

ANNUAL REPORT 2016

CAREPILEPSY ETHIOPIA



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1. AN OVERVIEW OF CAREEPILEPSY

ABOUT US

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

OUR PEOPLE

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

VISION

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

MISSION

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

VALUES

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

BELIEFS

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

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

2. From the Desk of The Executive Director



The Federal Ministry of Health estimates that more than 1 million people live with epilepsy in Ethiopia, yet there is a poor state of epilepsy care and treatment in health institutions. The lack of knowledge of epilepsy within the society resulted in stigma, which is part of the daily lived experiences of people with epilepsy and their families. Stigma has an enormous implication on education, employment and social life of the person concerned. CareEpilepsy Ethiopia takes the position that it is high time for the government to consider epilepsy as a public health issue and focus on improving epilepsy care and treatment.

The year 2016 was the first year since our launch in October 2015 that we made good progress on our overall vision. Our work in Ethiopia encompasses the full spectrum of issues: medical treatment, raising awareness, improving the wellbeing of people with epilepsy and advocating for accurate diagnosis, improved treatment, access to epilepsy service/care and treatment at a national and international level. Our service has been rendered to people with epilepsy, families and friends, and anyone whose life is affected by epilepsy. Throughout 2016, I am pleased to say that CareEpilepsy Ethiopia worked tirelessly so that people with epilepsy feel accepted, valued, listened to, respected, cared for through proper diagnosis and treatment.

The public education and awareness programme remained our primary pillar of intervention, and it is aimed 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. We produced flyers/leaflets, which provide information about epilepsy, the risks of untreated seizure, prevention, causes and consequence of epilepsy and how to live well with epilepsy for our patients. This information was not available in the country before us producing this. It was through the media and information leaflets that we managed to penetrate the community and encourage patients to seek medical assistance for early epilepsy diagnosis and treatment.

As it is our main focus of epilepsy education, we taught epilepsy first-aid response to the community in various settings such as schools and on the streets. We celebrated the first National epilepsy week in Ethiopia as a joint initiative with the Federal Ministry of Health prompted by CareEpilepsy. We secured the Ethiopia-Cuba Friendship Memorial Park in Addis Ababa as the venue for the closing ceremony of the week and the starting point of the awareness walk. Over 200 people are estimated to have joined our walk.

Epilepsy treatment involves more than a routine medical diagnosis, hospitalised care or even the prescription of anti-epileptic drugs. When confronted by an illness such as epilepsy, it can affect the emotional, social, physical, and spiritual wellbeing of those living with epilepsy and their families. Considering this, we started off our patient support group programme for anyone affected by epilepsy. The programme aims to strengthen meaning, value, resilience, and dignity to patients and empower them to look after their health, and develop a definite sense of self-worth.

Our telephone helpline provides help, information and advice on a variety of issues. Our face-to-face counselling service Our focus is on improving the quality of life and relieving emotional suffering as well as providing practical help on living well with epilepsy.

We have been continuously growing, learning, and identifying our key partners and funders who play a role in the prevention of epilepsy and boost our finances has been one of our objectives for this year.

I am pleased to say that Wolkite University and Jimma University invested financially in our awareness-raising campaign.

There is much to celebrate, but we are also clear about where we need to keep improving. Some of our priorities for 2017 include; supporting more patients to access medical care and receive anti-epileptic drugs, increase neuro-diagnostic equipment such as an EEG machine, improving human capacity and leadership for epilepsy care by strengthening local nurses', health officers' and health extension workers' competence in the provision of adequate and sustainable epilepsy care, deepen our current relationship with our stakeholders and partners, continuing to raising awareness about epilepsy, and identify new partners both nationally and internationally.

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. They 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 auspicious beginning for CareEpilepsy Ethiopia.

Finally, I would like to thank every person who, at considerable personal cost and time, made this year a success. Some members travelled many miles and stayed late in the office to meet deadlines, moved equipment and cleaned the office, and I look forward to working with you in 2017.

Focus on Epilepsy



Enat Yewnetu
Founder, Chief Executive Officer

3. Epilepsy

NEURONS



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



WHAT IS A SEIZURE?

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

- Movement
- Sensation
- Behavior
- Awareness

WHAT IS EPILEPSY?

