Trustees' Annual Report for the period

	Period start date				Period end date		
From	01	10	2023	To	30	09	2024

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

Names of the charity trustees who manage the charity

	Trustee name	**Office (if any)**	**Dates acted if not for whole year**	**Name of person (or body) entitled to appoint trustee (if any)**
1	Heather Dunbar (C)	Chair		
2	Mark Farrar (F)	Treasurer		
3	Barbara Edmonds (F)			
4	Jade Davies (C)			
5	Roxanna Dixon (C)			
6	Emily Fletcher (C)			
7	Alex Ford (F)			

Cavernoma Alliance UK is a charity run by and for the cavernoma community. Given the importance of lived experience we pride ourselves on having a Board of Trustees that is reflective of the community we support.

C = Trustee with cavernoma

F = Trustee who has immediate family with cavernoma.

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	**Dates acted if not for whole year**
N/a	N/a

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Clinical Medical Advisor	Professor Rustam Al-Shahi Salman	University of Edinburgh
Clinical Medical Advisor	Professor Diederick Bulters (appointed 11th of September 2024)	University Hospital Southampton

Name of chief executive or names of senior staff members (Optional information)

Helen Evans, Charity Manager

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.

Change in Legal Entity

In 2021, in keeping with common practice across the charity sector a decision was taken in principle at CAUK's AGM that year to transition to a Charitable Incorporated Organisation (CIO) legal entity, a more modern legal structure without any other changes to the way the charity operates. Due to the pandemic and then later on changes in key staff and Trustees in 2022-23, the transition to this legal entity took longer than anticipated.

On the 1st of February 2024, the Transfer Agreement and Vesting Declaration were signed and assets transferred from the old entity (charity registration number 1114145) to the new entity (charity registration number 1197257) following the opening of a new bank account. It took longer than anticipated to change direct debits, standing orders and other income/expenditure meaning the old bank account remained open until December 2024 with a small portion of funds transferred at this date.

Aside from the change in legal entity effective the 1st of February 2024 there were no other material changes to the charity. We hope the preparation of two sets of accounts and annual reports mid-year does not cause undue confusion or concern to potential donors, as this matter is to all intents and purposes a technicality to ensure we are operating within the most modern legal framework for a charity.

For clarity, in 2023-24 our organisational income was £111,957 and our organisational expenditure was £93,169, with 8 months expenditure held in reserves. Differences in the figures listed on the Charity Commission website are due to the transfer in funds as we moved from our old entity to our new CIO entity.

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 Commission on public benefit)

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.

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 4,000 members with a small, remote team of part-time staff and self-employed contractors. Volunteers remain at our core, with more than 50 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

2023 to 2024 was a milestone year for Cavernoma Alliance UK. Thanks to a collaboration with Cavernoma Ireland and the generosity of a CAUK member philanthropist, ***we secured nearly £100,000 in funding for University College London to launch the UK's first gene therapy research project for cavernoma***. Although clinical trials remain some way off, this marked a major step forward in the search for a cure for familial cavernoma, which is inherited and affects around 20 per cent of people living with the condition. This success was underpinned by our newly refreshed and expanded Advisory Board, which brings together the UK's leading scientific and clinical experts on cavernoma alongside experienced patient advocates.

It was also a year of transformation in how we support our members. ***We embraced the power of volunteers and transitioned to providing all support services, with the exception of counselling and our interactive webinars, through our dedicated team of 59 peer-supporter volunteers.*** This work was coordinated by our Volunteer Manager and Member Support Assistant. While the shift was prompted by a forecast reduction in income for 2023 to 2024, it is one we have fully embraced. It enables more people to connect with others in the cavernoma community who share their lived experience. *Thanks to the incredible efforts of our volunteers and staff, we were able to provide* ***direct support to 1205 people this year, with over 30,000 people reached through our website, newsletter and social media.*** We are incredibly grateful to our volunteers for making this possible.

