About us

The Williams Syndrome Foundation

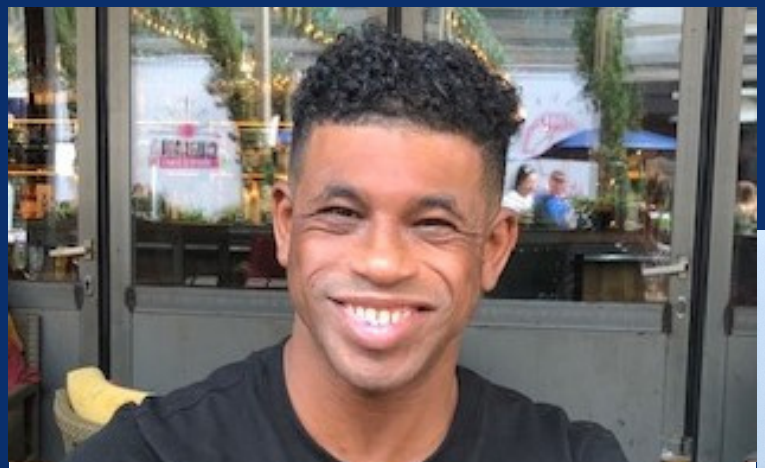
The Williams Syndrome Foundation (WSF) was registered as a charity in 1980. We were the first charity in the world dedicated to helping those with Williams Syndrome and to instigate and fund research into the condition, and are still the only charity doing so within the UK.

Our purpose has remained consistent:

- To provide support for individuals with WS and those who love, care for and educate them
- To explain the impact of WS on all those affected by WS
- To create and raise awareness of WS
- To provide opportunities for members and their families to access information, share support and have fun safely - overcoming the social isolation caused by the rarity of the condition.

How do we help?

- We fund and promote research in order to create new comprehensive guidelines and webinars and to keep our current library of WS specific publications updated.
- We provide online, email and phone support for families and carers, practitioners and professionals – supported by the expertise of our Professional Advisory Panel.
- We organise fun national and regional events for families, providing social opportunities to meet and share support.
- We support an Educational Health Care Plan (EHCP) assessment service to help families gain the framework of support needed for their child.
- We provide respite opportunities for families through specialised care holidays for their adults with WS.
- We host an online Zoom Club to combat social isolation.
- We host online parent support groups to connect parents of similar aged children.
- We keep families connected and informed through our website, media channels, e-newsletters and magazines.
- We host weekend family conventions every 2-3 years with informative presentations from WS experts.
- We celebrate the joys and achievements of our WSF community.
- We raise awareness of Williams Syndrome.



The Foundation supports people with WS & those who love, care for and educate them

How to donate

The Williams Syndrome Foundation is run for families by families and is almost completely reliant on voluntary fundraising and donations. We do not pay fundraisers; our funds go directly into research, family support and to cover our minimal administrative expenses.

- **JUSTGIVING:** www.justgiving.com/wsf
- **TEXT DONATE:** Text WSF followed by the amount you would like to donate (up to £20) to 70085 e.g. WSF10
- Or support us through **Paypal Giving, CAF Donate, Facebook Fundraisers, Amazon Smile** and / or **Easy Fundraising**

Contact:

Registered with FUNDRAISING REGULATOR

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Registered Charity No. England & Wales: 201014, Scotland SCO49892

