

IN THE LOOP



TOP NEWS OF THE QUARTER

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OUR GREAT HEROES

- **Research Initiative: Study Launched in Addis Ababa to analyze epilepsy management trends and identify gaps.**
- **Policy Advocacy: Secured key partnerships to champion the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) as essential for transforming epilepsy care by addressing treatment gaps, reducing stigma, and improving access to quality care across Ethiopia.**
- **Holiday Support: Supported families with epilepsy through essential food aid this Ethiopian Easter.**
- **Medication Support: Exceeded target by supporting 320 patients with medication.**
- **Clinical Services: Delivered Epilepsy Follow-Up Care to 230 Patients and Advanced Diagnostics to 107 Individuals.**
- **Raising Awareness: Educated 1,800 Individuals and Partnered with Somali Physicians to Advance Epilepsy Awareness.**
- **Community Support: Reached 1,310 patients and families through support activities to enhance their mental health and well-being.**

MESSAGE FROM THE CEO Building Hope, One Life at a Time

“We lost more than a center, we lost a sanctuary..”

Enat Yewnetu

Founder and CEO

CareEpilepsy Ethiopia



Dear Friends and Supporters,

I write to you today with a heavy heart and a deep sense of urgency.

Due to ongoing financial constraints, CareEpilepsy Ethiopia has been forced to vacate the epilepsy centre that served as a critical hub for medical care, psychosocial support, and community for people living with epilepsy. This decision was not taken lightly—it marks a significant setback for the patients and families who depended on this space for stability, dignity, and hope.

Our former centre was more than a medical facility. It was a safe haven where individuals could access EEG testing, counselling, nutritional support, and vital community programs like our weekly Coffee Mornings, which offered emotional relief and peer connection. For many individuals with epilepsy—some travelling days from remote regions—the centre served as a place to rest, reset, and recover before and after treatment. It provided not only medical support but also the compassion and stability often missing in their daily lives.

We have relocated to the second floor of an office building, a space that is neither safe nor easily accessible. Parents have to carry their children on their back.

Our staff, too, are struggling. Once operating in a conducive environment, they now work in cramped, overcrowded rooms without privacy or proper facilities. The suspension of our EEG diagnostic services has further compromised our ability to provide timely and effective interventions.

We are doing everything possible to adapt—but the reality is clear: our current environment is unsustainable. We urgently need your support to secure a new, accessible, and medically appropriate facility where we can resume full services.

With sincere gratitude,

Enat Yewnetu CEO,
CareEpilepsy

OUR IMPACT: TRANSFORMING LIVES WITH CLINICAL EXCELLENCE

Every number has a heartbeat.

192 patients walked through our clinic doors this quarter, seeking more than just treatment—they sought hope. Among them, 105 were met by neurologists who listened, cared, and crafted specialized plans for their healing. For many, it was the first time someone truly understood their struggles. 345 patients received life-saving medication—almost triple what we had planned for. Each bottle of medicine represented a chance for someone to sleep without fear, work without stigma, and dream without limits. 434 individuals sat in workshops and awareness programs, their expressions shifting from skepticism to understanding. Minds were opened, myths shattered, and the heavy burden of stigma began to lift, one person at a time. In therapy sessions and support groups, 361 families came together to share laughter, tears, and stories of resilience. It wasn't just therapy—it was connection. Together, they built strength from one another, creating a community where none had existed before. These numbers aren't just data points. They're lives changed. They're proof that care, compassion, and advocacy can move mountains. And with your continued support, the stories behind these numbers will only grow.



ADVANCING CARE, SAVING LIVES

190 Patients Treated,
75 EEGs Conducted,
15 MRIs Supported, and
345 Provided with Medication

434

Professionals Trained in
Epilepsy Awareness

COMPREHENSIVE EEG TRAINING FOR BETTER EPILEPSY CARE

On August 16, 2024, CareEpilepsy hosted a vital EEG Training via Zoom, uniting healthcare workers to revolutionize epilepsy care. Led by Dr. John R. Pollard, Director of the ChristianaCare

Epilepsy Center and Associate Professor of Neurology at the University of Pennsylvania, the session focused on interpreting EEG results, guiding treatment decisions, and adapting EEG technology to resource-limited settings. In addition, Dr. Etsegenet Tizazu, an experienced adult epileptologist, brought invaluable expertise to the training, guiding participants on practical strategies for managing epilepsy in resource-limited settings. This hour empowered junior neurologists, nurses, and health officers to interpret EEG results, ensuring better, cost-effective care for epilepsy patients.

