FOWLER'S
SYNDROME UK

FOWLER'S SYNDROME UK (FSUK)
ANNUAL TRUSTEE REPORT 2025

UK registered charity
Charity number: 1196903

London Borough of Richmond upon Thames
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For the financial period:
1 January 2025 to 31 December 2025

FOWLER'S SYNDROME UK

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FOREWORD FROM THE CHAIR OF TRUSTEES

We are delighted to present the 2025 Annual Trustee Report for Fowler's Syndrome UK (FSUK), reflecting on a year of significant progress in supporting women and people assigned female at birth (AFAB) living with Fowler's Syndrome and Chronic Idiopathic Urinary Retention (CIUR).

2025 has been a year of continued growth and development for FSUK. Building on the foundations established through our three year £271,626 National Lottery Reaching Communities grant, we have strengthened our patient support services, expanded our community networks, advanced important research collaborations and increased awareness of Fowler's Syndrome nationally and internationally.

Our Patient Helpline continued to provide vital emotional and practical support, exceeding its annual target. Feedback demonstrated the importance of this service, with 100% of respondents reporting feeling extremely supported and less lonely or isolated. Our Patient Council also grew significantly, exceeding its target and ensuring that lived experience continues to shape research priorities, clinical discussions and the development of services.

Alongside our patient support work, FSUK strengthened its relationships with leading clinicians and researchers, supporting important studies and contributing to the development of clinical consensus recommendations for chronic urinary retention. We continued to provide accessible educational resources, expert-led webinars and opportunities for peer connection, while national media coverage helped bring greater attention to Fowler's Syndrome and the challenges faced by those living with the condition.

Financially, 2025 was another important year for the charity. Alongside our continued National Lottery funding, we secured a £65,000 educational grant from Medtronic, supporting our work to improve awareness and education and preparations for our international Fowler's Syndrome meeting in February 2026. The generosity of our supporters and community fundraisers also continued to play an essential role in sustaining and expanding our work.

As we look ahead, FSUK remains committed to its three core objectives: providing support and resources, promoting awareness and education, and facilitating research. The progress made throughout 2025 has further strengthened our foundations for long-term change, bringing us closer to a future where women living with Fowler's Syndrome are better understood, supported and able to access appropriate care. I am proud to be Chair of Trustees of this wonderful charity.

Ingrid Hoeritzauer

"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, 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.

FINANCIAL ACCOUNTS

FSUK's total income for the financial year ending 31 December 2025 was £158,305, an increase of £59,653 (60.5%) compared with £98,652 in the previous financial year. Income was primarily driven by grants totalling £153,902, up from £90,542 in 2024. This included continued funding from the National Lottery Community Fund under its Reaching Communities programme, with grant payments having commenced in June 2024, together with additional uplift funding. The charity also secured a £65,000 grant from Medtronic to support activities scheduled for 2026, of which £50,000 was received in 2025. Donations contributed a further £4,403, in line with the charity's fundraising strategy to focus primarily on grants and donations.

The charity's total expenditure increased to £92,072, compared with £63,925 in 2024, primarily driven by operational costs, including staff remuneration and the delivery of the charity's Helpline service. The charity recorded a net surplus of £66,233, compared with £34,727 in 2024. The CEO remained employed throughout the year, with a salary increase from October 2025, whilst the Patient Liaison Officer's fixed-term contract concluded in August 2025. Other operational costs included administrative and HR support, shared office space, fundraising activities, governance and compliance, and digital infrastructure and subscriptions.

Kindly find below the financial accounts statement for the financial year 1 January 2025 to 31 December 2025:

FOWLER'S SYNDROME UK

Fowler's Syndrome UK

Registered Charity Number 1196903

Receipts and Payments Accounts

For the Period 01/01/2025 to 31/12/2025

	Unrestricted Funds to the nearest £	Restricted Funds to the nearest £	Total Funds to the nearest £	Total Funds Last Year to the nearest £
Receipts				
Donations	4,403	-	4,403	7,846
Grants	-	153,902	153,902	90,542
Income from Activities	-	-	-	264
Operations	-	-	-	-
Total Receipts	**4,403**	**153,902**	**158,305**	**98,652**
Payments				
Income-Generating Activities	6	-	6	332
Operational Costs	2,011	89,651	91,662	63,414
Asset and Investment Purchase	-	403	403	180
Total Payments	**2,017**	**90,055**	**92,072**	**63,925**
Net of Receipts/ (Payments)	**2,386**	**63,847**	**66,233**	**34,727**
Transfers between Funds	-	-	-	-
Cash Funds Last Year End	30,113	46,187	76,300	41,573
Cash Funds at This Year End	**32,499**	**110,034**	**142,534**	**76,300**

