

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

TOP NEWS OF THE QUARTER

- Thanksgiving Event: Our annual celebration honored supporters, with special recognition for our dedicated neurologists.
- Inspiring Patient Triumph: Soliana Jembola's remarkable journey showcases the life-changing impact of our support for epilepsy patients.
- Africa Epilepsy Conference Prep: We're preparing for the Africa Epilepsy Conference in November 2023, a significant milestone for epilepsy care and awareness.
- Education Initiatives: We're strengthening epilepsy education by placing advocates in schools and hosting joint teaching sessions for patients and their families.
- Training Healthcare Professionals: Our efforts to train more nurses and health officers in epilepsy care are gaining momentum.
- Public Awareness Drive: Increasing public education is breaking the stigma and misperceptions surrounding epilepsy, encouraging more individuals to seek medical help.
- Expanding Outreach: Our network of partner organizations is growing, bolstering our advocacy efforts and policy influence.

These highlights underscore our dedication to saving lives and changing perceptions. Thank you for your unwavering support.

CEO MESSAGE: REFLECTING ON GROWTH AND ACHIEVEMENTS

Dear CareEpilepsy Community,

I am delighted to welcome you to our 3rd Quarter Newsletter, a platform that keeps us connected and engaged with the remarkable work being done to support people living with epilepsy. This quarter has witnessed significant progress in our mission to enhance lives and transform perceptions.

We informed you in our previous newsletter that Ethiopia will host the Africa Epilepsy Conference from November 20-21, 2023. This quarter, planning and organizing the conference have gained momentum, thanks to collaborative efforts with regional teams. We will provide you with updates on the outcomes in our upcoming newsletter.

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.

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

Regrettably, I must bring a crucial matter to your notice. Currently, our organization is grappling with a significant funding challenge that may necessitate the closure of our services. Maintaining our commitment to providing care is at risk unless we receive much-needed financial support. We sincerely appreciate any assistance you can offer or any guidance you can provide on potential sources of financial support.

Thank you for being an essential part of our journey. Let's persist in our efforts to save lives and change perceptions, one step at a time.

Warm regards,

Enat Yewnetu CEO, CareEpilepsy Ethiopia







CLINICAL SERVICES

In the third guarter of 2023, we are excited to share our significant accomplishments:

Thanks to the unwavering commitment of our volunteer neurologists, health officer, and nurse, we have achieved the following milestones:

- Twenty individuals living with epilepsy were referred to their nearest health centers to make use of government services and ensure continuity of
- Provided care to 138 patients who visited our nurseled epilepsy and health promotion clinic.
- Conducted three monthly neurologist-led epilepsy clinics at the CareEpilepsy Clinic Center.
- Extended medical care to 59 adult patients through our free community clinic.
- Provided essential medical care to 125 children through our free community clinic.
- Supported 360 patients by covering their transportation costs, ensuring they could attend clinic appointments and patient support group meetings.
- Engaged 11 volunteer neurologists in our clinical operations, with two neurologists responsible for interpreting EEG diagnostic results.

In addition to these accomplishments:

- We supported 193 individuals with epilepsy (PWE) by providing medication and financial assistance to purchase anti-seizure medication.
- We are actively engaging in discussions with stakeholders to obtain a license for importing antiseizure medication.

Moreover:

- We offered EEG services to 51 individuals with epilepsy.
- Our services now include MRI access for 11 individuals with epilepsy (PWE).
- These achievements underscore our unwavering commitment to improving the lives of those affected by epilepsy and expanding access to essential healthcare services. We take immense pride in the progress made during the second quarter and remain wholeheartedly dedicated to our mission.

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.



Meron Worku teaching at Bole Police Station





Sister Meron Providing Epilepsy Training at Mekedonia Humanitarian Association for Nurses



Dr. Belin Mamo, Neurologist Instructing on Epilepsy Management at Kaliti Prison

PUBLIC EDUCATION

Our incredible youth volunteers dedicated their time at Morning Star Mall and on the streets to educate people about epilepsy as part of our awareness-raising program.

They successfully reached over 10,000 individuals, spreading valuable awareness about epilepsy. Their efforts were truly commendable, and we're incredibly proud of their work.