OUR IMPACT: BREAKING STIGMA THROUGH EDUCATION

We reached over 1,100 individuals through community education and distributed educational materials to 40 health centers. Our "SafeAtSchool" program was a standout success, equipping 87 teachers and over 700 students with the knowledge to support those with epilepsy. Media campaigns in Somali, Oromia, and Tigrigna languages are ensuring that critical information reaches even the most remote areas.



Dr. Bezawit and Kebrom appeared on Fana FM, a leading radio station, to raise awareness about epilepsy and associated disorders. Additionally, we translated our educational leaflets into Somali, Oromia, and Tigrigna, ensuring broader access to vital information. These efforts represent a significant step forward in breaking stigma and supporting those living with epilepsy.



SUPPORTING EMOTIONAL AND SOCIAL WELLBEING OF OUR PATIENTS

At CareEpilepsy Ethiopia, we understand the importance of holistic wellbeing which encompasses more than just physical health. Therefore, we have expanded our services to encompass various wellbeing initiatives. During the second quarter, CareEpilepsy Ethiopia achieved significant milestones in counseling and support services, enhancing patients' mental well-being and support networks. We provided individual counseling to 95 patients, reaching 95% of our 100-patient target. We actively recruited more psychiatry volunteers and conducted 10 group therapy sessions with 139 participants, achieving 125% of our goal. Our patient support group program engaged 323 individuals, surpassing our 150-patient target by 215.3%. We covered transportation costs for 323 patients to attend essential meetings, achieving 215.3% of our target. Although home visits were deferred, our telephone helpline served 291 callers, reaching 97% of our 300-caller target. Additionally, our GP-led home monitoring service supported 751 individuals, achieving 200.3% of our 375-patient goal. We expanded our epilepsy resource center by updating information on our website and conducted a three-month research study on epilepsy management in Addis Ababa health centers. For individual livelihood support, we distributed essential food items to 15 families for Ethiopian Easter and conducted 12 weekly CareCraft sessions, providing training and raw materials to participants. These accomplishments highlight our dedication to improving epilepsy care, support, and awareness, exceeding many of our targets and making a significant impact on the lives of those affected by epilepsy.



GENEROUS EASTER TRADITION

Every Easter, Mame's generosity shines brightly in our community. Understanding the importance of the Orthodox fasting period, she donates funds to CareEpilepsy, allowing us to purchase chicken, oil, and eggs. These ingredients are used to prepare doro wat, a cherished dish that brings joy to our patients after weeks of fasting. Aster's yearly contributions not only provide nourishment but also enable our patients to partake in this significant religious tradition. We are deeply grateful for Aster's unwavering support and the happiness she brings to our community during Easter.



Miss Emebet Ameneshewa

UNVEILING THE JOURNEY: A PATIENT'S STORY

Miss Emebet Ameneshewa: Thriving Beyond Challenges

At 15, Emebet's life was upended by epilepsy. Mocked as "possessed by demons" and ostracized by classmates, she endured years of isolation and worsening seizures. When medical treatment began, inconsistency and stigma further derailed her education and dreams. "The initial shock and confusion left me feeling helpless, unsure of what was happening to me. Facing stigma and social judgment in our community, my teenage years became a dark period. Bullied and cruelly nicknamed by classmates, I sought solace in spiritual treatments. However, my condition worsened, with frequent seizures and a declining mental state due to the isolation I endured. Two years after my first seizure, I sought medical help at Paulos Hospital and was diagnosed with epilepsy. Starting treatment with Phenobarbital offered some relief, yet my battle with depression and hopelessness persisted. Inconsistency with medication led me to abandon my education and work, overwhelmed by despair. In 2020, a ray of hope appeared through a CareEpilepsy Ethiopia post on Facebook. This organization offered me clarity and support, helping me understand epilepsy and providing avenues for a normal life. Through patient support groups and counseling, CareEpilepsy restored my hope and commitment to treatment. I am now two years seizure-free, actively contributing as a volunteer and advocate preventing others from enduring the challenges I faced. My success is a testament to the power of support groups, quality care, and acceptance of life with epilepsy."



