What is Neurofibromatosis?

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

- 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.
- Neurofibromatosis (NF) is the most common neurological disorder caused by a single gene.
- Every hour 3 people are born with NF.

Who gets NF?

- NF affects 1 out of every 3,000 people worldwide.
- NF equally affects people of both genders, all races and ethnic origins.
- Fifty-percent of those with NF inherit the disorder from a parent and approximately 50% will have no family history of NF.
- Individuals with NF have a 50% chance of passing the disorder to his or her child.

What are the symptoms of NF?

- NF 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, chronic pain, brain tumors, cancer and even death.
- Currently there is no cure, no long-term treatments, nor any prevention for NF.
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 is to meet the needs of people challenged with neurofibromatosis by providing care, comfort, support, information, education, funding and other resources for its treatment, prevention and cure.

What We Do

Supporting NF Research

TNNF 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 such as the “Neurofibromatosis May Awareness Month” proclamation by Governor Perry in May of 2011 and 2012.
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 Medical Center of Dallas
  - U.T. Southwestern Medical Center
- Fort Worth
  - Cook Children’s Health Care System
- Houston
  - M.D. 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.
Milestones and Highlights

2011  TNFF celebrates 20 years of hosting NF Family Camp.

2010  TNFF awards over $2 million in donations to support NF clinicians and scientists who are dedicated to treating NF patients and advancing NF research.

2010  TNFF joins forces with Children’s Tumor Foundation to fund research project.

2009  Dr. Luis Parada, U.T. Southwestern Medical Center, develops first NF1 dermal neurofibromatosis mouse.

2009  TNFF helps fund a new adult NF clinic at U.T. Southwestern Medical Center, Dallas, TX.

2008  Cook Children’s Medical Center in Fort Worth, Texas opens new NF clinic.

2005  TNFF publishes 14 Stories, an educational storybook for newly diagnosed NF patients and their families.

2000  Dr. Luis Parada, U.T. Southwestern Medical Center, regenerates malignant tumors in mice.

1998  TNFF funds new pediatric NF clinic at Children’s Medical Center in Dallas, TX.

1996  TNFF joins the National NF Coalition to secure federal funding for NF research.

1993  The Carolyn Farb Endowed Lectureship at MD Anderson Cancer Center has brought together twelve outstanding and distinguished scientists and researchers.

1991  TNFF opens NF Family Camp for patients and their families.

1990  TNFF funds a new NF clinic at MD Anderson Cancer Center in Houston, TX.

1987  National Institutes of Health adopts Dr. Riccardi’s two classifications of NF: NF Type 1 (NF1) and NF Type 2 (NF2).

1986  TNFF funds the publication of the first book¹ about NF published since 1956.

1982  TNFF co-founder, Dr. Vincent Riccardi publishes the first article² identifying two types of Neurofibromatosis (NF).

1981  TNFF assembles medical advisory board.

1980  TNFF founded by Ms. Doris Kraft and Dr. Vincent Riccardi.

² Neurofibromatosis: Clinical Heterogeneity, Curr Probl Cancer, 7(2):1-34, 1982