

# **Fowler's Syndrome UK ("FSUK")**

## **Annual Trustee Report**

**UK Registered Charity**  
**Charity number: 1196903**

**27 OLD GLOUCESTER STREET**  
**LONDON**  
**WC1N 3AX**  
**UNITED KINGDOM**

**For the financial period:**  
**3 December 2021 to 31 December 2022**

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## **EXECUTIVE SUMMARY**

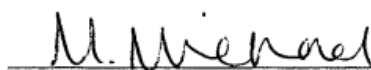
Since registering the charity, substantial work has gone into laying the foundation for success, both for Fowler's Syndrome UK ("FSUK") and for the growing community it supports. Achievements reached to date are 'firsts' in the advancement of Fowler's Syndrome awareness. Some key highlights include:

- Convening a Medical Board of expert clinicians and surgeons based in the UK who are renowned in their respective specialisms;
- Proposed lay and professional definition for diagnosing Fowler's Syndrome;
- Established a website and social media presence to unite the community;
- Conducted what is thought to be the largest survey of Fowler's Syndrome sufferers;
- Hosted a series of roundtables with patients;
- Preparatory works to create webinar content;
- Secured a sizable grant of GBP 30,000, enabling the charity to permanently hire its Founder in the capacity of CEO during the charity's second financial year.

The charity's income for the financial period was GBP 40,724 with total expenditure kept lean at GBP 897. Income primarily came from the grant of GBP 30,000 as well as from donations. The charity's results for its first financial year ending on 31 December 2022 are deemed satisfactory.

Going into 2023, the charity will continue its effort to secure future funding via grants and donations, with the aim of furthering initiatives which promote the charity's mission, vision and objectives. Securing sizable grants in the future may allow the charity to onboard temporary and eventually paid employees, which will in turn enhance the available resources for day-to-day operations and reduce the dependency on voluntary efforts.

The Board of Trustees of FSUK presents the first annual report for the time period of 3 December 2021 to 31 December 2022, and confirms that, to the best of our knowledge, it complies with the requirements of the Charities Act 2022.



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Marguerite Michael, Chair of Fowler's Syndrome UK

Signed: 27/10/2023.

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

Fowler's Syndrome UK ("FSUK") is a unique patient and clinician led charity that works to raise awareness, promote education and encourage research into the debilitating bladder condition: Fowler's Syndrome.

## **What is Fowler's Syndrome?**

Fowler's Syndrome (sometimes known as idiopathic chronic urinary retention) is a condition in which women have problems passing urine due to a difficulty in relaxing the urinary sphincter and coordinating urination. The condition causes full or partial urinary retention and solely affects women<sup>1</sup>. The peak of onset is 26 years of age. It was first described by Professor Clare Fowler in 1985.

Fowler's Syndrome was seen as a psychological condition until 1985, and is still desperately under-researched, under-funded and under-treated, with urinary retention in women being poorly understood compared to urinary retention in men.

We estimate that there are in excess of 20,000 women in the UK suffering from, but not necessarily diagnosed with, the condition. Due to a lack of awareness and guidelines amongst health professionals, it takes on average 3.8 years for a patient to be correctly diagnosed and receive the treatment they need.

## **About FSUK**

FSUK, a registered charity since 3 December 2021, offers multi-faceted, inclusive, unparalleled access to healthcare resources for all women with Fowler's Syndrome, or chronic idiopathic urinary retention.

To the best of our knowledge, FSUK is the only charity supporting Fowler's Syndrome globally, and as a result, women with the condition have been left without support, information or resources. Current resources for women with Fowler's Syndrome are scarce, with the majority of specialists based in limited centres, where there is a significant waiting time for referral. FSUK has started to bridge the gap between what the NHS offers and what patients actually need. When we first set up FSUK, we surveyed 200 women on what they would like from a charity. The overwhelming response was more information, more resources and a community/helpline – we made these the heart of our mission, vision and values. Results showed:

- **85%** of women with Fowler's Syndrome said the condition has had a severe or **devastating impact** on their life.
- 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

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<sup>1</sup> Women and Assigned Females at Birth ("AFAB").

Syndrome. Once diagnosed, there are few resources available for patients and limited treatment options. Many women feel alone and unsupported.

- 76% of those with Fowler's Syndrome have been told their urinary symptoms are due to **anxiety** or '**all in their head**'.

These are the women FSUK are supporting; they may not have been diagnosed with Fowler's Syndrome yet and may have been deterred from receiving care due to stigma.

