

# **FOWLER'S SYNDROME UK (FSUK) ANNUAL TRUSTEE REPORT 2024**

**UK registered charity  
Charity number: 1196903**

**London Borough of Richmond upon Thames  
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**For the financial period:  
1 January 2024 to 31 December 2024**

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## EXECUTIVE SUMMARY

*"FSUK has honestly been a lifeline. During my pregnancy, when I felt scared and isolated, the support and understanding I found here meant everything. It's so scary when a lot of healthcare professionals don't know what FS is or how to help. I don't know how I'd have coped without it. Honestly this group really helped me get through it all, even now thinking about another one when I thought one was impossible!"*

*Zoe, Fowler's Fox and mum to a Fowler's Foxlet*

We are delighted to present the Annual Trustee Report 2024 for Fowler's Syndrome UK (FSUK).

2024 has been a landmark year for FSUK. In June 2024, we received the highly competitive Reaching Communities Grant from the National Lottery. This is an award of £271,626 and will secure the charity funding from 2024-2027 and allow FSUK to expand our work supporting women and AFAB who have Fowler's Syndrome or Chronic Idiopathic Urinary Retention (CIUR).

Through our Helpline, Community Networks, Patient Council, Research Collaborations, and National Awareness Campaigns, FSUK has established itself as the leading national voice for women with Fowler's Syndrome. We have built infrastructure for long-term change: a growing patient council, a developing research portfolio, and a rapidly expanding national and international profile.

### Key Achievements:

#### **1. Increased Public Awareness**

FSUK's visibility and reach have grown exponentially in 2024. Led by our ambassador Elle Adams (@ellenextdoor), Fowler's Syndrome reached more than 1.6 million people through coverage in national press outlets including The Daily Mail, The Sun, The Express, The Metro, and The Daily Star. We also launched Fowler's February, an awareness month amplifying patient stories, clinical education, and myth-busting facts about the condition. These campaigns have directly improved public and professional awareness, demonstrated by a 323% rise in website traffic from Q1 2023 to Q1 2024, with over 11,000 users on the website in 2024.

#### **2. Launched First International Fowler's Syndrome Helpline and Patient Council**

In September 2024, FSUK launched the first dedicated international Patient Helpline and Patient Council for women living with Fowler's Syndrome; a world first in patient-led support for this rare condition. The helpline, designed and co-produced by women with

lived experience, provides one-to-one guidance, specialist information, and signposting to clinical care pathways across the UK and beyond.

The Patient Council brings together over 100 active participants to shape research priorities, policy discussions, and service design; ensuring that the voices of those affected by Fowler's Syndrome drive systemic change. Together, these initiatives have created a transformative model for patient engagement, combining peer support with strategic advocacy and co-production of resources on an international scale.

### **3. Research Advocacy**

FSUK has become a nationally recognised collaborator in Chronic Idiopathic Urinary Retention (CIUR) / Fowler's Syndrome research, championing the integration of lived experience into scientific and clinical development. Working alongside leading experts, including Trustee Board Chair Dr Ingrid Hoeritzauer (University of Edinburgh), Professor Jalesh Panicker (UCLH), Ms Helen Simpson (NHS Fife), Professor Jon Stone (University of Edinburgh), and Dr Caroline Selai (UCLH), FSUK has strengthened the national research landscape for this rare and under-recognised condition. We co-created a publication on the largest Fowler's Syndrome patient study in the world, conducted by FSUK and published in [Continence](#) (Volume 4, Issue 4, December 2024). Continence is an international, peer-reviewed journal published by Elsevier, and one of the leading global publications in the field of urology and pelvic health.

Throughout 2024, FSUK supported the development of collaborative studies, convened multidisciplinary meetings, and laid the groundwork for a unified research and clinical framework to improve diagnosis, management, and long-term outcomes. By embedding patient voice and lived experience at the centre of this work, FSUK has helped to ensure that future research reflects the priorities and realities of those affected by Fowler's Syndrome.

### **4. Educational Impact**

In 2024, FSUK strengthened its role as the leading source of education for both patients and professionals affected by Fowler's Syndrome. Our Webinar series with Prof Jalesh Panicker, Professor Jon Stone, Dr Caroline Selai and Mr. Davis Ellis, provided accessible, expert-led learning on clinical updates, symptom management, and self-advocacy, while our Mental Health Support Series exceeded expectations, reaching 2,640 people against a target of 300 through our webinar with Dr Caroline Selai and ambassador Elle Adams, downloads of the Anxiety and Fowler's Syndrome booklet, and related social media engagement. The reach was amplified by Elle's 150,000-strong Instagram audience, significantly expanding FSUK's educational impact. Following publication of our scientific paper, FSUK also translated the findings into plain-language summaries and shared them widely across social media,

ensuring new knowledge reached patients, families, and NHS professionals. Collectively, these initiatives deepened understanding, improved confidence in care, and advanced public and professional awareness of Fowler's Syndrome across the UK.

