Neurofibromatosis, or NF, is an under-recognized genetic disorder that can cause tumors to grow on nerves throughout the body. NF has three distinct forms: NF1, NF2, and Schwannomatosis.

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

The most common symptom 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, genders, and ethnicities equally.

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

We’re here to help. For more information on schwannomatosis, contact the Children’s Tumor Foundation at 1-800-323-7938 or go to ctf.org