



Trustees' Annual Report for the period

Period start date			Period end date		
From	01	10	To	30	09
	2024			2025	

Section A

Reference and administration details

Charity name Cavernoma Alliance UK

Other names charity is known by CAUK

Registered charity number (if any) England and Wales
1197257

Charity's principal address Po Box 366

Watlington

Oxfordshire

Postcode OX10 1GF

Trustees who manage the charity

Cavernoma Alliance UK (CAUK) is a charity run by and for the cavernoma community, and every member of our Board of Trustees has lived experience of cavernoma. Trustees are elected by our members at the Annual General Meeting. Each year, around one third of trustees step down to allow regular renewal, and members vote to reappoint trustees or fill any vacancies.

Trustee name	Office (if any)	Dates served (if part year)
Heather Dunbar (Cavernoma) Chair@cavernoma.org.uk	Chair	
Elizabeth Blackshaw (Supporter) Treasurer@cavernoma.org.uk	Treasurer (Current)	Appointed 21 st June 25
Mark Farrar (Parent)	Treasurer (Former)	Re-Appointed 21 st June 25 Resigned 31 st December 25
Roxanna Dixon (Cavernoma)	Lead for Human Resources	Re-Appointed 21 st June 25
Barbara Edmonds (Relative)	Lead for Support	
Jade Davies (Cavernoma)	Lead for Communications	
Emily Fletcher (Cavernoma)	Lead for Fundraising	
Alex Ford (Parent)	Lead for Research	
Ailsa Chanrai (Relative)	Lead for Inclusion	Appointed 21 st June 25

Advisors who provide expert scientific and clinical guidance

Our work is guided by a Board of Scientific and Clinical Advisors, made up of the UK's leading cavernoma experts alongside international specialists. They ensure our information is accurate and up to date, advise on advances in treatment and research, and help drive improvements in care for people affected by cavernoma across the UK.

Advisor name	Role (if any)	Dates served (if part year)
Professor Rustam Al-Shahi Salman	Chair and Neurological Lead	
Professor Diederik Bulters	Neurosurgical Lead	
Mr Neil Kitchen	Patron and Neurosurgery	
Dr Ellie Chilcott	Pre-Clinical/Science	
Lesley Foulkes	Neurovascular Nursing	
Mr Patrick Grover	Neurosurgery (Adult)	
Dr Kirsty Harkness	Neurology (Adult)	
Mr Greg James	Neurosurgery (Paediatric)	
Peetra Magnusson	Pre-Clinical/Science	
Dr Anita Rose	Neuropsychology (Adult)	
Dr Stewart Rust	Neuropsychology (Child)	
Dr Grace Vassallo	Neurology (Child)	
Mr Daniel Walsh	Neurosurgery (Adult)	
Professor Phil White	Neuroradiology	
Dr Susanna Zuurbier	Neurology (Adult)	

We are also supported by CAUK Member Advisors. These are members of our community who bring relevant pre-clinical or clinical knowledge, helping to ensure the patient voice is clearly heard within the Advisory Board.

CAUK Member name	Role (if any)	Dates served (if part year)
Jana Bergholtz	European Cavernoma Alliance	
Connie Lee	Alliance to Cure	
Yasemin Cole	Pre-Clinical/Science	
Charlotte Cuffe	Pre-Clinical/Science	
Iman Muzafar	Medical Student	
Dawn Smith	Public and Patient Involvement	

Our day-to-day work is delivered by a small staff team, supported by dedicated volunteers, who manage CAUK's services, projects and operations and work closely with trustees and advisors to support the cavernoma community.

Staff, contractors and volunteers who deliver our work

CAUK Member name	Role and weekly hours	Dates served (if part year)
Helen Evans (Relative)	Charity Manager (37.5 hours)	
Tracey Hammond (Cavernoma)	Volunteer Manager (17.6 hours)	
Nicola Steers (Cavernoma)	Member Support Assistant (7 hours)	Joined 1 st December 24
Batool Raza	Events Assistant	Joined 1 st December 24 Left 31 st August 25
Robyn Hughes	Therapist (variable hours)	
Jade Davies	Social Media Consultant (4 hours)	
Michael Nelson	IT Consultant (variable hours)	

We are also supported by an incredible team of 62 volunteers, all with lived experience of cavernoma. Volunteers play a vital role across the charity, including peer support through the helpline, buddying, community meet-ups and online support groups, as well as social media, administration, fundraising and IT, with governance provided by volunteer trustees. Their commitment, insight and generosity of time enable CAUK to reach more people and do far more than would otherwise be possible.

