93% of patient support group attendees felt less isolated and part of a broader community of people with epilepsy (112 out of 120)
  - 75% of patient support group attendees felt more confident discussing epilepsy with healthcare professionals (90 out of 120)
  - 25% (30 out of 120) of patient support group attendees felt more confident being open about their epilepsy.
4. 56 people received support through counselling service.
5. 120 patients and family members were supported financially to cover their transportation cost.
6. 100% of women who were involved in CareCraft training felt empowered, and their self-esteem increased.

**Table 4 – Beneficiaries who received counselling and psychotherapy**

Beneficiaries who received psychological support during 2019	
Male	Female
180	234

**Figure 2 – Percentage of beneficiaries who received psychological support**



Distribution of Presenting Complaints by the gender of the patients during counselling and psychotherapy sessions. Illustrated below is the gender distributions of presenting complaint.

**Table 5 - Distribution of Presenting Complaints by sex patient**

Distribution of Presenting Complaints by sex patient		
	Female	Male
<b>Unemployment</b>	120	180
<b>Stigma</b>	300	150
<b>Family neglect</b>	250	100
<b>Courtship</b>	80	90
<b>Feeling Unloved</b>	40	79
<b>Poor Sex Drive</b>	70	55
<b>Seclusion from social activity</b>	67	120
<b>Depression</b>	57	89
<b>Worries/Anxieties</b>	44	70
<b>Hopelessness</b>	67	52
<b>Irritated or stressed</b>	57	57
<b>Loss of interest</b>	22	41



## ***Strategic Objective 4 (SO4)- Advocacy in partnership during 2017***

We continued to advocate with critical partners and stakeholders for public policies that protect the rights of people with epilepsy and to address the medical, social and environmental factors contributing to epilepsy. 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:***

Establishing Patient and Family Representatives have been a difficult journey than expected. We are working on empowering patients to take a leap of faith in the power of coming together to change the lack of focus on the improvement of medical care for people with epilepsy and eradicate the stigma associated with the condition.

### ***Activity 4.1 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***

CareEpilepsy Ethiopia organised a 1-day workshop to initiating community conversation and involvement in the prevention of epilepsy and support for people with epilepsy and their families in Mizan Tepi town. The community conversation workshop was led by Mr Teklit Tesfom, the Zonal Health Office Director, and Enat Yewnetu, CareEpilepsy Ethiopia Director. The highlight of the workshop was the various representations of the community led by the zonal health office director. The workshop provided an opportunity for participants to move from seeing themselves as passive recipients of information to active problem-solvers and reducing silence and stigma surrounding epilepsy. The discussion addressed both the care and prevention of epilepsy and included the involvement of faith leaders and traditional healers. The need to increased community responsiveness to the needs of people with epilepsy was evident during the workshop, which leads to improved quality of life of people with epilepsy.

### ***Activity 4.3. Partner4epilepsy***

Involving partners and stakeholders we plan to develop partnership strategies for epilepsy prevention, care and support.

Our specific aim of partnership with the Federal Ministry of Health is

- For the Ministry to agree to the 2015 the WHO adopted a resolution to address the health, social and public knowledge of epilepsy in Africa.
- To form a task force to spearhead the implementation of the WHO's 2015 resolution.
- Have a national epilepsy plan to implement the resolution. This should include measures to ensure sustained epilepsy awareness, training of health workers, research, funding, treatment guidelines, human resourcing, medicines supply, operation of the national task force and other issues.

#### ***Activity 4.4. Research and Develop Best Practice Guidelines***

It is one of the priorities of CareEpilepsy Ethiopia to conduct clinical audit and develop best practice guidelines in collaboration with national and international experts. This activity is expected to add to the quality of people with epilepsy's life as a result of evidence-based programs.

Mizan Tepi University showed an interest to work with us to do prevalence study of epilepsy expected to provide evidence-based data from the Bench Maji Zone population which is expected to inform policy-makers of interventions that are scalable and effective.

#### ***Impact of our strategic activities to achieve objective 4***

- The Federal Ministry of Health paid the printing cost for 30,000 epilepsy information leaflets worth 80,000 Birr.
- The Southern Nations Nationalities and People Regions Health Bureau covered the cost of printing epilepsy information leaflet, media coverage and T-shirt for the event.
- 120 attendees, including faith leaders, health officers, nurses and community leaders, attended a community conversation workshop. The various representations of attendees of community conversation workshop were enabled to brainstorm concrete action plans for responding to epilepsy stigma and service.
- During 2017, although there is no tangible commitment yet, the need for improvement of epilepsy service for accessible clinical care, the availability of affordable anti-epilepsy medication and free medication for those who cannot afford to pay is acknowledged by the Federal Ministry of Health. Other partners also recognise the unique need for reducing stigma. 2018 expected to be a year that we rip the fruit of our work.
- Guraferda woreda received anti-epileptic medication for the first time.
- As a regulator, we continue to 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 to revise education policy to give equal access to education for children with epilepsy.

