

Neurofibromatosis Information Sheet

Neurofibromatosis (NF) is a genetic disorder that interrupts cell growth in the nervous system, causing tumors to form on nerve tissue. These tumors may develop anywhere in the nervous system, including in the brain, spinal cord and nerves. The tumors are usually benign (noncancerous), but some are malignant (cancerous).

Symptoms

Three types of neurofibromatosis exist, each with different signs and symptoms.

Neurofibromatosis 1 (NF1) usually appears in childhood. Symptoms include:

- Flat, light brown spots on the skin.
- Freckling in the armpits or groin area.
- Soft bumps on or under the skin.
- Tiny bumps on the iris of the eye.
- Unusual bone structure, such as a curved spine or bowed lower leg.
- Larger-than-average head size.
- Learning disabilities.
- Attention-Deficit/Hyperactivity Disorder (ADHD).
- Short stature.

Neurofibromatosis 2 (NF2) is far less common than NF1. Symptoms generally appear in the late teen and early adult years and may include:

- Gradual hearing loss.
- Ringing in the ears.
- Poor balance.

The third type of NF is Schwannomatosis. It is a rare form of NF that rarely affects people before their 20s or 30s.

Treatment

NF treatment aims to maximize healthy growth and development, control symptoms and manage complications. When NF causes large tumors or tumors that press on a nerve, surgery

may help ease symptoms. Some students may benefit from other therapies, such as very precise radiation therapy, medications to control pain or physical therapy. There is no known cure for any form of NF.

Educational Implications

The effects of NF are unpredictable and have varying presentations and degrees of severity. These include hearing loss, vision loss, heart and blood vessel complications, discomfort from unusual bone structures, seizure disorders, cognitive impairments and learning disabilities, which may involve language development, reading and organization.

Educational Options

Those students whose neurofibromatosis adversely affects their educational performance may benefit from special education under the Individuals with Disabilities Education Act (IDEA). To qualify under IDEA, a student must meet eligibility criteria in one of thirteen specific disability categories. IDEA entitles a student with a disability to a free appropriate public education (FAPE) and an individualized education program, including individual goals, objectives, related services, accommodations and modifications.

Students that do not qualify for services under IDEA may qualify under Section 504 of the Rehabilitation Act. To qualify under Section 504, a student must have a physical or mental impairment that substantially limits one or more major life activities (for example learning, breathing, thinking, concentrating, walking, bodily functions). Under Section 504, a student is entitled to equal opportunity, and may qualify for a Section 504 plan that provides regular or special education and related aids and services.

A student with a health condition who does not require special instruction and related services can receive, as appropriate, a wide range of supports in the general education classroom, including accommodations, individualized health plans (IHP), emergency care plans (ECP) and local education agency supports.