



CTF Engage is the patient engagement initiative of the Children's Tumor Foundation, dedicated to transforming the landscape of NF research through the curation of high-quality, meaningful interactions between patients and families with research stakeholders. Our mission is to support scientific projects of merit that generate value for the NF community.

By collaborating with Patient Representatives, your team can better understand the issues that are important to NF patients of all backgrounds, and build trust and connections with the community.

If you are looking to collaborate with Children's Tumor Foundation Patient Representatives, please reach out to engage@ctf.org to discuss how we can work together.



The NF Registry represents the collaborative efforts of patients from around the world diagnosed with NF, including neurofibromatosis type 1 (NF1) and all forms of schwannomatosis (SWN), including *NF2*-related schwannomatosis (*NF2*-SWN), formerly called neurofibromatosis type 2. The database was created to accelerate research and therapy development for patients affected by NF.

The database houses the information necessary to determine the prevalence and natural history of these conditions and to assist in identifying appropriate candidate patients for a particular study who have agreed to be contacted by CTF about potential beneficial research. For centers conducting clinical trials, participants who may be candidates for studies will be contacted by the NF Registry administrator and provided with contact information; if the patient is interested in potential participation in a study, he or she will contact the study center.

At CTF Engage, we are here to support our Patient Representatives in lending their perspectives to your projects at key decision points. They can:

- Serve as study advisors or members of community advisory boards
- Provide input on study design, such as protocols, endpoints, and recruitment materials
- Guide research priorities and give insight on community perspectives for therapies
- Be storytellers and speak with your team about lived experiences

Reasons to Use the NF Registry

- Recruit for a clinical trial or research study
- Request de-identified data reports to answer a specific research question
- This NF Registry is a contact registry. When patients join, they can choose to opt-in to receive emails from the registry about clinical trials & research. Emails are sent to registrants who align with recruitment goals

To learn more about how you can use the NF Registry, please contact Kate Kelts at kkelts@ctf.org. All requests are reviewed by an external review committee composed of clinicians and representatives from the NF community.

For data requests, a data transfer and use agreement is necessary and will be provided after the request is approved.

The standard fee for working the NF Registry for research institutions or the pharmaceutical industry is \$5,000.