



# Trustees' Annual Report for the period

		Period start date			Period end date		
From	1	Oct	2016	To	30	Sep	2017

## Section A Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

Postcode

### 1 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	David White	Chair	Existing Trustee	Annual General Meeting
2	Emily Fletcher		Existing Trustee	Annual General Meeting
3	Anna Farrar		Existing Trustee	Annual General Meeting
4	Roxanna Dixon		Existing Trustee	Annual General Meeting
5	David Scott		Existing Trustee	Annual General Meeting
6	Karen Bennett	Secretary	Existing Trustee	Annual General Meeting
7	Tabitha Kassem		Existing Trustee	Annual General Meeting
8	Peter Swinburne	Treasurer	Existing Trustee	Annual General Meeting
9	Simona Stankovska	Press Officer	Elected 2 May 2017 Confirmed at AGM	Board of Trustees
10	Dean Evans		Elected 2 September 2017	Board of Trustees
11				
12				
13				
14				
15				
16				
17				

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

Name	Dates acted if not for whole year

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

Type of adviser	Name	Address
Clinical medical adviser	Mr Neil Kitchen	National Hospital for Neurology and Neurosurgery
Clinical medical adviser	Professor Rustam Al-Shahi Salman	University of Edinburgh

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

Dr Ian Stuart - Co-ordinator

## 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)	Trust
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.

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.

CAUK provides information, support and services for those with cavernoma and their carers, providing the only readily available information in the UK. CAUK creates support networks and raises awareness among medical professionals.

We are a membership organisation, starting our year with 1305 members and ending with 1668, an increase of 363, an average of about 7 new members per week. Of these, 292 (80%) were from the UK and the other 71 from 29 other countries worldwide. Our members, and others who use our services, range from the parents of babies/young children who have been diagnosed to adults of all ages plus carers and relatives of those with cavernoma and medical professionals with an interest in cavernoma.

Of the 292 new UK members, 259 had a cavernoma (or were the guardians of children with cavernoma (15)). This is much greater than the number of new diagnoses in the UK (c.160) predicted from the literature.

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)

We have continued to provide:

- **Individual advice and support** (via the internet, email, phone, letter, or face-to-face)
- **Information Leaflets** - covering a range of issues that those diagnosed with cavernoma most commonly want to know
- An informative **Website**.
- **CaverBuddies** - a one-to-one relationship between new and experienced members
- **CaverFamilies** - a group for all families who have children with cavernoma.
- **CaverCentres** - groups of members in geographical proximity, meeting from time-to-time, sometimes with an invited guest to lead a discussion of interest
- **Annual Forum** - an opportunity to meet each other and medical professionals and share information and experiences
- **CaverHubs** - regional community events
- **Brain Awareness Week** talks - similar to CaverHubs but during Brain Awareness Week and targeted to wider audiences
- **CaverClinics** - for those with cavernomas to meet 1:1 with medical experts
- **CaverChat, Facebook Twitter and Instagram** - social media on-line discussion amongst members
- **Membership Database** - a vital resource to connect members with similar challenges, including members' stories
- **Research** - extend knowledge about cavernomas
- **Medical community** - raising awareness of the condition amongst the medical community

## STAFFING

We now have four part-time staff:

- Ian Stuart, CAUK founder and Co-ordinator
- Debbs Urch, Southern Community Worker
- Ailsa Crowe, Northern Community Worker
- Sian Oliphant, Communications and Administration Officer

## TRUSTEES

Nine of our ten Trustees either have, or are carers of individuals with cavernoma, as are Ian Stuart and our two community workers.

## MEETINGS AND EVENTS

### The 2017 CAUK International Forum

Following feedback from members, this year's Forum was held away from London for the first time, at the University of York.

Members heard talks from Dr Jenny Thomson, Clinical Geneticist, Chapel Allerton Hospital, Leeds, "*Genetics of Cerebral Cavernous Malformations*"; Mr. Nitin Mukerji, consultant neurosurgeon, James Cook University Hospital, "*Operating on Cavernomas in Difficult Places*"; Dr Connie Lee, President, and CEO, Angioma Alliance USA "*Moving Toward Better Cavernoma Treatments*"; Leon Rinkel, University of Groningen with Professor Rustam Al-Shahi Salman, University of Edinburgh, "*What's the quality of life for people with cavernomas? The results of a CAUK survey*".

There were also five workshops from which members chose two: "*Measuring quality of life with cavernoma: a focus group*" with Connie Lee; "*Singing for your body and brain*" with Dr Susie Mackenzie; "*Symptoms and practicalities of living with a cavernoma*" with Emma Tait and "*Surgery: preparing for the operation and dealing with life after*" with Simona Stankovska.

