



One World.  
One Standard.®

2019 PROGRAM REPORT

# FOCUS ON AFRICA

Addressing the  
treatment gap faced  
by ten million Africans  
living with epilepsy

## A Privilege!

In June, I had the privilege of visiting a key partner of ROW in Mbale, Uganda. This children's hospital is doing world-class neurosurgery for very poor patients, as well as providing treatment medication to children with epilepsy. Our partnership is an important part of a deliberate effort by ROW to expand our activities in Africa. In fact, 9 of our 19 project countries are on the continent.

So, why Africa? While ROW also helps address the treatment gap in the United States, following our mission leads us more often to under-resourced countries and regions. And that means a presence in Africa. Eighteen out of the 20 world's poorest countries are there. And, for those with epilepsy, poverty translates directly into a devastating lack of treatment options.

Just how wide is the epilepsy treatment gap in Africa? While the gap is often below 10% in wealthy countries, it is more than 90% in many African countries. Additionally, because of high levels of stigma and superstition, African children with epilepsy are often forced out of school, while adults are ostracized from their communities. It is truly a very serious problem for millions of families.

Our partnerships in Africa support epilepsy diagnosis, training, and treatment, as well as the equipping of community health workers to support affected households. This report highlights some of these partnerships. In it, you will meet a few people whose lives you have touched in Africa and beyond by your support for the ROW Foundation. It was both an exciting and impactful year! Thank you for being a part of it!

With much appreciation,



Ken Koskela  
Director of Global Programs / Acting President



## Untreated epilepsy in Africa

### Why is the treatment gap so large?

Approximately 80% of the 50-70 million people affected by epilepsy live in lower-resource regions where access to appropriate care is lacking. While the gap in low- and low-middle income countries is estimated at 75%, in many African countries a staggering 90% or more are left untreated. The epilepsy treatment gap is caused by numerous factors:

