nervetumours.org.uk

NERVE TUMOURS UK

Support for medical professionals treating Neurofibromatosis Type 2 (NF2).

What is NF2?

Neurofibromatosis Type 2 (NF2) is a rare genetic condition caused by a "misspelling" on chromosome 22. NF2 occurs in 1 in 30,000 of the population.

Neurofibromatosis is a collective name for a group of conditions: Neurofibromatosis Type 1, Neurofibromatosis Type 2, Schwannomatosis and Legius Syndrome. Three of the four conditions cause nerve tumours, and all involve health complications.

NF2 patients often need operations on their brain or spinal cord, due to the tumours that typically grow their as a result of the condition. The hallmark of NF2 is the development of benign tumours called vestibular schwannomas which grow on both hearing nerves. These tumours can cause hearing loss, deafness, and mobility problems due to the pressure exerted on key nerves. Benign tumours may also develop on the nerve roots as they leave the spine and on the coverings of the brain. Some people with NF2 have a few benign tumours on the skin nerves.

In addition to these, other benign tumours associated with the nervous system may occur, in particular:

- The lining of the brain (meningiomas)
- The spine (meningiomas, schwannomas)
- The skin (schwannomas)

NF2 can also cause some ocular (eye) changes such as cataracts. These are often present from an early age but may not cause any significant visual problems.

They are very different conditions and it is extremely unlikely that your patient would have both NF1 and NF2.

NF2 can also be passed on from parent to child at the time of conception, a person who has NF2 has a 50% (or 1 in 2) chance of passing on the condition to his/ her children.

How is it diagnosed?

NF2 is a genetic disorder that is caused by a misprint in a single gene on chromosome 22. The misprinted gene will be present at birth but signs of the condition do not usually appear until the teenage years, twenties or later.

Most NF2 tumours are slow growing and may cause minimal problems for years. Although they are not malignant (not cancerous) their position may produce significant symptoms. For the majority of people, the most common first symptoms of NF2 are:

- **Gradual hearing Loss**
- **Tinnitus (ringing or roaring in the ears)**
- **Unsteadiness, particularly when walking on uneven ground or in the dark.**

These symptoms are caused by tumours on the hearing nerves (vestibular schwannomas). Other symptoms may relate directly to the pressure caused by tumours on the spine or on the lining of the brain. For example:

- **Headaches**
- **Change in vision**
- **Change in sensation, pain or weakness of an arm or leg.**

Medical Guidelines

Medical guidelines for NF1 are available from Nerve Tumours UK website. NF2 guidelines are not offered, as it is the role of the National Genetic Centres of Excellence. However, you can reach out to **Nerve Tumours UK Helpline** at **07939 046 030** (open Mondays and Wednesdays 9am – 5pm) to request advice. They can also put you in contact with the Genetic Centres if needed.

Nerve Tumours UK Support Specialists

Nerve Tumours UK is the leading voice for neurofibromatosis support in the United Kingdom and we play a crucial role for anyone living with nerve tumours. One way in which we maintain this position is by funding a network for Support Specialists.

Our specialists are experts on neurofibromatosis, all of whom are highly qualified professionals with a background in nursing, social work or occupational therapy. They all work from a hospital base in their region, and collaborate with many other professionals involved the care of patients with nerve tumours.

Our Specialists are an excellent resource for anyone with neurofibromatosis. They provide an all encompassing support service that follows an individual through all stages of their life.

Current NHS Service for people with Neurofibromatosis

All children with a diagnosis of neurofibromatosis have health checks with a paediatrician throughout childhood. Once children reach adulthood, care is transferred to either their GP, Specialist Neurofibromatosis Clinic or other hospital based doctor depending on their circumstances and health status.

National 'Complex NF1' Service

London

Professor Rosalie Ferner (national lead)
Guy's & St. Thomas's NHS Foundation Trust
Neurology Department
Southwark Wing
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London SE1 9RT

Tel: Co-ordinator – Henry Neville 020-7188-3959
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The National NF2 Service

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Do you have nerve tumours? We're here to help.

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/NerveTumoursUK **@NerveTumoursUK** **@NerveTumoursUK**

Our Nerve Tumours UK Specialists are available to offer support to anyone living with nerve tumours.

Call our helpline on 07939 046 030
Monday and Wednesday 9am-5pm

Nerve Tumours UK
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Never Tumours UK is the trading name of the Neurofibromatosis Association.
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