

IN THE LOOP

Quarterly
E-Newsletter #4/2022
(October-December)

CareEpilepsy Ethiopia Saving Lives | Changing Perceptions

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Dear friends,

We started the year by processing a license to begin operating our epilepsy clinic, which we successfully registered in line with the many requirements that needed to be met, such as moving to a bigger and more accessible premises and having a dedicated health officer to run the clinic. The new premises have helped us deliver our clinical, diagnostic, and psychological services efficiently. I have witnessed the difference it has made to our patients and staff first-hand. But covering the cost of rent has been a genuine challenge, eating deeply into our reserves. In addition, we faced a shortage of anti-seizure medication throughout the year. We are grateful to the ROW Foundation, who kindly donated Lamotrigine and Keppra.

In February, we celebrated the yearly anticipated International Epilepsy Day, followed by National Epilepsy Week. This week-long program included raising awareness at schools, health centres, press conferences, and training for school nurses and teachers. We also participated in celebrating Africa Epilepsy Week in September.

CareEpilepsy Ethiopia continues to be considered a hub for information and support within our country. As a result, there has been an increase in our service uptake by regional hospitals and centres.

I am delighted to announce the growth in engagement of our national and international partners. We have been discussing strategies to collaboratively improve our epilepsy services, raise awareness about epilepsy and gain advocacy platforms. As a result, we have seen an increase in the number of national neurologists involved in our clinical and training services whilst gaining diaspora neurologists' commitment to our program during 2023. We welcomed the Emmanuel Ability Centre, the Nehemiah Autism Centre, the Ethiopian Human Rights Commission, the ROW Foundation and the International Bureau for Epilepsy as our new partners and have already begun working together. In addition, we have started a one-year project working with Debre Berhan Comprehensive Referral Hospital, and so far, we have provided epilepsy awareness training for health professionals and epilepsy information leaflets to patients. Mr Amos Action's visit, the Vice President of the International Bureau of Epilepsy Africa Region, made this year a memorable one. He was impressed with our work, and I am happy to announce that we are now a member of the Bureau. This is an achievement for Ethiopia. Two new staff members, Meron and Bezawit, joined our team and will focus on clinical service, community outreach and awareness projects.

We held our first virtual fundraising event on the 17th of July 2022 with the theme of an Ethiopian Food Masterclass given by Chef Yohanis, a renowned Ethiopian chef. His Excellency Mr Teferi Melesse Desta, Ethiopian Ambassador to the UK, was the guest of honour. I would like to express my deep appreciation to Tsion Tesfay, Beth Getachew and Kirubel Tesfay for all the hard work they did in planning and executing the fundraising event. We raised over £1,700, and the money was used to cover the cost of running a full-time clinic and providing medication.

We were delighted to hold our annual Thanksgiving Service at Jupiter International Hotel on the eve of the Ethiopian New Year (10th September). It was an opportunity to show appreciation to our neurologists, youth volunteers, patients, and stakeholders.

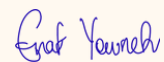
On a less welcome note, unprecedentedly high inflation in Ethiopia has pushed up the cost of goods and services, especially for staff and our beneficiaries. In addition, financial support from local donors and companies dropped drastically this year. The Government has required significant contributions from businesses to support infrastructure and other projects, reducing their ability to provide us with support. The effects have been very painful.

2023 offers CareEpilepsy Ethiopia an exciting opportunity to strengthen our projects and another chance for us to get them right. Our priorities are to continue our current programs and to focus on raising funds. Our success is the

the community's success. It would not have been possible without the ongoing support of our donors, partners, board members, volunteers, and of course, our staff. I can't wait to see the continued lifesaving work we will do together next year! But for now, I wish you nothing but a fantastic 2023 blessed with health and happiness.

I look forward to updating you next quarter.

Yours sincerely,



Enat Yewnetu
Founder and CEO



CLINICAL SERVICES

At CareEpilepsy, we provide daily outpatient consultations and EEG testing to optimize anti-seizure therapy, manage epilepsy related behavioral or psychological problems, and give psychological support and counseling to families. In addition, we offer monthly outpatient clinics staffed by volunteer neurologists. In order to compensate for the low number of neurologists available in Ethiopia, we have completed prerequisite arrangements to operate a telemedicine service that will provide epilepsy care remotely.

