unlock the *power* of patient driven research

enroll today

Quick Start Guide:

1. Create your own unique Clinical Research ID number
   - **www.theCRID.org**
2. Create an account in Matrix
   - **new account:** https://glut1x.acrossmatrix.com/#/user-request
   - **returning login:** https://glut1.acrossmatrix.com/
3. Upload the genetic report and/or lumbar puncture test results to confirm your diagnosis (in the **documents** section)
4. Fill out all surveys listed in your account **dashboard** under **surveys and studies,** including putting your CRID number in the **additional patient ID's** survey
5. Turn on notifications in **settings** to be notified when you have messages or new surveys (under the **person icon** in top right corner)

use any additional Matrix tools and features that may be helpful to *you*

Glut1 Deficiency natural history STUDY

Glut1 Deficiency Foundation

www.G1DFoundation.org

in partnership with

Matrix

COMBINED

Across Healthcare

Glut1 Deficiency natural history STUDY

patients and families...

you are the experts
you can best tell the story of Glut1 Deficiency

learn more

What is a natural history study?

Natural history studies collect information on how a disease affects a person over time. If the disease is rare, the collected data is especially valuable and can lead to new understandings, breakthroughs, and treatments. Natural history studies are important pieces in developing clinical trials to test new treatments to see how they may be changing the course of a disease. They also help give a more accurate count of the number of people who have been diagnosed with a disease.

What is the Glut1 Deficiency Natural History Study?

The Glut1 Deficiency Natural History Study is a secure database that uses standardized surveys to collect ongoing information about the life-long experiences of Glut1 Deficiency patients.

With rare conditions like Glut1 Deficiency, it is vital that we share information about genetic mutations, symptoms, the different treatments and therapies and how they've impacted patients. This information will enable researchers to discover patterns and clues that could lead to breakthroughs and more effective ways to manage or cure this disease.

What is the Glut1 Deficiency Foundation?

The Glut1 Deficiency Foundation is a nonprofit patient advocacy organization dedicated to improving lives in the Glut1 Deficiency community through its mission of increased awareness, improved education, advocacy for patients and families, and support and funding for research. Learn more at www.G1DFoundation.org

What is Matrix?

Matrix is a technology platform created by Jason Colquitt as a philanthropic arm of his company Across Healthcare. It is built by a rare disease patient (Jason) to help rare disease communities collect the critical pieces of information needed to run patient registries and natural history studies and to enable researchers to look at similarities across diseases. Learn more at www.acrossmatrix.com

What is COMBINEDBrain?

The Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders is devoted to speeding the path to clinical treatments for people with severe rare genetic neurodevelopmental disorders by pooling efforts, studies, and data. COMBINEDBrain is a non-profit consortium led by patient advocacy foundations, working with the clinicians, researchers and pharmaceutical firms that are developing treatments for the disorders they represent. Learn more at www.COMBINEDBrain.org

Why are we collecting data through surveys?

The data collected will help researchers and families learn more about Glut1 Deficiency and how the disease changes over time.

- patients and families will know more about what to expect at different ages
- healthcare teams will know more about helping manage and treat the disease
- researchers will learn details to better understand disease mechanisms and help lead to new discoveries and advances
- future clinical trial opportunities and information can be shared with patients and families who may qualify

Who is allowed to participate?

The Glut1 Deficiency Natural History Study is open to individuals from any location in the world with a confirmed Glut1 Deficiency diagnosis and/or their caregivers. Diagnosis may be confirmed by genetic testing results and/or lumbar puncture results.

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How does the Natural History Study work?

The Glut1 Deficiency Foundation, in partnership with Matrix and COMBINEDBrain, has created a customized health information portal for Glut1 Deficiency patients and caregivers to easily capture, track and share information related to symptoms, activities, medications, and electronic health records.

Patients and caregivers from around the world can enroll online and create an account in the Matrix portal. Once enrolled, you can begin taking surveys and entering information about the patient's Glut1 Deficiency experiences.

We are initially using brief, standardized, and validated Clinical Genome Resource (ClinGen) general health surveys so meaningful research can be conducted not only on Glut1 Deficiency, but also across different diseases as well under the larger COMBINEDBrain umbrella study. These ClinGen surveys cover all body systems and may help capture previously unknown symptoms of Glut1 Deficiency.

Eventually, we plan to add more specific Glut1 Deficiency surveys and set up hospital sites to collect clinic data from healthcare providers that can be combined with the information provided by patients and families in order to create a more complete picture of Glut1 Deficiency experiences.