## **5. Fundraising**

In 2024, FSUK achieved a major milestone in its fundraising history, securing a £271,626 grant from the National Lottery Reaching Communities Fund in April, a significant increase from our previous largest award of £30,000. This transformative grant has enabled us to establish a national helpline, expand staff capacity, and drive forward research collaborations aimed at developing a long-term care pathway and preparing for an international consensus meeting in 2026.

The charity's total income for the financial year was £98,652, with expenditure of £63,925. Income was primarily derived from grants and donations, and while FSUK aims to diversify and increase income sources going forward, the results for the financial year ending 31 December 2024 are deemed satisfactory.

Looking ahead, the charity will continue to use its National Lottery funding wisely to create long-term stability and improve the landscape for women with Fowler's Syndrome by focusing on its core missions: to provide resources, promote education, and facilitate research. We look forward to reporting further progress in our 2025 annual review.

The Board of Trustees of FSUK presents this annual report for the charity's third financial period, covering 1 January 2024 to 31 December 2024, and confirms that it complies with the requirements of the Charities Act 2022.

*"FSUK what can I say...The level of support is brilliant, it honestly feels like a big Fowler's family community, it's a place that understands life with Fowler's syndrome. I was able to attend the Fowlers first in-person meet event and I finally felt heard, I was able to share my experiences, battles and what life is like. I also felt it normalized life with Fowler's syndrome. Extra special thanks to Dani who is always there with a smile always willing to try and help and has truly made a difference to my journey with Fowler's Syndrome"*

*Emma Harris, Nurse and Fowler's Fox, 2025*

# ABOUT FOWLER'S SYNDROME AND FOWLER'S SYNDROME UK (FSUK)

Founded by Danielle Coombe in December 2021, FSUK is a patient-led charity dedicated to transforming care for women with Fowler's Syndrome or CIUR, a condition that causes chronic urinary retention due to abnormal sphincter relaxation. The condition, first described by Professor Clare Fowler in 1985, affects thousands of women but remains under-diagnosed, under-researched, and poorly understood.

It is estimated that over 20,000 women in the UK live with Fowler's Syndrome, yet many remain undiagnosed. The average time to diagnosis is 3.8 years, and 76% of patients are told their symptoms are "imaginary" or "all in their head."

FSUK's mission is to provide resources, promote education, and facilitate research into Fowler's Syndrome, ensuring that women have stigma-free access to timely diagnosis, effective treatment options, and appropriate psychological support.

Our vision is to change the clinical landscape for women with Fowler's Syndrome through science, advocacy, and empathy.

Our objectives are to:

- Provide support and resources to patients and professionals.
- Promote national awareness and education.
- Encourage and facilitate research and innovation in treatment and care.

We have found that: i) 85% of women with Fowler's Syndrome said the condition has had a severe or devastating impact on their life; ii) there is low awareness of the condition among the medical community outside of specialist hospitals. Only an estimated 30% of GPs are aware of Fowler's Syndrome. Once diagnosed, there are few resources available for patients and limited treatment options. Many women feel alone and unsupported.

*"FSUK Helpline is fast becoming the number 1 go to tool for Fowler's patients - there is no judgement, embarrassment or dismissiveness given here. It's the phone number I recommend new Fowler's patients have on speed dial, your new ally."*

*Sam, Fowler's Fox*

# FINANCIAL ACCOUNTS

FSUK's income was £98,652 for the financial year ending on 31 December 2024, up from £29,820 in the previous financial year. Income was primarily driven by grants (£90,542), all of which generously came from The National Lottery Reaching Communities Fund. Only de minimis income was received from the charity's activities and operations in line with the fundraising strategy to focus on grants and donations going forward.

The charity's costs increased to £63,925 in 2024, mainly driven by operational costs, including CEO and paid staff salary payments. Other operational costs include the charity's occupation of shared office space and costs related to fundraising activities, governance and compliance, and digital infrastructure and subscriptions.

Going into 2025, FSUK will focus its fundraising strategy on grants with income from such expected to increase materially over the coming years. Subject to securing grants, operational costs are also expected to increase, as more paid employees are expected to be onboarded to support FSUK's operations and activities.

Kindly find below the financial accounts statement for the financial year: 1 January 2024 to 31 December 2024:

<b>Fowler's Syndrome UK</b> <small>Registered Charity Number 1196903</small> <b>Receipts and Payments Accounts</b> <b>For the Period 01/01/2024 to 31/12/2024</b>				
	<b>Unrestricted Funds</b> <small>to the nearest £</small>	<b>Restricted Funds</b> <small>to the nearest £</small>	<b>Total Funds</b> <small>to the nearest £</small>	<b>Total Funds Last Year</b> <small>to the nearest £</small>
<b>Receipts</b>				
Donations	7,846	-	7,846	25,735
Grants	-	90,542	90,542	4,000
Income from Activities	264	-	264	5
Operations	-	-	-	80
<b>Total Receipts</b>	<b>8,110</b>	<b>90,542</b>	<b>98,652</b>	<b>29,820</b>
<b>Payments</b>				
Income-Generating Activities	332	-	332	50
Operational Costs	19,238	44,175	63,414	28,024
Asset and Investment Purchases	-	180	180	-
<b>Total Payments</b>	<b>19,570</b>	<b>44,355</b>	<b>63,925</b>	<b>28,074</b>
<b>Net of Receipts/ (Payments)</b>	<b>- 11,460</b>	<b>46,187</b>	<b>34,727</b>	<b>1,746</b>
<b>Transfers between Funds</b>	-	-	-	-
<b>Cash Funds Last Year End</b>	<b>41,573</b>	-	<b>41,573</b>	<b>39,827</b>
<b>Cash Funds at This Year End</b>	<b>30,113</b>	<b>46,187</b>	<b>76,300</b>	<b>41,573</b>

The charity held cash equivalents of £41,573 at the beginning of the financial year. FSUK's cash balance was £76,300 as at 31 December 2024, resulting in a net movement of £34,727. As with 2023, the charity's liabilities relate solely to remuneration payments as at the end of 2024.

