



ANNUAL REPORT 2023

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Acronym

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

FROM THE DESK OF THE EXECUTIVE DIRECTOR

Dear supporters and partners,

It is with great pleasure that we present the annual report for CareEpilepsy Ethiopia, detailing our activities, achievements, and impact throughout the year 2023.

Our dedicated team of healthcare professionals, including health officers, nurses, and neurologists, continues to provide training and clinical care that is expanding and evolving. Their commitment to offering high-quality service and support to individuals living with epilepsy is highly commendable. We have witnessed the positive impact of this clinical care on many lives. Our programs, from educational initiatives to support groups, continue to make a positive difference by spreading hope and knowledge.

One of our standout moments in 2023 was hosting the International Bureau of Epilepsy Africa Region Conference on November 20th and 21st. Attended by delegates from over 30 countries, this event emphasized our organization's growing influence in epilepsy advocacy. We were honored to have His Excellency Dr. Dereje Duguma, State Minister of Health, Ethiopia, and Rakeb Messele Aberra, Deputy Chief Commissioner of the Ethiopian Human Rights Commission (EHRC), deliver speeches, highlighting the significance of our work and the collaborative spirit driving our efforts.

I'm incredibly proud of our team's dedication and resilience this year. Together, we've conquered challenges, celebrated successes, and made a positive impact. Our journey has been remarkable, but it's not just ours; it belongs to everyone who believes in transforming lives.

As we move into 2024, we'll continue our work to enhance access to quality care, combat stigma, and empower those with epilepsy. However, the financial constraints of this year have affected us significantly. Without continued <u>SUPPORT</u>, we anticipate worse challenges in 2024.

On behalf of the entire CareEpilepsy team, I extend my heartfelt gratitude to each and every one of you for your support.

Warm regards,

Enat Yewnetu Founder and CEO, CareEpilepsy Ethiopia

SECTION I. AN OVERVIEW OF CAREEPILEPSY ETHIOPIA

1.1 Our History, and Beliefs

Our History

CEE is a nationally registered (Registration Number 3380) charitable organization and was born out of the passion of Enat Yewnetu, an Ethiopian who has lived with epilepsy and its challenges for the last 30 years. She feels fortunate to have reasonable control over her seizures using anti-seizure medication (ASM), as she lived in England, where she gets the needed epilepsy care. However, realizing the reality being far different for those living in Ethiopia, she wanted to change the face of epilepsy by closing the gap between knowledge and action in medical care and treatment so that people with epilepsy (PWE) and associated disabilities receive the quality medical care they need and the public respect, fairness and understanding they deserve so that they can live a healthy and productive life, free from discrimination and stigma.

Beliefs

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

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

1.2 Our Vision, Mission, Values, and Objectives

Our Vision

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

Mission

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

Values

Our core ethics which we abide by, are compassionate care, integrity, accountability, innovation, inclusiveness and a holistic approach to health and wellbeing based on the World Health Organization guideline.

General Objectives

CareEpilepsy aims to provide and facilitate early epilepsy diagnosis and treatment, increase the number of nurses and health officers to treat epilepsy, raise awareness of epilepsy, improve the emotional, social and economic wellbeing of our patients; expand our partner organizations and influence policies that affect people with epilepsy through advocacy.

1.3 Project Beneficiaries

Last year, our project aimed to provide support to children, women, and men affected by epilepsy in our project areas. We focused on delivering comprehensive services to address the needs of People With Epilepsy (PWE) and their families. Through our efforts, we aimed to alleviate stigma, provide medical treatments, empower primary health providers to better manage epilepsy, and advocate for improved epilepsy care through strategic partnerships. Our initiatives directly benefited PWE and their families, ensuring they received the necessary support and resources. Additionally, our outreach efforts indirectly benefited the wider public by raising awareness and promoting understanding of epilepsy within the community.

