



CHARITY COMMISSION  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From Period start date 01/02/2024 To Period end date 31/01/2025

Charity name: Cavernoma Society

Charity registration number: 1184406

### Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	To provide information and support to those affected by cavernoma, and raise awareness of the condition.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	To raise awareness of cavernoma and support those affected through information and support groups and services.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have run the charity as proposed in the governing document and have therefore met all of the key objectives set out by the charity.

### Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	N/A
Policy on social investment including program related investment	Para 1.38	N/A

Contribution made by volunteers	Para 1.38	We are grateful to all of our volunteers who have worked hard to help us to run the charity and continue supporting members through our vital services. As a small charity with no paid employees we rely on volunteers and our trustees to run our charity. In particular thank you to Hannah Westbury, Karen Smallman, Paul, James and Lizzie Murray, Lisa Goldapple, Jessica Jones, Chloe Robson, Cena Jovanovska, Wayne and Michelle Wright, and all of our trustees.

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Other		<p>We'd like to extend our thanks and gratitude to the following organisations and people for their generous donations.</p> <ul style="list-style-type: none"> <li>• The Knowle Golf Club and Ali Coombs for choosing us as charity of the Year and raising £5,000</li> </ul> <p>Anne Flett, in memory of Dicky Flett, who donated £2200</p> <p>Eva Mainwaring, who raised £3919 for us by walking several miles every day!</p> <p>Thank you to Hamilton Brown for providing pro-bono services and rebranding our charity.</p> <ul style="list-style-type: none"> <li>• Thank you to Hannah Westbury and the Cummins and friends for raising money by taking part in the Bradford Dragon Boat Race.</li> <li>• Thank you to Paul Smallman, Suzan Smallman, Karen Smallman, Gary Miller, Nigel Lawry, and Tracy Lawry for the Cornwall Trek and raising funds.</li> <li>• Thank you to JC Decaux for donating billboards for Raspberry Day</li> </ul> <p>Thank you to Michelle Bartholomew for your donation.</p> <p>Thank you to David James for a donation of £100.</p>
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		<p>Thank you to Eden trust for the generous donation.</p> <p>Thank you to Tracy Lewis, our Northern Irish representative and Jill O'Reilly, for helping us to launch the charity in Northern Ireland and the Republic of Ireland.</p> <p>Thank you to Dr Ellie Stankovska for donating her time and supervising our therapists.</p> <p>Thank you to our trustees.</p> <p>Thank you to Eva for raising over £3,000</p> <p>Thank you to James and Lizzie Murray for the Crochetforcavernoma raffles.</p> <p>Thank you to everyone who took part in the Christmas raffle and raised £400.</p> <p>Thank you to Jess Jones for helping source raffle gifts</p> <p>Thank you to Independence at Home grant for helping us to support a member with home renovation to help her disability.</p> <p>Thank you to all of our podcast guests.</p>
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## Achievements and Performance

	SORP reference	
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<p>Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.</p>	<p>Para 1.20</p>	<p>The Cavernoma Society had another successful year supporting its members and providing services that really made a difference.</p> <p>This year we had a full rebrand, with our iconic raspberry logo being redesigned to represent people hugging - showing our cavernoma community. We also have a brand new website (which is being designed), as well as new merchandise and a brand new colour-scheme! We are excited for the next stage of the charity's growth.</p> <p>Fundraising proved more difficult this year and we had to come up with new ways to raise funds.</p> <p>We sadly had no retreat this year - it had to be cancelled at the last minute due to our organiser getting seriously ill and having to be admitted to hospital.</p> <p>We attended several PIP tribunals with members and WON all of them, meaning that our members have the right support in place.</p> <p>Our free counselling service has helped even more people in crisis, and this year we saw roughly 80 members for counselling. This year we said goodbye to two therapists and gained one new trainee.</p> <p>We were chosen as charity of the Year by the Knowle Golf club and also The Eden project, so received vital funds - thank you.</p> <p>We once again celebrated our annual awareness day – Raspberry Day in September and were supported by JC Decaux, who donated more than 2,000 billboard marketing across the UK - helping raise awareness.</p> <p>We also wrote many GP referral letters, Blue Badge support letters, and helped members to get a second opinion, genetic testing, and neuro rehab services.</p>
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		<p>We also took part in several fundraising events, including the London marathon, The Cornwall Trek, and The Bradford Dragon Boat race.</p> <p>Thank you to Anne Flett who donated £2200 in memory of her late husband Dicky Flett</p> <p>We'd like to share our condolences with Tracey Lawry and The Lassman family. This year we lost Nigel Lawry and Ben Lassman, who were avid supporters of the charity.</p> <p>We helped a member by securing grants to help her home renovation in order to aid her mobility.</p> <p>We helped several members to get a second opinion with Mr Mario Teo on the NHS.</p>

