

NEW AND IMPROVED

# The Way to Talk About NF

You may have heard that some exciting new discoveries have changed the way we talk about NF. Part of the mission of the Children's Tumor Foundation is to expand knowledge. With new knowledge comes a better understanding and now, an improved way of talking about NF.



## Let's Get to the Point: A New Definition of NF

**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.**



## Let's Break it Down

**NF collectively refers to NF1, schwannomatosis, and NF2**

The abbreviation "NF" is **not** being used solely as a short form of the word neurofibromatosis.

### NF1 refers to neurofibromatosis type 1

NF does not refer to just NF1.

**Since 2022, SWN refers to schwannomatosis, which is an umbrella term to refer to many sub-types of schwannomatosis**

These sub-types are named according to the genetic information used to diagnose the condition (with gene names in italics):

- *NF2*-related schwannomatosis
- *SMARCB1*-related schwannomatosis
- *LZTR1*-related schwannomatosis
- 22q-related schwannomatosis
- Schwannomatosis NOS or NEC (used when there is no genetic information)

### NF2 and NF2-SWN refer to *NF2*-related schwannomatosis

The term "neurofibromatosis type 2" is no longer used.



## Let's Get to the Nitty-Gritty

**NF is caused by a pathogenic variant, or a "change in a gene"**

The word "mutation" is no longer used.

### NF is a genetic condition or a disease

The word "disorder" is being phased out.

### Gene names are in *italics*, but the diagnosis is not

For example: A change in the *NF1* gene causes a diagnosis of NF1.



## Let's Talk Numbers: The Birth Incidence of NF

We now know NF is more common than previously reported.

<b>NF</b> (all types)	<b>ABOUT 1 IN</b> <b>2,000 BIRTHS</b>
<b>NF1</b>	<b>ABOUT 1 IN</b> <b>2,500 BIRTHS</b>
<b>SWN</b> (all SWN types)	<b>ABOUT 1 IN</b> <b>20,000 BIRTHS</b>
• <b>NF2-SWN</b>	<b>ABOUT 1 IN</b> <b>25,000 BIRTHS</b>
• <b>SWN</b> excluding <i>NF2</i> -SWN	<b>ABOUT 1 IN</b> <b>70,000 BIRTHS</b>



## Let's Stick with NF

CTF will no longer compare the incidence of other conditions with that of NF. In the past, our talking points included "*NF is more common than ...*" and named several conditions thought to be more well-known than NF. That information may no longer be accurate. More important, thanks to the incredible awareness efforts of the NF community over the past 20 years, that message is no longer needed.

We hope you are as excited about these changes as we are! Over time and with practice, this new way of talking about NF will feel natural. What's most important...**LET'S TALK ABOUT NF!** This and other NF fact sheets and resources can be found at [ctf.org/education](https://ctf.org/education)