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CHAMP
Coalition for Headache and Migraine Patients

Part three: Why join a clinical trial

There are many reasons that people choose to volunteer for clinical research, but it's important to weigh these against potential risks. Some of the top benefits of taking part in research include:

Access to care.

People who take part in a clinical trial receive access to the latest treatments in development, and for many patients looking for options, this is a real benefit. In fact, according to a CISCRP survey of 2,194 former clinical trial participants, 44% of people surveyed cited "obtain better treatment" when asked to share their top reasons for participation.[1] In some cases, patients are able to continue taking the drug after the trial is over, as well. Also, in many cases, patients receive either the standard of care or the investigational drug, removing the risk of receiving a placebo.

Financial benefits.

Treatments administered during a clinical trial are often given at no cost to patients; in fact in many cases, volunteers are compensated for their time, travel, or participation in general. Treatments administered during a clinical trial are often given at no cost to patients; in fact in many cases, volunteers are compensated for their time, travel, or participation in general. The amount of payment often has to do with the phase of the trial. Phase 1 trials, for example, pay more (around $2,000 on average)[2] because the treatments being studied are less well-understood. To find a paid clinical trial, you'll likely need to find a few trials for which you may qualify, then contact the sites to learn about potential payment.

Quality of care.

Patients in clinical trials report a high level of personalized care while participating in research. While trials may require more office visits than normal, or more tracking of symptoms, this extra time spent on health can mean a higher quality of care.

Helping advance science for future generations.

The goal of clinical trials is to discover new, better treatments (and cures) for the condition being studied. This means that, if successful, patients with that condition in the future will have better options than current patients. This is an important motivator for many patients today. In the CISCRP survey[1] referenced above, nearly half of participants cited "help advance science, treatment of disease/condition" as one of their top reasons for participation.

[1] https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Participation-Experience.pdf
[2] https://www.moneytalksnews.com/7-things-to-know-before-you-join-a-clinical-trial/

On the other hand, of course, clinical trials also come with some degree of risk. There is a chance that the treatment being studied might not work as expected or be a better option than the standard of care. The study drug could also cause an unexpected side effect, especially in earlier phase trials.

With that said, there are several protections in place for patients who take part in clinical trials:

- An Institutional Review Board (IRB) ensures that trials are ethical and that participant rights are protected, and the FDA provides oversight for all clinical trials testing new drugs or devices.
- Participant rights include informed consent, meaning that volunteers are given all the facts about a trial and can ask any questions they'd like before enrolling. These questions might include:
    - How long will the study last?
    - What is the goal of the study?
    - Will I be reimbursed for my expenses?
    - Does the study include a placebo?
    - How will I receive the treatment?
    - Can I continue taking the study drug after the trial if it works for me?
    - How will my privacy be protected?
    - What can I expect at each study visit?
    - What happens if I leave the study early?
    - What happens if my condition gets worse or I am injured during the trial?
    - Who will be conducting the study?
    - What did previous studies find out about the treatment? Have the results been published?
    - What are the potential risks and benefits of the study drug?
    - Will I receive follow-up care after the study?
    - Will the results of the trial be provided to me?
- After signing an informed consent, a participant can still leave a clinical trial at any time, for any reason. In addition, if unexpected risks emerge during the trial, patients have a right to be informed about them and be removed from the study if appropriate.
- Special protection is also given to children who participate in trials as well. Often, both parents must give legal consent, and children over age six need to agree to take part as well.