

Has your child been diagnosed with galactosemia?

Classic galactosemia can cause premature ovarian insufficiency (POI)

What is POI: POI occurs when your ovaries stop functioning normally before age 40. In girls and women with galactosemia, POI may occur early in life. When this happens, the ovaries don't produce normal amounts of the hormone estrogen or release eggs regularly. This condition may lead to infertility.

We are conducting a study to learn why POI happens in classic galactosemia, and if cryopreserving (freezing) ovarian tissue might help to preserve fertility in this population

Eligible participants:

- Girls ages 4-12 years old with classic galactosemia who have not yet started puberty.

What will happen during this study:

- Participants will have ovarian tissue removed by a trained surgeon at the NIH. Travel costs will be reimbursed by the NIH.
- Most (80%) of the removed tissue will be cryopreserved (frozen) for the participant's own use later in life. A small piece of removed tissue (20%) will be designated for research.
- The first year of storage costs will be covered by the NIH, but all subsequent storage costs will be the responsibility of the participant's family.

There is no cost for participation and all study related tests and procedures are at no cost to you, beyond the long-term frozen sample storage fees.



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