

Charity:	Fowler's Syndrome UK (Registered Charity Number 1196903)
Role:	ADMINISTRATOR
Location:	Remote/Twickenham, semi-flexible.
Remuneration:	£27,000 pro rata (based on a 40 hour week)
Time commitment:	24 hours per week
Reporting to:	CEO
Holiday:	28 days pro rata (including bank holidays)
Contract:	Fixed term

Benefits:

- Semi-flexible hours
- Career progression
- Wellness allocation (for gym, spa, massage or private healthcare)
- Enhanced pension
- Mental health support
- Birthday off

Overview of FSUK

'To put everything into one sentence. FSUK has positively changed my life in a time of darkness and I will forever be indebted to the charity for this. Thank you.'

Sam, Fowler's Fox, 2022

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.

Fowler's syndrome is a life changing and currently almost untreatable 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.

We estimate that there are in excess of 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.

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'

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.

Our mission is to provide resources, promote education and facilitate research into Fowler's syndrome; so women with the condition have stigma free access to a timely diagnosis, suitable and effective treatment options, care and psychological support.

* *Women and AFAB*

The Role: Administrator

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 and events, fundraising and research. It will also include supporting the CEO and Patient Liaison with seminars and conferences, and support groups.

Administration: Support the CEO 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. Objective: Improve efficiency and quality of the charity's management

Resources: Supporting the CEO and working 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.

Comms: Manage the patient database including GDPR, manage newsletters, PR, website. 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

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.

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

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

Research: Assist the CEO and work with the Patient Liaison 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.

There may be occasions where staff are required to work out of hours or support at events, including wish related activities such as our annual wish family Christmas party or wish community events, cheering runners at the London marathon or working at our annual fundraising gala. The above is not an exhaustive list of duties and you will be expected to perform different tasks as necessitated by your changing role within the organisation and the overall business objectives of the organisation.

Personal Qualities for the role:

- Preferred: Lived experience of bladder conditions
- Demonstrate commitment to the charity, its strategic objectives and cause
- Exhibit strong relationship building abilities
- Strong networking capabilities
- Good team player
- MS Office, Zoom, social media, Wordpress, Mailerlite proficient
- Good written and communication skills
- Enhanced DBS check

To apply:

Use Quick Apply via charityjob.com or via our website www.fowlerssyndrome.co.uk