nervetumours.org.uk

NERVE TUMOURS UK

Support for medical professionals treating Neurofibromatosis Type 1 (NF1).

What is NF1?

NF1 is a common genetic condition that causes nerve tumours to grow where they shouldn't. The "spelling mistake" in the gene is found on chromosome 17 and occurs in 1 in 2,500 of the population. There are over 25,000 people in the UK diagnosed with NF1.

NF1 varies widely in how it affects those who have the condition. Many people with the disorder will be affected very mildly and may have nothing more than skin changes. A minority of people (around a third) who have NF1 will have medical problems related to the disorder at some time in their life. Some of these problems will be mild and easily treatable and others will be more severe

NF1 is normally easy to diagnose, but if there is doubt, a genetics department can usually help to clear up any uncertainty.

How is it diagnosed?

NF1 usually appears in childhood and the diagnosis is confirmed if two or more of the following signs are present:

- Six or more flat, café-au-lait patches (brown coffee-coloured skin marks), which are the size of a pencil top or bigger. These usually appear during the first year of life and can increase in size and number. Café-au-lait patches are generally harmless and there is no connection between the number or size of café-au-lait patches and the severity of the condition. They sometimes fade later in life.
- Neurofibromas (small benign pea-sized growths or lumps) on or under the skin. These are a common feature of NF1. They usually appear during adolescence and tend to increase in number throughout life.
- Freckles under the arm or in the groin. Again, these are harmless but can be another sign of NF1.
- Plexiform neurofibromas. These represent growths around large nerves and can first appear as a swelling.
- Lisch nodules – these are small pigmented areas in the iris (coloured part) of the eye. They are often not visible except during examination with an eye microscope called a slit lamp. Lisch nodules are harmless and never cause symptoms, but can help in making a diagnosis of NF1.
- Another close family member has NF1.

Medical Guidelines

Medical guidelines for NF1 are available from Nerve Tumours UK. You can reach out to **Nerve Tumours UK Helpline** at **07939 046 030** (open Mondays and Wednesdays, 9am–5pm) to request advice. They can also put you in contact with the Genetic Centres if needed.

Nerve Tumours UK Specialist Advisors

Nerve Tumours UK is the leading voice for Neurofibromatosis support in the United Kingdom and we play a crucial role for anyone living with nerve tumours. One way in which we maintain this position is by funding a network of specialist nurses.

Our specialists are experts on Neurofibromatosis, all of whom are highly qualified professionals with a background in nursing, social work or occupational therapy. They all work from a hospital base in their region, and collaborate with many other professionals involved the care of patients with nerve tumours.

Nerve Tumours UK Specialist Support

Our Specialists are listed by region below:

Leeds & Yorkshire

Ruth Drimer
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North East and Cumbria & Teeside

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Wessex

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Do you have nerve tumours? We're here to help.

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info@nervetumours.org.uk
020 8439 1234

/NerveTumoursUK **@NerveTumoursUK** **@NerveTumoursUK**

Our Nerve Tumours UK Specialists are available to offer support to anyone living with nerve tumours.

Call our helpline on 07939 046 030
Monday and Wednesday 9am-5pm

Nerve Tumours UK
First Floor, 44 Coombe Lane, London SW20 0LA

Never Tumours UK is the trading name of the Neurofibromatosis Association.
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