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#### **TOP NEWS OF THE QUARTER**



10-Year Anniversary Milestone: Celebrated a decade of commitment to epilepsy care and raising awareness during National Epilepsy Month in February 2025.



international epilepsy day, 10 February 2025



Patient Care: Treated 472 patients, with 131 receiving specialized care by neurologists, and provided telemedicine consultations with national and international neurologists.



Diagnostics & Medication: Conducted 22 EEG tests, funded 34 MRI scans, and supplied anti-seizure medication to 376 patients.



Awareness Campaigns: Reached over 8,400 students through our 'Seizure at School' initiative.



Webinar Launch: Announced a series of educational webinars, starting with "Introduction to Epilepsy" on February 8, 2025, and "Pediatric Epilepsy" on March 8, 2025.



Media Outreach: Expanded reach through appearances on major TV and radio networks, increasing awareness across Ethiopia.



#### MESSAGE FROM THE CEO

Dear Friends,

Our 1st quarter marks a profound milestone, 10 years since the founding of CareEpilepsy Ethiopia. What began as a personal mission has grown into a national movement for epilepsy awareness, care, and advocacy.

From early awareness sessions to nationally and internationally recognized care, training, and advocacy programs, our journey has been one of resilience, creativity, passion, and impact. We've stood beside thousands of people living with epilepsy, amplifying voices, improving access to care, and fighting the stigma that too often surrounds this condition.

#### A Celebration to Remember:

The celebration was held at the beautiful Addis Ababa Golf Club. We were honoured to welcome an extraordinary guest of honor, Professor Redda Tekle-Haimanot, Ethiopia's first neurologist, whose work laid the foundation for neurology in the country and who also made the founder's epilepsy diagnosis.

The event brought together a distinguished gathering of those who've shaped our work — Ministry of Health delegates, neurologists, board members, patients, families, and volunteers. Their presence symbolised the strong community we've built over the last ten years. There were speeches of resilience, music, laughter, and heartfelt recognitions. A timeline of our journey showcased milestones and the lives touched along the way.

This day was about every child now going to school, every mother who understands epilepsy, every health worker who is trained, and every life that has been changed.

We also remembered those we've lost, honoring their memory by recommitting to the work that remains.

With gratitude,

#### **Enat Yewnetu MPH**

Founder and CEO, CareEpilepsy Ethiopia





#### HIGHLIGHTS FROM TEN YEARS



### **©** OUR MISSION

Our mission is to radically improve the quality of life of people with epilepsy and associated disabilities and change perceptions of epilepsy in the community.



### **OUR VISION**

We envision a future where people with epilepsy are protected, respected, and free from discrimination and stigma, with the opportunity to realize their full potential as healthy, productive, and empowered individuals.



### @ OUR GOAL

Our goal is to ensure access to epilepsy treatment, train healthcare providers, raise awareness, improve patients' wellbeing, and advocate for policies prioritizing epilepsy care through collaboration with partners, patients, families, and communities.



**Enat Yewnetu** Founder and CEO

"This 10-year mark is not a finish line; it's a launchpad."





## HIGHLIGHTS FROM 10 YEARS: CLINICAL CARE

**Establishing the First NGO-Led Epilepsy Care Service** 

CareEpilepsy Ethiopia is a charity dedicated to providing care and support to anyone affected by epilepsy and associated conditions.

We established Ethiopia's first Epilepsy Monitoring and Support Unit, offering diagnosis, treatment, follow-up, and counselling under one roof.

To date, we've provided direct, sustained care to over 3,000 people, many travelling from across the country to receive the care they cannot find elsewhere.

#### Access to Life-Saving Medication

We ensure the availability of essential anti-epileptic drugs (AEDs) for seizure control—because treatment only works when it's consistent.

Our efforts include financial support, subsidised medication access, and advocacy for inclusion of epilepsy care under Universal Health Coverage (UHC).

Over the past six years, we've helped 3,000 patients continue their treatment without interruption—removing one of the biggest barriers to seizure control in Ethiopia.

#### **⚠** We Brought Care Home

We launched Ethiopia's first home-based epilepsy support program—because care shouldn't stop at the clinic door.

Our Home Monitoring Program supports treatment adherence and continuity of care at the community level, bridging the gap between diagnosis and daily life.

So far, we've served 9,500 people through this model of compassionate, community-based care.

#### Advancing Diagnosis with EEG & MRI

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Since 2022, we've provided EEG and MRI diagnostics to over 1,700 people—many from the poorest communities who could not afford testing.

