



Resiliency for Adolescents with NF Study

A research project to enhance stress and symptom management

Does your adolescent have NF? Are their NF symptoms bothersome and stressful for them?

The Family Center for Neurofibromatosis and the Integrated Brain Health Clinical and Research Program (IBHCRP) at the Massachusetts General Hospital are conducting a research study to compare 2 programs that teach stress and symptom management skills for adolescents with NF1 and NF2.

The Department of Defense is paying for this study.

What does the study involve?

- 8 group sessions led by an MGH psychologist with expertise in NF.
- Completion of questionnaires with help from study staff over the phone at the beginning, end, 6 months and 12 months after the sessions.
- All sessions will take place from your home, using Vidyo, a secure software program you can use with a computer and a webcam to have live video-conferences, that we will help you install at no cost to you.
- Sessions are 45 minutes long and held once a week.
- This study DOES NOT involve taking medication.
- This study DOES NOT involve travel to MGH.

Who can participate?

- We are looking for adolescents ages 12-17 who have a diagnosis of neurofibromatosis 1 (NF1) or neurofibromatosis 2 (NF2).

What are the benefits?

- If your adolescent participates in this research study, they will learn about stress management (both related to NF and general life stress). They will also interact with other adolescents with NF and be able to see and hear them in real time by using the Vidyo software program.
- For completing study assessments, your adolescent could receive up to \$70 of compensation.
- There is no cost to participate in this study and your decision to participate will not affect your medical care.

How do I join?

- If you would like to learn more about this research study, please contact the study coordinator, Mira Reichman, mreichman@mgh.harvard.edu, or the principal investigator, Ana-Maria Vranceanu, avranceanu@mgh.harvard.edu.

Thank you for considering our research study! You will be helping us gather important information about a training that may help other patients in the future.