CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

ABOUT SCHWANNOMATOSIS (SWN)

- **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*-SWN), 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