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Institution (CIO)
Trustee selection methods (eg. appointed by, elected by)	Elected / re-elected at Annual General Meeting Between AGMs, can be elected by the Board

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

The trustees meet at least every other month, and more often if required. Trustees hold designated roles to support clear accountability and well-defined responsibilities. Key risks are identified and managed through appropriate systems and policies. Trustees receive induction and ongoing training as needed, and as a member of the National Council for Voluntary Organisations (NCVO), the charity also has access to external governance advice and support.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

1. To promote and protect the physical and mental health of those with cavernoma through the provision of support, education, research and practical advice.
2. To advance the education of the general public in all areas relating to cavernoma.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity)

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.

**Commission on
public benefit)**

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 62 volunteers 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, and have been the Patient and Public Involvement (PPI) Lead in all of the most recent Cavernoma research studies in the UK.

Vision

To have a cure for cavernoma that people living in the UK can access

Aims

- To provide peer-led support to people with cavernoma and their supporters living in the UK
- To improve consistency in the current diagnosis and treatment of UK patients
- To promote research to cure cavernoma and advocate for UK access to new treatments

Values

- Collaboration - Achieving more by working together
- Information - Providing reliable and accurate information
- Inclusion - Embracing and valuing every voice
- Empowerment - Supporting informed health decisions
- Trustworthiness - Acting with integrity and reliability

Objectives

- 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.
- Under-pinning Operations - CAUK will be a resilient organisation that is responsive to a changing world.

Summary

The year 2024-25 was a significant one for Cavernoma Alliance UK, marking **20 years since our founder, Dr Ian Stuart, established the charity in 2005 to ensure that no one faces cavernoma alone**. What began as a volunteer-led helpline from his home in Dorchester has grown into a national charity supporting more than **4,200 members** with peer-led support, trusted information and advocacy for better treatments.

During this anniversary year we reflected on the progress made over the past two decades while also looking ahead through the launch of our new **five-year strategy (2025–2030)**. The strategy sets out a clear pathway towards our long-term vision: **a cure for cavernoma that people living in the UK can access**, supported by four strategic

priorities focused on **support, information and clinical care, research and resilient operations.**

Encouraging progress was made across these priorities during the year. Demand for support from the cavernoma community continued to grow, with 316 people supported through 484 helpline calls and emails, representing a **14% increase in people supported and a 19% increase in contacts compared with the previous year.** Our counselling service supported 26 people, while 23 people were matched through our buddying programme. Community connection also expanded through 13 in-person meet-ups attended by 128 people, 10 interactive webinars with 365 live attendees, and 21 online support group sessions, alongside a very active online peer-support community.

Our community also continued to grow, with **266 new members joining during the year,** bringing total membership to **4,217 people.** Awareness of cavernoma and of CAUK's work also continued to increase through our digital channels, which now connect with **8,167 followers across social media,** with awareness campaigns during the year reaching **over 142,000 views** on Facebook and Instagram.

Improving access to reliable information remained an important focus of our work. During the year we created or substantially updated **12 information resources,** produced **two new films,** and continued to strengthen our website as a trusted source of clinician-reviewed information. Awareness campaigns including Rare Disease Day, Brain Awareness Week and Cavernoma Awareness Month helped ensure the voices and experiences of people living with cavernoma continued to be heard.

Progress in research was another important highlight of the year. CAUK continued its collaboration with researchers at the **University of Edinburgh as a co-applicant on the proposed CARE Aspirin trial,** with a second-stage funding application submitted to the National Institute for Health and Care Research (NIHR). If successful, this study would represent the largest clinical trials ever undertaken for cavernoma in the UK.

Alongside this, work continued on **novel gene therapy research at University College London,** which CAUK helped initiate in the previous year. During 2024-25 the research progressed with the successful establishment of cavernoma mouse models in a UK laboratory and the securing of additional funding to enable the project to continue into **2025-26.** While still at an early stage, this work represents an important step in exploring treatments that could one day address the underlying genetic causes of cavernoma.

The charity's work during the year was made possible through the dedication of our volunteers and trustees, the generosity of our community fundraisers and donors, the commitment of clinicians and researchers who collaborate with us, and the care and professionalism of our small staff team who support the charity's work every day.

Looking ahead to 2025–26, the external environment for charities remains challenging, particularly for smaller organisations facing rising costs, increasing demand for services and growing competition for limited fundraising and grant income. In this context, the Trustees remain committed to a cautious and sustainable approach to growth, focusing on consolidating recent progress while steadily delivering the priorities set out in our new strategy.

As we enter our third decade, we are proud of what our small charity continues to achieve alongside the cavernoma community and remain committed to doing everything we can to support people living with cavernoma and advance research towards better treatments.