### ***a) Volunteering in 2017***

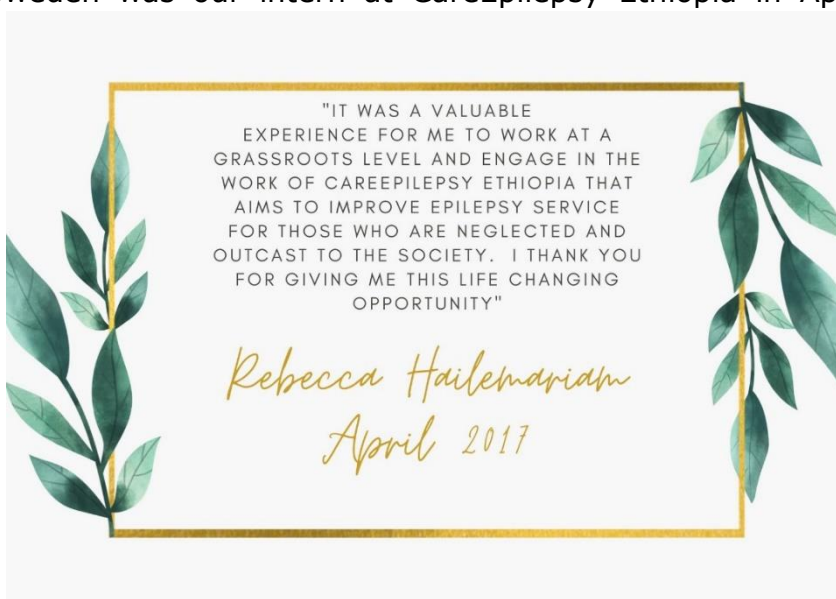
CareEpilepsy Ethiopia's volunteering opportunity has a variety of programmes that is appealing to the those in education as well as professionals of any age.

During 2017, our Youth4Epilepsy Ethiopia volunteers continued to make an impact through their involvement with our programmes such as organising and participating in the 2nd National Epilepsy Week and distributing printed information leaflets about epilepsy via epilepsy clinics in government hospitals.



### ***b) Internship at CareEpilepsy Ethiopia***

Rebecca Hailemariam from Sweden was our intern at CareEpilepsy Ethiopia in April 2017 as part of her degree programme in social work in Sweden. She had the opportunity to learn about epilepsy and its impact on health and healthcare in Ethiopia. She got the chance to participate in two of our focus areas, such as wellbeing and awareness-raising. We found Rebecca to thrive on a challenge and to be passionate about making a difference.



## Impact

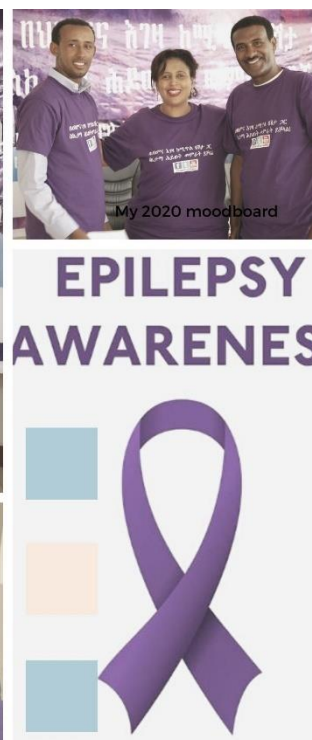
- 120 volunteers in Addis Ababa actively engaged in supporting the activities of CareEpilepsy Ethiopia.
  - 10,800 hours were given volunteering to help us complete our objective for the year.
  - 120 volunteers received a half-day in-house training on facts about epilepsy and epilepsy first aid response.
  - A storybook for children about epilepsy, one depicting city life another depicting rural life, was designed as part of summer youth volunteers' activity. Children and their families will be able to understand epilepsy in an illustrative and enjoyable manner.
- 20 volunteers from Mizan Tepi University's drama club performed epilepsy first-aid response (recovery position) in the street of Mizan Aman Town during the final day walk, 18<sup>th</sup> June 2017.
- 5 days of street campaigns were held in Mizan Tepi town.
- 75 hour of work in the community were donated by an intern from Sweden.

