ANNUAL REPORT
Glut1 Deficiency Foundation 2019

2019 was an extraordinary year for the Glut1 Deficiency Foundation – a year of milestones and turning points and a period of visible and tangible progress that will continue to help shape the future of our patient community. We are extremely excited and thankful for the opportunities that have come our way and for those we are confident, with your help, will continue to come in the future.

We continue to expand and grow our programs so that we can better meet needs, fill gaps, and drive progress in our mission work. While we are still a small nonprofit, we have undertaken some big projects in the last year that will hopefully reap benefits for our patients for many years to come. Some highlights include our first major grant project on the adult experiences in Glut1 Deficiency, hosting our 8th and largest family conference, awarding our largest number and total amount of scientific research grants, and the invitation to join the Chan Zuckerberg Initiative's Rare As One Network, which is an incredible opportunity for funding, training, mentoring, and tools to establish a collaborative research network.

We also continue to see steady growth in the number of patients diagnosed, which we believe to be influenced by our educational efforts to raise awareness among healthcare professionals. We hosted our largest and most diverse number of educational exhibits in 2019, and we also had the opportunity to participate in new advocacy trainings and meetings to enhance our skills, further raise awareness and provide a voice for our patient community. Our mailing list, social media, and website audiences continue to grow rapidly, and we had our most successful year for our annual Love Some1 with Glut1 fundraising and awareness campaign, meeting our $100,000 goal for funding our research grant awards given in 2019.

All of these important and impactful efforts would not have been possible without the support of our donors, our team of leaders, advisors, and volunteers, and the inspiration we are provided daily from our patients and families. We are incredibly excited about the progress sure to come as we continue our work to bring help and hope to the Glut1 Deficiency community.

With sincere gratitude,

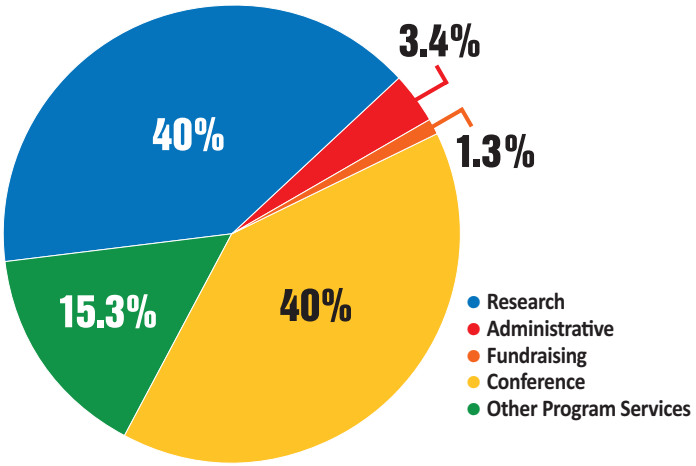
Glenna Steele
Executive Director, Glut1 Deficiency Foundation

Our mission.

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

financials

Income	**$335,465**
• Donations	$202,776
• Merchandise Sales	$10,817
• Conference Income & Grants	$121,176
• Other Income	$696
Expenses	**$416,254**
• Administrative/Management *accounting, payroll, taxes, fees, insurance, bank fees, office supplies*	$13,966
• Fundraising *transaction fees, software, charity registrations*	$5,509
• Program Expenses *research, conferences, educational exhibits, advocacy, outreach programs, resources*	$396,779
Total Year-End Assets	**$97,299**
Total Year-End Liabilities	**$703**



THIS WORK WOULD NOT BE POSSIBLE WITHOUT OUR SUPPORTERS

awareness

So more patients can get a life-changing diagnosis and find support on this journey.

We have participated in a number of events over the last year to help raise awareness for Glut1 Deficiency, including many of our fundraising, educational, and advocacy efforts where the awareness component is an added and equally important bonus. Every opportunity to highlight the disease or to spotlight a patient, family, or our Foundation is an opportunity for someone to learn about Glut1 Deficiency and find the open arms and open hearts of the community here to help. We have undertaken new initiatives and are forging new partnerships that will help us further the awareness efforts in the coming year.

education

So healthcare professionals can diagnose and treat, and families know what to expect.

We hosted our 8th biennial conference in Washington, DC in July to bring all stakeholders together to meet, share, and learn. We welcomed a record crowd of 430 from 33 states and 14 countries. We also used the conference gathering to share results and get further insights for a patient survey on adult experiences in Glut1 Deficiency, and those much-needed insights will be published soon and shared broadly. We continued our efforts to educate medical professionals by hosting exhibits at six major medical meetings across the United States. We distributed 2,500 brochures across a wide range of settings and provided 125 informational welcome packets to newly diagnosed families. We continue to build our online resources and information through an average of 400 weekly unique visits to our website, and we teamed up with Osmosis to create an easy-to-understand educational video.

research

So there is better understanding, better treatments, and ultimately a cure.

We continued our research grant award program and were able to fund five scientific research projects at three institutions. These projects provide $187,000 in direct research support for 2019 and bring our total research giving to $689,000.

- Impact of the Ketogenic Diet on Glucose Metabolism at the Neurovascular Unit in Vitro
- Exploring the Genotype(s) Associated with Glut1 Deficiency-Like Phenotypes
- When, During Life, is the Glut1 Protein Most Required to Prevent Disease?
- Identification of Compounds Increasing Glut1 Activity
- Infrastructure for Rapid Clinical Trials in Glut1 Deficiency

advocacy

So rights of patients and families are protected, voices are heard, and lives are valued.

As members of NORD and Global Genes and as part of Rare Connect from Eurordis, we've given the Glut1 Deficiency community a voice on the national and international stage. Through these umbrella organizations, we've been able to take part in advocacy trainings and take advantage of learning opportunities to help strengthen the G1DF as we work to be a more effective and representative patient advocacy organization. We've met with legislators to discuss policies that have a direct impact on our community and on all rare disease patients, and we've helped provide resources on disability, social security, financial planning, and schooling. In March, we presented a proposal to the Centers for Medicaid and Medicare Services ICD-10 Coordination and Maintenance Committee for a unique, specific diagnostic code for Glut1 Deficiency.