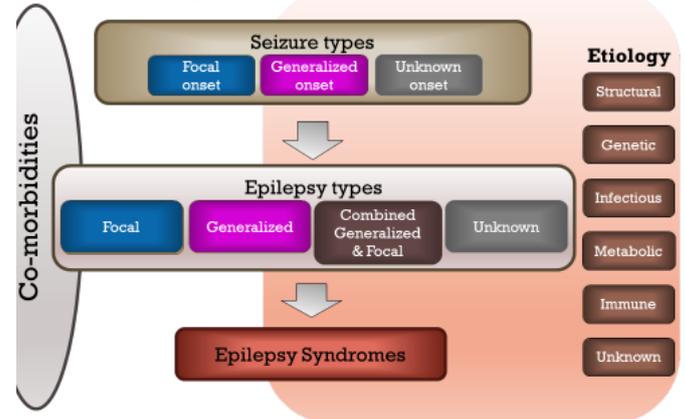


Epilepsy is a chronic neurological disorder characterized by a tendency to have recurrent seizures



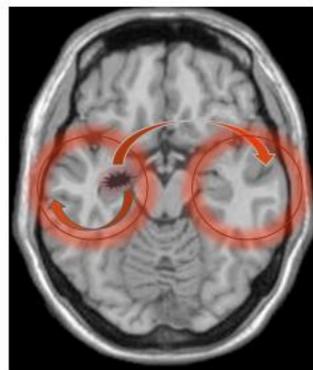
Epilepsy is also known as a "seizure disorder"

Identifying Seizures



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

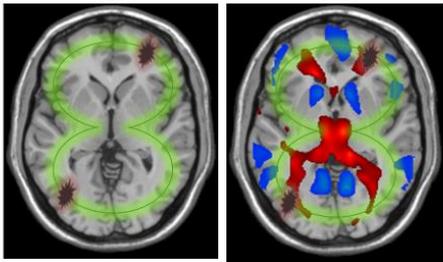
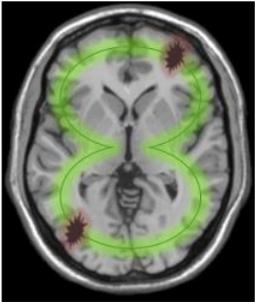
SIMPLE PARTIAL SEIZURES (FOCAL ONSET AWARE SEIZURES)

-  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)

4. Highlights of the Year (Achievements And Performance)

Below are the highlights of the key activities from the year 2016.

- The greatest achievement of the year was to organise the first National Epilepsy Awareness Week which brings attention to a condition affecting more than 1.5 million people in Ethiopia. Volunteers recorded a theme song for epilepsy and this was used during the entire week and sung by the walkers on the day of the awareness walk.

-  **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!!!

- We established a monthly peer-support group meeting to help people with epilepsy and their families cope with their condition and improve their sense of belonging and connectedness.
- We produced epilepsy information leaflet (flyers, posters and banners) to fill in the gap of knowledge in epilepsy within the community.
- We utilised the media (television, radio, print media, internet) enabled us to spread information and raise awareness of clinical facts of epilepsy, promote medical seeking behaviour and influence public opinion on epilepsy.
- Established a counselling service for people with epilepsy and their families to provide information about epilepsy, adherence to anti-epileptic drugs, practical advice as to living well with epilepsy and in general create a lasting wellness plan.
- CareEpilepsy organised 2 TV interviews with neurologists that explained the medical facts about epilepsy and epilepsy first-aid response.
- Recruited volunteers to participate in awareness raising campaigns.
- An awareness raising video was produced to teach about epilepsy and show the extent of the devastating effects epilepsy has on a person living with it in Ethiopia.

5. Our Objectives and Strategic Objectives for 2016

5.1 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.

5.2 Our Strategic Objectives for 2016 were to

- a) Facilitate access to medical care and anti-epileptic medications
 - Organise consultation and referrals to available epilepsy clinics, both government and private
 - Increase access to anti-epileptic drugs
- b) Continue to educate the public and raise awareness of epilepsy
 - Reduce the epilepsy information gaps in the country.
 - Develop and pilot seizure first-aid response training for patients, pupils, and teachers.
 - Organise the 1st National Epilepsy Week in Addis Ababa in partnership with the Federal Ministry of Health.
- 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.
- 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.
- 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.

6. Review of Planned Activities for 2016

Objective	Activities	Achieved	Not Achieved	In Progress	Remarks
Objective 1	Facilitate access to medical care and anti-epileptic medications. We do this by engaging in the following activities.				
	Activity 1.1. Clinic-based epilepsy management <i>- Organise consultation and referrals to available epilepsy clinics, both government and private</i>	✓	✓	✓	
	Activity 1.2. Anti-epileptic Drugs <i>- Supply and maintain cost-effective and adequate supplies of anti-epileptic drugs of proven quality.</i>	✓	✓	✓	
	Activity 1.3. Neuro-diagnostic service <i>- Building up an adequate resource of modern diagnostic equipment.</i>	✓	✓	✓	
	Activity 1.4. Improve Human Capacity and Leadership (Clinical Training) <i>- Face-to-face training</i>	✓	✓	✓	
Objective 2	Public Education and Awareness - to increase social acceptability. We do this by engaging in the following activities.				
	Activity 2.1. Epilepsy Education Materials	✓	No DVDs were produced		Lack of finance
	Activity 2.2. Epilepsy Education Program <i>- Establish educational program for children, youth and adults living with epilepsy.</i>	✓	✓	✓	
Objective	Activities	Achieved	Not Achieved	In Progress	Remarks

