CAREEPILEPSY

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CAREEPILEPSY

SAVING LIVES | CHANGING PERCEPTIONS

WELCOME TO OUR CHARITY

Contents

The Founder Story

Enat Yewnetu
Founder and CEO

I was diagnosed with seizures 30 years ago; I went from having multiple seizures a week to now only having them once or twice a year. I have generalized tonic-clonic seizures that involve my entire body. My seizures usually result in rigid muscles, followed by violent muscle contractions, loss of consciousness and increased secretions (foam at the mouth). I have to be on anti-epileptic medication for the rest of my life and live with the drug's side effects. As many of you who experience seizures know, the storm may come. Still, I embrace each day as if it will not.

It wasn't always easy for me. A diagnosis of epilepsy brings along with it a parade of side effects, social problems, and mysteries that are impossible to ignore. I have had many seizures with physical injuries such as almost drowning, bruising, head injury, broken teeth, burns, and bitten tongue, most of which required hospitalization or surgery. I remember having a seizure on the road when I was 8 months pregnant and waking up in hospital expecting to be told that I had lost the baby. It was one of the darkest moments of my life.

My issue with my memory is one of the most significant challenges I face, which sometimes causes me a great deal of distress. I also live with the knowledge that the risk of premature death due to my epilepsy is high. I spent many years questioning why I had to live with the challenges of epilepsy and as a result, I had been through so much physical and emotional pain.

20 years ago, it dawned on me that my epilepsy wouldn't change. It was a choice I had to make; either I win, or epilepsy wins. I certainly wasn't going to be defeated. I decided that epilepsy would not stop me from achieving my dreams and living my life to the fullest. I had to accept and discover myself as a person living with epilepsy. My attitude is to enjoy my life with epilepsy and make a difference while I am still around, this gives me a reason to get up and live each day. Of course, all my decisions in life have to consider my epilepsy, which sometimes means giving up certain activities. I am blessed with a beautiful son who cares for me. I completed my Master of Public Health (MPH) and Bachelor of Business Administration (BBA) in the United Kingdom and have a 20-year track record in managing activities in changing health services within the National Health Service of England.

Though I am fortunate to have reasonable control over my seizures as a result of the treatment I received in England, where I get the latest medication and diagnostics, I realize the reality is far different for others, especially those living in developing countries such as Ethiopia, where I come from.

Throughout my travels across the country, I have witnessed the heart-wrenching experience of girls and women who have suffered life-threatening burns and a lifetime of disfigurement due to seizures happening while cooking or discharging the usually dangerous day-to-day tasks that society has imposed only on them.

At the time of feeling comfortable with my life, I felt the call to advocate and help everyone who has been affected by epilepsy, whether diagnosed, a parent, spouse, sibling, you name it. I also want to educate and raise awareness of epilepsy to dispel the myths about epilepsy. Therefore, I founded my own charity, CareEpilepsy, seven years ago in Ethiopia, and it is growing. Moving to Ethiopia was a huge decision and a shift from my career path. But, I wanted my story to inspire others and make them believe that all things are still possible to achieve whilst living with epilepsy.

When I moved to Ethiopia, I went with a huge vision and little funds (£2,000) for something I wanted to create in my country. But the thing about CareEpilepsy is that we are overcomers. I refuse to be victims of our problem but creators of the future. Achieving CareEpilepsy's vision will take hard work, courage and consistency. But, together with you, I am determined to make it a success.

I now live to serve people living with epilepsy, and this brings me great fulfilment. I believe every person living with epilepsy both in developed and developing countries, deserves to get anti-epileptic drugs with fewer side effects. The individual's economic status should not dictate the choice of medication he or she receives. Near enough is not good enough! Serving as the Chief Executive of CareEpilepsy and an Epilepsy Advocate is an awesome responsibility and privilege, and I walk humbly in this calling. It means I get the honorable task of turning back the page in the history book of epilepsy, and I get to contribute by writing the next chapter.

Enat Yewnetu

CareEpilepsy Over View

Our History

Founded in 2013, CareEpilepsy is the only non-governmental, non-religious epilepsy focused charitable organization supporting the neglected community of people with epilepsy in Ethiopia. Our office was established in Addis Ababa in March 2016 with a small thin mattress to sit on, 1 computer desk and with an enormous vision that looked crazy at the time for many people. Our first donation was 2 old chairs and a desk.