Reflecting on the challenges of last year, the ***Board dedicated time to developing the charity's first five-year strategy. A key element in shaping this work was our Lived Experiences Survey, which received nearly 500 responses.*** The findings highlighted the significant difficulties still faced by people with cavernoma. On average, respondents waited nearly one year for a diagnosis, one third were misdiagnosed before receiving the correct diagnosis, and many reported missing a combined total of nearly 400 days of education or work following a stroke. The survey helped inform four new strategic objectives and the revision of our vision, aims and values, which we outlined in the preceding section. The resulting strategy, with clearly defined outcomes and outputs, is ambitious, but with the support of the cavernoma community, we are hopeful of making meaningful progress over the next five years. You can find our strategy online at https://bit.ly/CAUK-Plan-2025-2030.

Other notable successes this year included:

- The **publication of the CARE Pilot trial results**, the UK's largest cavernoma study, which demonstrated that research of this kind is possible and opened the door for further studies
- A significant **increase in our social media reach**, with more than 7,250 people now following us across Facebook (Page and Support Group), Instagram, LinkedIn and YouTube
- The **return of our in-person meet-ups**, with 100 people coming together at 10 venues across the UK as part of Brain Awareness Week
- Our second Snowdon Climb during Cavernoma Awareness Month, which raised both awareness and nearly £20,000 to support people affected by cavernoma

- The launch of two new **Cavernoma Stories** films, with *Jade's Story* named a finalist in the Big Syn International Film Festival
- The launch of our new **Schools and Colleges Guide for Cavernoma**

We are a charity run by and for people living with cavernoma. We could not do what we do without the dedication of our incredible volunteers, including peer supporters, buddies, community hosts, fundraisers, grant writers, IT helpers, alert card volunteers and Trustees. We are also deeply grateful to the trusts, foundations, sponsors and individual donors whose financial support, alongside the efforts of our community fundraisers, makes our work possible.

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

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

Norway Tax Liability

During this financial year the charity received tax advice about a Norway tax liability first identified as a potential concern by our new 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 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 (100%)
- I feel more empowered to advocate for better care from professionals (95%)
- I feel more resilient when faced with challenges related to cavernoma (95%)
- I have new coping strategies for managing cavernoma (94%)
- I feel more connected with others from the cavernoma community (93%)
- It has made a positive difference to my mental health and wellbeing (93%)

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

- Being part of this group gives you peace of mind in all the chatter. You have so many fears and questions when you are diagnosed and this group is amazing at calming you down and giving you the knowledge, you need to cope.
- They have been a life-changing experience.
- "I would not be living as well as I am without you all. Thank you.

- Speaking with others who have similar experiences helped me feel less alone, and their webinars gave me a better understanding of my condition. Their support has made a real difference in how I manage cavernoma.

Among our achievements, it is also important to acknowledge areas where we can do better. Members told us they would like to see greater visibility of ethnically diverse people within our community, more tailored support for those living with spinal cavernoma, and improved partnership working. These are all important priorities that we will be taking forward into 2024–25 as we continue to identify opportunities to improve.

In the section below, we go into more detail about the difference we've made this year covering the following activities:

- Helpline - 277 people, 406 emails/calls
- Counselling - 22 people
- Buddying -26 people
- In-person meet-ups - 100+ people
- Interactive webinars - 9 webinars, 250 people
- Online Support Groups - 150+ registered for drop-ins & 2,400 on Facebook
- Membership - 296 new members
- Medical Alert Cards - 77 cards issued
- Medical and Scientific Advisory Board - 15 experts & 8 lived experience members
- Information Resources - Education Guide, Hormone Therapy Advice, new Films
- Awareness Raising - 7,250 social media followers
- Research - CARE Pilot, CARE Prep, Gene Therapy, Lived Experiences Report
- Volunteering -59 volunteers, of which 10 newly trained

Helpline

Living with a rare neurological condition can be an isolating and lonely experience. For many people, CAUK's helpline is the first time they connect with someone else who understands what they are going through. Each year, around 160 people are diagnosed with cavernoma, and the NHS website signposts exclusively to CAUK for support. Most of the emails and calls we receive come from people who have been newly diagnosed alongside people with new symptoms, treatment concerns (e.g. surgery) and increasingly poor mental health. In 2023 to 2024, ***we supported 277 people through 406 helpline calls and emails*** *and have seen this figure grow further in 2024 to 2025.*

Since 2023 to 2024, our helpline has been delivered entirely by specially trained volunteer peer supporters, all of whom have lived experience of cavernoma. People can access the helpline by emailing helpline@cavernoma.org.uk or by booking a telephone call using our online system at www.calendly.com/caukhelpline/phonecall. This year, we trained 10 new volunteers to provide peer support via the helpline. All volunteers receive safeguarding training and have access to our clinician-approved helpline handbook. They are DBS and reference checked, receive regular supervision from our Volunteer Manager, and are part of an active and supportive WhatsApp group.