Kindly find below the balance statement for the financial year: 1 January 2024 to 31 December 2024:

<b>Fowler's Syndrome UK</b> Registered Charity Number 1196903 <b>Statement of Assets and Liabilities</b> at 31/12/2024			
	<b>Unrestricted Funds</b> to the nearest £	<b>Restricted Funds</b> to the nearest £	<b>Total Funds</b> to the nearest £
<b><u>Cash Funds</u></b>			
Cash in Bank	£30,113	£52,013.98	82,127
<b>Total Cash Funds</b>	<b>£30,113</b>	<b>52,014</b>	<b>82,127</b>
<b><u>Assets</u></b>			
Other Debtors	-	-	-
Fixed Assets - Net Book Value	-	718	718
<b>Total Assets</b>	<b>-</b>	<b>718</b>	<b>718</b>
<b><u>Liabilities</u></b>			
Net Wages	-	5,357	5,357
PAYE	-	1,188	1,188
<b>Total Liabilities</b>	<b>-</b>	<b>6,545</b>	<b>6,545</b>
<b><u>Net Assets</u></b>	<b>£30,113</b>	<b>46,187</b>	<b>76,300</b>

**Basis of Preparation:** The Receipts and Payments Account and Statement of Assets and Liabilities have been prepared under historical accounting convention.

**Funds:** Funds are both restricted and unrestricted.

**Income and Expenditure:** Both are shown when received or paid.



**Reserves:** The charity seeks to keep a reasonable reserve at any given time to maintain its ongoing solvency. Cash management and available reserves are monitored on an ongoing basis. The charity's cash reserve policy focuses on keeping a reasonable and sufficient buffer at any time and the charity will not commit to long term expenses for which funding will be considered highly uncertain.

**Accounting period:** The charity's accounting period is 1 January to 31 December following the calendar year.

**Trustee emoluments:** The Trustees receive no remuneration or reimbursement for personal expenses from the charity.

**Special Thanks:** FSUK would like to extend its sincere thanks to Katie Parry, formerly of the Financial Conduct Authority (FCA), who continues to manage all of FSUK's accounting and financial governance work entirely on a voluntary basis. Despite an exceptionally demanding professional schedule, Katie goes above and beyond in maintaining the charity's financial systems, reporting accuracy, and compliance, ensuring our operations run to an exceptionally high standard. We are deeply grateful for her exceptional dedication and continued support of FSUK.

## REVIEW OF ACTIVITIES AND ACHIEVEMENTS

*“Over the years I have worked with a number of charities and I can say that FSUK is one of the most well-organised, productive, creative, innovative and successful that I have had the pleasure to be involved with. I will not here rehearse the sheer breadth of achievements in terms of support for patients, innovation and fund-raising. The catalogue of activities speaks for itself.”*

*Dr Caroline Selai, UCLH psychologist and FSUK board member*

2024 was a transformative year for FSUK. Due to receiving The Reaching Communities Grant from the National Lottery in June 2024, two new staff members were employed from August 2024, resulting in our biggest year of growth yet. Our objectives are to provide support and resources, promote awareness and encourage research. In the following sections, please find selected highlights as well as an update on fundraising activities.

### Helpline

FSUK's helpline provides a safe, confidential space for anyone who has, or suspects they may have, Fowler's Syndrome, Chronic Idiopathic Urinary Retention (CIUR), or unexplained urinary retention. The helpline offers emotional and practical support from advisers with lived experience of Fowler's Syndrome, ensuring that every caller is met with understanding, empathy, and specialist knowledge.

Launched on 4 September 2024, FSUK's helpline is the first and only dedicated service of its kind worldwide. It is free to access and available via WhatsApp, phone, text, or video call in the UK or via WhatsApp internationally. Callers can book a 30-minute appointment, join open drop-in sessions, or text/WhatsApp. The helpline provides emotional support, guidance on managing symptoms, information about treatment options, and assistance navigating healthcare systems. It also offers advice for family members and carers seeking to better understand the condition.

The service is non-clinical and does not replace professional medical advice. Advisers are able to provide written and verbal signposting to ensure callers know who to contact in urgent or emergency situations relating to their medical or mental health needs.

### Understanding the Need

In August 2024, FSUK conducted a Helpline Needs Survey to identify what women most wanted from the service.

