



## JOB DESCRIPTION

Job Title	Chief Executive - Research and Operations Lead
Hours	25 hours per week (0.67 FTE)
Salary	£20.14 per hour = £26,182 per annum (£39,273 FTE)
Benefits	16.7 days annual leave rounded to 17 days (25 days FTE) Pension with 3% employer contributions
Contract	Permanent
Location	Home-based with some travel
Line Manager	Chair of Trustees
Line Management	IT and website support contractor

### **Cavernoma**

1 in 625 people have a cavernoma; a cluster of abnormal blood vessels in the brain or spine that look like a raspberry. Whilst most people don't experience symptoms, those who do can have haemorrhages, seizures, headaches, neurological problems and a range of other life impacting symptoms.

### **Cavernoma Alliance UK**

Cavernoma Alliance UK (CAUK) is a member led organisation, run by and for those impacted by cavernoma. We work from a model of empowerment, recognising the value of our members' lived experience to provide mutual support, improve standards of care and drive research into finding a cure. We are there for people at every point in their lives, providing holistic person-centred support. All that we do is underpinned by our values of being: Empowering, Inclusive, Informative, Trustworthy, Confidential and Approachable.

### **'Caver-no-more 2030' Strategy**

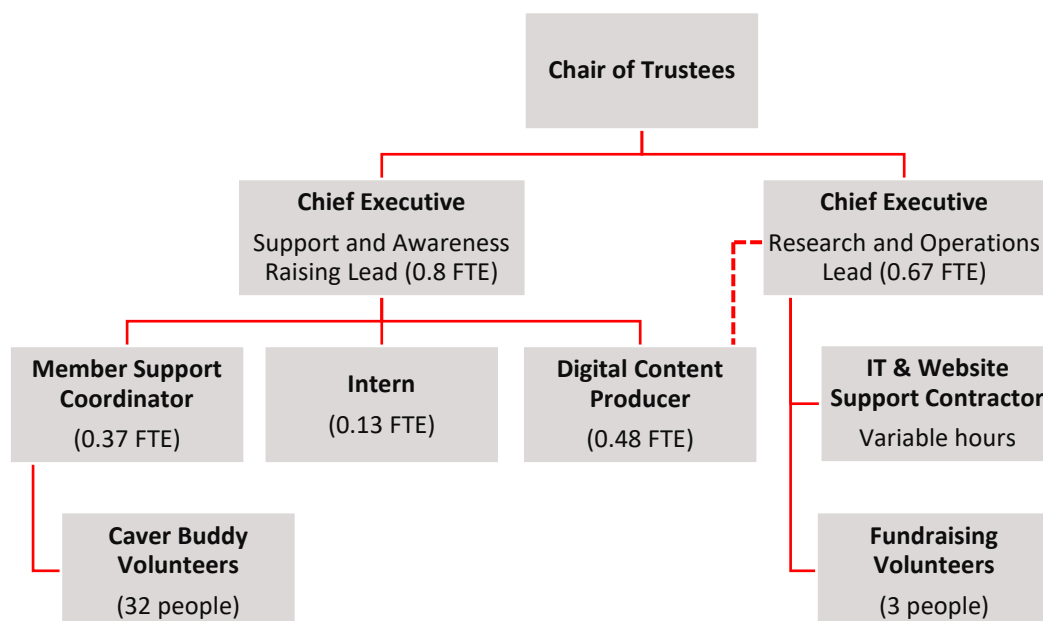
Since 2005 CAUK has grown from a volunteer led organisation based in Dorchester to a UK wide registered charity with 4 part-time staff, 40+ volunteers, 3100+ members and an income of around £100,000 per annum. In 2021 we launched a Strategic Development Plan for 2021 to 2024 titled 'Caver-no-more 2030' to support our vision "to help find a cure for cavernoma by 2030" and our mission to "to promote and protect the physical and mental health of all those affected by cavernoma including patients, their relatives and carers through the provision of support, education, research and practical advice." Our objectives are:

- **Care:** To grow direct engagement with our membership by ensuring access to up to date information and new and existing services. This will build on those developed through COVID-19, recognising the importance of the mental health and wellbeing of our membership.
- **Response:** Engage with opportunities where we can have direct impact on clinicians and their treatments of patients, raising awareness of cavernoma and CAUK as the go-to organisation for information and support. Ensure CAUK has a two-way relationship with, and an information presence in all listed neurological centres across the UK.
- **Cure:** To develop UK research in cavernoma via a minimum of one funded research project per year, help implement the CARE study by 2024 and thereby contribute significant findings to international efforts to finding a cure by 2030.
- **Values:** We believe how we do things is as important as what we do. Our members have chosen four values to under-pin our new strategic plan, which are: Trustworthy, Informative, Inclusive and Empowering.