SECTION II. Our Programs/Services and Activities

2.1 Area of Operation

In 2023, CEE operated from Addis Ababa, conducting extensive awareness campaigns across all sub-cities, with a focus on Yeka sub-city and regional healthcare providers. These efforts included workshops, informational sessions, and distribution of educational materials.

2.2 Programs and Services

Last year, our programs focused on holistic community care that incorporated medical and non-medical support and addressed a full spectrum of issues:

- Stigma and social barriers;
- Medical treatments;
- Strengthening the role of primary health providers to enable them to treat epilepsy;
- Advocacy through partnership.

We worked at all health system levels, from the household to the community to the health facility to national authorities. In addition, we worked through volunteers and partners who were our agents of change to execute our work.

SECTION III. ACHIEVEMENTS AND HIGHLIGHTS

The strategic objectives (SO) show our plan of action to achieve our objectives, in other words, how we do it.

SO#1 Providing and Facilitating Early Epilepsy Diagnosis and Treatment.

Program Title & General Objectives	Our Specific Objectives for 2023	Accomplishments in 2023
Free Epilepsy community clinic Aim: CEE is an urgent treatment and referral center where nurses will do some assessments at the center and make referrals to tertiary hospitals.	expert care. c) Increase our number of neurologists by 5 new neurologists	 a) Operated a weekday epilepsy clinic staffed by a health officer and nurse. b) Provided early diagnosis and treatment for 1,152 individuals with epilepsy (435 by our Health Officer and Neurologist-led clinics, benefiting 314 adults and 385 children). c) Conducted 12 monthly neurology clinics with volunteer neurologists. d) Successfully recruited 7 national and 2 international neurologists as volunteers. e) Collaborated with tertiary hospitals to facilitate referrals.
Telemedicine/ telehealth	a) Develop our International Telemedicine Service to diagnose and treat epilepsy and provide consultation on epilepsy and care management.	a) Unfortunately, we faced obstacles in developing an International Telemedicine Service due to shortage of staff. We will continue to seek diverse funding, partnerships, and staff reallocation to develop International Telemedicine Service efficiently in 2024.

Dispensation of anti- seizure medication Aim: Making AEDs more available and affordable through negotiation and provision.	 a) Provide AEDs for 330 patients b) Work with the MOH and the Ethiopian Food and Drug Administration Authority to import AEDs. c) enrol 50 patients in the Tena Medhin (Health Insurance). 	 a) Provided antiseizure medications (ASMs) to 717 individuals with epilepsy. b) Covered health insurance expenses for 24 individuals. c) Successfully secured donations for the importation of Keppra and Lamotrigine, marking their first inclusion in our medication inventory. Observation: The distribution of ASMs exceeded the planned target, and the introduction of Keppra and Lamotrigine has transformed the lives of individuals, particularly those with previously uncontrolled seizures on the old medication.
Provide and facilitate diagnostic service. Aim - To develop our electroencephalography (EEG) service to give access to diagnostic services to make an accurate diagnosis of epilepsy.	 a) Run a weekly EEG testing service at our center and provide EEG testing for 192 patients. b) Support 20 patients financially to access MRI testing. 	 a) Conducted 166 EEG tests at the CEE center. b) Provided financial assistance to 50 individuals for MRI scans, prioritizing those with urgent diagnostic needs."
Home Monitoring	 a) Continue to develop our home monitoring service by making follow-up phone calls to 1,200 PWE to check our patient's health status. 	b) Expanded our home monitoring service with follow-up phone calls to 1,366 patients with epilepsy to assess their health status, surpassing our target for 2023.