- 89% wanted support around physical symptoms
- 80% wanted support for emotional impact
- 80% wanted information on treatment options
- 58% rarely or never feel supported by medical professionals
- 55% rarely or never feel listened to by doctors
- 43% said friends and family are unaware of their condition

These results confirmed the immense gap in emotional and practical support available to women with Fowler's Syndrome. The same survey showed that 82% of respondents preferred accessing the helpline by text message, 55% by phone, and 23% by video call; highlighting the importance of multi-channel accessibility.

### **Helpline Delivery and Reach**

Between September and December 2024, the helpline supported 117 women through 43 phone calls and 74 text sessions, meeting its quarterly engagement target despite its short operating period. The helpline quickly became one of FSUK's most valued services, reaching women across the UK, Republic of Ireland, and internationally via WhatsApp.

As the only service providing lived-experience-led peer support for Fowler's Syndrome, the helpline is uniquely placed to bridge the gap between clinical care and emotional wellbeing. Many callers reported that it was their first time ever speaking to someone else with the condition.

### **Exit Survey Outcomes**

A post-call Exit Survey was introduced in December 2024 to measure impact. Results from the first cohort (n=12) were overwhelmingly positive:

- 100% felt supported by the adviser
- 83% said the call made them feel more equipped to deal with daily life
- 83% said it made them more hopeful about the future
- 100% said they would contact FSUK again
- 100% said they would recommend the helpline to someone else

These early indicators show an extremely high satisfaction rate and confirm that FSUK's helpline is delivering meaningful emotional and informational impact.

*"The helpline helped me. I felt alone, I didn't know if my symptoms were normal. Just offloading and hearing that I'm not the only one with the symptoms I get helped me so much. Just feeling listened to and valued helped so much."*

*Anonymous Fowler's Fox, 2024*

### **Caller Feedback**

Feedback from callers highlights the personal and transformative value of the service:

*"Thank you so much. You've really lifted my daughter tonight and given her hope and opened her eyes to the success of the mitrofanoff. Thank you for the call. It is appreciated so much!"*

“It was reassuring to speak to someone who has experienced similar symptoms and gone through the process. Rachel listened and signposted where needed. This was extremely helpful.”

“Thanks Rachel for being there for me when I need you most. It means a lot to me.”

“I’m so grateful to have this service. It’s such a big thing being able to talk to someone who understands how you’re feeling.”

“Rachel was the first person I have spoken to with Fowler’s Syndrome since I was diagnosed. She made me feel less alone and isolated.”

“The helpline helped me. I felt alone, I didn’t know if my symptoms were normal. Just offloading and hearing that I’m not the only one helped me so much.”

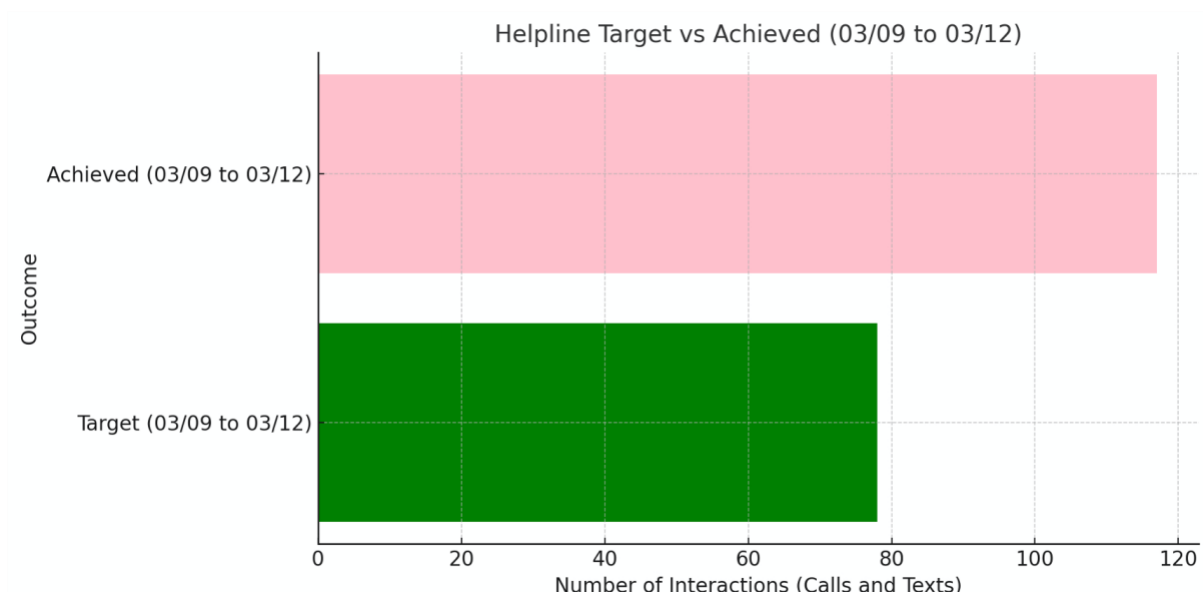
Such feedback demonstrates how the helpline reduces isolation, builds hope, and empowers women to navigate their condition with confidence.

