

WSUK are always pleased to hear from families and those affected by the condition.

Donations and contributions of support are always gratefully received so that we may continue to provide information, support and help fund research into trying to find medication to provide the best treatment.

Donations can be made via post or online by going to our website and following one of the links there.



## Wolfram Syndrome UK (WSUK)

9 Church Way  
Worthing  
West Sussex  
BN13 1HD

Phone: 01903 211358  
E-mail: [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk)  
[www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

Reg Charity No: 1152445



June 2016 saw co-founders Tracy & Paul receive the Prime Minister's Points of Light Award.

### Prime Minister David Cameron said:

Since Jennifer's diagnosis, Paul and Tracy have taken phenomenal steps to raise awareness and find a cure for Wolfram Syndrome. Their work is having an impact in the medical community and has the potential to transform the lives of those living with this rare condition. I'm pleased to name Paul and Tracy the 555th and 556th UK Points of Light."

### Tracy and Paul's local MP, Sir Peter Bottomley MP said:

"Paul and Tracy have built a charity in Worthing that is supporting people across the country living with this rare condition. I'm delighted that their achievements are being recognised by the Prime Minister with this Point of Light award."

<https://www.pointsoflight.gov.uk/working-wolfram-syndrome/>

In Partnership with



Tracy Lynch

CEO & Co-  
Founder WSUK



Professor Timothy Barrett

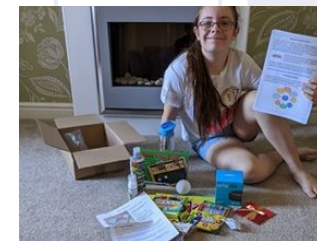
Leonard Parsons Professor of  
Paediatrics

Lead Researcher of Wolfram  
Syndrome at University Hospital  
Birmingham

## WSUK Information Leaflet



**WOLFRAM SYNDROME UK**  
*Inform, Support, CURE*



Registered Charity :1152445.  
Registered in England & Wales

## How it all started



Wolfram Syndrome is a rare, progressive neurodegenerative condition, which is life shortening.

Wolfram Syndrome UK (WSUK) is the only national charity and support group to help fund research and provide support to those affected by the condition as well as their families in the UK.

The support group and website were started in 2010 by Paul & Tracy Lynch from Worthing, West Sussex after their daughter, then aged eight, was diagnosed with WS. The only website associated with WS then was a worldwide site. There was no easy to read information available and no real support, as many medical professionals had or still have never heard or come across the syndrome.

WSUK became a registered charity in June 2013. Prior to that we had been raising funds for research via WellChild, the national charity for sick children, and our fundraising group 'The Charity Roadtrip'.

## About Wolfram Syndrome.....

The first signs of someone being affected by WS are usually juvenile onset Diabetes Mellitus and Optic Atrophy (reduced vision). Some patients go on to develop hearing loss and Diabetes Insipidus (water diabetes).

These four conditions are the main features of WS, also known as DIDMOAD. There are also other health problems for those with WS which can include irregular breathing, loss of the sense of smell, depression, loss of the gag reflex and impulsive and aggressive behaviour to name but a few. Not everyone is affected the same or develops all the features. WS affects 1 in 770,000 people in the UK.

## What we are doing

We have a website giving up to date information on events, research, trials, along with links to other helpful sites; multi disciplinary clinics and Social Media pages for anyone linked to WS to post on. We hold an annual conference for families and doctors to receive useful information and to just meet up. We have a quarterly newsletter with news of fundraising events and other useful information which is emailed out as well as posted on our website along with an audio version.

WSUK are working in alliance with Birmingham Children's Hospital and Queen Elizabeth Hospital, Birmingham to raise awareness, bring support to patients and families and to advance research into trying to find a way of halting or slowing down the progression of this syndrome. We recently signed a contract with BCH to assist with the children's clinics.



## Research & Awareness

Research is being carried out at Birmingham Children's Hospital and The Queen Elizabeth Hospital in Birmingham, as well as at other hospitals and universities around the world. We help to provide funding towards research projects and have helped to fund travel and accommodation costs for UK participants of the TREATWolfram clinical drug trial currently being run.

WSUK keeps up to date with the medical research and is in contact with medical experts who can offer advice.

We maintain the only UK database of those affected by this disorder.

We are endeavouring to raise awareness & get information to hospitals, GP practices & related organisations not just around the UK but globally. Working in association with other Patient Support groups around the world we now have an annual WS Global Awareness Day (WSGAD) on 1st October for this aim.