You may choose to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

Please see Section D for contribution made by volunteers

Section D Achievements and performance

Summary of the main achievements of the charity during the year

Overall

As an organisation run by and for people living with cavernoma, what matters most to us is the difference our members tell us we are making. Each year, we invite everyone who has received support to share their views on how we are doing. We are proud to report that more than nine in ten people feel our support has made a substantive difference to their overall quality of life.

When asked about their experience of support this year, the following percentages of people told us they strongly agreed or agreed with the following statements:

- I have a better understanding of cavernoma (96%)
- I feel more empowered to advocate for better care from professionals (91%)
- I feel more resilient when faced with challenges related to cavernoma (100%)
- I have new coping strategies for managing cavernoma (95%)
- I feel more connected with others from the cavernoma community (100%)
- It has made a positive difference to my mental health and wellbeing (91%)

In addition, we received an outpouring of positive feedback. Here is just a small selection of the comments shared with us:

- I would like to tell you that I was anxious when I found out that I have a cavernoma. I was upset and had no desire to live. I felt that everything was over for me, until my son sent me this website and I read about this condition. I gained strength and began to feel alive again. It is not easy to endure pain and to notice various problems with the immune system. But together with you, we - the cavernoma community - will succeed.
- My Caverbuddy has been so lovely and supportive... I really appreciate the help and support this has given me over a difficult time (after being diagnosed earlier this year after a bleed) when I really knew very little about spinal cavernoma. It has been invaluable for me to be able to share experiences. I thank you all for such a fabulous scheme.
- Cavernoma UK has been a strong support to me, giving me a bright new hope to life, they also help me to have a better understanding of what cavernoma is and better ways to manage my situation, thank you
- I am very recently diagnosed so still at the beginning of my journey - but I have been blown away by the support, resources and information that are readily available... Thank you so much for everything you do - it has made such a difference already.
- I love cavernoma alliance UK's, because they are reliable, fast in response, consistency. And I lot more

Section D Achievements and performance

- I'm newly diagnosed and would have been lost without the support I received from CAUK.
- Your support has made a positive difference to my mental health and well-being

Among our achievements, it is also important to acknowledge areas where we can do better. Members told us they would like to see the number of therapy sessions extended beyond the current 4 free sessions, to see our podcast re-started and also more opportunities to connect with people living in Scotland. This is helpful feedback that we will be reflecting on in 2025–26 as we continue to identify opportunities to improve.

In the section below, we set out in more detail the difference we have made this year across our key activities of:

- Support
- Information and Clinical Care
- Research

At a glance this year we have supported the cavernoma community in the following ways:

- Helpline - 316 people, 484 emails/calls
- Counselling - 26 people
- Buddying - 23 people
- In-person meet-ups - 128 people
- Interactive webinars - 10 webinars, 365 people
- Online Support Groups - 21 meet-ups held & 2,504 on Facebook
- Membership - 266 new members
- Medical Alert Cards - 31 cards issued
- Medical and Scientific Advisory Board - 15 experts & 8 lived experience members
- Information Resources - 12 new or updated information guides, and 2 new films
- Awareness Raising – 8,167 social media followers
- Research - Patient and Public Involvement lead in two research projects, CARE Aspirin at the University of Edinburgh (2nd Stage application), and Novel Cavernoma Gene Therapy at UCL
- Volunteering - 62 volunteers, of which 10 newly trained

1. SUPPORT

Helpline

Living with a rare neurological condition can be isolating, and for many people CAUK's helpline is the first time they connect with someone who understands. The helpline is run by trained volunteers with lived experience of cavernoma and overseen by our Volunteer Manager, reflecting the value we place on peer support. Each year around 160 people are diagnosed with cavernoma, with the NHS website signposting exclusively to CAUK for support. This year, ***we supported 316 people through 484 helpline calls and emails, a 14% increase in people supported and a 19% increase in contacts.***

Counselling

Cavernoma can have a significant impact on mental health, from the uncertainty of living with the risk of a bleed, to seizures, neurological symptoms, recovery after treatment and, for some, the emotional weight of a familial diagnosis. This year, we provided ***one-to-one online therapy to 26 adults and young people***, each receiving four or more sessions with a qualified therapist experienced in supporting people affected by cavernoma. For many, this service is a vital lifeline while waiting for NHS support, with contact typically made within five to ten working days and sessions arranged soon after. In 2025-26, in response to feedback from our community, we plan to build on this support by extending our monthly group therapy offer to include themed courses of four sessions, providing additional shared support for people facing similar challenges.