### **Key Learnings and Future Development**

The helpline’s early success has revealed an even greater level of need than anticipated. Many callers expressed relief at finally having someone to talk to who truly understood their condition. Common themes include lack of support from healthcare professionals, emotional distress, and uncertainty about treatment pathways.

To ensure resilience and sustainability, FSUK is developing a dual-advisor model, enabling coverage in case of staff illness or increased demand. Structured supervision and reflective practice will be embedded to safeguard the wellbeing of advisers.

FSUK will continue to monitor satisfaction and outcomes through post-call surveys, qualitative feedback, and engagement tracking. As part of our Reaching Communities funding, we aim to scale the FSUK’s service to support over 2,000 women by August 2026, expanding into specialist areas including catheter care, mental health, and pregnancy-related support.



## Patient Council

Launched on 26 November 2024, the FSUK Patient Council represents a major milestone in the charity's commitment to ensuring that the voices of women living with Fowler's Syndrome are central to every aspect of care, research, and advocacy. Created by patients, for patients, the Council provides a formal mechanism for lived experience to shape the future of healthcare and research for this under-recognised condition.

The launch included a new dedicated webpage, newsletter announcement, and social media campaign, supported by a live Google registration form for patients and loved ones to join. Within the first two weeks, 74 people signed up, with 68 confirmed members continuing active participation by year end.

The Council's purpose is to amplify patient perspectives and ensure that women with Fowler's Syndrome are not passive recipients of care, but partners in improving it. By joining, members are helping to guide decisions that affect their own care while influencing national-level awareness, education, and research.

*"FSUK has been an invaluable source of help and support to me over the course of the last 6-8 months. The helpline has been great for support and guidance. Rachel is always great to talk to and to gain advice and knowledge from as well as knowing what I am going through and being able to tell me that things will get better. The face-to-face meet up with Dani and other FS sufferers was also fabulous as we could all bounce ideas and talk about our lived experiences. I have also volunteered with FSUK in creating a database for the information postcards and contact information for who they should go to on the first round send out. I have also used the GP factsheet in my own GP surgery when going for appointments to help educate my GPs about FS"*

*Leah Philips, Fowler's Fox and FSUK volunteer*

## **Role and Structure**

The Patient Council serves as a collaborative platform where members:

- Work with clinicians and researchers to enhance patient experience and service design.
- Ensure that the patient voice is embedded within all FSUK-led projects and research studies.
- Advocate for awareness, policy, and research initiatives that reflect real-world needs.
- Develop patient-informed solutions to improve access, communication, and empathy within healthcare settings.

Members are invited to share their experiences through surveys, focus groups, and direct feedback on clinical resources, pilot studies, and communications. The Council also provides opportunities to:

- Participate in medical studies, surveys, and questionnaires.
- Offer feedback on research design and patient-facing materials.
- Join roundtable discussions with leading urologists, neurologists, and researchers.
- Collaborate on awareness campaigns through storytelling, social media, and press features.

Each participant's lived experience adds a vital dimension to the national conversation about Fowler's Syndrome. The Council embodies FSUK's ethos of co-creation, ensuring that every new initiative is grounded in patient reality and guided by compassion, insight, and shared purpose.

## **Safeguarding**

Safeguarding remains a cornerstone of FSUK's operations, ensuring that all participants, patients, staff, and volunteers, feel safe, respected, and protected.

In 2024, Rachel Ingram (Patient Liaison) was designated as FSUK's Safeguarding Lead. She has completed multiple safeguarding qualifications, including:

- Designated Safeguarding Lead training (February 2024)
- Level 3 Advanced Helpline Skills Safeguarding Course (17 September 2024)
- Annual safeguarding training for the past four years

All FSUK staff and volunteers, including those supporting helpline delivery, patient council activities, and peer-to-peer support, are required to complete basic safeguarding training. This training ensures that everyone involved in FSUK understands how to recognise potential concerns and follow correct reporting procedures to the Safeguarding Lead.

A Safeguarding Incident Recording Form has also been developed to maintain accurate, confidential documentation of any disclosures or welfare concerns. This system ensures that all incidents are managed consistently and in line with national charity sector standards.

FSUK's safeguarding framework reflects best practice from the NSPCC, NCVO, and Samaritans guidance, ensuring that even as the organisation grows, the emotional and physical wellbeing of its community remains its highest priority.

## **Education**

We provide barrier-free access to the latest scientific information and in 2023/4 started a world-first series of webinars on Fowler's Syndrome. The initial webinar was *An Introduction to Fowler's Syndrome*, by Mr. David Ellis, and in February 2024 we launched *Fowler's Syndrome and urinary retention in women*, by Professor Jalesh N. Panicker.

77% of women with Fowler's Syndrome have a diagnosis of anxiety. Our survey showed that 96% of women experienced stigma around the condition, and 76% of women have been told the condition is 'all in their heads'. It is vital for us to dispel myths around mental health and Fowler's Syndrome, and our Anxiety and Fowler's Syndrome series is a small part of that stigma breaking. In December 2023 we launched a short film of our excellent ambassador Elle Adams (@ellenextdoor) discussing Fowler's and anxiety with Dr. Caroline Selai, Senior Lecturer in Clinical Neuroscience at UCL, chartered psychologist and Associate Fellow of the British Psychological Society. In February 2024 we followed this up with an anxiety workbook, created by Dr Caroline Selai in association with Uzma Razzaque-Bibi.

