

Charity:	Fowler's Syndrome UK (Registered Charity Number 1196903)
Role:	PATIENT LIAISON
Location:	Remote/Twickenham, semi-flexible
Remuneration:	£27,000 pro rata (based on a 40 hour week)
Time commitment:	30 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: Patient Liaison

The PL's role is to support our community of women who have, or suspect they have, Fowler's Syndrome. This will include establishing and running a new patient helpline, patient council, , online support group, in person support groups and drop in weekly zoom sessions. It will also include supporting the CEO and Admin with seminars and conferences, and community led research.

Patient Helpline: Manage a helpline to offer support, information and signposting to those with FS. Develop a set of guidelines, in partnership with the CEO, trustees and medical board, that set out the parameters and scope of the engagement and advice we give callers. Recruit, train and manage a team of helpline volunteers. Yearly appraisal of the helpline. Create a signposting and FAQ handbook after month three. Drive awareness and publicity of the helpline. We intend for our patient liaison to run a telephone helpline for 5 hours a week. There will be four 30-minute bookable slots available per week, plus six drop-in slots. Set up peer to peer support network for helpline.

Patient Council: Efficiently and effectively lead the patient council, following the CEO's guidelines and the charity's mission and vision. This will include management of zoom and in person groups, disseminating information on studies and surveys to the patient council, and focus groups. Supporting and supervising the CEO and acting as a channel of communication between the charity and patient council.

Peer to peer support: Connecting women who are further along in their Fowler's journey to be able to support women at the earlier stages of the condition so they can benefit from their wisdom and experience, via the patient helpline, patient council and outreach. Support our network of volunteers.

In person support groups: Run six in-person support groups per year, spread throughout England. These will be an opportunity for people to meet others locally to them with the condition, form peer support networks, ask questions and receive literature and resources. Work with local likeminded groups, such as charities, local GPs and disability groups to be able to communicate with women who may not have otherwise heard of FSUK.

Online Support groups: 71.5% of respondents to our survey said they sometimes or frequently have their mobility impacted by Fowler's Syndrome. That's why it's important to us to have online as well as face-to-face sessions. The patient liaison will run online support mornings once per month on zoom, where people can meet and chat.

Drop-in individual Zoom sessions: Run one weekly drop-in zoom session per week, with varying times to give everyone a chance to attend. These sessions will provide space for informal chats about Fowler's and anything related that attendees would like to speak about if they have a last minute query or need support before or after an appointment.

Community led 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.

Resources: Supporting the CEO in working to deliver first class resources. Working with the CEO and administrator 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 management of zoom and in person groups, disseminating information on studies and surveys and email and social media support.

Outreach and events: Drive awareness of FSUK in the local community and beyond. Work 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: Work with the CEO and administrator to encourage and grow trust, corporate and individual giving

Safeguarding: Safeguarding lead. Ensure that all FSUK policies and procedures are adhered to, including safeguarding, health and safety equal opportunities Ensure full compliance with legislation and statutory guidance. Advise on safeguarding matters, monitor and share changes in legislation and guidance

Email and social media: Responsible for replying to email queries from women with the condition. Responsible for manning the FSUK social channel inboxes, including Instagram and Facebook (*Social media posts will be created by the administrator, following the CEO's guidelines*)

Administration: Support the CEO and the Finance and Governance lead with daily activities including project management, project delivery, database management, office management. Improve efficiency and quality of the charity's management.

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

- 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, or ability to learn in own time
- Good written and communication skills
- Enhanced DBS check

To apply:

Via our website www.fowlerssyndrome.co.uk, by 14th July 2024.