



Neurofibromatosis Type 1 Research Study

- We are recruiting patients with Neurofibromatosis type 1 (NF1) to take part in a research study.
- The name of the study is “Developing Novel Biomarkers of Plexiform Neurofibroma Tumor Burden”.
- The Principal Investigator (study doctor) is Carlos Prada, MD.

BACKGROUND

People with NF1 are at risk of having a type of tumor called plexiform neurofibroma, with children being at higher risk. Currently, detecting the risk factors for these tumors is difficult and requires whole body imaging, such as magnetic resonance imaging (MRI).

WHAT IS THE PURPOSE OF THE STUDY?

We want to identify and increase our understanding of tumor biomarkers in children and adults with NF1. Biomarkers are like signals in the body that we can measure. They can tell us about the progress of a disease or treatment.

IMPORTANT INFORMATION FOR STUDY PARTICIPANTS

- We are recruiting patients with Neurofibromatosis type 1 (NF1) to take part in a research study.
- Participation is completely voluntary and will not change the standard of care you or your child receive
- If you decide to participate in the study, you or your child will be scheduled for a study visit at the main hospital. During the visit, you may complete:
 - » Blood sample drawn (2 to 4 teaspoons)
 - » Whole-body MRI
 - » Dietary log (before visit)

HOW LONG WILL THE STUDY LAST?

If eligible, we will ask you to return one more time about one year from your first visit to complete the study. You will be paid \$100 for the first visit and \$100 for the second visit.

Questions?

Please contact one of our study coordinators:

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