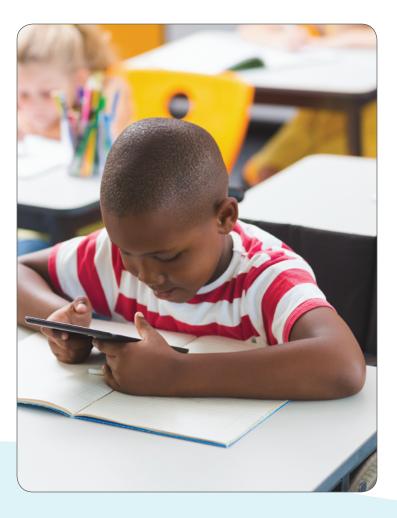
## Let's Talk About ...

# Neurofibromatosis type 1: Genetic disorder causing non-cancerous tumors

Neurofibromatosis (NEW-roh-FIBE-row-muh-TOH-siss) type 1, also called NF1, is a genetic disorder that causes non-cancerous (benign) tumors to grow around the nerves and on the skin. NF1 is the most common type of neurofibromatosis, and 1 in 3,000 people worldwide will be born with it each year.

Children with NF1 have multiple light brown skin spots and can have large non-cancerous tumors on the nerves, called neurofibromas (NEW-roh-fibe-ROW-muhs). They may also have learning challenges, scoliosis (a curved spine), brain tumors, and health problems from tumors pressing on tissues.



#### What causes neurofibromatosis type 1?

Neurofibromatosis type 1 is a genetic disorder, which means your child either inherited the disorder from a parent or was born with the disorder. Some children who have NF1 are the first in their family to have the disorder.

## What are the signs of neurofibromatosis type 1?

The signs of NF1 include:

- Light brown skin spots, called café au lait (caff-AY-oh-LAY)
- Neurofibromas on or under the skin that can cause pain and itching
- Optic gliomas (tumors on the optic nerve)
- Learning problems
- Curved lower leg bones (called tibial bowing)
- Early or delayed puberty
- High blood pressure
- Scoliosis (a curved spine)
- Small stature

## How is neurofibromatosis type 1 diagnosed?

Your child's healthcare provider will look at your child and ask questions about their pain and symptoms. They will look for café au lait spots, freckling under the arms and around the groin, and colored spots on the eyes. The healthcare provider may ask about their medical history and whether any relatives have NF1. Your child may also have genetic testing (blood or tumor samples with DNA).

If your child is diagnosed with NF1, they must have TWO of the following:	Notes
<ul> <li>6 or more café au lait spots (5 mm or bigger in young children and 15 mm or bigger in teens)</li> </ul>	
• 2 or more neurofibromas	
An optic glioma	
• Freckles under the arm or on the groin area	
• Abnormal growth (dysplasia) of the sphenoid bone behind the eye or lower leg bone	
• A close relative (parent or sibling) with NF1	
• 2 or more Lisch nodules (harmless colored spots in the eyes)	
How is neurofibromatosis	
type 1 treated?	
If your child has NF1, they will be treated at a neurofibromatosis clinic with providers who have experience treating the disorder. Your child may also be referred to healthcare providers who work in:	
• <b>Genetics:</b> Help with genetic disorders	
• <b>Ophthalmology</b> (OP-thall-MALL-oh-gee): Help with eye and vision problems	
• <b>Dermatology:</b> Help with skin, nail, and hair problems	
Orthopedics: Help with muscle and	
bone conditions	
• Neurology: Help with brain and nerve conditions	
• Oncology: Help with benign and cancerous tumors	
What if I have questions about	
neurofibromatosis type 1?	
If you have questions about NF1 or your child's	

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symptoms, contact your child's healthcare provider. You can also find more information about NF1 on the Children's Tumor Foundation website, ctf.org.