



The ● Pituitary Foundation

For hormones • For health • For life



CEO Recruitment Pack



Chair welcome

Welcome, and thank you for your interest in becoming the next CEO of The Pituitary Foundation. This is a special opportunity to lead a trusted, compassionate charity with a powerful purpose: helping people affected by pituitary conditions to live well.

We are looking for an ambitious, inclusive and values-led leader who can build on strong foundations, champion our community and work with trustees, staff and volunteers to shape the Foundation's next chapter.

I hope this pack gives you a clear sense of who we are, what matters to us, and the difference you could help us make.

Deborah Cooper
Chair of Trustees





The Pituitary Foundation
NHS Norfolk and Norwich University Hospitals
NHS Foundation Trust

Clinical outcomes following supply-driven transition from intranasal to oral desmopressin in AVP-Deficiency- A single centre experience

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- Background**
 - Arginine vasopressin deficiency (AVP-D) requires lifelong desmopressin replacement
 - In March 2025, the national suspension of intranasal desmopressin necessitated urgent transition to oral alternatives
 - However, optimal conversion ratios and clinical response remain undefined. We evaluated clinical outcomes following this supply-driven transition
- Aims and methods**
 - To conduct a retrospective review at a tertiary UK centre (01/01/2025 – 01/01/2025), which identified patients with confirmed AVP-D switched from intranasal to oral desmopressin
- Results**

Symptomatic requirement:
Overall, 55% (24/42) reported inadequate symptom control, 1 required hospitalisation due to dehydration

Conversion ratios

Initial conversion ratio of symptomatic recurrence group, before desmopressin transition

Final conversion ratio of non-symptomatic recurrent group
- The Pituitary Foundation national survey (224 patients)**
 - 79% of people were using desmopressin nasal spray to manage their AVP-D, prior to the current shortage.
 - Of these, 77% are now using tablets and 23% are now using melts
 - 32% have had difficulty obtaining alternative forms of desmopressin from their GP, pharmacist or endocrine teams
 - Over 45% reported negative impacts on their symptom management, daily routines and psychological wellbeing, as a result of switching medication
 - Almost 34% reported needing additional support from their endocrine team, suggesting an increased pressure on NHS services resulting from this switch
- Impact on services**
 - Within the NNUH, the transition led to:
 - 16 patient calls to endocrine nurses
 - 79 additional blood tests
 - 1 hospital admission
- Question**



Introduction



Thank you for your interest in the role of CEO at The Pituitary Foundation.

The Pituitary Foundation is the UK's leading charity providing support and information for people living with pituitary conditions, their families, friends and carers. For more than 30 years, we have advocated successfully for our community on the issues that matter most, and we are recognised globally for the quality of our services.

Pituitary conditions are uncommon, usually lifelong and can be life-threatening. They include acromegaly, Cushing's, prolactinoma, AVP-deficiency and hypopituitarism.

Our office is in central Bristol, with staff working either from the office or remotely. Our trustees and volunteers are located across the UK.

It is an exciting time to join our organisation. We have an engaged, experienced and committed board of trustees, volunteers and staff team. We are in a financially secure position, with solid operational and service foundations on which to build. As we move towards the end of our current strategy, we are eager to work with our new CEO on ambitious strategic priorities for the next five years.

Our Information and Support Services are central to our work. These include specialist Endocrine Nurse and general helplines, PIF Tick accredited health information, education webinars, in-person opportunities to connect through our support groups and 'get togethers', and our psychological support service offer. Our communications across our website and social media are first-rate, providing trusted information and building a strong community.

We have an incredible team of more than 100 volunteers who make our work possible and have been central to The Foundation since we started. Volunteers run our support groups, meeting in person and online across the UK, as well as our information helpline and telephone buddy service. They play a vital role in supporting people living with pituitary conditions.

We work alongside peer patient support groups, the NHS, pharmaceutical companies and advocacy groups to ensure that the voice of pituitary patients is at the heart of thinking and development. Campaigning on specific areas, and raising awareness is central to our ambitions.