On top of our clinical services, we also provide patients and their families with epilepsy information to learn more about managing seizures. Recently, we have also expanded training services for local staff. Our health officer has benefited from our first teletraining program, a remote live lecture via videoconferencing given by Dr Etsegent and Dr Wong, epilepsy specialists from the USA. This has helped her to specialize further in epilepsy care.

This quarter, we delivered medical care, including medication and counseling, to 63 adults and 50 pediatric patients. In addition, we provided our EEG service to 31 patients. 136 patients were served by our home monitoring service, which involves nurses assessing the condition of patients' seizures and recommending further action.

We believe giving quality epilepsy care services can significantly affect health outcomes. Our patients and their families who access our services often express improvement in their physical and mental wellbeing since they started using our services. In addition, our service-user involvement activities promote social bonding and allow patients to learn new skills and access services that help patients live a more integrated community life.

THE WELLBEING OF OUR PATIENTS

- 167 patients received information and advice through our 'telephone helpline' service;
- 98 patients benefited from our 'home monitoring service'
- 86 people attended our weekly 'coffee morning' program, where patients get together to socialize and participate in craftwork which helps them gain new skills and self-confidence. We provided the training and raw materials to carry out the craftwork.
- 234 patients and their families attended our monthly patient support group meetings;
- 63 used our counseling service, which helps ease the burden of living with epilepsy.



TOP STORIES OF THE QUARTER!

- Dr Etsegenet Tizazu, an epileptologist (a neurologist specializing in the treatment of epilepsy) based in the USA, joined CareEpilepsy's Board, and we have already benefited from her expertise.
- Our long awaited teletraining program was launched, and operations for our telemedicine service are expected to begin in January 2023.
- We have appointed S/r Meron SHEMELES to the position of Outreach Nurse to support our community outreach work and epilepsy training.
- Dr Nardos Asfaw and Dr Yergalem Gizachew joined our volunteer neurologists team.
- We have had a gust from Total Energy.
- Meron Worku, our administrative officer, just had a baby and will be on maternity leave for 5 months.
- We have appointed Bezawit Almayew to the position of Community Education and Engagement Officer post, who will also cover our administration work covering maternity leave.
- We managed to secure a place in the Christmas bazaar at the Addis Ababa Exhibition Center. We want to thank Dream Come True (DCT) Entertainment Plc, the bazaar's organizer.

THE PATIENT STORY

My name is S/r Tesfanesh Yerfu, and I have epilepsy. I was born in 1986 in Mizan Tepi town. I was first diagnosed with epilepsy at the age of 7 years old and have had to deal with many physical injuries as well as depression and hopelessness. At the time of joining CareEpilepsy, I used to have seizures more than 2 times a day. I have since been taking Phenytoin regularly and putting into practice what I have learned from CareEpilepsy. As a result, I have achieved reasonable seizure control and continue to attend my follow-ups at Amanuel hospital. I came in contact with CareEpilepsy in September 2018 when I saw an advert about their work. I went to have a chat with them and saw their work with my own eyes; they impressed me. Since then, I have been receiving help for my seizure medication and counseling, and this has significantly benefited my physical and emotional health. I continued my membership with CareEpilepsy and provided support to the organization when I could.

The confidence I gained helped me finish my nursing degree at Yanet college, and I am currently employed as a clinical nurse at Zewditu Hospital. I am married and have a beautiful girl. I continue to make use of CareEpilepsy clinical service and psychological support. I also volunteer to raise awareness about epilepsy.

For us, S/r Tesfanesh Yerfu is a hero for overcoming the challenges of living with epilepsy and tackling depression and anxiety head-on to live well with epilepsy.



RAISING AWARENESS IN HEALTH CENTER



The more everyone talks about epilepsy, the fewer people living with the condition have to fear discrimination, worry about receiving improper first aid, or keep their epilepsy hidden in the shadows. We want all people with epilepsy to know the extent of treatment options to help control their seizures. Ensuring access to quality health care that is affordable, physician-directed, and person-centered. Most people believe that anyone who has epilepsy is unable to participate in any activities. This stereotype can influence the economic independence of people with epilepsy through loss of productivity; the essential point to give awareness at health centers is we get to teach people from every walk of life, including children, adolescents, adults and elderly persons. This makes our effort a crucial first step towards ensuring early detection and effective treatment of seizures and is key to eradicating the stigma associated with epilepsy.