Section D Achievements and performance

Buddying

Many people who come to us, whether through counselling or the helpline, are looking for longer-term, one-to-one support from someone who truly understands what they are going through. Living with cavernoma can feel isolating, and being matched with someone with lived experience, and where possible a similar cavernoma journey, can make a real difference. Our buddying service provides this ongoing support, pairing individuals with trained volunteer peer supporters through regular phone calls and emails. This year, **23 buddying matches were completed and 15 new people matched.**

In-Person Meet-Ups

This year we hosted our Autumn Lecture at the Art Workers' Guild, opposite the National Hospital for Neurology and Neurosurgery. Eighty people registered, with a mix of in-person and online attendance. The event was opened by Consultant Neurosurgeon Mr Neil Kitchen, followed by a lecture from Consultant Neurosurgeon Mr Patrick Grover on *Cavernoma Management, Surgery, Radiosurgery and Surveillance*.

This year also marked the second year of our UK-wide in-person community meet-ups during Brain Awareness Week (10–16 March 2025). Thirteen meet-ups were held across the UK, including in Scotland and Wales, with 98 people attending. Meet-ups were led by volunteer peer-supporters with lived experience of cavernoma and focused on bringing people together locally for mutual understanding and support. This included a special all-day meet-up for children with cavernoma at an inclusive activity centre.

Interactive Webinars

This year our webinar programme continued to grow and went from strength to strength. In 2024–25 we delivered webinars on a regular monthly schedule, enabling us to reach more people across the cavernoma community. A total of 766 people registered, with 365 attending live and many more watching on demand afterwards.

Our webinars alternate between sessions led by the UK's leading cavernoma specialists and sessions led by members of our community who are experts by lived experience. Each includes a presentation followed by an interactive Q&A, creating space for learning, discussion and connection.

Webinar topics in 2024–25 included:

- Emergency surgery and recovery
- Mental health and emotional wellbeing
- Stereotactic radiosurgery (SRS)
- Epilepsy treatment and management
- Grief and recovery
- Recovering movement after brain injury
- Brainstem cavernoma
- Statins and cavernoma: AT-CASH EPOC trial insights
- Managing overlooked symptoms
- What we have learnt about cavernoma over the last 20 years
- Cavernoma 101: understanding your diagnosis

Online Support Groups

Each month, we offer two online drop-in support groups for members of the cavernoma community. These sessions are a vital part of our support offer, particularly for people who face barriers to attending in-person events, such as reduced mobility or neuro-fatigue.

Members can choose between two formats, each running once a month. Our Community Chat provides a relaxed, informal space to connect and share experiences. This year, we extended facilitation of Community

Section D Achievements and performance

Chat to experienced volunteer peer-supporters, with oversight from our Volunteer Manager. Our Therapeutic Group is facilitated by our Counsellor, who has specialist knowledge of cavernoma and leads small group therapy sessions around a different theme each month.

Over the year, we held **21 group meet-ups in total**. These sessions are open to anyone affected by cavernoma, including people with a diagnosis, parents, carers and others who support them.

Alongside our monthly online support groups, we also host a very active closed Facebook group, moderated by CAUK. The group now has 2,504 members, with multiple new posts each day, providing ongoing peer support and connection for our community.

Membership

Everyone affected by cavernoma, whether they live with the condition themselves or support someone who does, can register for free as a member of Cavernoma Alliance UK through our website www.cavernoma.org.uk. Becoming a member connects people with a community that understands what they are going through, which can be life-changing when living with a rare condition that most people have never heard of.

Membership also gives access to our core support services, including buddying, counselling, meet-ups and medical alert cards. These services are reserved for members so that we can maintain a safe and supportive environment where people can connect and feel understood. This year, **266 people registered as new members** of CAUK, bringing our **total membership to 4,217 people**. This represents an 7% growth and reflects the growing need for support, information and connection within the cavernoma community.

Medical Alert Cards

For people living with cavernoma, the risk of a seizure or haemorrhage makes it especially important to carry clear medical information in case of an emergency. This year, CAUK **provided 31 people with a free Medical Alert Card**, personalised with their photo, name, emergency contact details and essential information about their condition.

These cards can offer real peace of mind to those affected and their families, ensuring that emergency responders have the information they need to act quickly and appropriately. We are incredibly grateful to our dedicated volunteer who kindly prints and posts each card, helping make this small but potentially life-saving support possible.

Volunteering

Volunteers remain at the heart of CAUK. Almost all of our support services are delivered by volunteers, including the helpline, buddying, monthly community chats and in person meet ups across the UK. Their lived experience of cavernoma enables them to offer understanding, practical support and connection to others facing similar challenges.