	Activity 2.3.	Raise awareness of epilepsy in the community - <i>Epilepsy Education at hospitals and health centres</i> - <i>Campagne4epilepsy</i> <i>Hold the 2nd National Epilepsy Week in Bench Maji Zone.</i>	✓	✓	✓	
	Activity 2.4.	Raise awareness of epilepsy in other professions - <i>'School Epilepsy Champions' - Seziure@school</i> - <i>'Employer Epilepsy Champions' - Seziure@work</i>	✓	✓	✓	
Objective 3	Improve the wellbeing of people with epilepsy by addressing the psychosocial factors affecting their lives. We do this by engaging in the following activities.					
	Activity 3.1.	CareEpilepsy Rehabilitation Center - <i>Establish a CareEpilepsy rehabilitation centre to provide training in life skills, vocational skills, and self-management skills, and to house modern diagnostic facilities to improved quality of life.</i>	✓	✓	✓	
	Activity 3.2.	Helpline4epilepsy - <i>Establish a telephone helpline and an Epilepsy Emergency Ambulance Service.</i>	✓	✓	✓	
	Activity 3.3.	Connect4epilepsy - <i>Establish peer support groups to provide counselling, social and recreational activities.</i>	✓	✓	✓	
Objective	Activities		Achieved	Not Achieved	In Progress	Remarks
	Activity 3.4.	Counselling4epilepsy	✓	✓	✓	
	Activity 3.6.	Income Generating Activities (IGA) - CareCraft - <i>Design Income Generation Programs. This aims to provide PWE with opportunities for both social and economic development.</i>	✓	✓	✓	

Objective 4	Advocacy in partnership to influence public policy and organizational practice. We do this by engaging in the following activities.					
	Activity 4.3.	Partner4epilepsy <i>- Build partnerships with joint stakeholders develop partnership strategies for epilepsy prevention, care and support.</i>	✓	✓	✓	<i>Lack of focus and engagement from partners.</i>
	Activity 4.4.	Research4epilepsy <i>Conduct clinical audit, epidemiological surveillance, research and develop best practice guidelines in collaboration with national and international experts.</i>		x		<i>Lack of funding and partnership to start the project.</i>

7. Activities and Impacts of Work in the Community in 2016

Strategic Objective 1 - Facilitating Medical Care and Anti-epileptic Drugs



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

Activity 1.1 Clinic-based epilepsy management

Continued to organise consultation with and referrals to available epilepsy clinics, both government and private

Activity 1.2 Anti-epileptic Medication

- Encouraged those who had stopped taking medication to start again and supported them financially to purchase anti-epileptic drugs.
- Covered the transportation cost for people with epilepsy who could not afford to pay to attend outpatient clinics.

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 Clinical Training (Train-the-trainer (TOT))

- No clinical training was provided due to lack of funding.

Impact of our strategic activities to achieve objective 1

1. 15 people with epilepsy were made to be self-motivated to access and receive epilepsy care by attending hospital for the first time.

2. 45 people with epilepsy were educated about the risk of non-adherence to anti-epileptic medication and encouraged to constantly continue with their clinical care and treatment.
3. 3 patients were provided with anti-epileptic medication where CareEpilepsy Ethiopia covered the cost.

Strategic Objective 2

Public Awareness & Education

We provided clinical information in the form of leaflets and posters about epilepsy to improve knowledge, perceptions, attitudes and practices concerning epilepsy to achieve enhanced wellbeing for those living with epilepsy and their families. Various hospitals, schools and community places received epilepsy information leaflet. 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 Campagine4epilepsy

We initiated campaigns to create general awareness and understanding of epilepsy to eradicate stigma and discrimination.

- National Epilepsy Week in Addis Ababa

We celebrated the first-ever National Epilepsy Week held during the week of 16th – 22nd May 2016, with a walk on the final day, 22nd May 2016, held at Ethio-Cuba Friendship Memorial Park located along Churchill Avenue, where more than 200 people living with epilepsy, their families and volunteer supporters attended the walk.

The event was a joint initiative, prompted by CareEpilepsy Ethiopia, between us and the Federal Ministry of Health. This event was an educational event as well as a fun and exciting way to create awareness with the focus on reducing stigma and increasing social acceptability, starting community conversation and connecting with others living with epilepsy. One of the activities that made a tremendous impact was teaching seizure first-aid response.



