

*Solutions in*  
**Global  
Epilepsy**

ROW<sup>®</sup>  
PROGRAM  
REPORT  
2021-2022





*Dear Friends,*

Epilepsy is a chronic non-communicable disorder of the brain that affects an estimated 65 million people worldwide. It's characterized by recurrent seizures in people of all ages. Risk of premature death for those with epilepsy is two-to-three times higher than in the general population. Fear, discrimination, and social stigma have surrounded epilepsy for centuries.

Fortunately, epilepsy is treatable with medication in about 70% of cases. In economically developed regions, most people with epilepsy live seizure-free lives thanks to effective, widely-available treatments. However, in low- and middle-income countries—where about 80% of those with epilepsy live—the reality is very different.

In lower-resource regions, access to care is lacking, stigma is widespread, and people with epilepsy find all facets of life impacted by the condition. While the average treatment gap across these regions is 75%, in many countries a staggering 90% or more are left untreated.

It's our mission to change this. ROW Foundation, together with OWP Pharmaceuticals, has worked to address the epilepsy treatment gap since 2015. In 2021, we welcomed the newest member to the ROW family of organizations, ROW Global Health — a U.S. 501(c)(3) public charity established to make it easier for others to join this effort.

Thank you for your ongoing support of our mission. With your help, ROW reached a new milestone in 2021: We have now formed partnerships to address the treatment gap in 30 countries! I hope you enjoy reading this report and seeing what we're accomplishing together.

With much appreciation,

Paul Regan, President  
ROW Foundation

# Epilepsy is a global problem that deserves a global solution.



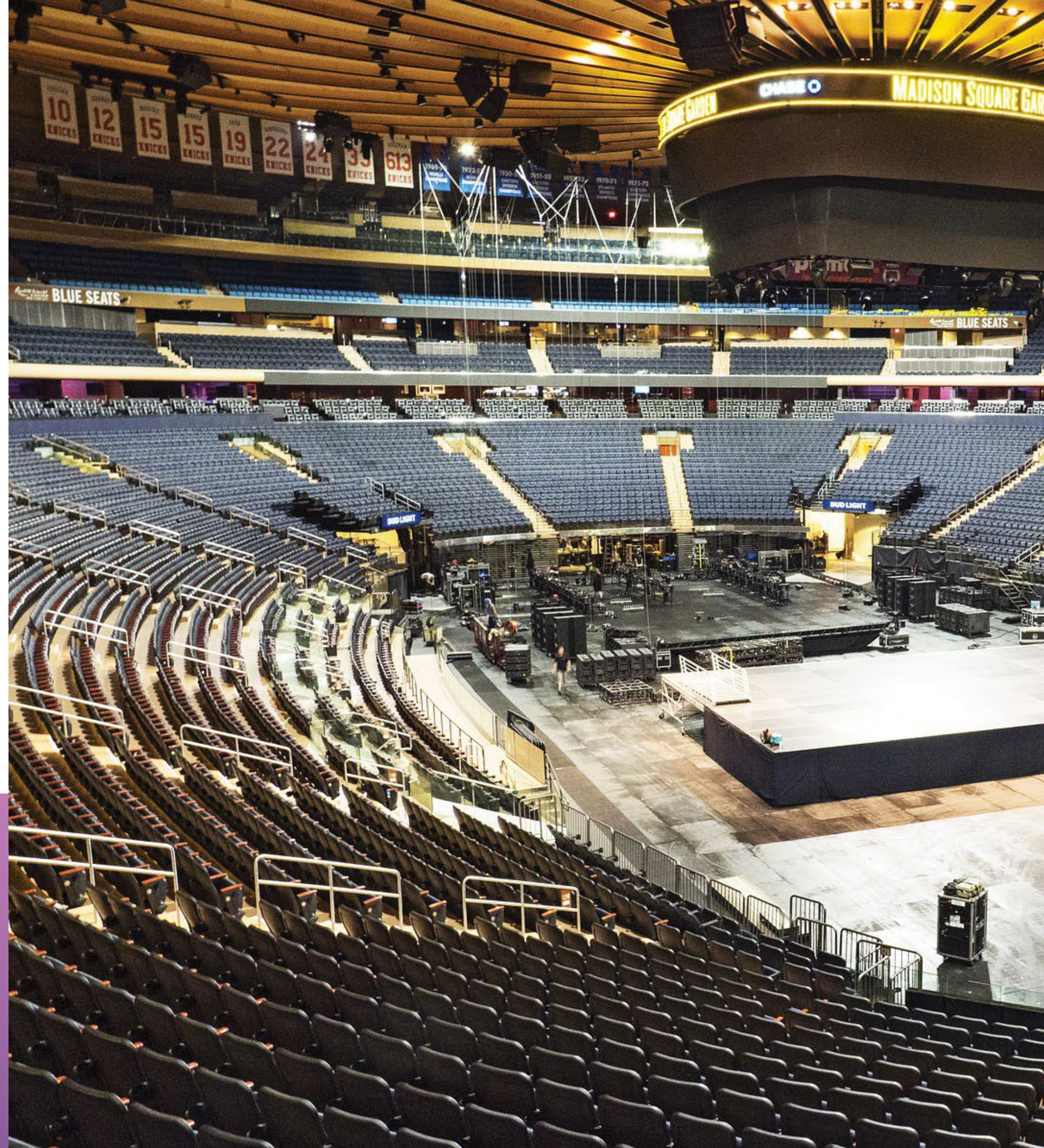
## Just how big is the global epilepsy treatment gap?

