



The Leeds
Teaching Hospitals
NHS Trust

Inherited White Matter Disorders

Information for Schools and Nurseries



Leeds children's
hospital

caring about children



What are Inherited White Matter Disorders?

White matter is part of our brain - it is made up of a substance called myelin which wraps around nerves to help send messages (like the insulation on an electrical cable) and provide nutrients to keep our nerves healthy.

Inherited White Matter Disorders (IWMD's) may also be referred to as leukodystrophies. They are a group of genetic disorders which affect the white matter in the brain. This results in neurological problems such as issues with mobility/ movement, speech, feeding, vision, hearing and cognitive skills. Many, but not all IWMDs are progressive meaning that difficulties may get worse with time. (NHS England. 2022)

How can the Inherited White Matter team help our school/nursery?

We are a team of specialised practitioners and are here to answer questions about diagnosis, tests and the future. We work closely with the child's local teams and are a point of contact for any worries and advice. As a team we can help with:

- School or nursery visits to discuss the child's condition and needs.
- Supporting families in the EHCP process.
- Emotional support for the child/ child's family.
- Advice if you feel the child is needing support with day-to-day school life.

Who are the Inherited White Matter Disorders team? And how can I contact them?

Dr Lydia Green - Paediatric Consultant Neurologist Specialising in Inherited White Matter Disorders - Leeds Teaching Hospitals NHS Trust

Dr Dipak Ram - Paediatric Consultant Neurologist Specialising in Inherited White Matter Disorders – Manchester Royal Children’s Hospital

Hannah Geldart - Inherited White Matter Disorders Nurse Specialist.

Telephone: 0797 774 1977

Jade Belton - Inherited White Matter Disorders Team Coordinator. **Email:** Jade-lauren.belton@nhs.net

Are there any charities which I can be in touch with?

We are fortunate to work alongside Alex TLC (The Leukodystrophy Charity) who have a mission to:

- Provide support for those living with leukodystrophy, and their families/carers.
- Raise awareness of leukodystrophy.
- Improve best practice in prevention, diagnosis & treatment.
- Support research initiatives.

Alex TLC is a charity based in London which gives support and advice for families affected by leukodystrophy. The charity was set up by and is run by people with lived experience of leukodystrophy. They have a very helpful website (alextlc.org) or if you would prefer you can also give them a call on **020 7701 4388**.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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