Main Characteristics of Wolfram Syndrome

Characteristic	Symptom	Average age of onset
Diabetes Mellitus The body cannot convert sugar or glucose to energy due to a lack of insulin hormone.	Excessive thirst, frequent passing of urine and weight loss	5 years
Diabetes Insipidus The body cannot concentrate urine due to lack of vasopressin hormone.	Excessive thirst, frequent passing of urine.	Teenage years in about 60% of people
Deafness	Difficulty hearing in a crowded room, difficulty hearing high pitched sounds.	Teenage years
Optic Atrophy Shrinkage of the optic nerve	Difficulty seeing in the classroom at school, everything going grey.	10 years
Renal Problems	Loss of control over bladder function, patient may wet bed.	Twenties in about 60% of people
Neurological Problems	Loss of balance, sudden jerks of the muscles, depression and breathing problems	Thirties in about 60% of people

Not all of the characteristics shown in the table are necessarily present in those diagnosed with Wolfram Syndrome, and each one can vary in severity and onset. The challenge with some of these symptoms is that they can be initially overlooked.

Wolfram Syndrome Conference

Our annual family conference offers a unique opportunity for those with the syndrome, their families and/or carers to get together, hear talks from experts on how best to manage the condition and meet others affected by Wolfram Syndrome.

For more information about the family conference: https://wolframsyndrome.co.uk/ws-conference/

Feedback from past conferences –

"Conference gave us so much more new information "

What did you enjoy most? – *"meeting everyone and general swapping stories and info"*

"The range of speakers was very good - informed the families of the updates within the research projects"

The majority of our work is funded by donations and fundraising events.

If you or a family member/work colleague would like to set up a regular donation, or help to raise funds; please contact the office, details below.

Remember if you are a tax payer we can re-claim Gift Aid on your donation.

Registered with FUNDRAISING REGULATOR

Wolfram Syndrome UK (WSUK)

9 Church Way
Worthing
West Sussex
BN13 1HD

Phone: 01903 211358

E-mail: admin@wolframsyndrome.co.uk

www.wolframsyndrome.co.uk

Reg Charity No: 1152445

WOLFRAM SYNDROME UK
Inform, Support, CURE

Wolfram Syndrome UK

Information Leaflet

Facts about Wolfram Syndrome and how we can support you

WOLFRAM SYNDROME UK
Inform, Support, CURE

Registered Charity :1152445.
Registered in England & Wales

What is Wolfram Syndrome? (WFS)

Wolfram Syndrome Spectrum Disorder is a rare genetic condition affecting around 1 in 770,000 people in the UK. Affected people commonly have diabetes mellitus and optic atrophy. It is not an easy condition to diagnose. Many patients experience symptoms for years before an accurate diagnosis of WFS is confirmed.

Treatment

There is no cure for WFS, however each symptom can be managed with treatment. Diabetes Mellitus can be controlled with insulin injections and Diabetes Insipidus can be controlled with medication. Vision problems may be improved with the use of glasses and hearing loss may be improved through the use of hearing aids. Any cure is a long way off. The current research is to understand why mistakes in the Wolfram gene cause the syndrome. There are research groups in the UK, America, France, Spain, Estonia, Belgium, Italy and Japan, all investigating this problem. For more information about current research, visit the "resources" page on the WSUK website: www.wolframsyndrome.co.uk

What support is available?

Family Support

WSUK have two family support co-ordinators, Georgina King and Olivia Edwards. Their role is to support young people and their families affected by WFS to ensure they feel fully supported by the healthcare professionals working with them both at Birmingham Children's Hospital and locally. They support families to ensure they receive the correct level of additional support, in both a social and educational capacity.

If you require any support and assistance, please contact Georgina 07592629813 or georginaking@wolframsyndrome.co.uk or Olivia 07756 778545 or oliviaedwards@wolframsyndrome.co.uk

Adult Support

My name is Abby Hannibal and I am the Adult Support Coordinator for WSUK. In my role I support adults with WS and their families. My goal is to ensure you receive both emotional and practical support including helping you navigate statutory support, benefits and ensuring you have access to helpful resources to live an empowered and fulfilled life. You will also find me at the adult WS clinic at the QEH, Birmingham where I will be on hand to provide guidance and be a friendly, welcoming face!

You can contact me via email at abby.hannibal@wolframsyndrome.co.uk or mobile on 07752 193635. I work 18.75 hrs Mon-Thurs.

Wolfram Syndrome Multidisciplinary Clinics

Specialist Children and Adult Clinics have been set up at Birmingham Children's Hospital and Queen Elizabeth Hospital, Birmingham. By attending these clinics, families and adults can get advice on the best treatments available to help maintain a good quality of life. The clinics are available, by invitation, to anybody with a confirmed or suspected diagnosis of Wolfram Syndrome in the UK.

For more information about the clinics: https://wolframsyndrome.co.uk/clinic-dates-information/

Wolfram Syndrome UK Charity

Paul and Tracy Lynch, whose daughter Jennifer has Wolfram Syndrome, set up WSUK because they felt the UK needed a support organisation where families can find useful information, from when they first receive their diagnosis, which was lacking when Jennifer was diagnosed in 2010.

The charity focuses on increasing awareness of the condition, funding research, and supporting people in the UK affected by Wolfram Syndrome.

For more information visit www.wolframsyndrome.co.uk

Wolfram Syndrome Global Awareness Day (WSGAD)

1st October marks our day of global awareness. WS patient organisations and the WS affected community aim to focus on raising awareness amongst medical professionals and organisations of conditions linked with WFS. It is also a day where we can raise funds with more focus. https://www.globalwsday.org/

1st October relates to the date a paper identifying the WFS1 gene was published, written by the late Dr Alan Permutt and his team from Washington University Hospital, St Louis, USA.