

CLOSING THE EPILEPSY KNOWLEDGE GAP

2023-2024 Program Report

ROW[®]

One World.
One Standard.[®]

It has been said that “knowledge is power.” Knowledge helps individuals, communities, and societies to advance. On the other hand, a lack of knowledge can have the opposite effect of hindering progress and promoting powerlessness. So, how does this connect to epilepsy?

Discussions about epilepsy in low-resource regions typically revolve around the treatment gap, the percentage of people not receiving appropriate care (generally 75% or more). The treatment gap is compounded by an epilepsy “knowledge gap” among healthcare providers, patients, and the public. Beyond delaying and hindering effective treatment, this additional gap creates very serious social and economic challenges for people with epilepsy, whether they receive treatment or not.

For a patient, this lack of knowledge about epilepsy leads to confusion at the doctor’s office over what medicine to prescribe for his or her “spells”. Neighbors avoid people with epilepsy for fear it is contagious, while parents keep children out of school to avoid shaming the family. Raising the level of epilepsy knowledge across the health care, education, and community sectors is key to resolving these issues.

Working together with our partners and generous supporters, ROW is taking action to help remove barriers created by both the treatment and knowledge gaps. We’re proud to share this program report which highlights successes in lessening these gaps that keep people with epilepsy from achieving their full potential.

As always, THANK YOU for your support!



*On behalf of
the ROW team*

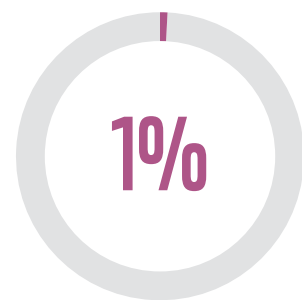
Paul Regan
President, ROW Foundation



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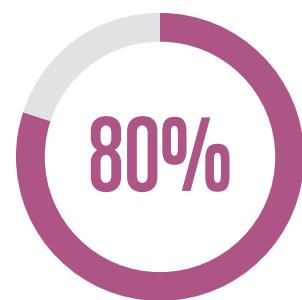
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THE TREATMENT GAP LEAVES AT LEAST 48 MILLION PEOPLE LIVING WITH UNTREATED EPILEPSY IN LOW-RESOURCE REGIONS.



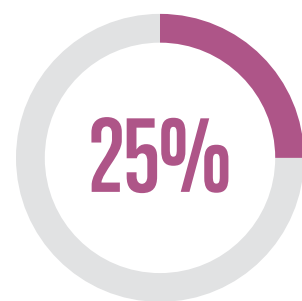
Official estimates of the number of people with epilepsy (PWE) range from 50 - 65 million worldwide, but these figures may be greatly understated.

Epilepsy prevalence is estimated at 1% in countries with confirmed statistics, like the U.S., U.K., and Australia. The current global population above 8 billion supports an estimate of 80 million PWE.



80% of PWE, perhaps 64 million, live in low- and middle-income countries (LMICs).

Epilepsy prevalence is greater in LMICs than in high-income countries.



On average, only one-fourth of PWE receive medical treatment in LMICs.

In some African countries, just 5-10% of PWE can access treatment.



Treatment gaps aren't caused solely by lack of access to health care. In LMICs, the **epilepsy knowledge gap** creates barriers for PWE, even where health care is available. Some examples include:

- Cultural beliefs about epilepsy's origin lead PWE to seek out traditional healers, exposing them to ineffective "cures" and potential abuse.
- Stigma prevents PWE from going to a clinic to avoid association with the condition.
- Lack of epilepsy education can leave health care workers unsure of how to recognize or treat seizures.

As the global population grows, so do the knowledge and treatment gaps. Solutions are needed now to create a better future for those with epilepsy and their families. Together with global partners, ROW is at work to lessen these gaps.



ROW ADDRESSES EPILEPSY TREATMENT AND KNOWLEDGE GAPS THROUGH 3 PROGRAM AREAS

TRAINING

- Health care provider education
- Public awareness initiatives

DIAGNOSIS

- EEG equipment
- Telemedicine clinics

TREATMENT

- Ongoing medication grants
- Emergency shipments

Tackling epilepsy treatment and knowledge gaps requires a team approach. Our social enterprise is designed for sustainable philanthropy.



