



CareEpilepsy Ethiopia Saving Lives | Changing Perceptions

In this issue....

- Message from the CEO
- Clinical Services
- Top stories of the QUARTER!
- The wellbeing of our patients
- The Patient Story
- Raising Awareness at Schools
- Raising Awareness at work
- Get to know our staff
- Our Partner Story
- Meet our Volunteers
- Celebrating our great heroes
- Acknowledgements and Thank you
- Tip for living well with epilepsy
- Ways to support us

Dear friends,

This is obviously not a case of 'time flies when you're having fun' – we would never call the 2nd quarter fun. Still, it certainly was a hectic and challenging one for everyone at CareEpilepsy Ethiopia. First, we spent time planning and preparing for the launch of our Epilepsy and Health Assessment Clinic. Secondly, we continued to arrange the new epilepsy center, which we moved into during March 2022, making it easier to offer our services.

As always, we continue to offer various services and programs this quarter. We are in the process of setting up a Health Officer Health Assessment clinic and running more neurologist-led epilepsy clinics for our patients.

We are creating an epilepsy training opportunity and planning to set up a telemedicine service involving electronic communications and software to provide clinical services to patients without an in-person visit. International neurologists will support this service. Finally, we are recruiting national volunteer psychiatrists to offer psychological care at our center.

Our community outreach worker resigned this quarter, but we plan to recruit shortly. On another note, I would like to warmly welcome CareEpilepsy's new partners and volunteers. A special welcome goes to Dr Etsegenet Tizazu, an Epileptologist from Newark, Delaware, USA, who joined our national advisory board. She is already making her presence felt by helping to expand our epilepsy clinic and EEG services and promoting our work with the international community.

Reflecting on this quarter, the most important thing for me as a CEO is our ability to recruit and work with both professional and youth volunteers to run our services. I want to acknowledge their commitment to serving anyone affected by epilepsy during the 2nd quarter of 2022.

I look forward to updating you next quarter.

Yours sincerely,

Enat Yewnetu
Founder and CEO



CLINICAL SERVICES

CareEpilepsy Ethiopia has a medical office that is led by Ms Haimanot Altaseb (HO). She has gathered volunteers, including doctors, to help serve our patients. We also have a patient support group. This group has a free clinical service for patients once per month. During this monthly service, we provide counselling and medication services, where we always give as much as possible. We serve almost 52 adults and 75 paediatric patients with medication along with 71 for counselling. Our support programs also include group meetings. In this quarter about 234 patients along with their families attended these meetings. The meeting by itself motivates the patient's family members by helping them understand how they will treat and support their babies. We offered our EEG service 36 times, of which most of them were referred, so we resolve the problem of costs that patients have with the lack of money. We served 4 patients from Gurage zone (the rural part of Ethiopia) with medication.

TOP STORIES OF THE QUARTER!

- We have received 'A Health Center Licence' from The Ethiopian Food and Drug Administration, the National Regulatory Body of Ethiopia under the Ministry of Health. Our Health Officer and neurologists will run the center. Our team is delighted as we have worked for three years to achieve this status.
- Dr Etsegenet Tizazu, an Epileptologist from Newark, Delaware, USA, has joined our National Advisory Board

THE WELLBEING OF OUR PATIENTS

- 101 patients received information and advice through our 'Telephone Helpline' service;
- 63 patients benefited from our 'home monitoring service' where our nurse checked on their seizure status and advised further actions;
- 72 people attended our weekly 'coffee and chat morning', where patients get together to socialise and participate in craftwork which helped them gain new skills and self-confidence. CareEpilepsy Ethiopia provided the training and raw materials to carry out the craftwork.
- 236 patients and their families attended our monthly patient support group meetings;
- 88 made use of our counselling service, which helps ease the burden of living with epilepsy.



