



ANNA HARLAND
-Lives with NF1

How do I register?

Joining the NF registry is quick and easy. Go online to nfregistry.org, click "Join Registry Now," and create your private account.

The NF Registry will then ask some questions about the person with neurofibromatosis. The questionnaire should take less than 30 minutes to fill out. You don't have to answer all of the questions. And you can stop any time and return to it later if you need to. The information includes basic data—name, contact information, age, gender, and the like—and more specific questions about medical history, the NF diagnosis, and experiences with the condition.

We'll ask you for permission to contact you later about:

- Opportunities to participate in clinical trials or research studies.
- Updating the information you have entered.

Remember: The NF Registry will only contact you if you give specific permission.

Join nfregistry.org today

**CHILDREN'S
TUMOR
FOUNDATION**
ENDING NF
THROUGH RESEARCH
120 Wall Street, 16th Floor
New York, NY 10005

UNITE TO FIGHT
NEUROFIBROMATOSIS:
Overcoming NF depends on
people with NF

JOIN THE
NF REGISTRY

www.nfregistry.org

"We joined the registry to make ourselves available for anything and everything we can possibly do to make a difference in the life of our son."

JASON COLE
-Son Owen
Lives with NF1



**CHILDREN'S
TUMOR
FOUNDATION**
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THROUGH RESEARCH

You are not alone

NF is one of the world's most common genetic disorders. But it takes many forms, and can be hard to diagnose and treat.

Research is the key. And the NF Registry is the key to research. If you have been diagnosed with any form of neurofibromatosis (including NF1, NF2, and schwannomatosis), or if your child has NF, unite with thousands of others with NF and join the NF Registry today.

If a friend or family member has NF, please tell them about nregistry.org now.

How does the NF Registry help?

The Children's Tumor Foundation (ctf.org) created the NF Registry to:

- Let people with NF know if they might be eligible for clinical trials of new treatments.
- Notify people with NF of new research studies in which they might participate.
- Understand the different forms NF can take, and how these affect the patient's life.



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

MICHIE O'DAY
-Lives with NF2

What do I get?

Private Record. You get a private NF Registry record of your own (or your child's) NF history. And you will be able to see an anonymous summary of other NF Registry members' responses, so you can tell how your experience compares with theirs.

Clinical Trials and Research. If you say we can contact you about clinical trials or research programs, we will let you know when there is an opportunity for you or your child to participate in a study. You can then contact the researchers if you wish to participate—they will not get your personal information and will not be able to contact you.

The NF Registry will not contact you about all clinical trials. We will reach out only if your questionnaire indicates that you are likely to qualify for a particular study. You can also use the Registry at any time to find information about all current studies.

How else might my data be used?

The NF Registry may also strip out all identifying information to give researchers anonymous medical information about how NF starts and progresses. This information could, for example, help doctors understand the connections between specific genetic mutations, different sets of NF symptoms, different patterns of NF development, and responses to treatments.

How private is private?

Your NF history is very personal and very important to you. The NF Registry protects your privacy and uses the highest standards for data security. Your name, contact data, and identifying information are kept separate from the medical data: Only you and the NF Registry administrators can see it. The NF Registry will only contact you if you give permission. It is never used for fundraising.



"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."

DREW LEATHERS
-Lived with schwannomatosis

You can withdraw from the NF Registry any time you want by sending written notice to the NF Registry Program Manager at the Children's Tumor Foundation (see below). If you cancel, the NF Registry will stop contacting you about clinical trials or updating your information.

Who should I contact?

For questions about the NF Registry, or to withdraw from it, please contact:

Clinical Program Manager
Children's Tumor Foundation
120 Wall Street, 16th Floor
New York, NY 10005
(212) 344-6633
nregistry.org

Join nregistry.org today