A free, downloadable, GP Factsheet launched in August 2024. The one-page leaflet provides an overview of what Fowler's Syndrome is, what symptoms may be experienced, as well as information on different treatment options available, and is intended for clinicians. The GP factsheet was created by FSUK's Medical Board, led by Professor Jalesh N. Panicker, and agreed with FSUK and FSUK's Patient Partners.

## **FSUK Website and social media**

FSUK launched its website in December 2021. It hosts a library of information and webinars about the condition as well as important information about the charity itself. The site is easily located and is receiving interest and visits from viewers across the world. In 2024 we added several sections in our resources area, including the GP Factsheet, Webinars, a Helpline section, the Patient Council, and a dedicated research section.

In 2024, the Fowler's Syndrome website continued to perform strongly, attracting a total of around 11,000 active and new users over the year. Visitors viewed approximately 21,000 pages, with an average engagement time of 1 minute 17 seconds per user, showing consistent interest in the charity's online information and resources. The majority of web traffic came through organic search (8.2K sessions), followed by direct visits (5.1K), indicating that both search visibility and returning user engagement remained healthy. Referral traffic (847 sessions) and organic social (485 sessions) also contributed to visitor numbers, reflecting a balanced mix of discovery channels.

Most users were based in the United Kingdom (8.8K), with additional reach in the United States, Australia, Ireland, and Canada, highlighting growing international awareness. The most visited pages included the homepage, 'Symptoms and Causes of Fowler's Syndrome', and 'Meet Our Team', showing continued public interest in educational and organisational content. Overall, 2024 demonstrated a stable and engaged audience, with strong organic visibility and steady traffic growth supporting the charity's mission to raise awareness and provide accessible information.

Our social media page is a growing community where those with Fowler's Syndrome, along with their families, friends, and clinicians, can find information, support, guidance, signposting, news, events, and resources. Our following has continued to grow steadily over the past year, with 1,600 followers on Instagram (up from 1,259 in December 2023) and 1,200 followers on Facebook (up from 1,012).

### **FSUK Ambassador, Elle Adams**

FSUK are proud to partner with Elle Adams (@ellenextdoor) as our ambassador. Elle lives with Fowler's Syndrome and uses her platform as a lifestyle content creator to raise awareness and share her lived experience with authenticity and warmth. With over 120,000 followers on Instagram, Elle's posts have reached wide audiences and sparked meaningful conversations about Fowler's Syndrome. Since partnering with FSUK in December 2023, her reels have attracted exceptional engagement: one video featuring FSUK reached over 100,000 accounts and received more than 4,000 likes. Her openness and creativity have brought vital visibility to a condition that remains under-recognised, and we are deeply grateful for her continued advocacy and support.

### **Press**

In 2024, Fowler's Syndrome UK (FSUK) received valuable press coverage helping to raise awareness of Fowler's Syndrome and the charity's work. Highlights included an article by FSUK Founder and CEO Dani Coombe in Health Awareness UK's Bladder & Bowel campaign - [\*"Only 30% of GPs know about Fowler's Syndrome: here's what it is and how to recognise it"\*](#) published during World Continence Week 2024. FSUK was also featured in the Barclays Private Banking Magazine's [\*"International Women's Day 2024: A Philanthropy View"\*](#), which highlighted the role of women-led charities in driving health advocacy.

### **Medical Board**

The Medical Board is made up of 9 healthcare professionals in the field of urology, neurology, psychology and psychiatry. We are very proud that Professor Clare Fowler CBE sits on this board in the capacity of patron of the charity. We are so grateful to all of our medical board.

### **Research**

In 2024, FSUK played a central role in advancing research and clinical understanding of Fowler's Syndrome. The charity co-authored the largest ever patient-led phenotyping study



of the condition, published in Continence magazine. This landmark publication represented a major step forward in characterising the lived experience and clinical presentation of women with Fowler's Syndrome.

FSUK also contributed to the first-ever international consensus guidelines on non-surgical interventions for Fowler's Syndrome, led by Dr Ingrid Hoeritzauer, marking a pivotal move toward standardised, evidence-based management of the condition.

In late 2024, FSUK was invited to collaborate on a forthcoming Transcutaneous Tibial Nerve Stimulation (TTNS) research project with Aidan Trevelyan and Professor Kier Nazarpour at the University of Edinburgh. This project, scheduled to commence in Q2 2025, aims to evaluate the effectiveness of TTNS as a potential treatment for Fowler's Syndrome and will further strengthen FSUK's role in patient-centred research innovation.

### **Fundraising**

In 2024, Fowler's Syndrome UK continued to grow its reach and impact through a series of awareness and fundraising initiatives. The charity's annual Fowler's February campaign once again united the community with online support sessions, personal story-sharing, and nationwide social-media activity highlighting the realities of living with Fowler's Syndrome. Throughout the year, supporters organised and took part in fundraising events including the London Marathon 2024, the Royal Parks Half Marathon, the Edinburgh Kiltwalk, and the Rawreth Equestrian Charity Ride. In July, the charity proudly announced new support from The National Lottery Community Fund's Reaching Communities programme, helping to expand outreach and resources for those affected by the condition.

