

NF1 Plexiform Neurofibroma Pain Scale Research Study

Do you or your child:

Have neurofibromatosis type 1 (NF1)?

Have a plexiform neurofibroma (PN)?

Experience any tumor pain?

Help evaluate new scales for NF1 PN pain in our research study!



Eligibility Criteria:

- A clinical or genetic diagnosis of NF1
- A plexiform neurofibroma tumor
- Report at least a minimal amount of PN-related tumor pain
- Are at least 8 years old
- Read, speak, and understand English

About the study:

- Participants will meet either in-person or remotely to download a mobile app to their cell phone
- Participants will complete brief questionnaires regarding demographics and well-being
- For two weeks, participants will complete brief questionnaires daily from home
- Participants will be paid for completing the study

- This study is being led by the National Cancer Institute at the NIH Clinical Center in Bethesda, Maryland
- Two other participating sites are John Hopkins University and Children's Hospital of Philadelphia

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