



What is Neurofibromatosis

[Pronounced noor•oh•fahy•broh•muh•toh•sis]

Neurofibromatosis (NF) is the most common neurological disorder caused by a single gene and it affects one out every 3,000 people worldwide. NF is more prevalent than Cystic Fibrosis and Muscular Dystrophy combined. **Currently there is no cure, no long-term treatments, nor any prevention for NF.**

NF involves the uncontrolled growth of tumors along the nerves anywhere in the body, internal and external, and at any time throughout an individual's life. It is linked to learning disabilities, high blood pressure, epilepsy, and can affect the development of the brain, cardiovascular system, bones, and skin. NF can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer and even death.

NF affects people of both sexes in all races and ethnic origins equally. An estimated fifty-percent of those with NF inherit the disorder from a parent and approximately fifty-percent will have no family history of NF. Their disorder is the result of a spontaneous gene mutation. Individuals with NF have a fifty-percent chance their child will be born with NF.

NF is a highly variable, yet progressive disorder that affects each person differently. Some patients experience severe complications, even death while a few people will live their life never knowing they have NF because of their minor symptoms.

Because of NF's close connection to many common diseases and disorders such as cancer, learning disabilities, heart disease, memory loss, and brain tumors, NF research stands to benefit 175 million Americans in this generation alone.

Who We Are

In 1980, the **Texas Neurofibromatosis Foundation® (TNFF)** a nonprofit 501(c)(3), voluntary organization was formed to battle Neurofibromatosis (NF) and to serve the needs of those living with this disorder and their families.

Our mission: We are committed to meeting the needs of people impacted by neurofibromatosis by providing comfort, support, education, advocacy and funding for a treatment, prevention or cure.

What We Do

Supporting NF Research

TNFF has awarded over \$2 million to support NF clinicians and scientists who are dedicated to treating NF patients and advancing NF research. Our research grants support preliminary clinical studies and serve as a bridge to larger grants from national or government funding.

National NF Coalition

In an effort to promote federally-funded NF research, TNFF joined the National NF Coalition in 1996. Securing federal funding for NF research is one of the most important parts of our mission. In partnership with the coalition, we work with our representatives to encourage continued and increased federal funding of NF research. We seek funding from the U.S. Army Congressionally Directed Medical Research Program – Neurofibromatosis Research Program (CDMRP-NFRP) and the National Institutes of Health (NIH).

Creating Awareness

Neurofibromatosis affects more people than cystic fibrosis and muscular dystrophy combined yet many people have never heard of it. We are trying to change that. TNFF works to raise awareness about NF and we look for opportunities for media exposure.

Supporting NF Patients and Families

The Foundation provides referrals to NF clinics and specialists for those diagnosed with NF. TNFF supports the following NF Clinics providing patient care needs:

- Dallas Children's Health
U.T. Southwestern Medical Center
- Fort Worth Cook Children's Health Care System
- Houston MD Anderson Cancer Center
Baylor College of Medicine
Texas Children's Hospital of Houston

Patient Outreach

TNFF organizes informative gatherings across the state such as the annual NF Symposium and support group meetings. TNFF provides information packets and brochures to patients and their families, physicians and teachers as part of our public education program. If requested, we provide a mentor program where we introduce people to other NF patients and/or families for support.

- Charline and Red McCombs **Annual NF Family Camp** provides a weekend of learning, laughing and companionship for those struggling with the unknown future of living with NF.
- Peter Lowry **Family Assistance Fund** enables the foundation to provide families with financial assistance for a portion of their transportation.
- John D. Wagner and Elisabeth R. Wagner **Scholarship Fund** awards scholarships each school year for people living with NF who seek higher education.

The Benefit of NF Research

Because of NF's close connection to many common diseases and disorders; NF research stands to benefit over 175 million Americans in this generation alone.

- **Cancer:** NF shares the same pathways with 70% of human cancers, affecting approximately 65 million Americans. Recent research has more clearly defined the pathways inside the cells leading to tumor proliferation and other manifestations.
- **Heart Disease:** Recent research has found a link between NF and vascular disorders such as congenital heart disease and hypertension, affecting more than 50 million Americans.
- **Learning Disabilities:** NF is directly linked to learning disabilities affecting over 35 million Americans. NF1 is the most common cause of learning disabilities.
- **Memory Loss:** NF is directly linked to memory loss affecting at least 25 million Americans.
- **Brain Tumors:** Both NF1 and NF2 are associated with brain tumors affecting at least 30 thousand Americans.
- **Deafness:** The NF2 gene causes 5% of all genetic forms of deafness.