NIEMANN-PICK TYPE C RESEARCH STUDY

CAREGIVER & G-TUBE

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

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The National Institutes of Health (NIH) is looking for those who care for those with NPC to be in a sub-study looking at gastrostomy tubes (g-tube).

This study will look at g-tubes and what shaped the decision for caregivers to either have one placed in an individual who has NPC. This research study will be remote, with no need to come to the NIH.

To participate in this study, one must:

- Provide consent
- Caregiver of an individual diagnosed with NPC, with significant swallowing dysfunction
- Be able to complete a questionnaire with study team

What is involved?

- Consent review
- Virtual questionnaire with NIH study team
- There is no cost for study-related tests or procedures

Location:

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

Contact Information

If you are interested in finding out more about this study, please scan the QR code to provide contact information.