

# IN THE LOOP

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CareEpilepsy Ethiopia Saving Lives | Changing Perceptions

Quarterly E-Newsletter #1/2022



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Dear friends,

Reflecting on the first quarter of 2022 we realise how much our commitment to serving anyone affected by epilepsy has been reaffirmed, as has our wish to create a caring environment for the vulnerable.

The first quarter of 2022 has given us plenty of moments to be proud of despite how busy we've been as an organisation. As promised, we continue to offer high-quality assistance to our patients suffering from epilepsy. We have developed new and more efficient ways to deliver our clinical and psychological services and have witnessed, first-hand, the difference it has made or our patients.



Using the ever-growing social media platforms, our educational team has continued to develop exciting content and campaigns to spread our message. It is with great pleasure that I can tell you that CareEpilepsy Ethiopia continues to be a major source of epilepsy-care information in Ethiopia. This achievement stems from our continued persistence in shedding light on epilepsy.

Unfortunately, I have spent more than a year away from the team due to health-related issues. I made a short visit in February, lasting a month. Although I would have loved to stay longer, seeing the dedication the team works with brought joy to my heart. The CareEpilepsy team has displayed remarkable resilience, adaptation and unity throughout the year. I must commend these qualities that ensure the continued delivery of life-saving services. I have been inspired by the compassion and care that I have witnessed; the genuine interest from the team to help our patients live a more fulfilled life is genuinely heart-warming to see.

The Ethiopian government carried out several different projects this year that required significant contributions from established organisations, meaning we had to carry out this year's National Epilepsy Week despite very few donations; donations which traditionally are our most important portion of income. It would be an understatement to say the effects of this were felt.

I would again like to thank the brilliant CareEpilepsy team for their continued efforts despite the obstacles the last three years have thrown their way. Additionally, I would like to offer a warm welcome to CareEpilepsy's new partners, staff and volunteers. They have been excellent to work alongside and have definitely increased our ability to tend to the needs of our patients.

Reflecting on this quarter, the most important thing for me as a CEO is our ability to work in line with the culture and values of our organisation. These are providing quality compassionate care, working with a quiet determination to consistently deliver at our best and pulling together when the demands placed on us are at their most challenging.

I look forward to updating you next quarter.

Yours sincerely,

Enat Yewnetu  
Founder and CEO

## NEUROLOGISTS TREATING PATIENTS

Thanks to our medical professional volunteer neurologists, psychiatrists, and nurses, we provided clinical care for 258 patients this quarter. This quarter, we have seen an increase in the number of neurologists involved in our programs, such as in training and at our clinic. Emergency anti-epileptic medication, EEG and MRI services were provided for 171, 15, 6 patients respectively. We are delighted with our accomplishments, but we still need to increase the service compared to the need.



**Epilepsy Clinic.  
Dr Enkutatah  
(adult neurologist)  
and  
Dr Endayen Degnet  
(pediatric neurologist)**

March 2022



## EPILEPSY AWARENESS TRAINING

This quarter, we have provided epilepsy training for 91 school nurses, supported by the Association of Ethiopian Neurologists. We offer this training hoping that it will help them provide the highest level of care for children with epilepsy in a school environment. In addition, it is designed to provide school nurses with information, strategies, and resources that will enable them to better manage students with seizures. It is also hoped that they will help reduce the stigma of epilepsy that children face in and around school, thus increasing inclusion.

Our organisation is grateful to the Addis Ababa Education Bureau, which provided the venue and catering, allowing us to run this successful programme. The picture on the top right shows school nurses representing 60 different schools receiving training. Drs Hilina Dagnachew (a neurologist) and Ruth Tsegiebrhan (a psychiatrist) are shown, bottom-right, after concluding their teaching.



## THE WELLBEING OF OUR PATIENTS

- 551 patients received information and advice through our 'Telephone Helpline' service;
- 136 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.
- 301 patients and their families attended our monthly patient support group meetings;
- 127 made use of our counselling service, which helps ease the burden of living with epilepsy.



*Craft work done by women  
with epilepsy at our center*

# OUR PATIENT STORIES

This quarter's story is about Zewdenesh Alemu, a 46 years old woman living with epilepsy. She has one child, Yabsera, aged 7, born due to rape whilst living on the street. He also has epilepsy. They live in slums, and the physical environments of slums present many challenges, such as having no sanitation and water facilities, no secure fences and a clean cooking area. As you can see from the picture, she sustained a burn injury whilst cooking on an open fire. She is unemployed due to uncontrol seizures and stigma related to epilepsy. CareEpilepsy Ethiopia currently covers the cost to purchase her medication, provides psychological support and other urgent needs. Zewdenesh is one of the many single women we meet daily. We want to enrol Zewdenesh on an income-generating craft business to enable her to be self-sufficient to care for her and her child's needs. Please donate and be part of this project.



## TOP STORIES OF THE QUARTER!

- With great joy, I can announce that our epilepsy center has moved into bigger and more accessible premises. Our staff and beneficiaries are ecstatic about the space we have. One of our patients said to me, "now we have a home to go to".
- We held a fundraising event on the 10th of March in our new office premises.
- We celebrated International Epilepsy Day on the 14th February and National Epilepsy week from the 15th-20th February.
- CareEpilepsy Ethiopia is now widely recognised as a hub for information and support.
- We welcomed Emmanuel Ability Center and Nehemiah Autism Center as our partners. We will be working to improve awareness of our causes, learn and share new skills and resources.