Estimates indicate a staggering 39 million people in low- and middle-income countries go untreated—enough to fill Madison Square Garden every day for five years and two months. Up to 70% of them could gain seizure control, but tragically, they can't access anti-seizure drugs that can cost as little as a cup of coffee each month. Children are particularly vulnerable as delayed recognition of seizures can result in significant developmental impairments.

Beyond the massive size of the treatment gap, it's personally devastating for those caught in it. Living with untreated epilepsy means enduring more than medical harm. Discrimination, social stigma, isolation, and assaults are common. Human rights violations are widespread, including denial of an education, employment, and the right to marry. People with epilepsy are often assumed to be spiritually possessed and are cut off from their communities.

## Addressing the gap

ROW Foundation, ROW Global Health and OWP Pharmaceuticals (OWP) represent the world's first epilepsy-focused social enterprise. OWP's revenues and donated medication combine with ROW Global Health's philanthropic capital to expand ROW Foundation's ability to address medical and social treatment gaps.



### THE GAP

**Madison Square Garden filled 1,876 times**

“

*Globally, the burden of epilepsy is huge: Of the top 5 chronic conditions among children and adults, epilepsy is the costliest and second most common.*

[cureepilepsy.org](http://cureepilepsy.org)





## Focused on the “Rest of World”



### ROW's Origins

#### A GLOBAL NAME FOR A GLOBAL MISSION

The names “ROW Foundation” and “ROW Global Health” trace back to co-founder Scott Boyer’s pharmaceutical consulting days. In reviewing sales data, Scott noted high sales figures for wealthy sectors like the U.S., Japan, and the European Union. While there were moderate sales in emerging markets like China and India, most remaining countries were consolidated into one negligible category titled “ROW,” or “Rest of World.”

Though overlooked as markets by most pharmaceutical companies, these ROW countries are where the majority of the global population lives, often in poverty and unable to afford the standard healthcare available in high-income countries. Scott named the “ROW Foundation” in honor of those living in the Rest of World, with the name serving as a constant reminder to all why OWP and ROW exist.

## The ROW Family of Organizations



**ROW Foundation** – A U.S. 501(c)(3) private foundation founded in 2014, ROW Foundation serves as the project manager for all ROW programs. The foundation is the conduit for all resources (funding and medication) from OWP and ROW Global Health.



**ROW Global Health** – A U.S. 501(c)(3) public charity founded in 2021, ROW Global Health mobilizes resources from the public sector for ROW Foundation programs. While initially focused on epilepsy, ROW Global Health anticipates addressing additional healthcare gaps in the future.



**OWP Pharmaceuticals** – A for-profit pharmaceutical company founded in 2014 along with the ROW Foundation as a “pharmaceutical social enterprise” supporting U.S. providers and patients with beneficial neuroscience medications. OWP shares profits and medication with ROW Foundation, leveraging commercial success for the common good through ROW humanitarian projects.

