

## What is this study about?

We invite you to join a research study of neurofibromatosis type 1 (NF1) in adults at the National Institutes of Health (NIH). We are trying to answer a simple question: in adults, how fast (or how slow) do neurofibromas grow? By answering this question, we hope to lay the groundwork for future trials of new drugs to control the growth of neurofibromas. We also hope to find genes that control the growth of neurofibromas in NF1.

## Who can participate?

To be in our study, a person must:

- 1) Have a diagnosis of NF1.
- 2) Be between the ages of 20 and 50 years.
- 3) Have both parents willing to be involved with the study. It does not matter if they have neurofibromatosis type 1. We need to ask your parents some medical questions and draw some blood.
- 4) Be willing to travel to the NIH in Bethesda, Maryland for 6 visits. The first visit will last about a day, but the others will each last a half-day. We can pay for travel and lodging expenses.
- 5) Be able to have a biopsy of a neurofibroma and skin. This will be done with numbing medicine.
- 6) Have a doctor to follow-up with you after your visit to NIH.

This is a shortened list. There are some other criteria that we can discuss with you.

## What is involved in the study?

If you are eligible for the study, we will:

- 1) Help arrange travel for you (and family members, in some cases) for your 6 visits to NIH in Bethesda, Maryland.
- 2) Ask you questions about your medical history and do a physical exam (like in any doctor's office). In addition, we will draw some blood, take some pictures of your skin using several different cameras and remove a neurofibroma and a small piece of normal skin. At the follow-up visits, only photography and in some cases, a blood draw, will be performed.
- 3) Answer your questions about NF1. We can help you find doctors near you for follow-up.
- 4) Discuss our findings with you. We will send you a letter summarizing your visit.

## What is the cost of the study?

The visit and all testing are free and there is no cost to you, your family or your insurance company for this study.

## What about travel?

We will pay your travel expenses, subject to NIH regulations. If you live locally (near the NIH) we will cover some of your travel expenses to come to NIH. If you live further away, we will pay for your transportation to NIH (plane, car, train), hotel, meals and expenses. Travel must be arranged by NIH.

## Will I get paid for joining the study?

No, participants in the study do not receive any compensation other than travel and lodging expenses (subject to NIH regulations).

## Why should I join the study, or what's in it for me?

People join research studies for many reasons. In NF1, there is a long history of cooperation between patients and doctors. Animal models of the disease are helpful only up to a point.

## Where can I learn more about the study?

You can read more about the study at the website below:

The NHGRI website:  
<http://www.genome.gov/17516967>

## How do I enroll?

You may contact either Dr. Jennifer Sloan (genetic counselor) at [jsloan@mail.nih.gov](mailto:jsloan@mail.nih.gov) or Dr. Douglas Stewart (principal investigator) at [drstewart@mail.nih.gov](mailto:drstewart@mail.nih.gov). Additional contact information is listed below.

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