

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

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



2021

ANNUAL REPORT



The resilience, determination, and commitment of our community helped the Glut1 Deficiency Foundation reach higher and shine brighter than ever in 2021. Although the challenges of COVID-19 continue to demand innovation and flexibility from all of us, we are incredibly grateful that we've been able to continue to move our mission forward and find new ways to serve. It is only through the dedicated and generous support of our community that any of this work is possible.

The previous two years with the CZI Rare As One Network have been busy but transformational as we've learned and grown alongside the now 49 other RAO organizations. In the next year, we are looking forward to putting so much of what we've learned and built into service, both through efforts to make our work more efficient and effective, but also initiatives we're launching to help support and drive research and serve our community in new ways. We are incredibly grateful to CZI for giving us this opportunity, believing in the power of patients, and supporting us in so many ways - including a new grant and extended time in the RAO Network.

Even though we are full of hope and optimism, we know that there will continue to be new and ongoing challenges in 2022. Our patients and families continue to inspire and motivate us to keep our mission in motion to bring help and hope in tangible ways to the Glut1 Deficiency community. Please read on for more about our big goals for the coming year and the accomplishments over the past one, none of which would be possible without the support we receive from so many. We are excited about the opportunities ahead and the progress and growth that are happening, and we're so grateful for these gifts that so many of you are giving our community.

thank you!

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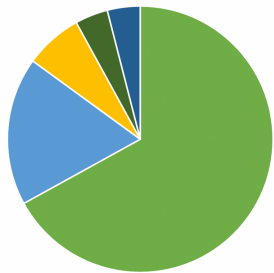
2021 HIGHLIGHTS



- completed a large scale patient voice survey to identify needs and priorities of the patient community
- presented a scientific poster on ketogenic diet experiences in Glut1 Deficiency at the 7th Global Symposium on Ketogenic Dietary Therapies
- conducted a community survey to capture and report COVID-19 illness and vaccination experiences
- hosted our first scientific convening (virtually) and welcomed 208 participants
- hosted our first virtual family meeting and welcomed 170 attendees
- hosted our annual Love Some1 with Glut1 campaign and surpassed our \$100,000 fundraising goal
- sponsored Team Glut1 in the Million Dollar Bike Ride and secured a matching grant to fund a \$64,465 research project
- awarded 2 additional research grants totaling \$116,750
- hired our first part-time Science Director - Dr. Sandra Ojeda
- started a new biorepository for patient-derived cell lines
- developed our Research Compass to help focus and drive research progress
- mailed 139 welcome packets to new families
- grew our social media following
- helped organize the global community to establish the first International Glut1 Awareness Day - July 10th
- attended NORD, Global Genes, CZI, and FasterCures virtual conferences
- continued virtual Glut1 Gatherings to bring the community together to meet, share, and learn from all corners of the globe
- launched the Community Connect forum as a safe, protected space to get and share information and support
- participated in a wide range of capacity building trainings through the Chan Zuckerberg Initiative Rare As One Network
- active membership in COMBINEDBrain and the Rare Epilepsy Network

2021 FINANCIALS

EXPENSES



- research grants and support - 67%
- education and awareness - 18%
- management and general - 7%
- advocacy - 4%
- fundraising - 4%

2022 GOALS

LIABILITIES AND NET ASSETS

ASSETS

cash: \$379,805
contributions receivable: \$2,702
inventory: \$640
prepaid expenses: \$18,594
TOTAL: \$401,741

LIABILITIES

deferred revenue: \$122,676
accounts payable: \$696
accrued payroll: \$3,130
TOTAL: \$126,502

NET ASSETS: \$275,239

- host our 9th family conference to bring families together to meet, share, and learn
- host our 2nd scientific convening for researchers and clinicians to exchange knowledge and ideas
- launch our Research Roundtable program to build and grow a collaborative research network
- begin implementing and funding our newly developed patient-led Research Compass (\$969,806 in research funding to date!)
- launch a natural history study to better understand life-long patient experiences
- expand our educational exhibits to reach new audiences of medical professionals
- build new partnerships for family support and international awareness day projects
- create a new website to serve as a hub for information, support, connection, and hope