Neurofibromatosis

Neurofibromatosis is a type of disease affecting the growth and development of nerve cell tissues. Tumors end up growing on the nerves, and it can affect a number of different systems inside of the body, such as the skeleton, skin and brain. Even though the tumors are benign, they end up growing on the nerves within the body, as well as underneath and on the skin.

The disease can cause changes in skin, deformities of the bones and a host of other problems. In many instances, symptoms are present at birth or they develop during childhood. Some individuals have symptoms that are mild or almost entirely unnoticeable. In other instances, the disease causes significant disabilities. It's a genetic problem, and if a parent has neurofibromatosis then the children will have a 50% chance of developing the condition. However, some cases are just random mutations that occur in the foetus and other family members are not affected.

Generally these problems are present at birth, and are nearly always apparent by the time the child enters teenage years. It can present as light brown spots on the skin, a tumour on the eye or optic nerve, or as a scoliosis. Learning difficulties are also commonly present.

Even though there isn't a cure for the disease, many of the symptoms can be managed and treated. Children who have severe symptoms will require more attention medically than those who only have mild symptoms. As the individual grows older, the symptoms tend to get worse.

In some cases of neurofibromatosis, lumps and growths can occur all over the body, especially the face, hands, and torso.

Neurofibromatosis Types:

Type 1 (NF1): nerve tissue grows tumours or neurofibromas. These tumours can grow anywhere on the nerve. NF1 is more common.

Type 2 (NF2): these tumours affect cranial nerve VIII (vestibulocochlear nerve). This nerve is important in hearing and balance, so children can be deaf or have poor balance. It is rarer than NF1 and can affect 1:25,000. It is also more severe than NF1 and can cause brain damage.

Schwannomatosis. Even rarer affecting around 1:40,000, and it's a variation of NF2.

Neurofibromatosis is worldwide, affects both sexes equally, and has no preference for race, geographic area, or ethnicity.

How to Treat Neurofibromatosis:

1. Surgery

To help eliminate tumors in the body, surgery might be needed to cut them out of the various areas where they are located. It is often recommended, especially as some tumours can become cancerous.

2. Radiation

Beams of radiation can help to shrink any tumors and destroy cells causing cancer. It can also be used to prevent loss of vision.

3. Chemotherapy

Chemotherapy is a type of drug treatment that is often used to kill off the tumors and any cancer that is spreading. It is often used in the beginning as a means of shrinking the tumor and making it easier to move without having to undergo surgery.





4. Bracing

If your child has a 15-25 degree spinal curve and still in the growing phase, they might have to wear a brace. Even though bracing doesn't straighten out the curve, it can help slow its progression and prevent them from becoming worse.

Tips:

- Family counseling, support groups and genetic counseling can help those who are dealing with the disease, as well as their families.
- Some individuals might experience issues emotionally or psychologically due to their illness becoming withdrawn and isolated because of their feelings of indifference.
- Many children and their parents struggle with feelings of anger, shock, sadness, guilt, confusion and anxiety.
- Six or more lightly colored birthmarks often appear somewhere on the body before nine years of
- Some people are born with the condition and show symptoms at birth, while others develop the disease later on in life.