Our staff are trained to perform EEGs on-site, while MRIs are outsourced to partner facilities. These services are essential for accurate diagnosis, ruling out secondary causes, and guiding effective treatment. Without this program, most would never receive the care they need.



## Epilepsy often comes with emotional and psychological challenges. Our holistic approach includes:



### **Mental Health Matters**



#### Psychotherapy Clinic

One-on-one psychosocial care tailored to the emotional needs of people living with epilepsy.



#### Peer & Group Support

Includes monthly peerled support group
meetings, weekly
group therapy, and
weekly Coffee
Mornings—all
designed to build
connection, reduce
isolation, and foster
shared understanding.



#### Family Therapy

Strengthens family understanding of epilepsy while teaching seizure first aid, emotional support skills, and how to help loved ones live well with epilepsy at home and in daily life.



#### CareCraft Program

Creative therapy through craft-making, rug-weaving, and painting—offering confidence-building and, for some, incomegenerating skills.



#### Helpline & Social Support

Our telephone helpline provides:

- Guidance on epilepsy care and up-to-date medication availability information.
- A listening ear for emotional support

We provide food aid, transport support, essential items like diapers, and clothing for vulnerable individuals through sponsors.







## HIGHLIGHTS FROM 10 YEARS:

## RAISING AWARENESS & CHANGING PERCEPTIONS

#### Awareness has been the foundation of our work for the past 10 years.

In our first three years, this was our primary focus—challenging stigma, educating communities, and opening the door to care. We've implemented nationwide, multilingual, and multi-sectoral education campaigns designed to replace myths with understanding and fear with facts.

## Our key awareness initiatives include:

#### i Health-Centre Epilepsy Education

Provided face-to-face education at health facilities, reaching over 11,000 people in local communities.

#### School-Based Epilepsy Education

Delivered epilepsy education to 130,000 students-empowering youth and reducing stigma in schools.

#### Workplace Epilepsy Education

Reached 3,300 workers and management staff across offices and institutions with tailored awareness training.

#### 듣 EpiLearning: Educational Resources in Ethiopian Languages

Disseminated nearly 500,000 flyers, posters, and booklets in local languages to ensure inclusive and accessible learning across Ethiopia.

#### National Epilepsy Awareness Program & Annual Walks

Established a yearly national epilepsy awareness program, including public awareness walks that continue to grow each year.

#### Regional Outreach Campaigns

Carried out awareness campaigns and distributed materials in regions outside Addis Ababa, extending our impact to rural and underserved populations.

#### Ď ■ Media & Social Media Engagement

We raise nationwide awareness through radio, TV, and digital campaigns, reaching more than 1.2 million people across Ethiopia to challenge stigma and promote understanding.







## **HIGHLIGHTS FROM 10 YEARS:**

#### PARTNERSHIP DEVELOPED









#### **Step One**

Our work is best told by those who experience it firsthand.

Read more about what our patients say and how epilepsy care is changing lives across Ethiopia:

careepilepsyethiopia.org

#### **Step Two**

Mobilised diaspora professionals for clinical support, telemedicine, and specialist training

Leveraged diaspora networks to enhance national webinar programs

#### **Step Three**

We believe real change must be informed by real data:

Perception studies conducted with frontline workers-highlighting widespread myths, diagnostic gaps, and barriers to care.

#### **Step Four**

Mobilised professionals and youth volunteers nationwide to support care delivery, awareness drives, home visits, and peer education—turning once-hidden communities into empowered advocates.







## **HIGHLIGHTS FROM 10 YEARS:**

#### PARTNERSHIP DEVELOPED

- Empowering Ethiopia's health system from the inside out:
- 1,200+ healthcare
   providers trained in person
   to diagnose, treat, and
   refer epilepsy in line with
   WHO mhGAP guidance.
- Monthly webinars launched in 2024, creating ongoing professional development for frontline workers—over 1,000 participants so far.
- Includes doctors, nurses, health officers, psychologists, and Health Extension Workers.

Training the Frontlines

GLOBAL STAGE

- As a chapter member of the International Bureau for Epilepsy (IBE), CareEpilepsy Ethiopia is proudly representing the country in global conversations on epilepsy care.
   We've presented our work in
- We've presented our work in Lisbon, Zambia, London, and the USA, and continue to build strong international partnerships –including with the Band Foundation—to strengthen local impact and global solidarity.

CareEpilepsy Ethiopia on the Global Stage ADVOCACY

- Health, WHO, and national partners to improve the quality of epilepsy services, expand access, and strengthen health worker training.

  In recent years, we took the
- In recent years, we took the lead in establishing the IGAP Technical Working Group, now coordinated by the Ministry of Health, to support the domestication of the global epilepsy action plan.

