WOLFRAM SYNDROME UK

Inform, Support, CURE

www.wolframsyndrome.co.uk

Parent's Pack

WOLFRAM SYNDROME UK
Inform, Support, CURE

CONTENTS OF PACK:

1. Wolfram Infographic

2. Why should I attend the WS clinic?

3. Clinic Information

4. Benefits/Financial Help

5. Helpful organisations

6. Facilities at the hospital and Floorplans

7. Frequently asked questions

8. Claiming travel costs

9. Meet the Expert

10. The Wolfram Syndrome child at school: give this sheet to your child's teacher.

11. Wolfram Syndrome Variants

12. Forms for Clinic

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

Georgina King – Mobile: 07592 629813
Email: georginaking@wolframsyndrome.co.uk

Olivia Edwards – Mobile: 07756 778454
Email: oliviaedwards@wolframsyndrome.co.uk



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/

WOLFRAM SYNDROME UK

Inform, Support, CURE

SECTION 2

Why should I attend the WS Clinic at BCH?

WOLFRAM SYNDROME UK
Inform, Support, CURE

Why should I attend the WS clinic at Birmingham Children's Hospital?

1. Your child will be seen by medical professionals who have expert knowledge of Wolfram Syndrome ~ knowledge which is usually lacking locally.

2. You'll get an update on the latest research into potential therapies to slow the progression of the condition.

3. You and your child will have the opportunity to take part in this research, and may be invited to take part in clinical trials when they take place.

4. Your child will typically see the same consultants each time they attend, which means they really get to know your child and his / her / their health needs.

5. The team at the Wolfram clinic will provide information to your child's local health team to support them in delivering high quality care.

6. By attending, you and your child are providing the team with invaluable knowledge about Wolfram Syndrome.

7. Having you and other families come together at the Birmingham Children's Hospital provides a vital focal point for undertaking research.

8. You get to meet other families who understand what you and your child are going through.

9. You'll be supported by the WSUK Family Support Co-Ordinators, who will not only be there for you during clinic, but can also provide support and information for problems you may be experiencing outside of the clinic.