RAISING AWARENESS IN SCHOOLS

Educating the school community means educating society as a whole, as the two work harmoniously. At CareEpilepsy Ethiopia, our school awareness programs aim to increase society's knowledge of epilepsy and reduce its stigma.

For some children, having epilepsy will not affect their ability to learn or achieve academically, but others may need extra time or support in class. We work with schools to create an environment where teachers are empowered to deal with epilepsy and are open to supporting the child in need.

This quarter we have trained 4,800 students and 50 teachers about epilepsy and taught epilepsy recovery positions. Teachers and other school staff are in a good position to spot seizures and help.

OUR PARTNER STORY

We want to introduce you to Rosetta General Business PLC in Addis Ababa this quarter. Rosetta is a well-established private company owned by Mr Tewodrose Shiferaw, a diaspora with a genuine desire to support the continued growth of Ethiopia. Rosetta is currently engaged in hotel and real estate development, import and export Trading (supply chain management of agricultural commodities), media and communication, and a coffee shop. Mr Tewodrose Shiferaw, CEO of the company, visited our office in 2021 and has been helping us since then. He has purchased medication for patients and provided a meeting space at his hotel free of charge. We want to acknowledge Mr Tewodrose and the organization for his continued support of our project.

GET TO KNOW OUR TEAM Meron Worku

Meet Meron Worku, our Administrative Officer. She was born in Addis Ababa, the capital city of Ethiopia. She has a degree in Language and an MBA degree in Business administration. She joined CareEpilepsy Ethiopia 4 years ago and is responsible for overseeing administrative operations across CareEpilepsy's office. In addition, she is involved in organizing and giving epilepsy education, various campaigns and programs and working with volunteers. Here is her take on her work:

"Being a part of the only organization working for people with epilepsy in Ethiopia makes me happy, and I like to contribute to the efforts of our charity. I am delighted to serve people affected by epilepsy and in need of our help."

Moreover, working at Care Epilepsy has helped me increase my expertise as an individual and added much more experience to my professional life". Meron was married in January 2022 and is now a mother of a baby girl, who is 7 days old. CareEpilepsy congratulates you on your new arrival. Each employee is like a family at CareEpilepsy. And it's great to hear that a new member is joining your family. Take good care of yourself and enjoy this special time.



MEET OUR STAR VOLUNTEERS

Emawayish Asrat

All our volunteers have the ability to help staff deliver person-centred care. Here is Emawayish Asrat telling her story.

My name is Emawayish Asrat, and I am married and a mother of two daughters. I am a devout Ethiopian Orthodox Church believer and attend church regularly. I enjoy cooking, doing craft work and being involved in social activities. I have learned the discipline of giving and volunteering from my faith and enjoy being a part of volunteering work, be it at church or CareEpilepsy Ethiopia.

I was introduced to CareEpilepsy three years ago, and since then, I have been training patients in craft work. I hope the skills I teach them will enable them to be confident in themselves and, if possible, earn money and gain some independence. I share the opportunity of volunteering at CareEpilepsy wherever I go. I promise to support CareEpilepsy Ethiopia by contributing to the craft program.



MEDICAL DIASPORA VOLUNTEER PROGRAM

Dr Hirut Gebrewold, Internal Medicine

Dr Hirut A. Gebrewold is an internist in Glen Burnie, Maryland and is affiliated with multiple hospitals in the area, including Greater Baltimore Medical Center and the University of Maryland Baltimore Washington Medical Center. She received her medical degree from Gondar College of Medical Sciences and has been in practice for over 20 years.

She has spent a week at CareEpilepsy Ethiopia, training our health officer in general health assessment and preparing general health education materials. CareEpilepsy acknowledges that the medical diaspora can play a vital role in supporting our programs through providing clinical services, training and policy formulation. We thank Dr Hirut for her willingness to share her expertise.



