



First Specialist Neurofibromatosis (NF) Nurse for Wales

Press Release

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Nerve Tumours UK and Cardiff and Vale University Health Board have appointed the first ever Specialist Neurofibromatosis (NF) Nurse for Wales, to be based at the University Hospital for Wales (UHW) in Cardiff.

Neurofibromatosis (NF) is one of the most common neuro-genetic conditions causing tumours to grow on nerve endings and with many associated medical, physical and psychological conditions e.g. Scoliosis and 60% of those diagnosed will have learning disabilities. NF affects more than 26,500 in the UK alone, which is more than those diagnosed with Hereditary Muscular Dystrophy, Huntington's Disease and Cystic Fibrosis combined, yet few, including medics have heard of the condition.

The tumours can be very disfiguring and painful; and can interfere with crucial neurological pathways; they are usually inoperable and can sometimes be fatal. Therefore, early diagnosis and intervention are crucial for this very complex and varied condition, ensuring patients receive adequate and appropriate lifelong care.

Helen Swann, who has been appointed to the new role, will have a national remit, covering the whole of Wales, but will work closely with Nerve Tumours UK's Specialist NF Nurse, who is based in Liverpool, and already sees many patients from the North part of Wales.

Karen Cockburn, Charity Director, Nerve Tumours UK, said, "I am absolutely delighted to welcome Helen to the team. This has taken several years of negotiation and organisation, and I would like to offer my gratitude to The Morrison's Foundation, who are sponsoring this post, and to Professor Jean White, the Chief Nursing Officer for the Welsh Government, who has been instrumental in helping to get this proposal up and running, as well as The University Hospital for agreeing to house the post. I now hope the people of Wales will receive the support they both deserve and need."

Speaking on behalf of Cardiff and Vale University Health Board, Nursing Director Ruth Walker said, "I am immensely grateful to everyone involved in facilitating such a needed service, which I am sure will be of huge relief and support to the patients and families affected by Neurofibromatosis across Wales.

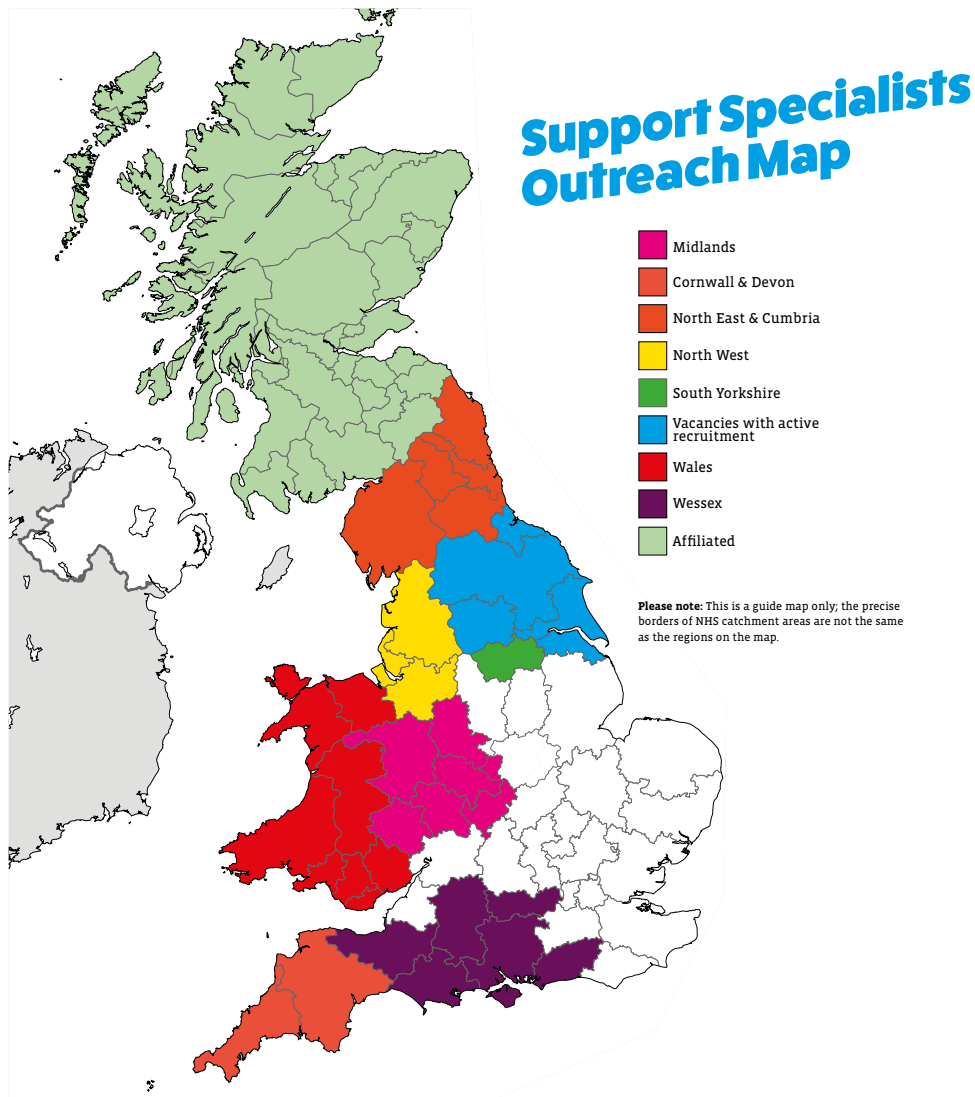
Helen's appointment is a welcomed addition to our fantastic nursing team, and we are so fortunate that she brings with her a wealth of experience in midwifery and health visiting. Throughout her career Helen has supported and educated families and children with a diverse range of illnesses and conditions in community and hospital settings. I am confident her expertise will be an asset to our health service and to our patients."

Helen will commence working with Jennifer Gardner, Consultant Geneticist at the University Hospital, from January 2021, to enhance and expand the support network for families and patients with Neurofibromatosis throughout Wales.

She joins a UK wide network of Specialist NF Nurses who are based within NHS trusts. Nerve Tumours UK now funds a network of 10 nurses in regions across the UK. NF is not well understood by most of the medical profession. GP's and non-medical professionals may have little or no knowledge at all of Neurofibromatosis. Demand for services has increased dramatically over the years and specifically since the onset of Covid-19 in March 2020.

Further escalation is anticipated post lockdown due to increases in loneliness and poverty affecting both general and mental health. People diagnosed with NF can be vulnerable and isolated; and are immensely distressed as some of their complications make them more susceptible to catching Covid-19.

Nerve Tumours UK funds a team of Specialist Nurses to care for people of all ages, who are diagnosed with NF. It is a predominantly community-based service, that offers both medical and non-medical advice and support. They operate, not just in clinics, but in schools, in places of employment, helping to navigate the welfare system, and acting as advocates in tribunal and legal cases. The service allows equal opportunities and accessibility for all, and empowers patients, enabling them to achieve their potential in spite of their diagnosis.



Initial enquiries about the new service can be made to the Nerve Tumours UK Head Office

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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 trading name to Nerve Tumours UK.