

INTRODUCING THE WSF TO NEW MEMBERS



WHAT IS WILLIAMS SYNDROME?

Williams Syndrome (WS) is a rare congenital disorder that occurs randomly in approximately 1 in 18,000 births in the UK. It is non-hereditary, caused by a tiny new deletion on chromosome 7 (which includes the elastin gene). It can be diagnosed by a microarray test or a FISH test. Williams Syndrome usually causes an array of health issues, including cardiac problems; learning difficulties; behavioural, social and sensory difficulties; and mental health problems – particularly anxiety.

WHO ARE WE?

The Williams Syndrome Foundation (WSF) is a small charity founded 40 years ago after Lady Cooper and her late husband Sir George Cooper reached out to fellow parents of individuals with Williams Syndrome through newspaper adverts. 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 the same:

- To provide support for individuals with WS, their families and carers
- To explain the impact of WS on all those affected by WS
- To create and raise awareness of WS in the UK
- To maintain a commercially sustainable organisation
- 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.

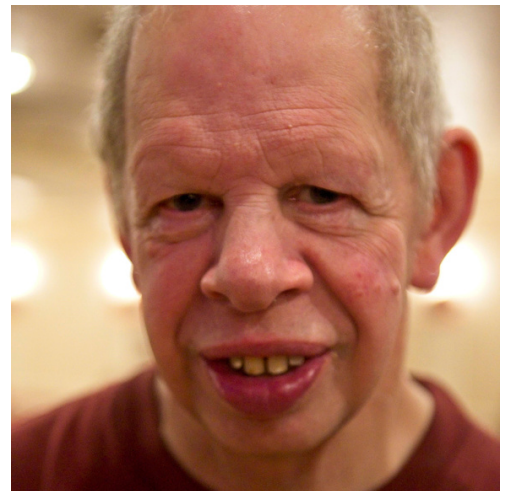
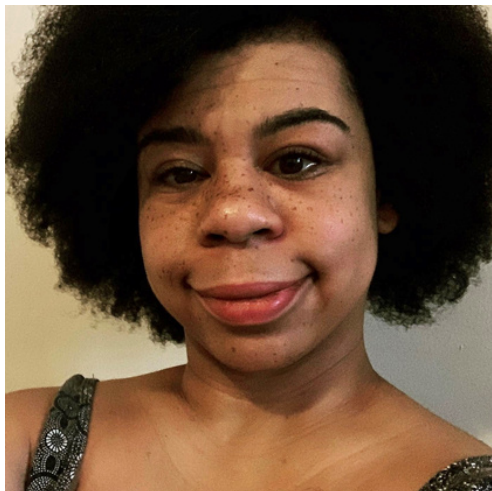
The Foundation is managed by a board of nine dedicated trustees with four part-time members of staff – most having a loved one with WS. We are supported by a regional network of volunteers (who provide a regional programme of events for families) and a Professional Advisory Panel (comprising of health professionals, psychologists and therapists) who support our members and direct our research to ensure that it provides real benefit to our members.

WHO ARE OUR MEMBERS?

We have 2000+ members - 976 individuals with WS, their family members, and a small number of education and health professionals involved with WS.

HOW DO WE HELP?

- We fund research in order to create and maintain comprehensive Clinical Guidelines for the care of those with WS as well as specific guidelines for: Anaesthesia; feeding difficulties; anxiety; EHCPs; and guidelines for parents; teachers; employers; dentists and carers of adults with WS.
- We provide online, email and telephone support for families and carers, as well as for education, health and social-care professionals – all supported by the expertise of our Professional Advisory Panel.
- We organise a national family picnic almost every year and a programme of regional events for families to participate in, allowing them the opportunity to meet and share support.
- We support an EHCP assessment service so that children can be supported effectively in their learning and reach their potential.
- 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 in adults with WS.
- We keep families connected and informed through our website, social media channels, monthly e-newsletters and a twice-yearly magazine.
- We host weekend family conventions every three years with informative presentations and workshops from WS experts.



HOW ARE WE FUNDED?

Approximately 80% of our income is raised by our membership through donations and fundraising activities. We do receive some financial support from grant awarding organisations in delivering some of our specific projects and we have a small income from our merchandise and Christmas card sales (although the primary purpose of these is to create and increase awareness of WS). Over the last five financial years, our average income has been £225k.

Please visit our website, www.williams-syndrome.org.uk for more information on the WSF.
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