williams
SYNDROME FOUNDATION

Where do your donations go?

Registered Charity No. 281014 (England & Wales)
SCO49892 (Scotland)

FR FUNDRAISING REGULATOR

What does the Williams Syndrome Foundation do with your donations?

The Williams Syndrome Foundation’s primary goal is to support people with Williams Syndrome and those who love, educate and care for them.
We do this in a number of ways:

WE SUPPORT FAMILIES

Peer Support

We fund face-to-face opportunities for families to connect, share support and have fun through our regional events programme, covering all four nations of the UK. These events include visits to farms, zoos, museums, play areas and we also host Christmas parties across the country.

Our office team also includes parents of individuals with WS, so we offer a help line providing a listening ear, empathy and signposting to internal and external resources. We are fortunate to be supported by a Professional Advisory Panel who can provide additional expert advice.

We fund a fully supported activity break for our adults with WS (which in turn provides respite for their families). Our adults love spending time with their “WSF brothers and sisters” and supporting each other to challenge themselves in undertaking the exciting activities on offer at Calvert Trust Kielder.

In addition, ***we fund*** an activity break for adolescents (supported by one of their parents) so that they can form friendships and spend time with their peers.

> *“It has been such a valuable experience for Dylan, spending time with others with similar needs to him has been confidence building. He felt he belonged and called them all his brothers and sisters. I cannot thank you enough for making it happen!”* ***Dylan’s mum***

Online Support

Our office team hosts Zoom friendship groups twice weekly for adults with WS as well as regular support groups - for parents, adult siblings and grandparents.

Guides and Webinars

We fund research that we can translate into useful information for parents / professionals to help them navigate the challenges of WS. We share printed and online resources and host a large number of useful webinars on our website.

EHCP (Education & Health Care Plan) Assessment Clinic

We fund an assessment clinic with Professor Jo Van Herwegen (Dr Jo) who provides families with the results of the assessments and recommendations for teaching staff in a comprehensive report which many schools use as the basis of their EHCPs.

> “Since the convention, I’ve reflected on just why it felt so utterly wonderful. I think much of the emotion derives from spending the weekend in the company of the only people in the UK who ‘understand’, to be in such a totally supportive and non-judgmental environment and yet to also have the wrapper of the magnificent team of professionals who are devoting their life’s work to help us all learn how best to support our loved ones. It’s a winning combination. The thought of the next convention is what sometimes keeps me going through the most challenging times of battling with the LA and NHS for the right support for Thomas.”
> **Steph, Thomas’s mum.**

Conventions

We fund a family weekend convention (every three years), connecting families with WS with each other and professionals who share their expertise on WS during a series of conference sessions. These conventions bring together 150+ families living with WS. Our members love to be in such a large group of people just like them – living with a rare condition which affects just 1 in 18,000 is isolating and most individuals with WS will not know anyone else with WS within their local community. This is our “jewel in the crown” of the support we offer but hosting a raft of professionals and 150 families for a weekend, including entertainment and full board, is a very costly endeavor. For those who attend, it is worth every penny:

Here is a snapshot from our 2022 convention:
https://vimeo.com/manage/videos/761618600
Our next convention will be held in July 2025 at Butlin’s in Skegness

Communications

There would be little point in providing all these support activities and resources if we did not communicate them to our members, new and existing, as well as the wider WS community.

We fund two printed magazines which we post out to our members every year. In addition, we provide monthly email newsletters, a regularly updated website, and manage content for our social media channels.

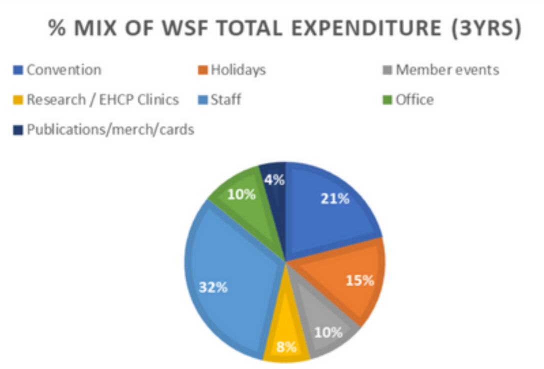
Our communications are also a fundamental part of our secondary objective of raising awareness of WS within the general population and within key populations such as providers of healthcare, socialcare and education.

Office

As a charity we are required to manage our resources responsibly, reporting on governance and legal requirements – such as managing our accounts, data protection, safeguarding and insurance. When we are not supporting members, organising and facilitating events, producing publications or compiling communications, our small staff team of four (1.8 FTE) ensures that the WSF continues to function within the framework of these legal and ethical best practices.

Three Year Spending Summary

Over the last 3 years (up to 31/3/25) the WSF had an average expenditure of £217k and income of £205k. 84% of our income came from donations and subscription payments (we have a free digital membership option and a paid family subscription option of £10 per year). Opposite is a breakdown of our expenditure:



Please get in touch....

If you would like to know more about how the WSF support our members with the monies generously donated to us, or if you would like to raise funds to help us in continuing to provide and improve the support we offer those with WS and those who love, care for and support them; please do get in touch via: **enquiries@williams-syndrome.org.uk.**

To all our lovely members, and their friends and family, who have supported us with fundraisers and donations – thank you! We would not be able to continue without such fabulous support!