- *National Epilepsy Week in Regions*

Other regions also participated in the celebration of the National Epilepsy Week within their area.

- Mekelle University and Jimma University, two of Ethiopia's leading universities, were involved in raising awareness and celebrating the National Epilepsy Week of 2016. The followings are methods used to raise awareness;
 - o Distributed epilepsy education leaflets and posters inside and outside the university, where the student body makes up 10% of Mekelle's population.
 - o A two-day phone-in on FM 102.2 radio, which covers all of Tigray region, was held manned by neurology specialist Dr. Kinfe Abraha, answering public questions about epilepsy.
 - o The Epilepsy Clinic at Jimma Referral Hospital received epilepsy educational flyers and posters to raise awareness of epilepsy. The medical students at the university attended a presentation on epilepsy management.

- *Raising awareness in A Bazaar and Community Festivity*

CareEpilepsy Ethiopia was presented with the opportunity to raise awareness of epilepsy, a yearly community festival Bazaar & Exhibition, at Ghion hotel for a week.

- *Raising awareness on International Volunteer Day (IVD)*

Epilepsy was the focus of the International Volunteer Day programme on the 5th December 2016, which is an international observance day to celebrate the power and potential of volunteerism.

Representatives of the volunteers involving organizations, government officials, youth-led volunteer associations joined the young students from the Mesekerem Elementary School of Addis Ababa to echo the theme of IVD 2016 "#Global Applause – Give Volunteers a Hand".

In addition to the 200 students and staff from Mesekerem Elementary School, the event, facilitated by the UN Volunteers programme in Ethiopia was attended by representatives from the Korean International Cooperation Agency, Volunteer Service Overseas, Rotary Club, Cuso International and Care Epilepsy.



Activity 2.3 Seizure@school

Our School Epilepsy Champions' initiative was launched, and we gave presentations about epilepsy and training in seizure first-aid response 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.



EPILEPSY AWARENESS AT SCHOOLS 2016



Impact of our strategic activities to achieve objective 2

1. Designed epilepsy information leaflet to help the general public learn more about epilepsy and its treatment. This information leaflet is made available in the country for the first time.
2. Printed and distributed 10,000 epilepsy information leaflets in three Ethiopian languages: Amharic (spoken by 30% of the population) Oromo language (spoken by 34% of the total population) and Tigrinya (spoken by 6% of the total population).
3. 540 pupils in 9 secondary schools were taught about epilepsy and received training in seizure first aid response.
4. We secured a school admission for a boy aged 11 years who was rejected for three consecutive years due to his epilepsy.
5. More than 19 million people expected to have been reached through radio broadcast during the 1st National Epilepsy Week in Addis Ababa.
6. 1,000 epilepsy educational leaflets and 50 posters written in Tigrinya language were distributed in the town of Mekele, Hyder Hospital and the university.
7. 31,000 students at Mekele University have gained knowledge about epilepsy.

8. 1 million people expected to have learned about epilepsy via radio interviews in Mekele.
9. Patients and families who attend epilepsy outpatient service at Jimma Referral Hospital received 1,000 epilepsy educational leaflets and 50 posters written in the Oromo language.
10. 250 people with epilepsy who attend the epilepsy clinic at Jimma Referral Hospital and around 500 undergraduate medical students received information about epilepsy.
11. More than 1000 people who participated in the Bazaar & Exhibition at Ghion hotel received new information about epilepsy.

Strategic Objective 3

Wellbeing



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.

Activities, Impacts of Work in the Community

Activity 3.1. Patient Education

- 7 teaching sessions were organised to educate people with epilepsy of the risks of untreated seizure, prevention, causes and consequence of epilepsy.
- Epilepsy information leaflet was designed to help patients and their family learn more about epilepsy, and work with healthcare professionals. Seizure record sheet was designed for patients to record their seizure pattern to assist doctors to prescribe the right dosage of medication.

- Designed a booklet "My epilepsy care" providing knowledge about epilepsy, and care planning for people with epilepsy.

Activity 3.2. Helpline4epilepsy

We launched epilepsy telephone helpline, the first of its kind in Ethiopia. This service is a confidential helpline where we offer counselling, provide up-to-date information about epilepsy care providers, pharmacy list, help for patients to contact relevant people, or contact them on their behalf, and listen to their views and concerns.

