

Neurofibromatosis

Background

Neurofibromatosis (NF) is a genetic neurological disorder affecting the brain, spinal cord, nerves and skin. Genetic mutations cause the body to produce small benign growths, called neurofibromas, that can grow around nerves and on the skin. Sometimes a benign tumor can grow inside the body, pressing on vital organs and affecting function. NF may lead to developmental abnormalities and an increased risk of learning disabilities.

Neurofibromatosis has been classified into three distinct types. NF Type 1 (NF1) is the most common form and usually diagnosed in childhood. Signs of NF1, such as patches on the skin that are darker than the surrounding area called café-au-lait spots, can be present at birth and grow in number. Occasionally, tumors may develop in the brain, spinal cord, or optic nerve. Signs and symptoms of NF1 include:

- Skin spots
- High blood pressure
- Skeletal abnormalities like short stature and scoliosis
- Changes in vision or vision loss

NF Type 2 (NF2) is less common. Symptoms of NF2 usually begin in adolescence or adulthood. The most common tumors associated with NF2 may grow along the auditory nerve, causing hearing loss, ringing in ears, and poor balance. NF2 can also cause eye abnormalities and increased tumor growth along the lining of the brain and spinal cord.

Like features of NF2, schwannomatosis is a disorder characterized by uncontrollable growth of specialized cells that normally form an insulating layer around the nerves. These tumors, called schwannomas, cause chronic and debilitating pain during early adulthood.



Top Takeaways for School

Neurofibromatosis (NF) is a group of genetic conditions known as neurocutaneous disorders that affect the skin and nervous system, causing tumors to grow on and under the skin. NF Type 1 (NF1) is the most common form in children.

Physical symptoms include fatigue, dizziness, clumsiness, and stomachache. The growth of tumors can also cause gross and fine motor impairment.

Most children with NF1 will have some degree of learning disability that affects memory, attention, and processing.

Visual-motor, visual-spatial, and visual-perception impairment may require advanced planning and accommodations.

The student may experience difficulties with organization and impulse control.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnoses: Risk for injury, impaired thought process and pain (acute/chronic)
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Consider emergency action plans (EAPs) and emergency evacuation plans (EEPs) related to special health care needs, including staff education/training

Discussion Starters for the Educational Team

1. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
2. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
3. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
4. Does the student need support with gross or fine motor skills in the classroom?
5. Will staff receive education/training to implement the student-specific emergency plan?

Resources

Kennedy Krieger Institute: Neurology and Neurogenetics Clinics
[kennedykrieger.org/patient-care/centers-and-programs/neurology-and-neurogenetics-clinics](https://www.kennedykrieger.org/patient-care/centers-and-programs/neurology-and-neurogenetics-clinics)

Children's Tumor Foundation
<https://www.ctf.org/>

Neurofibromatosis Network: Understanding Neurofibromatosis
<https://nfnetwork.org/data/uploads/nf1-educational-materials/understanding-nf-3rd-edition.pdf>



For more information, please scan the QR code or visit: [KennedyKrieger.org/SHNIC](https://www.KennedyKrieger.org/SHNIC)