• We work with the Ministry of

 Our collaboration is helping shape stronger, nationwide epilepsy care.

Driving National Policy

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**EDITION #1** 

10-Year Celebration - Golf Club, Addis Ababa









## 10 YEARS OF COURAGE, CARE, AND COMMUNITY!

From heartfelt speeches to shared laughter and powerful stories, our 10th anniversary was more than a celebration, it was a tribute to everyone who's walked this journey with us.

Thank you to our volunteers, supporters, and epilepsy warriors. Here's to a decade of impact, and the decades still to come!













## OUR IMPACT: SAVING LIVES WITH CLINICAL CARE

Every number has a heartbeat.

In the 1<sup>st</sup> quarter of 2025, 472 people walked through the doors of our community clinic, each carrying a story shaped by epilepsy.

341 were cared for by our GPs, and 131 received specialist treatment from volunteer neurologists, including children who had never seen a specialist before. 10 were referred for advanced care, while 22 received free EEG testing, and 34 were financially supported to get an MRI, a test they couldn't afford on their own.

We also provided anti-seizure medication to 376 individuals, helping them regain seizure control and stability.

Behind every number is a life changed, a mother sleeping peacefully, a child returning to school, a family finding hope. We believe access to care is a right, not a privilege.

Dr. Neal Sankhla, Assistant Professor of Pediatrics at Emory School of Medicine, and Dr. Sefali Patel, PGY-5 Child Neurology resident, graciously visited our clinic and office during their time in Addis Ababa as part of the 2024–2025 Emory Global Health Residency Scholars Program at Black Lion Hospital. We were honoured to host them, and equally delighted that they had the opportunity to meet Dr. Kindu and Dr. Ayalew, our paediatric neurologists volunteering in our community clinic at the time.



### **MENTAL HEALTH SUPPORT**

Mental health support isn't a service it's a lifeline.

At CareEpilepsy Ethiopia, we understand that epilepsy is not just a physical condition, it is a condition that deeply impacts every aspect of a person's life. People living with epilepsy often face emotional distress, social isolation, and stigma, all of which affect their daily wellbeing. That's why, alongside clinical care, we have built comprehensive support systems that care for the whole person, not just their seizures.



Because epilepsy doesn't just affect the brain, it impacts the whole person. Our wellbeing program meets them there.



Between January and March 2025, our mental health program provided psychotherapy service to 225 individuals, helping them navigate fear, anxiety, and depression. In our monthly peer group sessions, 145 others found strength in shared stories and the comfort of community.

Because epilepsy affects more than the brain, our wellbeing program ensures people feel seen, supported, and strong. At CareEpilepsy, we provide goal-focused, practical support to help individuals manage stress, build healthier habits, and take control of their lives with confidence and clarity.

This quarter, our helpline supported 220 callers with emotional and practical guidance, ensuring no one felt alone in their journey. We followed up with 216 home-based support calls, helping patients stay on track and feel cared for where it matters most. Our Patient Support Network reached 538 individuals, offering connection, encouragement, and consistent support throughout their epilepsy journey.





Her little hands trembled, not from the cold, but from the epilepsy she's lived with since she was four. Today, those hands held a gift of love.

This Gena, she received a special food package thanks to Aynabeba, a mother in Canada whose heart still aches for a son she lost to epilepsy. For the third year, Aynabeba has turned her grief into giving, supporting children like this sweet girl with food, comfort, and dignity during the festive season. We want to express our sincere gratitude to Aynabeba from Canada, who generously supported the cost of these food packages. On behalf of our patients, we want to thank you so much for your kindness.

Behind every smile is a story of pain, hope, and quiet strength. This one is for all the children who fight battles we can't see, and the angels like Aynabeba who never forget them.



## **CLINICAL TRAINING**

Training remained a central pillar of CareEpilepsy's Q1 strategy. As part of National Epilepsy Month, CareEpilepsy Ethiopia hosted a two-day clinical training from February 11-12, 2025, in Adama, bringing together over 90 healthcare professionals from across the country. The training aimed to strengthen frontline care for people living with epilepsy, particularly in the regions.

The sessions focused on key areas, including pediatric epilepsy, seizure emergencies, maternal epilepsy care, and mental health support. Participants also engaged in hands-on demonstrations of seizure first aid, with clear guidance on how to act during crisis situations. The WHO's Intersectoral Global Action Plan (IGAP) framework on epilepsy was also introduced. What made the training especially powerful were the personal stories shared by individuals living with epilepsy. Their voices reminded everyone that behind every statistic is a life, someone who deserves dignity, care, and understanding.

