CLINICAL TRIALS FAQ

Is there a fee to join a clinical trial?

There is typically no fee to join a clinical trial. All trial-associated clinic visits and drug or intervention costs are covered as part of the trial. Health insurance is not required to participate in a clinical trial; however, some routine lab exams may need to be paid by patients and/or their health insurance.

Do I get paid for joining a clinical trial?

Some, but not all, clinical trials compensate participants. Financial support for travel sometimes is available.

Is it safe to join a clinical trial?

All clinical trials are approved and closely monitored for safety concerns by an Institutional Review Board (IRB) at the research institution conducting the trial. However, there is an inherent risk to any investigational therapy, and each person, with their physician, must weigh the potential benefits and risks before deciding to participate in a clinical trial.

What does the IRB do?

The IRB's goal is to protect the rights and welfare of participants enrolled in clinical trials at their institution.

How often will I need to visit a doctor or hospital for a clinical trial?

The frequency of visits will depend on the trial plan. In general, a study will consist of a screening visit, where your eligibility is confirmed and the baseline is established. Then there will be a visit to receive the intervention and several follow-up visits to monitor disease progression and make sure the drug is safe.

Will I still see my primary healthcare provider while I'm in a clinical trial?

Yes. Most clinical trials provide trial-associated care during the term of the study, but they do not provide overarching healthcare. It is helpful for your primary healthcare provider to work with the research team to ensure that other medications or treatments will not conflict with the trial protocol.

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What is a placebo, and why is it used in interventional clinical trials?

A placebo is an inactive substance, like a sugar pill, that is given in place of medication. During a placebo-controlled clinical trial, one group of participants (known as the control group) is given a placebo, while another group is given the drug being studied. Using this study design, researchers can compare the therapeutic effects of the drug against the effects of a substance without medicine in it.

What is the difference between a disease registry and a clinical trial?

Disease registries collect basic health information over time from volunteers with specific diseases or conditions. This information can then be used for many purposes, including historical studies that "look backward" and examine the outcomes resulting from prior patient care. Clinical trials are investigational; they "look forward" at the outcomes of participants who undergo a specific treatment or drug protocol to study that therapy.

Why is genetic testing important with regard to clinical trials?

Genetic testing can confirm your clinical diagnosis and potentially provide information about your prognosis and/or likelihood to respond to certain treatments. Therefore, when applicable, a confirmatory genetic test is often required to participate in a clinical trial.

What happens if I decide to leave a clinical trial while it's in process?

You can leave a clinical trial at any time. Depending on the study, leaving can be simple, with just a few requirements to transfer back to regular care. In other cases, you may need to be closely monitored until you are safely off of the study drug. The researchers will generally ask to follow up with you from time to time. These follow-ups can provide them with additional information that may be important for the study, as well as to ensure your safety.

Can I participate in multiple clinical trials?

It is recommended that patients enroll in only one clinical trial at a time. Each trial is designed to focus on a specific therapy, and participation in multiple trials makes it difficult to identify the risks and benefits of each therapy on its own. However, some people participate in several clinical trials in succession.

How will participating in one clinical trial affect my ability to participate in another clinical trial?

Each clinical trial has a set of inclusion and exclusion criteria. These are the rules about who can participate in the study, and they may include characteristics such as genetic diagnosis, age, or medical history. Participation in one clinical trial may either make you eligible or ineligible for future studies, depending on the inclusion/exclusion criteria of the later study.

To find a trial for you or a loved one, use MDA's Clinical Trial Finder at mda.org/clinical-trials. Read Clinical Trials 101 at mda.org/clinicaltrials101 to learn more about clinical trials, or contact the MDA National Resource Center at 833-ASK-MDA1 (275-6321).

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