ROW Foundation

A United States 501(c)(3) private foundation, founded in 2014. ROW ("Rest of World") Foundation serves as the project manager for all ROW projects and partnerships. ROW Foundation is also the conduit for all resources (funding and treatment medication) from OWP Pharmaceuticals.



ROW Global Health

A United States 501(c)(3) public charity, and the newest member of the ROW family. Founded in 2021, ROW Global Health mobilizes resources from the public sector for programs and partners identified by ROW Foundation. While initially focused on epilepsy, ROW Global Health anticipates filling additional healthcare gaps in the future.



OWP Pharmaceuticals

A pharmaceutical company created as part of the ROW social enterprise. OWP's focus is supporting providers and patients in the U.S. with beneficial medications. OWP then donates profits for the common good by supporting humanitarian projects rather than solely maximizing profits.

EPILEPSY TRAINING

TARGETED TRAINING: PEDIATRIC EPILEPSY

Diagnosis and treatment of epilepsy in children is an urgent matter. Untreated seizures can disrupt healthy brain development.

ROW supports training of health care providers (HCPs) at all levels of practice, including basic care in rural communities and clinical care at national hospitals.

Community Health Worker Training - Rwanda Pediatric Association (RPA)

Building on ROW-supported community health worker (CHW) initiatives in Zambia and India, our partnership with RPA began with building knowledge among health care workers on what epilepsy is and how to treat it. As children with epilepsy are successfully treated and CHWs interact with families, epilepsy knowledge expands to the wider community to help reduce stigma.

PET-1 Training - British Paediatric Neurology Association (BPNA)

With funding from BAND Foundation and the International League Against Epilepsy (ILAE), the PET-1 (Paediatric Epilepsy Training) course was presented to non-specialist providers from Zambia and Zimbabwe, including pediatricians, primary care doctors, trainees, and nurses. Because BPNA employs a train-the-trainer model, teams will run the course in their respective countries for colleagues and hold additional courses over the next five years.

Epilepsy remains a significant public health concern in Africa. One in fifty children in Africa are suffering from this preventable and treatable medical condition.

-Biset, Abebaw, Gebeyehu, et. al.
BMC Public Health 24, 771 (2024)

EPILEPSY ASSESSMENT AND MANAGEMENT COURSE (EAMC)

Pretola Global Health and Consulting (UK)

ROW has supported the EAMC annually since its launch in 2021. Growth has exploded from 53 trainees in the first cohort to 720 in 2024! The 3-month virtual course provides core training in epilepsy basics plus specialty topics, at no cost to participants.

Past courses yielded research projects that contributed valuable epilepsy data, which is in short supply across LMICs. New in 2024: the launch of EAMC centers in The Gambia, Malawi, and Nigeria. Participants met to view on-line sessions, then engaged in discussion groups to learn and network.

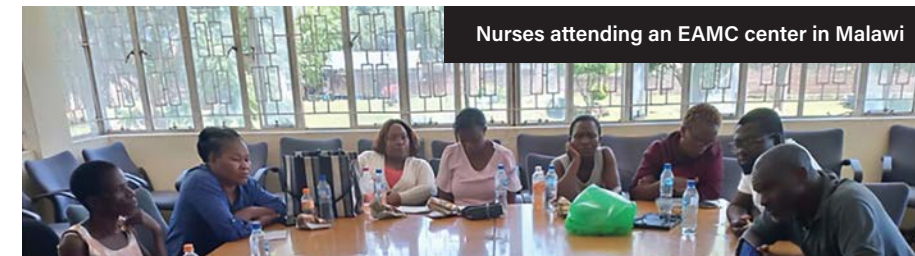


WHAT PARTICIPANTS SAY ABOUT EAMC:

"There were a lot of gaps in management of epilepsy and this training has helped fill those gaps. I've gained more knowledge and will manage our clients with more confidence."

"Looking at the psycho-social problems patients face, especially discrimination and social neglect, was eye-opening. I'll use this knowledge to teach officers and nurses I work with."

"My clinical practice is improving after each session."



