



A ST. JUDE STUDY

# GENOMES FOR KIDS



# THE GENOMES FOR KIDS RESEARCH STUDY

## About our study

Thank you for considering Genomes For Kids.

Genomes for Kids is a research study being led by staff at St. Jude Children's Research Hospital. This study is for children and teens who have been diagnosed with a solid or a liquid tumor. A liquid tumor is also known as leukemia or lymphoma.

In this study, we will use a new technology called genomic sequencing to learn about your child's tumor and his or her healthy cells.

Most children with tumors do not yet have this kind of test as part of their regular care.

By doing this study, we hope to learn more about:

- Why childhood tumors form,
- Whether this test can help doctors predict how tumors will respond to treatment, and
- The best ways to share the results of genomic sequencing with families.

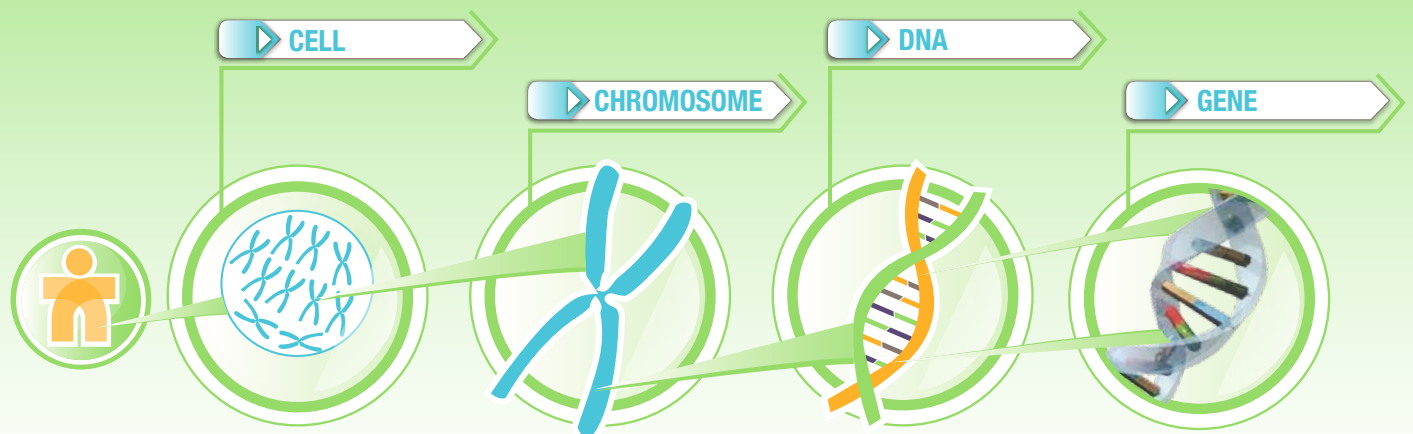
## Why is this study important?

Genomic sequencing is a new test to help us find changes in your child's genes.

- Many gene changes are harmless. These are considered normal variations from one person to the next.
- Some gene changes can cause health problems. For example, they can make cells divide and grow into a tumor.
- Other gene changes do not directly cause tumors to grow, but they can make a person more likely to get them. These gene changes can sometimes be passed through the generations of a family (inherited).

In this study, we will test your child's tumor for gene changes that may have caused it to grow. If you are interested, we will also test your child's healthy cells for any gene changes that could increase the risk of future tumors.

## 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.**

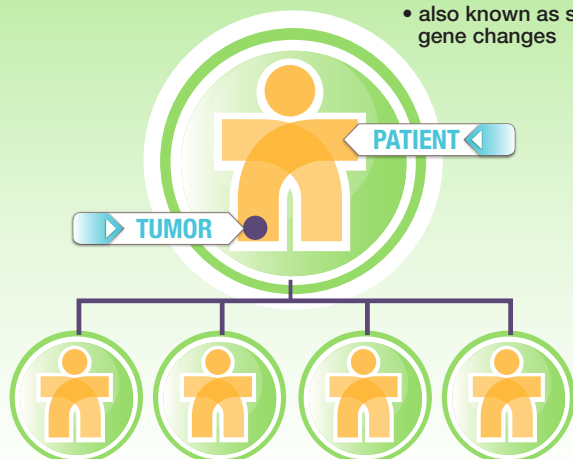
**Genes are instructions that tell our cells how to function. The complete set of human genes is called our "genome."**



# GENE CHANGES: DID YOU KNOW?

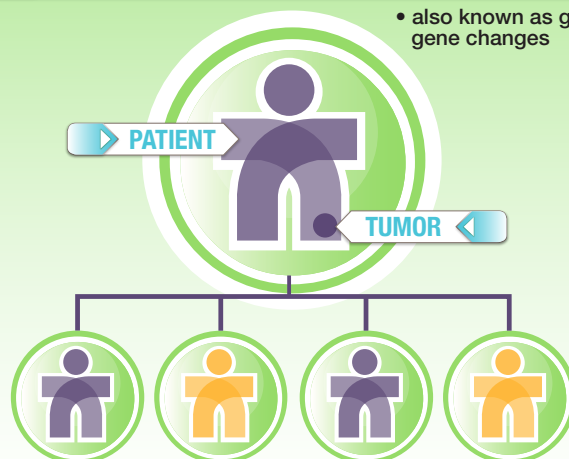
## SOME GENE CHANGES ARE ONLY IN TUMOR CELLS

- also known as somatic gene changes



## SOME GENE CHANGES ARE IN ALL CELLS

- also known as germline gene changes



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 during genomic testing?

Genomic sequencing is different than other genetic tests. It allows us to study DNA thoroughly and to examine many genes at the same time.

### To complete genomic sequencing, we will:

- Use a sample of your child's tumor or bone marrow,
- Collect a small blood sample (about 1–2 teaspoons), and
- For leukemia patients and some others, we may need to collect a very small skin sample instead of blood.

## What will we learn in the Genomes for Kids study?

### If we find gene changes in your child's tumor:

- We may learn more about why the tumor formed.
- We may learn more about how the tumor will respond to treatment.
- We may learn more about which treatments will work best.

### If we find gene changes in your child's healthy cells:

- We may learn more about why the tumor formed.
- We may learn more about how the tumor will respond to treatment.
- We may learn more about which treatments will work best.
- We may learn that your child has a greater risk for future tumors or other health problems.
- The information might help your child make family planning decisions later in life.
- The information might help family members who could also have the condition but not yet know it.

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.

## What happens when the results are ready?

The Genomes for Kids study team will tell your child's St. Jude doctor when the tumor or bone marrow results are ready.

- If you would like to learn about the tumor or bone marrow results, you can speak with your child's St. Jude doctor.
- You can choose whether you want to learn about the results from the genomic sequencing of your child's healthy cells. If you do, a genetic counselor or other member of the study team will meet with you and your child's St. Jude doctor to explain them. They will work with you and your child's St. Jude doctor to discuss whether anything about your family's health care should change based on the results.

## Questions?

Genomic sequencing is exciting new technology, but it is important to think carefully about what you and your family would like to learn. Some people may prefer not to know about gene changes, while others find the information useful. How much you learn is up to you.

## 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](mailto:genomes4kids@stjude.org).**

