

## 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).



## Notes

- [illegible]

If you have questions about NF1 or your child's symptoms, contact your child's healthcare provider. You can also find more information about NF1 on the Children's Tumor Foundation website, [ctf.org](http://ctf.org).

© 2018 Intermountain Healthcare, Primary Children's Hospital. All rights reserved. The content presented here is for your information only. It is not a substitute for professional medical advice, and it should not be used to diagnose or treat a health problem or disease. Please consult your healthcare provider if you have any questions or concerns. More health information is available at [intermountainhealthcare.org](http://intermountainhealthcare.org). Pediatric Education, Practice, and Research 801.662.3500 LTA418 – 03/18 Available in Spanish.