During lunchtime, Dean Evans acted as Auctioneer for four of Carolyn Nicholls paintings. These fetched the grand total of £2,350.

The Forum was preceded on the Friday evening with an informal supper attended by 64 members.

We held an informal get-together (a CaverMorning) on the morning after the Forum at the Priority Street Centre in York. During the morning, Paul Bennett taught us drumming on wonderful West-African drums, Simona Stankovska enabled us to develop our artistic talents and Dave Scott ran a session on volunteering for CAUK and CaverBuddies.

### Brain Awareness Week Lectures (March 2017)

We held four meetings (in Manchester, Glasgow, Sheffield and London) during the Dana Alliance New York's **Brain Awareness Week**.

- In Manchester, five consultants from the Royal Manchester Children's Hospital gave presentations on the theme "From conception to grand-parenting - the Cavernoma family journey": Dr Sue Huson, "Genetics of Cavernoma", Dr Dipak Ram, "Presentations of Cavernomas in Children", Dr Vivienne Tang, "Neuroimaging of cavernomas" Dr Catherine Pringle, "Neurosurgical procedures in Cavernomas" and Dr Grace Vassallo "Neurorehabilitation journeys for Cavernoma families".

- In Glasgow, Mr. Jerome St. George talked about cavernoma microsurgery.
- In Sheffield, Dr Kirsty Harkness talk was titled “Cerebral Cavernous Malformations”
- In London, Dr David Werring, presented a talk entitled “Cavernous Malformations - the neurologist's perspective”.

## **CAVERFAMILIES**

We had a two-day event in Slough/Windsor for CaverFamilies in April 2017. The first day was funded by Children in Need, and the second day by Legoland. The CiN day was in two parts (i) for the children and (ii) for their parents.

We held our fifth CaverFamilies residential weekend in mid-July at a campsite by the sea in Northumberland. This was run by Simona Stankovska with six volunteers. Eight families took part. The weekend was a mixture of fun activities for the children (and parents) including visiting a local zoo and a garden centre. The adults had sessions of Yoga and Reflexology and the families were offered individual therapy sessions from a Cognitive Behavioural Therapist.

In May, we were awarded a grant from Global, a consortium of independent radio stations in their children's charities “Global's Make Some Noise” programme with Simona Stankovska as project manager. Although the funding does not start until April 2018, Simona and members of CaverFamilies have spent time recording their experiences for promotion on the Global radio stations, and we will get wonderful publicity when these are broadcast in October.

## **CAVERCENTRES**

Three more CaverCentres were established during the year, in Milton Keynes, Plymouth and Norwich.

## **CAVERNOMA PRIORITY SETTING PARTNERSHIP (PSP)**

Ian Stuart and David White attended the Scientific Meeting of our sister US charity Angioma Alliance in November to learn about current research in the US, and to present the output of our findings from the PSP. See: [www.cavernoma.org.uk/psp](http://www.cavernoma.org.uk/psp)

## **INTERACTIONS WITH CLINICIANS**

### **Attendance at professional medical societies**

In order to increase our visibility with clinicians, Ian Stuart and our Community Workers attended the following meetings of professional medical societies, with a display stand: two meetings of the Society of British Neurological Surgeons, British Neurovascular Group, British Association of Neuroscience Nurses and the British Society of Neuroradiologists. In addition, we have written to all UK Medical Schools and Foundation programmes.

## **MEDICAL ADVISORY PANEL**

We have a Medical Advisory Panel. This expands the medical support we have always enjoyed from our two long-term medical advisors [Mr Neil Kitchen (neurosurgeon) and Professor Rustam Al-Shahi Salman (neurologist)] with new specialities [Dr Jennifer Thomson (clinical geneticist), Dr Grace Vassallo (paediatric neurologist), Dr Stewart Rust (Neuropsychologist) and Lesley Foulkes (a neurovascular nurse)]

## **PUBLICATIONS**

### **E-mailshots**

We have continued to publish a monthly e-mailshot which is sent to all members electronically.

### **Information Booklets**

We published two new information booklets during the year:

- a. *Spinal Cavernomas*, written by Mr Adrian Casey from the National Hospital for Neurology and Neurosurgery
- b. *Pregnancy, childbirth and Cavernoma*, written by Dr Patricia Spallone.

This brings our complement of information booklets to seven.

All of our published booklets have been awarded the Crystal Mark by the Plain English Campaign.

## **MEMBERS' DATABASE**

CAUK has probably the best database of people with cavernoma in the UK. Although this is kept securely and confidentially, it has been used on two occasions to run anonymous surveys during the year:

- For Genetic Alliance to provide evidence to the Human Fertilisation and Embryology Authority to register Preimplantation Genetic Diagnosis of carriers of the most severe genetic form of cavernoma, CCM3.
- For Professor Salman to determine the “Quality of Life of those with Cavernoma” as part of the evidence he needed to apply for funds for Clinical Trials for the top priority research project identified in the Priority Setting Partnership (see above).