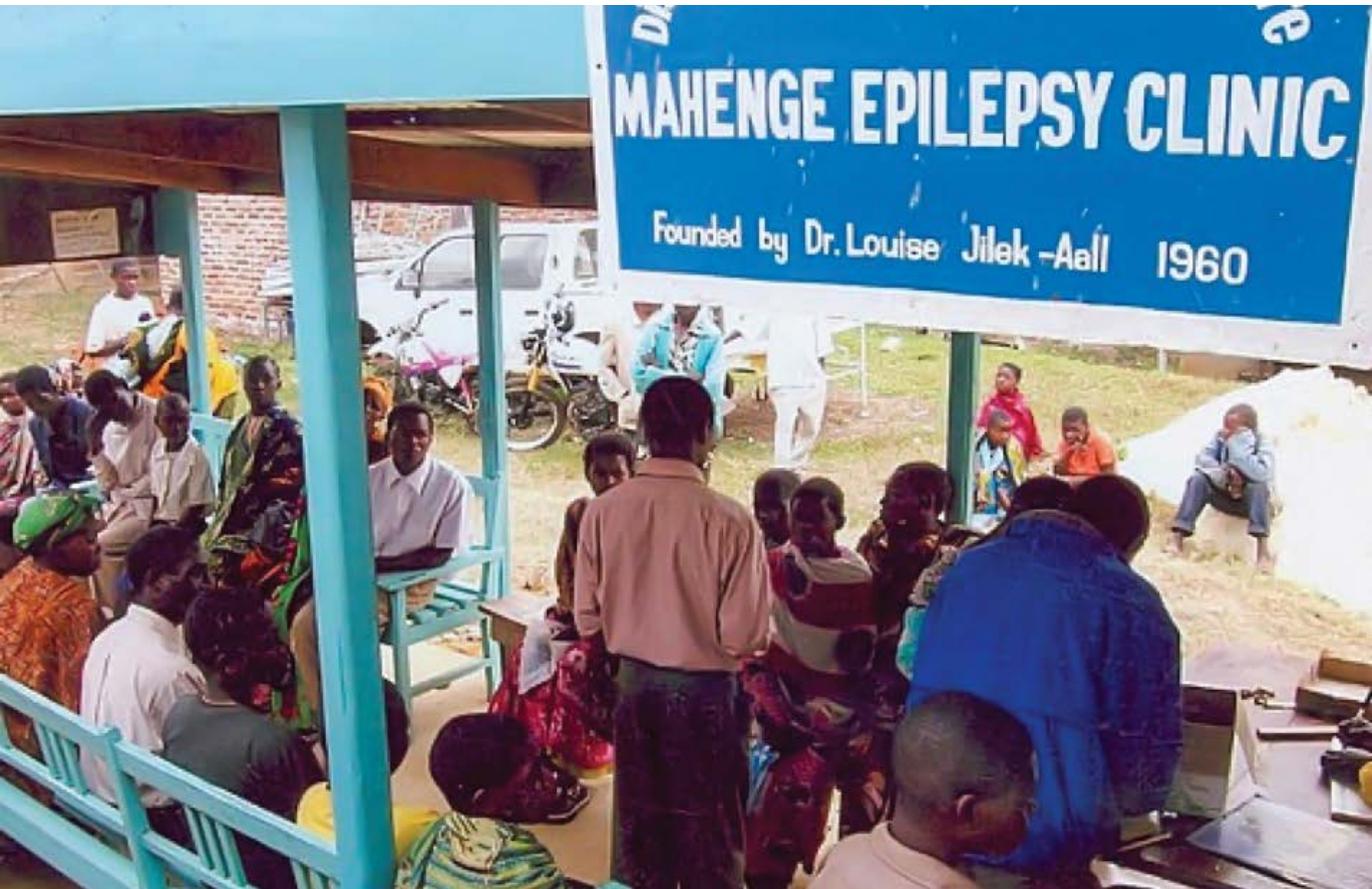
- 1 Individuals with the skills to diagnose and treat epilepsy are in short supply – It's not uncommon to have 0-2 neurologists in an entire country.
- 2 There is a lack of medical equipment to diagnose epilepsy – EEG machines and skilled technicians to record EEGs are not widely available.
- 3 There is a lack of awareness of effective treatment options – Many believe seizures are caused by evil spirits, leading families to seek care from traditional healers first.
- 4 Diagnosis and treatment are not affordable – The costs of healthcare, including travel, can be prohibitive for many.
- 5 The best quality medications are not widely available – Beyond that, frequent shortages of medication occur.

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***It is estimated that most clinics and hospitals in Africa have one antiepileptic medication available only 50% of the time.***

