

# IN THE LOOP



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## TOP NEWS OF THE QUARTER!

- Ethiopia is set to host the highly anticipated 2023 Epilepsy Africa Congress, proudly organized by the International Bureau of Epilepsy. Our team has been buzzing with excitement as we dive into discussions with the incredible Mr Amos Action, the Vice President of the International Bureau of Epilepsy-Africa, to meticulously plan all the thrilling logistics that will make this event truly unforgettable!
- We are fortunate to have supportive partners like the Garbet Tehadiso Mahber Rehabilitation Center and the Ethiopian Human Rights Commission (EHRC). They contribute to raising awareness about epilepsy, expanding clinical care, and advocating for the rights of affected individuals. Together, we are making significant strides in improving lives and fostering a supportive community.
- Nurse Meron Semeles: Passionate Advocate for Epilepsy Wellbeing. With extensive qualifications in Nursing and Public Health Nutrition, Meron excels as a Community Outreach Nurse at CareEpilepsy Ethiopia, dedicating herself to enhancing the lives of individuals affected by epilepsy through diverse initiatives.
- Neurologists at the Forefront: Providing Expert Care to Patients

# MESSAGE FROM THE CEO

Dear CareEpilepsy Ethiopia Community,

I hope this message finds you all in good health and high spirits.

At CareEpilepsy Ethiopia, our mission has always been clear: to provide comprehensive clinical care, foster public education about epilepsy, promote wellbeing, and build strong partnerships to expand our work. Over the first quarter, we have continued to make significant progress in our mission to make a real difference in the lives of people affected by epilepsy.

Our clinical care services continue to grow, ensuring that individuals living with epilepsy receive the best possible medical attention and support. We've built a squad of national and international skilled healthcare heroes who aren't just experts but also caring and understanding. In addition to our clinical work, education remains a core pillar of our work. Through the organization of public awareness campaigns, informative workshops, and epilepsy training sessions, our efforts have successfully contributed to the eradication of misconceptions surrounding epilepsy and fostered the development of a more inclusive and empathetic society.

Our commitment to overall wellbeing extends beyond medical treatment. We offer counseling services for individuals to explore their thoughts and emotions in a supportive environment. Our group therapy sessions provide connection and understanding among participants. Our crafts training program fosters creativity and self-esteem. Lastly, our "Coffee Morning for Epilepsy" event brings patients together to socialize and build lasting friendships, combating loneliness.

Notably, our remarkable accomplishments would not have been possible without the invaluable partnerships we have forged along our journey, including esteemed partners such as the Ethiopian Public Health Institution, the Association of Ethiopian Neurologists, our dedicated youth volunteers, and the Garbet Tehadiso Mahber Rehabilitation Center, just to name a few.

On another somber note, it is disheartening to mention that despite our dedicated efforts, we are still facing challenges in securing the necessary financial resources for our epilepsy work. As we navigate the demanding path of conquering substantial financial hurdles, I find myself deeply disheartened by the overwhelming responsibility of maintaining our center and retaining our devoted staff. As the CEO, there are times when the fatigue sets in, and being a beacon of hope feels utterly exhausting.

Inspired by the timeless words of Martin Luther King, Jr., who urged us to embrace infinite hope amidst infinite disappointment, I embark on the journey ahead with unwavering optimism and boundless enthusiasm to further enhance our services and create a world where epilepsy is not a barrier but an opportunity for growth, support, and understanding. I invite each and every one of you to join us on this journey. Whether through volunteering, making a donation, or spreading awareness, your contribution will make a lasting impact.

We express heartfelt gratitude to those who support us, unwavering in their commitment and belief in our mission. To everyone, we extend an invitation to consider volunteering your time and expertise to support our cause. We are currently seeking dedicated individuals who can contribute to event planning, social media and PR work, and fundraising efforts. Your involvement will have a profound impact on expanding our reach and making a difference. Together, we can amplify our advocacy and bring about positive change for those affected by epilepsy.

With warmest regards,

Enat Yewnetu  
CEO, CareEpilepsy Ethiopia



## CLINICAL SERVICES

- Thanks to our dedicated clinical staff, volunteer neurologists, psychiatrists, and nurses, we conducted over 258 consultations, addressing a wide range of epilepsy and associated health concerns and providing personalized treatment plans during the first quarter of 2023.
- 64 children and 74 adults with epilepsy received specialist care from our neurologists.
- 140 patients received were seen by our health officer at our nurse-led epilepsy and health promotion clinic.
- 10 volunteer neurologists participated in our clinic and EEG reading
- Emergency anti-epileptic medication and financial support to purchase medication was given to 171 patients.
- We have also continued to give home monitoring services to 290 patients to enhance the accessibility of care, allowing patients to consult with our clinical staff remotely.
- We have seen a surge in Neurologist Engagement: Boosting Training and Clinic Support.
- Implemented electronic health records to enhance efficiency and provide seamless continuity of care for our patients.
- Received positive feedback from patients regarding the compassionate and patient-centered approach of our healthcare providers.

