

# Is Research Right for Me? You decide.

## What is a Clinical Research Study?

A research study is a planned experiment or careful collection of information to gain new knowledge. Many doctors at Children's Mercy Hospitals and Clinics do research to test new medicines and treatments so they can find the best ways to help children get well and feel better. All research studies are done with the approval and oversight of an ethics committee called the "Institutional Review Board" or IRB.

## What do I Need to Know Before I Decide to be in a Research Study?

Before you decide, you need to know exactly what is involved and what to expect. You should ask questions such as:

*Why is the research being done?*

*What will I have to do?*

*How much time will it take?*

*How often will I need to come in for study visits?*

*What are the good parts about being in the study?*

*What are the not so good parts about being in the study?*

*Is there anything related to the study that my parents will have to pay for?*

*Will I get a choice about which medical treatment I get?*

*What other choices do I have if I choose not to be in the study?*

*Who do I call if I have questions?*



## Will Being in a Research Study Help Me?

The main purpose of a research study is to gain new knowledge that will help doctors and nurses provide better medical care for children. Sometimes being in a study will help you and sometimes it does not help you directly. What doctors learn from research may help other children in the future.

## Saying "YES" or "NO" to Study Participation

**If I say NO:** You do not have to be in a research study at all. If you say "no" your doctors and nurses will not be upset with you.

**If I say YES:** One of the study staff members will give you a form to read called the "Parent Permission and Child Assent Form". This form has all the information about the study written down. Assent means that you agree to be in the study. Before you agree to be in a research study, you should discuss it with your parents and make sure it is OK with them. The study staff will answer your questions so you and your parents can decide if you want to take part.

## What are My Rights as a Research Participant?

- I don't have to be in a research study if I don't want to.
- My doctor will take care of me no matter what I decide.
- I can ask questions anytime I want to.
- I can stop being in the study if I start and then find out I don't want to keep doing it and no one will be upset with me.

## What are My Responsibilities as a Part of the Research Team?

- I need to keep all my appointments and be there on time.
- I have to follow all the special study instructions.
- I need to tell my doctors and nurses if I get sick or take any other medicines during the study.
- I should talk to my parents about any questions or concerns I have.



## Will Anyone Else Know That I Am in a Research Study?

Your medical information will be kept private and only be identified by a unique study number or your initials so that no one outside of Children's Mercy Hospital will know who you are. For some research, your personal information will be shared with other trusted people like the Food and Drug Administration or a company which may have asked your doctor to do the research. If this is done, you will be identified only by your study number or initials. Also, the CMH Institutional Review Board may need to look at your research file. Your information will not be shared with others without your permission.



## Research at Children's Mercy Hospital

Children become sick for lots of reasons and it is important for doctors to know the best way to help them. Doctors and companies must do research to test ways of treating disease and to find answers to questions like:

- How can we help kids stay healthy?
- What is the best medicine to use?
- What is the best treatment to use?

Clinical research studies help us find out more about illness and are important in making new medicines, medical devices and treatments available for kids.