SUDEP: Sudden Unexpected Death in Epilepsy

People with epilepsy have a 2 to 3 times greater risk of early death, oftentimes from SUDEP, the sudden death of someone known to have epilepsy with the absence of any obvious cause of death. General SUDEP risk is 1 in 1000, but for those with uncontrolled seizures the risk is 1 in 150.

With high rates of untreated epilepsy, large numbers of people are at risk for early death across LMIC regions. SUDEP awareness among HCPs and patients is also very low, leading Pretola to design a specialized course to address the issue.

NEW training: In August 2023, Pretola offered a one-day SUDEP masterclass. ROW teamed up with *Danny Did Foundation* to fund the training with no fees for participants. Due to large treatment gaps in LMICs and very low awareness of SUDEP, this class provided urgently needed training tailored to LMICs. More than 300 HCPs, advocates, and family members of PWE participated virtually from 50 countries.



ROW Foundation selected Pretola's CEO Tolu Olaniyan to receive the 2023 Amanda Award. This award honors the memory of Amanda Brooke de los Santos, who passed away from seizures at a young age. The award recognizes a leader or organization making significant impact on the epilepsy treatment or knowledge gaps. Included is a grant of \$5,000, co-funded by ROW and Amanda's mother, Lisa.



EPILEPSY DIAGNOSIS IN THE DOMINICAN REPUBLIC



The epilepsy treatment gap across Latin America and the Caribbean averages 50%. Accurate diagnosis with an EEG (electro-encephalogram) helps doctors determine appropriate treatment. ROW Foundation partner and U.K.-based charity *TeleEEG* provides clinical sites in LMICs with equipment, training, and remote EEG reading.

ROW funding enabled *TeleEEG* to launch a clinic at *Hospital Infantil Regional Universitario Dr. Arturo Grullon* in Santiago. *TeleEEG* service allows the public hospital to provide EEGs in the ICU to patients in need. The EEG device is portable and can be used for patients who cannot be transported to the hospital.

This is the 7th telemedicine clinic supported by ROW, including clinics in Ecuador, Sierra Leone, and South Sudan.



"There was previously no availability for EEGs at the public children's hospital in Santiago, the second largest city in the country." -Dr. Andrea Lowden



ROW has also provided multiple EEG workstations to qualified hospitals and clinics, including *CURE Children's Hospital of Uganda*. Where EEGs are not available, patient background and history can help lead to an appropriate diagnosis and treatment plan.

Several diagnostic apps have been developed to aid in this process. Additionally, ROW Foundation is exploring the potential and effectiveness of new low-cost, smart-phone-enabled diagnostic equipment.



TeleEEG clinic at Ola During Children's Hospital in Freetown, Sierra Leone

"It's important to accurately diagnosis epilepsy. With an accurate diagnosis, [TeleEEG] can then target medications to treat the epilepsy correctly. Correctly treated epilepsy can lead to 70% of patients being free from seizures!"

-Dr. Stephen Coates, Founder & CEO TeleEEG



EPILEPSY TREATMENT

CURRENTLY, THERE'S NO CURE FOR EPILEPSY. BUT THERE IS EFFECTIVE TREATMENT.

70%

of patients can live seizure-free with access to the right medication.

In high-income countries, doctors and patients can access a wide range of anti-seizure medications (ASMs). But in LMICs, availability of seizure control options is severely limited.



In the U.S., there are about 40 ASMs on the market. Across LMICs, it is common to have only one or two drugs offered, often older medications like phenobarbital and phenytoin. With additional problems of frequent drug shortages and high prices, many patients find it difficult to stay on treatment.

Since 2016, ROW Foundation has provided stable supplies of effective ASMs to hospitals and clinics in LMICs on four continents. ROW has also met emergency medication needs in the aftermath of natural disasters (Puerto Rico), economic collapse (Venezuela), and war (Armenia, Syria, Ukraine).