At the end of the year the charity was supported by 62 volunteers, including 52 peer supporters delivering the helpline, buddying, online support groups and community meet ups. Volunteers also contributed specialist skills in areas such as IT support and medical alert cards, grant writing, and community fundraising and administration. Our seven Trustees also serve in a voluntary capacity, providing governance and strategic oversight.

During the year demand for support increased significantly. Helpline enquiries grew substantially compared with the previous year, and volunteers played a central role in ensuring that everyone who contacted the charity received a thoughtful and timely response. Alongside this, our community chats continued to grow, offering more opportunities for people affected by cavernoma to connect with others who understand.

Supporting and sustaining this volunteer network is led by our Volunteer Manager, Tracey Hammond, assisted by our Member Support Assistant, Nicola Steers, who joined the team in December 2024. Volunteer management includes recruitment, training and ongoing guidance, as well as ongoing 1:1 support

Section D Achievements and performance

to help volunteers feel confident in their roles. We are deeply grateful to all of our volunteers for the time, compassion and lived experience they bring to the charity.

2. INFORMATION AND CLINICAL CARE

Updating and strengthening the information on our website was a key focus for Cavernoma Alliance UK this year. With support from our Scientific and Clinical Advisory Board, we created or substantially updated **12 web pages**, ensuring content remains accurate, up to date and relevant.

Accessible information on cavernoma remains limited beyond a brief NHS overview and academic research papers, meaning CAUK's resources are often used as a first point of reference following diagnosis and to support discussions with professionals.

All information is developed and reviewed with input from leading UK and international clinicians alongside experts by lived experience. Our website continues to be widely used, with **27,000 new users** visiting during the year, including a growing international audience.

Alongside written content, we produced **two new videos**, one of which has been nominated for a **Smiley Charity Film Award**.

New and updated resources published this year include:

- Treatment options, including neurosurgery, stereotactic radiosurgery and medical management
- Mental wellbeing and emotional support
- Pregnancy, HRT and oral contraception
- Gut health and diet
- Flying and head injury
- Insurance
- Research developments, including gene therapy
- *Georgina's Story*: Spinal cavernoma
- *Michael's Story*: Supporting a loved one with cavernoma

When someone receives a diagnosis of cavernoma, it is common for those around them, including family, friends, employers and even healthcare professionals, to have never heard of the condition. Although rare, cavernoma affects an estimated 108,000 people in the UK, and low awareness can leave people feeling isolated and misunderstood.

This year marked **CAUK's 20th anniversary**, which was a central focus of our awareness-raising work. Throughout the year, we shared regular content across Facebook, Instagram, YouTube and LinkedIn, with our social media platforms now reaching 8,167 followers.

A key part of our anniversary year was **Cavernoma Awareness Month in June**, when we relaunched our *I Am Cavernoma* campaign. By sharing stories and images from people affected in the UK and internationally, the campaign helped people feel less alone and reached more than **142,000 views** on Facebook and Instagram.

Key awareness-raising moments during the year included:

- **Rare Disease Day (28 February)**, including attendance at a Westminster event
- **Brain Awareness Week (10-16 March)**, marked by UK-wide in-person meet-ups
- **Cavernoma Awareness Month (June)**, featuring the *I Am Cavernoma* campaign, the Annual Snowdon Climb (in-person and virtual) and Annual Conference
- **Cavernoma Awareness Day (14 June)**, recognised by global patient advocacy groups

CAUK was also represented at professional and scientific events, supporting collaboration and shared learning within the rare disease and neuroscience communities. These included:

Section D Achievements and performance

- British Neurovascular Group Conference, Oxford (6-7 February 2025)
- International Conference on Vascular Anomalies, Berlin, Germany (11-14 February 2025)
- Crick Rare Disease Conference, London (3 March 2025)
- Neuro Convention, Birmingham (19 March 2025)
- Cambridge Rare Disease Showcase, Cambridge (18 June 2025)
- Society of British Neurosurgeons Conference, Bristol (24-26 September 2025)
- RAREsummit25, Cambridge (6 November 2025)
- CCM International Scientific and Clinical Care Meetings, Atlanta USA (6-7 November 2025)

By maintaining a consistent public presence and sharing lived experience, we continue to raise awareness of a condition that remains little known and help ensure no one feels alone in living with cavernoma.