FSUK's cash balance increased from £82,127 at 31 December 2024 to £148,214 at 31 December 2025. After accounting for fixed assets and year-end liabilities, total net assets stood at £142,534, compared with £76,300 at the end of 2024. Of these net assets, £110,034 was held in restricted funds and £32,499 in unrestricted funds. The increase in restricted funds largely reflects grant funding received ahead of associated expenditure, including from Medtronic for activities scheduled in February 2026 and ongoing National Lottery funding supporting FSUK's operations through to May 2027.

Kindly find below the balance statement for the financial year: 1 January 2025 to 31 December 2025:

Fowler's Syndrome UK

Registered Charity Number 1196903

Statement of Assets and Liabilities

at 31/12/2025

	Unrestricted Funds to the nearest £	Restricted Funds to the nearest £	Total Funds to the nearest £
Cash Funds			
Cash in Bank	32,499	115,714	148,214
Total Cash Funds	**32,499**	**115,714**	**148,214**
Assets			
Other Debtors	-	-	-
Fixed Assets - Net Book Value	-	1,614	1,614
Total Assets	**-**	**1,614**	**1,614**
Liabilities			
Net Wages	-	6,107	6,107
PAYE	-	991	991
Operational Costs		197	197
Total Liabilities	**-**	**7,294**	**7,294**
Net Assets	**32,499**	**110,034**	**142,534**

Looking ahead to 2026, FSUK will continue to focus on its fundraising strategy on grants and donations, alongside delivering activities supported by existing funding commitments. Further instalments are expected under the existing grant from The National Lottery in June and December 2026, with the remaining £15,000 of Medtronic funding received in February 2026. Operational expenditure will continue to be managed in line with available funding, with the Trustees maintaining oversight of the charity's financial sustainability and unrestricted reserves.

Basis of Preparation: The financial statements have been prepared under the historical cost convention, with receipts, payments, assets and liabilities presented in accordance with the charity's accounting policies.

Funds: FSUK maintains both restricted and unrestricted funds. Restricted funds are held for specific purposes in accordance with the conditions of the relevant grants or donations, whilst unrestricted funds are available to support the charity's general charitable activities and operating costs.

Income and Expenditure: Both income and expenditure are reported in accordance with the accounting policies applied in preparing the financial statements, including relevant year-end adjustments.

Reserves: The charity seeks to maintain sufficient unrestricted reserves to support its ongoing operations, meet financial commitments and provide a reasonable buffer against unexpected expenditure or interruptions in funding. Cash management and available reserves are monitored regularly, and FSUK seeks to avoid entering into long-term financial commitments where the necessary funding is materially uncertain. As at 31 December 2025, unrestricted net assets stood at £32,499, compared to £30,113 in 2024. Restricted net assets of £110,034 were held for specific charitable purposes and commitments.

Accounting period: The charity's financial year runs from 1 January to 31 December.

Trustee Remuneration and Expenses: The Trustees received no remuneration or reimbursement of personal expenses from the charity during the financial year.

Special Thanks

FSUK would like to extend its sincere thanks to Katie Parry, formerly of the Financial Conduct Authority (FCA), for her continued voluntary support in managing the charity's accounting, financial reporting and financial governance. Her expertise, dedication and generous contribution of time have been invaluable in maintaining the charity's financial systems and supporting effective financial management and compliance. We are extremely grateful for her ongoing commitment and contribution to FSUK.

REVIEW OF ACTIVITIES AND ACHIEVEMENTS

2025 was a year of continued growth and progress for Fowler's Syndrome UK. . Building on the foundations established through the National Lottery Reaching Communities grant awarded in 2024, we strengthened our patient support services, expanded our community networks, increased awareness of Fowler's Syndrome and advanced important research collaborations. Throughout the year, we continued to ensure that the voices and experiences of women living with Fowler's Syndrome and Chronic Idiopathic Urinary Retention (CIUR) remained central to our work.
Our activities continued to focus on three key objectives: 1) providing support and resources; 2) promoting national awareness and education; and 3) encouraging and facilitating research and innovation in treatment and care.

