BabySeq™

Frequently Asked Questions

What is genome sequencing?

- **Genes** are made of DNA. Genes determine how we look, like eye and hair color, and give instructions to help the body function.
- **Genome sequencing** is a lab test that looks at all of someone's DNA. This type of test can help find changes that cause health risks.

Will all babies get genome sequencing?

- Half of babies, chosen at random, will get genome sequencing.

How is this type of testing done?

- We will collect a few drops of blood by pricking the baby's heel. If a heel stick is not possible, we may collect the sample in a different way (e.g., drawing blood from a vein).

Is a heel stick painful?

- A heel stick may cause a small amount of pain, or a temporary bruise or "black and blue mark" on your baby's heel. Your baby has already received a heel stick as part of newborn screening.

What do I get if my baby is not in the sequencing group?

- You will still meet with a study doctor or genetic counselor to learn about health risks that might run in your family and any preventive care.

When will I get my baby's results and who will I speak to?

- About 4 months after your first study visit. You will meet with a study doctor or genetic counselor who will go over your results and answer any questions you may have.

How much time will it take?

- You will be in the study for at least 1 year. The study visits and surveys will take about 3 hours total.

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Will I be able to access my baby's results after the study is over?

- You will be given a copy of your baby's results at the second visit with the study doctor or genetic counselor. The results will also be sent to your baby's doctor and put in your baby's medical record.

What are the costs?

- There is no cost to be in the study.

Will I be paid?

- Yes! We appreciate your time. You will receive up to $150.

What resources will be available if my child tests positive for a health risk?

- The study team will assist in making referrals to specialists and connecting you to helpful resources. Resources may include financial assistance, additional counseling, and mental health services.

Who will have access to my baby's health information?

- The study team and hospital staff. Results from this study will become part of your baby's medical record. After the study is over, hospital staff can see medical records to do their jobs.

Where will my baby's data/samples be stored? For how long?

- If your baby is in the genomic sequencing group, their sample will be sent to a lab for testing. The lab is required to hold onto the sample and its data two years after the study ends.

Who can I talk to if I have more questions?

- Please contact the BabySeq study team to learn more!