SO#2 Increasing the number of nurses and health officers to treat epilepsy by 200 at the primary health care level

Program Title & General	Our Specific Objectives for 2023	Accomplishments in 2023
		Accomplishments in 2025
Obiectives		

Epilepsy Management Clinical Training Aim - to build the capacities of the trainees to enable them to diagnose and treat epilepsy.	 a) Epilepsy Management Clinical Training for 200 nurses and health officers to allow them to treat epilepsy, coordinate care and co-manage patients' follow-up in primary health care settings;) Provide 2-day Clinical Training for 200 nurses and health officers at the primary care level. b) Four on-the-job training at health centers. c) Produce a training manual and guidelines. 	 a) Conducted Epilepsy Management Clinical Training for 323 nurses and health officers, enabling them to treat epilepsy, coordinate care, and manage patient follow-up in primary healthcare settings. b) Provided awareness training to 50 teachers to enhance epilepsy understanding and support at the primary level. c) Produced epilepsy training manuals and guidelines.
Aim: To decrease the knowledge gap in epilepsy and improve the service of epilepsy in primary health care centers.	 a) Grow the service of our 'Epilepsy resources Center', which holds a physical and online library of epilepsy journals, books, and leaflets. b) Design a guideline for schools and nurses for caring for students and patients with epilepsy. 	 a) Procured 15 epilepsy teaching books and journals to enhance educational resources. b) Completed the development of the school education guideline, ensuring comprehensive coverage of epilepsy awareness and support.

SO#3 Increasing epilepsy education for patients and the general population

Program Title & General Objectives	Our Specific Objectives for 2023	Accomplishments in 2023

Education Materials Aim: Epilepsy literacy about the prevention, causes and the risks of untreated seizure	Update and distribute 10,000 epilepsy information leaflets, 1,000 posters as a teaching aid. Update epilepsy information content on our website and social media.		 Distributed 50,000 epilepsy information leaflets and 2,000 posters to health centers in Addis Ababa and regional hospitals. Updated content related to epilepsy on our website and social media platforms.
Campaigns including Street Campaigns. Aim: Public education to eradicate stigma, promote medical- seeking behavior	February 2023.	a) b)	Collaborated with the Ethiopian Public Health Institution and the Association of Ethiopian Neurologists to celebrate International Epilepsy Day and National Epilepsy Week. Hosted the 3rd African Epilepsy Week/strips week during 18-22 September 2023, featuring street campaigns and school education initiatives to commemorate the occasion.
Program Title & General Objectives	Our Specific Objectives for 2023		Accomplishments in 2023
Seizure@school Aim - To help teachers and students support children with epilepsy and make the school a safer environment for them.	400 teachers and approximately 2,400 students at school. Recruiting 48 schools to participate in our		Conducted one-day epilepsy awareness training for 50 teachers. Engaged 600 teachers and 35,046 students in our school education program. Recruited 5 new schools to join our 'Epilepsy Education at Schools' program.

	a) Provide training for 20 faith leaders. b) Provide epilepsy awareness training for 30 media personnel. Recruit 6 organizations to join our 'epilepsy at work program'.	 a) Conducted training for 10 faith leaders, albeit fewer than planned due to limited interest from faith organizations. b) Despite financial constraints, continued efforts to raise epilepsy awareness; however, could not provide training for 30 media personnel. Expanded our 'Epilepsy at Work Program' by recruiting an additional 3 organizations which gave us access to 5,321 furthering inclusivity and support for individuals with epilepsy in the workplace.
Seizure @Community Health Center Aim - to help clinical staff and the public understand epilepsy.	Run community epilepsy education at 10 hospitals and 50 health centers	Conducted community epilepsy education sessions at 3 hospitals, reaching 675 individuals, and engaged with 1,830 individuals at health centers, amplifying awareness and support for epilepsy within the community.

