



"Knowing my son is part of the NF Registry helps me to trust this journey, even when I do not understand it."

HEATHER FRAZIER AND HER SON RYAN who lives with NF1

Join the NF Registry

When you join the NF Registry you have access to the latest discoveries about the many ways living with NF can affect individuals and families, which helps you and your family find the best possible care.

As an NF Registry participant, you complete a yearly health survey. This data helps researchers study how NF affects everyone differently and how NF changes over time. You can then choose whether to receive personalized emails about:

- Clinical trials and research studies relevant to you or your child
- Updates to NF care recommendations
- Research announcements and news
- Surveys designed to get patient input on key NF challenges
- Educational materials specific to you
- Resources to help you on your path with NF

Even if you choose not to be contacted, your participation helps researchers learn from the real experts - NF patients and families.

Join at nregistry.org today



 **NF REGISTRY**
UNITE TO FIGHT NF
nregistry.org



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STAY INFORMED. IMPROVE CARE.
ADVANCE NF RESEARCH.



"Sometimes there are good days and sometimes there are bad days, but it's a matter of taking it one step at a time. Take the NF Registry on your journey with you."

SEQUOYAH DANIEL-ROBINSON
who lives with NF2-SWN

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

The NF Registry is a patient-driven resource for accelerating research and finding treatments for all forms of NF, including neurofibromatosis type 1 (NF1), and all types of schwannomatosis (SWN), including NF2-related schwannomatosis (NF2-SWN), formerly known as neurofibromatosis type 2. Sponsored by the Children's Tumor Foundation, the NF Registry is a safe and effective tool to empower NF patients and their caregivers by inviting them to take an active role in advancing NF research.


If you or your child is living with NF, unite with thousands of others by joining the NF Registry today. Go to nregistry.org and click on "Create a New Account" to get started.

The NF Registry's first principle is that patients are always in control of their own information. You only share what you want to share, and you control the permissions on when or if you are to be contacted. All information is carefully protected with the strictest privacy protocols in place.

Information in the NF Registry is used for only two purposes:

1. Communicating with you about news and clinical trials that match your needs
2. Providing qualified researchers a summary of anonymous patient data about NF symptoms



"I joined the NF Registry because I know there is power in numbers, and I know and trust the Children's Tumor Foundation." 

MICHELE HOLBROOK
who lives with schwannomatosis

How do we know the NF Registry is working? Has it had results?

Yes, absolutely! In addition to connecting NF patients with specific research studies and clinical trials, NF Registry studies have provided critical information about where and what type of NF care is available to patients, especially for adults with NF. This is helping doctors and researchers better plan for future care and treatment options for patients with all forms of NF. Increased knowledge about specific manifestations of NF is also helping researchers improve treatment considerations, and patients are reporting back improved lifestyles. For example, an adult NF2 patient maintained his hearing because of the chance to use a specific drug, and the parent of an NF1 patient was given a more comprehensive range of treatment possibilities for her young child.

How private is private?

Your NF history is very personal and important to you. The NF Registry protects you by using the highest standards for data security (HIPAA, GDPR) and ethical use (Western Institutional Review Board). When filling out the patient questionnaire, you are free to answer (or not answer) the questions at your personal comfort level. The NF Registry will then only contact you if you give permission. Your information is not shared with the Children's Tumor Foundation or any other organization, and it will never be used for fundraising or marketing.

Who should I contact?

For questions about the NF Registry, please email nregistry@ctf.org.

Researchers: To apply to the Data Usage Committee, go to nregistry.org and click "For Researchers."



"I joined the NF Registry as an investment in all of the patients who share my disorder, and in all of the families who share their burden." 

CHRISTOPHER EDWARDS
who lives with NF2-SWN

About the Children's Tumor Foundation



Founded in 1978, the Children's Tumor Foundation (CTF) began as the first grassroots organization solely dedicated to finding treatments for

NF. Today, CTF is a highly recognized global nonprofit foundation, the leading force in the fight to end NF, and a model for other innovative research endeavors.

Learn more at ctf.org, or reach out to us at info@ctf.org or 1-800-323-7938 or (212) 344-6633.

Join at nregistry.org today