



**WOLFRAM SYNDROME UK**

*Inform, Support, CURE*

[www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

# **New Parent's Clinic 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



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

## 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

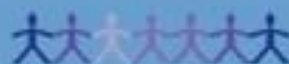
Diabetes | Vision loss  
Hearing loss  
Renal problems  
Neurological problems



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