#### **Additional information (optional)**

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	<p>We met our objectives, as we provided information, support, events, and raised awareness. Our Raspberry Day is having a bigger impact every year. This year's billboard was designed by Hamilton Brown, and it looked incredible! Thank you to JC Decaux for helping us spread the word in The UK.</p> <p>Our founder went to Northern Ireland and met with ministers at Stormont with our Irish representative Tracy Lewis, with the aim of registering the charity in Ireland too.</p>
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Performance of fundraising activities against objectives set	Para 1.41	Fundraising has been difficult this year. People are being squeezed for money and therefore have less to donate. We also didn't have our Facebook donate button (we are working to fix this), so we lost vital fundraising. We are looking at new ways to raise funds by giving members something back in return, like raffles etc. We are also taking part in bigger fundraising events, such as the London Marathon.
Investment performance against objectives	Para 1.41	<b>N/A</b>
Other		<b>N/A</b>

## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The Charity is performing consistently and sustainably. We are incredibly grateful to our members for fundraising and keeping the charity going, as well as our volunteers and trustees who dedicate their time to the charity to make sure that it is delivering its objectives.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Because we are only a small charity, we try to only hold back £500 in reserves to cover our website costs and annual insurance.
Amount of reserves held	Para 1.22	£500
Reasons for holding zero reserves	Para 1.22	
Details of fund materially in deficit	Para 1.24	
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	We have no uncertainties about the charity continuing to operate as we are in a stable financial position.

## Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	At the moment, our principal source of funds is monies raised by our members.
Investment policy and objectives including any social investment policy adopted	Para 1.46	N/A
A description of the principal risks facing the charity	Para 1.46	We need to continue to encourage our members to keep fundraising.
Other		

## Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Our Trustees are reviewed annually and we have to vote in a new trustee

## Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	Each trustee is sent the governing document and information from the Charity Commission.
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The charity's organisational structure and any wider network with which the charity works	Para 1.51	We are run by trustees and have no employees.
Relationship with any related parties	Para 1.51	<b>N/A</b>
Other		

### Reference and Administrative details

Charity name	Cavernoma Society
Other name the charity uses	
Registered charity number	1184406
Charity's principal address	5 Riverdale Gardens, Twickenham, TW1 2BX

### Corporate trustees – names of the directors at the date the report was approved

Director name		

### Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole	
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	year	

### **Funds held as custodian trustees on behalf of others**

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

### **Additional information (optional)**

#### **Names and addresses of advisers (Optional information)**

**Type of adviser      Name      Address**


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

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**Exemptions from disclosure**

Reason for non-disclosure of key personnel details

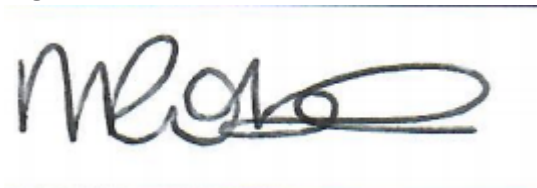
**Other optional information**

**Declarations**

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

Signed on behalf of the charity’s trustees

Signature(s)



Marie Robinson
Trustee

Full name(s)

Position (eg Secretary, Chair, etc)

Date: 29/11/2025



CHARITY COMMISSION  
FOR ENGLAND AND WALES

The Cavernoma Society

1184406

## Receipts and payments accounts

CC16a

For the period  
from

01/02/2024

To

31/01/2025

### Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
<b>A1 Receipts</b>					
Member fundraising	14,939		-	14,939	31,691
Retreat deposits			-	-	
Merchandise Sales	258	-	-	258	1,006
Savings		-	-	-	5,000
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b> (Gross income for AR)	15,197	-	-	15,197	37,697
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total receipts</b>	15,197	-	-	15,197	37,697

### A3 Payments

Running costs	1,264	-	-	1,264	2,146
Therapy	5,932	-	-	5,932	2,920
Postage	59	-	-	59	328
Services	1,485	-	-	1,485	-

Retreats	-	-	-	-	17,687
Chelsea Flower Show		-	-	-	15,827
misc	6,688	-	-	6,688	2,862
Merchandise		-	-	-	438
	-	-	-	-	-
<b>Sub total</b>	<b>15,428</b>	<b>-</b>	<b>-</b>	<b>15,428</b>	<b>42,208</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	
	-	-	-	-	
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	
<b>Total payments</b>	<b>15,428</b>	<b>-</b>	<b>-</b>	<b>15,428</b>	<b>42,208</b>
<b>Net of receipts/(payments)</b>	<b>- 231</b>	<b>-</b>	<b>-</b>	<b>- 231</b>	<b>- 4,511</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>- 231</b>	<b>-</b>	<b>-</b>	<b>- 231</b>	<b>- 4,511</b>

## 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 £
<b>B1 Cash funds</b>		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>4,724</b>		<b>-</b>
	(agree balances with receipts and payments account (s))	Agreement Error	OK	OK
		<b>Unrestricted funds</b>	<b>Restricted funds</b>	<b>Endowment funds</b>

**B2 Other monetary assets**

Details	to nearest £	to nearest £	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)
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-

## B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	
		-	
		-	
		-	
		-	

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

Signature	Print Name	Date of approval
	Simona Stankovska	29/11/2025
	Dr Marie Robinson	29/11/2025