Raising awareness about epilepsy campaigns has also been a highlight of the quarter. Our fantastic team member, Abiy, who manages our administration and finances, worked his magic and secured a free space for CareEpilepsy at Millennium Hall in Addis Ababa. This coincided with the Century Promotion Exhibition Program, a two-week event in September 2024, which included a bustling business trade show attended by a diverse crowd. It presented a wonderful opportunity to educate people about epilepsy, and we distributed informative flyers for educational purposes. We were thrilled to have the chance to engage with the public and spread awareness about epilepsy. Our heartfelt thanks go to the organizers Barok Event Coordinator and Century Promotion for their generous support.

We needed to print and distribute epilepsy education materials, including Epilepsy Information Leaflets and posters, to raise awareness about epilepsy. Regrettably, budget constraints hindered us from carrying out this initiative as planned.



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.



RAISING AWARENESS AT KALITY PRISON

We had a great time hosting over 10 engaging education sessions for health institution attendees, all packed with lively epilepsy awareness discussions!

OTHER PLATFORMS

<u>Morning Star mall shoe shineing for epilepsy</u>





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 home monitoring services 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 information, and offered each other mutual support.

SPREADING SMILES AND **SUPPORT:**

A Delightful Visit to CareEpilepsy Ethiopia



NURTURING BONDS:

Patient Support Group Led by Kibrom Sahele



CONNECTING OVER COFFEE:

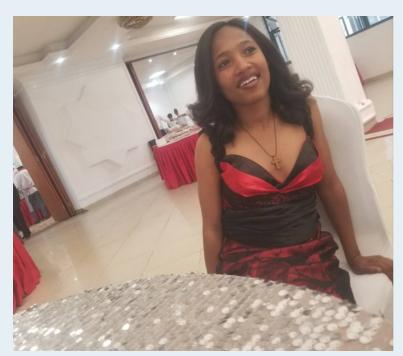
The CareCraft Social Club

- 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.

A Delightful Visit to CareEpilepsy Ethiopia

During this quarter, we were delighted to host Senait Fitwe from Canada at the CareEpilepsy Center. She dedicated a substantial amount of time to meet with our team and discuss our work. Senator Fitwe has been a long-time supporter of our organization, and she expressed her pride and admiration for the extent of our services. Her visit encouraged us to persist in our efforts. We extend our gratitude for taking the time from her holiday to visit our work.





UNVEILING THE JOURNEY: A PATIENT'S STORY

Soliana Jembola



Soliana Jembola is a remarkable young woman whose journey with epilepsy has been one of resilience and hope. Diagnosed with epilepsy at the tender age of 14, Soliana's life took an unexpected turn. Her mother, desperate to find a solution, sought medical help, but despite their efforts, her seizures remained uncontrolled. Frustrated and in search of answers, Soliana's mother turned to her faith, hoping that holy water and prayers would bring her daughter relief.

It was a radio broadcast that would change the course of Soliana's life. She heard about CareEpilepsy's invaluable work, and it sparked a glimmer of hope. Determined to find the treatment, medication, and support she needed, Soliana reached out to us.

Under the care of our dedicated neurologists, Soliana's journey began to take a turn for the better. Through their expertise and guidance, her seizures were brought under control, and a sense of normalcy returned to her life. Most significantly, Soliana was able to rejoin her education and continue her schooling.

Her determination and hard work paid off when she successfully completed her 12th-grade school leaving exam in Ethiopia with flying colors. Soliana's dreams and aspirations are once again within her reach, and she looks forward to a brighter future.

During one of our support group meetings, Soliana stood before the attendees and expressed her gratitude, saying, "I can only thank you for what you have done for me." Her story is a testament to the transformative impact of CareEpilepsy, saving lives and providing renewed hope for a better tomorrow. Soliana's journey is a powerful reminder that with the right support and care, individuals with epilepsy can overcome challenges and achieve their dreams.

TIPS FOR NURTURING YOUR MENTAL HEALTH



Life is all about balance, right? So, let's strike that perfect balance between living active lives and caring for our mental wellbeing. Whether you have epilepsy or not, finding joy in our leisure activities is a fantastic way to uplift our spirits and feel more fulfilled.

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.

