

A woman is celebrating at a marathon. She is wearing a white t-shirt with 'FOWLER'S SYNDROME UK' printed on it, blue arm sleeves, and a black hydration pack. Her race bib, which says 'TCS TATA CONSULTANCY SERVICES' and '57163', is pinned to her shirt. She is holding a water bottle in her right hand and has her left arm raised in a fist pump. Other runners are visible in the background.

**FOWLER'S
SYNDROME UK**

**FSUK CANDIDATE INFORMATION PACK
ADMINISTRATOR ROLE**

'FSUK offers a ray of hope to women with Fowler's Syndrome struggling to find help and information about this devastating condition'

Professor Jalesh N. Panicker

Professor in Uro-Neurology and Clinical Neurology, UCL
Clinical Lead, Department of Uro-Neurology
The National Hospital for Neurology and Neurosurgery/UCLH NHS
Foundation Trust, Queen Square, London





WELCOME LETTER FROM THE CEO

Fowler's Syndrome UK (Registered Charity number 1196903) 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. The condition solely affects women and Fowler's Syndrome UK (FSUK) is the only charity in the world to directly support women with this condition.

I was diagnosed with Fowler's Syndrome in 2016 and set up FSUK in December 2021. In the two years since I founded FSUK, we have conducted the world's largest survey on Fowler's syndrome (peer-reviewed publication mid 2024), provided advice and support to 500+ women with Fowler's Syndrome, participated in the creation of the first ever national guidelines on nonsurgical management of Fowler's syndrome, and brought together an incredible medical board including esteemed University College London Hospitals professors. We are now working to raise awareness, promote education and increase research into Fowler's Syndrome, with the aim of reducing nationwide diagnosis time, and increasing treatment and support options for those with the condition.

We are looking for two exceptional people to join our team. I am delighted that we will be able to employ new people to help us support women with Fowler's. I hope you'd like to play a part in this, and I look forward to hearing from you.

Dani

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ADMINISTRATOR ROLE

Charity: Fowler's Syndrome UK (1196903)

Role: Administrator

Location: Remote/Twickenham

Flexibility: Semi-flexible

Remuneration: £27,000 pro rata

Time commitment: 24 hours per week

Reporting to: CEO

Holiday: 28 days pro rata (including bank holidays)

Contract: Fixed term

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BENEFITS

Semi-flexible hours

Career progression

Wellness allocation (for gym, spa, massage or private healthcare)

Enhanced pension

Mental health support

Birthday off

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ADMINISTRATOR ROLE

The administrator's role is to support the CEO in the daily management of the charity. This will include administration, delivering resources, comms including social media and website, outreach, events, fundraising and research. It will also include supporting the CEO and Patient Liaison with seminars and conferences, and support groups. This is a role with great potential career progression

i. Administration: Support the CEO, the Patient Liaison and the Finance and Governance lead with daily activities, including but not limited to grant applications, basic finance administration, project management, project delivery, database management, office management. Improve efficiency and quality of the charity's management.

ii. Resources: Supporting the CEO to deliver first class resources. Working with the CEO and Patient Liaison to efficiently and effectively run the roll out of our resources, following the CEO's guidelines and the charity's mission and vision. This will include Healthcare professional (HCP) leaflets, Patient leaflets, a catheter support series, mental health support series, Pain management support from pharmacists and Physiotherapist led sessions. This will also include management of zoom and in person groups, dissemination of information on studies and surveys.

iii. Comms: Manage FSUK's social media, with direction from the CEO. Daily posts plus responding to queries and signposting. Social media partnerships. Monthly email to database. Basic updates to website. Manage the patient database inc GDPR. Assist with PR.

