



VOLUNTEER ROLE DESCRIPTION

Volunteer role	Trustee (with clinical or scientific experience)
Location	Home-based
Points of contact	Chair of Trustees, Heather Dunbar heather@cavernoma.org.uk , 07909 526545 Charity Manager, Helen Evans helen@cavernoma.org.uk , 07836 587242
Minimum hours	Trustee meeting (19:00-21:00, every other month, virtual) Annual away-day (11:00-17:00, once a year, in-person in London) Reading papers and emails (on average 2-3 hours a month)
Expenses	Reasonable expenses will be covered, including travel and accommodation to attend the annual away-day.

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 was founded by Dr Ian Stuart after his life changed overnight following a devastating cavernoma bleed. Lacking information and support networks, he resolved to make sure that no-one else faced cavernoma alone. 20 years after his first bleed Ian's dream became a reality and he formed Cavernoma Alliance UK in 2005.

What started as a volunteer-led helpline run from Ian's home in Dorchester quickly became a national charity with over 4,200 registered members and 4 part-time staff (equivalent to 2.1 people) working from home, supported by self-employed contractors.

Volunteers are still at the heart of our charity, with over 50 volunteers running our helpline, buddying, meet-ups and online chats. Alongside our support activities we provide information through our website, social media, monthly webinars and annual conference; all of which is approved by our Medical Advisory Board.

We also promote research. We led the only James Lind Alliance Priority Setting Partnership for cavernoma, we were partners in the first clinical trial of neurosurgery and stereotactic radiosurgery for cavernoma funded by the National Institute for Health and Care Research, and were proud to announce in 2024 the start of novel gene therapy research at University College London.

Trustee Role

Our trustees are legally responsible for the governance of the charity. This means they must make sure that CAUK achieves its objectives, which are set out in our governing document. The trustees ensure that we have a strategy, and that our assets and resources are only used for charitable purposes in line with the governing document. Trustees make sure that we operate in line with any relevant laws, particularly the Charities and Companies Acts. Trustees have a collective responsibility, they work together in the best interests of CAUK.

We are currently seeking trustees who bring transferable clinical or scientific skills and experience, alongside lived experience of cavernoma. This may be through personal experience, supporting someone in a personal capacity, or professional involvement. Trustees are not expected to provide clinical advice, as CAUK is supported in this area by our [Medical Advisory Board](#). Rather, we are looking for individuals who can use their expertise at a governance level to provide informed oversight, independent judgement and constructive challenge in relation to our work on Information and Clinical Care and Research. Further detail on our strategic priorities can be found in our [Strategy 2025-2030](#).

Main responsibilities

Governance

- To understand CAUK's aims and objectives as set out in our governing document and ensure that we operate in accordance with them.
- To help set the strategy for the organisation, including the financial strategy, and ensure implementation and progress is monitored.
- To use your skills, knowledge and experience to further our work, putting aside any personal interests, and declaring any conflict of interest if/ when they arise.
- To identify any risks to CAUK and ensure they are monitored.
- To contribute towards an annual review of the board's performance.
- To help to identify, recruit and induct new board members and the chair.
- To attend and contribute to meetings of the board as relevant, and undertake agreed tasks between meetings.
- To uphold any policies and procedures relevant to the trustee role including confidentiality, safeguarding and data protection.
- To uphold and contribute to our approach to equity, diversity, and inclusion.

Clinical and scientific expertise (governance contribution)

- To use your clinical or scientific expertise to support Board level oversight of CAUK's research activity, partnerships and Patient and Public Involvement and Engagement (PPIE), ensuring appropriate scrutiny and alignment with our strategic aims.
- To contribute to Board discussions relating to evidence, risk and developments in clinical care and research, helping trustees exercise informed and proportionate judgement.
- To support the Board in overseeing CAUK's patient information materials, ensuring they are developed with appropriate input from the Medical Advisory Board and reflect current evidence and best practice.

Working with staff/ volunteers

- To understand and maintain boundaries between the governance perspective of the board, and the work of any staff and volunteers.
- To provide support and challenge to the Charity Manager and other staff to ensure they are carrying out their roles and achieving the set objectives for CAUK.
- To help with the recruitment and/or induction of the Charity Manager/other staff as required.

Representing CAUK

- To represent the board's agreed position when speaking publicly on behalf of CAUK.
- To act as an ambassador and champion for CAUK at events and online.

Volunteer experience and skills

- Lived experience of cavernoma either as a person with cavernoma or a supporter of someone with cavernoma, and being at a point in your own journey when you feel emotionally ready to offer support to others.
- Willingness and ability to understand and accept their responsibilities and liabilities as trustees and to act in the best interests of the organisation.
- Ability to think strategically, exercise good, independent judgement and work effectively as a board member.
- Effective communication skills and willingness to participate actively in discussion.
- Team-player who is flexible in their approach and responsive to emergent needs.
- A strong personal commitment to equality, diversity and inclusion.
- Enthusiasm for our vision and mission.
- Commitment to Nolan's seven principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership.
- Understanding of personal boundaries and the importance of safeguarding and confidentiality in order to safeguard the interests of the people being supported
- Commitment to CAUK's values of being Empowering, Inclusive, Informative, Trustworthy, Confidential and Approachable, and at no time bringing the charity into disrepute.

Volunteering agreement

CAUK appreciate your commitment to us and will do the best we can to make your volunteer experience with us enjoyable and rewarding. To make sure you have the best possible experience, we have created this agreement alongside our Volunteering Policy, which sets out our commitment to you and what we hope you can contribute.

CAUK's commitment to you, we will:

- Be responsive to your requirements.
- Explain the standards we expect and encourage and support you to achieve and maintain them.
- Be flexible in relation to your volunteering hours, recognising your need for holiday time and other commitments.
- Honour the time commitment you have agreed to give us and will not expect more from you unless offered and agreed.
- Reimburse agreed out-of-pocket expenses following procedures set out in our

Expenses Policy.

- Ensure that all volunteers are treated fairly and in accordance with our Equality Opportunities Policy.
- Keep your personal information confidential and manage all personal data in accordance with the requirements of the General Data Protection Regulation and Data Protection Act 1998.
- Try to resolve fairly any issues or difficulties you may have whilst you volunteer with us before they become problems. In the event of an unresolved problem, to offer an opportunity to discuss the issue in accordance with the relevant policies.
- Follow up on any feedback or questions you may have regarding your involvement as a volunteer.

Your Commitment to us:

- Performing my volunteering role to the best of my ability and in accordance with CAUK's values.
- Working as agreed in my volunteer role description and with the prior agreement and approval of your point of contact within CAUK.
- Following the organisation's policies and procedures including Volunteer Policy, Code and Conduct, Expenses Policy, Health & Safety, GDPR, Equal Opportunities and Safeguarding.
- Advise CAUK of any activities undertaken by me that may conflict with CAUK's interests.
- Familiarising myself and asking if I'm not sure about what to do stay safe whilst volunteering.
- Maintaining the confidential information of the organisation.
- Meeting time and other commitments as agreed but when unable to do so to give reasonable notice so that other arrangements can be made.
- Returning any loaned equipment when ending my volunteering.
- Using your own computer and phone for any volunteering work that you carry out taking the necessary steps (e.g. secure passwords) to protect your computer.
- To provide referees, as agreed, who may be contacted, and to agree to a DBS check being carried out.

This agreement is binding in honour only, is not intended to be a legally binding contract between us and may be cancelled at any time at the discretion of either party. Neither of us intends any employment relationship to be created either now or at any time in the future.

Agreed to:

Volunteer signature

On behalf of Cavernoma Alliance UK

Date: