Schwannomatosis affects all populations, genders, and ethnicities equally.

THERE IS NO CURE FOR SCHWANNOMATOSIS YET but promising advancements in research are underway.

Schwannomatosis (SWN) is an umbrella term for a group of genetic conditions that cause tumors to grow on nerves throughout the body.

Approximately 1 in 20,000 births will one day be diagnosed with SWN (1 in 70,000 excluding NF2-related SWN).

Schwannomatosis is characterized by the development of benign tumors called schwannomas usually on spinal, peripheral nerves, or vestibular (hearing) nerves.

Schwannomatosis is caused by pathogenic variants in genes located on chromosome 22.

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.

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

There are many types of schwannomatosis, which are referred to by their specific gene variant. So far, we know of:

- NF2-related schwannomatosis
- SMARCB1-related schwannomatosis
- LZTR1-related schwannomatosis
- 22q-related schwannomatosis
- schwannomatosis NOS (not otherwise specified)
- schwannomatosis NEC (not elsewhere classified)

Signs and symptoms of SWN usually develop during the teen to adulthood years, though they can occur at any time.

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