

# Considering Clinical Trials

Clinical trials are research studies that may help improve outcomes, or results, for patients. They may also offer treatment options that are not widely available yet.

## THIS FACT SHEET TELLS YOU:

- What clinical trials are
- Your rights and safety in a clinical trial
- Costs of being in a clinical trial
- Resources to help you find and join trials
- Questions to ask your doctor

## WHAT IS A CLINICAL TRIAL?

A clinical trial is a way to learn:

- How well a new treatment or test works
- How well a new treatment works compared to an old one
- What the side effects are and how to manage them
- How people feel during or after treatment

Clinical trials may:

- See if a medicine used to treat one disease works well to treat another
- Study the safety and side effects of a new treatment
- Compare 2 different but well-known ways to treat a disease
- Find out what tests help doctors decide the best way to treat disease

## ARE CLINICAL TRIALS SAFE?

Clinical trials follow strict rules to keep patients safe. In the U.S., clinical trials may be checked by these organizations:

- [Office of Human Research Protections \(OHRP\)](#)
- [Food and Drug Administration \(FDA\)](#)
- [Institutional Review Board \(IRB\)](#)

Throughout a trial, researchers report to the OHRP, FDA and IRB. A trial can be shut down at any time to protect the people in it. Trials are stopped if there is any unexpected harm, such as dangerous side effects.

## YOUR RIGHTS IN A CLINICAL TRIAL

**The right to information.** Before joining a clinical trial, you have the right to learn about it in a way that you can understand. This is called the **informed consent process**. During this process, you and your study coordinator will discuss:

1. The purpose of the clinical trial
2. The possible benefits and harms associated with participating in the trial
3. Other treatment options you may have
4. Your rights as a participant in the clinical trial

### **The right to not join and the right to leave.**

Joining a clinical trial is your choice. If you're uncomfortable joining a trial, tell your doctor. Even after you've joined a clinical trial, you may quit at any time. You don't have to do anything that you're uncomfortable with.

**The right to privacy and confidentiality.** Privacy means you have the right to decide when and how to share your body, thoughts, and experiences with others. Confidentiality is how your doctors will protect your information.

## COSTS AND FINANCIAL HELP

If you join an approved clinical trial, the law requires most insurance companies to pay for costs related to your regular care. These costs include your regular visits to the doctor, hospital stays, X-rays and lab tests.

Your insurance may **not** cover costs specific to the clinical trial. These may include the cost of the study drug and tests done only for the trial.

Every insurance plan is different, so talk to your insurance company and financial coordinator. They can help you find out what you will have to pay. If you don't have insurance, you may still be able to join a clinical trial.

You also may have to travel to join a clinical trial. Our **Clinical Trial Travel Grant** helps qualified patients pay for air travel, ground transportation and lodging. Your medical team needs to submit the application on your behalf.

## FINDING A CLINICAL TRIAL

Your doctor can tell you if you're eligible to join a clinical trial at your hospital. Our Clinical Trials Navigators can also help you find clinical trials anywhere in the U.S. All of our support is free.

- **Call:** 1 (888) 814-8610
- **Email:** [Contact@CTSearchSupport.org](mailto:Contact@CTSearchSupport.org)
- **Search for trials:** [CTSearchSupport.org](https://CTSearchSupport.org)
- **Get information:** [CTSearchSupport.org/Contact](https://CTSearchSupport.org/Contact)

## JOINING A CLINICAL TRIAL

For any clinical trial, you will have an informed consent meeting with the study doctor or nurse. Informed consent means that you have been told about and understand the risks and benefits of the trial before you agree to be in it. You will never be part of a clinical trial without your signed agreement to participate.

If you'd like to join a clinical trial, your doctor or research nurse will tell you:

- What they are trying to learn from the trial
- What the treatment and tests are
- The potential benefits and harms to you
- Other treatment options available to you

## QUESTIONS FOR YOUR DOCTOR

You are allowed (and encouraged!) to ask questions at any time before, during or after participating in a clinical trial. Here are some questions to ask:

- Is this clinical trial a good fit for me? Why?
- What are my options if I don't join this trial?
- Are there other trials that might help me?
- What is this clinical trial trying to do?
- How long will the trial take?
- Why do researchers think this new treatment might work?
- Have there been other trials like this one? If yes, what were the results?
- How will I know if the treatment is working?
- What are the possible side effects of this treatment?
- What will I have to do if I join?
- Who will pay for treatment?

## RESOURCES TO LEARN MORE

Getting started with clinical trials:

[CTSearchSupport.org/resources/basics](https://CTSearchSupport.org/resources/basics)

Read trial results:

[CTSearchSupport.org/research-studies](https://CTSearchSupport.org/research-studies)



## AT EVERY STEP, WE'RE **HERE TO HELP**

Be The Match has a team dedicated to providing information and support to you before, during, and after transplant. You can contact our Patient Support Center to ask questions you may have about transplant, request professional or peer support, or receive free patient education materials.

CALL: 1 (888) 999-6743 | EMAIL: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org) | WEB: [BeTheMatch.org/one-on-one](https://BeTheMatch.org/one-on-one)



Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.