This is all made possible by our tireless fundraising work. We receive around £500,000-£550,000 a year and are seeking to increase this in line with rising base costs and our ambitions to grow our work. We are grateful for the generosity of our community, with around 60% of our income coming from individual giving. Alongside our membership scheme and regular giving, we also host challenge events, support third-party fundraising and are looking to build on our Trusts and Foundations work, while maintaining our focus on legacies, commercial and earned income.



Our strategy 2023-2027

Our vision

Our vision is that all people with pituitary conditions can **live well, now and in the future.**

Our ambitious strategy, developed in 2023, has guided our work in a post-pandemic landscape and against a backdrop of unprecedented challenges facing the NHS, helping us continue to provide vital support for thousands of people each year.

Our mission The way in which we achieve our vision

We work with everyone with a pituitary condition, their support networks and healthcare professionals to raise pituitary awareness and reduce time to diagnosis. We empower patients to navigate the UK healthcare system and obtain the best clinical outcomes possible, and provide support to enable everyone with a pituitary condition to live as well as possible.

Our values How we act

Our values underpin the way in which we work and help us achieve our vision. These are that we are **welcoming, caring, empowering, trustworthy and collaborative.**

Our objectives

We have four objectives which breakdown how we will achieve our vision. These focus on;

1

Raising awareness (for example with GPs and emergency services, endocrinologists and with the general public)

3

Providing support to people affected by pituitary conditions (for example through our helplines, resources and events)

2

Empowering people affected by pituitary conditions (for example by advocating with NHS and seeking patient involvement in research and development)

4

Ensuring The Foundation is robust and sustainable (for example having the right resources, policies and frameworks)

You can read our strategy [here](#). You can read our most recently published annual report [here](#)

What we achieve

2024/25 Highlights



30

years of serving
our community
was celebrated



Over 800

visitors to our
psychological
support hub



16

Online
educational
events held



30,000+

followers
across social
media



100

volunteers



7

updated PIF TICK
accredited health
information items



2,100+

members



1,100

people
supported via
our helplines



22

support groups
that meet in-
person or online

Our Vision

As the only organisation in the UK supporting people affected by pituitary conditions, our impact is huge. We regularly hear from our community how valuable our support services are.

“They clearly know all the relevant information on the subject and they really filled me with confidence. I felt so much better for my chat with them and it's comforting to know that they are there when needed” (quote from a community member).

Our services provide spaces for people to engage with others affected by similar conditions. This helps them to feel less alone and understood.

Our health information is high quality and includes a portfolio of PIF Tick accredited literature. Providing accessible and trusted information is essential and remains a priority area for maintenance and development.

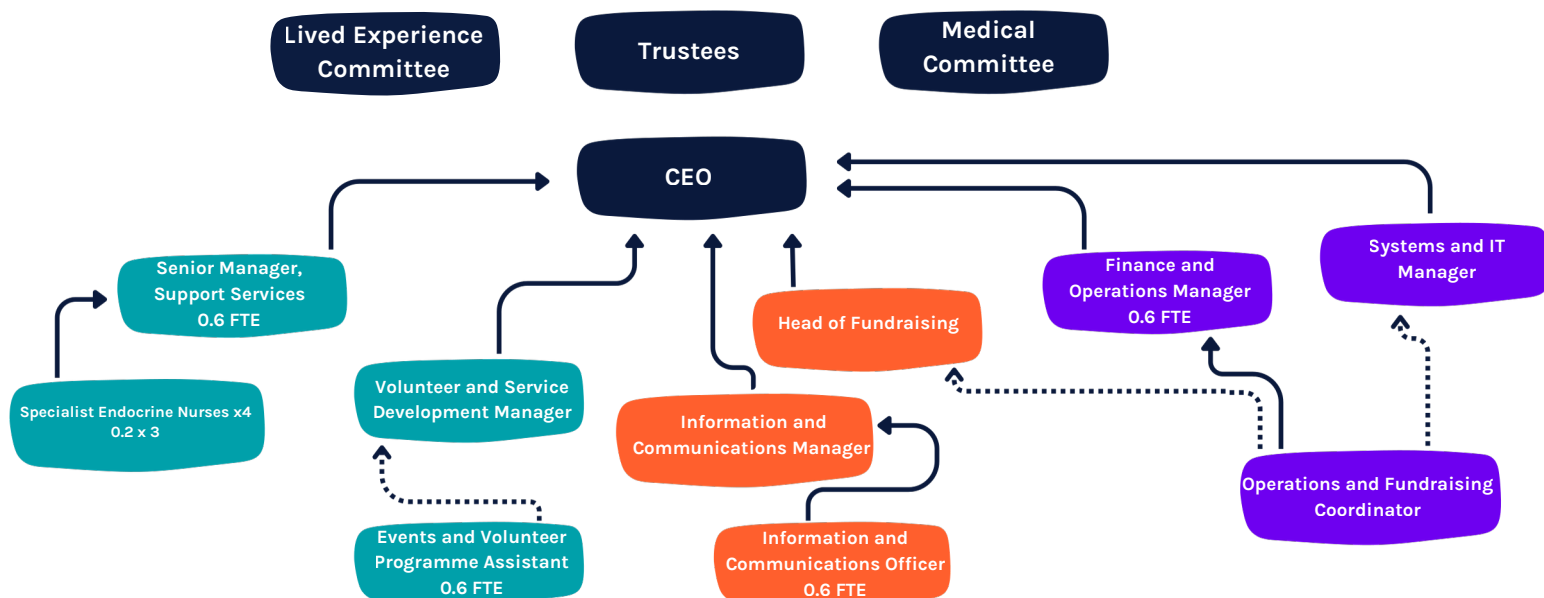
We recognise the importance of community. Pituitary conditions are rare, and people can feel isolated and afraid. We provide opportunities for people to connect with others who share similar experiences and who ‘get it’.

