NERVE TUMOURS UK

MEDIA PACK

About Nerve Tumours UK

Nerve Tumours UK is the authoritative voice of over 26,000 people in the UK who are born with one of the neurofibromatoses - genetic disorders that have a major impact on the nervous system and lead to tumour formation. Nerve tumours can be uncompromising, painful and punishing without the right support network. As long as the condition is around, we will strive to provide better and more targeted support.

We achieve this by providing first class information, support and advice; facilitating and promoting innovative research, and being an advocate for those with nerve tumours.

Our Nerve Tumours UK Helpline and Specialist Support Network is available in the United Kingdom, and we endeavour to support those outside of the UK wherever possible.

Our mission is to help those who are courageously living with nerve tumours to live the best life they can.

What are nerve tumours? And what is neurofibromatosis?

Neurofibromatosis loosely translates to mean 'nerve tumour increase'.

Neurofibromatosis is in fact an umbrella term for four conditions: Neurofibromatosis Type 1, Neurofibromatosis Type 2, Schwannomatosis and Legius Syndrome. Three of the four conditions cause nerve tumours, and all involve health complications.

Every day in the UK, a child is born with neurofibromatoses – some inherit the condition, others are affected by a random mutation. Nerve tumours can affect anyone: any ethnicity, class or sex.

Neurofibromatosis Type 1 (NF1)

- NF1 is caused by a "spelling mistake" in the gene found on chromosome 17. It occurs in 1 in 2,500 of the population.
- The early signs of NF1 are café au lait spots (flat brown birthmarks) on the skin, freckles in unusual places, and neurofibromas (growths) on the skin.
- People with NF1 may have some form of learning disability. NF1 patients typically have normal intelligence, but experience specific problems with reading, writing and the use of numbers.

Neurofibromatosis Type 2 (NF2)

- NF2 is caused by a "spelling mistake" in the gene found on chromosome 22. It occurs in 1 in 30,000 of the population.
- With NF2, people typically develop nerve tumours in the brain and spine.
- These tumours are mainly benign, but they can cause hearing loss, deafness, and mobility problems due to the pressure built up on key nerves.

Schwannomatosis

- Schwannomatosis shares some features with NF2, but does not typically featuring hearing loss.
- In Schwannomatosis, patients don't get schwannomas (a type of tumour) in the skin itself but these develop on the nerves as they leave the spinal cord or in the major nerves supplying the arms and legs.

Legius Syndrome

- Legius Syndrome has been known as "NF1-like syndrome" because of the similarities the conditions share. Legius syndrome is located on chromosome 15.
- Typically, patients with Legius Syndrome have multiple cafe au lait patches on their skin. They also tend to have mild learning difficulties.
- Legius patients do not develop neurofibromas. Nor do they have many of the health complications that are linked to NF1.

Issues for people with nerve tumours

- Despite being more common than Hereditary Muscular Dystrophy, Huntingdon's Disease and Cystic Fibrosis combined, Neurofibromatosis has very low awareness amongst medical professionals.
- Mis-diagnosis (which is frequent) can mean missed opportunities to address complications early.
- Even when one of nerve tumours conditions is correctly diagnosed, treatment and support is very patchy.

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Never Tumours UK is the trading name of the Neurofibromatosis Association. Registered Charity Number: 1078790 and SC045051

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