Our Vision

We envision a future where people with epilepsy are protected, respected, live free from discrimination and stigma and given the opportunity to realize their full potential.

Our Mission

We exist to radically improve the quality of life of people with epilepsy in Ethiopia and change perceptions of epilepsy in the community.

Our Values

Our moral compass for beneficiaries and our employees

- Compassionate care
- Integrity
- Accountability
- Innovation
- Inclusiveness
- Holistic Approach to Health and Wellbeing

Our Goals

Our goal is to facilitate and deliver epilepsy care services, anti-epileptic drugs and diagnostics, increase epilepsy education to reduce stigma, and improve and promote the wellbeing and protection of the rights of people with epilepsy.

Our Activities

01

1. Providing and facilitating early epilepsy diagnosis and treatment for 1,000 patients

- Providing urgent treatment and facilitating referral for patients to receive appropriate medical care;
- Dispensation of emergency anti-seizure medication and purchase of government-subsidized health insurance for those who can't afford to enable them to buy medication;
- Provision and/or facilitation of diagnostics such as EEG and MRI. (We currently use the EEG machine donat¬ed by our partner organization in the USA).

Our Activities

02

2. Increasing the number and the competency of nurses and health officers to treat epilepsy by 200 at the primary health care level.

- Run 4 epilepsy management training sessions where 50 nurses and health officers will attend each session;
- Provided the nurses and health officers with an epilepsy information manual to take to their workplace for future reference;
- Provide a Telemedicine service which makes use of audio, video and data communications in the delivery of epilepsy clinical care and information;
- Establish an epilepsy resource centre which is a library of books and journals about epilepsy for the community.

Our Activities

03

3. Increasing education for patients and the general population to promote medical-seeking behavior, inclusion and disassociate the undue stigma and exclusion placed on people with epilepsy.

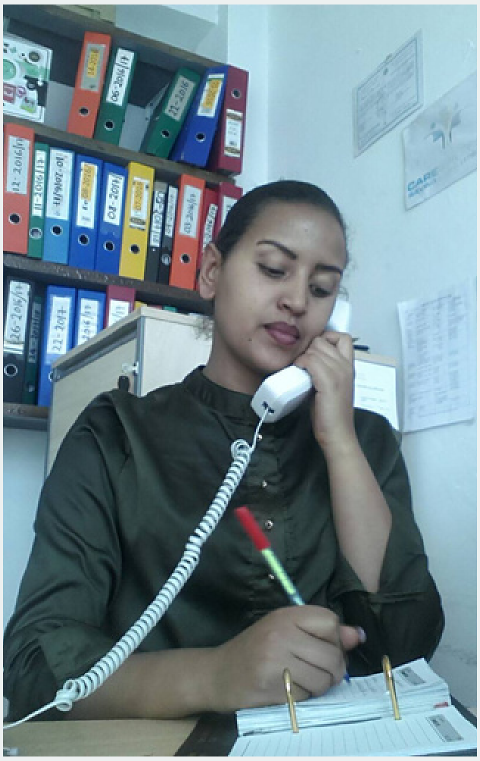
- Run epilepsy literacy campaigns such as National Epilepsy Week which reaches 2.5+ million residents;
- Render factual information about epilepsy and causes and risk factors of epilepsy in the form of newsletters, posters, leaflets and a resource centre that is open to the public, website and social media;
- Lead epilepsy awareness workshops in schools, workplaces and 'faith' communities;
- Run community epilepsy education at hospitals and health centres.

EPILEPSY EDUCATION AT SCHOOLS

Our Activities

04

4. Improving the emotional, social and economic wellbeing of children and adults with epilepsy.



The emotional, social and economic wellbeing service is part of CareEpilepsy's activities and is commissioned to provide early intervention to build resilience, develop positive coping skills and empower them to build the future they want. Our activities include:

- Providing individual and group counselling
- Holding epilepsy support group meetings;
- Provide confidential telephone helpline by staff who are trained extensively in epilepsy to give available treatment options, friendship and support;

Our Activities cont....

04

4. Improving the emotional, social and economic wellbeing of children and adults with epilepsy.

- Promote people with epilepsy's empowerment for self-reliance and sustainable living through providing income-generating training such as craftwork skills.

Our Activities cont....

04

Improving the emotional, social and economic wellbeing of children and adults with epilepsy.

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Our Activities cont....