Activity 3.3. Connect4epilepsy

Our support group sessions fulfilled many functions:

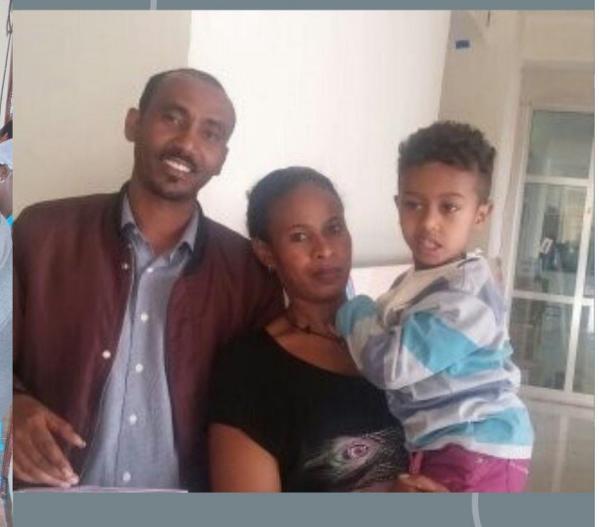
- Seven monthly patient support group sessions were held educating patients/family about epilepsy, emotional and moral support for one another, sharing epilepsy experience, providing a coping mechanism to patients and families, raising public awareness, and improve their sense of belonging and connectedness.
- Refreshment was made available to the attendees of the meetings.
- Transportation cost was covered for those who could not afford to pay.

Activity 3.4. Counselling4epilepsy

We established the first 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.

Various guest speakers taught patients how to live well with epilepsy and provided practical advice and information for families how to take care of their family member with epilepsy.

Patient Support Group Meetings in 2016



Activity 3.5 Microenterprise Development

- CareCraft

CareCraft, an income-generating project as well as a platform where women with epilepsy receive training for life skills, vocational skills, and self-management skills, which addresses the psychosocial and economic issues which they face, was launched. We entirely covered the cost of a trainer, tools and raw materials for their practical work, food and transportation of patients who were registered for the programme.

We started project CareCraft in partnership with Hamilton college as a one-year long program funded by Levitt Social Innovation Post-Graduate Fellowship, led by Tsion Agajie Tesfay, Post-Graduate Fellow. The project is designed to promote holistic economic and social empowerment for women with epilepsy through craft making, business training, and health care awareness raising. The activities include:

- individual therapy to learn about self-management;
- group discussions and games to encourage them to open up and build a friendship;
- Rug weaving;

- prepare breakfast and lunch in rota, which developed teamwork and communication skills.



Impact of our strategic activities to achieve objective 3

1. 165 people received advice and support through our confidential epilepsy helpline.
2. 83 people with epilepsy were provided with help to be self-motivated to access and receive epilepsy care by attending hospital.
3. 42 people gained support through our face to face counselling service, and they appeared to have confidence, knowledge, skills, and support they need to manage their epilepsy or their family member's with epilepsy effectively.
4. 8 women completed 6-month self-management and rug weaving training.
 - a. 100% of women who participated in the training felt empowered and increased confidence and self-esteem.
 - b. 100% of women acquired new skills in rug weaving.
 - c. 100% of women were less worried about having a seizure in front of their peers.
5. 45 people living with epilepsy and their families attended patient support group meetings.

- a. 89% of patients felt less isolated and part of a larger community of people with epilepsy (40 out of 45).
 - b. 71% of patients felt more confident in discussing epilepsy with healthcare professionals (35 out of 45).
 - c. 33% of patients felt self-confident to talk about their epilepsy (15 out of 45) openly.
6. 7 teaching sessions were organised to educate people with epilepsy of the causes and consequence of epilepsy, risks of untreated seizure, and none-adherence to anti-epileptic drugs.

Table 4 – Total Number of Attendees of our Programmes During 2016

Helpline	Patient Support Group	Counselling and Psychotherapy (face-to-face)	CareCraft	Education Sessions
165	45	42	8	45

STRATEGIC OBJECTIVE 4

ADVOCACY FOR EPILEPSY



Strategic Objective 4 - Advocacy for Epilepsy

Stigma surrounding epilepsy continues to fuel discrimination and isolates people with epilepsy from the mainstream of life. In Ethiopia epilepsy remains a formidable barrier to educational opportunities, employment, and personal fulfillment among older children and adults. CareEpilepsy Ethiopia advocates on behalf of people with epilepsy and their family members to overcome the challenges of living with epilepsy, accelerate medical treatment to stop seizures and change in public policies to protect the rights of people with epilepsy. Our advocacy work is derived from the principles outlined by the World Health Organisation "...the highest attainable standard of health as a fundamental right of every human being." Our advocacy priorities for 2016 include:

1. Increased access to epilepsy care and treatment
 - o Ensuring equitable access to quality epilepsy care that is affordable, physician-directed and patient-centred;

Activities:

We have been engaging the Federal Ministry of Health and regional governments to make epilepsy one of their health priorities and to invest in the service for accessible clinical care, the availability of affordable anti-epilepsy medication and free medication for those who cannot afford to pay. We have had several meetings to identify way forward.

2. Establishing 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:

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.