## **MEMBERSHIPS**

CAUK is a member of Neurological Alliance, National Voices, NCVO, Findacure, Brain & Spine Foundation and Rare Diseases UK.

The above all comply with the guidance issued by the Charity Commission on public benefit.

## Additional details of objectives and activities (Optional information)

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

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

Volunteers play an important part in our activities and the support we provide, including:

- A Trustee (David Scott) who is also the Volunteer Co-ordinator
- A Trustee (Simona Stankovska) who is also our Press Officer
- A CaverBuddy Co-ordinator and 15 CaverBuddies, all of whom have been trained with a new training programme
- A group of volunteers who distribute our literature to hospitals and GP surgeries
- Ten Trustees, of whom nine are either patients or carers of individuals with cavernoma
- A volunteer who helps Ian Stuart in the office one day per week.

Summary of the main achievements of the charity during the year

CAUK's main achievements this reporting year have been:

1. The help and support that we have given to the 363 new members who have joined CAUK. This is an increase of a 60% on last year. Of these new members, 292 were from the UK and 71 came from 29 other countries worldwide, a reflection of our international impact. A major part of our work is providing this support to individuals (largely unseen by others) who have just been diagnosed with cavernoma, particularly in the days immediately following diagnosis.
2. The efforts we have made to improve awareness of cavernoma among medical professionals, resulting in an increase in the number of members learning about CAUK from their medical consultants, and showing a confidence on their part of CAUK's quality. These efforts include attending the professional societies of key medical organisations at which we maintain a 'stand' with our literature: Society of British Neurological Surgeons, British Neurovascular Group, British Association of Neuroscience Nurses and the British Society of Neuroradiologists. We have sent information packs to 234 neurologists, and have lobbied all 40 medical schools and 18 foundation schools in England to ensure that cavernoma is taught to all medical students.
3. CAUK Forum, held away from London for the first time, in York with 86 attendees; 5 CaverHub or Brain Awareness Week meetings in Birmingham, Newcastle, Sheffield, London x2; CaverFamilies events (Residential weekend at a Campsite in Northumberland, Royal Manchester Children's Hospital with children's neuroscience nurse with 2 families); 5 CaverCentre meetings.
3. Social Media: we have 737 members on our secret CAUK Facebook site who averaged 4 originating posts with 28 comments per day, with 487 Twitter and 112 Instagram followers.
4. There were 34,840 visits to our website, up 64% from last year.
5. We published two new information booklets: on *Spinal Cavernomas* and *Pregnancy, Childbirth and Cavernoma*
6. We appointed a second Community Worker, Ailsa Crowe, to have responsibility for the north of England and the devolved countries of the UK.
7. We were one of the "Charities of the Year" of the Mayors of both Richmond (in London) and Dorchester.
8. A major award from Global's Make Some Noise for children with cavernoma (starting in April 2018), ensuring that we have funds for an extended programme for children and young persons (up to 26-year-old) with cavernoma.

**Section E Financial review**

**Brief statement of the charity’s policy on reserves**

The Charity's policy on reserves was revised slightly, and is now (with an additional phrase in italics) “to retain a minimum reserve of 50% of the UNRES expenditure and 33% of the Big Step expenditure, *except that if the expenditure figures are abnormally high or low then the minimum reserve is based on the budget.*”

**Details of any funds materially in deficit**

None

## 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.

The five-year Big Lottery grant continues to be our major single source of funds, providing salaries for three part-time staff as well as running costs for an ambitious development programme. This report is roughly co-extensive with the third year of the Big Lottery award which this year funded about 60% of the Big Step project.

We are very grateful to the following for their generous grants awarded during this reporting period:

- The Alice Ellen Cooper Dean Charitable Foundation for a grant of £10,000 for our general funds.

We are also very grateful to the large number of members and friends of CAUK who raised over £60,000 from fundraising events and donations. We value all contributions, but wish to mention the following for eclectic reasons:

- The production by Simona Stankovska of a play (farce) in a London theatre over a weekend in aid of CAUK "It Runs in the Family" by Ray Clooney.
- A Masquerade Ball held by Ellie and Dean Evans.
- Gift of four paintings by Carolyn Nicholls that were auctioned at the Forum.

