



CureGRIN

Seeking treatments and cures for
GRIA, GRID, GRIK & GRIN Disorder

2022

CureGRIN Foundation Impact Report



CUREGRIN'S MISSION

CureGRIN Foundation is dedicated to improving the lives of people around the world with GRI Disorder, and their families, through research, education and connectivity.

WHAT IS GRI DISORDER?

GRI Disorder is a set of rare genetic diseases affecting the brain. Symptoms vary from person to person but usually include physical and intellectual disabilities. Sometimes, these disabilities are mild. But some people with GRI Disorder aren't able to walk or talk, and need help with all their daily activities. Many have epileptic seizures. Also common: Symptoms related to vision, sleep and digestion, as well as movement disorders and seizure-like storms or spells.

So what's causing all this? In people with GRI Disorder, there's a spelling error in one of the GRIA, GRID, GRIK or GRIN genes. These genes are numbered, with names like GRIN2B and GRIA3.

THE FAMILY OF GRI GENES (GRIA, GRID, GRIK AND GRIN)

Those in **red** designate families in our community.

We work closely with scientists and the medical community to drive patient-centered research that will lead to treatments and cures.

The genes contain the instructions to make brain receptors—tiny structures that help neurons to connect. When these receptors aren't working properly, the brain can be prone to epilepsy and can have a harder time learning and forming memories.

Only a few thousand people have been diagnosed with GRI Disorder, but there are probably tens of thousands still to be diagnosed.

While there's no cure for GRI Disorder, there are medicines that might help some patients, such as antiseizure drugs.

GRIA1	GRID1	GRIK1	GRIN1	GRIN3A
GRIA2	GRID2	GRIK2	GRIN2A	GRIN3B
GRIA3		GRIK3	GRIN2B	
GRIA4		GRIK4	GRIN2C	
		GRIK5	GRIN2D	

"The CureGRIN Foundation has been an important catalyst for advancing basic research and translational efforts directed at finding treatments and a cure for patients with GRIN variants. The work of CureGRIN, enabled by generous and forward-looking donors, is a critical element providing hope for families and patients."

DR. STEVE TRAYNELIS, GRI RESEARCHER, EMORY UNIVERSITY, USA



"Without the fabulous work that CureGRIN does for GRI conditions, we would still not know much about Ashleigh's condition. We were able to get the correct medication, and the treatment is helping far beyond what I expected!"

MICHELLE KELLY, GRIA2 MOM TO ASHLEIGH

A MESSAGE FROM OUR CEO

Dear GRI family,

On behalf of the team at CureGRIN, I'm excited to update you on how your support is helping to improve the lives of people affected by GRI Disorder.



Our most recent fiscal year marked a significant evolution for CureGRIN as we broadened our scope to advocate for people with GRIA, GRID, and GRIK Disorders as well as GRIN Disorders.

Other highlights included receiving an additional \$150,000 in funding from Chan Zuckerberg Initiative, and helping to secure more than \$1 million from Simons Foundation to fund gene therapy trials on GRI mice.

This year promises to be even bigger. CureGRIN will invest as much as \$900,000 in funding towards treatments and cures. And, after years of pandemic-related delays, we are committed to finally hosting an in-person conference in Boston / Cambridge March 23 to 26, 2023.

Whether you're a patient, family member, scientist, clinician, donor, or industry partner, we're grateful for your support and are honored to count you as a valued member of our GRI family.

KEITH MCARTHUR

CEO AND BOARD MEMBER GRIN1 DAD, CANADA



DENISE REHNER
PRESIDENT AND
BOARD MEMBER
GRIN1 MOM, USA



HEATHER CARTWRIGHT
BOARD CHAIR
GRIA4 MOM, GERMANY



KAITLYNE LEBLANC
BOARD MEMBER
GRIN1 MOM, USA



LAUREN WILLIAMS
COMMUNITY
COORDINATOR
GRIN1 MOM, USA



ROBERT YOCKEY
TREASURER
GRIA2 DAD, USA



FEDERICA MATTEI
BOARD MEMBER
GRIN2A MOM, ITALY



MEAGAN COLLINS
RESEARCH
COORDINATOR
MD/PHD CANDIDATE,
USA



TINA ROBERTS
SECRETARY
GRIN2B MOM, UK



NATASHA LESMANA
BOARD MEMBER
GRIN1 MOM, INDONESIA



JILLIAN HASTINGS
WARD
BOARD MEMBER
GRIN1 MOM, UK



PAULO DOMINGUES
BOARD MEMBER
GRIN2B GRANDFATHER,
BRAZIL

YEAR 3 HIGHLIGHTS

Here are highlights from CureGRIN's third fiscal year (May 1, 2021 through April 30, 2022).

