



Wolfram Syndrome UK Family Support Co-ordinator

Wolfram Syndrome UK (WSUK)

WSUK is a small national charity based in West Sussex that supports children, young people and adults affected by Wolfram Syndrome (WS) and their parents/wider families. WS is an ultra-rare, progressive genetic disorder which causes a complex range of symptoms, including diabetes mellitus, vision problems, renal problems, deafness, and neurological problems. WSUK provides current, accurate and family-friendly information, raises awareness of WS among health professionals and the public, and helps to fund WS research. For further information visit: <https://wolframsyndrome.co.uk/>

WSUK Family Support Co-ordinator Role

WSUK is seeking a part-time Family Support Co-ordinator [FSC; 22.5 hours per week (with some flexibility in hours), across 4-5 days, 0.6 FTE, £14.6 k - £17.6k per annum]. Together with the established FSC, this home-based role will provide on-going support to children and young people affected by WS and their families and facilitate their engagement with the NHS WS multi-disciplinary (MDT) clinic services provided by Birmingham Children's Hospital (BCH). This role will encourage and help families to attend the WS MDT clinics at BCH and gain the most value from their interactions with expert health professionals. Through liaising with schools, colleges and other external support organisations, this role will also provide advocacy services to families of WS affected children/young people, helping to facilitate access to the services to which they are entitled. The family support co-ordinator will also act as an important point of contact for these families, providing advice and support in confidence.

Skills and experience

Applicants should have several years' experience in a similar position, working with children/young people affected by sensory loss, long-term medical/genetic condition, or disability. Applicants should also have a strong desire to improve the lives of children and young people living with a long-term condition or disability and be confident in talking with families with a range of abilities and diverse cultural backgrounds.

Applicants should have experience in working effectively as part of a remote team, be confident in working independently and in managing conflicting priorities.

Some UK travel will be required (WS MDT clinics at BCH in Birmingham, the annual WS conference and to visit WS families, schools or colleges). A DBS check will be required.

To apply, please email/ send your cv to admin@wolframsyndrome.co.uk by **23rd July 2024**.