What happens when the results are ready?
If you choose to join the G4K study, you will meet with a genetic counselor or other study team member. They will explain your child’s test results. Your family’s health care might need to change based on these results. The study staff will talk with you and your child’s doctor about any changes.

Questions?
Learning about your family’s genes can be exciting. But you should think carefully about how the information might affect your child and family. You might not want to learn about your child’s gene changes. Or, you might find the information useful. Please think about this before you decide about joining the study. The decision is very personal, and there is no right or wrong choice.

To contact us
To answer your questions, our team of doctors, nurses and genetic counselors is here to help. You may request a visit with our team or contact us at:
901-595-8459 or genomes4kids@stjude.org.

St. Jude complies with health care-related federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

ATTENTION: If you speak another language, assistance services, free of charge, are available to you. Call 1-866-278-5833 (TTY: 1-901-595-1040).


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THE GENOMES FOR KIDS RESEARCH STUDY

About our research study

Thank you for considering Genomes for Kids. Genomes for Kids, also called G4K, is a research study led by staff at St. Jude Children’s Research Hospital. It is for children and teens who have a tumor or cancer and are being treated at St. Jude.

In this study, we use a technology called “genomic sequencing” to learn about your child’s healthy cells. We hope to learn more about:

• Why childhood tumors and cancers form,
• If knowing this information can help doctors predict how tumors or cancers will respond to treatment, and
• The best ways to share the results of genomic sequencing with patients and families.

Why is this research study important?

Genomic sequencing is a test to help us find changes in your child’s genes. Many gene changes are harmless. They are considered normal variations between one (1) person and another. However, some gene changes can cause health problems. For example, they can make cells divide and grow into a tumor or cancer. Other gene changes do not cause tumors or cancer directly, but they can make you more likely to get them. These gene changes can sometimes be passed from parent to child (inherited).

This study is important because it helps researchers learn more about:

• What causes childhood tumors or cancers, and
• What raises the chances of getting them.

This information can help doctors find more effective ways to treat or prevent tumors or cancers.

How is the G4K research study different from clinical genetic testing?

A doctor might order clinical genetic tests to learn if you have certain gene changes. The G4K researchers look at many genes at once. Doctors look at more genes with the G4K test results than they normally do with clinical genetic testing. Some of the genes are associated with development of cancer in children. Others may be associated with development of cancer in adults. Because G4K is a research study, your test results go into a secure database. Other researchers may look at them to help understand how gene changes can be part of diseases like cancer.

You must sign a consent form for both clinical genetic testing and the G4K research study. We will share the results once they are available, and they become part of your medical record. Your doctors and a genetic counselor will decide if your care should change based on the results of either type of test.

GENES AND DNA: DID YOU KNOW?

- Our bodies are made up of very tiny building blocks known as cells.
- Our cells contain chromosomes, which are made up of DNA.
- DNA is organized into smaller units called genes.
- Genes are instructions that tell our cells how to function. The complete set of human genes is called our “genome.”
**GENE CHANGES: DID YOU KNOW?**

Either kind of gene change can cause a tumor. Only gene changes in healthy cells can be passed down to the next generation.

What happens in G4K genomic sequencing?

Genomic sequencing allows us to study many genes at once. Scientists study at least 150 genes in the G4K study. We know certain changes in these genes are linked to an increased risk of cancer. You will learn the results of this test. We will also study a large number of other genes. You probably will not learn these results, because they are very early results. We need to learn more before we know if they are important for your health.

To perform G4K genomic sequencing, we need:

- A small blood sample (about 1-2 teaspoons).
- For leukemia patients, a very small skin sample may be used instead of blood.

We might have taken a blood or skin sample from your child already. If so, we might be able to use it.

If we find gene changes in your child’s healthy cells

Gene changes might tell us more about the following:

- Why the tumor or cancer formed.
- How it might respond to treatment.
- What treatments might work best.
- Your child’s risk for future tumors, cancers or other health problems.
- Information that might help your child make family planning decisions later in life.
- Information that might help family members learn if they have a higher risk for tumors or cancers – If they do not know this yet.

There is also a chance your child will not directly benefit from taking part in this study. Even so, this research may help us to better diagnose and treat children with cancer in the future.