### **Grants**

2024 marked a landmark year for FSUK, underpinned by the award of a £271,626 grant from The National Lottery Community Fund's Reaching Communities programme. This transformative three-year grant forms the cornerstone of our current delivery programme, enabling FSUK to establish a sustainable foundation for patient support, awareness, and research engagement at national scale.

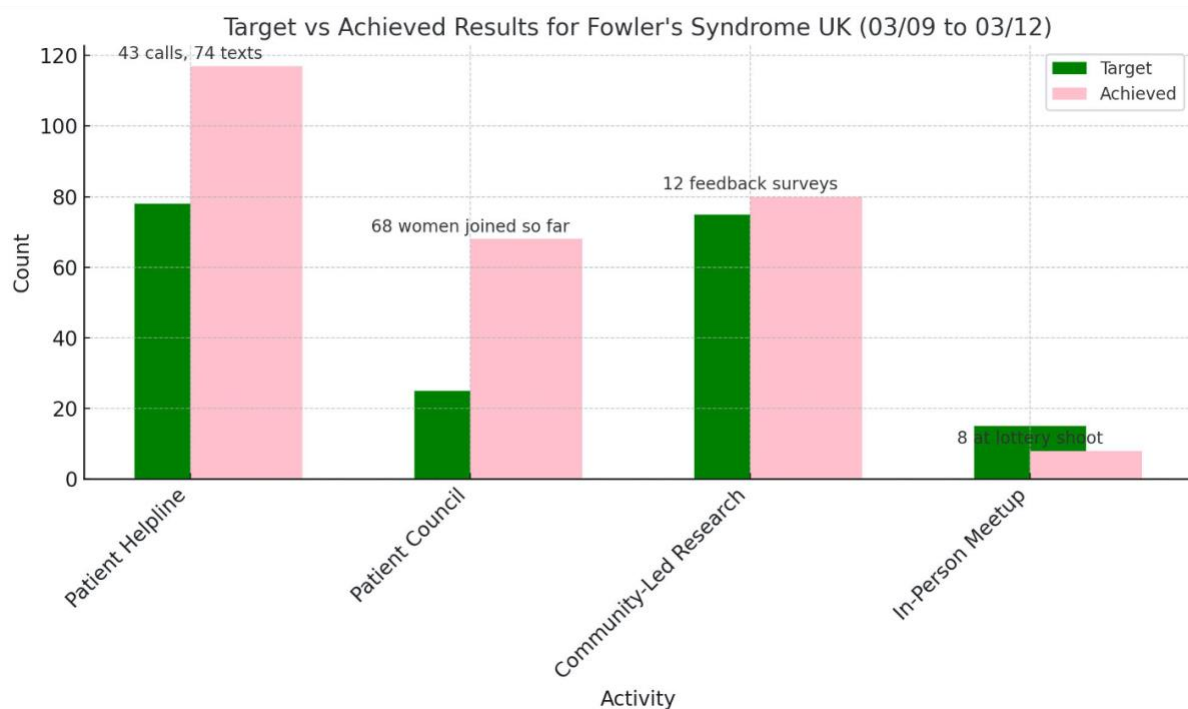
The grant supports core salaries, infrastructure, service development, and evaluation. It has directly funded the creation and delivery of key services including:

- The FSUK Helpline, launched in September 2024, the first and only dedicated helpline worldwide for Fowler's Syndrome, providing one-to-one peer-led emotional and practical support to women across the UK and beyond.
- The Patient Council, launched in November 2024, empowering women with lived experience to influence healthcare, research, and policy decisions.
- Development of new educational and mental health resources, including our anxiety workbook and awareness campaigns co-produced with women with the condition and clinicians.

- Implementation of robust impact measurement and safeguarding systems, ensuring safe, effective, and evidence-led service delivery.

The National Lottery grant has enabled FSUK to employ a small, high-impact team led by CEO Danielle Coombe, supported by Patient Liaison Rachel Ingram and a Media & Communications Officer, with external consultancy for governance, HR, and evaluation. It has also provided the capacity to deliver over 350 helpline support sessions in Year One, reach over 1.6 million people through press and media, and recruit 103 members to the FSUK Patient Council.

We are deeply grateful to The National Lottery Community Fund for recognising the urgent, unmet needs of women with Fowler's Syndrome and investing in FSUK's mission to close the care gap. This partnership has enabled us to deliver tangible, life-changing impact while embedding sustainability, professional standards, and lived experience at the heart of everything we do.



# CHARITY STRUCTURE, MANAGEMENT AND GOVERNANCE

Danielle Coombe, the charity's Founder and CEO, is responsible for the strategy and day-to-day activities as well as the running of the charity. She is supported by members of the Medical Board as well as by volunteers. The charity is governed by its Board of Trustees.

The Trustees whose skills include finance, fundraising, HR, marketing, volunteer management and digital. Trustee meetings are held at least annually. Rachel Ingram resigned from her position on the Board of Trustees as she became a paid employee in function as of Patient Liaison.