### **FSUK's mission, vision and objectives**

FSUK's **mission** is to *provide resources, promote education and facilitate research* into Fowler's Syndrome; such that women with the condition have stigma-free access to a timely diagnosis, suitable and effective treatment options, care and psychological support.

FSUK's **vision** is to *change the clinical landscape* for women with Fowler's Syndrome.

FSUK's **objectives** are:

- to provide **support and resources** to both patients and professionals regarding the symptoms, diagnosis, management and treatment of the condition
- to promote national level **awareness, education and training** that is scientifically driven and engaging on Fowler's Syndrome and related conditions
- to **encourage, commission and facilitate research** on Fowler's Syndrome and related conditions, causes and treatments.

A central pillar of our values is that resources need to be free, readily available, scientifically driven and engaging for diverse audiences. We offer multichannel access to information and offer support and education to patients, professionals and the general public. Our trustees agree that in order to execute all of the above accurately, we need to ensure we work with a variety of medical professionals to help identify research gaps and unmet needs of women living with Fowler's Syndrome, provide expert analysis on topics related to Fowler's Syndrome, conduct surveys and provide access to database search facilities, as well as creating deliverables addressing the needs of Fowler's sufferers in the areas of science, support, and education. Note we acknowledge the formal Fowler's Syndrome diagnosis but also support women with urinary retention, whatever the cause.

# FINANCIAL ACCOUNTS

At the end of the year (December 2022), the charity received a grant for GBP 30,000 from The Fore to assist in enabling the Founder to take a salary to continue the work that was previously done voluntarily. Salary payments are expected to be seen in the charity's payments for next year's financial accounts.

Aside from the grant, the charity has generated income through the sale of branded T-shirts, however, most of the remaining income comes in the form of donations, through individual fundraising efforts. As the charity matures over the coming financial periods, the aim is to increase income via securing grants and donations.

Operational costs were fairly lean due to the use of volunteers; however, reviews are being conducted to assess whether technical costs can be reduced in 2023. The charity's running costs are anticipated to increase over time as the organisation will look to convert voluntary roles into temporary employment. This is to allow for FSUK to achieve its ambitious objectives. Such employment, however, will be subject to securing funding while maintaining sufficient financial headroom. It is imperative that the charity holds sufficient liquidity reserves before it onboards sizable permanent recurring expense commitments such as for employment.

Kindly find below the financial accounts statement for the financial year.

<b>Fowler's Syndrome UK</b> Registered Charity Number 1196903 <b>Receipts and Payments Accounts</b> For the Period 03/12/2021 to 31/12/2022				
	Unrestricted Funds to the nearest £	Restricted Funds to the nearest £	Total Funds to the nearest £	Total Funds Last Year to the nearest £
<b><u>Receipts</u></b>				
Donations	10,227	-	10,227	-
Grants	30,000	-	30,000	-
Income from Activities	497	-	497	-
<b>Total Receipts</b>	<b>40,724</b>	<b>-</b>	<b>40,724</b>	<b>-</b>
<b><u>Payments</u></b>				
Income-Generating Activities	433	-	433	-
Operational Costs	464	-	464	-
<b>Total Payments</b>	<b>897</b>	<b>-</b>	<b>897</b>	<b>-</b>
<b>Net of Receipts/ (Payments)</b>	<b>39,827</b>	<b>-</b>	<b>39,827</b>	<b>-</b>
Transfers between Funds	-	-	-	-
Cash Funds Last Year End	-	-	-	-
<b>Cash Funds at This Year End</b>	<b>39,827</b>	<b>-</b>	<b>39,827</b>	<b>-</b>

The charity held cash equivalents of GBP 39,941 as at year-end with a loan amount outstanding of GBP 114. The loan relates to reimbursable items from software packages needed to run day-to-day operations of the charity. In addition to this, the charity may be charged for historical website domain and hosting costs. Such charges are not expected to have a material impact on the charity's financial situation. Also refer to the balance statement below.

**Fowler's Syndrome UK**  
Registered Charity Number 1196903  
**Statement of Assets and Liabilities**  
at 31/12/2022

	<b>Unrestricted Funds to the nearest £</b>	<b>Restricted Funds to the nearest £</b>	<b>Total Funds to the nearest £</b>
<b><u>Cash Funds</u></b>			
Cash in Bank	39,941	-	39,941
<b>Total Cash Funds</b>	<b>39,941</b>	<b>-</b>	<b>39,941</b>
<b><u>Liabilities</u></b>			
Loan from CEO	114	-	114
<b>Total Liabilities</b>	<b>114</b>	<b>-</b>	<b>114</b>
<b><u>Net Assets</u></b>	<b>39,827</b>	<b>-</b>	<b>39,827</b>

## Accounting Policies

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

**Funds:** All funds are unrestricted.

**Income and Expenditure:** Both are shown when received or paid with the exception of loans which are recorded when they were incurred rather than 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. As time progresses, a detailed cash reserve policy is expected to be defined.