## 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. Outdoor media such as signboards; posters were placed in hospitals, clinics, health centres, inside and outside cars, shops, and organisations. as well as digital media such as email, Facebook, Twitter, and the CareEpilepsy website.

### 8.1 Media

- A press conference was held in Bench Maji Zone Administrative Office on the 11<sup>th</sup> June 2017. Mr. Mitiku Tamiru (Deputy Director, Bench Maji Zone), Mr Abebaw Ayalew (Mental Health Advisor at the FMOH) and Enat Yewnetu (Founder and CEO of CareEpilepsy Ethiopia).





- Three radio interviews on Fana Radio, Debub FM 100.9, and Ethiopia News Agency were held with the Chief Executive Office of CareEpilepsy Ethiopia to discuss epilepsy and the work of the organisation.

## **8.2 Communication**

### **Website**

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

### **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.

### **Speaking Engagements**

It was a fantastic opportunity to be invited to speak about epilepsy at the United Nations Office for Project Services (UNOPS) which is an operational arm of the United Nations, supporting the successful implementation of its partners' peacebuilding, humanitarian and development projects around the world.

## **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.
- As a result of our presentation at the United Nations Office, Dr Kindu W/Michael (a paediatric neurologist) and Sr Kelemework Tesfay (UN Lead Nurse) attended our patient support group meeting and committed to start a free clinic for children with epilepsy.

## **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 2017, 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.

- There is a dim light of acknowledgement from the Federal Ministry of Health about the inadequacy of epilepsy care.



- The Southern Nations and Nationalities People Region Health Bureau, Bench Maji City Administration, and Bench Maji Zone health office expressed their interest to engage in raising awareness and establish epilepsy service to address the issues affecting their region.
- Mizan Tepi Hospital showed enthusiasm in receiving support from CareEpilepsy Ethiopia on the development of best practice guideline to address epilepsy service challenges and to ensure that epilepsy services provided at all levels expected to meet quality standards.
- Discussion is continued with the Ethiopian Midwives Association (EMA) to achieve best practice for people with epilepsy.
- In conversation with Ethiopian Teachers' Association to look into best practice at special needs class for children with epilepsy.

## ORGANISATIONAL DEVELOPMENT AND CULTURE

### ***a) Organisation Policy and Procedures***

CareEpilepsy Ethiopia Staff Plan in 2017 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.

### ***b) Recruitment and Selection***

We believe recruitment along with financial and material resources, contribute to the accomplishment of our objectives.

### ***Achievements During 2017***

We have started with the following policies to assist us at our workplace: The following policies were completed.

- Code of conduct
- Recruitment policy
- Internet and email policy
- Mobile phone policy
- Non-smoking policy
- Drug and alcohol policy
- Health and safety policy
- Anti-discrimination and harassment policy
- Grievance handling policy
- Discipline and termination policy
- Using social media.

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

### ***Achievements During 2017***

- We designed the Staff development and training plan.
- We hold eight 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 Response, Communication Skills, Teamwork, Presentation Skills, Conflict resolution and Careepilepsy Ethiopia. The course delivered medical and statistical information and knowledge about the resources Care Epilepsy Ethiopia can provide in the form of leaflets, posters and DVDs.

### ***Impact***

- Staff increased their knowledge about epilepsy and epilepsy first aid, communication skills, 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.
- Increased productivity levels across the board, meaning more quality work is being performed.
- Cross training alleviated the burden of shortage of staff during the year. 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.
- Help build relationships amongst staff.
- Staff felt valued and appreciated.

## **GOVERNANCE, MANAGEMENT, AND CAPACITY BUILDING**

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 2017, we made a focus to build good governance which is key to the growth and sustainability of Careepilepsy Ethiopia and spent hours of discussions with our governing body on building strategic thinking and oversight characterise 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 started 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.

### **11.1 Governance**

#### 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.

### **11.2 Operational and Project Management**

#### Operational Management

The chief executive director is responsible for the overall direction in which Careepilepsy Ethiopia moves, and the day-to-day activities of the organisation. Moreover, she managed financial and administration work and teams to achieve our financial goals.

#### Project Management

We did not recruit for the post, but we established a Task Force with the assignment to organise the various activities using our volunteers. 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.