The following sections highlight our key achievements across these areas during 2025, alongside an overview of our fundraising activities and the progress made towards improving care and outcomes for women affected by these conditions.

Provide Support and Resources

Helpline

FSUK's Patient Helpline remains a core part of the charity's support in 2025, providing a safe, confidential space for people living with, or seeking answers about, Fowler's Syndrome, Chronic Idiopathic Urinary Retention (CIUR) and unexplained urinary retention. Family members and carers can also access support to better understand the condition and its impact.

Our Helpline advisor offers informed, compassionate support with the emotional and practical challenges of living with urinary retention, alongside information about symptoms, treatment options and navigating healthcare services. As a non-clinical service, the Helpline complements professional medical care, with signposting to appropriate services where callers need clinical advice and medical or mental health support.

Helpline Development and Impact in 2025

In 2025, FSUK continued to respond directly to the needs identified through the Helpline Needs Survey, further developing the Patient Helpline as a core part of our support. The service provided condition-specific information, emotional support and practical signposting by telephone, email, text and WhatsApp, giving women access to knowledgeable support from people who understand the realities of living with Fowler's Syndrome. The service

continued to evolve around how patients told us they wanted to access support, particularly through text-based channels, helping ensure support remained accessible to women regardless of location or their ability to travel.

Throughout 2025, demand for the Patient Helpline remained strong, with FSUK supporting hundreds of women, exceeding our annual target. Feedback also demonstrated the impact of the service: as of December 2025, 100% of respondents felt extremely supported, 94.4% felt calmer following their call, 88.9% felt more hopeful about the future and 100% felt less lonely or isolated. These results demonstrate both the continued demand for the Helpline and the important role it plays in providing specialist, condition-specific support that women with Fowler's Syndrome may struggle to access elsewhere.

FSUK continued to monitor satisfaction and outcomes through post-call surveys, qualitative feedback and engagement tracking. As part of our Reaching Communities funding, we remain focused on expanding the reach and impact of the service, including support around specialist areas such as catheter care, mental health and pregnancy-related concerns.

"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

Patient Council

In 2025 the Council became an increasingly important way for FSUK to involve patients directly in its research, clinical and community work, ensuring that lived experience and the questions that matter most to women with Fowler's Syndrome were represented as new projects developed.

Throughout the year, members were given opportunities to contribute to a number of specific projects. This included chronic and recurrent UTI research, where the community was invited to contribute to the Chronic and Recurrent UTI Priority Setting Partnership, helping identify and prioritise important unanswered research questions. The Council was also involved in FSUK's developing work around Fowler's Syndrome and pregnancy. Following the first clinician meeting specifically focused on Fowler's Syndrome and pregnancy, members were asked to share the real questions they wanted clinicians and researchers to address across pre-conception, pregnancy, birth and postpartum care. These

included questions around sacral neuromodulation, medications, catheterisation, UTIs, pain and birth options.

Patient insight was brought directly into discussions around Fowler's Syndrome and co-morbidities, providing a valuable body of lived-experience insight to sit alongside clinical discussion. The Council was kept closely involved in preparations for FSUK's first Fowler's Syndrome Community Conference, with the programme designed to bring lived experience together with clinical expertise across areas including FND, pain, pregnancy, UTIs and sacral neuromodulation.

Alongside the Patient Council, FSUK expanded opportunities for peer connection towards the end of 2025 by introducing dedicated community groups, including a general community group, an under-21s group, an over-40s group, a Global Majority group, and a pregnancy and postpartum group. These created more tailored spaces for people at different ages, life stages and backgrounds to connect, share experiences and support one another.

Together, these developments strengthened the Patient Council's role beyond consultation alone, creating a direct route for patient priorities, questions and lived experience to inform FSUK's research, clinical discussions, education and future service development.

"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 GP's about FS"

Leah Philips, Fowler's Fox and FSUK volunteer, 2025

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.

The Patient Council plays a central role in ensuring that the voices and lived experiences of women with Fowler's Syndrome and Chronic Idiopathic Urinary Retention (CIUR) shape FSUK's research, services and wider activities.

The Council provides a collaborative platform where members work alongside clinicians, researchers and healthcare professionals to identify unmet needs, influence research priorities and contribute to improvements in clinical care.

