



Dear General Practitioner,

There are 26,500 people, in the UK, who have a condition that you probably have not heard of since medical school: NF - the group name for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN).

NF, one of the most common neuro-genetic conditions, causes tumours to grow on nerve-endings, and has many associated medical, physical and psychological conditions e.g. Scoliosis; 60% have learning disabilities; up to 70% are registered disabled. 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. 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.

Nerve Tumours UK, a national registered charity is at hand to help the whole NF community. The charity funds a unique Specialist Support Network, comprising regional nurses, a national helpline, clinical guidelines, information days, an interactive website, online communities, medical guidelines and literature, to help both children and adults diagnosed with NF, along with their parents, carers and the many medical professionals involved in their care.

The NTUK national helpline, 07939 046 030, is available on Monday, Wednesday and Friday 9am-5pm, and further information, can be found at nervetumours.org.uk or by calling the head office on **020 8439 1234**.

Request for Registration on the Learning Disability Register (LDR)

There are many ways in which the charity can help children and adults with NF, who are experiencing difficulties whilst in school, at university or in the workplace.

Over 60% of children with NF1 will have learning difficulties, but many teachers are unaware of the condition, which can make the child's experience at school difficult and unproductive. Although NF is a common genetic condition, the learning and behaviour problems that affect a high proportion of children tend to be regarded as "just part of NF". Talking this through with one of Nerve Tumour UK's Specialist NF Nurses, ensures children are supported correctly, diagnosed with any associated conditions, for example, ADHD, ADD or ASD, and plans put in place for the child to receive the correct additional support.

As the patient's GP, you can help regarding registration on the LDR. This extra support for individuals when dealing with medics, can be one of the first steps in making a child's learning experience in school more positive; or in supporting an adult in their work environment and with daily tasks, all of which is conducive to increasing their confidence and achievements.

Therefore, please can you register my child/ myself (mark as appropriate) at your earliest opportunity.

Name:

Signature

Date

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