



Support for medical professionals treating NF2-related Schwannomatosis (NF2)



What is NF2?

NF2-related Schwannomatosis (NF2) is a rare genetic condition caused by a 'misspelling' on chromosome 22. NF2 occurs in 1 in 30,000 of the population.

NF is the medical group name for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN) 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 there 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.

NF1 and NF2 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 the Nerve Tumours UK website. You can also sign up to the Healthcare Professionals section for further information.

NF2 guidelines are not offered, as it is the role of the National Genetic Centres of Excellence. However, you can contact the **Nerve Tumours UK Helpline 07939 046 030/ Freephone 0300 102 17 22 or email helpline@nervetumours.org.uk** (Monday, Wednesday and Friday 9am – 5pm) to request advice. They can also put you in contact with the Genetic Centres if needed.

Healthcare Professionals

Sign up to access relevant information, lectures & guidelines for administering to patients with NF1, NF2 and SWN.



Nerve Tumours UK Support Specialists

Nerve Tumours UK is the leading voice for NF 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 NF, 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 NF. They provide an all encompassing support service that follows an individual through all stages of their life.



Current NHS Service for people with NF

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

Nationally Commissioned 'Complex NF1' and NF2 Centre

London (covering London and South East England)

Professor Rosalie Ferner (national lead NF1)

Guy's & St. Thomas's NHS Foundation Trust
Neurology Department
Southwark Wing
Great Maze Pond
London SE1 9RT

NF1 Service

Tel: 0207 188 1029

NF2 Service

Tel: 0207 188 9976

Text only: 07894 709 116

Nationally commissioned NF1 and NF2 Service

Manchester (covering Liverpool, Newcastle, Leeds and Sheffield)

Prof Gareth Evans (national lead NF2)
Genetic Medicine
6th Floor
St Mary's Hospital
CMFT
Oxford Rd
Manchester M13 9WL

NF1 Service

Tel: 0161 701 0286

NF2 Service

Tel: 0161 701 0285

NF2 Service

Cambridge (covering Cambridge, East Anglia and the Midlands)

Mr Patrick Axon/ Juliet Buttimore
Dept. of ENT
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 2QQ

Tel: 01223 348672

Text only: 07752 562927/ 07514 622138

Email: nf2.cambridge@nhs.net

Oxford (covering Oxford and South West England)

Dr Dorothy Halliday, Consultant
Geneticist

Dr Allyson Parry, Consultant
Neurologist

Oxford NF2 Service Neurosciences
Level 3, West Wing
John Radcliffe Hospital
Headley Way
Headington
Oxford, OX3 9DU

NF2 office

Tel: 01865 231 889

Email: nf2@ouh.nhs.uk



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

nervetumours.org.uk
info@nervetumours.org.uk
020 8439 1234

f /NerveTumoursUK **in @NerveTumoursUK** **@NerveTumoursUK**

Our Nerve Tumours UK Specialists are available to offer support to anyone living with NF, the medical group name for NF1, NF2 and SWN, all of which cause tumours to grow on nerve endings.

Call our helpline on 07939 046 030/ Freephone 0300 102 17 22 or email helpline@nervetumours.org.uk
Monday, Wednesday and Friday 9am-5pm

Nerve Tumours UK
First Floor, 44 Coombe Lane, London SW20 0LA

Nerve Tumours UK is the trading name of the Neurofibromatosis Association.
Registered Charity Number: 1078790 and SC045051

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