This year marked the first time the helpline has been delivered entirely by volunteers, supported by a booking system that accommodates volunteer availability. This replaced the previous model where a phoneline was answered during office hours. The change was prompted by funding challenges in 2022 to 2023, which led to a 26 per cent reduction in staff hours. However, it was also a strategic decision to emphasise peer-led support and create more volunteering opportunities within the cavernoma community. We anticipated a drop in the number of people supported during the transition, which has been the case. However, we are already seeing engagement increase in 2024 to 2025, supported by ongoing promotion through our social media channels.

Counselling

Cavernoma can have a profound impact on a person's mental health. The uncertainty of not knowing if or when a bleed might occur, the effects of physical symptoms such as seizures or neurological deficits, recovery following treatment such as neurosurgery, and, for those with the familial form, the knowledge that the condition may be passed on, all contribute to significant emotional strain.

This year, we provided one-to-one online therapy to 22 adults and young people, each receiving four or more sessions with a qualified therapist who has over six years' experience supporting people in the cavernoma community.

Our counselling service can be a vital lifeline, particularly for those facing long waiting times for NHS counselling. Once a request is made, our therapist typically makes contact within five to ten working days, with the first appointment arranged soon afterwards. Receiving timely, specialist support from someone who understands cavernoma can be life-changing.

In the words of one person who accessed our service: "Just wanted to say thank you once again... Your encouragement and support helped a great deal, and it really made me think about my life and what I need out of it to survive."

Buddying

Many people who come to us, whether after counselling or through the helpline, are looking for someone who truly understands what they are going through. Living with cavernoma can feel isolating, and being able to connect with someone who has similar lived experience can make a real difference. Our buddying service matches individuals with trained volunteer peer supporters who provide emotional and practical support through regular phone calls and emails.

This year, alongside existing buddying partnerships, ***26 new people were matched with a volunteer peer supporter and 22 of the matched partners were still in a buddying partnership*** by the end of the current year. Most buddying partnerships last past one-year, although some continue for longer. Many end with lasting friendships, which is always wonderful to see.

Our buddying service, alongside our helpline, is one of CAUK's longest standing and most valued forms of support. It continues to be a popular way for people to feel heard, supported and less alone. In the words of one person we supported: "I would not have coped anywhere near as well without CAUK and my caverbuddy. It has made such a difference to have someone who really gets it to talk to."

In-Person Meet-Ups

This year marked a return to in-person meet-ups, with ***10 meet-ups held across the UK, including in Scotland and Wales, with around 100 people attending.*** Our meet-ups were led by volunteer peer-supporters, all with lived experience of cavernoma, with the aim of bringing people together in their local community to make new cavernoma connections, offering each other mutual understanding and support. Our meet-ups also included a special all-day meet-up for children with cavernoma held at an inclusive activity centre.

The feedback from the meet-ups was very positive. In the words of one person: "It was wonderful to sit with others living with Cavernoma & make new friends. Each of us had a unique & important story to tell. We are all very keen to meet up again soon." After each meet-up people were given the opportunity to join a local cavernoma community WhatsApp group, moderated by the volunteer who led the in-person meet-up.

Going forward it's our intention to host these meet-ups each year during Brain Awareness Week in March, with the option for volunteer peer-supporters to then arrange meet-ups in between those times if there's interest from members. All meet-ups are advertised widely by CAUK on social media, with volunteers supported through facilitator packs, and supervision from our Volunteer Manager.

Interactive Webinars

This year, we made the decision to formalise our popular webinar series by scheduling them every other month, typically on the last Wednesday. In 2024 to 2025, we increased the frequency to monthly, enabling us to reach even more people. ***Over the course of the year, we held nine webinars, with more than 250 people attending live and over 2,600 watching the recordings via our YouTube channel:*** https://www.youtube.com/@cavernomauk/videos.