OUR TREATMENT PARTNERS

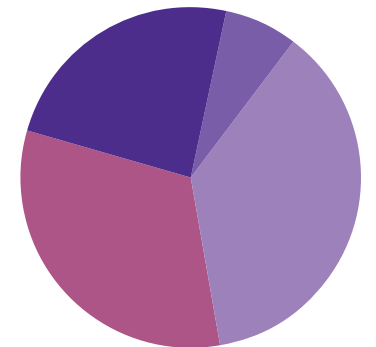
Treatment Grants Made in 2023: \$1,022,311 (USD)

Cumulative Treatment Grants, 2016-2023: \$22,826,771 (USD)



ASMs are not affordable for many families in low-resource regions. For example, epilepsy-affected households in El Salvador spend about \$130 monthly on ASMs. A family living on minimum wage earns just \$300 per month.

- Faith-based Hospitals/Clinics: 24%
- Private Hospitals/Clinics: 7%
- Public Hospitals: 37%
- Non-governmental Organizations: 32%



In 2023, ROW Foundation mobilized 692 cases of ASMs to 21 countries, enough medication to treat approximately 1,500 patients throughout the year.

2023 Prescription Months*: 18,177

Cumulative Prescription Months (2016-2023): 197,561

**A prescription month represents a one-month supply of ASM for a typical epilepsy patient.*

Roweepra[®], donated by OWP Pharmaceuticals and granted by ROW Foundation, offers physicians in LMICs a first-line treatment option.

ROWEEPRA[®]
(levetiracetam tablets USP)

OWP[®]
Pharmaceuticals, Inc.

New partnership in El Salvador: Fundación Compasión Púrpura

After experiencing uncontrolled epilepsy as a young child, Rebeca Figueroa underwent brain surgery at the age of seven. At 11 years, she started *Compasión Púrpura* to help other Salvadoran children with epilepsy. The organization educates communities about epilepsy and secures donations of medical equipment and ASMs. ROW is proud to support this work with ongoing grants of Roweepra while making progress toward our goal of supporting more PWE in Latin America.



IMPROVING TREATMENT CHANGES LIVES.

"I can't express enough how much difference this has made for our family. Without access to medication, Djojip's quality of life would have remained significantly compromised. His seizures were affecting his ability to learn and thrive in school, but the donated medication has given him a chance at a normal childhood and a brighter future."

Madienkoueng Madeleine, Parent
CAMEROON



"Roweepra has helped our patients who were not responding to the phenobarbitone or carbamazepine that is provided by the hospital. Some of our patients have been seizure-free for over a year. We are really grateful."

Fridah Chiwanza, Epilepsy Care Team Coordinator
Chikankata Mission Hospital
ZAMBIA



"I feel good on this medicine."

Dorica Kazonga, Patient
ZAMBIA

"You're changing lives. When you talk about medicine availability, it's very limited. And the medicines have to be purchased. ROW Foundation medications are free. That's a huge barrier that's been lifted. Apart from that, we're able to give it to patients that don't respond to other medication. You're filling in a very important gap."

Josephine Garnem, Executive Director
Healey International Relief Foundation
SIERRA LEONE



"This drug is different from the one I was using. On that drug I never used to know when I was about to have a seizure and fall to the ground. On this new drug, during the times that I usually have an attack, I just have a headache and feel a bit dizzy. Then after some time I feel okay."

Alfred Zulu, Patient
ZAMBIA



"We were using a single drug; phenobarbital. It's a very old drug, made in 1912. ROW Foundation came forward and supported us with Roweepra which we distribute to our patients."

Max Bangura, National Coordinator
Epilepsy Association of Sierra Leone

COUNTRY SPOTLIGHT

SIERRA LEONE

National Challenges

- Still impacted by civil war of 1991-2002
- #182 of 189 in Human Development Index
- Gross national income per capita: \$500 (\$1.37 per day)
- 60% live in poverty

