



Annual Report 2020

www.G1DFoundation.org

our message

It is difficult to find words to explain the triumphs and the tragedies that have taken place over the previous year, touching all of the patients and families in our community no matter where they live. We understand the worries and uncertainties our families face under normal circumstances, and this past year has amplified and compounded those struggles and for far longer than any of us anticipated. As we've all learned to flex and bend, plan and prioritize, improvise and innovate, we've done the same here at the Glut1 Deficiency Foundation. We have been very thankful for new opportunities that have emerged as we've looked for ways to continue learning, growing, and serving our Glut1 Deficiency community.

The CZI Rare As One Network has been a tremendous source of knowledge, support, and opportunity over these last few months. We've had numerous webinars, training sessions, mentorings, and community calls on a variety of topics to strengthen and grow our capacity to become the driving force for patient-led research progress in our disease. We have learned a lot, and we are anxious to begin putting the pieces in place as we head into a new year and focus on the grant goal of building a collaborative research network.

We've also forged new relationships with like-minded organizations who are working hard to help patients in their communities, too. We have joined the Rare Epilepsy Network and COMBINEDBrain this past year - two umbrella organizations that are helping members solve some of the difficult challenges we share and to find better, faster, and easier paths to the solutions. We've added a new Science Director to our Board of Directors, and we have three new members on our esteemed Medical Advisory Board. As we've been planning for the inaugural scientific meeting for Glut1 Deficiency this summer, we've also had the privilege of finding new people in new places who are ready to jump in and help our patients and families by adding to the knowledge and deepening the science.

While some of our more traditional mission programs have been hampered in some areas due to restricted travel, we've developed new programs and embraced new technology and tools to keep raising awareness, educating others, supporting research, and connecting our community.

It is already apparent that 2021 will still hold challenges, but our patients and families continue to inspire and motivate us to press on in our efforts 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. Thank you for the part you've played in these triumphs, and we hope we can count on your continued partnership as we keep our focus on building a brighter future for all of our loved ones.

our mission

The Glut1 Deficiency Foundation is a nonprofit patient advocacy organization dedicated to improving lives in the Glut1 Deficiency community through increased awareness, improved education, advocacy for patients and families, and support and funding for research.

Glut1 Deficiency Foundation | PO Box 737 | Owingsville, KY 40360

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2020

our financials

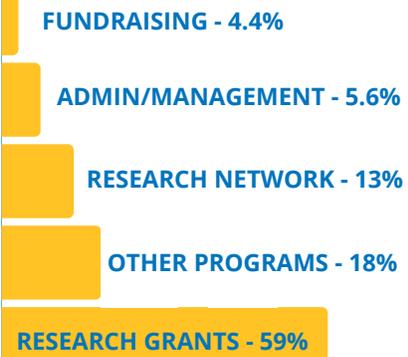
INCOME

donations	\$194,505
grants	\$476,800
merchandise sales	\$797
other income	\$2,264
TOTAL	\$674,366

EXPENSES

admin/management	\$16,217
programs	\$257,131
fundraising	\$12,651
TOTAL	\$285,999

EXPENSES



our activities

AWARENESS

EDUCATION

ADVOCACY

RESEARCH

- celebrated the launch of a new ICD10 code for Glut1 Deficiency as a result of our proposal to the CMS/CDC (E74.810)
- created a new and improved educational brochure
- debuted a new educational video in collaboration with Osmosis.org
- mailed 95 welcome packets to newly diagnosed families
- hosted three educational exhibits at professional medical meetings
- presented at the NIH/NINDS Workshop on Metabolism-Based Therapies in Epilepsy
- added new website resources and newsletter features
- launched monthly Glut1 Gathering groups on Zoom and hosted virtual meetings with Glut1 Deficiency experts
- welcomed new members to our Medical Advisory Board - Dr. Toni Pearson, Dr. Michèl Willemsen, Beth Zupec-Kania
- added a Science Director position to our Board of Directors - Dr. Sandra Ojeda
- attended Data DIY training sessions on developing registries and natural history studies
- participated in Rare Disease Day events at the NIH
- participated in Rare Disease Week on Capitol Hill and spoke about Glut1 Deficiency with seven Members of Congress
- joined the Rare Epilepsy Network to improve outcomes by fostering patient-focused research and advocacy
- joined COMBINEDBrain to speed the path to treatments for people with rare genetic neurodevelopmental disorders
- hosted our annual Love Some1 with Glut1 awareness and fundraising campaign and surpassed our goal - thank you!
- grew our following on Facebook and Instagram to help raise awareness in new audiences
- attended NORD, Global Genes, PCORI, Epilepsy Foundation Pipeline, CZI, and FasterCures virtual conferences
- participated in a number of capacity-building trainings through the CZI Rare As One Network
- joined natural history studies and centers of excellence collective impact workstreams through CZI and NICHQ
- hired a Science Advisor - Dr. Matthew Gentry
- hired an Educational Intern - Chantal Sanchez
- launched a mentorship with Kari Rosbeck and the Tuberous Sclerosis Alliance through CZI and FasterCures
- sponsored the first Team Glut1 in the Million Dollar Bike Ride, helping fund a \$64,000 grant for Glut1 Deficiency research
- awarded new research grants to Columbia University Medical Center and UT Southwestern - \$125,000 total

2021 our goals

- capture patient voice through a large-scale community survey
- host our first virtual family conference
- host our first scientific convening for researchers and clinicians
- begin building a collaborative research network to drive progress
- create and begin implementing and funding a strategic research plan
- build and launch a natural history study to better understand life-long patient experiences

