Introducing the WSF to new members

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 (unless a parent has WS), caused by a tiny new deletion on chromosome 7 (which includes the elastin gene). It can be diagnosed by a 'microarray' test. Williams Syndrome is usually associated with a number of health issues, including cardiac problems; learning difficulties; behavioural, social and sensory difficulties; and mental health problems – particularly anxiety.

Please visit: **www.williams-syndrome.org.uk**
for more information on the WSF.

Registered Charity Number England & Wales: 281014, Scotland: SCO49897

williams
SYNDROME FOUNDATION

Who are we?

The Williams Syndrome Foundation (WSF) is a small charity founded 40 years ago after Lady and 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 WS.**

The Foundation is managed by a board of nine dedicated trustees with five 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 2300+ members - 1000+ 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 that translates in to useful information for parents and professionals to help navigate the challenges of 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 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 and adolescents with WS.
- We host an online Zoom Club to combat social isolation in adults with WS.
- We hold monthly Zoom parent support groups as well as supporting adult siblings and grandparents.
- 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.
- We campaign for greater awareness of WS and celebrate our members' achievements.

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 three financial years, our average expenditure has been £193k.

Membership options

Online Membership

Free

Benefits:

- Twice yearly digital magazines
- Monthly e-newsletters keeping you updated of our activities
- Access to WSF webinars
- Online support groups
- Access to our We Support Friendships Zoom sessions (for adults with WS)
- Access to the members area of our website
- Online resources and materials
- Access to advice and support from our office team (supported by our Professional Advisory Panel)

Full Membership

£10 a year

ALL the benefits of online membership, PLUS :

- Twice yearly hard-copy magazines
- Printed resources and guidelines
- Access to our subsidised regional / national events
- Access to our subsidised national conventions (held every 3 years)*
- Access to our subsidised holidays*
- Access to Professor Jo Van Herwegen's EHCP Assessment Clinics*

*Places are limited

FUNDRAISING REGULATOR