Our webinars usually alternate between sessions led by the UK's leading cavernoma specialists and those led by individuals from our community who are experts by lived experience. Each session includes a presentation followed by an interactive question and answer segment, offering members of the cavernoma community a valuable opportunity to connect, share and learn from one another. We actively encourage participants to use the chat function during webinars to foster conversation and connection. In 2023 to 2024, our webinar topics included:

- Managing Tinnitus with Cavernoma
- The Spinal Cord and Cavernoma
- Oral Contraception, HRT and Cavernoma
- Lived Experience Panel Discussion
- Personal Independence Payments (PIP) and Cavernoma
- Predicting Familial Cavernoma
- Cavernomas: A Randomised Effectiveness (CARE) Study
- Research to Treat Cavernoma with Medications
- Research to Treat Cavernoma with Focused Ultrasound

Online Support Groups

Each month, we offer members of the cavernoma community the opportunity to join an online drop-in support group. These sessions are a vital part of our support offer, especially as many people with cavernoma face barriers to attending in-person events, such as reduced mobility or neuro-fatigue.

Participants can choose between two group formats. Our Community Chat is led by our Volunteer Manager and offers a relaxed space for people to meet informally, share experiences and connect with others affected by cavernoma. Alternatively, our Therapeutic Group is facilitated by our Counsellor, who has in-depth knowledge of cavernoma and leads small group therapy sessions with a different theme each month.

By the end of the year, more than 150 people had registered to attend these monthly support groups, with an average of 10 or more participants at each session. These groups are open to anyone living with cavernoma, including individuals with a diagnosis as well as parents, carers and others who provide support.

Alongside our monthly online support groups, we also have a very active closed Facebook Group moderated by CAUK. This group now has ***nearly 2,400 members*** with multiple new posts each day providing members with much needed mutual support.

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, ***296 people registered as new members*** of CAUK, bringing our ***total membership to 3,951 people***. This represents an 8% 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 77 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.

Improving Access to Information

At Cavernoma Alliance UK, we are committed to ensuring that everyone affected by cavernoma has access to clear, accurate and supportive information. This year, we began a major review and update of our information resources to make sure they reflect the latest research, respond to the real concerns of our community and are as accessible and inclusive as possible.

This work is especially important because accessible information on cavernoma is still limited. Aside from a brief summary on the NHS website (www.nhs.uk/conditions/cavernoma), most published material is found in complex academic papers. For many, our resources provide a first point of clarity after diagnosis and are used to inform conversations with GPs, teachers, employers and other professionals who may not have encountered the condition before.

We are proud that our website continues to serve as a trusted and widely used source of information. This year, **over 30,000 new people** visited our website. While we primarily serve people across the UK - who made up **40.5 per cent** of visitors - we also support a growing international audience, reflecting the global need for reliable information on this rare condition. It is encouraging to see that so many people are turning to CAUK as a first point of support and guidance.

As part of our efforts to strengthen our information offer, we also refreshed and expanded our **Advisory Board**. This group now includes **15 scientific and clinical advisors** and **8 experts by experience**, forming a strong multi-disciplinary team that helps ensure our content is trustworthy and relevant. A full list of members is available at www.cavernoma.org.uk/advisory-board.

We are fortunate to have **Professor Rustam Al-Shahi Salman** continuing as **Neurological Lead and Chair**, with **Professor Diederick Bulters** joining as **Neurosurgical Lead**. We extend our sincere thanks to **Mr Neil Kitchen**, who stepped back from co-chairing the Board this year and into a patron role, following many years of valued leadership and service.

