Neurofibromatosis

Children's Special Health Parent's Sheet

Description

Neurofibromatosis is progressive in nature, signs and symptoms may not manifest at birth they may begin in the first few years of life. There are two types of Neurofibromatosis:

- Neurofibromatosis Type 1 (NF1)
 - NF1 (aka Von Recklinghausen) is a hereditary disease with about 50% of patients having a fresh
 gene mutation. It is characterized by café-au-lait spots, cutaneous and plexiform neurofibromas,
 pigmented iris hamartomata, macrocephaly of postnatal onset and mild short stature. Occasional
 abnormalities may include optic glioma, astrocytomsa, seizures, mental deficiency, and headaches.
- Neurofibromatosis Type 2 (NF2)
 - NF2 (acoustic neurofibromatosis) usually has a later age onset during the second and third decades. NF2 is often more severe than NF1 because multiple intracranial tumors can develop in childhood, in addition to cataracts.

What services will CSH cover?

- Only **providers** listed on the Eligibility Letter will be paid
- Labs/Tests must be performed by a Wyoming Medicaid provider
- Well Child Checks (coverage limited to Pediatrician) according to AAP Periodicity Schedule
- Medications
 - None (If child is diagnosed with seizures, refer to Convulsive Disorders policy for coverage)
- Equipment/Supplies
 - None

Contact CSH for questions regarding additional medication and/or equipment/supplies

Minimum requirements for coverage to continue with CSH:

- Compliance of medical care and care coordination
- Annual review with Public Health Nurse, financial eligibility
- Please keep your Public Health Nurse informed of any changes throughout the year for example: address, provider, diagnosis and/or insurance coverage
- Keep in contact with the local Public Health Office for additional requirements





