FOWLER'S SYNDROME UK

Your Guide to
Making a Difference:

Fundraising for Fowler's Syndrome UK





Welcome & Thank You

Thank you for choosing to fundraise for Fowler's Syndrome UK - your support truly makes a difference. Every pound you raise helps us push for better awareness, research, and support for those living with this rare and often misunderstood condition.

With your help, we are:

- Funding vital research to improve diagnosis and treatment
- Providing crucial support to women navigating Fowler's Syndrome
- Raising awareness to ensure no one feels isolated or unheard

This guide is here to support and inspire you every step of the way. Whether you're hosting a bake sale, a sponsored walk, or something completely unique, know that your efforts are changing lives.

Why We Need Your Help

Fowler's Syndrome remains poorly understood, even among healthcare professionals, with many women waiting an average of 3.8 years for a diagnosis*. Resources are scarce, and support is vital.

"There is zero support currently, very few people are educated on the matter, which means it is a very long and lonely journey"

- FSUK Fowler's Fox, 2022.

FSUK bridges the gap by advocating for earlier diagnosis, improving treatment pathways, and providing much-needed resources for women with Fowler's and their families. Together, we can create a brighter future.

* All statistics shared in this document are taken from Fowler's Syndrome; Preliminary patient-led phenotyping of 265 patients, E. Cox, J.N. Panicker, I. Hoeritzauer, 2024.



What Your Fundraising Achieves

Every pound you raise helps to:

Reduce diagnosis delays
Currently, women wait an average of 3.8 years for a Fowler's Syndrome diagnosis.

Support peer networks
£15 can help build local support groups for women living with Fowler's.

Fund emergency helpline slots
£10 provides a vital drop-in call for women after a challenging appointment.

Promote inclusive outreach
£15 ensures that underrepresented communities are included in our work.

Together, we're breaking barriers and making sure no woman feels alone.



Fowler's Fact

75% of Women Say Fowler's Syndrome Has Severely Impacted Their Relationships



Fundraising Ideas

Get moving

Organise a sponsored walk, run, or swim.

Get creative

Host a bake sale, craft market, or art show.

Get connected

Arrange a virtual quiz or movie night with friends.

Get daring

Try a personal challenge, such as a skydive or shave-a-thon.

Whatever you do, have fun and know you're making a difference!

"FSUK has positively changed my life in a time of darkness and I will forever be indebted to the charity for this. Thank you."

FSUK Fowler's Fox, 2022

How to Get Started

1. Set your goal	Decide how much you'd like to raise and what type of fundraiser excites you.
2. Create a fundraising page	Set up your JustGiving page here to make it easy for supporters to donate.
3. Spread the word	Share your fundraiser with family, friends, and colleagues on social media, email, or in person.
4. Share on social	Share your #fowlerssyndrome fundraiser, story & photos with our community! Tag @fowlerssyndrome & email rachel@fowlerssyndrome.co.uk
5. Buy and wear the Tee	Buy an FSUK t-shirt to wear on the day of your event.

Making it Happen

- Plan ahead: Choose a date, venue, and goal.
- Stay safe: Follow health and safety guidelines for your event (details below).
- Engage your supporters: Share regular updates on your progress and milestones.

Check out our fundraising tips on the next page.

Tips for Fundraising Success

1. Share Your Why

Personal appeals work best. Tell your followers why you're fundraising and what Fowler's Syndrome UK means to you.

2. Make It Visual

Photos, videos, and reels get more engagement. Show behind-the-scenes moments, milestones, and progress updates to keep people invested in your journey.

3. Collaborate & Tag

Tag @fowlerssyndrome and use hashtags like #FowlersSyndrome to reach a wider audience.

4. Show Gratitude

Publicly thank your donors and supporters. A simple "Shoutout to [@name] for your amazing support!" encourages others to give.

5. Stay Consistent

People need to see a fundraising post three times before taking action. Don't just ask for donations once!

6. Donation Link to Hand

Make sure your donation link is in your Instagram bio, your Stories, every fundraising post caption, and pinned comments.

