

What Are My Rights as a Research Participant?

- You have the right not to take part in a research study.
- You have the right to drop out at any time.
- You have the right to ask questions at any time and have them answered as soon as possible.
- You have the right to be told about any new information or changes in the study.

You also have the responsibility to stay informed during your participation in a research study. You should ask questions about anything you do not understand or simply want to know.

How Are Research Participants Protected?

Research participants are protected by being told honestly the known and potential risks for participating in the research study. The Institutional Review Board (IRB) at Cedars-Sinai protects the rights and welfare of people in research studies. The IRB includes scientists, non-scientists and community members. The IRB reviews, approves and monitors all research at Cedars-Sinai in which people take part. This oversight keeps risks to research participants as low as possible. The IRB also keeps track of ongoing studies to make sure they are being done in the right way. The IRB requires that all researchers treat research participants with respect. If you take part in a research study, the IRB protects your rights and welfare.

Who Do I Contact about Research Concerns or Complaints?

If you have a concern, complaint, or compliment about research, please contact the Cedars-Sinai Institutional Review Board (IRB). The IRB takes all complaints very seriously and investigates all complaints and concerns. You may contact the IRB at any time by calling 310-423-3783. You may also email the IRB at researchconcerns@cshs.org, or you can mail a letter to the Institutional Review Board, 6500 Wilshire Blvd., Suite 1800, Los Angeles, CA 90048.



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Cedars-Sinai Medical Center

8700 Beverly Blvd.

Los Angeles, CA 90048

Phone: 310-423-6252

Website: cedars-sinai.edu

 [Facebook.com/CedarsSinai](https://www.facebook.com/CedarsSinai)



**Learning More About
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What is Research?

Research is a way to answer questions and to gain knowledge. We use knowledge gained from medical research to learn more about diseases and to discover new treatments.

Medical practice is different from research. The main purpose of medical practice is to care for the health and well-being of patients. The main purpose of research is to test new scientific ideas or new treatments. Research may help individual participants, but this is not always the case.

What Are Some Types of Research or Clinical Trials?

Doctors and scientists at Cedars-Sinai conduct many different kinds of research studies. Some research does not include living human beings. Research that includes humans is clinical research. Clinical research helps researchers learn more about a particular condition or disease, or helps them understand how best to treat patients. There are many different types of clinical research. One common type is a clinical trial, where researchers test new drugs, new ways of giving patients approved drugs, new surgical techniques or medical devices, or new treatments.



How Do I Take Part in a Research Study?

Each research study is different. Each study tries to find answers to a specific question. Researchers must follow strict rules to decide who may take part in research. Not everyone with a disease or medical problem that is being studied can take part in a research study. If your doctor thinks that you might qualify for a research study, he or she may ask if you want to participate. Many patients also look for research studies on their own through support groups or websites. The Cedars-Sinai website for information about clinical research is www.cedars-sinai.edu/Research/Clinical-Research.

To be included in research, you must agree to take part. You may drop out of a research study at any time, even if you have already agreed to participate. Saying “no” to participating in research will not change your medical care at Cedars-Sinai in any way. If you have questions, you may talk to your doctor, the research team staff or to another doctor who is not a member of the research team, about your other choices.

What Is Informed Consent?

Informed consent is the process that gives information to people who are thinking about taking part in research and helps them learn about the research study. After learning about the research, you should understand:

- The purpose of the research study
- The procedures involved in the study
- The possible benefits and risks of taking part in the study

- The rights of people who take part in research
- That taking part in research is your choice
- What you can do instead of taking part in the study
- How the research team will give you any new information that may be learned after you decide to take part in a study that might cause you to change your mind

After learning about the research study, you will be able to ask the researcher or his/her staff questions. You should only agree to take part after you clearly understand the study and feel comfortable about participating. You should take time to talk over your decision with your doctors, family, and friends. If you agree to take part, you will be asked to sign an Informed Consent Form. The informed consent process goes on even after you begin taking part in the study. If researchers learn new information about the study, they must share this with you.

Will It Cost Me Anything to Take Part in a Research Study?

In some cases, taking part in a research study will not cost you or your insurance company anything. In other research studies, the research team may bill your insurance company for drugs, devices, and services they provide. It is possible that your insurance company will not pay for some or all of the charges, and you may receive a bill for those costs. The Informed Consent Form will describe any costs to you in detail. If the information in the consent form is unclear, you should ask the research team to explain any costs before you sign the consent form.