## SIGNIFICANT ISSUES AND CHALLENGES WE FACED IN 2017 AND REMAIN AHEAD OF US ARE

It is true that many of the objectives were achieved. However, we found it difficult to find sufficient, appropriate and continuous funding for our work. We found accessing donors as challenging as dealing with our funding conditions. This was largely attributed to our organisation being new and having no track record, poor networking, limited resource mobilisation skills, lack of international grant money for epilepsy, and lack of international connections for fundraising.

In order of impact	Challenges/Issues	Challenges/Issues Explained	Proposed Solutions
1	<b>Federal Ministry of Health</b>	<ul style="list-style-type: none"> <li>- Epilepsy does not receive adequate attention in existing national health plans, albeit epilepsy is planned to be integrated at district level plan developed to provide primary care-based care for people with psychosis, bipolar disorder, depressive disorders, alcohol use disorder and epilepsy. The district Mental Neurological and Substance Abuse care plan is based on a task-sharing model.</li> <li>- FMoH does not show commitment to adopting a strong catalytic role in order to improve epilepsy health in poor, underserved areas.</li> <li>- Technical dialogue with health authorities has not been fruitful and did not lead to the implementation of sustainable actions.</li> </ul>	
2	Financial sustainability	<ul style="list-style-type: none"> <li>- Difficulty in securing funding to cover essential operational and administration cost. (Funders prefer longer-established NGOs and desire to see results only in the defined project activities, and as such, they forbid or limit the use of funds for organisational overheads.</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> </ul>

		<ul style="list-style-type: none"> <li>- Lack of epilepsy specific grants on the international level.</li> <li>- Lack of a named person with real experience or skill in donors/grant pursuits/searches causing loss of opportunity.</li> </ul>	
<b>3</b>	Manpower/staff	<ul style="list-style-type: none"> <li>- CEO covering many of the jobs has proven to be a great challenge and affected productivity.</li> <li>- We still rely on our volunteers as our office has got only 3 full time and 1 part-time member.</li> <li>- The amount of workload has affected the efficiency of our staff.</li> <li>- The lack of expertise has a drawback on our engagement.</li> </ul>	<ul style="list-style-type: none"> <li>- Identify volunteers to work as an assistant as work experience.</li> <li>- Develop strategies to generate revenue to finance the justifiable, affordable and minimum level of staff.</li> <li>- Increase expertise at the national level through training and partnership with higher education institutions.</li> </ul>
<b>4</b>	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> </ul>	<ul style="list-style-type: none"> <li>- Discussions need to start to get support from the government.</li> </ul>
<b>5</b>	Patients Expectations and engagement	<ul style="list-style-type: none"> <li>- Patients are putting increasing demands on Careepilepsy Ethiopia to provide financial assistance 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 organizations to realize affordable or free medication.</li> </ul>
<b>6</b>	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</li> </ul>	<ul style="list-style-type: none"> <li>- Build on the work that has been done so far</li> <li>- Engage more with national and regional government offices, community leaders, the media</li> </ul>

		in comparison with other charities because of the nature of our work.	- Approach recognized members of the community and personalities such as celebrities to serve as goodwill ambassadors.
<b>7</b>	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 work.</li> <li>- The government, as well as the public, is skeptical of charities work.</li> <li>- Delayed input and feedback from institutions.</li> <li>- Financial resources of the health sector are available to support prioritised actions.</li> </ul>	Continue discussion.
<b>8</b>	Lack of proper networking	The 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.

## ACTIVITIES FOR THE YEAR 2018

In order of Priority	Activities	Strategies
1.	Fundraising	CareEpilepsy would need to expand its access to finance and do global /cross-border fundraising. Because of the new charity law in Ethiopia, we can only fundraise internationally. We do this by <ul style="list-style-type: none"> <li>▪ Establishing corporate partnerships. We are searching for strategic corporate partnerships to help them achieve their goals for corporate social responsibility or public relations. We aim to develop a partnership with at least 2 organisations for this year.</li> <li>▪ Fundraising Event – 2 significant fundraising events in London</li> <li>▪ Use online fundraiser/crowdfunding using various fundraising platforms such as MyDonate, GoFundMe, and JustGiving.</li> <li>▪ Trek - Semien Mountain Trek in Ethiopia to raise funds</li> </ul>
2.	<b>Raise awareness</b>	<ol style="list-style-type: none"> <li>1. Continue raising awareness of epilepsy: <ol style="list-style-type: none"> <li>a. Celebrate 3<sup>rd</sup> National Epilepsy Week in Addis Ababa</li> <li>b. Organize community conversation workshop.</li> </ol> </li> <li>2. Engage more schools to “Schools4Epilepsy” programme</li> </ol>
3.	Networking	Strengthening and building partnerships/networks, both nationally and internationally. Working in collaboration with the FMoH, establish regional support teams and provide access to patients to the district epilepsy support teams. These teams consist of a neurologist/general doctor, an epilepsy specialist nurse, psychotherapists, faith leaders with a particular interest in providing care for people with epilepsy.
4.	Foster and facilitate regional and international collaborations	- 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.	Anti-epileptic drugs	- Increase access to anti-epileptic medication for 200 people with epilepsy. 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 enroll 200 patients in the program this year (375 Birr per person for a year). Patient's ability to access medical care and afford anti-epileptic medication is expected to improve.
6.	EEG machine	- Find a donor to purchase an EEG machine to build up an adequate resource of modern diagnostic equipment at Yekatit 12 hospital.
7.	Patient Support	- We aim to open two more satellites which involve more than 400 new patients by 2018 for patient support group meetings,



