

IN THE LOOP



TOP NEWS OF THE QUARTER

IN THIS ISSUE

MESSAGE FROM THE CEO

OUR SERVICES

**UNVEILING THE JOURNEY:
A PATIENT'S STORY**

MEET OUR STAFF

**EMPOWERING CHANGE:
MEET OUR DYNAMIC
YOUTH VOLUNTEERS**

**BUILDING BRIDGES: OUR
VALUED PARTNERS**

OUR GREAT HEROES

CEO MESSAGE: REFLECTING ON GROWTH AND ACHIEVEMENTS

Dear CareEpilepsy Community,

Welcome to CareEpilepsy Ethiopia, your dedicated charity on a mission to improve the lives of those affected by epilepsy. Our efforts revolve around raising awareness, providing access to essential medical services, enhancing the skills of healthcare professionals, and offering support to individuals living with epilepsy. Now, let's dive into our 4th Quarter Newsletter, your window into the impactful initiatives shaping our journey.

Our dedicated team of healthcare professionals, including health officers, nurses, and neurologists, continues to provide daily 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.

As we expand our efforts to raise epilepsy awareness and advocate for those affected, I am continually inspired by the dedication and passion of our team, volunteers, and partners. Together, we've made a substantial impact, reaching more individuals and families affected by epilepsy. Furthermore, our focus on education, empowerment, and support has remained steadfast. 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. The stimulating conversations, crucial perspectives, and substantial results that arose from this occasion reaffirmed our joint dedication to furthering the advocacy for epilepsy on a global scale. Particularly noteworthy was the establishment of the Call to Action, signifying a momentous achievement and underscoring our mutual resolve to tackle the pressing issues confronting individuals impacted by epilepsy.

This quarter marked a significant achievement in expanding our network of partners. Mr. Adelard Kakunze, currently heading the Non-Communicable Diseases and Mental Health Unit at the Africa Centres for Disease Control and Prevention (Africa CDC), visited the CareEpilepsy Center. Impressed with our work, he expressed a keen interest in collaboration, ultimately participating in a panel discussion on IGAP implementation in Ethiopia at the IBE Africa conference.

Sofia Seid and Jemal Teshome from the Ministry of Health's Mental Health Unit visited to witness our activities and exchange ideas. PSI Ethiopia, represented by Mr. Abel and Mrs. Hirut, explored potential collaborations to enhance patient care and education, particularly for individuals living with HIV. Further engagements included discussions with Tsion Terefe, Executive Director of Parkinson's Patients Support Organization-Ethiopia (PPSO-E), and Dr. Yared Zenebe, founder of Alzheimer's Ethiopia, exploring collaboration opportunities addressing commonalities in epilepsy, Alzheimer's, and Parkinson's issues while focusing on awareness-raising initiatives.

Your ongoing support is deeply appreciated. Together, we will continue to push boundaries, challenge stigmas, and make a real difference in the lives of those living with epilepsy.

Warm regards,

Enat Yewnetu
CEO, CareEpilepsy Ethiopia



Enat Yewnetu
CEO, CareEpilepsy Ethiopia

We take immense pride in our achievements and our positive impact. Our journey has been remarkable, but it's not just ours; it belongs to everyone who believes in transforming lives. Your support fuels our progress, reinforces our determination and makes a world of difference. Join us in shaping a future where epilepsy is understood and lives are transformed. If you're inspired, consider clicking on "**Donate**" to support us financially.

Together, let's make a lasting impact.



IBE AFRICA REGIONAL CONFERENCE

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DR DEREJE DUGUMA, STATE MINISTER OF HEALTH



DR RAKEB MESSELE ABERRA, DEPUTY CHIEF COMMISSIONER OF EHRC



FRANCESCA SOFIA PRESIDENT OF IBE



DONNA WALSH CEO OF IBE



ENAT YEWNATU, CEO OF CAREEPILEPSY ETHIOPIA



MR ACTION AMOS AFRICA REGION VP



IBE CHAPTER MEMBERS AT CAREPILEPSY ETHIOPIA CENTER

As the second day of the conference drew to a close, our guests embarked on a journey to the heart of our mission - the CareEpilepsy Center. Here, they were warmly welcomed by a vibrant tapestry of individuals, from our dedicated volunteer neurologists to our enthusiastic youth volunteers and diligent staff members, all united in our commitment to epilepsy care. Our guests were able to see evidence of our work including clinical care, awareness raising activities, and discovered a marketplace filled with treasures crafted by the talented hands of our patients, each item telling a story of resilience and creativity. Yet, the true highlight awaited them - the enchanting Ethiopian coffee ceremony, accompanied by the rhythmic beats of traditional music and the joyous movements of dancing. Immersed in this cultural celebration, our guests not only savored the flavors of Ethiopia but also witnessed firsthand the profound impact of our work within the epilepsy community. Their expressions of wonder and appreciation echoed through the center, reaffirming our shared dedication to transforming lives and fostering a brighter future for all those affected by epilepsy.

