

Do you or your child have CLASSIC GALACTOSEMIA?

If so, an important research study needs your help!



What? Where?

- We are researchers at Emory University in Atlanta, Georgia, conducting an observational, longitudinal study to define the timing, prevalence, modifiers, and potential changes over time of long-term complications in classic galactosemia. The more people participate, the better the study will be.
- This study has been approved by the Emory University Institutional Review Board (IRB Protocol 00024933; Principal Investigator: Judith Fridovich-Keil, PhD)
- Participation is easy and non-invasive -- no extra needle stick, really!
- No study-related costs to you or your insurance company.
- No special travel -- all required components can be completed remotely.
- Subjects who complete all their surveys will be compensated \$50 for their first year of participation, and \$25/year for up to 4 additional years of participation.
- Results from this study may answer important questions about outcomes experienced by patients and may aid the development of new treatments. Please help!

Who is eligible?

- Anyone with a confirmed diagnosis of classic galactosemia may be eligible to enroll.

What's involved?

- After you complete the informed consent process we will ask you to fill out a set of online surveys that ask questions about your or your child's medical and family history. Then, every 6 months through age 5, and annually after that, we will ask you to send updated information using online follow-up surveys. We will also ask for authorization to request medical records from relevant healthcare providers.
- We may ask for a saliva sample to allow genetic studies. When you or your child are scheduled to have a clinical blood draw, we may ask if the doctor could please collect a small extra tube of blood for research. If both you and the doctor agree, we will send you a kit with the tube, instructions, packing materials, and a pre-paid shipping label. There is no cost to you or your insurance company for this procedure, and no extra needle stick.
- Participants who donate a blood sample may receive free *GALT* genotype analysis, and girls who donate a blood sample may also receive free analyses of hormones related to ovarian function.

Questions? Comments? Might want to join?

- Please email Judith Fridovich-Keil at jfridov@emory.edu, or contact our research team at galactosemia@emory.edu

THANK YOU!!! THANK YOU!!! THANK YOU!!!