3. Public Policy Change

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

Activities:

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

4. Research for evidence-based care

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

Activities:

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

5. Disability and Discrimination

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

Activities:

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

6. Establish Ethiopian Epilepsy Association

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

Impact of our strategic activities to achieve objective 4

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

8. Volunteering and Internship

During 2016, our initiative to engage the community in volunteering work and internship, both for professionals and the youth, to be a channel of change was launched. Our initiative gave the participants the opportunity to make a difference within their community. As a by-product of this work, we help our volunteers and intern team to learn life-skills for their future, for example leadership, teamwork, communication, accountability and the satisfaction that comes from doing good in the community.

8.1 Volunteering

Youth4Epilepsy Ethiopia is one of the programmes we run tapping into the time and experiences of young volunteers. We have recruited 90 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. Volunteers' activities during 2016 include:

- a) Assisting the organisation of the 1st National Epilepsy Week in May 2016;
- b) Covering the information booths on the promotion day;
- c) Answering our epilepsy telephone helpline and providing information and support to patients and families
- d) 14 volunteers performed a seizure first-aid response which includes care and comfort steps that should be taken for anyone during or after a seizure.
- e) Gave a service of free 'shoe shine' at Megenagna, on 14th May 2016 with the hope to change the community's perceptions of epilepsy.

VOLUNTEES OF 2016



8.2 Internship

Edom Bekele, from New York University in the USA, was our intern for 2016. She worked with us from June 9th to August 10th, 2016, for approximately 30-35 hours per week. She had the opportunity to learn about epilepsy, its impact on health and healthcare in Ethiopia. She states, "it was a valuable experience for me to work at a grass-roots level, engage in the work of a non-profit organization that aims to improve epilepsy service for those who are neglected and outcast in society."

Impact

- 90 volunteers received a half-day in-house training course on epilepsy.
 - 12 volunteer training days were given.
 - 30 volunteers were able to create awareness through the 'shoe shine' programme.
- 16,672 hours were given volunteering to help us complete our objective for the year.
- 50 new volunteers gained epilepsy knowledge on the International Volunteer Day.

9. Media and Communications

We can't connect our donors and our beneficiaries unless we tell the story of what we are working on; therefore, communications is a vital tool for the community to be aware of our work fundraising. Our main goal for 2016 was to establish strong cooperation between the media and CareEpilepsy Ethiopia. We used various means of communication such as broadcasting (radio & TV), publishing, our website and social media (Facebook and Instagram) for our mass communication programme to educate the public about epilepsy.

9.1 Media

CareEpilepsy Ethiopia organised a press conference to generate news that can advance the launch of the 1st National Epilepsy Week. The press conference was held at the Federal Ministry of Health organised the first press on Friday 13th May 2016. The panelists at the Press Conference were Dr Mahlet Kifle (Director General, Office of the Minister), Dr Tedla W. Giorgis (Mental Health Advisor) and Enat Yewnetu (Founder and Chief Executive of CareEpilepsy).



- 10 journalists attended the press conference.

- Epilepsy was discussed on EBC, Nahoo TV during the National Epilepsy Week and radio station such as Sheger Radio (twice), Zami Radio, Ahadu Radio and Tenawo Beбето.
- The Chief Executive of CareEpilepsy Ethiopia gave 7 radio interviews.
- Dr Abenet Mekonen and Dr Hana Demessie (neurologists) were interviewed by EBC and Nahoo TV. Both neurologists explained the medical facts about epilepsy and one of our volunteers demonstrated the recovery position.

9.2 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**

- o 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.
- o Unfortunately, during 2016 our communication activity was not a great success. 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**

During 2016, CareEpilepsy Ethiopia was presented with the opportunity of speaking at Yekatit 12 hospital on 10th March 2016 and 20th September at Amanuel Mental Health specialised hospital. The focus of the presentation was to increase knowledge of epilepsy among staff and identify ways for partnership to strengthen epilepsy service in their organisation.

Impact

- 15 nurses and 11 doctors who work at Yekatit 12 hospital received information about epilepsy.
- 7 nurses and 1 EEG technician who work at Amanuel Hospital received information about epilepsy.
- Developed a strong relationship with national media.
- Created a communications plan, a document that guides the external communications effort of CareEpilepsy Ethiopia.

10. 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, during 2016 we encouraged community involvement to address the medical, social and environmental factors contributing to epilepsy such as poverty, female and child health, mental health, communicable, education, and employment.