Archana Patel,  
MD, MPH

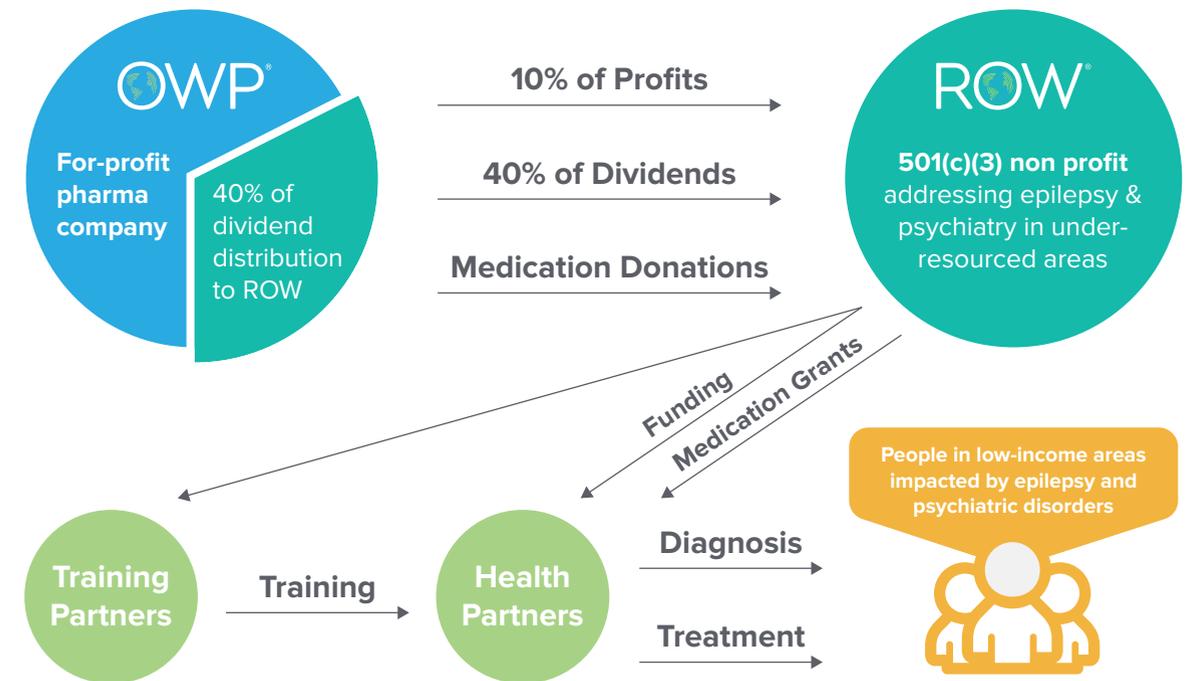
## Our Mission



The ROW Foundation works to improve the quality of training, diagnosis and treatment available to people with epilepsy and associated psychiatric disorders in under-resourced areas of the world. We partner with other organizations to maximize impact in under-served areas, both domestically and internationally.

## Our Model

### The Pharmaceutical Social Enterprise<sup>®</sup>



The ROW Foundation and OWP Pharmaceuticals form a unique social enterprise. The foundation will hold a large ownership stake in the business. Significant shares of OWP profits will flow to ROW, providing an ongoing source of revenue to carry out our mission. OWP also donates generous quantities of Roweepra<sup>®</sup> (levetiracetam USP) and Subvenite<sup>®</sup> (lamotrigine USP) for ROW Foundation treatment grants.

# 2019 - A Year of New Horizons

## New Partnerships Formed

- » Armenia Artsakh Fund
- » Boston Children’s Hospital
- » Grenada General Hospital
- » Loma Linda University Health
- » Provision Charitable Foundation
- » Syrian American Medical Society
- » TeleEEG
- » UTH Pediatric Hospital
- » West Atlantic Brain and Stroke Foundation
- » Yale University

(35 partners cumulative)

## Additional Countries Reached

Grenada, Malawi, Suriname, Syria, Tanzania, Zambia and Zimbabwe

(19 countries cumulative)



## Subvenite Introduced

This year, ROW began making grants of Subvenite, providing another anti-seizure drug option for low-resource patients in Armenia, Grenada, Sierra Leone and Tanzania.

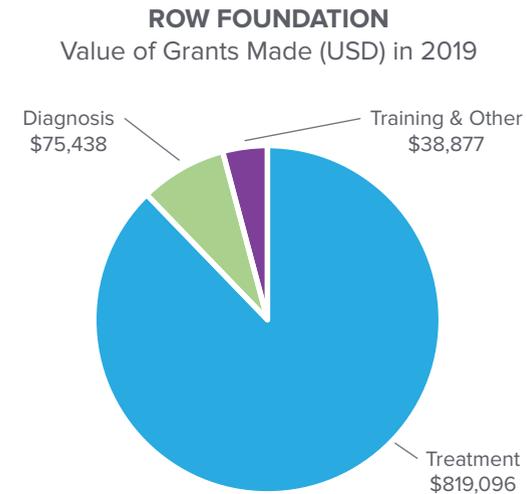


## Reaching patients outside the capital cities

ROW funded an initiative to improve epilepsy care for children in a low-resource compound just outside of Lusaka, Zambia, using a community health worker and advocacy approach.

## Launching into psychiatric care

ROW began a partnership with Yale University to increase access to treatments for mental and neurological disorders in Nigeria. This program provides training and clinical support in rural communities to screen for and manage these disorders.