THE PATIENT STORY

As usual, we would like to introduce one of our patients during the 2nd quarter of 2022. He comes with a very encouraging background story. His name is Abdi Daba (shown on the right), and he lives with epilepsy. His seizures developed at age 3, and he attends regular medical follow-ups at St Paulo's Hospital. When Abdi came to CareEpilepsy on the 14th of July 2021, his seizures were happening daily. He is now on a combination therapy taking Phenobarbital and Phenytoin and has achieved reasonable seizure control. He receives support for his seizure medication and counselling. He enjoys participating in our craft workshop once a week. He has developed into a very productive and confident man.

RAISING AWARENESS AT SCHOOLS

To educate the school community means educating society as a whole, as the two work in harmony. Every school has a team made up of a teacher, student, admin, and parents so if one teaches all individuals, you can address the society immediately. Schools are our target to increase society's awareness of epilepsy.

We work with schools to create an environment where both the children and the teacher with epilepsy can develop awareness. In this quarter we have trained 3,836 students and 20 teachers about epilepsy and taught the recovery position. Most of the trainers said the training offered helped students and teachers understand that most pupils with epilepsy can participate in all school activities. Although we are happy with our progress thus far we are aiming to do even better than this for the next quarter.



School Education



RAISING AWARENESS IN THE WORKPLACE

Stigma is a huge issue that those with epilepsy suffer in the workplace. Most people believe that anyone who has epilepsy is unable to participate in employment. This stereotype can influence the economic independence of people with epilepsy through loss of productivity, employment or underemployment.

We provided training for employees in three cooperative organizations; Selamta Family Project, Rehoboth Feeding and Studying Center, and Addis Guzo Organization. We hope the training helps develop open-minded employees who can handle seizure emergencies. Roughly 378 employees attended the training.



Birhane Habte is one of our administration members. We are going to share her story this quarter.

Birhane was born in north Gondar, a zone in the Amhara Region of Ethiopia, in a place called Eliwari. She is the 2nd of 4 children. She grew up in a challenging environment. She accidentally came in contact with Kevin Christian, whom she met whilst he was climbing Ethiopia's highest peak on the Ras Dashen summit trek adventure in the Simien Mountains of Ethiopia. Kevin has been volunteering for CareEpilepsy for a while now by supporting our accounting team when preparing budgets and financial reports. He, in turn, introduced her to us in 2018 where she became a volunteer. This led to her joining the team as a paid staff member in 2019. Birhane enjoys listening to music and watching movies.

Birhane holds a diploma in Information and Technology studies. She plays a significant role within administration, finance, awareness raising and clinical services. In addition, she handles our telephone helpline service. Her favourite responsibilities include working with volunteers, raising awareness, and teaching seizure first aid in schools. When we asked about her job at CareEpilepsy, she replied, "being a member of CareEpilepsy makes me feel lucky. I am happy to work here and get to run several activities along with my responsibilities in the office. I love my job. My role is not limited to the office but also includes educating my family and friends. In most of our education sessions, I play the role of a person having a seizure. I am happy to utilize my skills to educate others." Of course, being the youngest in the offices means she does most of the running around; what can I say, the perks of being young. It is fantastic to see the transformation of Birhane from a quite timid girl to an active, confident young adult. Birhane, You are the star of the office!

GET TO KNOW OUR TEAM Meet Birhane Habte





OUR PARTNER STORY

Nebyu leaves behind so much love and memories



“Nebyu leaves behind so much love and memories and a huge hole that can never be filled.”

When Anna Argaw’s son, Nebyu Taddese, was diagnosed with epilepsy, it came as a shock. He was in Grade 10, and his seizures appeared suddenly. We were even more shocked to hear of his unexpected death from SUDEP only a few years later at the age of 19. Nebyu was a lovely and extraordinary person who lived with and battled epilepsy. He enjoyed sports, especially hockey and dreamed of being a sportscaster.

When Anna tragically lost Nebyu at the age of 19, she decided that there was no better way to remember him than by raising money for those affected by Epilepsy, especially those who can’t afford treatment.

