

## ABOUT NEUROFIBROMATOSIS TYPE 1 (NF1)



- **Neurofibromatosis type 1, or NF1**, is a genetic condition that causes tumors to grow on nerves throughout the body.
- NF1 occurs in **1 in 2,500 births** and affects millions worldwide.
- NF1 is characterized by **café-au-lait** (light brown) spots and **neurofibromas** (small benign tumors) on or under the skin.
- **NF1 affects all populations** regardless of race, ethnicity, or gender.
- About half of the individuals with NF1 also have learning disabilities.
- Some patients with NF1 develop softening and curving of bones and curvature of the spine (scoliosis).
- **Roughly half of all cases** arise in families with no history of the condition.
- Occasionally, tumors may develop in the brain, on cranial (brain) nerves, or on the spinal cord.
- While NF tumors are generally benign (not cancerous), they may cause health problems by pressing on nearby body tissues.
- NF1 is usually diagnosed in childhood.
- While there is not yet a cure for NF1, there is an FDA-approved treatment for NF1 inoperable plexiform neurofibromas.
- Because of the Children's Tumor Foundation, there are many promising clinical trials in progress, NF clinics providing the best NF care, and more treatment options in development that will better the lives of all NF patients.

Help end NF by joining the confidential **NF Registry**. To learn more and participate, please visit **[nfregistry.org](https://nfregistry.org)**

For more information about NF1 please visit **[ctf.org/nf1](https://ctf.org/nf1)**