

Announcement of Research Study



****We are recruiting for children (8+ years), adolescents, and adults with NF1 and plexiform neurofibromas (pNFs) for a research study to complete pain questionnaires electronically over a two-week period from home****

Investigators at the National Cancer Institute are conducting a research study to evaluate questionnaires we have developed to assess plexiform neurofibroma (pNF) pain to use as outcome measures in clinical trials of new drug therapies. Currently, most questionnaires used to assess pain and the impact of pain on daily life have not been studied to see if they are appropriate for individuals with neurofibromatosis type 1 (NF1) and pNFs. In the first part of our study, we adapted two of these questionnaires after having interviews and focus groups with individuals with NF1 and pNFs.

Our primary goal for this next part of the study is to evaluate if these questionnaires accurately and reliably tell us about pain in people with NF1 and pNFs, and if not, continue to adapt them so they do.

To be eligible, patients must:

- Have a clinical or genetic diagnosis of NF1
- Have a plexiform neurofibroma (pNF) tumor
- Report at least a minimal amount of tumor pain related to your pNF tumor
- Be at least 8 years old
- Read, speak, and understand English

During the study:

- Participants will meet either in-person or remotely with the study team for about 1 hour 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 short pain questionnaires daily from home
- Participants will receive a small compensation (up to \$30) for completing the study

If you are interested in participating or if you have questions about the research study, you can email the study investigators:

- Jayla Melvin, the Study Coordinator, at jayla.melvin@nih.gov
- Pam Wolters, Ph.D., the Principal Investigator, at woltersp@mail.nih.gov