



# 2024 annual GLUT1 DEFICIENCY FOUNDATION impact report

2024 marked the 15 year anniversary of the very first meeting organized by what would later become the Glut1 Deficiency Foundation. That meeting started with the intentions of being a social gathering hosted by the Lazar family in Chicago, and it accidentally became a conference. It was there we realized that there was so much to learn about this rare disease and so many needs, but we also understood that it would be largely up to us as a patient community to try to fill the gaps and move the mountains.

We've learned and grown a lot in these 15 years, but that same grass roots mentality is still the driving force of the work we do on behalf of the beautiful and precious community we serve and have built together.

This community and all of you who support it have made many important things happen that will benefit patients for years to come – funding research grants, hosting conferences and scientific roundtables and educational exhibits at medical meetings, building a collaborative research network, developing cell lines and research tools, establishing a biorepository and natural history study, and helping us provide connection, resources, and support for patients and families on this rare disease journey and ensuring their voices and priorities lead all of the work we do.

We are so grateful to everyone who believes in our work, has joined us on this mission, and who has made the progress possible. We celebrate together, but we also know there is much still to be done together to give our loved ones the brighter and easier futures they deserve. Thank you for being part of all of it and giving the best gift of all - hope.

-The Glut1 Deficiency Foundation Board and Staff

*Thank you!*

# education *and* awareness highlights **2024**

We hosted our 11th convening of the community with the Glut1 Deficiency Summit in July in Dallas.

There were sessions focused on basic research to drive progress and foster collaborations, improve patient care, and help families navigate the day to day challenges. We also attended three professional medical conferences with our exhibit booth to raise awareness and spread education so that more patients can get an earlier diagnosis and can receive better care. Our website provides updated and reliable content so that families, medical professionals, and researchers alike can find a wealth of resources and information.

- 7,900** website visitors
- 3** educational exhibits
- 2** ketogenic diet resources
- 1** Glut1 Deficiency Summit

- **4** days of sessions
- **357** attendees
- **48** speakers
- **11** scientific posters



## *Mission:*

The G1DF is a parent-led nonprofit patient advocacy organization dedicated to improving lives in the Glut1 Deficiency community through awareness, education, advocacy, and research.

# advocacy *and* support highlights **2024**

We're engaged in a number of organizations and initiatives to give the Glut1 Deficiency community a voice on the national and international stage and to advocate for policies and services that will improve lives. We also work hard to make sure that voice is representative of the diverse experiences and backgrounds that make up this community, and our Patient Advisory Board is ensuring we hear directly from those impacted most. We've provided more direct support and connection through monthly online group meetings, our new private Facebook group, and welcome packets for those newly diagnosed. Individualized support is available for dietitian and behavior support services.

- 125** welcome packets
- 48** Glut1 Gatherings on Zoom
- 24** Bright Horizons Project sessions (behavior support consultations)
- 22** Keto Care Project sessions (dietitian consultations)
- 15** advocacy letter sign ons
- 10** Patient Advisory Board members
- 1** new Facebook support group

# research *highlights* 2024

We've continued our efforts to grow and strengthen our collaborative research network to have more people motivated to help move the science forward in new ways, and we're building and sharing tools and funding promising projects to make their work easier, faster, and focused on the things that are most meaningful for patients and families. We've been educating the community on the research process and building clinical trial readiness as new treatments are being developed, and we are proud to have authored our first independent research publication.

- 100 natural history study participants
- 5 Research Ready Series events
- 5 new research collaborators
- 4 Research Roundtables
- 4 research projects funded
- 3 cell lines developed
- 3 scientific meetings
- 1 new biomarker project
- 1 new G1DF research publication
- 1 new G1DF research study launched



## *Vision:*

A brighter future where Glut1 Deficiency will be easy to diagnose early, treat effectively, and cure completely.

# 2025 *goals*

- fund clinical trials for two potential new treatments
- complete the puberty experiences in Glut1 Deficiency research project
- develop additional open source disease models for research
- host our first Research Workshop to tackle projects and topics collaboratively
- launch a new international patient registry/census
- establish a Center of Excellence program for model clinical care
- launch a new support program to help navigate school experiences
- launch a new parent peer support program for mentoring and connection
- provide dietitian support through the Keto Care Project
- provide behavior support through the Bright Horizons Project

# 2024 *financials*

## INCOME

- donations - \$315,754
- grants - \$127,368
- interest - \$6,126
- program revenue - \$64,959
- other - \$500

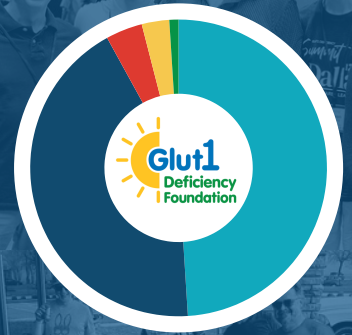
**TOTAL: \$514,707**

## EXPENSES

- 49% research support - \$297,124
- 43% education/awareness - \$263,401
- 5% management/general - \$29,738
- 3% fundraising - \$18,231
- <1% advocacy - \$484

**TOTAL: \$608,978**

**NET ASSETS: \$326,848**



Platinum  
Transparency  
2024

Candid.

Charity  
Navigator



FOUR-STAR



# learn *more*

[www.G1DFoundation.org](http://www.G1DFoundation.org)



## leadership *team*

### Board of Directors

April Breen  
Leigh Hopkins  
Kelly Jones  
Erin Meisner  
Rob Rapaport  
Maria Rebbecchi  
Debbie Stoddard

### Executive Director

Glenna Steele

### Science Director

Sandra Ojeda, PhD

### Community Coordinator

Natalie Chrisman

### Medical and Scientific Advisory Board

L. Felipe Barros, MD, PhD  
Mackenzie Cervenka, MD  
Darryl De Vivo, MD  
Kris Engelstad, MS, CGC  
Kelly Faltersack, MS, RDN, LDN, CD  
Elizabeth Felton, MD, PhD  
Matthew Gentry, PhD  
HC Glick, MD  
Eric Kossoff, MD  
Prof. Dr. Jörg Klepper  
Umrao Monani, PhD  
Juan Pascual, MD, PhD  
Toni Pearson, MBBS, MD  
Karthik Rajasekaran, PhD  
Thomas Rebbecchi, MD  
Jong Rho, MD  
Dong Wang, MD  
Prof. Dr. Michél Willemsen  
Beth Zupec-Kania, RDN, CD

## meet the *team*



### Special Projects Consultant

Chantal Sanchez

### Parent Patient Liaison Consultant

Dana Pottschmidt, MSW, LCSW

### Our Valued Volunteers