05

5. Increase advocacy and our partner organizations by 10 to expand our impact and influence on policies that affect people with epilepsy.

- Organize joint epilepsy management training for primary health care workers and midwives with the Ministry of Health, Addis Ababa and Regional Health Bureaus;
- Engage patients to be part of the solution to epilepsy problems;
- Work with other multi-sectoral government agencies to address the medical, social and environmental factors contributing to epilepsy; that affect the lives o

Workshop with multi-sectoral professionals

Our Activities cont....

05

5. Increase advocacy and our partner organizations by 10 to expand our impact and influence on policies that affect people with epilepsy.

- Inspire health professionals to participate in providing free community epilepsy clinic;
- Engage young people as volunteers in improving epilepsy education using their new ideas, energy and enthusiasm.

Neurologists and youth volunteers celebrating the Ethiopian National Epilepsy Week

Why we do what we do

- Epilepsy is viewed as a supernatural phenomenon due to a lack of understanding discouraging modern medical treatment;
- Limited access to and inadequate state of epilepsy care in health institutions, sporadic supply and high cost of antiepileptic medication is the leading cause of disabilities and death;
- Stigma, rejection, bullying and exclusion from the general population are reasons children and adults with epilepsy develop challenging behavior, physical disability, homelessness and begging, drug abuse and psychiatric symptoms such as depression, anxiety and psychotic disorders, including schizophrenia;
- Lack of opportunity for primary health workers for speciality training in epilepsy is the main reason for reduced access to specialist care;
- Lack of knowledge about the facts of epilepsy is the principal cause of child neglect, divorce resulting in women carrying the sole responsibility of raising the child;
- Women are vulnerable and increasingly subjected to displacement, physical, psychological and sexual abuse due to their epilepsy resulting in unplanned pregnancies and emotional problems;
- Life with epilepsy can result in reduced opportunities for education and barriers to human rights ;
- Lack of skills training and denied access to employment due to stigma is the primary cause of permanent dependency on family, poverty and unaffordability to purchase medication and pay for diagnostics;
- The epilepsy problem requires global engagement for a global problem.

How do we fund our programs?

- Fundraising events such as gala dinners and virtual fundraising;
- Volunteers donate their time and expertise;
- Corporate partnerships and company gifts;
- Joint programs in partnership with stakeholder organizations who can share the program's cost, such as training and awareness campaigns;
- Diaspora financial and skills investment into our program.

In 5 years' time, we hope

- Epilepsy will be recognized by the Federal Ministry of Health as one of the priorities of chronic non-communicable diseases with the budget and human resources that it deserves;
- Adoption of CareEpilepsy's successful programmes and initiatives by Ethiopia's Federal Ministry of Health;
- Epilepsy care and treatment will become part of the mainstream health service offered at all local health posts;
- Local service users will be able to run sustainable support group meetings and activities;
- CareEpilepsy will have 1 branche (office) in the regions of Ethiopia;
- CareEpilepsy will have a training institute dedicated to education, training, care and support of people with epilepsy;
- Over 50 new volunteers will have been recruited to work with CareEpilepsy in the regions of Ethiopia;
- People with epilepsy will face less stigma and discrimination because of our community awareness campaigns.

Partner with us

At CareEpilepsy Ethiopia, our vision is to see people affected by epilepsy and associated disabilities receive the quality medical care they need, and the public respect, fairness and understanding they deserve so that they can live a healthy productive life, free from discrimination and stigma, and have opportunity to realize their full potential. Your financial support helps us continue in our mission and assist people living with epilepsy in Ethiopia.

CareEpilepsy relies on the generosity of supporters such as yourself to expand our impact and reach out to more people through a full-service epilepsy clinic where we can provide anti-seizure medication, diagnostic services, and rehabilitation programs.

How to make a donation

By Bank

You can give your bank the details below and your bank will give you a receipt as proof of payment.

CareEpilepsy
Account Number: 11621491
Sort code: 40-07-27 HSBC

50-52 Kilburn High Road
London
NW6 4HJ

SWIFTBIC: HBUKGB4143G
IBAN: GB51HBUK40072711621491

By Post

You can send a cheque or postal order made payable to CareEpilepsy to:

Apartment 39
131 – 143 Belsize Road
London
NW6 4BR

By Direct Debit

You can set up a Direct Debit here or call +44 7802 432943 today