SO#4 Improve patients' emotional and social wellbeing

Program Title & General Objectives		Our Specific Objectives for 2023		Accomplishments in 2023
Counseling Aim: To make PWE self- confident, gain self-worth, and take a more active role in the management of their epilepsy and their physical life in general.	b)	Provide individual counseling sessions for 360 individuals, in addition to our daily walk-in clinic services. Facilitate group therapy sessions for individuals with epilepsy (PWE) and their families.		Our health officer and outreach nurse conducted individual counseling sessions for 267 individuals. Facilitated 35 group therapy sessions for patients and their families, with a minimum attendance of 12 people per session.
Patient Support Group Aim: To share experiences encouraging them to cope with their condition and improve their sense of belonging and connectedness.	1	Organize 12 monthly patient support group meetings for individuals to learn about epilepsy and share experiences. Cover transportation costs for 576 vulnerable patients to attend support group and other meetings. Conduct 10 home visits with the involvement of Patient Representatives and volunteers."	,	Organized 12 monthly patient support group meetings to provide support and education. Provided transportation assistance for 1,021 vulnerable patients to attend support group meetings and other events. Conducted 8 home visits with the participation of Patient Representatives and volunteers.
Aim – To provide a confidential	b)	1,000 telephone callers to be served in 2023. A dedicated staff will be assigned to support this service.	,	Provided support to 1,200 telephone callers in 2023, including individuals from Addis Ababa and surrounding regions, offering assistance and guidance. Assigned dedicated staff to enhance and sustain this service, ensuring continued support and accessibility for callers.

Epilepsy Rehabilitation			
Center			

Aim: Increased self-esteem, improved collaboration and social skills, enhanced creative thinking skills, and a developing c) Render basic needs and other timely friendship.

- a) Acquire housing from the Public Housing Agency office to be used as a center for Epilepsy.
- for children.
 - emergency needs like food and clothing.
- a) Engaged in discussions with government officials regarding subsidized housing to reduce our costs, although without success.
- b) Run 1 event of music and sports activities b) Unfortunately, due to a lack of funds, we were unable to organize music and sports activities for our patients.
 - c) Provided clothing support and emergency food assistance to patients in need."

SO#5 Promoting people with epilepsy's empowerment and self-reliance for a sustainable living

Program Title & General Objectives	Our Specific Objectives	Accomplishments in 2023
CareCraft and Income- Generating Activities Aim – To address the economic issues women with epilepsy faces by training vulnerable patients in skills acquisition for gainful employment to bring them out of poverty.	 a) Run 48 weekly CareCraft programs where patients do craft work whilst enjoying friendship and drinks. b) Participants will receive craft-making training and raw materials to work with for potential gainful employment and self-reliance for sustainable living. 	 a) Conducted 190 craft training sessions with the participation of 30 individuals in the program. b) Provided raw materials for the project and covered transportation costs for the participants. c) 5 women received injera metad to start their own business.

SO#6 Increase our partner organizations to expand our impact and influence on policies that affect people with epilepsy.				
Patient Representatives	a) Hold 12 monthly meetings with	a) Over the past year, we successfully held 12 monthly		
Committee	patient represtnatives.	meetings with patient representatives, fostering		
	b) Provide training sessions for	regular communication and collaboration.		
Aim: to secure their rights, represent their interests and obtain services they need.	_	b) We have provided comprehensive training sessions for committee members on patient rights, advocacy skills, effective communication, and conflict resolution, equipping them with the necessary tools to effectively represent patient interests.		

