



**Cavernoma
Alliance UK**

Recruitment Pack Chief Executive



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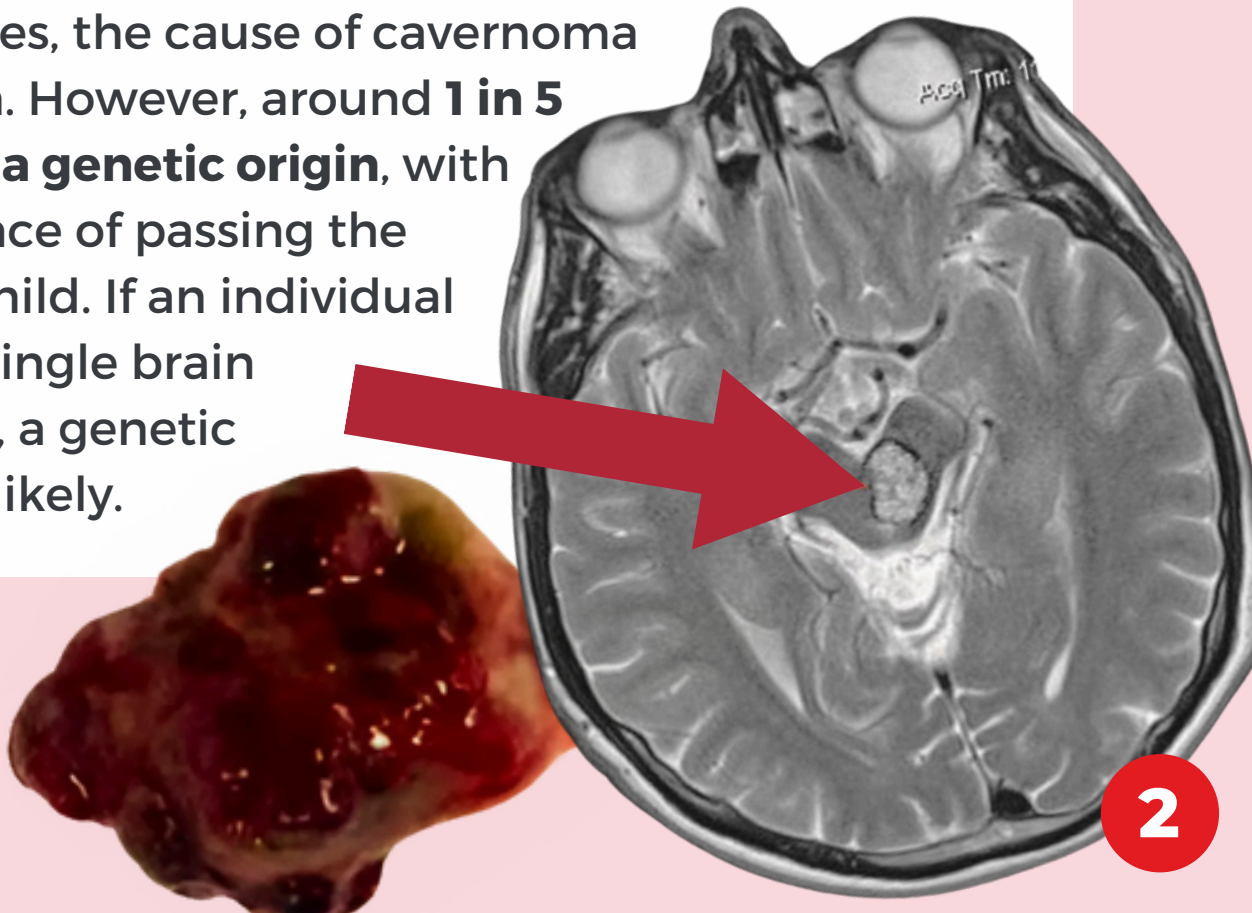
About Us

Cavernoma

Cavernomas are abnormal clusters of blood vessels with thin, leaky walls, resembling raspberries. They can develop in the brain and spinal cord and may bleed at any age without warning. Cavernomas affect around 1 in 625 people in the general population, equating to around 108,000 people in the UK.