Anna and her friends have been supporting the work of CareEpilepsy in Ethiopia (where Nebyu originally comes from). “As a family, we decided that there’s no better way to remember him than by raising money to make a difference in our homeland, Ethiopia, where there is a lack of medication, treatment, and awareness about epilepsy”. “Nebyu leaves behind so much love and memories and a huge hole that can never be filled. Whilst as a family we may never make sense of his early passing, there is a determination and hope that by supporting CareEpilepsy in their work, we can help to raise awareness of epilepsy and support the provision of clinical care.”

This year, as always, the amazing Anna, her family and friends raised funds to support people living with epilepsy in Ethiopia and Epilepsy Toronto in the beautiful summer weather of June 2022.

MEET OUR VOLUNTEERS

Eskinder Lakew

Our volunteers have been excellent to work alongside and have increased our ability to tend to the needs of our patients.

Here is the remarkable story of Eskinder W. Lake. He has been involved in philanthropic work for a while. He works at the Ministry of Health as the Director of Logistics and General Service. When talking about people with epilepsy, he said, “we need to teach our patients that they can do anything they want if they believe in themselves and think outside of the box”. He continues to say, “it does not matter whether the activities are small or large, but they can do something”. Eskinder is a huge fan of art and theatre and does acting in his spare time. Using his performance skills, he acted in an epilepsy educational video without charging us, which CareEpilepsy uses for community education. He was also the master of ceremonies in our fundraising event in March 2022. We are grateful for his continued support of our work.





TIP FOR LIVING WELL WITH EPILEPSY

Do not miss doses of your medications.

Tip: Missing anti-seizure medications could mean a devastating effect on our life. There are many apps on smartphones that can assist with remembering to take your medications. You simply download the app, input your medications and the times that you take them, and then set up the reminders. That way, when you are cooking at home, in a classroom or in the office working hard and the time to take your medicine arrives, your phone can send you a subtle reminder, and you won't miss your dose. It's that easy! Here are only a few examples:

MedControl

Nile, the New Seizure Diary App

ACKNOWLEDGEMENTS & THANK YOU

CareEpilepsy Ethiopia wishes to thank everyone who has supported our work in kind and financially. Specifically, we want to thank Anna Argaw from Canada and Friends of CareEpilepsy in Atlanta for their generous donations during this quarter.

Additionally, we would like to thank our national youth and professional volunteers for their in-kind donations of service and other governmental and private organizations.

CONTACT US

Careepilepsy Ethiopia

Yeka Sub-City, Woreda 08, House No. 897
Around Hayahulet, Addis Ababa

Contact No. +251 11 669 4455 / + 251 97 526 4121
Email - info@careepilepsyethiopia.org

CELEBRATING OUR GREAT HEROES

Dr Kindu WoldeMichael, Pediatric Neurologist

Dr Michael W. Kindu is a member of our national advisory board who has worked with us tirelessly for the last six years. He is a pediatric neurologist with vast experience working in various medical institutions and currently works at the Africa Economic Commission. He also has a private practice. He is married and has two children, a daughter aged 6 years and a son aged 4 years. His neurology experience has brought added value to our work.

He believes that "charity is not a bone you throw to a dog, but a bone you share with a dog". That is why he shares his limited time and resources with our patients. When asked about his thoughts on CareEpilepsy, he said, "I feel happy when I come to CareEpilepsy Ethiopia. For me, success is not a matter of having money, properties or being famous but rather seeing improved health of patients who cannot afford to pay; to see this, I need to come to CareEpilepsy. Our work at CareEpilepsy Ethiopia has brought a tremendous change, and I am proud to be a part of it".

When we think of Dr Kindu's work for us it is hard not to have a tear in our eyes. What he has given us in kind in the last 6 years will amount to over £5,000 had he asked us to pay. He provides us with the strength and the hope to keep going. Thank you, Dr Kindu.

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

UK

Direct Debit to HSBC A/C - (Sort code: 40-07-27) - (A/C No: 11621491)

Give online - <https://www.careepilepsyethiopia.org/donate>

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.

USA - Give online - <https://careepilepsyusa.org/>

CareEpilepsy UK

Contact Number: +44 759 681 7212

Email - ceo@careepilepsyethiopia.org

www.careepilepsyethiopia.org

www.facebook.com/CareEpilepsy/