Program Title & General Objectives	Our Specific Objectives	Accomplishments in 2023
Patient Representatives Committee Aim: to secure their rights, represent their interests and obtain services they need.	c) Strengthen relationships with other patients, and healthcare providers to amplify the committee's advocacy efforts and enhance its impact.	c) Through dedicated efforts, we have strengthened relationships with fellow patients and healthcare providers, significantly amplifying the committee's advocacy efforts and enhancing its overall impact within the community.
Partnership Aim: Strengthen our current partnerships and build new partnerships to influence national policy to bring about actions that result in better epilepsy service and protection of PWE and their families.	 a) Increase our partner organizations by 10 and maintain current ones to expand our impact and influence on policies that affect people with epilepsy. b) Continue working with the AEN in training and clinical care. c) Promote equal access to education for children with epilepsy. 	 a) Expanded our network of partner organizations to include International Bureau for Epilepsy (IBE), World Health Organization (WHO), The Centers for Disease Control and Prevention (CDC), Ethiopian Human Rights Commission (EHRC), and other NGOs. b) Sustained collaboration with the AEN in training and clinical care initiatives. c) Maintained efforts to ensure equal access to education for children with epilepsy.
Youth and professional Volunteers Aim: Promote our Volunteering program to engage the community in epilepsy care and eradicate stigma by having a diverse team of volunteers, e.g. Youth, nurses, and doctors.	 a) Give 10 half-day in-house training sessions on epilepsy and epilepsy first aid. b) Increase the knowledge of our volunteers in epilepsy. c) Increase the number of youth volunteers by 50 and professional volunteers by 5 (national and international teams). 	 a) Conducted 42 sessions led by neurologists with the participation of 15 volunteer neurologists. b) Received support from 17 nurse volunteers. c) Assisted by 4 psychiatric doctors. d) Benefitted from the dedication of 259 youth volunteers.
Research for epilepsy	 a) Internal Audit and research depend on funding and interested donor. 	a) Conducted internal audit and surveys.

Program Title & Objectives	Specific Objectives for 2023	Activities/Program Title
Multi-disciplinary workshop	a) One workshop for 100 government officials and stakeholders.	Organize on mulit-disciplinary workshop at EPHI to discuss about way forward to increase epilepsy education.
Aim: to engage in a community conversation to develop a sustainable solution to eradicate stigma, increase public education to improve public attitudes, reduce stigma and promote the protection of the rights of PWE.		

SECTION IV. Financial Overview

We completed the year 2023 by complying with the Ethiopian government policy of charities finance guideline "20/80" (Remarks: "20/80" means 80% of our project income is used on direct project cost, and only 20% of our project income can be used to fund core organizational costs or capacity building). Our final output was 80/20 (where 80 percent of the financial income both in cash and kind was used on direct project cost). Despite financial constraints impacting our operations, we allocated 80% of funds directly to program expenses, ensuring efficient resource utilization to support our mission. Moving forward, we remain committed to enhancing financial resilience and invite your continued support.

For a detailed review of CareEpilepsy's financial performance in 2023, we encourage you to read our audit report. This report provides comprehensive insights into our income sources, expenditure categories, and financial management practices.

SECTION V. IMPACT STORIES

1. Mr. Fikadu Demmise's Journey to Empowerment:

Meet Mr. Fikadu Demmise, whose journey with epilepsy is a testament to resilience and triumph over adversity. Born in Gonder Gient town in 1973 E.C, Mr. Demmise's life took an unexpected turn when he was diagnosed with epilepsy at the age of 38. Initially faced with shock, physical injuries, and the weight of depression, Mr. Demmise found hope through CareEpilepsy.

Before joining CareEpilepsy, Mr. Demmise's daily life was overshadowed by frequent seizures, occurring more than once a day. However, with the support and guidance of CareEpilepsy, he began a transformative journey. Through regular medication and participation in educational programs, Mr. Demmise experienced a remarkable improvement in seizure control.

2. Soliana Jembola's Journey to Empowerment:

Soliana Jembola's journey with epilepsy is one of resilience and hope. Diagnosed at just 14 years old, her life took an unexpected turn. Despite her mother's efforts to find a solution, Soliana's seizures remained uncontrolled. Turning to faith for answers, they sought relief through holy water and prayers.

A radio broadcast introduced Soliana to CareEpilepsy's work, igniting a glimmer of hope. Determined to find treatment and support, Soliana reached out to us. Under our neurologists' care, her seizures were brought under control, allowing her to return to a sense of normalcy and resume her education. With perseverance, Soliana excelled in her 12th-grade exams, opening doors to a brighter future. At a support group meeting, she expressed gratitude for the

life-changing impact of CareEpilepsy. Soliana's journey showcases the transformative power of our organization, offering renewed hope and empowering individuals like her to overcome challenges and pursue their dreams.