## Section F Other optional information

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## Section G Declaration

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

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	David Clifford Stephen White	Peter Swinburne
Position (eg Secretary, Chair, etc)	Chair	
Date		



# Independent examiner's report on the accounts

## Section A

## Independent Examiner's Report

<b>Report to the trustees/ members of</b>	Charity Name Cavernoma Alliance UK		
<b>On accounts for the year ended</b>	30 September 2017	<b>Charity no (if any)</b>	1114145
<b>Set out on pages</b>	12 and 13 – Receipts and payments accounts form CC16a <small>(remember to include the page numbers of additional sheets)</small>		

### Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

### Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

### Independent examiner's statement

In connection with my examination, no matter has come to my attention

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
  - to keep accounting records in accordance with section 130 of the Charities Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

**Signed:**  **Date:**

**Name:** I M Carrington MA FCA

**Address:** Edwards and Keeping, Chartered Accountants  
Unity Chambers, 34 High East Street, Dorchester, Dorset DT1 1HA



Charity Name Cavernoma Alliance UK	No (if any) 1114145
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CC16a

## Receipts and payments accounts

For the period from	Period start date 01-Oct-16	To	Period end date 30-Sep-17
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### Section A Receipts and payments

	Unrestricted funds to the nearest £	Big Step Restricted funds to the nearest £	Other restricted funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Fundraising and donations	66,820			66,820	64,349
Lottery Grant		30,063		30,063	44,355
Other Grants	11,000		4,750	15,750	28,600
Other income	193			193	1,603
Interest	23			23	36
				-	-
				-	-
				-	-
				-	-
<b>Sub total (Gross income for AR)</b>	<b>78,036</b>	<b>30,063</b>	<b>4,750</b>	<b>112,849</b>	<b>138,943</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>78,036</b>	<b>30,063</b>	<b>4,750</b>	<b>112,849</b>	<b>138,943</b>
<b>A3 Payments</b>					
Salaries, Ni and pensions	1,111	35,223		36,334	55,033
Recruitment	127	1,291		1,418	610
Training		283		283	798
Consultancy(Finance & Website)	3,599	3,598		7,197	5,395
Payroll & Audit	468	468		936	792
Premises Costs	7,032	7,032		14,064	6,631
Telephone & Broadband	777	777		1,554	1,529
General Running expenses	3,990	3,255		7,245	5,081
Fundraising costs	5,574			5,574	12,652
Travel	272	6,501		6,773	5,254
Annual Forum Costs	9,525			9,525	10,185
Volunteer Costs (restricted)			1,613	1,613	387
Welfare Fund (restricted)			265	265	5,068
Regional expansion		4,061		4,061	7,070
CaverFamilies	7,857			7,857	-
CIN Project			2,348	2,348	8,565
PSP project				-	7,941
Other Events & Publications	1,183		650	1,833	486
Information packs				-	4,224
Other costs -insurance	217	217		434	437
				-	-
<b>Sub total</b>	<b>41,732</b>	<b>62,706</b>	<b>4,876</b>	<b>109,314</b>	<b>138,138</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>41,732</b>	<b>62,706</b>	<b>4,876</b>	<b>109,314</b>	<b>138,138</b>
<b>Net of receipts/(payments)</b>	<b>36,304</b>	<b>(32,643)</b>	<b>(126)</b>	<b>3,535</b>	<b>805</b>
<b>A5 Transfers between funds</b>	<b>(41,449)</b>	<b>40,786</b>	<b>663</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>46,870</b>	<b>22,254</b>	<b>9,407</b>	<b>78,531</b>	<b>77,726</b>
<b>Cash funds this year end</b>	<b>41,725</b>	<b>30,397</b>	<b>9,944</b>	<b>82,066</b>	<b>78,531</b>

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

Categories	Details	Unrestricted funds to nearest £	Big Step restricted funds to nearest £	Other restricted funds to nearest £
<b>B1 Cash funds</b>	Current accounts	18,934	-	-
	Deposit accounts	22,724	30,397	9,944
	PayPal	67	-	-
	<b>Total cash funds</b>	<b>41,725</b>	<b>30,397</b>	<b>9,944</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK

**NOTE: Unrestricted reserves at £41,726 are in line with the Charity's policy on reserves which states that 6 months of annual general charity operating cost and 4 months of Big Step annual operating cost are retained as a designated reserve. Based on 2016/2017 costs the reserves figure would be £41,768.**

Categories	Details	Unrestricted funds to nearest £	Big Step restricted funds to nearest £	Other restricted funds to nearest £
<b>B2 Other monetary assets</b>	Outstanding Gift Aid	1,500	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B3 Investment assets</b>			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>	HP notebook computer	Big Step fund	-	-
	2 NEC computer monitors	Big Step fund	-	-
	Bookcase, desk and filing cabinet	Big Step fund	-	-
	5 Chairs	Big Step fund	-	-
	Other office furniture & equipment	Unrestricted fund	-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>	Independent examination	Unrestricted fund	660	
			-	
			-	

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

Signature	Print Name	Date of approval
	D White	
	P Swinburne	