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 the most rare type of NF, and affects less than 1 in every 40,000 people.

Schwannomatosis is caused by pathogenic variants (previously called mutations) in genes located on chromosome 22. There are at least two genes, LZTR1 and SMARCB1 that are known to cause schwannomatosis, and there may be additional genes discovered in the future.

The signs and symptoms of schwannomatosis usually develop during 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 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.

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

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