Information Sheet about participation in a research study titled:
Breastfeeding and Puberty in G1D (Glucose Transporter Type 1 Deficiency)

To be conducted at
The University of Texas Southwestern Medical Center
Children's Medical Center of Dallas and any of its affiliated entities

Who is conducting the study? Dr. Juan Pascual, a professor at UT Southwestern Medical Center, is conducting this study. Dr. Maria Ramos-Roman, an associate professor at UT Southwestern Medical Center, is also conducting this study.

What is the purpose of the research? A survey is being done to gather information on breastfeeding and puberty in patients diagnosed with glucose transporter type 1 deficiency (G1D).

Who is asked to participate? You are invited to complete this survey because you are an adult (age 18 or older) diagnosed with G1D, or because you are the parent of a child with G1D.

Do you have to be in this study? You do not have to participate if you don't want to. You may also leave the study at any time. If you decide to stop taking part in this research study, it will not affect your relationship with the UT Southwestern staff or doctors. Whether you participate or not will have no effect on your legal rights or the quality of your health care. If you are a medical student, fellow, faculty, or staff at the Medical Center, your status will not be affected in any way.

What are the Research Procedures? We are interested in learning more about breastfeeding and puberty in patients with glucose transporter type 1 disorder (G1D) or who have symptoms of (G1D). We invite all adult patients diagnosed with G1D or the adult caregivers of minor patients with G1D to fill out a survey. The survey will ask for information about your G1D diagnosis, medical history, experience with breastfeeding, experience with puberty and supplements that you've used. The survey will take about 20 minutes to complete.

There are no study visits or treatments for this research study. You can complete the survey on your computer, tablet, or other electronic device at a time and place of your choice. When completing the survey, please do not provide any additional information that could identify you, such as names, phone numbers, date of birth, etc.

To respond to the survey and participate in the study, go to the survey link at https://ais.swmed.edu/redcap/surveys/?s=HW7MWA7A73. Answer the questions using the survey's drop down menus and/or check boxes. Submit the survey to send your responses to the study team.

If you have any questions about the survey or the research study, you can contact the research team at Rare.Diseases@utsouthwestern.edu

What are the Risks and Benefits? Any time information is collected there is a potential risk of loss of confidentiality. There is a risk that the information you provide in the survey could be seen by people not working on the study. Every effort will be made to keep your information confidential; however, this cannot be guaranteed. Only study team members will be allowed to have access to your responses on the survey.

You may not receive any personal benefits from being in this study. We hope the information learned from this study will benefit other people with similar conditions in the future.

Costs and Compensation There is no cost to you if you decide to be a part of this study. You will not be paid if you decide to be a part of this study.

IRB Approved Date: 3/31/2020

Confidentiality The survey will not collect any information that could identify you (such as your names or date of birth). Information we learn about you in this study will be handled in a confidential manner. If we publish the results of the study in a scientific journal or book, we will not identify you.

Any data collected as part of this study may be used for future research studies without your consent. Any information that identifies you will be removed before it is used for future research studies.

Contact Information for questions or comments:
The University of Texas Southwestern Medical Center Human Research Protection Program (HRPP) oversees research on human subjects. HRPP and Institutional Review Board (IRB) representatives will answer any questions about your rights as a research subject, and take any concerns, comments or complaints you may wish to offer. You can contact the HRPP by calling the office at 214-648-3060.

Before you agree to participate, make sure you have read (or been read) the information provided above; your questions have been answered to your satisfaction; and you have freely decided to participate in this research.

This form is yours to keep.