3. RESEARCH

Drug Repurposing: CARE Aspirin

Professor Rustam Al-Shahi Salman, University of Edinburgh

Promoting research that leads to effective treatments and ultimately a cure for cavernoma is one of Cavernoma Alliance UK's three strategic objectives. One promising pathway is drug repurposing, testing medicines that are already widely used for other conditions to see whether they could benefit people with cavernoma. During the year we worked closely with researchers at the University of Edinburgh as a co applicant on a major proposal to the National Institute for Health and Care Research (NIHR) to fund the CARE Aspirin trial. This large UK study would test whether daily low dose aspirin can reduce the risk of stroke caused by cavernoma compared with a placebo when added to usual care. The proposed trial would involve 392 participants recruited from around 27 hospitals across the UK. At the time of preparing this report and accounts we are awaiting the funding decision following submission of the second stage NIHR application. If successful, Cavernoma Alliance UK will lead the patient and public involvement (PPI) for the study, ensuring the research continues to be co produced with people living with cavernoma and reflects the priorities of the community.

Novel Drugs: Gene Therapy Research

Professor Rajvinder Karda, University College London

Alongside drug repurposing, Cavernoma Alliance UK is supporting longer term research aimed at treating the underlying genetic causes of cavernoma. During 2024 to 2025 work continued on a proof of concept gene therapy project funded by Cavernoma Alliance UK, with support from a CAUK member philanthropist and an initial contribution from Cavernoma Ireland. The research is being carried out in partnership with researchers at University College London and collaborators at Uppsala University in Sweden. As part of the project, cavernoma mouse models developed by our partners in Uppsala have been successfully rederived in a UK laboratory, enabling the first experimental studies to begin here in the UK. The research remains at an early stage, but it represents an important step in exploring whether gene therapy could one day treat the genetic causes of familial cavernoma. At the time of writing this report the work is progressing, and Cavernoma Alliance UK, with the continued support of a CAUK member philanthropist, has secured further funding to continue the project during 2025 to 2026.

Genetic Testing: TLNRD1

Professor Ben Goult, University of Liverpool

During 2024 to 2025 Cavernoma Alliance UK also began working with Professor Ben Goult at the University of Liverpool, whose research is exploring why some people appear to inherit cavernoma even though genetic testing does not identify changes in the known CCM genes. Working with clinicians at The Walton Centre, the research team has identified a candidate protein called TLNRD1 that may help explain how some cavernomas form. Over the past year we have established a relationship with the research group and have begun contributing the patient perspective to help inform the direction of the work. This ensures that the research reflects the experiences and priorities of people living with cavernoma.

Other Research Activities

Other activities during the year focused on encouraging wider research and industry interest in cavernoma. Cavernoma Alliance UK attended and presented at an Aspire Biosciences event, providing an opportunity to introduce cavernoma to pharmaceutical companies and highlight areas where further research and treatment development are needed. As a result of these discussions, we are now in ongoing follow up conversations with two pharmaceutical companies who have expressed interest in the condition. During the year we also

Section D Achievements and performance

began exploring the potential of low frequency focused ultrasound following promising pre-clinical studies. As part of this work we have begun discussions with Insightec and NaviFUS to identify a suitable low frequency focused ultrasound machine that could support a future clinical trial, should regulatory approval be granted for a study in the United States and early results prove encouraging.

Section E Financial review

Brief statement of the charity's policy on reserves

Reserves

The trustees review the charity's reserves policy annually, taking account of the charity's income profile and the wider funding environment.

As in previous years, despite diversification efforts and investment in grant writing, the majority of income continues to be derived from individual giving and community fundraising. This income is raised during the year and is therefore uncertain and subject to external factors such as the economic climate. Trustees expect this to remain the case in 2025–26.

Given this context, and the current economic uncertainty linked to global events, the Trustees have designated £45,960 (40% of unrestricted income generated in 2024–25) to support organisational expenditure in 2025–26. This designation reflects the trustees' assessment of financial risk and helps ensure the charity's financial sustainability and continuity of services.

With a year-end carry forward of £139,497 total cash funds, £118,515 in unrestricted funds, and £45,960 designated, **unrestricted free reserves as at 30 September 2025 stand at £72,555. This is equivalent to approximately seven months of operating expenditure**, based on planned ordinary expenditure of £119,330 for 2025–26. Also carried forward is £20,982 restricted reserves.

Details of any funds materially in deficit

Further financial review details (Optional information)

You may choose to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key

Sources of Funds

Members continued to be generous in 2024-25 and supported CAUK with donations totalling £109,703. Around 44% of this came from two community fundraisers, the Snowdon Climb for Cavernoma (£27,000) and the Rochester and Cobham Golf Club's fundraising (£21,000 in this financial year). This is a wonderful tribute to our community and their belief in CAUK, for which we are very appreciative.

