GLUT1 DEFICIENCY
puberty *experiences*
SURVEY STUDY

Glut1 Deficiency Foundation

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MEDICINE
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In partnership with [Dr. Eric Kossoff]() at Johns Hopkins Hospital, the Glut1 Deficiency Foundation is conducting a puberty survey with the goal of collecting information about puberty experiences and the ketogenic diet in the Glut1 Deficiency community.

This is the first of its kind research effort focused solely on puberty experiences for people with Glut1 Deficiency and is an important survey to find out if puberty is a problem (or maybe not?) for children/teens with Glut1 Deficiency.

Dr. Kossoff and Glenna Steele (Glut1 Deficiency Foundation) have been discussing this topic for years and it is a common concern of parents of children with Glut1 Deficiency about to reach puberty. Will seizures get worse? What about ketosis?

This research study is a way to learn information about puberty and Glut1 Deficiency and help others, and your insights will be important!

the what:

The Puberty Experiences in Glut1 Deficiency Project is a research effort from the Glut1 Deficiency Foundation. It is a survey to capture patient experiences during puberty, including the following areas:

- changes in symptoms during puberty
- changes in treatment during puberty
- ketogenic diet compliance and effectiveness during puberty

the why:

The results of this survey will be used to:

- better understand the patients' puberty experience
- better understand how symptoms change during puberty
- better understand how whether and how the ketogenic diet benefits patients during this critical stage
- help improve care for patients in the Glut1 Deficiency community

the who:

- The survey will collect anonymous information about people of any age diagnosed with Glut1 Deficiency who live anywhere in the world.
- People aged 18 and over who have Glut1 Deficiency may take the survey on their own, or their parent/caregiver can help them take the survey or take it on their behalf.
- People under age 18 who have Glut1 Deficiency will need to have the survey completed by an adult parent or caregiver. *Minors under the age of 18 should not take the survey themselves.*
- The survey is not open to individuals who do not have a confirmed Glut1 Deficiency diagnosis.

the how:

- Participation is easy and completely voluntary.
- This is an online survey using the Typeform platform.
- It takes approximately 7-10 minutes to complete the survey.
- The Typeform platform uses logic to display only questions that are relevant to you based on your previous answers.
- The survey questions and the Typeform platform do not capture any personally identifiable information, so your participation will be anonymous.
- The survey can be taken from any location on both desktop and mobile devices, although some of the question formats may be easiest viewed on a desktop or laptop rather than a phone or tablet.
- Please try to answer all the questions as thoroughly as you can. When questions are skipped, pieces of information about your story are missing and the full picture of your experience is less clear.
- Follow the link at the bottom when you are ready to begin.

the when:

- The Puberty Experiences in Glut1 Deficiency Project will be **open through February 1st**.
- Responses from the survey will be grouped together, analyzed, and the overall insights will be shared through multiple open-access sources in the future. Since this is an anonymous survey, no personally identifiable information will be collected or connected to your responses.

data storage and usage:

- Your anonymous survey responses will be stored on the Typeform platform according to all required privacy regulations.
- The Glut1 Deficiency Foundation will oversee the data collection, storage, and protection. Study Team members, including Dr. Eric Kossoff, will be responsible for analyzing and interpreting the data and for disseminating the findings.
- The anonymous data may be exported for further analysis and shared with other organizations in efforts to better understand needs and experiences so that gaps can be better addressed through planning, programs, support, services, and research.
- The research findings, including your anonymous data, may be published in peer reviewed journals, presented at conferences, and disseminated in other ways to share what is learned.
- Your anonymous data may be used in this and other research and shared with other organizations. You will not share in any commercial value or profit derived from the use of your data, nor will you have special access to any products created because of your participation in this research.

study team:

Co-Principal Investigator:
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Study Team Member:
Glenna Steele, MEd
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Institutional Review Board:
Castle Institutional Review Board (IORG #: IORG0010151 – Study Number G1D-PUB-01)
Johns Hopkins Institutional Review Board (IRB00473889)

questions:

Please reach out to any of the Study Team members listed above with any questions you might have.

If you have any questions about this research study and do not wish to contact the Study Team members, you may contact the independent ethics review board (Castle IRB) that reviewed this project at irbteam@castleirb.com.

Participating in the Puberty Experiences in Glut1 Deficiency Survey is voluntary.

By taking the survey, you provide explicit consent for the Glut1 Deficiency Foundation to collect, securely store, and selectively share your anonymous responses for the purposes and goals outlined above.

TAKE THE SURVEY