DEBUNKING COMMON MYTHS

ABOUT CLINICAL TRIALS (STUDIES)

UC DAVIS
CLINICAL AND TRANSLATIONAL SCIENCE CENTER

CISCRP
THE CENTER FOR INFORMATION & STUDY ON CLINICAL RESEARCH PARTICIPATION

MYTH

Some people who try to volunteer for a clinical trial are told by the research team that they are not allowed to be in the trial. The process seems unfair.

FACT

Clinical trials always have a list of rules (such as age, sex, what health conditions you cannot have) that must be met for someone to be in the trial. These rules are to protect volunteers and to help researchers understand if the effects they see are caused by the trial medicine. People who do not meet these rules cannot take part. The rules are different for each trial, and are listed in the informed consent document.

MYTH

The trial may include painful or unpleasant parts.

FACT

The activities are different for each clinical trial. The doctor will talk to you about this, and the activities are always listed in the informed consent document. The IRB checks to see that the benefits and risks are carefully weighed and that the trial is reviewed for unnecessary harm/discomfort before it starts.

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. The National Institute of Health has an online database that you can search to find appropriate trials: www.clinicaltrials.gov. Unfortunately, using that database requires quite a bit of skill (more than many medical practitioners have), so it's worth making contact with a patient advocacy group. Many of them have tailored services that can help you with your search.

MYTH

Clinical trials are dangerous because they use new practices and medicines.

FACT

Keeping trial volunteers safe is the top priority. All clinical trials are reviewed before they start by the Food and Drug Administration (FDA) and an institutional review board (IRB), made up of doctors, scientists, and community members, whose main purpose is to decide if the trial is safe to do. People in a trial are closely watched, and the treatments they receive have gone through a rigorous testing process before being given to people.

CISCRP has a free service called Search Clinical Trials. CISCRP staff will help you find clinical trials that are relevant to their needs. Visit www.searchclinicaltrials.org or call 1-877-633-4376.

MYTH
If I join a clinical trial, I might get a "sugar pill" or placebo instead of a real drug.

FACT
A placebo is a sugar pill that does not cause harm or good. The decision about whether to use a placebo in a clinical trial is based on how serious the illness is, whether an existing treatment is available, and other considerations that ensure a high standard of ethics. In trials where a treatment is already available for the disease or condition, or in the case of serious illness, the available treatment is usually used instead of a placebo. In other trials, one group gets the new treatment while another group gets placebo. This is done so that the new treatment can be compared with no treatment in similar people.

MYTH
If I join a clinical trial, I won't get the same level of care that I receive with my doctor.

FACT
The care people get in a clinical trial is usually excellent. People in trials often say that the trial doctor and staff watch them more closely than their own doctor or nurse does during a regular office visit. This is because trials have very detailed procedures and often include extra tests and extra visits.

MYTH
Being in a clinical trial does not help the volunteer.

FACT
Being in a clinical trial may improve your medical condition. You may also get extra tests, lab work, and monitoring that you might not otherwise have, as well as having the opportunity to receive a drug that would not otherwise be available to you. Trial volunteers also play a key role in helping scientists find new treatments that will help people live longer and have better lives.

MYTH
Being in a clinical trial costs a lot and isn't covered by medical insurance.

FACT
Many insurance companies pay for costs that are not covered by the research sponsors doing the clinical trials, especially the costs for routine care and normal activities that would be done even if you were not in the trial. Trial subjects rarely have to pay any trial costs. Sometimes volunteers are paid back for expenses they might have, such as transportation and parking.

Things to Consider Before Volunteering

BEFORE TAKING PART in a clinical trial, consider the possible benefits and risks.

BENEFITS

The investigational treatment studied in a clinical trial may or may not benefit you personally, but the benefits of participating are:

- Possibly getting treatment for an illness when no other treatment exists
- Receiving expert care for your condition
- Having early access to new treatments
- Knowing your participation is helping others

RISKS

Clinical trials study investigational treatments, therefore, some in about the treatments are unknown. Some risks include:

- Not being able to choose your treatment
- Receiving a treatment that may not work as planned
- Experiencing unpleasant or serious side effects

To help you decide if you should participate in a clinical trial, ask questions, search the library or Internet for information (See Learn More About Clinical Trials on back), and seek the advice of family members or a trusted doctor, clergyman or friend.

Remember, your participation in clinical trials is strictly voluntary and you can drop out at any time for any reason.

Questions to Ask Before Participating in a Clinical Trial

- What is the purpose of this clinical trial?
- Why would researchers think this treatment might work for me?
- What are my treatment options?
- How will this clinical trial help my family
- or my community?
- What will I be asked to do?
- How long is the clinical trial going to last?
- What are the possible risks?
- Will I have to pay for any part of the clinical trial, and will I be reimbursed for costs of travel, parking, or meals incurred while I am in a clinical trial?
- If the treatment works for me, can I keep using it after the clinical trial ends?
- How will this study affect my daily life?
- Will anyone else know about my participation?

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CISCRP
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CISCRP is an independent non-profit organization dedicated to engaging the public and patients as partners in the clinical research process through education and outreach programs. CISCRP services also assist clinical research stakeholders in understanding public and patient attitudes & experiences in research to improve patient satisfaction. *CISCRP is not involved in recruiting patients for clinical trials, nor is it involved in conducting clinical trials.*

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