	Group	one in Addis Abba, and one in Bench Maji Zone.
8.	Training for organisational staff	<ul style="list-style-type: none"> <li>- In order to grow and increase organisational workforce planning it is vital that we work on talent management and succession planning initiatives.</li> <li>- The time taken has the potential to show a high return on investment due to a workforce with renewed motivation, new skills, and strengthened morale. As such a crucial factor in staff development, training should be a fundamental requirement for all businesses.</li> </ul>
9.	Increase human resource capacity to treat epilepsy	<ul style="list-style-type: none"> <li>- Establish an online 'Train the Trainer' course to improve human capacity and leadership for epilepsy care. Our team of general practitioners and neurologists in the United Kingdom are designing online training for nurses.</li> <li>- Run a workshop on "patient-centered Service" during the 4<sup>th</sup> National Epilepsy Week.</li> </ul>
10.	Income Generating Project	Income Generating Project in Bench Maji Zone. Our programme CareCraft incorporates various income-generating activities such as crop farming, dairy farming, crafts work, and rug making that open doors of opportunities for people with epilepsy, to start their cooperatives or individual business or gain employment. Provide financial tools and training for people with epilepsy to build businesses/ cooperatives and become self-sufficient. Activities include farming, handicrafts, rugs and shopkeeper activities.

## OUR FINANCES

We complied with the Ethiopian government policy of charities finance guideline "30/70", where only 30% of our project income is used to fund core organisational costs.

### *a) Funding Sources*

Financial support came in the form of donations from sponsorships, fundraising activities and friends nationally and internationally.

- National
  - - 107,599.00 Birr from our head office, CareEpilepsy UK.
    - 30,000 Birr from Wachemo University situated in Hossana, Shewa
    - 200,000 Birr from Mizan–Tepi University situated in Mizan Teferi and Tepi
    - 75,000 Birr from Wolkite University situated in Guraghe Zone, SNNPR
    - 50,000 from Arba Minch University.
    - In-kind donations of service worth more than 300,000 Birr from received from Federal Ministry of Health, Southern Nations and Nationalities People Region Health Bureau, Bench Maji Zone Health Office, Bench Maji Zone City Administration and Red Cross Mizan Branch.

- **International**

USA Fundraising Meheret Kinfel helped CareEpilepsy by hosting a fundraiser in the summer of 2016 in Washington DC. "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 58,022 Birr! My journey with CareEpilepsy is just getting started as I hope to travel to Ethiopia in the summer of 2017 and collaborate with them. I am highly honoured to be part of such a great mission in helping those that suffer in the hands of epilepsy."

- We organised a trek for trek enthusiasts in the Isle of Man and London to experience the superb landscape and wilderness of the Simien Mountains of Ethiopia to raise funds for the operation of CareEpilepsy Ethiopia. Kevin Christian from the UK organised the Ras Dashen trek, the stunning mountain scenery, remote villages and abundant wildlife in the Simien Mountains National Park, which was proven to be a great success. We raised about £3000. There is a plan to do this again in 2018.



### **15.3 Auditors Report**

*The Auditors report is attached as Annex 2.*

## ACKNOWLEDGEMENTS & THANK YOU



## OUR OTHER IMPORTANT INFORMATION

How you can help

### *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:

CareEpilepsy Ethiopia  
Commercial Bank of Ethiopia

Account Number: 1000161849166

Finfine Branch

IBAN NO. ET0010252

+ Our account number

SWIFT CODE: CBETETAAFIN

Address: P.O.BOX 5656, Addis Ababa

*Thank you  
for caring.*

CAREEPILEPSY 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

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*"let's do something amazing."*