Members are actively involved in:

- Research and clinical collaboration: Contributing to research design, identifying priorities and providing feedback on studies, surveys and patient-facing materials.
- Clinical guidance and care pathways: Sharing lived experiences to inform the development of clinical recommendations, treatment pathways and educational resources.
- Patient engagement: Participating in focus groups, discussions and consultations
- Awareness and advocacy: Supporting campaigns, sharing personal experiences and contributing to media opportunities to improve public and professional understanding of Fowler's Syndrome.
- Service development: Helping FSUK identify gaps in support and develop resources and services that respond to the needs of the patient community.

Throughout 2025, Patient Council members contributed to a growing range of initiatives, including research into pregnancy and postpartum care, chronic and recurrent urinary tract

infections, comorbidities and treatment experiences. Their involvement also helped shape the research questions underpinning FSUK's clinical consensus work, ensuring that patient priorities were reflected alongside clinical expertise.

By embedding lived experience throughout its activities, the Patient Council ensures that women are not simply participants in research and service development, but active partners in shaping the future of Fowler's Syndrome care.

Safeguarding

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

In 2025, FSUK strengthened its Helpline team with the appointment of Ellie as a Helpline Advisor. Ellie previously worked as a Helpline Advisor at Antibiotic Research UK, bringing significant experience in patient support and a strong breadth of knowledge around chronic urinary tract infections (UTIs), an important area for many people living with Fowler's Syndrome.

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 the correct reporting procedures.

A Safeguarding Incident Recording Form is also in place to maintain accurate, confidential documentation of any disclosures or welfare concerns. This system helps ensure that concerns are recorded and managed consistently.

FSUK continues to place the emotional and physical wellbeing of its community at the heart of its work, ensuring that appropriate safeguarding processes remain in place as the charity, its services and its community continue to grow.

Webinars

In 2025, 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. We provide accessible and expert-led information to improve understanding of Fowler's Syndrome and support those affected by the condition. As part of Fowler's February, we hosted Fowler's Syndrome and Pain with Dr Ingrid Hoeritzauer, giving patients the opportunity to hear directly from a clinician with expertise in the condition and learn more about pain and approaches to managing symptoms. Alongside this, we hosted two dedicated community

sessions: a Music-Themed Social Zoom and a TV & Film-Themed Social Zoom. These sessions provided an informal and welcoming space for women living with Fowler's Syndrome to connect with others who understand their experiences, helping to reduce the isolation that can come with living with a rare and poorly understood condition. Through our educational resources, expert-led sessions and community engagement, we continued to improve access to reliable information, raise understanding of Fowler's Syndrome and strengthen the support available to our patient community.

GP Factsheet

Throughout 2025, FSUK continued to develop and promote accessible, condition-specific information for both patients and healthcare professionals. The patient information leaflet was downloaded 624 times, significantly exceeding its target of 260 downloads, while the healthcare professional leaflet was downloaded 276 times, also exceeding its target of 260.

FSUK also continued to provide its free Fowler's Syndrome and Anxiety workbook, designed to help women manage worry and uncertainty surrounding their symptoms and diagnosis. The resource addresses an important area of unmet need, with FSUK data showing that 75% of women with Fowler's Syndrome report anxiety around their condition, while only 30% have been offered mental health support. The workbook continued to be promoted to the community during 2025 as a freely accessible resource.

Together, these resources provided patients and healthcare professionals with clear, reliable and accessible information, while the strong download figures demonstrate continued demand for FSUK's condition-specific educational materials.

Social Media

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 social media community continued to grow throughout 2025. Facebook recorded 157 net new followers during the year, taking the community from approximately 1,200 followers at the end of 2024 to around 1,357 by the end of 2025. Instagram also continued to grow during the year, with 201.2k page vows (+100% yoy), a 338% increase in visits, and a 295% increase in link clicks.

FSUK Website

FSUK launched its website in 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. 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.

In 2025, the FSUK website continued to attract a strong and engaged audience, reaching 7,480 users over the year, including 7,463 new users. Organic search remained the largest source of website traffic, accounting for 4,927 users, followed by 2,199 users accessing the site directly.

FSUK Ambassador, Elle Adams

FSUK is proud that Elle Adams (@ellenextdoor) is 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.