There may be additional components added to the Natural History Study in the future, including biorepository samples, interviews, video recordings and apps, and other outcome measures you may see listed in the Informed Consent process. You may return to the Informed Consent document and change permissions at any time.

The Glut1 Deficiency Natural History Study will utilize the CRID system (Clinical Research ID) to assign unique identifiers to patient data that protects their identify. It can also link different sources of data about the same patient in an anonymous, de-identified way from the patient and family surveys, the clinical data entered by healthcare professionals, and also to patient samples in the biorepository if available.

You will be prompted to enter your CRID number under the Additional Patient ID's survey in the Surveys/Studies section on the patient dashboard.

Please visit www.theCRID.org to create an account and generate your own unique CRID number. This number is yours and will only be shared if and when you choose to share it.

Matrix is currently best utilized on a desktop, although enhanced mobile capabilities are under development

Why is it necessary to repeat the same surveys?

Updating surveys is extremely important so that there is not just a snapshot in time of patient experiences, but rather a natural history that tells the story of Glut1 Deficiency across the lifespan and shares insights on how the disease changes over time. Surveys that need to be completed or updated will automatically appear in your Matrix account under your patient dashboard. Most will be repeated annually.

What languages are available?

The Glut1 Deficiency Natural History Study Matrix platform is currently available in English, Spanish, Italian, French, and German, but the individual surveys are currently only available in English. We want to include as many of our Glut1 Deficiency families from around the world as possible in this important project, so we will continue to add more languages as these survey translations become available.

How will the data be kept safe and protected?

The Glut1 Deficiency Natural History Study is hosted on the Matrix platform and conforms to all standards and best practices, has robust safety and security measures, and is compliant with HIPAA and GDPR regulations. Learn more in the Informed Consent or by visiting www.acrossmatrix.com.

Who will have access to the identified data?

The Glut1 Deficiency Foundation will oversee the study. Only trained and credentialed staff from the Glut1 Deficiency Foundation and the Matrix technology support team will have access to any identifying data and only for administrative management purposes for the study.

Patients and caregivers own their own data and can share it with others any time they want – doctors, dietitians, teachers, family members, etc. They can also withdraw from the study or change any of the permission settings on the Informed Consent at any time.

make you and your *experiences* **count**

patient driven research
centered on patient priorities
with

PRO Matrix RWD

patient reported outcomes
What does the patient think, feel, or say about their health?

real world data
What is happening in their routine, every day life?

Who will have access to the de-identified (anonymous) data?

Learnings from the study will be shared back with the community through regular reports and snapshots, but only in a de-identified way. Researchers and clinicians who want to learn more about Glut1 Deficiency patient experiences may be granted access to the de-identified and consolidated data through a formal request and screening process managed by a governing board. Learn more in the Informed Consent process.

The governing board will be comprised of a Steering Committee, with two members appointed from the Glut1 Deficiency Foundation, two from Matrix/Across Healthcare, and one from COMBINEDBrain.

Members from the Glut1 Deficiency Foundation:
Sandra Ojeda, PhD: Science Director
Glenna Steele: Executive Director

watch an interview about Matrix
with creator Jason Colquitt
and Terry Jo Bichell and Kristin Hatcher
from COMBINEDBrain

How else can I use Matrix?

- use it as a personal health monitoring tool
- utilize tools and features that make managing daily care easier
- share health information easily with others

Matrix Tools

Symptoms and Activities Tracker
- track symptoms and activities on the platform, including seizure activity, movement episodes, medication or diet changes, ketone levels, doctor or therapy appointments, and more!
- use an existing favorites list or create your own symptoms and activities list to track those that are meaningful and important to you
- graphs can be created with multiple activities and symptoms to look for patterns and possible correlations

Medications Tracker
- log medications, dosages, and refill dates
- text and email notifications for medication administration and refill reminders

Important Document Storage and Organization
- upload your documents for easy organization and access - medical records, IEP's, evaluations, medication lists, physician contact list, guardianship, etc.
- documents can be shared as PDF files with healthcare providers, other caregivers, and anyone you'd like to have them

Journals
- keep notes and written narratives of important information such as changes in eating or sleep, unusual behaviors, parent-teacher interactions, or any other things you want to remember
- keep a list of questions for the next doctor appointment

Resource Center
- find important documents, forms, and information from the Glut1 Deficiency Foundation to help with natural history study participation or make day to day care easier
- find announcements and details about clinical trial opportunities

Sharing Center
- download and share any information you've entered into Matrix (your own personal health data) with anyone you'd like

Message Center
- two-way communication with the Glut1 Deficiency Foundation
- a safe, secure, and private way to share information and questions

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