**Accounting Period:** The start date of the Charity's accounting period aligns with the point at which the Charity was incorporated. Additionally, with this being the Charity's first accounting period (therefore having the flexibility to define the dates thereof, so long as it is no shorter than 6 months and no longer than 18 months), along with the desire to align with the calendar year, the Charity has defined its accounting end date as 31 December, making the accounting period for this first accounting period c. 13 months. Subsequent accounting years will be 12 months following the calendar year (1 January to 31 December).

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

# **REVIEW OF ACTIVITIES AND ACHIEVEMENTS**

Several key achievements have been reached during the charity's first financial year. Many of these have laid the foundation for future successes to come.

## **Establishment of the Medical Board**

The convening of the Medical Board is an impactful achievement to date that informs, influences and enables FSUK to deliver on its Mission and Objectives. The Medical Board is made up of 11 healthcare professionals; Consultant neurologists and surgeon experts in the field of urology. We are very proud that Professor Clare Fowler CBE sits on this board in the capacity of patron of the charity.

## **Definition of Fowler's Syndrome**

A new consensus definition for Fowler's Syndrome was drafted, following a series of impactful meetings held by FSUK with healthcare professionals and patient partners. This new definition is recognised as more inclusive and containing references to CUIR (Chronic Idiopathic Urinary Retention). It has been ratified by the Medical Board and incorporated into FSUK literature and will be disseminated to BAUS and other medical bodies in due course. The widening of this definition is a critical milestone in ensuring more women are diagnosed correctly and that they receive the treatment they need.

## **Provide Support and Resources**

### **Social Media**

FSUK has established a social media presence that is considered a cornerstone of the Fowler's Syndrome community. Instagram followers reached 928 while Facebook followers stood at 835 in December 2022. Whilst FSUK is currently a UK based charity, it is gaining followers and interest internationally.

### **FSUK website**

FSUK launched its website in 2021 and 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.

## **Promote awareness, education and training**

### **FSUK Ambassador**

FSUK has partnered with @ellenextdoor as the ambassador for the charity. Elle Adams has Fowler's Syndrome. She is a lifestyle curator on social media, with 120,000 followers on Instagram. Her reels have garnered huge interest in FSUK. Her most popular reel featuring FSUK reached +100,000 accounts and received +4,000 likes.



**Webinars**

FSUK are creating a world first series of webinars on Fowler's Syndrome. These webinars will be labelled according to the level of scientific material they contain and are aimed at both patients and clinicians. Many clinicians have limited to no understanding of Fowler's Syndrome, meaning foundational information is critical for all parties. The initial webinars start with *An Introduction to Fowler's Syndrome* and as they progress will disseminate the latest thinking on the condition. Our aim is to provide barrier-free access to the latest scientific information.

**Encourage, Commission and Facilitate Research****Patient Survey**

In December 2021, FSUK conducted what is thought to be the largest ever survey of women with Fowler's Syndrome. The findings of this survey will be written into a paper by Dr Ingrid Hoeritzauer and Dr Emily Cox and is expected to be published in late 2023. The survey is informing much of FSUK's strategy and objectives.

**Roundtable on Fowler's Syndrome**

In August 2022, FSUK held a roundtable event on 'Fowler's Syndrome and Stigma' with Dr Caoimhe McLoughlin and 12 women from the Fowler's community. The session explored the stigma experienced by patients with Fowler's Syndrome. The purpose was to gather information to help inform healthcare professionals and patients on where stigma exists and what we can do about it. Insights have informed several elements of the charity's work including the patient leaflet and the consensus roundtable.

**Fundraising**

In December 2022, FSUK was successful in securing a grant from The Fore, a charity committed to supporting small charities. The grant enabled FSUK to employ founding member and charity CEO, Danielle Coombe, during the following financial year (2023).

Fundraising events held by the community have increased year-on-year and are expected to account for a larger proportion of income over time. The charity will aim to raise additional capital via fundraising events going into the next financial year.