BEYOND GRIN

CureGRIN broadened its mandate to include people living with all GRI Disorders: GRIA, GRID, GRIK and GRIN.

REVENUE

CureGRIN raised \$438,648, about 18 percent below our goal of \$535,000. This included a \$150,000 grant from Chan Zuckerberg Initiative. The CZI funds help to cover our internal costs so we can focus individual donations on research into treatments and cures.

CLINICAL TRIALS

CureGRIN strengthened relationships with pharma and biotech partners. Our relationship with Homology Medicines led to gene therapy trials in mice. (See case study on next page.) And we're working closely with GRIN Therapeutics as they prepare to launch clinical trials on GRI patients with gain-of-function variants.

STRATEGIC PLANNING

CureGRIN's board of directors worked with a strategic planner to develop a detailed plan for the next three years. (See last page.)

RESEARCH INVESTMENTS

CureGRIN awarded seed funding to facilitate a novel gene therapy trial. Otherwise, we made a strategic decision to pause research investments while finalizing our Research Roadmap implementation strategy. Nevertheless, CureGRIN was instrumental in securing more than \$1 million in research funding for GRI researchers.

VIRTUAL CONFERENCES

CureGRIN brought together hundreds of families, researchers, clinicians, and industry representatives for two major online conferences. Replays from the conference are available on CureGRIN's YouTube channel with subtitles in 10 languages.

GRI CONNECT

We launched griconnect.community, an online portal to connect GRI families with researchers and clinicians around the world.

GRIA, GRID,
GRIK AND GRIN

\$150,000 GRANT



\$1 MILLION
IN RESEARCH
FUNDING



YEAR 4 PLAN

Year 4 promises to be a huge year for CureGRIN with major investments towards treatments and cures. Here's some of what we're working on this year.

RESEARCH INVESTMENTS

CureGRIN's first large-scale initiative to fund research is underway with plans to invest up to \$900,000 on research that will accelerate the path towards cures and treatments for people living with GRIA, GRID, GRIK and GRIN Disorder. We've launched a request for funding proposals for projects including testing various drugs on patient-derived cells, and using GRI mice to determine whether GRI Disorders can be cured in adults / teens or only infants / small children.

IN-PERSON CONFERENCE

After years of COVID delays, the global GRI community will come together March 23 to 26, 2023, for our first in-person conference since 2019.

AMBASSADOR PROGRAM

CureGRIN is recruiting family members around the world to be family ambassadors. Representing countries or regions, our ambassadors will help identify and onboard new patients, facilitate a two-way dialog between local family members and CureGRIN, and lead local awareness and fundraising campaigns.

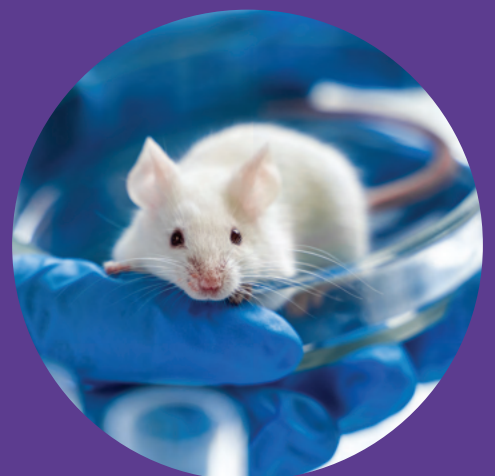
CASE STUDY

In 2019, CureGRIN CEO Keith McArthur met with Homology Medicines in Bedford, Massachusetts. As a result of this meeting, Homology expressed an openness to building gene therapy medicines that could be trialed on GRIN mouse models. In 2021, Keith learned about a grant opportunity involving public-private partnerships and brought it to Homology and researchers at the University of Toronto. This resulted in a grant of over \$1 million for gene therapy trials. Later, Keith looped in researchers at UC Davis who have developed a novel gene therapy treatment involving stem cells in bone marrow. The researchers agreed to work together to test this technique on mice with support of a \$10,000 grant from CureGRIN.



**INVESTING
\$900,000**

**IN-PERSON
CONFERENCE**



FINANCIAL PERFORMANCE

CureGRIN fell short of its financial goals in FY2022 due to a smaller-than-anticipated number of GRI families making personal donations or soliciting donations from friends and family. However, we ended the year with an accumulated surplus of \$785,000, due to a strategic decision to put research funding on hold until we completed our Research Roadmap implementation strategy. With that strategy complete, CureGRIN has launched a Request For Research Funding Proposals. The CureGRIN board of directors will invest up to \$900,000 in research funding in FY2023.

