

MYTH

I might be given a placebo without my consent instead of medicine I need.

FACT

Before agreeing to be in a trial, you are told if you might receive a placebo. A placebo looks like a treatment, but does not have any medicine in it. Researchers use placebos to help make sure any changes in the participants' health are actually caused by the trial treatment.

You do not get to choose if you get the trial treatment or the placebo, and you may not know if you get the placebo until after the trial. If you need medical treatment and your trial includes a placebo, the placebo would be given in addition to standard medical treatment.

Not all trials use a placebo. If there is a chance you may get a placebo and you do not want it, you do not have to join that trial.

MYTH

Being in a clinical trial costs a lot and is not covered by my insurance.

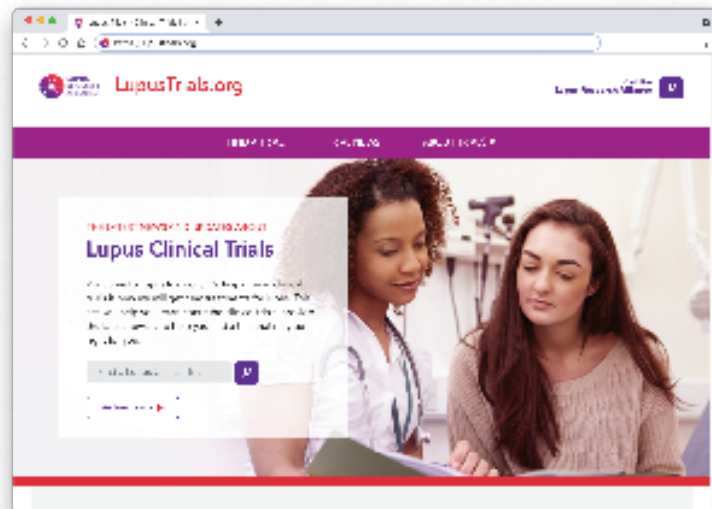
FACT

There are often no costs to you for being in a trial. You might have trial-related expenses such as travel, parking, hotel, or childcare. But, the researchers usually reimburse these expenses.

Before you agree to be in a trial, it is important to speak with the trial team and your insurance company about any costs you may have to cover.

Find Lupus Trials

Visit LupusTrials.org for all current lupus trials and to search for ones that may be right for you.



An editorial panel of patients, public, and professional representatives reviewed this educational brochure.

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The Lupus Research Alliance (LRA) is the world's largest private funder of lupus research. Lupus Therapeutics, an affiliate of the LRA, aims to accelerate drug discovery and diagnostic innovation for all patients living with lupus.

lupusresearch.org

CISCRP is an independent non-profit organization dedicated to engaging the public and patients as partners in the clinical research process.

CISCRP does not recruit patients for clinical trials and does not conduct clinical research. CISCRP is also known as the Center for Information and Study on Clinical Research Participation.

Visit www.CISCRP.org or call toll free 1-877-633-4376

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Common Myths About Clinical Trials

Lupus is a complex disease; only a few drugs have been developed and approved just for lupus. Joining clinical trials is key so researchers can better understand the disease and how to target its treatment.



MYTH

If I want to join a trial, I will not be told anything about the trial or treatments I might take.

FACT

Researchers are not allowed to give you treatment in a trial unless you fully understand what is going to happen.

Before agreeing to be in a trial, the trial team will walk you through the process. You can ask questions about anything you want, like what treatment you might get, what happens during visits, what the potential risks and benefits are, and how long the trial might last. This process is called “informed consent.” Information about the trial will be provided in a printed or digital document called an informed consent form.

You can take as much time as you need before deciding. It is very important to understand a clinical trial and to be comfortable with what is planned to happen before you agree to participate.

MYTH

I can join any trial.

FACT

Each clinical trial has a list of requirements about who can be in the trial. For example, the researchers might need to test people of a certain age, gender, or health condition. These requirements can be found in the informed consent form you will get before agreeing to join a trial. These requirements are in place to make sure each trial gets the most accurate results and is as safe as possible.

MYTH

Trials are scary. I don't know how I'm protected.

FACT

While there are some risks, every clinical trial has a detailed plan reviewed by many experts to make sure it is as safe as possible. As a participant, you are protected from unnecessary risk.

Experts from federal health agencies, such as the U.S. Food and Drug Administration (FDA) and the European Medicines Agency (EMA), review and approve trial plans. Institutional review boards (IRBs), which are comprised of doctors, scientists, and community members, also review the trial plan to make sure the potential risks to participants are not too high.

These experts continue to monitor safety throughout the trial. The potential risks for every trial are different. These can range from mild discomfort to long-lasting side effects or death.

All the potential risks must be explained to you before you agree to be in a trial. Doctors will monitor your health throughout a trial, and you can leave a trial at any time for any reason.

MYTH

If there is a clinical trial that could help me, my doctor will tell me about it.

FACT

Your doctor may not know about all available clinical trials. Patient advocacy groups like the Lupus Research Alliance can help you find trials and provide resources to help you decide if you should participate.

The National Institutes of Health has a website you can search to find trials: LupusTrials.org. You can also visit www.clinicaltrials.gov to find lupus trials.

You should always discuss any clinical trial with your doctor to help you decide if it is a good choice for you.

MYTH

Being in a clinical trial will not help me.

FACT

If you have lupus, the treatment and care you get in a trial may improve your symptoms or make you feel better. Many clinical trials use new treatments that are not available to the public. Some of these treatments may help you more than anything currently available.

But, it is always possible that the treatment might not work, or you might get a placebo, which does not have any medicine in it.