

Resource Summary Report

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NF Registry

RRID:SCR_006277

Type: Tool

Proper Citation

NF Registry (RRID:SCR_006277)

Resource Information

URL: <https://nfregistry.patientcrossroads.org/>

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Description: A patient registry to identify people with neurofibromatosis (NF) who are interested in participating in clinical trials, as well as determining the commonality of specific characteristics of NF. The NF Registry is committed to secure methodologies and pioneering research that will lead to improving the health and well-being of individuals and families affected by NF. This registry has been created to collect data on large numbers of people with NF. This has never existed before and will help: * Identify people who may be eligible for clinical trials or other research studies being conducted in the field of NF. New clinical trials are launched each year yet challenges identifying participants too often mean that these studies finish late or never really get started. Today, 80 percent of trials fail to recruit enough volunteers within planned timelines. Under enrollment is one of the most significant problems facing NF drug development. Together, we can solve it. * Determine the commonality of specific NF characteristics. This will help researchers and doctors devise better ways to care for people with NF If you or your child has been diagnosed with neurofibromatosis (NF) please join the NF Registry today. It's quick, it's easy, and it matters. The key to treatments lies within you researchers can't deliver treatments without committed volunteers.

Abbreviations: NF Registry

Synonyms: Children's Tumor Foundation NF Registry, Neurofibromatosis Registry, CTF NF Registry

Resource Type: patient registry, people resource

Keywords: clinical trial, research study, adult human, child

Related Condition: Neurofibromatosis

Funding: Childrens Tumor Foundation

Resource Name: NF Registry

Resource ID: SCR_006277

Alternate IDs: nlx_151888

Record Creation Time: 20220129T080235+0000

Record Last Update: 20260808T190449+0000

Ratings and Alerts

No rating or validation information has been found for NF Registry.

No alerts have been found for NF Registry.

Data and Source Information

Source: [SciCrunch Registry](#)

Usage and Citation Metrics

We found 1 mentions in open access literature.

Listed below are recent publications. The full list is available at [SPARC SAWG](#) .

Heaney A, et al. (2020) The development of the PlexiQoL: A patient-reported outcome measure for adults with neurofibromatosis type 1-associated plexiform neurofibromas. Molecular genetics & genomic medicine, 8(12), e1530.