



Shine A Light on Neurofibromatosis returns for 2019

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Nerve Tumours UK announces Shine a Light Campaign for World Neurofibromatosis Awareness Day

May 17 is World NF Awareness Day. Iconic buildings and landmarks around the world will show their solidarity with those affected by supporting the 'Shine a Light on Neurofibromatosis' campaign and lighting up in blue on the day. In 2018 more than 205 buildings and landmarks took part across the globe. Many of these were in Europe, and every country in the UK was represented. The worldwide total is almost double that of the previous year, which shows how the campaign's success and reach is growing

Neurofibromatosis, the umbrella term for a group of genetic conditions (NF1, NF2, and Schwannomatosis) translates to mean "Nerve Tumour Increase". "It is only by raising understanding and awareness that we will be able to meet our goals of providing first class support to those who need our services" says Karen Cockburn, Charity Director of Nerve Tumours UK.

The campaign has now been running for several years, started by American charity Children's Tumor Foundation and Nerve Tumours UK has been very happy to help coordinate the UK and European collaborations for the past four years.

"Increased recognition of Neurofibromatosis, is critical to driving the life-saving research that will benefit Neurofibromatosis patients and their families," said Simon Vukelj, Chief Marketing Officer of the Children's Tumor Foundation. "The campaign will open to all and be creative and engaging and draw lots of attention, but for Neurofibromatosis patients, their friends, and their families, it's also a chance to unite their voices and declare that Neurofibromatosis is a serious condition that deserves everyone's attention, and that Neurofibromatosis patients deserve a cure."

We are asking iconic landmarks, buildings, homes, to light up blue for Neurofibromatosis patients worldwide. We will be providing Social Media Toolkits to all willing organisations to showcase why they are lighting up, along with case studies, donation links and many other ways to support patients with Nerve Tumours on the upcoming awareness day.

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About **Neurofibromatosis**

Neurofibromatosis is one of the world's most common neuro-genetic conditions and the most common neurological disorder caused by a single gene mutation. The condition causes large tumours to form on nerve endings, which can be very disfiguring and painful, and can interfere with crucial neurological pathways. These tumours are usually inoperable and can sometimes be fatal. Neurofibromatosis affects more than 26,500 individuals in the UK alone, making it more common than Duchenne muscular dystrophy, cystic fibrosis and Huntington's disease combined.

About **Nerve Tumours UK**

Charity reg: 1078790 and SC045051

Nerve Tumours UK is the UK's national charity, and the authoritative voice dedicated to improving the lives of those affected by Neurofibromatosis. The charity funds a network of Neurofibromatosis Specialist Nurses & Advisors, who offer support, both medical & non-medical, to those with the condition and their wider support network.

Nerve Tumours UK was established in 1981 by families with a diagnosis of Neurofibromatosis to help others. It became a registered charity in 1982, and a limited company in 2000. In November 2018 it changed its name to Nerve Tumours UK.
