WOLFRAM SYNDROME UK

Inform, Support, CURE

www.wolframsyndrome.co.uk

Parent's Pack

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This QR code will take you to the Wolfram Syndrome UK website.

This pack has been produced by Wolfram Syndrome UK in support with Birmingham Children's Hospital.

The medical information was produced with guidance by Prof Timothy Barrett Wolfram Syndrome Children's Professional at Birmingham and Dr Renuka Dias Wolfram Syndrome Children's Clinical Lead at Birmingham Children's Hospital.

Family Support Co-Ordinator's (FSC) Details

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This QR code will take you to the Family Support Co-Ordinator's page on the WSUK website or you can use the link - https://wolframsyndrome.co.uk/family-support-coordinator/

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SECTION 1

Wolfram Infographic

Wolfram Syndrome is a very rare genetic condition that affects **1 in 770,000** of the UK population



Wolfram Syndrome

There are around **150 PEOPLE IN THE UK** with Wolfram Syndrome

Just **1 in 550,000 UK CHILDREN** has Wolfram Syndrome

It is so rare that many doctors will be **UNAWARE OF IT**

1 in 4 CHANCE of a sibling having the condition

It is usually caused by a mistake in the **WFS1 GENE**

SYMPTOMS MAY INCLUDE

Diabetes | Vision loss
Hearing loss
Renal problems
Neurological problems

Not everybody will get these symptoms and some can be managed with medication

Currently there is **NO CURE** but there are clinical trials to develop a therapy

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SUPPORT is available through the Wolfram Clinics, & Wolfram Syndrome UK

Parents of a child with Wolfram Syndrome usually have one abnormal copy of WFS1 and one normal

Both parents usually pass on one abnormal copy of WFS1 for a child to be affected