In 2019, ROW provided **29,525** prescription months of life-changing and life-saving medication. This brings the cumulative total to **94,168** prescription months. (2016-2019)

Grants Made (USD)	2019 Grants Made	Cumulative Grants Made
Treatment	\$819,096	\$4,995,002
Diagnosis	\$75,438	\$199,301
Training & Other	\$38,877	\$49,577
<b>Total</b>	<b>\$933,411</b>	<b>\$5,243,879</b>

# Partnerships in Africa

## CURE Children’s Hospital of Uganda

*Advanced neurosurgery, compassionate care*

Ken Koskela visited the hospital in June, seeing firsthand the dedication of the **CURE** staff and the positive impact our grants of Roweepra have made on local families. Ken met several young patients who have gained seizure control on Roweepra after their previous medications proved ineffective.



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In October, ROW helped secure donor funding and a gift-in-kind grant from **Natus Neurology** for a 256-channel EEG workstation for the hospital. This equipment will allow in-depth monitoring of epilepsy patients and new surgical options for those not responding to medication.

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**Thank you. You have changed our world.**

Esther Nalule, Epilepsy Program Director

ROW makes ongoing medication grants to eight hospitals and epilepsy clinics in Malawi, Nigeria, Sierra Leone, Tanzania, Uganda and Zambia. Throughout Africa, patients have a limited choice of anti-epileptic drugs. Grants of Roweepra and Subvenite provide access to more contemporary options for seizure control.



## Guiding Light Orphans (GLO)

*Limited resources, high impact*

**GLO** holds monthly epilepsy clinics, deploys “peer ambassadors” to encourage new patients and offers job skills training in Masindi, Uganda. ROW selected GLO to receive the 2019 Amanda Award in recognition of their holistic epilepsy care model. ROW social media followers joined the “Grow GLO” campaign and pledged over \$3600 to GLO’s medication fund.



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**I am very appreciative of the services I receive here every month. Not many people can access this kind of service. I have been seizure-free for almost two years now.**

Raphael,  
Epilepsy Patient

## Global Organization for Health Education (GOHE)

*A vision for Africa, and the world*

**GOHE** training programs funded by ROW in Ethiopia, Nigeria and Zimbabwe build capacity for epilepsy diagnosis in Africa. GOHE is passionate about delivering quality neurodiagnostic education in under-resourced countries through distance learning and a volunteer network of clinical trainers. GOHE’s work extends beyond Africa to include India with plans for expansion to Latin America.



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**This organization offers free and quality education in developing countries. Today I set out on my first mission to Harare representing GOHE. I will freely share the knowledge I have acquired.**

Elsa Yenshe,  
Neurodiagnostic  
Trainer, South  
Africa

## Supporting Providers and Patients

### Primary Care Providers in Nigeria

ROW's first psychiatry grant funded training for 27 primary care providers through the HAPPINESS Project, an initiative of the **Yale University** Global Mental Health Program. Due to a severe lack of psychiatrists and neurologists in Nigeria, PCPs are trained to recognize and treat epilepsy, mental health conditions and addiction, with specialist support.

### Pediatric Neurologist in Sierra Leone

Dr. Alusine Jalloh is one of only two neurologists in the country and the sole pediatric specialist. ROW provided funding to **Medical Assistance Sierra Leone** for Dr. Jalloh to attend an ILAE-sponsored EEG training course for neurologists in Cambridge, UK.

### Women in Tanzania

Our medication grant to **Provision Charitable Foundation | Mahenge Epilepsy Clinic** provides pregnant epilepsy patients with Subvenite, including titration kits for new patients and maintenance doses. This grant supplements government supplies of lamotrigine to ensure that medication is available to these women on a consistent basis.

### HIV Patients in Malawi

An ongoing grant of Roweepra to **Loma Linda University Health** provides anti-seizure medication to two hospitals in Malawi. The doctors value access to levetiracetam for HIV-positive patients with epilepsy, due to lower drug interaction with HIV medications.



# Emergency Response

## ROW Foundation is committed to providing medication humanitarian aid to meet emergency needs in times of crisis.

*For people with epilepsy, an interrupted supply of medication means the loss of seizure control. Twenty-six percent of ROW's treatment grants have gone to support individuals during national crises.*

### Venezuela

Through our partnership with **Cuatro por Venezuela**, we have shipped over 16,000 bottles of Roweepra, supporting thousands of epilepsy patients affected by medication shortages.

