



Dear GP,

Circa 26,500 children & adults living in the UK, have a condition that you probably have not heard of since medical school!

Nerve Tumours UK is a UK wide charity, working to improve the lives of those affected by NF, the new medical group for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN).

The effect on families of a new diagnosis is devastating, more so because they are unlikely to have heard of NF beforehand, and won't know where to find help.

The charity, a leading voice for NF in the UK, funds a team of Specialist NF Nurses that provide advice and support to patients, who are diagnosed with the either of the three conditions; raises awareness amongst medical professionals and the public; and collaborates and facilitates research into NF.

The Facts

- NF is one of the world's most common neurogenetic conditions
- Categorised into NF1, NF2 and SWN, the severity of the condition will vary from person to person
- NF1 affects 1 in every 2,500 people
- NF2 affects 1 in every 35,000 people
- Over 60% of those with NF1 have learning difficulties.
- A parent has a 1:2 chance of passing on the condition to their child
- There are over 26,500 children & adults diagnosed with the condition in the UK
- Up to 30% of NF1 patients will be registered as disabled
- Up to 75% of NF2 patients will be registered as disabled

This is a genetic condition, hence there is no cure. The severity of the condition will vary from person to person and whilst some may live a normal life, others of those with NF could have a multitude of medical, physical and psychological conditions.

NF1 is a genetic disorder of the nerve tissue, affecting 1 in every 2,500 people worldwide, some 25,000 in the UK. It can cause tumours on the optic nerves, which severely restrict sight or cause blindness. It can cause curvature of the spine; large benign tumours which can result in mobility and speech problems and over 60% of NF1 patients have learning difficulties. It can cause malformation of the long bones below the elbow and knee, that affect children's leg development and often results in operations or amputations.

NF2 is a much rarer genetic disorder of nerve tissue, affecting 1 in every 35,000 people. It is always serious. The chief characteristic is tumours on both auditory nerves. Complications include benign brain tumours, tumours of the spine, cataracts, skin tumours, deafness and lack of mobility. Surgery is the principal treatment.

Schwannomatosis shares some features of NF2 but not hearing loss. What distinguishes Schwannomatosis from NF2 is that people with this diagnosis rarely, if ever, develop vestibular schwannomas, the hallmark tumour of NF2.

We are here to help!

This letter has been passed to you, along with the accompanying guidelines, as you see patients with NF, but you may not know about our service, and how we can work together for the benefit of your patient.

Please do get in touch with us, and pass this information to any of your colleagues, who may have a shared interest.

For further information, please visit nervetumours.org.uk or call **020 8439 1234**.

Yours sincerely,
Nerve Tumours UK