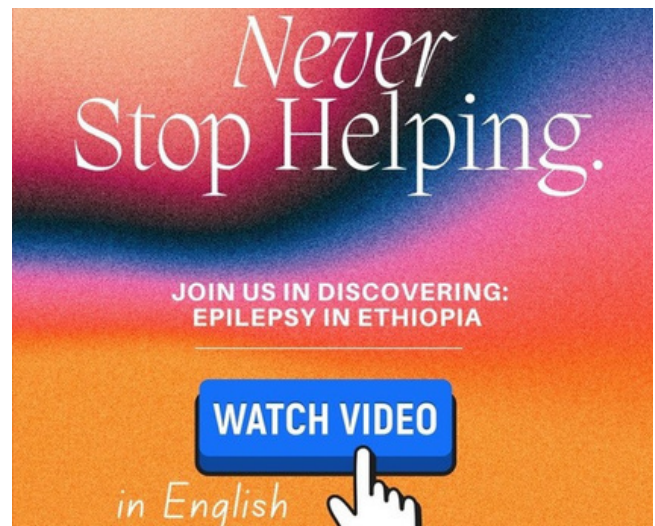
EMPOWERING CHANGE: MEET OUR VOLUNTEERS

write me a story of a
volunteer with his/her
picture

FACTS CORNER

HERE ARE 10 KEY FACTS ABOUT EPILEPSY TO SHARE!

- Epilepsy causes can vary (e.g., birth, fever, stroke, brain injury). Seizures result from disrupted brain signals. Epilepsy
- is not contagious. Different epilepsy types require varied
- treatments. Seizures have various triggers (e.g., stress,
- tiredness, missed meds). Most seizures are not emergencies
- but prioritize safety. Swallowing your tongue during a seizure is impossible; avoid mouth objects
-
-



MEET OUR STAFF

*Dr Bezawit Ketema, Clinical Lead
CareEpilepsy Ethiopia*

Born and raised in Addis Ababa, Ethiopia, I've always felt a deep calling to make a difference in my community. After graduating from Hayat Medical College in October 2023, I joined CareEpilepsy Ethiopia in March 2024 to serve those in need. My work here has opened my eyes to the profound challenges faced by individuals with epilepsy and associated disorders—revealing the pervasive stigma, discrimination, and scarcity of resources that hinder their lives and well-being. Through my work at Care Epilepsy Ethiopia, I have seen how deeply stigma isolates patients, affecting not only their health but also their families' emotional and social lives. The social exclusion, misunderstandings, and lack of access to appropriate care affect people's lives in multifaceted ways. For epilepsy patients in particular, limited access to essential medications and specialized care exacerbates their symptoms, leading to preventable complications and worsening their quality of life. These experiences have ignited a burning determination in me to advocate for comprehensive support for epilepsy and related conditions. At CareEpilepsy Ethiopia, my vision is to ensure those with epilepsy and related disorders live with dignity, free from stigma, and supported by an understanding community.



Epilepsy and Autism: Understanding the Link and Managing Care

The connection between epilepsy and autism lies in their shared neurological underpinnings. Both conditions often stem from disruptions in brain development, which may result from genetic mutations, prenatal factors, or early childhood events. Research suggests that individuals with autism may have an imbalance in excitatory and inhibitory brain signals, increasing their susceptibility to seizures. This overlap is especially pronounced in those with severe autism or intellectual disabilities. Managing both conditions requires a holistic approach. Early diagnosis is critical—parents and caregivers should monitor for signs of seizures, such as staring spells, muscle jerks, or unusual behaviors. Regular EEG tests can help identify seizure activity, even when symptoms are subtle.

Multidisciplinary care is essential, involving neurologists, psychologists, and autism specialists who can develop a coordinated treatment plan.

Treatment often combines anti-seizure medications with behavioral therapies, tailored to the individual's needs. For non-verbal individuals or those with sensory sensitivities, communication aids and sensory-friendly environments can improve their quality of life. Supporting caregivers with education and resources is equally vital, as managing both conditions can be overwhelming. Raising awareness about this connection helps reduce stigma and promotes better care. With the right support, individuals with epilepsy and autism can thrive, leading fuller, more inclusive lives.



OUR GREAT HEROES

Abel Mulugeta Neurologist

Dr. Abel, a dedicated neurologist, has been a pillar of support for CareEpilepsy Ethiopia.