With expert input and guidance, we published the following new and updated resources this year. We also have a full schedule planned for the coming year to further expand and enhance our information offer:

- **Guide for Schools and Colleges**
  www.bit.ly/CAUKGuidanceSchoolsColleges
- **Lived Experiences Report**
  https://bit.ly/EuropeanCavernomaPatientReport2024
- **Cavernomas: A Randomised Effectiveness Study (CARE)**
  www.cavernoma.org.uk/care-study
- **HRT and Oral Contraception Guidance**
  www.cavernoma.org.uk
- **Jade's Story: Familial Cavernoma**
  www.bit.ly/CAUKvideo

Raising Awareness

When someone receives a diagnosis of cavernoma, it is common for those around them, including family, friends, teachers, employers and even healthcare professionals, to have never heard of the condition. Although rare, cavernoma affects an estimated 108,000 people in the UK, enough to more than fill Wembley Stadium. Yet the lack of awareness often leaves people feeling isolated, misunderstood and without the support they need.

Cavernoma Alliance UK is working hard to change that. This year, we placed renewed focus on raising awareness through our social media platforms. We now post six days a week across Facebook, Instagram, YouTube and LinkedIn, with daily themed content designed to inform, engage and connect. As a result, ***our reach on social media has grown to over 7,250 followers***, nearly double our registered membership, helping us extend our voice and impact far beyond our immediate community.

Among the highlights of our awareness-raising efforts were major campaigns for:

- **Rare Disease Day** (29 February), including attendance at Westminster networking events
- **Brain Awareness Week** (11 to 16 March), celebrated with in-person meet-ups across the UK
- **Cavernoma Awareness Month** in June, featuring our Annual Snowdon Climb, Annual Conference, and widespread online engagement
- **Cavernoma Awareness Day** (14 June), marked by communities across Europe and the United States

In addition to these campaigns, we were proud to represent CAUK at key professional and scientific events. These included:

- Our Volunteer Manager speaking at the prestigious **10th European Stroke Organisation Conference** in Basel, Switzerland, sharing her lived experience of symptomatic brainstem cavernoma
- Attendance by our Founder and CAUK volunteers at the **Society of British Neurological Surgeons Conference** in Edinburgh, where Advisory Board member **Dawn Smith** presented a research poster
- Our Charity Manager participating in the **Aspire Biosciences 'Collaboration for Change' event** at the Royal Society of Medicine, and attending the **inaugural Vascular Voices Network** started in 2024

- Ongoing involvement in the **European Cavernoma Alliance**, where CAUK plays a leadership role chaired by our Charity Manager

By building partnerships, sharing lived experiences, and engaging in national and international forums, we are making cavernoma better known and better understood. Every conversation, post, and event helps bring us closer to a world where no one feels alone in their diagnosis.

Research

Pioneering Gene Therapy Research for Familial Cavernoma

Over 9 months our Charity Manager led a project to design and secure funding for the UK's first gene therapy research project to treat familial cavernoma. This was a huge step forward as it marked the UK's first pre-clinical research for cavernoma, and only the third known project of it's kind globally. CAUK were pivotal in bringing together research teams at University College London (UCL) who specialise in translation gene therapy research, Uppsala University who have a cavernoma mouse model, and funding from Cavernoma Ireland and a CAUK member philanthropist. As an outcome the project team was established, the research proposal shaped and ultimately £100k secured in funding to kick-start this proof of concept research. Whilst we are likely to be at least 10 years away from clinical trials, this research marks an important first step forward.

CARE Study: Advancing Treatment Research

This year saw the publication of the Cavernomas: A Randomised Effectiveness (CARE) pilot study, a major milestone in research into the treatment of symptomatic cavernoma with more information available at https://cavernoma.org.uk/care-study/. The study assessed the feasibility of conducting a larger randomised trial comparing medical management alone with medical management combined with surgery (either neurosurgery or stereotactic radiosurgery).

Between August 2021 and January 2024, 72 participants, 68 adults and 4 children, were recruited across 28 hospitals in the UK. The study successfully met its recruitment goals and showed that a larger trial is achievable. Importantly, stroke rates were similar in both treatment groups, and no serious adverse events were reported. Cavernoma Alliance UK was proud to be a co-applicant in the study, playing a key role in ensuring the patient voice was embedded throughout. We helped develop patient-facing materials and coordinated the Patient Advisory Group, which guided the study design and delivery. The success of this pilot study lays the foundation for a future international trial that could inform better, evidence-based treatment choices for people living with symptomatic cavernoma.