Following our center visit, we ventured to Yod Abyssinia, a pioneering cultural restaurant renowned for its live traditional music and dance performances. Here, amidst the vibrant ambiance, we gathered to share a meal and savor the rich flavors of Ethiopian cuisine, immersing ourselves in an unforgettable cultural experience.





CLINICAL SERVICES

In the fourth quarter of 2023, the success story of CareEpilepsy Clinic unfolds with pride and purpose. Our Nurse-Led Clinic, catering to 130 adults, stands as a testament to personalized care. The Neurologist-Led Adult and Children Clinics, treating 105 and 106 individuals, respectively, signify a commitment to specialized care. Our EEG service provided vital insights for anti-seizure therapy, guiding the way for 33 patients.

We funded the MRI expenses for 11 patients and provided antiseizure medication support for 227 individuals.

Anticipating the launch of telemedicine to address neurologist shortages, we are at the forefront of innovation. Our commitment and dedication shine through in our Home Monitoring Service, offering support to 470 patients.

Every number is a triumph, each story a reflection of our resolute commitment to delivering exceptional care to those impacted by epilepsy. We are incredibly proud of the achievements in the fourth quarter of 2023 and look forward to building upon them in the coming year.



NEUROLOGISTS AT THE FOREFRONT:

Our neurologists have been receiving heartfelt appreciation and blessings from our patients, showing the positive impact of their care and dedication.



CLINICAL TRAINING

@ Debreberhan Comprehensive Specialized Hospital, Debrebrhan

Our team has been running the Epilepsy Basics training course, focusing on those involved in epilepsy management, such as nurses and health officers.

- Conducted epilepsy management training for 50 caregivers and 60 health professionals affiliated with the Mekedonia Humanitarian Association.
- Provided training to 30 health professionals at the Yeka Sub City Police Office in Addis Ababa.
- Conducted training sessions for 100 health professionals at Kaliti Maximum Security Prison.
- Ran the Epilepsy Basics training course, catering to individuals involved in epilepsy management, including nurses and health officers.
- The online Epilepsy Resources Center is established with access to a library of epilepsy journals, books, and leaflets.
- We are in the process of acquiring neurologist support from abroad to enhance our clinical care including training, and we're currently working on logistics to run the service efficiently. In the meantime, our health officer and nurse have been providing valuable support to health workers via telephone calls from regional health centers regarding epilepsy management.



Sister Meron was awarded a Certificate of Appreciation on behalf of CareEpilepsy Ethiopia for providing training to nurses at Kaliti Prison.



Meron Worku conducting a teaching session at Bole Police Station.



Dr. Belin Mamo, a neurologist, providing instructions on epilepsy management at Kaliti Prison.



PUBLIC EDUCATION

This quarter, we continued our commitment to raising awareness by collaborating with Betemhired Yelmat Derjet and the Rotaract Volunteer's Organization. At Care Epilepsy Ethiopia, we firmly believe that educating the community is integral to fostering societal understanding. Our awareness programs are strategically designed to enhance knowledge about epilepsy, diminish stigma, and promote access to appropriate medical services.

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.

Furthermore, we were honored to be invited by Kality Prison to participate as guest speakers during their World Mental Health Day celebration. Our Director, Enat Yewnetu, delivered a compelling speech, emphasizing the importance of mental health awareness. Sister Meron received a certificate of appreciation on behalf of our organization for conducting three awareness sessions at the prison.

Additionally, we conducted epilepsy awareness education sessions for members of the Rotaract organization in Addis Ababa and at Bete Meheret Charity. These sessions served as a platform to engage with diverse audiences, fostering a deeper understanding of epilepsy and its impact on individuals and communities.

Our endeavors in raising awareness reflect our ongoing commitment to building a more informed and empathetic society, where epilepsy is understood, and individuals affected receive the support they deserve.