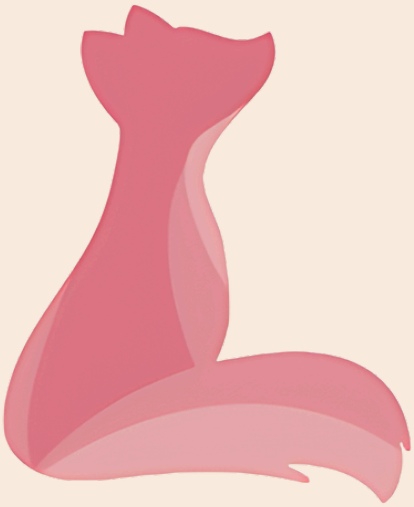
Fowler's Facts

76% were told their condition is 'all in their heads'



"'I was diagnosed 15 years ago after a lonely and traumatic search for the cause of my symptoms. No one had heard of Fowler's nor was there any opportunity to seek support or advice from fellow sufferers. It's heartwarming to know that other women will not feel so alone and will have access to support and accurate information. For me the charity most importantly raises the profile of this awful syndrome and will facilitate research and a better understanding of fowler's for health professionals and foxes alike."

FSUK Fowler's Fox, 2023



'91% of women with Fowler's Syndrome have frequent infections of chronic UTIs'

Buy an FSUK T-shirt

You can buy an organic cotton FSUK Tshirt via our website.

BUY A T-SHIRT

If you email hello@fowlerssyndrome.co.uk and pledge to raise over £300 we will send you one for free! *

*T&Cs apply. Postage only to UK mainland addresses.



"I have the Charity to thank for this - who 100% understands what you're going through from the illness to the belittling to how to handle and answer when someone makes a comment you feel is unfair and you want to know how to respond.

This is what's so important for FSUK, for the core of the Charity to be people who have first-hand experienced what the patient is going through, and who is a few steps ahead in their journey so can genuinely help guide you in the right direction."

FSUK Fowler's Fox, 2022

Keeping It Legal

- Ensure all activities meet local health and safety regulations.
- If under 16, get a parent or guardian involved in your planning.
- For raffles, lotteries, or selling items, check licensing requirements with your local council.

Paying In Your Funds

Once your fundraiser is complete, it's time to send in the money you've worked so hard to raise.

- Via JustGiving: Donations go directly to us - no need to lift a finger!
- Bank transfer: email us at hello@fowlerssyndrome.co.uk for details.
- Cheque: Send cheques payable to "Fowler's Syndrome UK" to our address: 42 York Street, Twickenham, TW1 3BW.



Stay Connected

Your support means the world to us, and we'd love to keep in touch after your fundraiser. Here's how you can stay involved:

Share Your Story

Send us your fundraising photos and personal experiences—we'd love to feature you! Email us at hello@fowlerssyndrome.co.uk.

Tag Us on Social Media

Share your journey using #FowlersSyndrome and @fowlerssyndrome so we can celebrate your impact and inspire others to take action.

Become a Volunteer or Advocate

Help us raise awareness, support more patients, and drive research forward. Sign up to volunteer for future events and campaigns.

Join Our Patient Council

If you or a loved one have Fowler's Syndrome, be a voice for the community and shape our work: fowlerssyndrome.co.uk/patient-council.

Stay Updated

Follow us on social media and sign up for our newsletter to get the latest updates @fowlerssyndrome https://fowlerssyndrome.co.uk/#newslettersignup

Your fundraiser is just the beginning. By staying connected, you're helping build a future where no one with Fowler's Syndrome feels unheard, unsupported, or alone. Thank you for being part of this movement!

Thank You For Your Support

Your efforts are helping us create a world where no woman with Fowler's Syndrome feels isolated or unsupported. Thank you for standing with us and making a difference.

Every donation, every share, and every conversation you've started helps bring us closer to a world where Fowler's Syndrome is recognised, researched, and treated with the urgency it deserves.

From all of us at FSUK, and from the entire community of women living with this condition—thank you for standing with us.

Fowler's Syndrome UK
Registered Charity Number: 1196903
42 York Street, Twickenham, TW1 3BW

fowlerssyndrome.co.uk
@fowlerssyndrome

"The charity helped give me a voice and a place to signpost those who are unaware of the condition. It's also helped me regain my confidence and regain some independence by enabling me to learn new self help skills as well as hearing from others who are experiencing similar symptoms and who kindly offer me advice and a listening ear from someone who understands."

FSUK Fowler's Fox, 2023