CARE PREP Study: Preparing for Future Drug Trials

This year, the CARE PREP study was published, offering hope for future drug trials for cavernoma in the UK with more information to be found at https://www.journalslibrary.nihr.ac.uk/eme/published-articles/TYUP6982#plain-language-summary. At present, surgery is the only available treatment for symptomatic cavernoma, but many in our community are seeking safer and less invasive options.

CARE PREP is a vital piece of research that explored how future clinical trials could be designed to test drug treatments for cavernoma, including the potential for using repurposed drugs, medications already approved for other conditions. The study sets the groundwork for making drug trials possible in the UK and helps move the conversation forward toward new treatment possibilities.

Cavernoma Alliance UK was closely involved from the outset, ensuring the patient voice shaped every stage of the research through our role in Patient and Public Involvement. Our contribution helped ensure the study reflected the real-world needs and experiences

Section D Achievements and performance

of people living with cavernoma. We are proud to have played a part in this important step towards developing future treatment options for our community.

Volunteering

This year we completed a successful round of online training for 10 new volunteers, covering key areas such as peer-to-peer support and safeguarding. Additional, role-specific training was provided for those supporting the helpline, with volunteers choosing to assist either through email responses or phone calls. Each volunteer received a role description, relevant policies, and a volunteer declaration form, along with access to our secure members' area containing handbooks, the latest volunteer newsletters, and all current policies. Volunteers were also trained on using our CRM contact log system to ensure consistent and secure record-keeping. To foster community and collaboration, a dedicated Volunteers WhatsApp group was set up, with a separate announcements section for important updates. An additional, smaller WhatsApp group was created specifically for helpline volunteers to coordinate Monday to Friday coverage and provide more focused peer support.

At the end of the year, there were 59 volunteers including:
49 Peer Supporters (Helpline, Buddying, Online Support Groups, In-Person Meet-ups)
1x IT support and medical alert cards
1x Grant writer
1x Secretary and community fundraising
7x Trustees

Building Capacity to Deliver Our Strategy

As part of a restructure to align with our new strategy for 2025 to 2030, two new part-time roles were created to strengthen our capacity in key areas. Both vacancies were successfully filled in December 2024, and we are pleased to report that both new team members remain in post and are performing well.

By the end of the year, our team comprised four part-time staff:

- Helen Evans, **Charity Manager** (23 hours per week)
- Tracey Hammond, **Volunteer Manager** (17.6 hours per week)
- **Member Support Assistant** (7 hours per week)
- **Events and Office Assistant** (7 hours per week)

While we remain a small team, our impact continues to grow, made possible by the unwavering support of our volunteer network. Their dedication and lived experience allow us to deliver meaningful, far-reaching support to the cavernoma community across the UK and beyond.

Section E Financial review

Brief statement of the charity's policy on reserves

In 2023-24 the charity's reserves policy was reviewed.

In undertaking this review particular consideration was given to the growth in individual giving and community fundraising as a source of income (78%), and the likelihood that this would continue to be the case going forward given increasing challenges securing grants from heavily over-subscribed Trusts and Foundation, with no grant income secured for 2024-25 at the close of 2023-24.

Given the uncertainty of income from individual giving and community fundraising (e.g. risk of event cancellation due to force majeure events like a pandemic) and the lead time to fundraise should there be a substantive loss in income due to a key event cancellation, a decision was taken to adopt a more conservative approach to the charity's reserves position, retaining reserves of 9 months of planned expenditure.

A decision was also taken to designate 50% of un-restricted income to organisational expenditure for the coming year, given the uncertainty of the charity's principle income source.

On this basis, as at the 30th of September 2024 the charity held reserves of £72,403, equivalent to 8 months running costs given planned expenditure of £115,766 in 2024-25.

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 objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Members continued to be generous in 2023-24 and supported CAUK with donations totalling £84,620 of which £33,000 was generously raised by the Rochester and Cobham Golf Club (with payment split across 2023-24 and 2024-25) and £19,722 (including Gift Aid) was raised by members supporting the Snowdon Climb for Cavernoma Awareness. This is a wonderful tribute to them and their belief in CAUK, for which we are very appreciative.