Dr. Abel's journey in medicine began at the Haramaya University, where he laid the foundation for a remarkable career. After completing his undergraduate training, he served as a general practitioner at Debre Birhan Comprehensive Specialized Hospital, providing vital care to countless patients. His thirst for knowledge and excellence drove him to pursue advanced studies in adult neurology, earning a second degree and a doctorate from Addis Ababa Health Science College, Ethiopia's leading medical institution.

With a wealth of experience from various hospitals, Dr. Abel now serves at Zewditu Memorial Hospital and several private institutions. His introduction to CareEpilepsy Ethiopia through his colleagues marked the beginning of a profound partnership.

Dr. Abel's commitment to improving neurological care and advocating for epilepsy patients is truly inspiring.

As a volunteer, he dedicates his expertise and valuable time to our outpatient clinics, often sacrificing personal moments with his family. His selfless service has brought hope and healing to many in need.

SPOTLIGHT:

Mr Teshome's Inspiring Journey Epilepsy Advocacy Committee Member

At 60, Mr. Teshome's life reflects resilience and service. Living with epilepsy for decades, he faced stigma, isolation, and countless challenges. Eight years ago, he found CareEpilepsy Ethiopia, where he received consistent care and a community that embraced him.



DR ABEL

As the founding member of the Epilepsy Advocacy Committee, Mr. Teshome visits patients at hospitals and homes, raises awareness, and fights stigma daily. Despite his struggles, he brings hope and courage to others. To CareEpilepsy, he is more than a patient; he is a mentor, an advocate, and an absolute gem. His journey reminds us that even in the face of adversity, it's possible to create meaningful change and uplift others.

HOW YOU CAN HELP

Your support makes a difference:

- **Donate:** Every contribution helps provide life-saving care.
- **Volunteer:** Be part of our movement for change.
- **Advocate:** Share our mission and fight stigma.
- **Give online** www.careepilepsyethiopia.org/donate
- **Contact us at** +251 11 669 4455 or +447596817212 (WhatsApp).

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ACKNOWLEDGEMENTS

LOOKING TO TALK TO SOMEONE?

»»»THANK YOU

CareEpilepsy Ethiopia wishes to thank everyone who supported our work in-kind through assistance or donations. We are especially grateful to our partners—the Ministry of Health, Addis Ababa Education Bureau, and the Association of Ethiopian Neurologists—for their continued collaboration.

We extend heartfelt appreciation to our sponsors:

- Our national youth and professional volunteers for their in-kind donations of service
- Neurologists for their in-kind donations of service
- Friends of CareEpilepsy in Ethiopia, London and Atlanta

Your dedication has been truly invaluable.

And to the CareEpilepsy UK Board of Directors and the CareEpilepsy Ethiopia Advisory Board—thank you for your continued guidance and leadership.

CareEpilepsy works with the most marginalised children, women and men who face barriers to getting the education and employment they deserve. We believe in the power of the individual and of a group of thoughtful, committed people to change the lives of people with epilepsy; indeed, it's the only thing that ever has. **Together we can save lives. Together we can change the perception of epilepsy. Together we can make a difference.** There are many ways to support us: [become a member](#), [volunteer your time](#), [become a corporate partner](#) and [donate](#).

Ethiopia: CareEpilepsy Ethiopia, Account Number: 1000161849166, COMMERCIAL BANK OF ETHIOPIA
or call us on 0911633077 nationally.

UK: Direct Debit to HSBC A/C - (Sort code: 40-07-27) - (A/C No: 11621491)
Give online - <https://www.careepilepsyethiopia.org/donate>

SAVING LIVES IS BETTER TOGETHER!

Our Address in Addis Ababa: Next to Denberwa Maternal and Child Health Hospital Yeka Sub-City Woreda 08, House No. 897, Addis Ababa

Our helpful Information & Advice Officers are available to assist you. Reach us at +251 11 669 4455. We extend support to carers, friends, and families, emphasizing the importance of maintaining your own well-being while caring for someone with epilepsy.

Let's create a future where no one with epilepsy walks alone.

DONATE

“You wonder why I want you to spread epilepsy awareness when you don't have epilepsy? At one point, neither did I.”

Help spread epilepsy awareness.

COURTESY OF EPILEPSY ACTION
CAREEPILEPSY