### How We Work

To address the epilepsy treatment gap, ROW focuses on partnerships in four critical areas and is inclusive of children and youth in each:



Improving epilepsy care through **training** of healthcare workers and by providing critical **diagnostic tools**



Expanding access to modern **medication** where not available or affordable locally



Supporting **epilepsy education** to address harmful stigma and discrimination



Meeting the greatest needs, including people with epilepsy in **rural communities** and those impacted by emergencies



# Improving Epilepsy Care



## Epilepsy Training for Doctors and Nurses

*Epilepsy Assessment and Management Course (EAMC):*  
**Pretola Global Health & Consulting**

Shortages of medical personnel trained in epilepsy contribute to the treatment gap. ROW supported two cohorts of the EAMC to train providers at the primary care level.

**EAMC 1.0 (2021)** – The online course trained 54 providers in 12 countries. Participants contributed to research with journal articles on status epilepticus treatment gaps and epilepsy mental healthcare published in *Epilepsy & Behavior*.

**EAMC 3.0 (2022)** – This expanded course enrolled 290 clinicians – a global cohort reaching 36 countries in Africa, Middle East, Asia, Latin America, and the Caribbean.



*The EAMC has improved my clinical practice and helps me manage epilepsy patients with more confidence. I'm an aspiring neurologist and epileptologist, so this course is a solid foundation for my career.*

**Dr. Mundih Noelar Njojham, Cameroon**

## Improvements to Pediatric Epilepsy Unit in Zambia

### 2021 Amanda Award

ROW presents this award annually in memory of Amanda Brooke de los Santos who passed away from seizures at a young age. In 2021, Amanda's mother Lisa personally presented the award to child neurologists Dr. Kafula Lisa Nkole and Dr. Nfwama Kawatu in Zambia. A cash grant accompanies the award and will

be used to make child-friendly improvements to an area of **UTH Children's Hospital** where young epilepsy patients are treated.



## TeleEEG Telemedicine Clinics

*With an accurate diagnosis we can target medications correctly, leading to about 70% of patients being free from seizures. This equates to around 35 million lives saved.*

**Dr. Steve Coates, TeleEEG**

TeleEEG provides EEG equipment, conducts training and provides access to remote EEG reading by its network of skilled EEG interpreters. This telemedicine approach delivers diagnostic services to underserved regions. ROW funding will support two new clinic installations in Sierra Leone in 2022.

## EEG Machine for Pediatric Epilepsy Unit

One of ROW's early grants provided EEG equipment to diagnose epilepsy in the pediatric intensive care unit (PICU) of Santokba Durlabhji Memorial Hospital in Jaipur, India. The PICU has 25-30 neurologically-affected children admitted each month and had no EEG unit to diagnose epilepsy. Instead, they borrowed one from the adult neurology department. With ROW funding, the PICU got its own machine. Children with seizures no longer need to wait a week or more or forgo critical testing altogether.

The equipment is still in use four years later, testing about 15 children monthly.

*The EEG machine has been life-saving equipment for our children with seizures admitted to the pediatric intensive care unit.*

**Dr. Vivek Jain, Pediatric Neurologist**



# Expanding Access to Medication

## Sometimes it's simply access to the right medication

The centerpiece of our work this year: Ongoing grants of anti-seizure medications donated by OWP Pharmaceuticals.

When patients can access the right medication for their seizures, *lives are transformed!*



In 2021, we granted more than 16,000 patient prescription months of anti-seizure medication to partner organizations, generously donated by OWP Pharmaceuticals—a quantity sufficient to treat more than 1,300 patients for one year.

Our cumulative total has reached more than 160,000 treatment months granted during the past five years. These months of treatment represent seizure reduction and seizure freedom for thousands of people living with epilepsy.



**Aminata** from Jorma, Sierra Leone has attended the Moyamba epilepsy outreach clinic since 2018. Previously, she saw a traditional healer for monthly seizures. Several times she had seized and fallen near a cooking fire, burning her face and arm.

It's a two-hour walk to the clinic, but Aminata says Roweepra makes her life better. Her seizures are under control, so she can care for her three children and provide for them with the crops she grows.

