

SEEKING PARTICIPANTS FOR A RESEARCH STUDY



Natural History Study of Cutaneous Neurofibromas in People with NF1



**VECTRA WB360 3D imaging
system photographs the entire
body in single capture.**

The Neurofibromatosis Therapeutic Acceleration Program (NTAP) at Johns Hopkins University seeks participants for a research project that will study how cutaneous neurofibromas form and change in people who have neurofibromatosis type 1 (NF1). The study will use a specialized 3D photography system to take whole-body pictures once a year for up to five years to track the progression of neurofibromas over time.

OVERVIEW:

At each annual clinic visit, participants will be asked to have a whole-body photograph, undergo a skin exam by a member of the research team, and complete a survey about the symptoms they may be experiencing. During the first visit, participants will be offered free genetic testing to determine the type of NF1 gene mutation they have. If previous genetic testing results are available this step may not be necessary.

Photographs will be taken at the Johns Hopkins Outpatient Clinic in Baltimore and will only be used for research purposes. The photographs or genetic information will be shared with other investigators for additional research in the future. No radiation or side effects are associated with the Vectra camera system, but there is a risk of loss of confidentiality.

Participants will be compensated with a one-time \$50 gift card provided during their first clinic visit. If you are traveling from outside of Maryland, you may be eligible for travel expense reimbursement for up to \$700 on each of your visits.

TO LEARN MORE:

Contact the study coordinator, **Amanda Johnson** at ajohn418@jh.edu
or call **410-502-7546**.

IRB study number: IRB00272137
Principal Investigator: Carlos Romo, MD