SPREADING EPILEPSY AWARENESS ACROSS DIVERSE SETTINGS

- School education was temporarily paused in the last quarter due to the three-month summer break.
- Our Teachers' Epilepsy Support Group has seen a growth in membership, and we've been actively engaging with them by providing information and addressing their questions. Additionally, we've established a team of 20 dedicated advocates to serve as valuable epilepsy resources in schools, offering them the necessary information and support to excel in their roles.



OTHER PLATFORMS

We continue to uphold our commitment to enriching our educational social media platform by sharing invaluable information about epilepsy with our community. Our media engagement efforts have been excellent, with a focus on public education through platforms like Facebook, Telegram, and Twitter. We've also made impactful appearances on television and radio presentations to further spread awareness.



THE 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, including:

Let's take a glimpse into the vibrant tapestry of activities that unfolded during the third quarter, all geared toward nurturing the wellbeing of our cherished patients:

1. Telephone Helpline: We are thrilled to share that 372 individuals successfully utilized our Helpline service, where patients received valuable information and advice, providing them with support, guidance, and a better understanding of epilepsy-related concerns. This marks a significant achievement for our outreach efforts.

2. Home Monitoring Service: We're pleased to share that 346 people with epilepsy benefited from our nurse-led home monitoring services through telephone check-ups. This initiative involved regular check-ins to monitor their seizure status, offering tailored advice to support effective management.

3. Counselling Service: 50 individuals living with epilepsy, along with their families, received one-to-one counseling support from CEE staff. Additionally, we conducted 12 group therapy sessions, providing an opportunity for them to learn about self-management and grow together.

4. Patient Support Group Meetings: We organized three patient support group meetings, providing a comforting space for 126 patients and their families to come together. During these monthly gatherings, they shared their experiences, exchanged valuable information, and offered each other mutual support.

NURTURING BONDS: Patient Support Group Meetings



EMPOWERMENT CIRCLES CareEpilepsy Group Therapy Sessions



Connecting Over Coffee: The CareCraft Social Club

5. Coffee and Chat Morning: Engaging 112 individuals in weekly coffee and chat morning sessions, where patients socialize, connect, and explore their creativity through craftwork. This initiative empowers patients with new skills and therapeutic expression, fostering relaxation and reducing stress.

6. CareCraft: We empowered 73 people with epilepsy with craft training and materials to promote creativity, therapy, and skill development. While our patients have shown a keen interest in crafting, we currently face financial limitations preventing us from buying materials for their creations.

7. Urgent Home Visits for Patients in Need. Four individuals living with epilepsy received home visits from our team and a patient representative. This reflects our commitment to providing personalized support, especially for those bedridden due to seizure-related accidents and poverty.



UNVEILING THE JOURNEY: A PATIENT'S STORY

Mr. Fikadu Demmise

I am Mr. Fikadu Demmise, and my journey with epilepsy is a powerful testament to triumph over adversity. Born in Gonder Gient town in 1973 E.C, my life took an unexpected turn when I was diagnosed with epilepsy at the age of 38. The initial shock was accompanied by physical injuries, as well as the weight of depression and hopelessness.

In February 2021, I found a beacon of hope in CareEpilepsy. Before joining, my daily life was overshadowed by frequent seizures, occurring more than once a day. However, with the support and guidance of Care Epilepsy, I began a transformative journey. Regularly taking Phenobarbital and applying the insights gained from Care Epilepsy's educational programs, I experienced a remarkable improvement in seizure control.

Attending follow-ups at Black Line Hospital became a routine that brought stability and reassurance. Embracing my role as a patient representative, I actively supported the organization that had become a lifeline for me. The benefits I gained from Care Epilepsy's services extended beyond medication; counseling played a crucial role in enhancing both my physical and emotional well-being.

In addition to my personal victories, I continue to contribute to CareEpilepsy as a patient representative, participating in various initiatives to raise awareness about epilepsy. On a professional note, I am employed as a Construction Assistant, and I take immense pride in being a devoted husband and a father of three.

This success story is a collective journey of overcoming challenges, advocating for quality medical care, and embracing life with epilepsy. I stand as a living testament to resilience, demonstrating that with unwavering support, determination, and the right resources, individuals with epilepsy can not only navigate life's challenges but also thrive.



