



What is a **CLINICAL RESEARCH STUDY**?

A clinical study involves research using human volunteers (also called participants) that is intended to add to medical knowledge. There are several types of clinical studies:

- **Clinical Trials** – Participants receive specific interventions according to a research plan created by the investigators. These interventions may involve testing new medical products, such as drugs or devices. Or, they may involve evaluating changes to participants' behavior, such as diet.
- **Observational Studies** – Investigators track health outcomes over time in groups of participants according to a research plan that may reveal patterns in disease onset or progression.
- **Genetic Testing/Biosamples** – Some studies evaluate biological samples (biospecimens) provided by participants, such as a cheek swab to examine DNA/genes.
- **Registries & Surveys** – Participants answer questions to help provide insight into the challenges of the patient journey that may generate ideas for new research or treatments. The *NephCure Kidney Network* is a patient registry for all people with primary Nephrotic Syndrome and related kidney diseases.

Your healthy family members can also participate in some clinical studies.

Why **PARTICIPATE** in **CLINICAL RESEARCH**?

- You get to play a very active role in your own health care.
- You play a vital role in improving medical care for all people with Nephrotic Syndrome.
- You motivate researchers to keep fighting to find the cause and cure for Nephrotic Syndrome.
- You may be compensated for your time.





What is a **CLINICAL DRUG TRIAL**?

A carefully conducted clinical drug trial is the safest and fastest way to find therapies for patients with NS. They are designed to test the safety and effectiveness of new treatments or new ways to use existing treatments.

Clinical trials are one necessary step before a new drug can be brought to the market. Unfortunately, 80% of clinical trials fail – primarily due to low volunteer enrollment.

YOU can change that.

What are some **BENEFITS** of **PARTICIPATING** in a Clinical Trial?

- You may gain access to treatments that are not readily available to the general public. You may be among the first to receive a brand new treatment.
- If you are in a position in your patient journey where you have exhausted traditional options, clinical trials may give you and your doctor additional choices.
- You often have access to the best medical teams at leading hospitals and medical centers when you participate in clinical trials.
- Your participation is kept confidential within the clinical trial, and you may withdraw from a trial at any time.
- You don't have to leave your primary doctor to be a part of a clinical trial. Your doctor will be involved in following your treatment in the trial.

What are some **RISKS** of **PARTICIPATING** in a Clinical Trial?

- The study may require you to travel to the study site, receive treatments or have a hospital stay.
- You may not be in the study group that receives the experimental drug.
- There could be unpleasant side effects.
- You may feel inconvenienced or uncomfortable if you have to provide a biosample.
- Your health insurance may not cover all the study costs.
- The treatment may not be effective for you.

NephCure does not endorse participation in any specific clinical study. Individuals should consult with their physician or health care provider to discuss the benefits & risk of enrolling in a clinical trial.