We are also very grateful to the following trusts, foundations and other organisations for their generous grants received during this reporting period:

- National Lottery Community Fund (Support, 2 Years)
- Axiom Neuromonitoring (Counselling)
- Albert Hunt (Support)
- Movement for Good, Benefact Group
- David Family Fund (Support)
- Marsh Charitable Trust

objectives of the charity; • investment policy and objectives including any ethical investment policy adopted.	Our thanks also go to Recursion Pharmaceuticals for their £1,678 sponsorship for our 20 th Anniversary Party, with fund received in 2024-25.
---	---

Section F Other optional information

Going Concern

The Trustees have reviewed the financial position of the charity and considered its ability to continue operating for the foreseeable future, being a period of at least twelve months from the date of approval of these financial statements.

At 30 September 2025 the charity held unrestricted funds of £118,515, of which £72,555 represent free reserves after the designation of £45,960 to support organisational expenditure in 2025–26. The Trustees have reviewed projected income and expenditure for the coming year, considering the charity's income profile and its reliance on individual giving, community fundraising and grant income, which can be subject to external factors.

Income received since the year end has been in line with forecasts prepared at the time these financial statements were drafted. Based on current forecasts, the level of reserves held and the charity's ability to manage expenditure if required, the Trustees are satisfied that the charity has sufficient resources to continue its activities and meet its obligations as they fall due. Accordingly, the Trustees consider it appropriate to prepare the financial statements on a going concern basis.

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees:

Signature(s)	E Blackshaw	Heather Dunbar
Full name(s)	Elizabeth Blackshaw	Heather Dunbar
Position (eg Secretary)	Treasurer	Chair of Trustees
Date	16/4/2026	



CHARITY COMMISSION
FOR ENGLAND AND WALES

CAVERNOMA ALLIANCE UK

1197257

CC16a

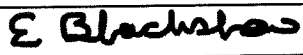
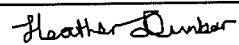
Receipts and payments accounts

For the period from	01/10/2024	To	30/09/2025
------------------------	------------	----	------------

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year (see Note 1) to the nearest £
A1 Receipts					
Donations	106,703	3,000	-	109,703	66,269
Grants	2,750	30,907	-	33,657	5,000
Sponsorship	-	1,677	-	1,677	4,930
Interest	2,621	-	-	2,621	1,615
Sub total (Gross income for AR)	112,074	35,584	-	147,658	77,814
A2 Asset and investment sales, (see table).					
Transfer of bank balance from Unincorporated Charity	-	-	-	-	106,844
Sub total	-	-	-	-	106,844
Total receipts	112,074	35,584	-	147,658	184,658
A3 Payments					
Salaries, NI and pensions	56,824	3,438	-	60,262	30,579
Norwegian Tax Authority (see Note 4)	18,641	-	-	18,641	-
Recruitment	-	-	-	-	383
Training	385	-	-	385	621
Consultancy (Finance, IT, Therapy)	5,679	6,951	-	12,630	6,221
Telephone & Broadband	20	30	-	50	281
General running expenses	4,047	2,400	-	6,446	4,618
Fundraising Costs	3,636	-	-	3,636	3,493
Travel	4,892	559	-	5,451	3,385
Other Events and Activities	3,582	1,943	-	5,526	3,305
Other Costs	540	250	-	790	6,246
Equipment and Office Supplies	814	13	-	827	1,636
Insurance	1,536	-	-	1,536	499
Merchandise	3,985	814	-	4,798	5,240
Governance costs:					
Independent examination	1,542	-	-	1,542	1,620
Payroll costs	1,008	-	-	1,008	450
Other	258	-	-	258	-
Sub total	107,389	16,398	-	123,787	68,577
A4 Asset and investment purchases, (see table)					
Equipment	-	455	-	455	-
Sub total	-	455	-	455	-
Total payments	107,389	16,853	-	124,242	68,577
Net of receipts/(payments)	4,684	18,732	-	23,416	116,081
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	113,830	2,250	-	116,081	-
Cash funds this year end	118,515	20,982	-	139,497	116,081

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	CAF Cash Account	4,505	-	-
	CAF Gold Account	113,505	20,982	-
	PayPal	505	-	-
	Total cash funds	118,515	20,982	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Other debtors	2,841	-	-
	Purchases for Event October 2025	1,502	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	Printer (medical alert cards)	Restricted	455	-
	Printer	Unrestricted	180	-
	6 Laptops	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
	PAYE	Unrestricted	918	
	Accountancy	Unrestricted	1,926	
	Trade creditors	Restricted	750	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		E Blackshaw	16/4/2026	
		Heather Dunbar	19/04/2026	

Notes

NOTE 1

During the previous year the charities activities transferred from the old charity (no SC048458) to a new CIO (no 1197257). The note below combines the transactions for the two charities.

