• **NF refers to** a group of genetic conditions that cause tumors to grow on nerves throughout the body. NF includes neurofibromatosis type 1 (NF1), and all types of schwannomatosis (SWN), including NF2-related schwannomatosis (NF2), formerly called neurofibromatosis type 2.

• **Schwannomatosis (SWN)** is an umbrella term for the following conditions, which are named according to the gene change causing the condition (with gene names in italics):
  - NF2-related schwannomatosis
  - SMARCB1-related schwannomatosis
  - LZTR1-related schwannomatosis
  - 22q-related schwannomatosis
  - schwannomatosis (NOS) not otherwise specified
  - schwannomatosis (NEC) not elsewhere classified

• SWN (all types) occurs in approximately 1 in 20,000 births.

• SWN (excluding NF2-related schwannomatosis) occurs in approximately 1 in 70,000 births.

• Schwannomatosis is caused by a change in one of the genes located on chromosome 22.

• The signs and symptoms of schwannomatosis usually develop during teen and adulthood years, though they can occur at any age.

• Schwannomatosis is characterized by the development of benign tumors — called schwannomas — usually on spinal and peripheral nerves.

• The most common symptom of schwannomatosis is **chronic pain**, which can occur anywhere in the body. It is believed to be caused at least in part by schwannomas pressing on nerves.

• Pain management is usually an integral part of care.

• Schwannomatosis affects all populations regardless of race, ethnicity, or gender.

• A majority of all cases arise in families with no history of the disorder.

• There is no cure for schwannomatosis yet, but promising advancements in schwannomatosis research are underway.

Help end NF by joining the confidential NF Registry. To learn more and participate, please visit nfregistry.org

For more information on schwannomatosis please visit: ctf.org/schwannomatosis