

Collaboration Agreement

Cavernoma Alliance UK (CAUK) and The Cavernoma Society (TCS) wish to collaborate for the benefit of the Cavernoma community worldwide. This agreement defines a framework for the collaboration and the standards expected by each organisation.

Specific behaviours are required from all trustees, employees, support staff and volunteers in order to put the agreement into practice. The Chair of the Board of Trustees, and an authorised representative of the Chair of each charity, have signed the Collaboration Agreement on behalf of their respective organisation. Through their signatures they pledge to uphold the agreed standards of behaviour and four core values that underpin the agreement. These are listed below:

- Trust
- Openness
- Transparency
- Integrity

TRUST

1. THE CAUK and TCS chairs and one other trustee or officer agree to meet regularly (quarterly) to build trust and monitor the implementation of this agreement.

The first meeting will be no more than two months after signature of this agreement.

OPENNESS

2. Once the agreement has been approved by each charities' trustees, both organisations will agree a joint announcement that will be placed on their respective social media platforms to explain the planned co-operation to their members. Both charities will ensure that those working for, and/or volunteering for their organisations will be made aware of the details of the agreement and their responsibilities therein.
3. In the event of any potential breach of this agreement by any member of staff, formal volunteer or trustee. The chair of one charity will contact the chair of the other to inform them of the potential breach as soon as possible. Wherever possible the matter will be investigated, discussed and resolved to the mutual satisfaction of both parties within 5 working days.

TRANSPARENCY

4. Both charities agree to advertise and promote the functions and events of the other charity and both will try to maintain a balance of giving and taking. Wherever possible, at least three weeks' notice should be given before any period of promotion. If this is not possible, late requests can be sent and each charity will try to accommodate the request.
5. All requests should be sent to the CEO or a designated contact (see appendices i and ii for details). Each charity reserves the right to decline a request for promotion if it believes an event is inappropriate or unworthy. The reasons for this decision will be provided to the CEO and or the Chair of the requesting charity.
6. Both charities agree to promote and support the imminent CARE pilot trial and will inform patients diagnosed with cavernoma about the trial in a positive way. Anyone interested in participating in the trial will be forwarded details of an appropriate participating clinician. CAUK will share information about the trial, which will be available on the CAUK website, with TCS. CAUK will connect patients interested in participating in the trial with an appropriate Consultant Cavernoma Contact in the CARE pilot trial network.


INTEGRITY

7. Both charities will ensure that they recognise the existence of the other and will always do so in positive terms. Both charities will never imply that they are the only cavernoma charity.
8. Both charities respect that members may choose to be members of either one or both organisations. There will be no attempt by either charity to poach members from the other charity.
9. Both charities agree that there will be no correspondence via any medium from employees, formal volunteers or trustees of either charity that could be interpreted as denigrating the character of an individual or their organisation. Wherever possible, any potential breach will be reported by one chair to the other within 24 hours and the matter will be investigated, discussed and resolved to the mutual satisfaction of both parties within 5 working days.
10. Employees, volunteers and trustees of one charity will never make adverse comments about the other charity to any member of the public or groups of people via any medium. Wherever possible any potential breach will be reported by one


chair to the other within 24 hours and the matter will be investigated, discussed and resolved to the mutual satisfaction of both parties within 5 working days.

11. Both charities agree not to copy content from the other charity without prior consent. If such agreement is given, the source of the copied content must be clearly specified. This applies to documentation that is largely the same but has been changed only cosmetically.
12. If one charity posts an event on a social media site, the other charity will not promote a similar event within 72 hours without prior agreement. If agreement is given, the new post will include a link to the original and a full acknowledgment of the source.

Signed for and on behalf of the Cavernoma Alliance UK:


Mark Farrar (Chair) 
Mark Farrar (Nov 24, 2020 11:22 GMT)

Date: Nov 24, 2020


Sharon Veiger (Trustee) 
Sharon Veiger (Nov 24, 2020 17:08 GMT)

Date: Nov 24, 2020

Signed for and on behalf of The Cavernoma Society:

Hugh Browne (Chair) 
Hugh M. Browne (Nov 24, 2020 19:09 GMT)

Date: Nov 24, 2020

Simona Stankovska (Trustee) 
simona stankovska (Nov 24, 2020 19:18 GMT)

Date: Nov 24, 2020

Appendix i:

Cavernoma Alliance UK
Unit 601 (CAUK) 20,
The Grove Industrial Estate,
Dorchester Dorset
DT1 1ST
T: 01305 213876

Contacts:

Chair – Mark Farrar (treasurer@cavernoma.org.uk)
Trustee – Sharon Veiger (Sharon@cavernoma.org.uk)

Appendix ii:

The Cavernoma Society
4 Arlington Court
Arlington Road
Twickenham, Middlesex
TW1 2AU
T: 0330 1224470

Contacts:

Chair – Hugh Browne (chair@cavernomasociety.org.uk)
Trustee – Simona Stankovska (simona@cavernomasociety.org.uk)