ADMINISTRATOR ROLE

Continued (1)

iv. Outreach and events: Drive awareness of FSUK in the local community and beyond Work with CEO to manage merchandising, registration, setup, logistics of events. Find, plan and represent FSUK at events. Manage yearly even calendar. Working with the CEO and administrator to plan, organise and run events, including transformative one-day seminar for healthcare professionals and a two-day seminar for FSUK users and clinicians.

v. Fundraising: Help the CEO and Patient liaison with fundraising, both on an individual and trust basis.

vi. Community led research: Assist the CEO in creating patient led community research.

vii. Research: Assist the CEO and work with the PL in creating and conducting research. Including Patient perspectives input into consensus guidelines for non-surgical management, Dr. Ingrid Hoeritzauer, Patient experiences with sacral neuromodulation, Dr. Caroline Selai, Awareness of FS among UK urology community, Prof Jalesh Panicker via University Cambridge, Physiotherapy treatment experiences with FS and CIUR, Dr. Ingrid Hoeritzauer. Our research will help enable women to receive the support they need and fulfil their potential, offering quicker diagnosis and better treatments and enabling our community to thrive.

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WHAT IS FOWLER'S?

Fowler's syndrome is a life changing and currently almost untreatable bladder condition, affecting up to 20,000 women in the UK.

It causes full or partial urinary retention and solely affects women*, meaning they have problems passing urine due to a difficulty in relaxing the urinary sphincter.

The peak age of onset is 26. It was first described by Professor Clare Fowler, Emeritus professor of Uro-Neurology at UCLh, and FSUK's patron, in 1985.

**and those afab*

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ABOUT FSUK

FSUK IS THE FIRST CHARITY IN THE WORLD TO EXCLUSIVELY SUPPORT THOSE WITH FOWLER'S SYNDROME. THE CHARITY PROVIDES RESOURCES, EDUCATION, SUPPORT AND RESEARCH TO THE FOWLER'S SYNDROME COMMUNITY.

CURRENT RESOURCES FOR WOMEN WITH FOWLER'S SYNDROME ARE SCARCE, WITH THE MAJORITY OF SPECIALISTS BASED IN LIMITED CENTRES, WHERE THERE IS A SIGNIFICANT WAIT FOR REFERRAL.

FSUK WILL CHANGE THIS LANDSCAPE, WORKING TOGETHER WITH PATIENTS AND THE TOP UROLOGISTS, NEUROLOGISTS AND GYNECOLOGISTS IN THE COUNTRY.

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WHY FSUK ARE NEEDED

FS 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. Current resources for diagnosing and treating women with Fowler's Syndrome are scarce, with the majority of specialists based in a single tertiary referral centre based in London at University College Hospital. Access to specialists is limited by location and waiting list times. Due to this, plus a lack of awareness and guidelines amongst health professionals, it takes on average 3.8 years for a woman to be correctly diagnosed. Current support and statutory provisions for women with Fowler's are almost non-existent.

We estimate that there are more than 20,000 women in the UK suffering from, but not necessarily diagnosed with, the condition, because of the lack of knowledge about Fowler's Syndrome both from a patient and clinician perspective.

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.

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

75% of those with FS have been told their urinary symptoms are due to anxiety or 'all in their head'

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FSUK'S OBJECTIVES

Provide RESOURCES

FSUK offers access to information, community and support regarding the symptoms, diagnosis, management and treatments of the condition, for both professionals and the public.

Promote EDUCATION

FSUK works to promote national level education, training and awareness on Fowler's Syndrome and related conditions. Create engaging, scientifically-driven content for diverse audiences on Fowler's Syndrome

Encourage RESEARCH

FSUK is dedicated to commissioning, encouraging and conducting research on Fowler's Syndrome and related conditions, causes and treatment.

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RECRUITMENT TIMETABLE

OPEN FOR APPLICATIONS: 15TH JUNE

CLOSING DATE FOR APPLICATIONS: 10^H JULY

SHORTLISTING: 10-12TH July

INTERVIEWS: 1ST JULY ONWARDS

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MORE INFORMATION

WWW.FOWLERSYNDROME.CO.UK

[@FOWLERSYNDROME](https://www.instagram.com/FOWLERSYNDROME)

**ANY QUESTIONS BEFORE YOU APPLY? EMAIL
DANI@FOWLERSYNDROME.CO.UK**



TO APPLY

Please apply by submitting your CV and a cover letter that sets out your motivation for applying and how you meet the person specification.

Email your application to

**Dani@fowlerssyndrome.co.uk or post to FSUK,
42 York Street, Twickenham, TW1 3BW**

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