

NIEMANN-PICK TYPE C RESEARCH STUDY

New research study for individuals with Niemann-Pick Type C (NPC)

The National Institutes of Health (NIH) is looking for those with NPC to be in a research study looking at the DNA of those with NPC and their medical history.

The study will look at the whole genome, family, and medical history. With this information we hope to gain a better picture of the heterogeneity of NPC, and why it presents differently in individuals. This research study will be remote, with no need to come to the NIH.

To participate in this study, one must:

- Provide consent
- Be diagnosed with NPC
- Provide one time DNA sample (e.g., blood)
- Be able to review medical history with study team

What is involved?

- Consent review
- One time DNA sample
 - Blood
- Virtual medical history review
- There is no cost for study-related tests or procedures
 - Compensation up to \$190, in the form debit card, direct deposit, or check may be given after completion of study.

What to expect?

- If family expresses interest, study team will meet with family, virtually, to review consent and medical history
- Study team will work with family local facility and other resources to obtain DNA sample and medical records.

NPC GENOMIC SEQUENCING



Location:

(Remote)

National Institutes of Health (NIH)
Clinical Center
9000 Rockville Pike, Bldg. 10
Bethesda, MD

Contact Information

To find out more about this study, please call or email

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