

# What is Patient Engagement?

Patient engagement in research is increasingly recognized as an important component of the research process and promises to accelerate the development of new treatments by focusing researchers on real-life issues that they may not have otherwise considered.

We use the term “Patient Engagement” to mean the inclusion of patient representatives in NF research. The Patient Engagement Program at the Children’s Tumor Foundation (CTF) is committed to expanding awareness and facilitating opportunities for patients with neurofibromatosis (NF) to get involved in research through:

- Offering the Patient Representative Training Program.
- Facilitating patient participation in specific research opportunities for graduates of this program.
- Encouraging shared knowledge through partnership with organizations and groups committed to patient-centered research.
- Maintaining the Patients Help Doctors/Researchers Network, a resource pool of expert patients that facilitate reciprocal communication and collaboration with the NF research community.



## The value of patient input in research

“The role played by patient representatives has drawn our attention to some of the most important problems faced by NF patients. We are strongly convinced that the continuous interaction between scientists, physicians, and patient advocates will help us immensely to focus on the key unsolved issues on which we should direct our research efforts, in order to build tangible benefits for patients affected by neurofibromatosis.”

**Antonio Iavarone, MD**

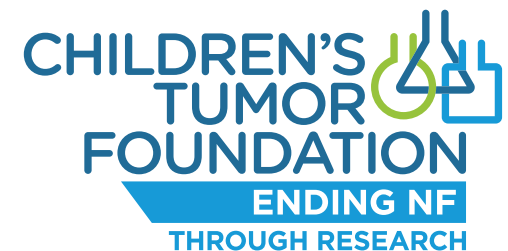
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# PATIENT ENGAGEMENT

Empowering the patient in NF research through the Patient Representative Training Program.



To learn more, visit  
[ctf.org/patientengagement](https://ctf.org/patientengagement)

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# CHILDREN'S TUMOR FOUNDATION Patient Representative Training Program



The Children's Tumor Foundation **Patient Representative Training Program** is CTF's initiative designed to prepare individuals with NF and their families to participate as advocates in the research process. Our goal is to help patients learn how to add their perspective during all phases of the research process – from the laboratory, to the clinic, to the community. Patient Representatives are trained to work with stakeholders such as researchers, research institutions, the pharmaceutical industry, the Food and Drug Administration, and patient advocacy organizations.

## TRAINING PROGRAM HIGHLIGHTS

This online training program provides an education for patients to increase their understanding about the research and drug development process, regulatory affairs, and neurofibromatosis. Activities to encourage critical thinking and engagement in research also play an important part in the training.

Certain training sessions may also include an in-person component. When the initial training has been completed, participants will receive a Certificate of Completion naming them as Patient Representatives of the Children's Tumor Foundation. They will continue their involvement in the program, and will have access to CTF's ongoing series of educational webinars.

Patient Representatives will be prepared to:

- Participate as co-reviewers and lay-patient representatives for the Children's Tumor Foundation Research Programs (such as NF Registry and Research Awards).
- Join committees with experts in a clinical setting – such as Response Evaluation In Neurofibromatosis and Schwannomatosis (REiNS).
- Join CTF's Patients Help Doctors/ Researchers Network, a resource pool of expert patients that facilitate reciprocal communication with researchers and other NF experts.

## Q&A

### Who are Patient Representatives?

Patient Representatives are individuals with an NF diagnosis and/or their caregivers who are interested in developing the skills to participate in research and motivated to make a broader impact.

### What is required of Patient Representatives?

- Computer and internet proficiency; have an email address
- Work in a team with flexibility to work with different groups of people
- Listen actively and communicate effectively
- Be comfortable speaking to groups of people
- May be required to travel overnight to attend conferences or meetings
- Eager to gain an education about the science behind NF and NF treatments

### What is the role of Patient Representatives?

Representatives can become involved in many aspects of research. For example:

- Serve as patient co-reviewers for research proposals
- Disseminate research results to the NF community
- Act as a spokesperson at meetings and conferences
- Be members of REiNS working groups to determine endpoints for clinical trials
- Increase awareness and understanding about the critical role that people with NF can play in treatment development
- Help align therapies development with the priorities of people living with NF