



Texas Neurofibromatosis Foundation® Fact Sheet

In 1980, the Texas Neurofibromatosis Foundation® (Texas NF), a non-profit 501 (c) (3), organization was formed to battle Neurofibromatosis (NF) and to serve the needs of those living with NF. Although not well known, NF affects 1 in 3,000 individuals and is linked to learning disabilities, epilepsy and can affect the development of the brain, bones and skin. NF can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and even death. This disorder poses lifelong challenges for NF patients. Texas NF is committed to meeting the needs of people impacted by neurofibromatosis by providing comfort, support, education, advocacy and funding of research for a treatment, prevention or cure.

Patient Outreach Services

- Texas NF provides a Clinic Liaison to offer additional information and support to patients at the NF clinics at Children's Health Dallas, UTSW Medical Center, Cook Children's Ft. Worth, MD Anderson Cancer Center and Texas Children's Hospital at no cost to the medical facilities and patients.
- The Foundation collaborates with Cook Children's Hospital by organizing quarterly support groups.
- The annual Texas NF Symposium provides the latest information on genetic testing, educational issues, current treatments and research trials. It is free of charge to all participants.
- Texas NF Family Camp is held each September: 90% of campers attend on full scholarships. Patients and families develop supportive relationships, discuss relevant issues and build self-confidence.
- Distribution of informational packets to patients, educators and physicians
- Referrals to physicians and clinics that specialize in NF
- Recommendations to community resources & social services
- Support group meetings in Houston, Dallas, Ft. Worth, San Antonio and Austin
- Promote Texas NF services available at professional medical conferences
- Higher Education Scholarships
- Travel Assistance Fund (Avg. 5/year)
- Distribution of electronic newsletters
- Organized mentoring program
- Raise public awareness of the disorder through various public relations and advertising methods

Research

Our research grants support preliminary clinical studies and serve as a bridge to larger grants from national or government funding.

Income

Texas NF does not receive government funding or any income from The United Way; income is generated from gifts from individuals, corporations, private foundations and special events. Sixty-five percent of our income is produced through special events. ***Dining Out in Dallas*** is our largest fundraising event providing over \$2 million to patient programming over the past 24 years.

Texas NF Staffing

We are careful stewards of the funding received and keep expenses to a minimum. We currently have two full-time employees, and three part-time employees.