## NEUROLOGISTS AT THE FOREFRONT: PROVIDING EXPERT CARE TO PATIENTS



## DIAGNOSTIC SERVICES

- 128 patients received medication and financial support to purchase anti-seizure medication.
- Ongoing discussion with stakeholders to get a license to import anti-seizure medication.
- 22 patient with epilepsy was covered health insurance.

We are delighted with our accomplishments, but we still need to increase the service compared to the need.



## PUBLIC EDUCATION

We believe that education is a powerful tool for reducing the stigma associated with epilepsy and empowering individuals to receive medical care. To that end, we have organized several educational workshops and seminars during the past quarter, focusing on a wide range of topics such as preventive healthcare, healthy lifestyles, mental health awareness, and disease management. Here are some key initiatives we have undertaken in the realm of public education:

### RAISING AWARENESS AT WORKPLACE

The visit by the Careepilepsy team to Bete Mehret Yelemat Derejet, where they educated staff about epilepsy and epilepsy first aid, was well-received with active participation from 28 staff members in the discussions.



### EPILEPSY EDUCATION AT SCHOOLS

In the first quarter, we worked together with local schools to deliver engaging epilepsy education sessions for children and adolescents. These sessions focused on important topics such as facts about epilepsy, seizure triggers, and seizure first aid. Here are the highlights of our accomplishments:

- We successfully raised epilepsy awareness among 17,683 students across 13 schools.
- Additionally, we established an online teachers' support group facilitated by CareEpilepsy staff. This platform serves as a valuable resource for educators, providing them with information about epilepsy and offering any necessary support. Currently, we have 45 members actively participating in this group.

### OTHER PLATFORMS

- We conducted six education sessions across six health centers, with a total of 1,815 community members attending our teaching sessions.
- Created an educational social media platform aimed at disseminating epilepsy-related information.



- A total of 4,000 leaflets and 400 posters were distributed to promote epilepsy education.

# CLINICAL TRAINING

Through initiatives like this training program, the aim is to bridge the gap in epilepsy care by increasing the number of healthcare professionals trained in its management. By expanding the expertise of primary healthcare workers, more individuals living with epilepsy can receive timely and accurate diagnoses, proper treatment, and the necessary support to manage their condition effectively. This training initiative represents a crucial step towards improving the overall quality of epilepsy care and positively impacting the lives of patients in the community.



# CAMPAIGN

## International Epilepsy Day & the 8th National Epilepsy Week

Celebrating International Epilepsy Day and organizing the 8th National Epilepsy Week with the theme "End Stigma" was an opportunity to educate the public, healthcare professionals, and policymakers about epilepsy, its impact on individuals' lives, and the importance of ending the stigma associated with the condition. Such initiatives contribute to creating a more inclusive and supportive society for people with epilepsy. Collaborating with the Association of Ethiopian Neurologists, Ethiopian Public Health Institute, and Ethiopian Human Rights Commission further highlights the significance of the event and the comprehensive approach taken to address epilepsy-related issues.

# MEDIA

During national epilepsy week, a press conference was given by Ms Enat Yewnetu (CEO CareEpilepsy Ethiopia), Dr Yared Zenebe (Neurologist) and Ms Rigbe Gebrehawaria Hagos (Commissioner for Disability Rights and the Rights of Older Persons, and Dr Beza Addis, Advisor to the Director General, Ethiopian Public Health Institute. Overall, the participation of these distinguished individuals in presenting a press release during the National Epilepsy Week conference highlights the importance of collaboration, knowledge sharing, and advocacy in addressing epilepsy-related challenges in Ethiopia. It reinforces the commitment to creating a more inclusive and supportive environment for individuals with epilepsy while raising awareness at a national level.



