



**The Leeds  
Teaching Hospitals**  
NHS Trust

# Inherited White Matter Disorders

Information for parents and carers



Leeds children's  
hospital

caring about children



## What are Inherited White Matter Disorders?

White Matter is another name for part of the brain called myelin. This is the insulating cover on nerves. Myelin is needed to help the brain send signals and keep 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)

## Who are the inherited white matter team in leeds?

### Dr Lydia Green

Paediatric Consultant Neurologist Specialising in Inherited White Matter Disorders.

### 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

## What may happen at my child's clinic appointments?

You and your child will attend clinic appointments at the Children's Outpatient's Department which is in Martin Wing on level C. The regularity of appointments will be decided by Dr Green based on you and your child's needs. At these appointments Dr Green will ask questions about your child's medications, eating and drinking, movement, sleep, behaviour and any other concerns you may have. Dr Green will assess your child's muscle tone and may measure your child's head.

Hannah the Nurse Specialist will usually be present at the clinic appointments and will help to distract your child to make the assessment easier. If you would like to speak to Dr Green or have questions you wish to ask without your child present, then Hannah can take your child to the play area to allow you time to do this.

Further testing may also be discussed, and you will have a chance to ask any questions you may have.

## How can the inherited white matter team help me and my child?

We are a team of specialised practitioners and are here to answer questions about your child's diagnosis, tests and the future. We will work closely with your child's local team to enable the right support for you and your child and are a point of contact for any worries and advice.

We recognise that some families don't need much from us and this is fine. You may have good support from your family, friends and local medical teams and we are here for as little or as much as needed.

## As a team we can help with:

- Linking with your child's local teams.
- School or nursery visits to discuss your child's condition and needs.
- Advice regarding specialist equipment and services.
- Emotional support for you and your child.
- Home visits/ Virtual calls

## 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](http://alextlc.org)) which outlines the various ways in which they can support you and your family. If you would prefer you can also give them a call on **020 7701 4388**.

You can Scan this QR code to access the website:



What did you think of your care? Visit [bit.ly/nhsleedsfft](https://bit.ly/nhsleedsfft)  
*Your views matter*

© The Leeds Teaching Hospitals NHS Trust • 1st edition (Ver 1)  
Developed by: Hannah Geldart, Inherited White Matter Disorders Nurse Specialist  
Produced by: Medical Illustration Services • MID code: M20231017\_010/BP

LN00005715  
Publication date  
01/2024  
Review date  
01/2027