

Are you the parent or guardian of a baby with CLASSIC GALACTOSEMIA? If so, an important research study needs your help!



What? Where?

- We are researchers at Emory University in Atlanta, Georgia, conducting a longitudinal, observational, study to define the timing, prevalence, 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 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 aid the development of new treatments. Please help!

Who is eligible?

- Babies and children who are less than 2 years old at enrollment with a confirmed diagnosis of classic galactosemia.

What's involved?

- After you complete the online informed consent process to enroll we will ask you to fill out a set of online surveys that ask questions about your baby's medical and family history. Then, every 6 months through age 5, and annually after that, we will ask you to send updated information via online follow-up surveys.
- When your baby is scheduled to have a clinical blood draw we will ask if the doctor could please collect a small extra sample 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.
- Babies who donate a blood sample may receive free *GALT* genotype analysis, and girls who donate a blood sample may also receive free analyses of two hormones related to ovarian function: follicle stimulating hormone (FSH) and anti-Müllerian hormone (AMH).

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!!!