To deliver these strategic objectives, we then have our under-pinning operations including Finance, Fundraising, Human Resources and Systems.

## Role

The role of the Chief Executive is to develop and deliver a strategy that helps to grow the charity and promote CAUK's vision and mission. The Chief Executive has overall responsibility for the day-to-day running of the charity, including management of the staff team and key volunteer roles. The Chief Executive reports to the Chair of Trustees and is accountable to the Board of Trustees who meet every two months. The role of the Chief Executive is currently under-taken as a job-share with the role split as follows:



- **Chief Executive (Support and Awareness Raising Lead):** Overall responsibility for delivering our 'Care' and 'Response' strategic objectives leading on support services, information resources, awareness raising, UK partnerships, human resources, safeguarding and overall charity management.
- **Chief Executive (Research and Operations Lead):** Overall responsibility for delivering our 'Cure' and 'Underpinning Operations' strategic objectives leading on research, medical advisory board, international partnerships, finance, fundraising, systems, policies/procedures, governance and data protection.

This job description is for the role of Chief Executive (Research and Operations Lead).

## Responsibilities

### *Key Responsibilities*

- Work with the Board and staff to shape the organisation's strategic and operational plans.
- Build diverse income streams, to ensure the charity's growth and long-term financial sustainability, whilst maintaining excellent relationships with existing funders.
- Oversee the efficient and effective management of the charity's finances, managing budgets and ensuring robust financial controls.
- Work with the Chair of the Board to ensure good governance and regulatory compliance
- Ensure organisations policies and practices are fit for purpose, meet regulatory standards and promote best practice at all times.
- In collaboration with CAUK's volunteer scientific advisor, lead on research activities and oversee the running of the charity's medical advisory board.
- Engage with key international stakeholders to build strategic partnerships that help to raise awareness and promote scientific research.
- Maintain the highest standards in relation to confidentiality, probity and the provisions of Data Protection or other legislation within the charity.
- Work collaboratively with the Chief Executive (Support and Awareness Raising Lead) to ensure the success of the Chief Executive job-share.
- Provide a flexible approach to meet business needs with occasional work outside standard hours.

### *Specific Duties*

- Taking responsibility for the agreed budgets and monitoring expenditure.
- Ensuring finances are undertaken to a high standard, liaising with our Accountants
- Ensuring IT support is undertaken to a high standard, liaising with our IT contractor
- Ensuring data on the database is accurate and in compliance with GDPR requirements
- Co-ordination of fundraising and grant-writing.
- Undertaking research, medical advisory board and international partnership activities.

- Producing papers and information for Trustee Board meetings on all aspects in respect of our 'Cure' and 'Underpinning Operations' objectives, including identifying progress on key performance indicators (KPIs).

### ***Standard Responsibilities***

Adopt and comply with CAUK values, policies and procedures, and regulatory frameworks including:

- Code of Conduct
- Health & Safety
- Data Protection and privacy
- Regulatory standards and probity
- Human Resources policies and procedures
- Equality and Inclusion
- Work with the Chair to monitor/review own performance

No role profile can cover every issue which may arise within the post at various times. The post holder is expected to carry out other duties from time to time, which are broadly consistent with those described.

## **Person Specification**

### ***Essential Experience and Skills***

1. Experience of leading an organisation, improving sustainability and compliance.
2. Experience of successful income generation and fundraising from a range of sources including bid writing and grant applications.
3. Experienced in financial management, systems and data management and governance.
4. Experienced in research and engaging with scientific and clinical professionals.
5. Track record of managing contractors (preferably including IT contractors).
6. Excellent organisational abilities with demonstrable ability to prioritise/balance work load
7. Hold a valid Disclosure and Barring Service (DBS) certificate (this can be organised if you do not hold a DBS certificate but you must be willing to undertake necessary checks)
8. Excellent communication skills, with an ability and willingness to flex communication style and means (e.g. using social media) to meet different target audience needs.
9. Commitment to values-based working and adhering to organisational policies and procedures, as required to keep workers and members safe.

### ***Desirable Criteria***

10. Lived experience of cavernoma, or a similar condition, either personal or through supporting others, and a drive to apply this experience for the betterment of others.
11. Previous experience of working with a charity
12. Ability to work within organisational framework whilst utilising own initiative.
13. Willingness to learn and develop.
14. Willingness to learn and pro-actively invest in personal development.
15. Team-player who is flexible in their approach and responsive to emergent needs.