How we work

We have recently recruited new trustees, while some longer-standing trustees have retired. We are delighted to have breadth of experience, skills and enthusiasm across our board of 14 trustees. Together, they steer the work of The Foundation and meet quarterly either online or in person.

There is a Finance Committee, chaired by the Treasurer, which meets quarterly. Our Medical Committee and Lived Experience Committee provide expertise and insight to inform and shape our work outside governance requirements.

The staff are primarily based in the Bristol office, with some working remotely



The Role

This role combines ambition for The Foundation with the core importance of being a person-centred patient support group, offering kindness and support at challenging times. You will bring excellent interpersonal skills, financial acumen and an appetite for seeing the best possible service delivered to a wide demographic.

Leadership and strategy

- Provide leadership and strategic direction to The Pituitary Foundation.
- Lead by example, and act as a role model, upholding the core values and commitment of the organisation.
- Work closely with the Board of Trustees to formulate, set and deliver the vision, mission and strategic aims and direction, translating these into operational goals, plans and objectives.
- Lead, mentor and guide the senior team, and wider staff team, to develop plans and strategies for key areas of work across the organisation.
- Lead on organisation reviews and large-scale development projects.
- Lead on the effective management of the Medical and Lived Experience Committees.
- Lead on The Pituitary Foundation's commitment to develop equality, diversity and inclusion across the organisation.

Building and developing effective relationships

- Build effective networks and relationships with key stakeholders, including volunteers, health care professionals, commercial partners, policy makers, professional organisations and other charities, in the UK and internationally.
- Act as the key conduit between the staff team and Board and encourage a positive trusted relationship and a 'one team' ethos across the organisation.
- Promote the profile of the charity and its work through leading effective internal and external communications.
- Represent the charity and be the principal spokesperson for public relations, media and other opportunities, in conjunction with the Board, Medical and Lived Experience Committees.
- Take a lead role in fundraising by developing and maintaining relationships with key donors, including bid writing and reviewing grant applications.

Governance

- Provide information, support and advice to the Board to enable members to fulfil their governance responsibilities and make informed decisions.
- Guide the Board and staff team to ensure that the charity operates within all legal, governance and compliance requirements, including undertaking some company secretarial duties.