REVENUE	FY2022 ACTUALS (MAY 1, 2021 - APRIL 30, 2022)	FY2023 BUDGET (MAY 1, 2022 - APRIL 30, 2023)
Individual Donations / Fundraisers	\$264,648	\$360,000
Chan Zuckerberg Institute Grant	\$150,000	Grants \$200,000
Sponsorships	\$25,000	\$70,000
Total Revenue	\$439,648	\$630,000
EXPENSES		
Contractors / Advisors	\$163,932	\$215,500
Conferences	\$31,900	\$95,000
Research Funding	\$12,181	\$900,000
Other	\$42,420	\$100,200
Total Expenses	\$250,433	1,310,700

THANK YOU!

We are extremely grateful to the families and organizations that donated / sponsored at least \$2,500 in FY2022.



ED AND SUSAN GLYNN
WILLIAM LI
JORDAN AND SAMANTHA JIMENEZ
MAURICIO PILLA
CLAUDIA COLOMBO

WILLIAM AND DEIRDRE LESTER
MARCO MAGNI
JOHN AND KAITLYNE LEBLANC
JOHN AND JACKIE COLEMAN
SAM CHO

HOW TO HELP

THANK YOU FOR YOUR CONTINUED SUPPORT

CureGRIN relies on the generous support of donors to advance our mission. Whether you're making your first donation of \$100, ready to become a major giver of \$2,500 or more, or have the means to make a statement by becoming our first \$100,000 donor, we are honored to have your support.

CureGRIN Foundation
P.O. Box 2182
Parker, CO 80134
curegrin.org
curegrin.org/donations

Keith McArthur, CEO
(416) 357-1249
keith@curegrin.org

Denise Rehner, President
(303) 881-3425
denise@curegrin.org



TESTIMONIALS

"CureGRIN has provided a vital conduit between scientists, patients and their families, which has helped direct our research and shape a new area of medicine."

DR. IAN COOMBS, GRIA RESEARCHER, UNIVERSITY COLLEGE LONDON, UK

"My own research program has been enriched through interactions with CureGRIN and its dedicated leadership."

DR. GEOFFREY SWANSON, GRIK RESEARCHER, NORTHWESTERN UNIVERSITY, USA

"The grant we received from the CureGRIN Foundation was a lifesaver—literally. It helped us pay almost an entire month of rent which allowed us to catch up on our other bills and get back on track. Without it, who knows what would have happened."

NATALIA GORDON, GRIN1 MOM TO EZRA

"CureGRIN has provided us with an opportunity to interact with families, scientists and physicians, revolving around GRIN genes and disorders."

DR. KAREN AVRAHAM, GRIN RESEARCHER, TEL AVIV UNIVERSITY, ISRAEL

"We are grateful and humbled by the generosity of the CureGRIN community and their continued encouragement."

DR. AMY RAMSEY, GRIN RESEARCHER, UNIVERSITY OF TORONTO, CANADA



Strategic Plan 2022-2025

Our Mission

CureGRIN Foundation is dedicated to improving the lives of people around the world with GRI Disorders, and their families, through research, education and connectivity. We work closely with scientists and the medical community to drive patient-centered research that will lead to treatments and cures.

Values

- **Integrity:** We adhere to the highest standards of transparency and fiscal responsibility.
- **Collaboration:** We work closely with researchers, other GRI organizations and family groups. We promote collaboration and openness between researchers.
- **Optimism:** We believe that treatments and cures are coming that will make a significant difference in the lives of people with GRI Disorders.

Drive the research agenda to find treatments and cures by the end of the decade.

Vision

We collaborate with research partners to find answers to the 10 Essential Questions identified in our Research Roadmap, while encouraging and supporting clinical trials.

Strategies

1. Invest in research through CureGRIN-funded proposals, regional CureGRIN-affiliated charities, and by helping researchers to secure funding from external sources.
2. Deepen engagement with scientists, clinicians, and industry professionals from around the world.
3. Monitor progress on the plan through a publicly available dashboard.

Unite and empower the global GRI Community.

Vision

We act as, and are seen to be, a global organization, representing all GRI genes and patient families around the world.

Strategies

1. Increase global representation among CureGRIN Board, Advisory Board and staff.
2. Launch our new global Ambassador program to engage families around the world.
3. Invest in virtual and in-person events and platforms to grow our global network.

Strengthen operations, governance, and revenue in order to achieve our mission.

Vision

We have a robust and capable global team, with stable revenue from a variety of sources that allow us to accelerate our search for treatments and cures.

Strategies

1. Grow and strengthen our global Board of Directors.
2. Grow and strengthen our operations team through strategic staffing and volunteer support.
3. **Diversify** our revenue to support sustainable growth over the next three years.

3 Strategic Pillars for 2022-2025