Most people with a cavernoma remain asymptomatic. Symptomatic cavernoma is rare, affecting an estimated 1 in 2,700 people. **Symptoms can include haemorrhages, seizures, and other neurological issues.** Treatment options include monitoring ('wait and see'), neurosurgery, or stereotactic radiosurgery.

In most cases, the cause of cavernoma is unknown. However, around **1 in 5 cases have a genetic origin**, with a 50% chance of passing the gene to a child. If an individual has only a single brain cavernoma, a genetic cause is unlikely.



About Us

Cavernoma Alliance UK

Dr Ian Stuart founded Cavernoma Alliance UK (CAUK) after a life-changing cavernoma bleed. Struggling with a lack of information and support, he was determined that no one should face cavernoma alone. In 2005, his vision became a reality when he started CAUK.

What began as a volunteer-led helpline from Ian's home in Dorchester grew into a national charity. Today, **we support over 4,200 members** with a small, remote team of part-time staff and self-employed contractors. Volunteers remain at our core, with more than 60 running the **helpline, buddying, meet ups, online chats and medical alert cards.**

We provide clinician-approved information via our **website, social media, webinars, and annual conference,** overseen by our Advisory Board.

Committed to research, we proudly enabled novel gene therapy studies at University College London in 2024 by securing £100,000 in funding for UCL.



About Us

Our Strategy

In 2025, CAUK launched its **five-year strategy**, Together For A Cure: 2025–2030. The strategy is available on our website and the objectives below highlight the key priorities for the organisation over the coming years.

Support

Every person living with cavernoma in the UK will be aware of CAUK's peer-led support, and have their request for support met as we grow existing services.

Information & Clinical Care

People living with cavernoma and the professionals supporting them will have access to reliable, accurate and up to date information about cavernoma and will use this to improve care and support.

Research

Both children and adults with cavernoma will have access through the NHS to new and better treatment options, which have proven to be safe and effective.

Underpinning Operations

CAUK will be a resilient organisation that is responsive to a changing world.



Chair of Trustees Welcome

Thank you for your interest in the role of Chief Executive at Cavernoma Alliance UK.

My own connection to CAUK began following a cavernoma bleed, when I was trying to navigate the uncertainty of a diagnosis I knew very little about. Discovering a charity run by and for people affected by cavernoma made an enormous difference to me



and my family, providing trusted information and the reassurance of speaking to people who truly understood.

Today, I'm proud to serve as Chair of Trustees and help ensure others continue to receive that same support, while also driving forward the research and partnerships needed to improve treatment options and ultimately find a cure.

This is an important and exciting time for CAUK. As we continue delivering our **five-year strategy, Together For A Cure: 2025-2030**, we are looking for a new Chief Executive to help lead the charity through its next stage of development, including supporting new UK research activity planned for 2026.

You would be joining a charity with a **highly committed team of staff and volunteers, strong clinical and research partnerships, and a supportive Board of Trustees**. Above all, we remain a charity built by and for people affected by cavernoma, with community at the heart of everything we do.

Thank you for taking the time to learn more about this opportunity and the work of Cavernoma Alliance UK.

*Heather Dunbar
Chair of Trustees*

Chief Executive About the Role

The Chief Executive leads and co-ordinates the day-to-day work of CAUK, working closely with Trustees, staff, volunteers, clinicians, researchers and partners to deliver the charity's strategy.