07/11



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





VOLUME #3

MEET OUR STAFF

Right to Left: Birhan Habte, Abiy Asrat, Enat Yewnetu, Meron Shemelis





The CareEpilepsy Ethiopia staff is a diverse and dynamic team, each member contributing a unique character and skill set that enriches our organization's work. Enat, our CEO, is a force to be reckoned with, driven to get things done efficiently and effectively. Abiy, always looking at the bigger picture, ensures meticulous financial management, insisting on receipts for all expenditures-our ongoing office joke. Meron, a caring and detail-oriented individual, takes the time to listen to and assess patients, forming strong bonds with our dedicated volunteers who even surprised her with a heartfelt gift. Birhane is the embodiment of energy, tirelessly managing

Right to Left: Hirut , Birhan Habte

external payments, handling correspondence, supporting clinical work, and spearheading awareness campaigns. Hirute, our caretaker, covers all bases, ensuring nothing falls through the cracks. Kibrom, our patient representative and media coordinator, is a wellspring of brilliant ideas, though they often come with a price tag. His sense of humor and wit brighten up the office. Together, this team forms a beautiful, woven quilt of diverse characters, essential to our collaborative work as a team and as individuals, creating a harmonious blend of talents that significantly contributes to our mission.

The CareEpilepsy Ethiopia staff shares a profound sense of privilege in their roles within the field of epilepsy. They understand that they are not just working a job; they are leading a movement that carries historical significance. With a deep commitment to making a difference, they recognize that there is no other organization quite like ours when it comes to raising awareness and delivering programs for epilepsy. This uniqueness is something they not only acknowledge but also cherish. The staff takes immense pride in the knowledge that their collective efforts are transforming lives, offering hope, and making a lasting impact on people living with epilepsy. It's this sense of privilege, the opportunity to drive change and bring about historical progress, that motivates and unites the team in their shared mission.

Thank You



BUILDING BRIDGES: OUR VALUED PARTNERS

- Maintained collaboration with Addis Ababa Health Bureau, the Ministry of Health, the Association of Ethiopian Neurologists, various Addis Ababa sub-cities, and tertiary referral hospitals, focusing on epilepsy initiatives.
- During our annual Thanksgiving program held on September 30, 2023, we had the honor of recognizing some exceptional individuals who have made a significant impact on our work. Dr. Mehila Zebenigus and Dr. Kindu Woldemichael, our esteemed senior neurologists, were presented with the "Top Hero of the Year" award for their outstanding contributions. Additionally, our dedicated young neurologists, as well as partner organizations, received certificates of appreciation from us in recognition of their valuable support and commitment to our cause.



OUR GREAT HEROES

Dr. Endayen Deginet

Dr. Endayen is a vital part of Saint Paul Hospital and Yehulueshet Clinic, dedicated to serving young patients in Addis Ababa. His compassion extends beyond the hospital walls - he volunteers countless hours at CareEpilepsy Ethiopia, helping children with epilepsy.

Dr. Endayen consistently goes above and beyond, seeing each child as a unique and precious soul deserving of the best care. Parents not only commend his medical knowledge but also his ability to calm fears and bring smiles to their children's faces during illness.

With a warm smile, he introduces himself, saying, "I'm Dr. Endayen Deginet, a father of two hilarious kids, Luna, a one-year-old bundle of joy, and Eyuel, my sixyear-old little adventurer."

Dr. Endayen's life is a beautiful balance of dedicated fatherhood and selfless healing. His story illustrates that making a real difference in the lives of those in need, even when your own family waits at home in a world where life can be financially challenging, is possible.

He is a beacon of hope for patients and a beloved friend to our staff. In the bustling city, Dr. Endayen's story reminds us that heroes exist among us, shaping the world quietly with their love, one child at a time.

Thank you, Dr. Endayen.







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

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.

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.

>>>

WAYS TO SUPPORT US

Give online www.careepilepsyethiopia.org/donate

Ethiopia

CareEpilepsy Ethiopia

Account Number: 1000161849166 COMMERCIAL BANK OF ETHIOPIA

SAVING LIVES IS BETTER TOGETHER!

DONATE

Our Address in Addis Ababa:

Next to

Denberwa Maternal and Child Health

поѕрітаї

Yeka Sub-City

Woreda 08, House No. 897, Addis Ababa

+251 11 669 4455 OR + 251 97 526 4121 + WHATSAPP +447596817212 "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.