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 some acknowledgement from the Federal Ministry of Health about epilepsy being a public health issue and there is hope that it will be one of the health priorities for the country.
- Discussion is continued with the Ethiopian Midwives Association to achieve best practice for people with epilepsy.
- Discussion is underway with Gonder University, Jimma University, and Addis Ababa University to achieve best practice for people with epilepsy.
- Continued discussion with AFFORD African Foundation for Development for partnership and funding, further information at <http://www.afford-uk.org/>
- Continued discussion with the Southampton Hospital Epilepsy service team, who has been working in collaboration with colleagues at Jimma and Gondar University Hospitals for experience sharing in conjunction with the Tropical Health and Education Trust (UK).
- Discussion underway with UK-Uganda Health Alliance Butabika link - East London NHS Foundation Trust which is established to better mental health in Uganda. This link will help us explore future collaboration to develop these common interests into a project to promote awareness and reduce the stigma attached to Epilepsy common to Uganda and Ethiopia. Further information at <http://www.butabikaeastlondon.com/>

Impact

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

11. Organisational Development

a) Organisation Policy and Procedures

CareEpilepsy Ethiopia's policies are the director link between our vision, mission and objectives and our day-to-day operations. Our policies help us identify the key activities and provide a general strategy on how to handle issues as they arise.

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

CareEpilepsy Ethiopia organisation development objectives in 2016 set the following organisational development and culture goals:

- Develop regulatory 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.

Achievements During 2016

- Enat Yewnetu, Founder and CEO moved to Ethiopia in April 2016 to establish and run the CareEpilepsy Ethiopia office.
- Staff development and training plan was designed .

b) Recruitment and Selection

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

Achievements During 2016

We have started to work on the following policies to assist us at our workplace:

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

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

Our training programme allows our staff to strengthen those skills that each employee needs to be efficient at their work and reduce any weak links within the organisation who rely heavily on others to complete their work tasks. During 2016, CareEpilepsy Ethiopia was not able to engage it's staff in external training due to lack of finances; however, several in-house trainings were given.

CareEpilepsy Ethiopia has not been successful in giving external training for our staff due to lack of funds; however, internal trainings were offered to improve the level and quality of work

Achievements During 2016

7 in-house training sessions where staff had the opportunity to ask questions and receive resources for detailed reading were held and the training include:

The followings are in-house trainings delivered as 1-day courses:

- Epilepsy and Epilepsy First Aid Response
- Compassionate Care
- Communication Skills
- Teamwork
- Orientation
- Team meeting
- Careepilepsy Ethiopia's vision, mission, objectives and programme activities.

Impact

- o Staff increased their knowledge about epilepsy and epilepsy first aid, communication skills, compassionate care, and team work.
- o 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.
- o Increased productivity levels across the board, meaning more work is being performed.
- o Help build relationships amongst staff.

12. Governance and Management

12.1 Governance Body

a) Board of Director in the UK

During the year of 2016, CareEpilepsy Ethiopia functioned with the support of the Board of Directors from the UK. We spent hours of discussions with our governing body on building long-term strategy as well as services, projects, and campaigns and oversight characterise the Board's leadership role. The Board played an active role in forming all elements of CareEpilepsy Ethiopia's strategy and helping develop work programmes that are now in place.

b) National Board of Director in Ethiopia

Not yet in post.

12.2 Operational and Project Management

a) Operational Management

The chief executive director is responsible for the overall direction and management of the day-to-day activities of the organisation.

- Currently, the operational team includes a part-time accountant and a temporary secretary.
- In the process of building the human resources capacity for CareEpilepsy Ethiopia.

b) Project Management

There was no fund available to employ a project manager; therefore, all project assignments were completed by the chief executive officer and volunteers.

13. Significant Issues and Challenges in 2016

In order of impact	Challenges/Issues	Challenges/Issues Explained	Proposed Solutions
1	Federal Ministry of Health	<ul style="list-style-type: none"> - 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. - FMOH does not show commitment to adopting a strong catalytic role in order to improve epilepsy health in poor, underserved areas. - Technical dialogue with health authorities has not been fruitful and did not lead to the implementation of sustainable actions. 	
2	Financial sustainability	<ul style="list-style-type: none"> - 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. - Lack of epilepsy specific grants on the international level. - Lack of a named person with real experience or skill in donors/grant pursuits/searches causing loss of opportunity. 	<ul style="list-style-type: none"> - Diversify funding sources - Identify donors with a focus on corporate partnerships to help them achieve their social mission.