MINISTRY OF HEALTH COMMENDS PROGRESS IN EPILEPSY CARE

*Sofia Seid and Jemal Teshome from the
Ministry of Health's Mental Health Unit*

Following the visit from the Ministry of Health to review our progress, we are pleased to report that it was a fruitful and constructive discussion. They expressed appreciation for the strides we've made in epilepsy care and community support. Looking forward to continuing our collaborative efforts in advancing healthcare initiatives.



Tips for Nurturing Your Mental Health



**WELLBEING
HUB**

Life thrives on balance, doesn't it? Let's strive for that harmonious equilibrium between embracing our active lifestyles and nurturing our mental well-being. Regardless of whether epilepsy is part of our journey, deriving happiness from our engagement in meaningful relationships is a wonderful avenue to uplift our spirits and experience greater fulfillment.

Tips for maintaining good mental health: Prioritize self-care, stay connected with friends, limit stress, get enough sleep, seek support, practice gratitude, engage in physical activity, embrace hobbies and avoid substance abuse.



EMPOWERING CHANGE: MEET OUR DYNAMIC YOUTH VOLUNTEERS

I'm Dagmawi Shimeles (the person receiving an award in the picture), a 3rd-year medical student at Lorcan Medical College. As a volunteer for CareEpilepsy Ethiopia, I've had the incredible opportunity to raise epilepsy awareness among elementary and high school students, patients, and their families at hospitals and health centers. Alongside neurologists, I actively participate in monthly follow-up programs and have co-hosted an epilepsy awareness event in collaboration with CareEpilepsy Ethiopia at our college.

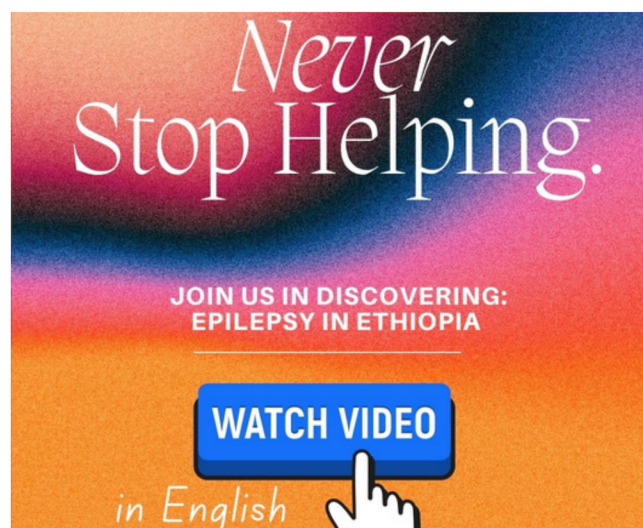
Recently, I took on the role of the main coordinator for the summer of 2023 volunteering program. This experience has been truly enriching and enlightening. The warm and welcoming support from the staff, especially Sister Meron, has been heartwarming. Working closely with some of the finest neurologists in our country and interacting with patients, each with their unique stories of bravery, has been an incredibly humbling experience.

Through this journey, I've learned far beyond what any textbook could teach about epilepsy and its profound impact on the lives of patients, families, and communities. I've become keenly aware of the prevalence of epilepsy and the lack of knowledge and stigmatization surrounding it in society. Above all, I've come to realize the incredible power of volunteerism and the positive changes we can bring to the lives of so many citizens through CareEpilepsy Ethiopia. Our volunteers, like myself, play a pivotal role in cultivating a compassionate and understanding community for those living with epilepsy.

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

Ruth Tilahun, our Administrative Officer

Introducing Ruth Tilahun, our Administrative Officer, originally from Gonder. Holding a Bachelor's Degree in Computer Science, Ruth joined Care Epilepsy Ethiopia three months ago, overseeing administrative operations. She actively engages in epilepsy education, campaigns, programs, and volunteer coordination. Ruth expresses her joy in contributing to the unique organization dedicated to epilepsy in Ethiopia, stating, "Being part of the only organization for people with epilepsy in Ethiopia makes me happy. I am delighted to serve those in need of our help." Ruth values the familial atmosphere at Care Epilepsy, where every employee is considered a part of a close-knit family. Her time here has not only contributed to her professional growth but also deepened her commitment to supporting those affected by epilepsy. Ruth resides with her family, finding fulfillment in both her personal and professional life.

Ruth dedicated the last quarter to skillfully managing the administrative aspects of the IBE Africa Regional Epilepsy Conference in November 2024. She adeptly navigated challenges related to immigration and logistics, showcasing her resourcefulness in overcoming these obstacles to ensure the success of this significant event.