We are also very grateful to the following for their generous grants received during this reporting period, alongside payments made by the University of Edinburgh in respect of a National Institute for Health and Social Care (NIHR) award for research funding:

- Chapman Trust
- Garfield Weston
- Albert Hunt
- Brendon Charitable Trust
- Marsh Charitable Trust

Our thanks also go to our two sponsors from the pharmaceutical industry. In keeping with our policy on pharmaceutical income and commitment to the ABPI Code of Conduct the amounts paid are detailed below:

- Ovid Therapeutics - £3,400
- Garfield Weston - £1,530

Section F Other optional information

Going Concern

The 2023 to 2024 financial year began against a backdrop of financial uncertainty. In early 2023, during the second quarter of the 2022 to 2023 financial year, it became clear that projected expenditure for the year ahead would exceed forecast income. With no confirmed grant funding at that time, the Board took the proactive step of restructuring the organisation to reduce costs and maintain financial stability.

Later in the year, during the final quarter of 2022 to 2023, we received a significant and unexpected boost from community fundraising. While this provided some welcome relief, the decision to restructure remained essential. It allowed us to enter 2023 to 2024 in a more sustainable position, albeit with a cautious financial outlook and the unfortunate need, following consultation, to make a role redundant at the start of 2023-24, with a redundancy payment of £1,661 made, in keeping with statutory redundancy pay.

Throughout the 2023 to 2024 financial year, our cautious approach has proven effective. We closed the year with a small surplus, supported by the continued generosity of our community, regular giving, and the success of our Snowdon Climb for Cavernoma. We also secured in-year grant, helping to further strengthen our financial position. These outcomes demonstrate the impact of our small but dedicated staff team, amplified by the vital contributions of our volunteers.

As we look ahead to 2024 to 2025, we remain mindful of ongoing challenges. While our income is currently matching expenditure, we began the financial year without secured grant income, and we continue to operate without any multi-year grant commitments in place for 2025 to 2026. This means we remain heavily reliant on community fundraising and individual giving, both of which are harder to predict in an uncertain economic climate.

We have therefore set a prudent budget for 2024 to 2025 and hold reserves equivalent to 8-months of planned expenditure as a protective measure. As at May 2025, we have maintained a balanced position, with income tracking closely against expenditure and reserves preserved.

We continue to monitor our position carefully, manage risks responsibly and plan with realism. While we are planning for the worst, we remain hopeful for the best, buoyed by the resilience of our community and the dedication of our staff, volunteers and supporters.

Section G Declaration

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

Signed on behalf of the charity's trustees

Signature(s)		Digitally signed by Dunbar, Heather Date: 2025.06.17 17:52:04 +01'00'
Full name(s)	Mark Farrar	Heather Dunbar
Position (eg Secretary)	Treasurer	Chair of Trustees
Date	18.5.25	

CHARITY COMMISSION
FOR ENGLAND AND WALES

CAVERNOMA ALLIANCE UK	1197257	CC16a

Receipts and payments accounts

For the period from	01/10/2023	To	30/09/2024

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 to the nearest £
A1 Receipts					
Donations	66,269	-	-	66,269	-
Grants	-	5,000	-	5,000	-
Sponsorship	-	4,930	-	4,930	-
Other Income	-	-	-	-	-
Interest	1,615	-	-	1,615	-
	-	-	-	-	-
***Sub total** (Gross income for AR)*	67,884	9,930	-	77,814	-
A2 Asset and investment sales, (see table).					
Transfer of bank balance from Unincorporated Charity	93,142	13,702	-	106,844	-
Sub total	93,142	13,702	-	106,844	-
Total receipts	161,026	23,632	-	184,658	-
A3 Payments					
Salaries, Ni and pensions	22,961	7,619	-	30,579	-
Recruitment	383	-	-	383	-
Training	252	369	-	621	-
Consultancy (Finance, IT, Therapy)	579	5,642	-	6,221	-
Telephone & Broadband	-	281	-	281	-
General running expenses	3,508	1,110	-	4,618	-
Fundraising Costs	3,493	-		3,493	-
Travel	2,878	507		3,385	-
Other Events and Activities	1,694	1,611	-	3,305	-
Other Costs	3,003	2,856	-	5,859	-
Equipment and Office Supplies	1,636	-	-	1,636	-
Insurance	499	-		499	-
Merchandise	3,710	1,530		5,240	-
Other	-	387	-	387	-
Governance costs:				-	-
Independent examination	1,620			1,620	-
Payroll costs	450			450	-
Other	-	-	-	-	-
Sub total	46,666	21,912	-	68,577	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	46,666	21,912	-	68,577	-
Net of receipts/(payments)	114,360	1,720	-	116,081	-
A5 Transfers between funds	(530)	530	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	113,830	2,250	-	116,081	-