CELEBRATING OUR GREAT HEROES

Dr Mehila Zebnegus is an Associate Professor of Neurology in the Department of Neurology, College of Health Sciences (CHS), Addis Ababa University (AAU), Ethiopia. The only University in the country where Neurology Discipline is offered as a Specialty Training. She is the first female neurologist with vast experience working at various medical institutions. Her story was written in Neurology Today Journal in October 2009 with the title "In Ethiopia, First Woman Neurologist Breaks the Glass Ceiling". We are proud that Dr Mehila paved the way for many more women neurologists presently working in Ethiopia. She currently works at Yehuleshet Specialty Clinic.

Dr Mehila Zebnegus has worked with us tirelessly since the launch of CareEpilepsy in Addis Ababa. She is presently a member of our volunteer neurologist team and sees patients at our free outpatient epilepsy clinic, reads EEG tests, and provides training for nurses organized by CareEpilepsy Ethiopia. Our project is special to her, and she plays many roles in making our programs successful.

We want to thank you and express our appreciation for your support. Thank you Dr. Mehila Zebnegus.



MEET OUR ADVISORY BOARD TEAM

Dr. Etsegenet Tizazu, MD

I was born in Ethiopia and immigrated to the USA as a child. I obtained my medical degree from Wayne State University School of Medicine. I completed my Neurology residency and Epilepsy fellowship at the University of Pennsylvania. I have had a lifelong interest in advancing the treatment of epilepsy in Ethiopia. My interest in epilepsy began in the fifth grade when a classmate with epilepsy was deemed "cursed" and hidden away by her family. So far, I have assisted in developing the first tele-neurology service in Ethiopia and helped lead the Bahir Dar Outreach for Neuroscience Education (BORNE), an initiative addressing the disparity in neurological care in Bahir Dar, Ethiopia.

Additionally, I serve as a board member of CareEpilepsy Ethiopia. Working with CareEpilepsy has allowed me to realize my lifelong dream of addressing the treatment gap of epilepsy in Ethiopia. I have always believed that caring for patients with epilepsy requires a holistic approach to address the physical, social and cognitive comorbidities unique to each patient, and CareEpilepsy Ethiopia does exactly that. Working with CareEpilepsy Ethiopia, I have formed the first functional International Bureau of Epilepsy (IBE) in Ethiopia and strengthened partnerships with other organizations, such as the ROW Foundation, to increase access to safe antiseizure medications as well expand access to care. In addition, I created the first epilepsy curriculum for our health officer to help her gain expertise in epilepsy. In the future, I hope to develop the first epilepsy fellowship program in Ethiopia and create an epilepsy surgery program.

WAYS TO SUPPORT US

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](#).

Ethiopia - CareEpilepsy Ethiopia

Account Number: 1000161849166, COMMERCIAL BANK OF ETHIOPIA

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

If you do your Amazon shopping through AmazonSmile at <https://smile.amazon.co.uk/ch/1151942-0>, Amazon will donate 0.5% to CareEpilepsy, at no cost to you.

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TIPS FOR LIVING WELL WITH EPILEPSY

Living Alone with Epilepsy

Tips on How
to Stay Safe

Having epilepsy does not mean one cannot live independently or happily. Of course, there will always be risks in living alone when one

has seizures—but if you take all necessary precautions and do the things geared to making independent living a safe and healthy environment, then it's not something you should fear.

HAVING SEIZURES CAN SOMETIMES PUT YOU OR OTHERS AT RISK OF HARM! THEREFORE DO:-

1. Place padding on furniture edges or corners that are sharp or stick out
2. have a shower instead of a bath
3. do not lock the bathroom door
4. use an electric stove so there is no open flame
5. place saucepans on the back burners and with the handles turned away from the edge of the cooker
6. Have a plan of action ready so that you can alert friends, family or neighbors if you need assistance.

THANK YOU NOTE

CareEpilepsy Ethiopia wishes to thank everyone who has supported our work in kind and financially during 2022. Specifically, we want to thank Jupiter International Hostel for sponsoring our Thanksgiving program, Wudassie and Viva Diagnostic centers for providing MRI service free of charge, Commercial Bank of Ethiopia and TotalEnergies Marketing Ethiopia S.C. for sponsoring our program.

Additionally, we would like to thank our youth and professional volunteers for their in-kind donations of service. We couldn't have done it without you.