



2025 *report* annual impact

This past year marked a powerful turning point for the GLUT1 Deficiency community. What began as a grassroots effort led by families determined to fill gaps and move mountains has grown into a movement shaping the future of care and research in meaningful, tangible ways.

2025 saw important and significant milestones, including partnering to support two clinical trials for potential new treatments and establishing the GLUT1 Deficiency Collaborative Care Network to recognize and support high quality, patient-centered care. Research efforts expanded to include new people, new places, and new partnerships, and new tools were created and made available to accelerate progress and discovery. We continued our work to translate science into better outcomes for patients while strengthening the resources, support, and sense of connection families rely on every day - ensuring they are informed, supported, and never alone as they navigate the many challenges of living with GLUT1 Deficiency.

None of this happens by accident. It is made possible by an extraordinary community that believes progress *is* possible and chooses to invest in the work needed to make it happen. We are deeply grateful for every project, resource, and collaboration built together, for every person who contributed, and we are motivated by what lies ahead as we continue this work.

♥ GLUT1 Deficiency Foundation

Thank you!



Mission:

The GLUT1 Deficiency Foundation is a parent-led, nonprofit patient advocacy organization dedicated to bringing help and hope to the GLUT1 Deficiency community through awareness, education, advocacy, and research.

awareness ensuring more patients receive timely diagnosis and families find support

Raising awareness remains a critical part of advancing progress for GLUT1 Deficiency. In 2025, we hosted educational exhibits designed to increase visibility, share information, and highlight ongoing advances in research and care. These exhibits help connect clinicians and researchers to the growing body of knowledge and momentum within the field. By increasing understanding and recognition of GLUT1 Deficiency, we continue to create pathways for earlier diagnosis, better clinical care, and greater collaboration, helping ensure that progress reaches more patients and at an earlier age.

3 educational exhibits | 2 awareness campaigns | 2 rare disease conferences | 1 podcast episode

education empowering healthcare professionals, patients, and families with knowledge

Building foundational knowledge helps individuals participate confidently in their care and in the future of research. In 2025, we completed our Research Ready Series, a focused educational initiative designed to build clinical trial readiness and increase research literacy among patients and families, helping them better understand the research process, engage more fully in opportunities to participate, and prepare for the next generation of clinical trials and treatments. We also served as a nonprofit sponsor for the INKS Global Keto Symposium and the European GLUT1 Conference.

2 Research Ready events | 2 conference sponsorships | 2 new print resources | 50 blog posts

advocacy protecting rights, amplifying voices, and ensuring patient-centered progress

Because science alone is not enough, we remain deeply committed to supporting individuals and families living with GLUT1 Deficiency. Throughout the year, we expanded our resources, programs, and opportunities for connection - meeting families where they are on this journey and helping them navigate day-to-day challenges so they are never walking alone, today or as new discoveries bring hope for the future. We also designated 25 centers as part of our new Collaborative Care Network, recognizing clinics that provide exceptional care and are committed to working across the network to continuously improve outcomes for all patients and drive research to fill the gaps in clinical care.

80 new family packets | 1 new peer support program | 45 virtual gatherings | 25 Collaborative Care Centers



research supporting, driving, and funding innovative and collaborative research

There was unprecedented research momentum in 2025. The collective community effort supported the development and funding of two clinical trials - signaling real progress toward better, easier treatments. We also funded additional pre-clinical research, developed and made available new research tools, and expanded our Natural History Study and biorepository, making it easier for researchers to access critical data that captures the patient experience and biosamples that accelerate discovery.

Collaboration was a cornerstone of this progress, including our first-ever in-person Research Workshop to bring experts together to share, plan, and partner. Five clinical and scientific work groups were launched at the workshop to focus efforts to make an outsized impact and in areas where patients need them most. We were honored to co-author a peer-reviewed publication with Dr. Eric Kossoff on puberty in GLUT1 Deficiency, contributing valuable insights and improving clinical understanding during a critical and particularly challenging stage of life.

Together, these efforts are building a stronger, more connected research ecosystem - one that moves faster, makes progress easier, and stays focused on what matters most to patients.