3	Manpower/staff	<ul style="list-style-type: none"> - CEO covering many of the jobs has proven to be a great challenge and affected productivity. - We still rely on our volunteers as our office has got only 3 full time and 1 part-time member. - The amount of workload has affected the efficiency of our staff. - The lack of expertise has a drawback on our engagement. 	<ul style="list-style-type: none"> - Identify volunteers to work as an assistant as work experience. - Develop strategies to generate revenue to finance the justifiable, affordable and minimum level of staff. - Increase expertise at the national level through training and partnership with higher education institutions.
4	Premises	<ul style="list-style-type: none"> - The frequent move of office in search of cheaper rental office causes loss of patients and stable engagement with communities. 	<ul style="list-style-type: none"> - Discussions need to start to get support from the government.
5	Patients Expectations and engagement	<ul style="list-style-type: none"> - 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. 	<ul style="list-style-type: none"> - Engage with government authorities, politicians, community leaders and other partner organizations to realize affordable or free medication.
6	Stigma	<ul style="list-style-type: none"> - Stigma about epilepsy is still a challenge affecting the involvement/ engagement of patients and their families in our activities. - CareEpilepsy Ethiopia faced a great deal of stigma in comparison with other charities because of the nature of our work. 	<ul style="list-style-type: none"> - Build on the work that has been done so far - Engage more with national and regional government offices, community leaders, the media - Approach recognized members of the community and personalities such as celebrities to serve as goodwill ambassadors.
7	External Factors	<ul style="list-style-type: none"> - Attitude and policy of the national and regional government offices towards charities have a crippling 	Continue discussion.

		<p>effect on our work.</p> <ul style="list-style-type: none"> - The government, as well as the public, is skeptical of charities work. - Delayed input and feedback from institutions. - Financial resources of the health sector are available to support prioritised actions. 	
8	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.

14. Activities Ahead for Next Year (January 2017-December 2017)

Proposed Projects for the year 2017.

- a) Develop financial capability through donors and partners.
- b) Strengthen human resources capacity.
- c) Expand network with national neurologists, government officials, local and international NGOs and pursue new alliances/partners to effect change successfully.
- d) Promote both national and international volunteering schemes and internship projects.
- e) Organise various fundraising activities.
- f) Advance our programme activities and develop strategies for implementation.
- g) Institute CareEpilepsy Ethiopia's National Advisory Board.
- h) Organise clinical training for nurse and health extension workers in collaboration with the Federal Ministry of Health and regional health bureau.
- i) Produce a clinical training manual for epilepsy.
- j) Conduct a needs assessment in the Amhara region in Ethiopia.
- k) Boost office essentials such as office furniture and equipment, desktop computer and accessories and communications such as telephone line and internet connection.
- l) Accomplish the running of the 2nd National Epilepsy Week in the Southern region of Ethiopia.
- m) Engage volunteers throughout the year to raise awareness of epilepsy at schools, health centres, and campaigns.
- n) Arrange a community dialogue sessions on eradicating the stigma of epilepsy.

15. Our Finances

During 2016, CareEpilepsy Ethiopia complied 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.

15.1 Funding Sources

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

15.2 Fundraising Success

a) National

- We received 50,000 Birr from Jimma University Specialized Hospital and to cover the cost of organising the 1st National Epilepsy Week event .
- All costs of media engagement were covered by local sponsorship, and which together were worth well over 210,000 Birr.
- We received Birr 440,119 Tsion Tesfaye, Fellow at Hamilton College in New York.
- 7,000 Birr in sponsorship from Gusteau restaurant.

- b) *International*
- USA Fundraising



Meheret Kinfe (top left) organised a fundraiser for CareEpilepsy Ethiopia in August 2016 in Washington DC. She stated that "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 Ethiopia. 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."

15.4 Auditors Report

The external audit report is attached as Annex 1.

16. Acknowledgements & Thank You

CareEpilepsy Ethiopia wishes to thank our patients and their families for believing in us. We are eternally grateful to everyone who has supported us in our fight to raise awareness of epilepsy, and we appreciate your efforts more than you know no matter how small or large, in-kind or monetary.

We wish to thank the following organisations and group for their generous donation, hard work, time and patience.

*Federal Ministry of Health
Wolkite University
Jimma University
Our youth volunteers*

We would like to take the opportunity to individually thank those who went above and beyond in supporting us:

*Mr and Mrs Wilson (UK)
Bereket Andargachew
Melaku Hailu
Dr Tedla W. Giorgis
Dr Abenet Mekonen*

a warm note to say

THANK
YOU

for being our partner in
2016

How You Can Help Us

There are many ways in which you could support our work.

Become a member

- Membership of CareEpilepsy is open to any individual and organisation living with epilepsy or that has an interest in the field of epilepsy.
- Join our TalkEpilepsy advocacy network and help us raise awareness with public officials about the public policy issues important 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, and artisans. For international volunteers, there are clear benefits that overseas volunteering brings to Ethiopia; 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."

Epilepsy Partners Advocacy Group

Join our Advocacy Network of partners that support policies that are advantageous to the epilepsy community. We advocate for these policies on the federal and regional level. Sign up for our Speak Up, Speak Out! Advocacy Network to join the effort here.

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**

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"let's do something amazing."