Championing Change: Empowered Young Women for Epilepsy 2024

CareEpilepsy Ethiopia had the privilege of participating in the Africa Champions for Epilepsy project, run by the International Bureau of Epilepsy, a significant initiative addressing the stigma faced by women with epilepsy in Africa. In Ethiopia, where misconceptions and stigma surrounding epilepsy persist, the project sought to empower young women as advocates, fostering greater acceptance and understanding within society.

The project successfully empowered 20 young women to become effective champions against epilepsy stigma. Through tailored interventions, these women gained a comprehensive understanding of the clinical aspects of their conditions. Embracing their identities as individuals living with epilepsy, they developed newfound confidence in openly discussing their experiences. This empowerment extended beyond awareness to active management of their health, fostering a sense of agency and control over their well-being.

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The project's efforts led to a significant elevation in awareness about epilepsy, resulting in a tangible reduction in stigma and improved social integration.

The increased knowledge among the young women not only eradicated personal stigma but also positively impacted their mental well-being. Dedicated sessions for families played a crucial role in creating a supportive environment, fostering understanding, and equipping them to provide effective support to their daughters, sisters, and relatives. The creation of short, informative videos further contributed to spreading awareness and knowledge about epilepsy in the community.

By empowering young women and fostering awareness, understanding, and acceptance, the project aligns with the overarching goal of IGAP in creating a community where every individual, regardless of their epilepsy diagnosis, can thrive and be embraced for who they are.



BUILDING BRIDGES: OUR VALUED PARTNERS

The Association of Ethiopian Neurologists serves as a vital hub for collaborative efforts among dedicated neurologists, clinicians, and healthcare professionals. With a mission to enhance neurological care, the association facilitates knowledge-sharing, conducts public awareness campaigns, and advocates for improved healthcare policies. Through regular meetings, conferences, and research initiatives, it strives to elevate the standards of neurological care in Ethiopia, contributing to a healthier society.

The Association is a cornerstone in advancing CareEpilepsy Ethiopia's clinical program, which happens to align closely with CareEpilepsy Ethiopia's mission and vision. They actively contribute to our cause. Engaging in free clinical care, providing training for healthcare professionals, and acting as educators and media advocates play an integral role in raising epilepsy awareness within our community.

Their unwavering support, dedication, and responsiveness make them an indispensable partner. Working hand in hand, we take pride in our collaboration, knowing that the association stands resolute in meeting the needs of our shared mission.



OUR GREAT HEROES *Dr. Blen Mamo*



Dr. Blen Mamo completed her training at Addis Ababa University Health Science College in Ethiopia. She earned her second degree in adult neurology after obtaining a doctorate from Gonder University, the sole institution in the country offering specialized training in Neurology Discipline.

With a wealth of experience acquired from working at various hospitals, Dr. Blen Mamo currently serves at Amaneul Hospital and Yehuleshet Specialty Clinic. Her journey with Care Epilepsy Ethiopia began when she discovered the organization during an exhibition bazaar, where she passionately joined the team there and raised awareness among attendees.

Driven by her commitment to the field since her undergraduate studies, Dr Blen joined the neuro resident program at Amaneul Hospital. Witnessing the psychosocial impact of treating 90 to 100 epilepsy patients daily, she has dedicated herself to our cause for the past year.

As a volunteer neurologist at our free outpatient clinic for epilepsy patients, Dr. Blen Mamo extends her service beyond expectations. Her commitment also involves seeing patients free of charge and providing training to nurses and health officers through CareEpilepsy Ethiopia's clinical training program. Her spirit of service and tireless efforts significantly contribute to the success of our programs. Dr. Blen Mamo reflects, "I'm more satisfied than anything when I get to work on and express my passion and provide a free service for my community."

We sincerely thank Dr. Blen Mamo for her selfless service and invaluable contributions to our mission.



ACKNOWLEDGEMENTS

»»» THANK YOU

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 Geneva
- Friends of CareEpilepsy in Atlanta
- ILAE Geneva

CareEpilepsy Ethiopia works with the most marginalised children, women and men who face barriers to getting the education and employment they deserve. At CareEpilepsy, 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.

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

LOOKING TO TALK TO SOMEONE?

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.

»»» WAYS TO SUPPORT US

Give online

www.careepilepsyethiopia.org/donate

Ethiopia

CareEpilepsy Ethiopia

Account Number: 1000161849166

COMMERCIAL BANK OF ETHIOPIA

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