## FURNDRAISING EVENT

This year's fundraising event is to strengthen our clinical service and build sustainable livelihoods through microenterprises for single vulnerable women and their children with epilepsy. No charity can afford to continue to buy medication, pay for treatment and meet the physical needs of their beneficiaries when their number is in the hundred thousand. The only way is to train them, support business ventures and find a market for them. You can find more information about this project on our website. So please donate and make this a reality for them.



## OUR VOLUNTEERS

Neurologists, nurses, and youth volunteers continued to significantly impact clinical care and awareness-raising programmes through their engagement with our work. This quarter, we've recruited 151 youth volunteers. It is so important that we take time out to thank our volunteers. To selflessly offer your time with the view of serving others is something I will never forget. CareEpilepsy is privileged to have you. Our achievements thus far would be impossible without your hard work and commitment. We hope you will continue to impact the lives of so many needy people.



## RAISING AWARENESS AT SCHOOLS

When a child has epilepsy, it's natural to worry about them having seizures at school. But with the right communication and support, having epilepsy should not stop any child from getting the most out of their education. Our school awareness-raising campaigns and trainings are planned to change behaviour and improve the focus on better outcomes for children with epilepsy allowing them to participate in education.

We work with schools to create a school environment where children with epilepsy can learn and thrive. This year we have opened dialogue with 60 schools in our attempt to stop the exclusion and prejudice children with epilepsy face. As a result, 33,224 students and 1,825 teachers received epilepsy and first-aid training. Many said the training to pupils and teachers helped them understand that most pupils with epilepsy can participate in all school activities.



## RAISING AWARENESS AT WORK PLACE

Having epilepsy does not necessarily stop someone from doing the job they want, but there are some issues that can affect them at work. Unfortunately, due to a lack of awareness of epilepsy, patients continue to suffer from stigma and, as a result, are marginalized. The picture on the right shows CareEpilepsy Ethiopia providing epilepsy training for Addis Ababa Revenues Bureau staff to increase their knowledge about epilepsy and understand the support an employee with epilepsy might need in the workplace. We hope this will help increase the chances of people with epilepsy earning employment. This is our first time doing a presentation at a respected government office with close to 200 attendees.



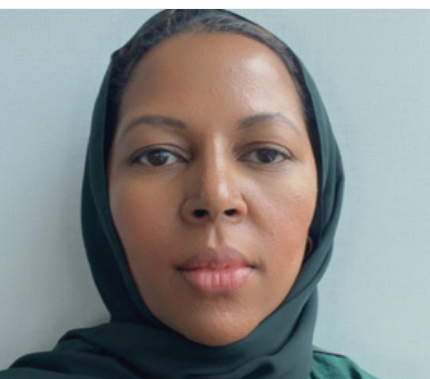
## Campaign - International Epilepsy Day and the 7th National Epilepsy Week

Unfortunately, due to a lack of awareness of epilepsy, people with epilepsy and their families suffer from stigma and discrimination. Our campaigns target these misconceptions so that those with epilepsy can be confident in living a fulfilled life. This is why we celebrate International Epilepsy Day and run the National Epilepsy Week campaign. The week-long program included raising awareness at schools, health centers, press conferences, training and a closing program in one of Addis Ababa's football stadiums. The Addis Ababa education bureau and the Association of Ethiopian Neurologists supported this year's event.

## GET TO KNOW OUR STAFF - MEET ABIY ASRAT

This quarter's story is about Abiy Asrat. Abiy is our administration and finance manager and stands-in for the CEO in her absence. He joined our team in 2017, the right time as we were getting ready to travel to the southern part of Ethiopia for a campaign and training program that we organized.

Abiy was born in Addis Ababa and is the 6th child of 7 in the family. The picture on the right is of him on an adventurous walk with his children in Entoto National Park in Addis Ababa. He enjoys music and sport. It's incredible how often he goes above and beyond to ensure our services run smoothly with the little resources he has at his disposal. Using his soft voice, he is the one who keeps the temperament down in the office; mind you, he can be very assertive when necessary. His unique perspective on issues and knowledge of how to manoeuvre the work culture in Ethiopia has proven invaluable to CareEpilepsy Ethiopia. When asked about his job Abiy said "I have been with CareEpilepsy Ethiopia for almost six years. I love what I do and the community I serve. I believe charity begins in the office, so we collect money monthly from staff so that when we go to visit patients, we take something with us. There's never a dull day working at CareEpilepsy. There's always something to do."



Our national advisory board comprises several members from a variety of backgrounds. Our advisory board has always supported us in any aspect necessary, none more prevalent than the recent COVID 19 pandemic.

Saada Mustefa is one of our board members who has helped us achieve our goals and support our patients. She is the Customer Relations Manager at Mullege Coffee Export and has recently opened her own coffee house. She is married and has four children. Her coffee specialist business network and leadership experience brought added value to CareEpilepsy.

Saada is never tired of our phone calls asking if she knows someone who can donate "money, paints, stationaries, printing etc." it is endless. But, she always comes through for us. We are amazed by her ability to help us focus on better days to come, no matter how tough a situation we are in. Saada, our team are always talking about your commitment, passion, hard work and helpful attitude. Thank you for being such a fantastic role model for serving others.

**CELEBRATING OUR GREAT HEROES**  
Saada Mohamed

## 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/>

## 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
- The Addis Ababa Education Bureau.
- The Commercial Bank of Ethiopia
- Tracon Trading
- Adulin Coffee Exporter
- Mulege PLC
- Novartis Ethiopia
- Woudase Diagnostic Service
- Friends of CareEpilepsy in Atlanta
- CareEpilepsy Ethiopia Advisory Board
- CareEpilepsy UK Board of Directors
- CareEpilepsy USA



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