“ *The treatment gap for epilepsy is unacceptably high . . . 70% of people with the condition can be seizure-free when they have access to medicines that can cost as little as US\$5 per year.* ”

Tarun Dua, World Health Organization

**ROWEEPRA<sup>®</sup>**  
(levetiracetam tablets USP)

Ongoing, sustainable grants to 28 hospitals, rural clinics and epilepsy associations in 16 countries

**Subvenite<sup>®</sup>**  
(lamotrigine tablets, USP)

Supporting patient study group for epilepsy research in Mahenge, Tanzania

Ongoing grants to nine additional clinical sites

Bulk shipments to the **Venezuelan League Against Epilepsy** and clinics across Venezuela

**Sallieu** also receives Roweepra from the quarterly clinic at Moyamba. This outreach is conducted by **Loreto Health Services** and it's the sole access to anti-seizure drugs available in the southern part of the country. Only 10% of Sierra Leoneans with epilepsy receive treatment.

Sallieu happily reports that his seizures are controlled! He has since encouraged others to seek treatment at the clinic.







“

*If we are able to reach more areas with general awareness about epilepsy, schools and colleges will not hesitate to encourage students to pursue their education.*

Shelly Gandhi, India Program Manager



# Epilepsy Education

## Addressing harmful epilepsy stigma by engaging children and youth in schools in India

One-sixth of all people with epilepsy globally live in India, where treatment gaps reach 90% in rural areas. Epilepsy is so stigmatized in parts of the country that, according to one study, 70% of married women with epilepsy concealed it from their husbands.

ROW believes that change begins with young people, which is why we support epilepsy education among children and youth in schools. Focusing on students and also engaging with teachers and administrators is critical.

During a recent site visit in Shahpura, India, we visited several schools and not a single student with epilepsy was present. Multiple sources reported that about 90% of kids with epilepsy are held out of school; often by parents, but schools and teachers share the blame. There may also be children in school who conceal their condition, due to stigma. Epilepsy stigma denies many children their education, resulting in lifelong disadvantages.

## Community-based education and leadership development in Uganda

Addressing the treatment gap at the community level is everyone's responsibility. It's about community-wide change and also about developing leaders among those with epilepsy.

In November 2021, ROW visited Uganda where our partner Purple Bench Initiative (PBI) mobilizes "epilepsy smart communities." With ROW's support, PBI targets entire communities with epilepsy education — and it's working! One memorable example was when a man with epilepsy spoke in front of his village. Epilepsy awareness in his community means he can now work as a barber. His neighbors no longer fear contracting epilepsy by associating with him, even allowing him to cut their hair.

PBI also develops leaders who have epilepsy as role models. One man explained to the community how he heard his entire life that he could not do certain things (hold a job, for example) because of his epilepsy. He finally decided to stop listening to the negativity and became a successful local businessperson. Today he volunteers with PBI to inspire others with epilepsy to ignore limits imposed by others. His changed life reflects the value of mentorship and leadership development.

“ *The stigma and discrimination that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves.*

World Health Organization





## Our Commitment to Rural Communities



Poor healthcare infrastructure, poverty, and pervasive social stigma mean people with epilepsy in rural areas of lower-income regions usually live with untreated seizures. We've chosen to develop initiatives that provide community health worker (CHW) care delivery, telehealth, and online healthcare training to narrow epilepsy treatment gaps:

- CHW programs in Zambia, India, and Rwanda
- Epilepsy telehealth call center in India
- Ongoing medication supplies to seven rural clinical sites

The pilot program in Zambia resulted in increased numbers of children receiving treatment and 75% were successfully treated with medication. Seizure control helps children with epilepsy stay in school and assimilate into their communities.

## Epilepsy Telehealth for Rural India

**Dr. Mamta Bhushan Singh**  
**Jan Swasthya Sahyog**

COVID caused a sharp pivot in the direction of our developing CHW program in India. With the focus shifting from CHW activities to implementation of a telehealth call center, prior patients of a mobile epilepsy clinic on the Lifeline Express have been receiving follow-up calls and care.

