It has been another year of projects, progress, and promise here at the Glut1 Deficiency Foundation. We were elated to have been able to take some steps toward the return of things we have cherished so much in the past but had to put on hold during the pandemic - our in-person conferences, scientific meetings, educational exhibits, and Team Glut1 in the Million Dollar Bike Ride. Being together, face to face and side by side, reminds us of the connections we treasure and the struggles we share, and it inspires and ignites the passion and urgency we feel to work hard to make the future for all of our loved ones easier.

Each year seems to grow busier than the one before, but it also means new opportunities come along with that growth. We wrapped up the final year of our Chan Zuckerberg Initiative Rare As One grant, but we’ll continue to stay connected as part of the Alumni Network to keep learning from other patient advocacy groups on similar journeys to build capacity and strengthen and grow our organizations to make our work more efficient and effective. One of the many things we did this past year in this area was to create our first strategic plan to help shape where we need and want to go based on the needs and priorities of patients and families and to help ensure we are able to sustain our work into the future so we can continue to serve this community we love so much.

Research progress continues to blossom as more people in more places are doing more projects that are changing the way this disease is understood and providing vital clues on the path to new treatments. Collaborative networks are forming within the research community, and we are working hard to help foster these relationships, give them a place to connect, and provide support and tools to make their work easier and led and directed by those same patient needs and priorities.

We are so thankful to all those who have given the gift of their support and made all of the progress in 2022 possible. Progress feeds hope, and real hope is the best gift we can give those who are living daily with the challenges and burdens of this disease. We still have much to do, but we can go farther and go faster when we all work together. We hope you’ll continue to join us on the journey and help us reach our goals in 2023 as we work earnestly to build the brighter future they deserve.

With gratitude,

Glenna Steele
Executive Director

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

- increased awareness
- improved education
- advocacy for patients and families
- support and funding for research

We dream of a brighter future where Glut1 Deficiency will be easy to diagnose early, treat effectively, and cure completely.
2022 highlights

- 4 educational exhibits
- 25 Glut1 Gatherings on Zoom
- 24 new part-time staff members
- 3 new educational videos
- 110 newly diagnosed welcome packets
- 5 scientific meetings
- 1 cell lines created
- 2 conference attendees
- 150 Research Roundtable participants
- 25 new Scientific Advisory Board members
- 1 $1 million mark for research grants
- 3 biorepository samples collected
- 3 new educational exhibits
- 3 new website
- Research Compass
- strategic plan

2022 financials

EXPENSES

- 48% awareness and education: $293,590
- 45% research grants & support: $276,319
- 4% administrative/management: $23,211
- 2% fundraising: $12,934
- 1% advocacy efforts: $5,757
TOTAL: $611,811

INCOME

- program service revenue: $36,378
- donations: $429,786
- private grants: $274,676
- public grants: $34,602
- other: $1,534
TOTAL: $776,976

NET ASSETS: $440,404

2023 goals

- partner with INKS to host the 8th Global Symposium on Ketogenic Therapies
- launch a regional conference program for more opportunities to meet, share, and learn
- expand our virtual Glut1 Gatherings to provide support to more people in more places
- grow our research network with new people and new ideas
- expand our Research Roundtable program to help foster collaborations
- host educational exhibits with new audiences of medical professionals
- expand our natural history study to better understand life-long patient experiences
- build new partnerships across the global patient community
- fund projects, connect researchers, and create tools for our patient-led Research Compass

www.G1DFoundation.org