### Syria

A new relationship with the **Syrian American Medical Society** enabled us to provide Roweepra to several hospitals in northern Syria. Shipping of the grant was generously provided by **Direct Relief**.



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***My daughter with epilepsy has benefited from your medication for the past two years. I do not have money to buy medication for her. Thank you for your support.***

L. Gonzalez, Venezuelan Parent

# Epilepsy Congress

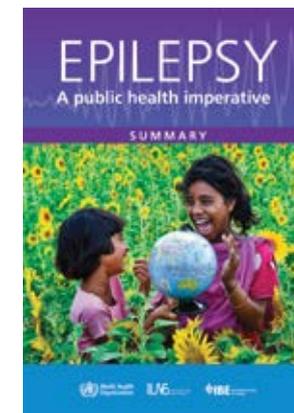
## 33rd International Epilepsy Congress Bangkok, Thailand



ROW attended its first joint congress of the **International League Against Epilepsy (ILAE)** and the **International Bureau for Epilepsy (IBE)** in 2019. ROW staff met with global epilepsy leaders, participated in the ILAE Access to Treatment Task Force meeting and attended educational sessions.

The Global Epilepsy Report also made its debut at the congress — the first global document on epilepsy, published by the **World Health Organization, ILAE and IBE**.

ROW Foundation contributed to the landmark publication by donating the work hours of 2018 intern Michael Stanley for survey development and data analysis conducted by a joint task force of ILAE and IBE.



# Reaching the Unreached

While under-resourced urban communities face a myriad of challenges, it is the individuals from outlying rural and peri-urban communities that are the last to afford and have access to a wide range of services, including health care. Community health workers (CHWs) have been instrumental in delivering low-cost care to those without previous access.



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CHWs are not typically equipped to support epilepsy care, but ROW Foundation believes they hold great potential for helping reduce harmful stigma, identifying patients in need, and connecting them to treatment options.

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Through generous donor support, we have launched a new partnership with **Boston Children’s Hospital** to impact children in a peri-urban area of Lusaka. In this pilot study, a team of community health workers will reach families with children affected by epilepsy, providing education on accessing care, how to use medication, and seizure first aid and precautions.



18-year-old Alimatu had taken anti-seizure medication for a few years but suffered side effects of poor concentration and memory loss. She took the same senior exam three times and failed because she was unable to study properly. After starting treatment with Roweepra this year, she stopped experiencing memory loss and is now doing very well at school.

# PARTNER WITH US ... AND CHANGE SOMEONE’S WORLD!



**It doesn’t cost a lot to create change for people with epilepsy in under-resourced countries.**

About 70% of epilepsy patients achieve seizure control with medication. Medication is relatively inexpensive, costing as little as \$1 per patient, per month. Yet **millions** of people remain untreated worldwide.

A basic EEG unit packaged with training and remote reading service is available for about \$8000. The impact of this single gift can be felt by hundreds of patients, and their families, for years to come.

With your contribution to programs like these, lives are improved, transformed, saved.

Because of our unique relationship with OWP Pharmaceuticals, **100% of your designated donation goes directly to ROW’s programs.** Your involvement helps us deliver more change to more people, more quickly.

Please reach out to us at [info@rowpharma.org](mailto:info@rowpharma.org) or visit [rowpharma.org](http://rowpharma.org).

\* ROW Foundation is a non-profit 501(c)(3) private foundation.



***For us, it is so gratifying to be even a small part of. Thanks for the vision you bring to it all and for connecting us with this project. My heart just feels filled up.***

Lisa,  
ROW Foundation  
Donor



EPILEPSY IS A GLOBAL PROBLEM  
THAT DESERVES A GLOBAL SOLUTION.

Learn more at: [rowpharma.org](http://rowpharma.org)



ROW Foundation has earned  
the GuideStar Platinum Seal  
of Transparency



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