\$167,100 for 4 research grants | 1 Research Workshop | 5 work group projects | 1 research publication





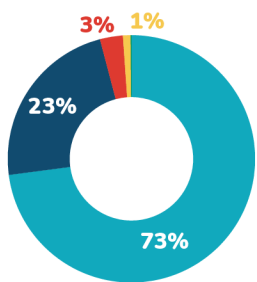
learn more about the work of the G1DF

www.G1DFoundation.org



2025 financials

NET ASSETS: \$358,299

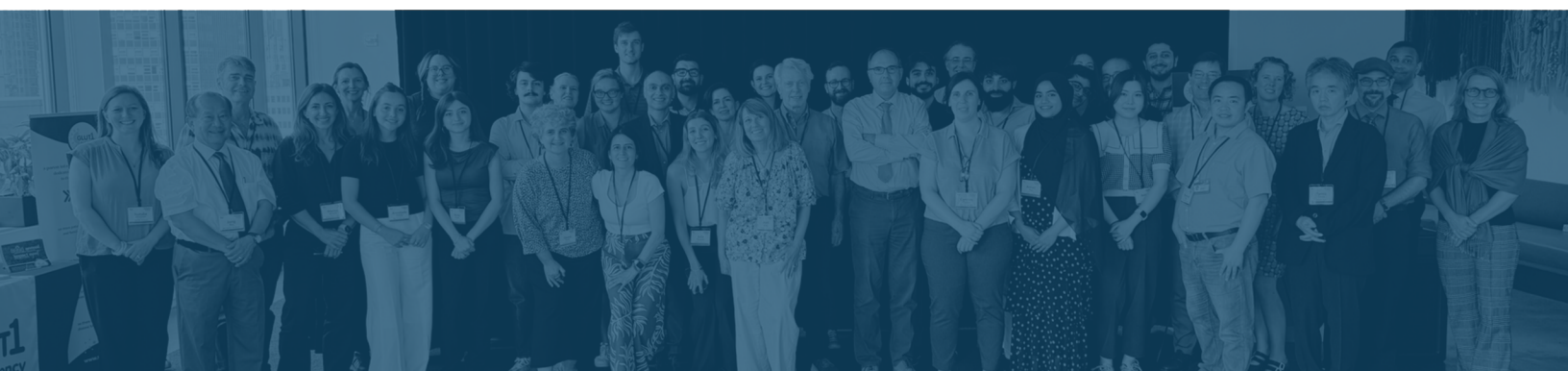
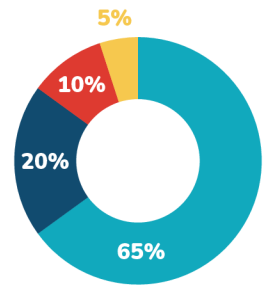


INCOME

73%	donations	\$367,792
23%	grants	\$116,036
3%	program revenue	\$13,777
1%	interest	\$6,294
.1%	other	\$850
TOTAL:		\$504,749

EXPENSES

65%	research support	\$313,254
20%	programs	\$96,231
10%	management/general	\$48,091
5%	fundraising	\$26,519
TOTAL:		\$484,095





2026 goals

- **Host the GLUT1 Deficiency Scientific and Family Summit** to bring families, clinicians, and researchers together to meet, share, and learn and to move the field forward together.
- **Fund research aimed at better, easier treatments** to support projects designed to speed the path toward options that can improve quality of life for people living with GLUT1 Deficiency.
- **Launch an international patient registry and census** to create a critical foundation for research, clinical insight, and a clearer understanding of the global GLUT1 Deficiency community.
- **Lead clinical and scientific working groups** to continue targeted projects that improve day-to-day patient care and provide building blocks for research progress.
- **Expand our governing board** to add diverse expertise and perspectives to guide the GLUT1 Deficiency Foundation with strong oversight and long-term vision.
- **Grow our team capacity** to help ensure the GLUT1 Deficiency Foundation has the people, skills, and support needed to carry out this critical work thoughtfully and effectively.
- **Plan strategically and sustainably for the future** so the progress we make today leads to lasting and meaningful impact for years to come.

gratitude and hope

As we look ahead, our goals are ambitious because the needs of this community are many and the opportunities before us are great. Every step forward is made possible through partnership, and we are deeply grateful to each family, clinician, researcher, volunteer, board member, staff, institution, company, organization, and donor who believes in what can be achieved and partner with us to move this work forward. Your generosity, trust, and commitment turn hope into action and ideas into real progress. Thank you for climbing mountains with us and for helping build brighter futures for all.

[learn more about the team behind the G1DF](#)