Our newly launched monthly epilepsy webinar series is already making a meaningful impact, with two sessions held so far, drawing 250 participants from diverse fields including healthcare, and featuring lectures by two international epilepsy specialists.









## **TEACHERS TRAINING**

We believe that building an inclusive and compassionate society starts in the classroom. On March 8, 2025, we brought together 70 teachers from across Addis Ababa for a special epilepsy awareness and seizure first aid training session in Bishoftu.

This program was organized in partnership with the Ministry of Health, the Association of Ethiopian Neurologists, and sponsored by the Ethiopia Public Health Institute.

Teachers are often the first to respond when a student has a seizure, yet many have never received formal training. This session aimed to change that by equipping educators with the knowledge and confidence to support students with epilepsy and create safe, welcoming school environments.

For many, this was the first time they had received structured guidance on epilepsy. The session also emphasized the importance of inclusive education, ensuring no student is left behind due to a medical condition. When we train teachers, we build communities of care.









## INTERNATIONAL EPILEPSY DAY, 10 FEBRUARY 2025

National Workshop on IGAP: Translating Global Commitments into Local Action for Epilepsy Care

The International Epilepsy Day Advocacy Workshop was held on February 10, 2025, at the Capital Hotel in Addis Ababa under the theme "Advocating for Policies and Practices Awareness for Enhanced Access to Epilepsy Treatment and Medication in Ethiopia", aligned with the WHO Intersectoral Global Action Plan (IGAP). The workshop was organized by the Ministry of Health, CareEpilepsy, the Association of Ethiopian Neurologists and CHAI.

The event opened with a keynote address from Dr. Dereje Duguma, State Minister of Health, emphasizing the urgency of prioritizing epilepsy in national health policy, followed by welcome remarks from Dr. Hiwot Solomon, Lead Executive Officer for Disease Prevention and Control at the Ministry of Health; Dr. Rahel Belete, Vice President and Country Director of the Clinton Health Access Initiative (CHAI); and Enat Yewnetu, Founder and Director of CareEpilepsy Ethiopia, all underscoring the importance of addressing persistent care gaps.

The workshop focused on key priorities: improving access to antiepileptic drugs, closing infrastructure gaps—especially in underserved areas like Southwest Omo—and aligning national policy with IGAP goals.







Building a stigma-free society. One step at a time.

## SCHOOL EDUCATION AND AWARENESS

Our awareness campaigns reached over 8,400 people, distributing more than 13,500 flyers, posters, and seizure response materials.



#### **RESHAPING MINDES**





Visits to 10 schools, where the "Seizure at School" program reached 5,743 students and teachers, dismantling stigma and promoting inclusion.

In schools, we have laid the groundwork by educating students about epilepsy, empowering them to become advocates for inclusion. We've worked with teachers to equip them with the knowledge to create supportive classrooms and engaged parents to help them overcome misconceptions.

Every action, every campaign, and every conversation is a step toward a healthier, more informed, and compassionate Ethiopia.











# MEDIA FOR IMPACT:

Promoting Awareness and Inclusion

CareEpilepsy Ethiopia continues to raise national awareness about epilepsy through powerful media engagement. From TV studios to radio stations, our staff and parents of children with epilepsy have shared their stories, bringing real voices to the forefront.

Our media work is all about breaking stigma, educating the public, and ensuring epilepsy is seen, understood, and supported across Ethiopia.





CareEpilepsy Ethiopia extends heartfelt thanks to 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.

**EDITION #1** 

- **Ethiopia Telecom** expanding our reach
- Our national and international volunteer neurologists giving their expertise freely
- Youth and medical volunteers driving grassroots change
- Friends of CareEpilepsy (London, Atlanta, DC, Minnesota) standing with us across continents and championing our mission
- Commercial Bank of Ethiopia supporting essential services that touch families in need
- Ministry of Health & Addis Ababa Health Bureau partnering with us to expand sustainable epilepsy care
- **Ethiopian Neurology Association** partnering with us to advance professional excellence



We stand alongside some of the most marginalised children, women, and men in Ethiopia, people who deserve the same chance at education, employment, and dignity as anyone else. We believe in the power of individuals, and the strength of committed communities, to transform lives.

Together, we save lives. Together, we change perceptions. Together, we create a difference.

**MARCH 2025** 



10 Years of Saving Lives & Changing Perceptions

## Ways to Support us

Donate Online <u>careepilepsyethiopia.org/donate</u>

CareEpilepsy Ethiopia Commercial Bank of Ethiopia Account Number: 1000161849166



<u> Medical Volunteer Application</u>
Form

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