Enat Yewnetu



Dr Beza Addis



Dr Yared Zenebe



Rigbe Gebrehawaria

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:

### Patient Support Group Meeting



### Craft Work



## THE WELLBEING OF OUR PATIENTS



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

- 1. Telephone Helpline:** 101 patients received information and advice through the helpline. This service likely helped them address their concerns, obtain guidance, and better understand epilepsy-related issues.
- 2. Home Monitoring Service:** 136 patients benefited from the nurse-led home monitoring service. This service involved regular check-ins to monitor their seizure status and provide further advice on managing their condition.
- 3. Coffee and Chat Morning:** 67 individuals attended the weekly coffee and chat morning sessions. This initiative provided an opportunity for patients to socialize, connect with others who share similar experiences, and participate in craftwork. By providing the training and raw materials for craftwork, we are not only fostering creativity but also empowering patients to develop new skills. Engaging in creative endeavors can serve as a form of therapy, allowing patients to express themselves, enhance their cognitive skills, and promote relaxation and stress reduction.
- 4. Patient Support Group Meetings:** 185 patients and their families attended the monthly support group meetings. These gatherings offer a supportive environment where attendees can share their experiences, exchange information, and provide mutual support.
- 5. Counselling Service:** 72 individuals made use of the counselling service. Living with epilepsy can bring various emotional and psychological challenges, and our professional counselling is instrumental in alleviating their burden and learning effective strategies for managing stress.

We couldn't be prouder of CareEpilepsy Ethiopia's exceptional wellbeing initiatives, showcasing a truly comprehensive approach to supporting individuals with epilepsy. Through the provision of vital information, diligent monitoring, engaging social activities, invaluable peer support, and dedicated counseling services, our organization is making an undeniable positive impact on the lives of those affected by epilepsy in Ethiopia. Together, we are driving meaningful change and transforming the epilepsy landscape.



## UNVEILING THE JOURNEY: A PATIENT'S STORY

### *Jemila Asefa*

Jemila Asefa, from Semera, Afar, has endured a challenging journey with epilepsy. Her diagnosis came unexpectedly at the age of 15, during the funeral of her mother. In her quest for treatment, Jemila sought assistance from traditional healers and spiritual practitioners, hoping to find relief from her seizures. Unfortunately, her struggle continued, and she experienced a devastating burn injury when she fell into an open fire during a seizure. It was during this difficult period that she first learned about CareEpilepsy through a radio broadcast. Determined to seek help, Jemila embarked on a journey from Semera to Addis Ababa (592km) in search of treatment.

Upon arriving at CareEpilepsy, Jemila received comprehensive medical care, vital medications, and the much-needed counseling support she had long awaited. After enduring a decade of seizures, this marked a turning point in her life. However, challenges remained, particularly in accessing the medication and follow-up care essential for her well-being.

Jemila's story is a testament to the life-saving impact of your charity, CareEpilepsy Ethiopia.

## MEET OUR STAFF

### *Sr Meron Shimelesh*

Nurse Meron Shemeles is an exemplary staff driven by her passion for improving the wellbeing of people with epilepsy. With a Bachelor's degree in Nursing and a Master's degree in Public Health Nutrition, she brings a wealth of knowledge and expertise to her current role as a Community Outreach Nurse at CareEpilepsy Ethiopia. Having joined the organization five months ago, Meron has quickly embraced her responsibilities, which encompass a wide range of tasks aimed at positively impacting the lives of individuals living with epilepsy. From raising awareness to providing support at epilepsy clinics, offering counseling services to patients and their families facing physiological and social challenges, to organizing community education initiatives in health centers, hospitals, schools, and various institutions.

In her own words, Meron says, "I am committed to creating a lasting difference. I consider myself fortunate to be part of the only organization in Ethiopia dedicated to serving people with epilepsy. It's an honor to contribute my knowledge and skills to this amazing cause."

We extend a warm welcome to Sister Meron.





# EMPOWERING CHANGE: MEET OUR DYNAMIC YOUTH VOLUNTEERS

Our dedicated volunteers played a pivotal role in our organization's efforts to raise awareness about epilepsy, particularly during the national epilepsy week. With unwavering commitment and passion, they actively participated in an array of awareness-raising programs, aiming to educate the community about epilepsy and combat the stigma associated with the condition. Through their tireless efforts, our volunteers ensured that crucial information reached a wide audience, fostering empathy and understanding. Moreover, these exceptional individuals provided invaluable administrative support to our clinical training initiatives, enabling our healthcare professionals to focus on delivering the highest standard of care to epilepsy patients. Their dedication and energy have been instrumental in advancing our mission, and we are grateful for their contribution.