Patients records from more than 100 clinics are under review for follow-up contact. More than 800 patients have been reached in late 2021, with 70 requiring immediate neurological care. The telehealth center is credited with providing a critical referral for a child with drug-resistant

epilepsy who needed, and promptly received, brain surgery in New Delhi.

For rural patients, the telehealth center is a crucial link to services usually only accessible in urban centers.





# Responding in Times of Crisis

## Ongoing Support for Venezuela

This was our fourth year partnering with **Cuatro por Venezuela** to deliver anti-seizure medication (ASMs) to patients in need.

More than 7,400 prescription months of Subvenite® was delivered to **LIVECE (Venezuelan League Against Epilepsy)** and numerous clinics in 2021.



## Conflict in Ukraine

In early March 2022, ROW began a series of shipments of ASMs to support Ukrainians with epilepsy. The Emergen Foundation in Warsaw, Poland successfully delivered the initial shipment to western Ukraine for distribution to neurology centers and physicians, with oversight by the Ukrainian League Against Epilepsy.

Through the generosity of OWP and in coordination with partners in the U.S., Poland and Ukraine, ROW has made grants of ASMs totaling more than 2,500 bottles. Future medication grants will support ongoing needs of refugees in Poland and donations from ROW supporters will fund wholesale ASM purchase within Europe for expedited delivery into Ukraine.



## COVID-19 in Uganda

A livelihood grant purchased goats for families affected by epilepsy, providing income opportunities during COVID-19 lockdowns and beyond. Even under normal conditions, people with epilepsy experience higher rates of unemployment.

Emergency assistance during lockdown helped young Passion visit a doctor and resume treatment with anti-seizure medication.







# A Global Response to a Global Problem



*61 partnerships in 30 countries since 2015*

## GRANTS MADE AS OF 2021 (DOLLAR VALUE)

Grants Made (USD)	2021 Grants Made	Cumulative Grants Made
Treatment	\$1,832,501	\$21,064,942
Training	\$ -	\$241,813
Diagnosis & Other	\$14,754	\$80,001
<b>Total</b>	<b>\$1,847,255</b>	<b>\$21,386,756</b>

## TOTAL # OF PRESCRIPTION MONTHS AS OF 2021

2021 Prescription Months	Cumulative Prescription Months
<b>16,869</b>	<b>160,449</b>

## New Partnerships, 2021

Pastoral Social Arquidiocesana Asunción	Paraguay
Epilepsy Medicare Foundation	Pakistan
Jan Swasthya Sahyog	India
Edward Francis Small Teaching Hospital	Gambia
CBC Health Services	Cameroon
Rachael K Foundation (U.S.)	Kenya
Dalhousie University (Canada)	Zambia
Chipata Community Hospital	Zambia
Chikankata Epilepsy Care Team	Zambia
BAND Foundation (U.S.)	Rwanda



# New U.S. Public Charity



Although ROW Foundation was conceived as part of a social enterprise with OWP, other contributors have chosen to support our work around the world.

To facilitate participation by all donor types, we've created a new public charity. Through donor support of **ROW Global Health**, we anticipate greater acceleration of our efforts to narrow epilepsy treatment gaps.

# ROW Global Health Giving Options

ROW Global Health offers streamlined giving options including:

- Direct giving from [Donor-Advised Funds \(DAF\)](#)
- International donations accepted via ROW's charity fund facilitated by [TrustBridge Global](#)
- Secure online donations at: [rowglobal.org/donate](https://rowglobal.org/donate)



## Available funding opportunities include:

- + EEG/telemedicine epilepsy clinic
- + Epilepsy training for pediatricians
- + Empowerment program for women and girls with epilepsy
- + Many more program options!

