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 7

Frequently asked questions

WOLFRAM SYNDROME CHILDREN'S CLINIC
FREQUENTLY ASKED QUESTIONS

1. **When does the clinic take place?**

Your child/young person will be invited to a clinic approximately every 12-18 months, depending on availability of appointments. If there is a diagnosis of Wolfram Related Syndrome, the time between clinics may be approx. every 2 years. Clinic usually takes place on a Monday and Tuesday. The WSUK Family Support Co-Ordinator will contact you approx. 6-8 weeks before the clinic to invite your child/young person to attend and will ask you to confirm your attendance. You will receive the invitation letter from BCH approximately 2 weeks before the clinic date.

2. Do I need to do anything before the clinic?

The Family Support Co-Ordinator will contact you closer to the clinic date to confirm that you are still able to attend. There will be some forms with the invitation letter that you will need to complete and send back or bring with you to clinic.

3. Why bother attending the clinic?

The advantage of attending the multi-disciplinary clinic is that your child has several tests and consultations in one place, over two days. The consultants are expert in Wolfram Syndrome, with a special interest in the condition. You also get to meet other families living with WS. Please see the separate "Why attend the clinic?" page for more information.

4. Where is the clinic held?

The clinic is held at the Rare Disease Centre in Waterfall House at Birmingham Children's Hospital – Waterfall House, Whittall Street, Birmingham. B4 6NH.

5. How long does the clinic last?

On Monday, clinic begins at 9am and finishes around 5pm. The fasting blood test usually takes place on Tuesday morning, which means you'll need to arrive at clinic for 8.30am that morning. We try to ensure that you are finished by Tuesday lunchtime.

6. What do we need to do for the fasting blood test?

Your child can eat up until midnight the night before the fasting blood test. After midnight, they may drink small amounts of water to keep them hydrated, which will make taking bloods slightly easier. Diabetes medication can be administered as usual. The fasting blood test usually takes place on the Tuesday morning at 8.30am when Main Outpatients opens. While parents and family members can have breakfast at the hotel, your child will need to wait until after their fasting blood test. Once completed, you will be given a food voucher for your child to have breakfast in the hospital restaurant.

7. Is there support available during clinic?

Your main point of contact is the WSUK Family Co-Ordinators who will be there to support you during the two days, to ensure you have everything you need and to sort out any problems or issues. There will be lots of other people available to help you including the Diabetes Nurse, the Transitions Officer and the Clinic Administrator(s).

8. Who can I take with me?

In addition to your child, we recommend that you attend clinic with another adult, as there is a lot of information to take in. This could be your partner, a family member, or a friend.

9. We live a long way from the hospital, can we stay in a hotel?

Yes, the WSUK Family Support Co-Ordinator will organise accommodation for you, free of charge, during your visit to clinic. You can stay on both Sunday and Monday nights. They will contact you nearer the clinic to arrange your stay.

10. Can I get help with my travel costs?

You may be able to claim travel costs whilst at the hospital. For more information refer to the “Claiming Travel Costs” information sheet.

11. What do we do about food during the clinic?

You can eat breakfast at the hotel or at the hospital on Tuesday morning (following the fasting blood test). BCH will provide you with lunch vouchers at the hospital. For dinner, there is an allowance of up to £20 per person per meal that you can claim for food and drinks (excluding service charge, delivery charges, alcoholic drinks or any non-food or drink items such as, tobacco, nappies, or personal toiletries) by completing the expenses form and providing copies of the receipt(s). The expense form will be provided by the WSUK Family Support Co-Ordinator at the clinic. Once the expense form has been completed and receipts provided to the Family Support Co-Ordinator, they will be sent to the WSUK office for checking and payment via BACS.

12. What happens at clinic?

When you arrive at Waterfall House, turn left inside the entrance and the clinic is through the double doors. Let the receptionist know you have arrived. A member of the clinic team will then introduce themselves and take you to your first appointment. Don't worry about getting to appointments on time, the team will organise all this for you and make sure you get to where you need to be.

13. Does my child have to take all the tests?

We would advise that your child has all the tests offered during the clinic. However, if there is a test or appointment, they feel particularly distressed about, please let the WSUK Family Support Co-Ordinator know **in advance of clinic** and the team will either cancel the test or arrange for a play specialist to work with your child prior to the test.

14. What happens at the end of the clinic?

Once you have finished your last appointment you are free to go home. A letter explaining the results of the appointments and tests, and summaries of each consultation, will be sent to you approximately six weeks after the clinic date. If you haven't received the results letter by this time, please contact your WSUK Family Support Co-Ordinator.

15. Who can I call if I need to contact the clinic?

If you have any questions about the clinic, please contact the clinic administrators, Lindsay Wilson or Clare Stevens on 0121 333 9267 or your WSUK Family Support Co-Ordinator.(Contact details can be found at the front of this pack).

WOLFRAM SYNDROME UK
Inform, Support, CURE