	Old Entity (No SC048458 / 1114145)	New CIO Entity (No 1197257)	TOTAL
	Period 01/10/2023 - 31/01/2024	Period 01/02/2024 - 30/09/2024	01/10/2023 - 30/09/2024
	to nearest £	to nearest £	to nearest £
Receipts			
Donations	18,351	66,269	84,620
Grants	15,173	5,000	20,173
Sponsorship		4,930	4,930
Receipts from fundraising activities	-	-	-
Gross receipts from other charitable activities	-	-	-
Other income	-	-	-
Interest	619	1,615	2,234
Sub total	34,144	77,814	111,957
Receipts from asset & investment sales			
Proceeds from sale of fixed assets	-	-	-
Proceeds from sale of investments	-	-	-
Sub total	-	-	-
Total receipts	34,144	77,814	111,957
Payments			
Salaries, NI and pensions	17,222	30,579	47,801
Recruitment	-	383	383
Training	42	621	663
Consultancy(Finance, Website, Therapy)	1,173	6,221	7,394
Premises Costs	396	-	396
Telephones & Internet	331	281	612
General Running expenses	1,159	4,618	5,777
Fundraising costs	1,992	3,493	5,485
Travel	829	3,385	4,214
Other Events & Activities	91	3,305	3,396
Other costs	48	5,859	5,907
Equipment and Office Supplies	28	1,636	1,664
Insurance	769	499	1,268
Merchandise	-	-	-
Printing & Postage	-	5,240	5,240
Other costs - restructure	-	-	-
Other	80	387	467
Governance costs:			
Independent examination	-	1,620	1,620
Payroll costs	432	450	882
Other	-	-	-
	-	-	-
Sub total	24,592	68,577	93,169

Notes continued**Payments relating to asset and investment movements**

Purchases of fixed assets	-	-	-
Purchase of investments	-	-	-
Sub total	-	-	-
Total payments	24,592	68,577	93,169
Net receipts / (payments)	9,552	9,237	18,788
Transfers to / (from) funds	-	-	-
Surplus / (deficit) for year	9,552	9,237	18,788

FUNDS RECONCILIATION

	Total Funds to nearest £
Cash and bank balances at start of year	97,293
(Deficit/ Surplus shown on receipts and payments account	18,788
Cash and bank balances at end of year	116,081

On the 1st February 2024, the Transfer Agreement and Vesting Declaration were signed and assets, including funds in the old entity (charity number 1114145) bank account transferred to the new entity (Charity number 1197257). The total transferred was £106,844, and this is shown in the section A4 comparative of the old entities accounts and section A2 in the new entities accounts.

NOTE 2

Before the end of the 2024-25 financial year, a grant of £18,907 was awarded by the National Lottery Community Fund to fund peer-support from 1 October 2025 to 30 September 2027. As the accounts are prepared on a receipts and payments (cash) basis, the grant has been recognised in the 2024-25 accounts when received, although the funding will be applied to activities across the 2025-26 and 2026-27 financial years. This grant accounts for the majority of the difference between income and expenditure in the year.

NOTE 3

At the 30 September 2025 the charity held total cash funds of £139,497, this comprises £118,515 unrestricted funds and includes £45,960 funds which have been designated to support operational expenditure in the financial period ending 30 September 2026. The charity also held restricted funds at 30 September 2025 of £20,982, of which £2,250 relates to the Caver no more essay prize fund and £18,732 relates to Direct Support fund.

NOTE 4

During the previous financial year (2023-24) the charity received tax advice about a Norwegian tax liability first identified as a potential concern by our Charity Manager and Chair following their appointments in 2022-23. This liability arose as a member of the staff team began working from home in Norway in 2021-22 towards the end of the pandemic, and there was a misunderstanding about the tax implications arising in respect of this.

As an outcome of this advice CAUK contacted the Norwegian tax authorities to disclose the tax liability, and the home-working arrangement that had precipitated this matter came to an end at the start of 2023-24. This matter was settled in March 2025, following correspondence with the Norway tax authorities and all monies owed have now been paid. As an outcome of this matter the Board of Trustees have strengthened governance practices and sign-offs required to ensure such a matter does not arise again.



Section A

Independent Examiner's Report

Report to the trustees

Cavernoma Alliance UK

On accounts for the year
ended

30 September 2025

Charity no
(if any)

1197257

Set out on pages

1-17

I report to the trustees on my examination of the accounts of the above charity for the year ended 30/09/2025.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011.

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

21 April 2026

Name:

Mrs S J Hough

Relevant professional
qualification(s) or body
(if any):

FCA

Address:

Edwards and Keeping, Chartered Accountants

Unity Chambers, 34 High East Street, Dorchester, DT1 1HA