3. Community Outreach Impact:

In a significant achievement, we successfully trained 3,200 individuals on epilepsy awareness, providing valuable insights into epilepsy recovery positions. The impact of these programs extends beyond knowledge dissemination, actively contributing to the destigmatization of epilepsy in society. These initiatives have not only reduced stigma but also empowered individuals to seek medical care and support, ultimately improving their overall well-being.

4. Partnership Success Stories:

Our collaborations with international organizations, government agencies, NGOs, and international organizations have yielded significant impact. For instance, our partnership with IBE has led to us hosting the IBE meeting in Addis Ababa. Similarly, collaborations with AEN have facilitated the trainings of nurses and health officers in epilepsy, furthering our mission of supporting individuals living with epilepsy.

5. Advocacy Achievements:

CareEpilepsy's advocacy efforts have led to tangible policy changes and increased awareness about epilepsy in Ethiopia. Through our campaigns and initiatives, we have successfully raised the profile of epilepsy as a public health priority, ensuring that individuals affected by the condition receive the attention and support they deserve.

These impact stories represent just a glimpse of the transformative work accomplished by CareEpilepsy in 2023. With your continued support, we remain steadfast in our commitment to improving the lives of individuals living with epilepsy and creating a more inclusive and supportive society.

6. Public Education

Throughout 2023, our efforts to increase public awareness, shift perceptions on epilepsy, and engage our beneficiaries have yielded significant results. Media activities aimed at raising awareness of epilepsy have demonstrated immediate and substantial impacts, promoting medical-seeking behavior and adherence to anti-epileptic drugs. Through education materials and various media outlets, including radio broadcasts, TV shows, social media platforms, and our website, we reached families affected by epilepsy and the broader population. We were interviewed on 20 radio broadcasts and 8 TV shows, while our social media activism successfully raised awareness within the social movement. Additionally, the production of four quarterly newsletters achieved our planned goal, further amplifying our message and fostering engagement

with our audience.

SECTION VI. FUTURE AND GOALS

- Empowering Individuals and Families: Our focus will be on empowering individuals and families affected by epilepsy through education, support services, and advocacy. We will continue to provide counseling, support groups, and educational resources to help individuals manage their condition and improve their quality of life.
- 2. **Fostering Partnerships and Collaboration:** Collaboration is key to our success. In 2024, we will continue to foster partnerships with government agencies, NGOs, healthcare providers, and international organizations to leverage resources, share best practices, and amplify our impact.
- 3. **Advocacy and Policy Change:** Advocating for policy change is essential to address the challenges faced by individuals living with epilepsy. In 2024, we will continue to advocate for policies that promote epilepsy awareness, ensure access to affordable treatment and medication, and protect the rights of individuals with epilepsy.
- 4. **Sustainability and Growth:** As we look to the future, we are committed to ensuring the long-term sustainability and growth of CareEpilepsy. This includes diversifying our funding sources, strengthening our organizational capacity, and investing in staff development and training.

By focusing on these strategic priorities, we aim to make meaningful progress in our mission to improve the lives of individuals living with epilepsy and create a more inclusive and supportive society.

7. ACKNOWLEDGMENTS:

CareEpilepsy Ethiopia wishes to thank everyone who supported our work in kind and financially. Specifically, we want to thank the following organizations and teams for their generous donations, hard work, time and patience during this quarter.

Our national youth and professional volunteers for their in-kind donations of service

The Association of Ethiopian Neurologists for their in-kind donations of service Friends of CareEpilepsy in Atlanta

CareEpilepsy UK

CareEpilepsy Ethiopia Staff

8. CONTACT INFORMATION:

For more information about CareEpilepsy or to get involved, please visit our website [CareEpilepsy Ethiopia], or contact us at:

- Email: ceo@careepilepsyethiopia.org, - Phone: +0940262581