Dear Practitioner

Nerve Tumours UK - NF

26,500 people have a condition that you probably have not heard of since medical school

I am a supporter of Nerve Tumours UK, the charity working to improve the lives of those affected by Neurofibromatosis (the group name for Neurofibromatosis Type 1 (NF1, NF2-related-Schwannomatosis (NFT2) and Schwannomatosis (SWN)). NF is one of the world's most common neurogenetic conditions. The effect on families is devastating, more so because they are unlikely to have heard of NF before diagnosis and won't know where to find help.

The charity, which is the authoritative voice of NF in the UK, funds Specialist NF Nurses that provide information and support to patients, who are diagnosed with the condition; raises awareness of this devastating condition; encourages and supports research.

The Facts

- NF is 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 30,000 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

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 30,000 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 need your help!

Please pass this letter on to anyone who is professionally involved in the care of those diagnosed with the condition, but who might not be fully informed, or a specialist in the field looking after NF patients, who do not know about our service. They can get in touch with us directly. Additionally, pass this information to anyone affected by the illness and tell them to get in touch with us.

If you need any further information, please visit **nervetumours.org.uk** or call **020 8439 1234.**

Thank you so much for all your support.

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