Glut1 Deficiency Foundation

annual 2023 report

www.G1DFoundation.org

The G1DF has enjoyed the privilege of representing and serving the Glut1 Deficiency community this past year in ways old and new. Thanks to the support we receive from so many, we've been able to continue to focus our work on raising awareness of this rare and under-diagnosed disease in the medical community so that patients can receive better care and we can help find the many who still need a diagnosis. We've participated in advocacy efforts while joining forces with other like-minded groups who are working to represent and bring meaningful progress to rare disease communities like ours.

Connections with patients, families, and professionals have been fostered through our monthly Glut1 Gatherings and our quarterly Research Roundtables. We're working to increase research literacy for all stakeholders through our Research Ready Series by hosting research fundamentals trainings, and we established our first Patient Advisory Board to help ensure people living with Glut1 Deficiency have a voice and their needs are at the center of everything we do.

We added two esteemed members to our Medical and Scientific Advisory Board who have expertise and experience to help focus on our growing adult population, and we partnered with the International Neurological Ketogenic Society and the International Society for Neurogastronomy to host the 8th Global Symposium on Ketogenic Therapies. We created a video to capture the history of Glut1 Deficiency and honor Dr. Darryl De Vivo on his retirement, created a new and updated version of our educational brochure, have added resources to our website, and mailed 112 welcome packets of information to newly diagnosed families in 23 countries.

Our collaborative research network has continued to grow in number and in new directions this past year, and we provided funding support for research to 8 different institutions, including 6 new ones for the first time. We were thrilled to see our ongoing support for Dr. Juan Pascual's research help lead to a prestigious Team Science Grant from the NIH, and there were 7 scientific publications where funding support for the research had been provided by the G1DF. Our natural history study and biorepository continue to expand to support research and better understanding of the patient experience.

Many people have played a role, and it will take many of us to continue the work of driving progress and building brighter futures. Together we did big things this year, and we have big plans for 2024, too, and we thank each of you for being committed to this cause and joining us on the journey!

thank you!

our mission:

The Glut1 Deficiency Foundation is a nonprofit patient advocacy organization dedicated to improving lives in the Glut1 Deficiency community through our mission of:

awareness

so more patients can get a life changing diagnosis and families can find support on this journey

education

so healthcare professionals can diagnose and treat and families know what to expect

advocacy

so rights of patient and families are protected, voices are heard, and lives are valued

research

so there is better understanding of this disease to lead to treatments and cures

our vision:

We dream of a brighter future where Glut1 Deficiency will be easy to diagnose early, treat effectively, and cure completely.

2023 impact

thanks to our supporters!

- 2 Research Ready trainings
- 8 research projects funded
- 7 publications supported
- 884 biorepository samples collected
- 112 newly diagnosed welcome packets
- 5 educational exhibits
- 2 new MAB Members
- 6 new research collaborators
- 53 enrolled in natural history study
- 4 Research Roundtables
- 1 new Patient Advisory Board
- 40 Glut1 Gatherings on Zoom
- 1 new educational brochure & video
- 4 cell lines developed
- 3 scientific meetings

2023 FINANCIALS

income

donations - $300,936
grants - $32,516
interest - $3,001
program revenue- $2,638
other - $1,125

TOTAL: $340,216

NET ASSETS: $421,119

expenses

53% research support - $190,951
31% education/awareness - $111,491
8% management/general - $29,543
6% fundraising - $21,051
2% advocacy - $6,465

TOTAL: $359,501

2024 goals

- host our 11th community convening - the Glut1 Deficiency Summit
- lead patient-centered research fundamentals training sessions
- host educational exhibits to reach and teach new medical professionals
- connect researchers and create tools for our patient-led Research Compass
- launch new support programs for dietitian services, behavior consulting, and parent-to-parent mentoring
- fund transformative and translational research projects ($1.2 million in research grants to date)
- expand our natural history study and biorepository to know more about life-long patient experiences
- plan an FDA listening session to share patient experiences and highlight needs for new therapies

Glut1 Deficiency Foundation | PO Box 737 | Owingsville, Kentucky 40360 USA