This is a **varied and hands-on role** within a well-established small national charity. The Chief Executive will be an ambassador for the charity and ensure it remains **sustainable, well governed, closely connected to the needs and lived experiences of the community.**

Key priorities for the role over the coming years include:

- **supporting delivery of a new UK-wide clinical trial** investigating drug repurposing, planned to begin in August 2026, with CAUK acting as the named Patient and Public Involvement and Engagement (PPIE) Lead and co-applicant;
- **maintaining sustainable income** through community fundraising, regular giving, philanthropic support and grant funding;
- supporting the Head of Volunteering and Member Services to continue delivering **high quality peer-led support services**; and
- overseeing the development of **accurate, accessible and clinician-approved resources** shared through CAUK's website, social media, webinars and leaflets

As one of the charity's **Designated Safeguarding Leads**, the Chief Executive works closely with the Chair of Trustees and Support Manager to help ensure safeguarding practices remain appropriate and effective across the organisation.

The role is centred on **collaboration, relationship building and valuing lived experience**, ensuring the voices of people living with cavernoma continue to shape CAUK's work. Appropriate training will be provided to support the successful candidate.

Chief Executive Role Overview

Hours: 28 hours a week, including some evening and occasional weekend work.

Salary: £48,000–£51,000 full-time equivalent (pro rata). For 28 hours a week, this equates to £35,840–£38,079.

Benefits: 33 days annual leave including statutory holidays (pro rata), equivalent to 24.6 days for 28 hours a week, plus NEST Pension.

Contract: Permanent.

Location: Home-based within the UK, with travel required every 1–2 months, typically to London for meetings.

Organisation overview: CAUK has a budget of approximately £157,000 (2025–26), 4 staff, 3 consultants and around 50–60 volunteers.

Responsible to: Chair of Trustees

Line management responsibilities: Head of Volunteering and Member Services, and Events and Operations Assistant, alongside consultants including Social Media, Bookkeeping, Grant Writing and IT Support.

The role also works closely with volunteer groups including the Patient Advisory Group and Fundraisers, as well as the Medical Advisory Board.



Chief Executive Applying

How to apply

Please read the full job description before applying.

To apply, please go to <https://bit.ly/JobApplicationCAUK> to complete our online application form. Once complete please also then send your CV to admin@cavernoma.org.uk

Key dates

Applications open: 27 May 2026

Closing date: 9am, 22 June 2026

Stage 1 interviews will be held virtually during the last week of June.

Stage 2 interviews will be held in person shortly afterwards.



Informal conversation

If you would like an informal conversation about the role before applying, we would be happy to arrange this with the current Chief Executive or Chair of Trustees. Please email admin@cavernoma.org.uk.

Chief Executive Responsibilities

Strategic Leadership

- Work with Trustees, staff, volunteers and advisors to support delivery of CAUK's 2025-2030 strategy.
- Help ensure the charity remains responsive to the changing needs and lived experiences of people affected by cavernoma.
- Ensure the voices of people living with cavernoma remain central to the charity's work, decision making and future development.
- Help CAUK continue to grow thoughtfully and sustainably while remaining closely connected to the needs of the community.

Fundraising and Financial Sustainability

- Lead on fundraising and income generation activity across the charity, recognising this as a key organisational priority.
- Support and grow CAUK's strong community fundraising programme, including flagship fundraising events such as the annual Snowdon Climb for Cavernoma.
- Develop and maintain strong relationships with regular givers, legacy givers, philanthropists, trusts and foundations.
- Lead the preparation of grant applications, funding proposals and reporting requirements linked to grant funded activity.
- Work with Trustees to support the charity's long-term financial sustainability through careful planning and resource management
- Oversee budgets, financial reporting and financial controls alongside the Treasurer and bookkeeping support.

Chief Executive Responsibilities

Research and Clinical Partnerships

- Support delivery of a new UK-wide clinical trial investigating drug re-purposing, planned to begin in August 2026, with CAUK acting as the named Patient and Public Involvement and Engagement (PPIE) Lead and co-applicant;
- Support the continued development of the CAUK co-funded cavernoma gene therapy project at University College London;
- Develop positive relationships with UK and international clinicians, researchers and advocacy organisations to promote collaboration and future treatment development.
- Help ensure the patient voice remains central within research.