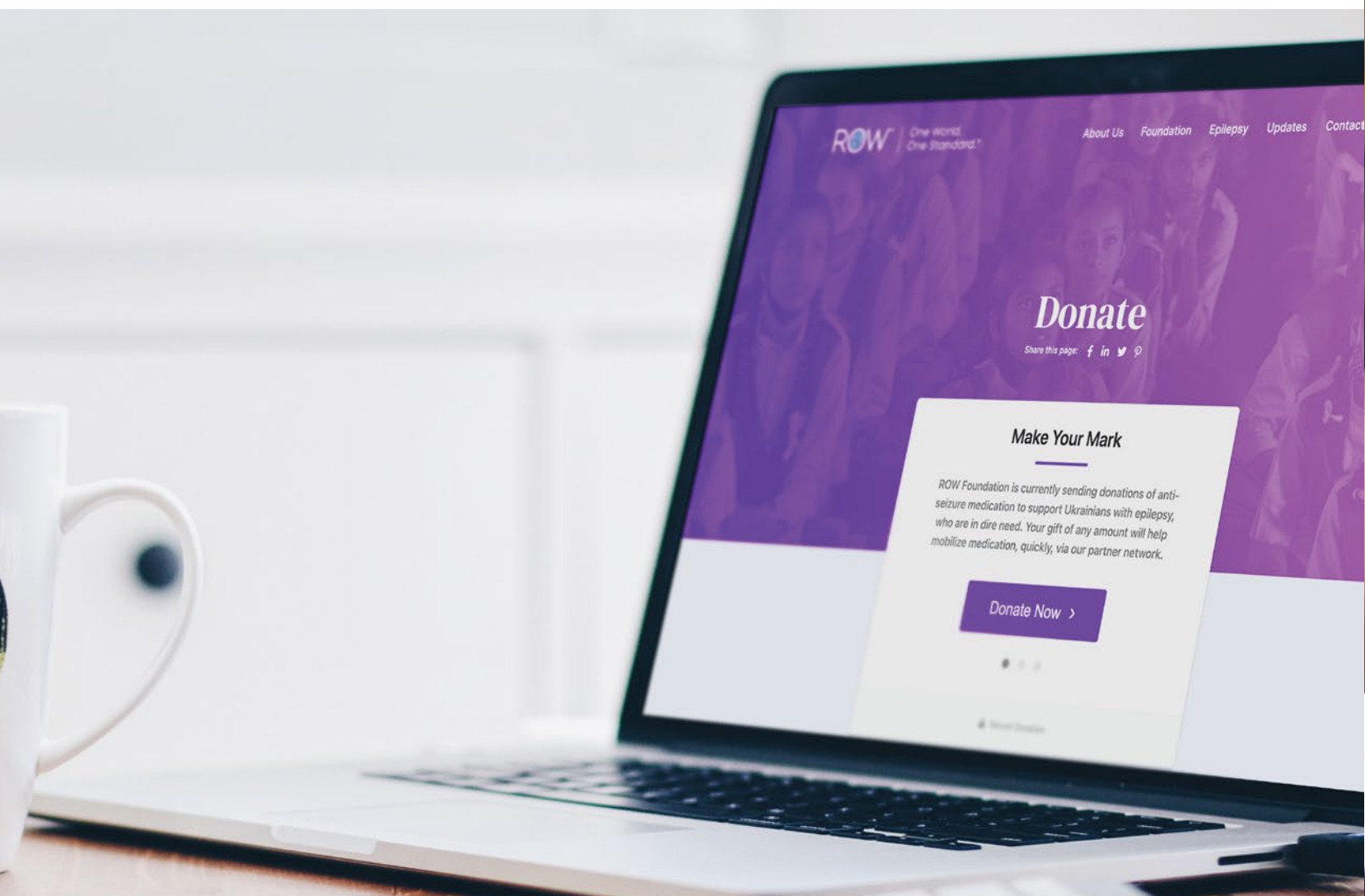




# Partner with us and change someone's world!

With the launch of **ROW Global Health**, it's easy for everyone to join us in reducing epilepsy treatment gaps around the world. Program opportunities are available in many locations and at all levels of giving.

Our worldprint graphic is a significant reminder of the power of one person. You can literally change the lives of individuals and families affected by epilepsy.



MAKE YOUR MARK TODAY BY VISITING [ROWGLOBAL.ORG/DONATE!](https://rowglobal.org/donate)



MAKE A  
*Lasting*  
IMPACT

Connect with us today:  
[info@rowglobal.org](mailto:info@rowglobal.org)



ROW Foundation  
has earned the  
GuideStar Platinum  
Seal of Transparency





# Epilepsy is a global problem that deserves a global solution.

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



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