Elle continued to support FSUK's awareness work throughout 2025. Towards the end of the year, she created a video for her platform promoting FSUK's upcoming Fowler's Syndrome conference, which was due to take place in February 2026. In the video, Elle helped explain the purpose of the conference and raise awareness of the event among her wider audience, continuing to use her platform and lived experience to increase understanding and visibility of Fowler's Syndrome.

Press

Since our 2024 report, FSUK has continued to increase awareness of Fowler's Syndrome through national and international media coverage and patient-led storytelling. Throughout 2025, Fowler's Syndrome featured across major publications including The Sun, The Mirror, The Independent and People. FSUK Ambassador Elle Adams was interviewed by Dr Zoe Williams for The Sun's Work It Out campaign, in association with TENA, discussing her experience of Fowler's Syndrome and self-catheterisation. Fowler's Fox Anna Gray shared her experience of living with the condition with the Mirror, with her story subsequently

receiving further national and international coverage. Fowler's Fox Evan Francis also received significant media attention, first speaking to The Independent about being refused access to a disabled toilet until she showed her catheter bag, and later featuring in The Sun, where she spoke openly about how Fowler's Syndrome has left her unable to pass urine naturally and the realities of living with a permanent catheter. Together, these stories have helped bring Fowler's Syndrome into wider conversations around women's health, urinary retention, catheterisation and invisible disability. Alongside this media activity, FSUK's website recorded approximately 7,500 active users during 2025, with website users increasing by 28% between October and November 2025 compared with the same period in 2024, demonstrating continued growth in engagement with FSUK's information and support.

Encourage, Commission and Facilitate Research

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.

During 2025, FSUK continued to strengthen its role in research, supporting and facilitating patient involvement and recruitment across a number of Fowler's Syndrome and Chronic Idiopathic Urinary Retention (CIUR) projects. A major focus was supporting recruitment for the University of Edinburgh's transcutaneous tibial nerve stimulation (TTNS) study, helping researchers reach people with lived experience of Fowler's Syndrome and enabling patients to participate in emerging research. FSUK also continued its work with Professor Jalesh Panicker and Dr Caroline Selai at UCLH, including involvement in work to develop consensus recommendations for nonsurgical interventions for chronic idiopathic urinary retention. Across these projects, FSUK has continued to connect researchers with the patient community and champion the inclusion of lived experience in research, helping ensure that future approaches to diagnosis, management and treatment reflect the priorities and realities of people living with Fowler's Syndrome.

Medical Board

The Medical Board is made up of 8 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.

Patient-Led Research and Clinical Collaboration

Throughout 2025, FSUK continued to strengthen its role in patient-led research, working alongside leading clinicians, researchers and academic institutions to improve understanding of Fowler's Syndrome and Chronic Idiopathic Urinary Retention (CIUR) and explore potential treatment options.

Building on the publication of the largest patient-led phenotyping study of Fowler's Syndrome in 2024, involving 265 patients, FSUK continued to use this evidence to inform research priorities and highlight gaps in diagnosis, treatment and care.

A key area of work was FSUK's collaboration with Dr Caroline Selai and Professor Jalesh Panicker at University College London Hospitals (UCLH), supporting the development of clinical consensus recommendations for non-surgical interventions in women with CIUR. This work aimed to address inconsistencies in clinical practice and strengthen the evidence base for treatment and management.

FSUK also supported the development of a Transcutaneous Tibial Nerve Stimulation (TTNS) pilot study in collaboration with the University of Edinburgh. Working with researchers including Aidan Trevelyan and Professor Kier Nazarpour, FSUK contributed to patient engagement and recruitment, helping ensure that lived experience informed the research. The study aims to investigate TTNS as a potential treatment option for women with Fowler's Syndrome and CIUR.

Throughout these collaborations, FSUK continued to champion meaningful patient involvement, ensuring that women living with these conditions had opportunities to contribute to research design, identify priorities and shape future approaches to treatment and care.

Fundraising

Our community play an important role in fundraising for FSUK. During 2025, supporters raised £1,494.99 through JustGiving fundraising pages alone. Katherine Carreira raised £415 through a church coffee morning, Sophie Bright raised £279.99 by taking part in the Thames Moonlight 10 Walk, Jodie Niblett raised £685 by running every day throughout October for

her mum, and Lydia Harris raised £115 through her 12 Dips of December for Fowler's UK challenge. These individual fundraising efforts not only generated vital funds for the charity but also helped raise awareness of Fowler's Syndrome within supporters' own communities.