People Management

- Provide supportive line management to staff and consultants, including oversight of recruitment, induction, well-being and day-to-day HR matters.
- Help maintain a positive, inclusive and safe working environment where staff, consultants and volunteers feel valued and supported.
- Ensure appropriate oversight, safeguarding and quality assurance arrangements are in place across support services delivered by staff and volunteers.
- Act as a Designated Safeguarding Lead for the charity, ensuring safeguarding concerns are appropriately managed and safeguarding policies and training remain up to date.

Chief Executive Responsibilities

Support Awareness and Information

- Support awareness raising campaigns and partnership activity to improve understanding of cavernoma and awareness, engaging with the European Cavernoma Alliance on our two annual campaigns (Rare Disease Day and Cavernoma Awareness Month)
- Oversee delivery of CAUK's programme of webinars, awareness events and annual conference, working with staff, volunteers, clinicians and people with lived experience.
- Oversee the development of accurate, accessible and up to date information resources informed by clinicians, researchers and people with lived experience.
- Support opportunities for people with lived experience to contribute to awareness raising, peer support, volunteering and research activity.

Governance, Compliance and Operations

- Work closely with the Board to ensure good governance and regulatory compliance.
- Ensure policies, procedures and systems remain up to date and reflect best practice.
- Maintain the highest standards of confidentiality, data protection and safeguarding.
- Oversee operational systems including IT and record keeping.
- Prepare papers for Board meetings, and ensure the Annual Report and Accounts are prepared and submitted in a timely manner with support from our Accountants.

Chief Executive Responsibilities

External Representation and Partnerships

- Build relationships with NHS clinicians and partner charities to improve awareness, referral pathways and support for people living with cavernoma.
- Represent CAUK at conferences, meetings, webinars and external events.
- Maintain strong relationships with key cavernoma and rare disease organisations.
- Support CAUK's participation in national and international collaborations that help improve support, awareness, clinical care and research.

Please note: No role description can cover every task that may arise. From time to time, you may be asked to help with other duties that are in keeping with the nature of the role.



Chief Executive Skills and Experience



Essential

- Experience of leading or managing a charity, organisation or significant area of work.
- Previous experience within the charity sector, or a strong understanding of how charities operate, including governance, fundraising, safeguarding and working with Trustees.
- Experience of fundraising and income generation, particularly community fundraising and relationship-based fundraising.
- Experience of managing budgets and financial processes.
- Experience of supporting staff, volunteers or contractors.
- Understanding of safeguarding responsibilities and confidence managing sensitive concerns appropriately.
- Strong organisational and communication skills, with the ability to manage competing priorities and build positive relationships with a wide range of stakeholders.
- Good understanding of governance, confidentiality, and data protection responsibilities.
- Good IT and digital communication skills, including Google Suite, Canva, Mailchimp, Zoom, Xero, WordPress and Calendly.
- Willingness to work flexibly, including occasional evening or weekend work.
- Willingness to undertake an enhanced DBS check.

Chief Executive Skills and Experience

Desirable

- It would be helpful, though not essential, if you also have:
- Understanding of Patient and Public Involvement (PPI) or health research partnerships.
- Experience within the health, neurological or rare disease sector.
- Experience of working with peer support or lived experience led services, clinicians, researchers or advisory boards.
- Experience representing an organisation externally through public speaking, partnerships or media engagement.



Chief Executive Personal Qualities

- Warm, approachable and able to communicate sensitively with people from a wide range of backgrounds and experiences.
- Collaborative and relationship focused, with the ability to build credibility and trust with staff, volunteers, Trustees, clinicians, researchers and people living with cavernoma.
- Confident representing the charity externally and comfortable engaging with senior clinical, research and funding stakeholders.
- Organised, dependable and comfortable balancing strategic priorities with practical day to day delivery.
- Comfortable working within a small charity environment where flexibility, teamwork and mutual support are important.
- Committed to CAUK's values and motivated by improving the lives of people affected by cavernoma.