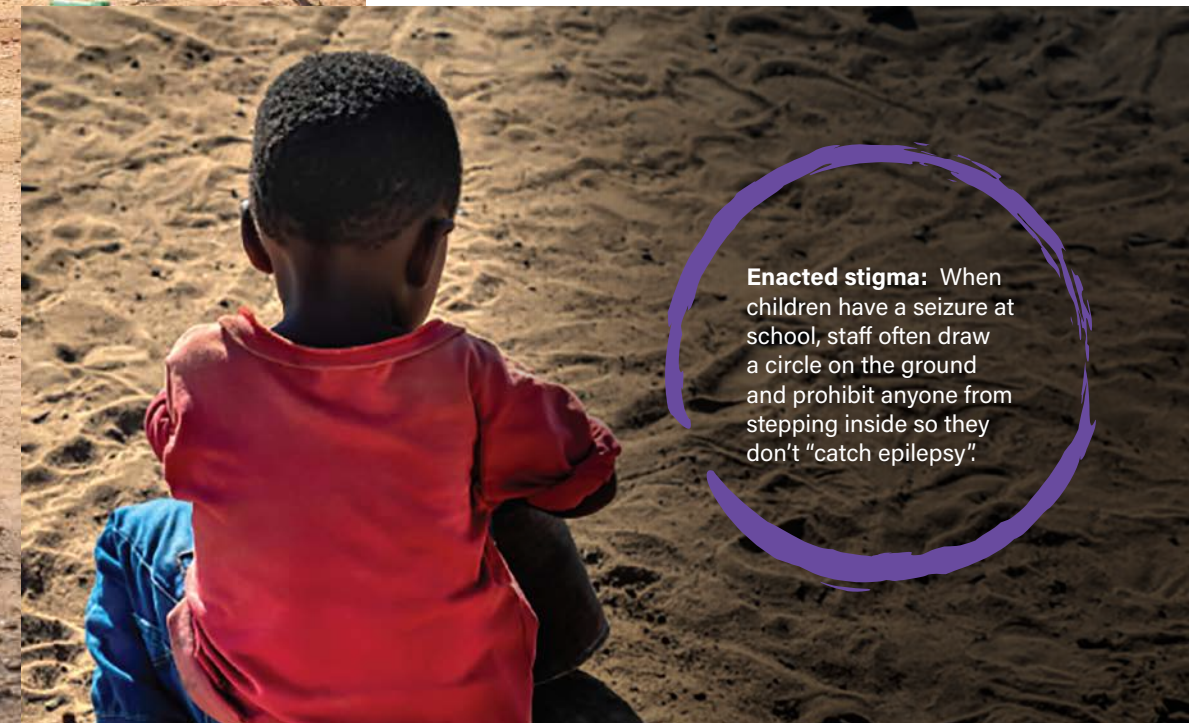
Epilepsy Challenges

- High prevalence: Up to 2% affected
- High treatment gap: 90-95% untreated
- Two neurologists for ~9 million people
- ASMs not covered by public health plan
- Seizures believed to be a spiritual issue
- Extreme cruelty and stigma toward PWE



ROW traveled to Sierra Leone in early 2024 and met many people facing extreme difficulties caused by epilepsy stigma, including:

- A girl forced by her family to sleep in a chicken coop, despite achieving seizure control with medication
- Ten single mothers whose husbands left them for bearing so-called “demon children”
- A mother who saved her daughter’s life by wresting a knife from the child’s aunt who attempted to murder her because she has epilepsy
- A woman whose family told her she should throw away her baby with epilepsy



Enacted stigma: When children have a seizure at school, staff often draw a circle on the ground and prohibit anyone from stepping inside so they don't “catch epilepsy”.



ROW launched its first Sierra Leone partnerships in 2018. Because of the high quality of our partner network and the dire need for epilepsy services there, we've made Sierra Leone a high priority.

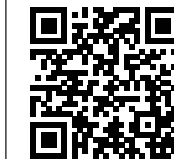
Over the past six years, ROW has:

- Granted 10,000 prescription months of medication to local partners: *Healey International Relief Foundation, Loreto Clinic, Connaught Hospital, Ola During Children's Hospital, and Epilepsy Association of Sierra Leone (EASL).*

- Provided financial support for an anti-stigma campaign, implemented by *Medical Assistance Sierra Leone and Epilepsy Association of Sierra Leone*. This included the distribution of an illustrated children's book, designed to teach kids (as well as teachers and parents) that epilepsy is a treatable medical condition. Schools were encouraged to adopt the "Our School Welcomes Pupils with Epilepsy" campaign and "Yes to Epilepsy" standards.
- Supported two TeleEEG diagnostic clinics with EEG training for eight health care providers.

