NTUK | MP letter - template

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Dear [name of MP]

Every day in the UK a child is born with neurofibromatosis (nerve tumours). Some inherit the condition, others are affected by a random mutation. Nerve tumours can affect anyone: any ethnicity, class or sex. Over 26,000 people in the UK have nerve tumours.

[If you or a family member has Neurofibromatosis, please mention that here.]

Nerve tumours occur in three genetic disorders of the nervous system: Neurofibromatosis Type 1, Neurofibromatosis Type 2 and Schwannomatosis. Each of these conditions has its own range of complications, which can be life-limiting and impairs the quality of life. For example, Neurofibromatosis Type 1 involves the nervous system, skin, eye and bone. It predisposes people to many complications, including tumours of the brain and spine; malignant peripheral nerve sheath tumours and breast cancer.

In addition to the physical impact of nerve tumours, many people experience social and economic disadvantages. It is a particularly isolating condition because it is often met with prejudice and bullying. Evidence suggests that the condition leads to severe financial hardship in the third generation.

Sadly, many health care professionals in the UK have little knowledge of nerve tumours and the manifestations of the neurofibromatosis. Obviously, this impacts on early diagnosis. NHS provision is patchy, support depends on location.

Nerve Tumours UK is the authoritative voice of over 26,000 people in the UK who are born with one of the neurofibromatosis. The charity seeks to expand knowledge of nerve tumours and advance the care for those with them.

Some years ago, the charity launched a scheme in partnership with the NHS, to provide regional specialist nurse advisors, but due to a lack of funding, this is not yet available throughout the UK.

[If you live in Scotland, [other areas], then your area is one that is not supported by a specialist Neurofibromatosis nurse. Add: Indeed, our own area is one of the losers in this postcode lottery – we do not have a specialist nurse advisor we can call on.]

I would be very grateful if you would raise these issues with the Secretary of State for Health.

Yours sincerely