Together, our grant funding, donations and community fundraising have helped FSUK continue to provide information, support and advocacy for people affected by Fowler's Syndrome while building greater financial sustainability for the charity's future work.

Grants

Throughout 2025, grant funding continued to play a vital role in supporting FSUK's services, organisational development and work to improve outcomes for women living with Fowler's Syndrome and Chronic Idiopathic Urinary Retention (CIUR).

In 2025, FSUK continued to strengthen and diversify its fundraising, securing vital grant funding alongside donations and fundraising from our patient and supporter community. We entered the second year of our three-year National Lottery Reaching Communities funding, which continued to underpin key areas of our work, including our national Helpline, staff capacity, patient support, research collaboration and the development of our longer-term clinical and educational work. This funding has been instrumental in strengthening FSUK's infrastructure, sustaining essential patient services and ensuring that lived experience remains central to the charity's activities. 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.

During 2025, the grant supported:

- Patient Helpline: Continued delivery and development of FSUK's dedicated Helpline, providing free, condition-specific emotional and practical support.
- Patient Council: Continued growth and development of the Council, which reached multiple members in 2025, providing opportunities for women with lived experience to contribute to research, healthcare improvements and FSUK's wider activities.
- Patient information and educational resources: Development and distribution of accessible information and resources to help women better understand their condition, navigate healthcare services and access appropriate support.
- Awareness and engagement: Activities to improve understanding of Fowler's Syndrome among patients, healthcare professionals and the wider public, including media engagement and awareness campaigns.

- Organisational capacity and governance: Support for staffing, infrastructure, safeguarding, evaluation and professional development, enabling FSUK to deliver services effectively and sustainably.

The funding continued to support FSUK's small team, led by CEO Danielle Coombe, providing the capacity to maintain and develop services while strengthening the charity's systems for monitoring outcomes and responding to the needs of its community.

The impact of this investment was reflected in continued demand for FSUK's services and positive feedback from beneficiaries. As of December 2025, post-call Helpline surveys showed that 100% of respondents felt extremely supported, 94.4% felt calmer, 88.9% felt more hopeful about the future and 100% felt less lonely or isolated.

FSUK remains extremely grateful to The National Lottery Community Fund for its continued support and commitment to addressing the unmet needs of women with Fowler's Syndrome. This funding has provided a vital foundation for the charity's development, enabling FSUK to expand its reach, strengthen patient involvement and work towards lasting improvements in care and support.

Additional Grant Funding Secured in 2025

A significant funding achievement in 2025 was securing a £65,000 educational grant from Medtronic to support FSUK's educational and awareness-raising activities, including preparations for the international Fowler's Syndrome conference scheduled for February 2026.

The first £50,000 instalment was invoiced in November 2025, providing important financial support for the development and delivery of this event.

This funding represented a further step towards diversifying FSUK's income and developing its capacity to bring together patients, clinicians and researchers to improve understanding and management of Fowler's Syndrome and CIUR.

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.

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)	Emeritus professor of Neurology	University College Hospital, London
Prof. Jalesh Panicker	Professor of Neurology	University College Hospital, London
Prof. Jon Stone	Consultant Neurologist	University of Edinburgh, Scotland
Dr. Ingrid Hoertizauer	Consultant Neurologist	University of Edinburgh, Scotland
Ms. Helen Simpson	Consultant Urologist	Victoria Hospital, Kirkcaldy, NHS Fife, Scotland
Dr. Caroline Selai	Chartered Psychologist	University College Hospital, London
Mr. David Ellis	Urologist	West Middlesex University Hospital, London
Dr. Caoimhe McLoughlin	Consultant Psychiatrist	University of Edinburgh, Scotland

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 December 2025	**Charity no (if any)**	1196903
Set out on pages	7 & 8		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/2025.

Responsibilities and basis of report

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").

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.

Independent examiner's statement

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:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- 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.

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.

Signed:		**Date:**	12/10/2026
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	-
Caroline Petersen	Trustee	3 December 2021	-
Rory James Layton Knighton	Trustee	3 December 2021	-
Hannah Marie Edwards	Trustee	3 December 2021	-
Matthew James Coombe	Trustee	3 December 2021	-
Margarida Fonseca	Trustee	21 October 2026	-
Konstantinos Charitopoulous	Trustee	3 December 2021	-
Jesper Jensen	Trustee	23 May 2023	12 June 2025

Contact details:

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