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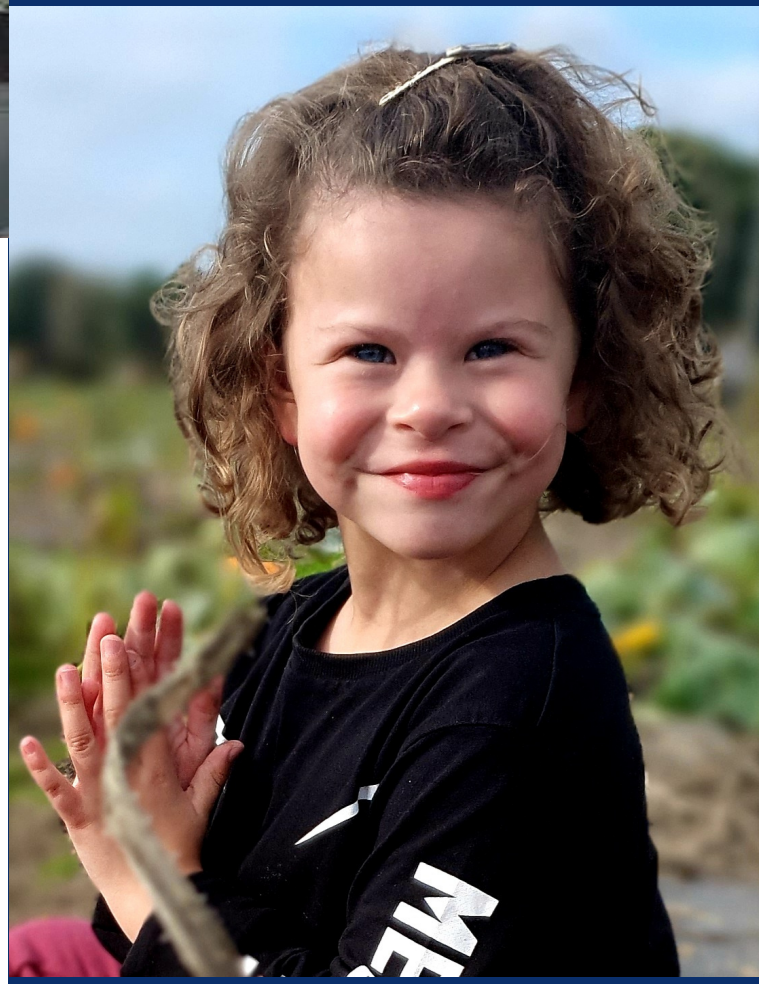
SYNDROME FOUNDATION



What is Williams Syndrome?

What is Williams Syndrome?

Williams Syndrome is a rare congenital disorder that occurs sporadically in approximately 1 per 18,000 births in the UK. It causes cardiac, physical and mental health problems. In addition, it usually causes learning disabilities which include sensory, behavioural, social and processing issues. There are an estimated 3,500 people with Williams Syndrome (WS) in the UK.

Diagnosis

The cause of Williams Syndrome is a tiny deletion of part of chromosome 7, which includes the elastin gene. It can be diagnosed by genetic tests that can establish whether the elastin gene and other genes are missing.

Heart problems

Most individuals with WS have a narrowing of the aorta above the aortic valve called supravalvular aortic stenosis (SVAS). In many cases this is insignificant but can be detected on cardiac ultrasound and must be monitored. Other heart and vascular abnormalities can occur.

Early clues

The most common features of WS are:

- Heart murmur / SVAS
- Typical facial features may include a wide mouth with full lips, a short, upturned nose and irregular teeth.
- Feeding /swallowing /digestive issues
- Delayed growth
- Global development delay

Possible early problems:

- Heart murmur / heart conditions
- Raised blood calcium (Hypercalcaemia)
- High blood pressure (Hypertension)
- Hernias
- Squint (Strabismus)
- Low birth weight
- Slow weight gain /weight loss
- Poor feeding / failure to thrive
- Delayed growth
- Severe colic and reflux
- Excessive vomiting
- Dehydration
- Constipation / prolapse
- Delay in meeting developmental targets
- Difficult weaning
- Irritability
- Texture intolerance
- Sleeping problems
- Hyperactivity
- Sensitivity to loud noises (Hyperacusis)

Later problems may include:

- Heart conditions (most commonly SVAS)
- High blood pressure
- Renal and bladder problems
- Constipation, abdominal pain & diverticulosis
- Scoliosis & musculoskeletal problems
- Aspects of premature aging
- Precocious puberty / early menopause
- Low IQ
- Attention difficulties
- Good verbal skills masking low cognitive ability
- Excessive talking
- Talking in an inappropriate manner
- Over-friendliness with strangers
- Obsessional interests
- Emotional immaturity
- Exaggerated emotional reactions
- Disinhibited behaviour
- Fear of heights, uneven surfaces / stairs
- Difficulties forming / sustaining friendships
- Attention seeking behaviours
- Poor navigational skills
- Hypochondria
- Mental health problems, anxiety & depression

Most children with WS have a happy, affectionate and empathetic nature and many parents report that the joys of WS outweigh the challenges

Hypersensitivity to noise

People with WS are often unable to tolerate, and are severely distressed by, noises which are sudden, loud and/or of certain pitch (Hyperacusis).

Most people with WS have superficial linguistic and social skills which may mask severe anxiety & limited understanding

Intervention

When hypercalcaemia is present, a low calcium diet can stabilise the situation. Early diagnosis will lead to better understanding of potential problems, better assistance and better outcomes. Early support and continuing education can help realise an individual's potential. While some children with WS begin their education in mainstream settings with dedicated 1-1 assistance, the majority require the support offered by specialist schools by secondary age.

People with WS often show an affinity with music which is a powerful learning tool, a source of pleasure and can be a natural skill