Like Family

For people with epilepsy abandoned by their families, the local staff of *Healey International Relief Foundation* and *Loreto Clinic* step in to provide love and emotional support. In addition to anti-seizure medication, the team gives hugs and encouragement to community members with epilepsy when others have turned them away.



Videos featuring Sierra Leone partners and their patients are available on our YouTube channel.



CLOSING THE KNOWLEDGE GAP: EPILEPSY AWARENESS IN RURAL ZAMBIA



Mfuwe is a rural region in Eastern Province, Zambia with widespread poverty and a high prevalence of epilepsy. *Mfuwe Epilepsy Foundation (MEF)* is at work identifying patients, diagnosing, and treating epilepsy. From March 2019 to February 2020, MEF's health care team surveyed over 15,000 people in the Kakumbi Chiefdom.

Results suggested a high prevalence of epilepsy in the region--much higher than the global average. Fewer than 20% of those diagnosed receive treatment.



To close knowledge gaps in Mfuwe communities, ROW secured grant funding from *Rotary Foundation* and *BAND Foundation* for a schools-based epilepsy education and anti-stigma initiative in the region. This opportunity was made possible by a host of collaborative partners, including *Mfuwe Epilepsy Foundation*, *Rotary Club of Howard West (Maryland)*, *Rotary Club of Mfuwe, Zambia* *Ministry of Health*, and *Zambia Ministry of Education*.

MEF is initiating meetings with school directors, teachers, students, health workers, and traditional healers to improve knowledge about epilepsy and seizure first aid while encouraging inclusive education for children with epilepsy. The aim is to reduce stigma and promote the integration of PWE into society.



Since 2021, ROW has provided ongoing grants of *Roweepira®* to Mfuwe area patients in partnership with *Dalhousie University (Canada)* and the *Zambia Ministry of Health*. Mfuwe programs are part of our broader initiative to impact epilepsy care in Zambia.

PARTNER WITH US

Your partnership provides essential funding to mobilize medication, epilepsy education, and diagnostic support to those who desperately need it.

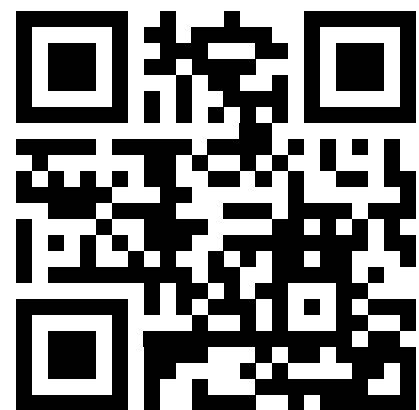
DID YOU KNOW?

Because of ROW's unique social enterprise model, the cost to provide anti-seizure medication to someone for an entire year is only \$20! How many more lives can you help us change?



Leave your legacy

CONSIDER A GIFT TO ROW TODAY TO MAKE AN IMPACT ON THE "REST OF WORLD"



Multiple ways to give:

- Securely online at rowglobal.org/donate
- Through your Donor-Advised Fund (DAF)
- Company-matched giving programs
- Gifts of stock

Or contact us today to discuss your giving goals!



ROW Foundation was registered in 2014 and, once again, has earned the Candid (formerly Guidestar) Platinum Seal of Transparency. Only 0.5% of non-profits registered with Candid achieve this recognition for transparency in reporting financial information and progress toward organizational mission.

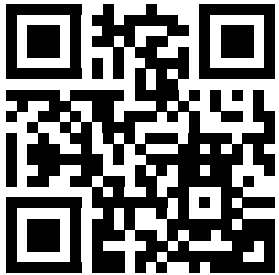


OUR WORLD IS ALWAYS EXPANDING!

What began with one EEG workstation sent to a pediatric hospital in Armenia has grown into so much more. Through our partner network, ROW-supported programs have impacted epilepsy treatment and quality of life for epilepsy patients in 69 of the world's 132 low-income and middle-income countries.

Partner with us to reduce the global epilepsy treatment and knowledge gaps!





**EPILEPSY IS GLOBAL.
EPILEPSY IS PERSONAL.**



One World.
One Standard.®

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