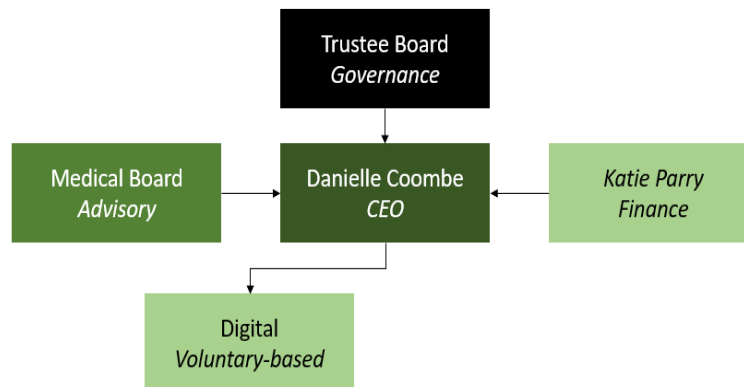
# CHARITY STRUCTURE, MANAGEMENT AND GOVERNANCE

FSUK currently has a team of Trustees whose skills include finance, fundraising, HR, marketing, volunteer management and digital. Trustee meetings are held at least bi-annually. In addition to a small management team and Trustee Board, FSUK has a Medical Board. Our Medical Board is led by consultant Urologist Mr. David Ellis and includes esteemed professors such as Professor Jalesh N. Panicker of UCLh. 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>
Mr. David Ellis	<i>Urologist</i>	<i>West Middlesex University Hospital</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. Elisabeth Adams	<i>Consultant Uro-gynaecologist</i>	<i>Nuffield, Bristol</i>
Dr. Caoimhe McLoughlin	<i>Consultant Neuro-psychiatrist</i>	<i>University of Edinburgh</i>
Ellen Thompson	<i>3rd year Medical student</i>	<i>St George's Hospital, Tooting.</i>
Ms. Helen Simpson	<i>Consultant Urological surgeon</i>	<i>Victoria Hospital, Fife</i>
Mr. Kostas Charitopoulos	<i>Consultant Urological surgeon</i>	<i>West Middlesex University Hospital</i>

The charity's CEO is responsible for the day-to-day activities<sup>2</sup>, and is supported by members of the Medical Board as well as by volunteers assisting with functions such as Finance, Digital, etc. The charity, including the role of CEO, are ultimately overseen and governed by the Board of Trustees. Kindly also refer to the organisational chart on the following page.

<sup>2</sup> Danielle Coombe, Founder, was permanently hired as the charity's CEO post year-end in 2023.



### 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 the diversity we see in the 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. Procedure: The board shall, at least annually, assess its composition in reference to:

- Necessary areas of expertise
- Balance between experience and newer members
- Desirable diversity in relevant areas
- Contributions from relevant stakeholders.

Should the board identify areas where there are perceived gaps in skills, knowledge, and 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 volunteer's webpage or use external advisors to assist in the process for board openings:

- All candidates will be evaluated using a standardised process
- All candidates will be required to complete an application form which will identify their skills, experience, suitability for the board, as well as any potential conflicts of interest
- Appointed members of the Board will review, shortlist, and interview appropriate candidates
- Identified candidates will be presented to the full board for consideration and recruitment decision 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	<small>Charity Name</small> Fowler's Syndrome UK		
On accounts for the year ended	31 <sup>st</sup> December 2022	Charity no (if any)	1196903
Set out on pages	6 & 7 <small>(Remember to include the page numbers of additional sheets.)</small>		
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 31/12/2022.</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: 25/10/2023
Name:	Georgina Deakin		
Relevant professional qualification(s) or body (if any):	ACCA – Membership number 2803472		
Address:	1 Derby Road, Eastwood, Nottinghamshire, NG16 3PA		

**Section B**

**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

## KEY INDIVIDUALS

### CHARITY TRUSTEES:

Name	Role	Date of appointment
Marguerite Michael	Chair	01 June 2023
Jesper Jensen	Trustee	23 May 2023
Konstantinos Charitopoulos	Trustee	03 December 2021
Rachel Emma Ingram	Trustee	03 December 2021
Caroline Petersen	Trustee	03 December 2021
Hannah Marie Edwards	Trustee	03 December 2021
Matthew Coombe	Trustee	03 December 2021
Rory James Layton Knighton	Trustee	03 December 2021

### FOUNDER & CEO:

Danielle Coombe (voluntary in 2022; permanently hired in the financial year 2023)

### FINANCE:

Katie Parry (voluntary)

### DIGITAL:

Laura Madden (voluntary)

### PATIENT COORDINATOR:

Rachel Ingram (voluntary)

### CONTACT DETAILS:

27 Old Gloucester Street, WC1N 3AX

London, United Kingdom

Email: [hello@fowlerssyndrome.co.uk](mailto:hello@fowlerssyndrome.co.uk)

Website: [www.fowlerssyndrome.co.uk](http://www.fowlerssyndrome.co.uk)