# BUILDING BRIDGES: OUR VALUED PARTNERS

- We are fortunate to have supportive partners like the Garbet Tehadiso Mahber Rehabilitation Center and the Ethiopian Human Rights Commission (EHRC). They contribute to raising awareness about epilepsy, expanding clinical care, and advocating for the rights of affected individuals. Together, we are making significant strides in improving lives and fostering a supportive community.
- Ethiopia is set to host the highly anticipated 2023 Epilepsy Africa Congress, proudly organized by the International Bureau of Epilepsy. Our team has been buzzing with excitement as we dive into discussions with the incredible Mr Amos Action, the Vice President of the International Bureau of Epilepsy-Africa, to meticulously plan all the thrilling logistics that will make this event truly unforgettable!
- It was an absolute joy to have Yayeneabeba, the founder of the Friends of CareEpilepsy Canada team, grace our conference on International Epilepsy Day. She and her team have been an unwavering pillar of support, standing by our side with relentless encouragement and financial backing.
- Our collaboration with the Association of Ethiopian Neurologists has been instrumental in providing training and clinical care for our patients and nurses, enabling them to deliver the best possible epilepsy care.



Garbet Tehadiso Mahber  
Rehabilitation Center



Yayeneabeba - CareEpilepsy  
Friends in Canada



## Marakesh Experience

Enat Yewnetu's attendance at the First African Brain Week, held from 14th to 18th February 2023 at the esteemed Palm Plaza Hotel in Marrakesh, proved to be an exceptional opportunity for engaging with professionals and organizations dedicated to advancing epilepsy care and support. The event served as a platform to bring together renowned experts, researchers, and advocates from across the African continent to discuss various neurological disorders, including epilepsy.



## OUR GREAT HEROES

*Sherard and Sheila Wilson*

Sherard and Sheila Wilson's journey with CareEpilepsy is deeply intertwined with their connection to Ethiopia, where they served as missionaries 55 years ago. Their first encounter with Enat Yewnetu, Founder of CareEpilepsy, occurred three decades ago, marking the beginning of a profound friendship. The Wilsons are the epitome of selfless dedication and unwavering support, playing an instrumental role in transforming the vision of Enat Yewnetu into a tangible reality. Their commitment has gone beyond mere fundraising and administration work required to run the charity; they have wholeheartedly invested their own resources, time, and energy into the cause. However, it is their empathy and comforting presence that have truly made a profound impact for Enat to enable her to continue to lead the charity. Words alone cannot express the depth of gratitude we hold for their immeasurable contributions. Their compassion and steadfast belief in our cause have propelled CareEpilepsy forward, igniting hope and changing lives. Their legacy will forever be engraved in the annals of CareEpilepsy, and we are profoundly grateful for their enduring support and dedication.

## FACTS CORNER:

***NEVER force something into the mouth of someone having a seizure.***

It is physically impossible to swallow one's tongue, and using objects like a wooden spoon or wallet as a "bite block" can cause serious injuries.

During a convulsive seizure, an individual may temporarily stop breathing and their skin may turn blue. This is primarily due to the stiffening of the diaphragm and other respiratory muscles during the seizure, which hampers the normal breathing process.

This is normal and brief, and the person will start breathing normally again as soon as their muscles relax. Do not attempt mouth-to-mouth or CPR during a convulsive seizure. Positioning the person on their side with their mouth pointed downward is the best way to keep their airway open.

## WELLBEING HUB



*Tips to for Better Sleep*

For people with epilepsy, anxiety can disrupt sleep, affecting its quality and duration. Lack of sleep can trigger seizures.

**Tips for better sleep:** Stick to a sleep routine, avoid daytime naps, go for walks, disconnect from devices before bed, and avoid eating or drinking near bedtime.



Epilepsy knows no discrimination; it can manifest in individuals of any age or background.

# 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 and other governmental and private organizations
- The Association of Ethiopian Neurologists for their in-kind donations of service
- Commercial Bank of Ethiopia
- Tracon Trading
- Adulin Coffee Exporter
- Mulege PLC
- Woudase Diagnostic Service
- Friends of CareEpilepsy in Atlanta

CareEpilepsy 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!**

**DONATE**

Next to  
Denberwa Maternal and Child Health Hospital  
Togo Street  
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Woreda 08, House No. 897  
Addis Ababa

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

## »»» WAYS TO SUPPORT US

### Give online

<https://www.careepilepsyethiopia.org/donate>

### Ethiopia

CareEpilepsy Ethiopia  
Account Number: 1000161849166  
COMMERCIAL BANK OF ETHIOPIA

### UK

UK Bank Name - HSBC  
Account Number: 11621491  
Sort code: 40-07-27  
SWIFTBIC: HBUKGB4143G  
IBAN: GB51HBUK40072711621491

You can make a Direct Debit or a one-off payment to HSBC Bank.

— ” —

"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