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

B1 Cash funds

Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
CAF Cash Account	3,043	-	-
CAF Gold Account	110,702	2,250	-
PayPal	86	-	-
Total cash funds	113,830	2,250	-

(agree balances with receipts and payments account(s))

B2 Other monetary assets

Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

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)
1 Printer	Unrestricted	180	-
6 Laptops	Unrestricted	-	-
		-	-
		-	-
		-	-
		-	-
		-	-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)	When due (optional)
PAYE	Unrestricted	213	
Accountancy	Unrestricted	1,542	
Trade Creditors	Unrestricted	-	
Norwegian government	Unrestricted	18,641	
		-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Digitally signed by Dunbar, Heather Date: 2025.06.17 17:47:28 +01'00'	
Mark	MARK FARRAR	10.5.25

Notes

NOTE 1

During the year the charties activites 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	Comparative
	Period 01/10/2023 - 31/01/2024	Period 01/02/2024 - 30/09/2024	01/10/2023 - 30/09/2024	01/10/2023 - 30/09/2024
	to nearest £	to nearest £	to nearest £	to nearest £
Receipts				
Donations	18,351	66,269	84,620	107,053
Grants	15,173	5,000	20,173	24,616
Sponsorship		4,930	4,930	
Receipts from fundraising activities	-	-	-	320
Gross receipts from other charitable activities	-	-	-	-
Other income	-	-	-	2,508
Interest	619	1,615	2,234	1,107
Sub total	34,144	77,814	111,957	135,604
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	135,604
Payments				
Salaries,NI and pensions	17,222	30,579	47,801	74,117
Recruitment	-	383	383	-
Training	42	621	663	937
Consultancy(Finance, Website, Therapy)	1,173	6,221	7,394	10,509
Premises Costs	396		396	738
Telephones & Internet	331	281	612	5,250
General Running expenses	1,159	4,618	5,777	4,583
Fundraising costs	1,992	3,493	5,485	3,986
Travel	829	3,385	4,214	1,018
Other Events & Activities	91	3,305	3,396	466
Other costs	48	5,859	5,907	-
Equipment and Office Supplies	28	1,636	1,664	-
Insurance	769	499	1,268	1,328
Merchandise	-		-	458
Printing & Postage	-	5,240	5,240	-
Other costs - restructure	-		-	-
Other	80	387	467	1,141
Governance costs:	-		-	-
Independent examination	-	1,620	1,620	1,620
Payroll costs	432	450	882	936
Other	-	-	-	-
	-	-	-	-
Sub total	24,592	68,577	93,169	107,087
Payments relating to asset and investment movements				
Purchases of fixed assets	-	-	-	-
Purchase of investments	-	-	-	-
Sub total	-	-	-	-
Total payments	24,592	68,577	93,169	107,087
Net receipts / (payments)	9,551	9,237	18,788	28,517
Transfers to / (from) funds	-	-	-	-
Surplus / (deficit) for year	9,551	9,237	18,788	28,517

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

NOTE 2

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 section A4 of the old entities accounts and section A2 in the new entities accounts.

Independent examiner's report on the accounts

Report to the trustees/ members of

Charity Name
Cavernoma Alliance UK

On accounts for the year ended 30 September 2024 **Charity no** 1197257

Set out on pages 1 to 17

(remember to include the page numbers of additional sheets)

I report to the charity trustees on my examination of the accounts of the above Charity for the year ended 30 September 2024.

Responsibilities and basis of report

As the trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Charity accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention giving me cause to believe that in any material respect:

1. accounting records were not kept as required by section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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:** 18 Jun 2025

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