- In liaison with Board Officers, support the preparation and delivery of key meetings, such as Trustees' Meetings, General Meetings and sub-committee meetings.
- Take and disseminate minutes for all meetings.
- Act as the Company Secretary as needed.
- Support the recruitment and development of Board members, including away days.
- Support the effective management and delivery of Board tasks and finish groups and projects, as required.
- In conjunction with the Board, identify, monitor and actively manage organisation risks.
- Oversee the policies and procedures of the organisation and produce key policies, policy and position statements and governance documents e.g. terms of reference.
- Review key legal documents and contracts on a day-to-day basis, within the remit of the delegation of authority matrix.

Operational and financial management

- Lead the development, and delivery, of annual organisation operational planning with the staff team, ensuring strategic alignment.
- Lead on key technical areas, such as HR and finance, drawing on external specialist services as required.
- Oversee the recruitment of staff and line manage the senior staff. Lead on the team's learning and development.
- Lead on financial planning and budgeting in conjunction with the Treasurer.
- Provide financial oversight, monitoring and analysis, ensuring budget control and overall financial health of The Pituitary Foundation.
- Oversee the management of key contractors, such as bookkeeping and accountancy, IT and HR contracted services, working with the senior team.
- Authorise key budgeted expenditure within the agreed delegation of authority.
- Monitor, report and evaluate the operational performance of the organisation to the Board and the Finance Committee.
- Undertake all administration relating to the role.

Person specification

- A proven track record of successful senior leadership in a multi-faceted environment.
- A passion for delivering high quality services, tailored to meet the needs of our community.
- A demonstrable practical commitment to achieving an inclusive culture and EDI ambitions in all areas of work.
- Proven track record in managing, developing and leading a high performing, connected and happy team of staff and volunteers who are geographically dispersed.
- Proven experience of developing and delivering department and/or organisation strategies and plans.
- Demonstrable ability to lead change whilst bringing others with you.

- Resourceful, resilient, with complex problem-solving, decision making and analytical skills.
- Strategic thinker with the ability to be innovative and present practical solutions to challenges.
- Previous experience of significant financial responsibility and proven track record of securing funding and effective financial management.
- Commercially astute and ambitious for the organisation, with the proven ability to drive results in a dynamic environment.
- Substantial experience of inspiring and motivating multiple external stakeholders and acting as a compelling ambassador.
- Excellent written and oral communication skills including public speaking.
- Experience of working effectively with a Board of Trustees and comprehensive understanding of charity governance, legal and regulatory requirements.
- Experience of working for a health or social care charity or an (a good) understanding of the UK health and social care environment.
- An empathetic understanding, or demonstrable ability to learn about the experiences of people affected by pituitary conditions or rare diseases.
- A commitment to The Pituitary Foundation's vision and values.

Employment Terms

Location: Based in the Bristol office, with flexibility for hybrid working

Salary: Circa £60,000 (Based on experience)

Reports to: Chair and Board of Trustees

Holiday: 30 days plus statutory bank holidays

Pension: 5% employer contribution

How to Apply

Emma Cooper, the outgoing CEO, and Deborah Cooper, the Chair, welcome informal phone conversations in advance of submitting an application. Please email recruitment@pituitary.org.uk to arrange this.

Please send a CV and cover letter of no more than two sides of A4, or a film of an equivalent length, which includes:

- Why you are interested in this role,
- How your experience or interest meets each point of the person specification.
- Complete this [short, confidential, equalities survey](#) to inform future recruitment.

Applications should be emailed to recruitment@pituitary.org.uk

Deadline for applications: Friday 14th August, 12 noon

We expect to hold interviews online between Tuesday 25th August and Friday 28th August 2026 .

If successful in the online interview you will be invited to an in person interview, expected to be in Bristol on Wednesday 16th September 2026

Welcoming applications

The Pituitary Foundation believes in diversity and equality. We especially welcome applicants who are under-represented within the charity sector and want to build a team with a diverse range of perspectives, backgrounds and skills. You do not need to have lived experience, or direct knowledge of pituitary conditions – just empathy and an appetite to learn. We know that a diverse team is a strength, and we look forward to hearing from all interested applicants.

Your Data

In line with GDPR legislation we will retain data that you share with us as part of the application process for up to nine months from the deadline date. Please only share data that is relevant to your application. There is no need to share reference details at this stage, and their details should not be shared without their explicit consent.



Thank you for your interest in the CEO role



The
● Pituitary
Foundation

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