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 5

Helpful Organisations

ORGANISATIONS THAT CAN HELP YOU AND YOUR FAMILY

Below is a list of some organisations that can be of use to you. This isn't a comprehensive list. Many more, including links to holidays and activities, can be found on the WSUK website - https://wolframsyndrome.co.uk/helpful-organisations/ and the WSUK Handbook https://wolframsyndrome.co.uk/ws-handbooks/.

Wolfram Syndrome UK (WSUK)

WSUK aims to raise as much awareness of this syndrome as possible whilst supporting individuals and families affected.

The WSUK Family Support Co-Ordinators (FSC) work with families with children and young people affected by WS, to provide information, support and advice. The FSC also helps families attend the multidisciplinary clinic at Waterfall House Rare Disease Centre at Birmingham Children's Hospital.

When a young person transitions to the Adult Service at the Queen Elizabeth Hospital, the support is provided by the WSUK Adult Support Co-Ordinator (ASC).

Website - https://wolframsyndrome.co.uk/

Office email – admin@wolframsyndrome.co.uk
Telephone – 01903 211358

RNIB

Offers practical and emotional support to help people with a visual impairment face the future with confidence.

https://www.rnib.org.uk/
Helpline: 0303 123 9999

RNIB SIGHTLINE DIRECTORY

An online directory of services and organisations that help blind and partially sighted people in the UK.

https://www.rnib.org.uk/sightline-directory/

LOOK

Provides support, information and activities for families with visually impaired children and young people, to help them gain the best outcomes and reach their full potential.

https://www.look-uk.org/
07464 351 958

ROYAL SOCIETY FOR BLIND CHILDREN

The Royal Society for Blind Children offers a range of services including emotional support and practical advice for families, opportunities for children and young people to build confidence and skills through activities, and a specialist further education college.

https://www.rsbc.org.uk/
020 3198 0225

VICTA

Provides support, information, activities, breaks and holidays for families with blind or visually impaired children or young people up to the age of 29.

https://www.victa.org.uk/
01908 240831

CONTACT

A UK charity that supports families of disabled children whatever their condition or disability.

https://contact.org.uk/
Freephone: 0808 808 3555 (Monday-Friday, 9.30am-5pm).

SIBS

Support and information for siblings of disabled people.

https://www.sibs.org.uk/

DIABETES UK

Self-help charity for diabetics. Information, diet advice, Teenzone.

https://www.diabetes.org.uk/
0345 123 2399

INFORMATION, ADVICE AND SUPPORT SERVICES NETWORK (IASS Network)

Provide free confidential advice, information and support to parents and carers about special educational needs. They are a statutory service, which means there must be one in every local authority.

https://councilfordisabledchildren.org.uk/

IPSEA

Provide free legal and independent legally based information, advice and support to help parents get the right education for children and young people with all kinds of SEN and disabilities.

https://www.ipsea.org.uk/
0300 222 5899 Open: Wednesdays, 9.30am – 3.30pm and Fridays, 9.30am – 12.30pm

DISABILITY GRANTS

A directory that allows you to search for national and local organisations that can provide a grant for a range of items and experiences such as equipment, holidays, housing, days out… anything above and beyond the normal costs of everyday living. https://www.disability-grants.org/

THE FAMILY FUND

The UK's largest provider of grants to low-income families raising disabled and seriously ill children and young people aged 17 and under.

https://www.familyfund.org.uk/
01904 550055

TURN 2 US

Helps people in financial need to access welfare benefits, charitable grants and other financial help.

https://www.turn2us.org.uk/

NEW COLLEGE WORCESTER

NCW is a national residential school and college for young people aged 11 to 19 who are blind or vision impaired.

Every student at NCW has a tailored programme, carefully planned and delivered to meet their individual needs in three key areas: - academic achievement, independent living skills and involvement in extracurricular activities at the College and in the community.

https://www.ncw.co.uk/

01905 763933

QUEEN ALEXANDRA COLLEGE

Queen Alexandra College (QAC) is a national residential College and charity that supports a diverse range of student abilities and needs based in Birmingham.

https://www.qac.ac.uk/

0121 428 5050

THE ROYAL NATIONAL COLLEGE FOR THE BLIND

The Royal National College for the Blind (RNC) is honoured to be the UK's leading specialist residential college of further education for people with a visual impairment.

Being a national centre of expertise for young people with visual impairment, RNC provides a broad curriculum which is underpinned by specialist skills for life. The College experience is more than vocational and academic qualifications. It's about achievement beyond the classroom - developing self-confidence, personal independence and communication skills that are needed for the future.

https://www.rnc.ac.uk/

01432 265 725

SUPPORT, INFORMATION AND ADVICE	EDUCATION	GRANTS, BENEFITS AND FINANCES	DAY EVENTS
WSUK	Contact	Disability Grants	LOOK
RNIB Sightline Directory	Royal Society for Blind Children	Family Fund	Royal Society for Blind Children
RNIB	IASS Network	Turn 2 Us	VICTA
LOOK	IPSEA	VICTA	
VICTA	Diabetes UK	Contact	
Contact	New College Worcester		
Royal Society for Blind Children	Queen Alexandra College		
Sibs	Royal National College for the Blind (RNC)		
Diabetes UK			