In addition to the management team and Trustee Board, FSUK has a stellar Medical Board. The Medical Board comprises a wide cross section of specialties, including urology, gynaecology, neurology, psychology, and psychiatry. The Charity Patron is Professor Clare Fowler CBE, the eminent uro-neurologist who first described the condition. See members of the Medical Board below.

FSUK Medical Board		
Prof Clare Fowler (PATRON)	<i>Emeritus professor of Neurology</i>	<i>University College Hospital, London</i>
Prof. Jalesh Panicker	<i>Professor of Neurology</i>	<i>University College Hospital, London</i>
Dr. Caroline Selai	<i>Chartered Psychologist</i>	<i>University College Hospital, London</i>
Dr. Ingrid Hoeritzauer	<i>Consultant Neurologist</i>	<i>University of Edinburgh</i>
Prof. Jon Stone	<i>Consultant Neurologist</i>	<i>University of Edinburgh</i>
Dr. Caoimhe McLoughlin	<i>Consultant Psychiatrist</i>	<i>University of Edinburgh</i>
Mr. Kostas Charitopoulos	<i>Consultant Urologist</i>	<i>West Middlesex University Hospital</i>
Mr. David Ellis	<i>Urologist</i>	<i>West Middlesex University Hospital</i>
Ellen Thompson	<i>5th year Medical student</i>	<i>St George's Hospital, Tooting.</i>

**Trustee Recruitment and Policies:**

FSUK recognises that an effective Board of Trustees are essential if FSUK is to be successful in achieving its mission. Our board members must seek to be representative of the community we serve. FSUK's Trustee Board Recruitment policy sets out how FSUK intends to recruit a robust and effective board. Board members should possess an appropriate mix of skills and experience to provide the necessary breadth and depth of knowledge and experience to meet the board's responsibilities and objectives. We aim for a board composition that will reflect our community. We embrace and encourage differences in race, nationality, ethnicity, marital or civil partnership status, caring responsibilities, disability, age, gender identity, social class, sexual orientation, or religion/belief.

The board shall annually assess its composition in reference to the necessary areas of expertise, the balance between experience and newer members, desirable diversity in relevant areas, and contributions from relevant stakeholders.

Should the board identify areas where there are perceived gaps in skills, knowledge, or experience, they shall attempt to recruit from FSUK networks, collecting suggestions from members and stakeholders to draw up a list of suitable candidates. The board may also advertise on FSUK's volunteers webpage or use external advisors to assist in the process for board openings.

All candidates will be evaluated using a standardised process and will be required to complete an application form identifying their skills, experience, suitability for the board, and any potential conflicts of interest. Appointed members of the Board and the CEO will review, shortlist, and interview appropriate candidates. Identified candidates will then be presented to the full board for consideration, recruitment, and election.

In addition to FSUK's Trustee Board Recruitment policy, the charity holds numerous policies covering areas such as, but not limited to, Social Media, Third Party Complaints, Volunteering, Diversity and Inclusion, Donation Gift Acceptance, and Privacy.

FSUK is a Charitable Incorporated Organisation registered on 3 December 2021.

# INDEPENDENT EXAMINER'S REPORT ON THE ACCOUNTS



CHARITY COMMISSION  
FOR ENGLAND AND WALES

## Independent examiner's report on the accounts

Section A		Independent Examiner's Report	
Report to the trustees	Charity Name Fowler's Syndrome UK		
On accounts for the year ended	31 <sup>st</sup> December 2024	Charity no (if any)	1196903
Set out on pages	7 & 8		
Responsibilities and basis of report	<p>I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/2024.</p> <p>As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").</p> <p>I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.</p>		
Independent examiner's statement	<p>I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:</p> <ul style="list-style-type: none"> <li>the accounting records were not kept in accordance with section 130 of the Charities Act; or</li> <li>the accounts did not accord with the accounting records; or</li> <li>the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.</li> </ul> <p>I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.</p>		
Signed:			Date: 07/10/2025
Name:	Georgina Deakin		
Relevant professional qualification(s) or body (if any):	ACCA – Membership number 2803472		
Address:	1 Derby Road, Eastwood, Nottinghamshire, NG16 3PA		

## KEY INDIVIDUALS

### Management:

Name	Role
Danielle Coombe	Founder & CEO
Katie Parry	Finance (voluntary)

### Board of Trustees:

Name	Role	Date of appointment	Date of resignation (if applicable)
Anne Ingrid Hoeritzauer	Chair	28 April 2024	-
Jesper Jensen	Trustee	23 May 2023	-
Konstantinos Charitopoulous	Trustee	3 December 2021	-
Caroline Petersen	Trustee	3 December 2021	-
Rory James Layton Knighton	Trustee	3 December 2021	-
Hannah Marie Edwards	Trustee	3 December 2021	-
Matthew Coombe	Trustee	3 December 2021	-
Danielle Coombe	Trustee	3 December 2021	5 April 2023
Rachel Emma Ingram	Trustee	3 December 2021	19 August 2024
Marguerite Michael	Chair	1 June 2023	22 March 2024

### Contact details:

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