



# Terms of Reference

## Cavernoma Alliance UK Advisory Board

### 1. Purpose

The purpose of the Cavernoma Alliance UK (CAUK) Advisory Board is as follows:

- Contributing to and reviewing information resources produced by CAUK for the benefit of patients, supporters and clinicians.
- Updating CAUK on advancements in the treatment of cavernoma patients informing updates to information resources and topics for webinars/lectures
- Providing both CAUK and clinicians with a forum to share two-way feedback to help inform and develop mutual understanding about the needs of patients
- Working collaboratively to identify opportunities to drive up standards of care for cavernoma patients UK wide, promoting best practice
- Identifying and working collaboratively where research opportunities arise that will benefit cavernoma patients and their supporters

### 2. Remit

The remit of the CAUK Advisory Board is not to make decisions, but rather to provide current knowledge, critical thinking and analysis to increase the confidence of the decision-makers who represent CAUK. This remit is different to that of the CAUK Board of Trustees or CAUK management.

### 3. Membership

Membership of the CAUK Advisory Board will be representative of the needs of cavernoma patients, including patients of all ages. Membership will also be reflective of CAUK's research interests, which are currently as follows as defined by the CAUK Board of Trustees:

- CARE Study (Professor Rustam Al-Shahi Salman)
- Novel Gene Therapy (Dr Rajvinder Karda)
- Female Hormone Therapy (Dr Yvonne Zuurbier)
- Diagnostic Imaging and Artificial Intelligence
- Mental Health

There are no set terms of office for membership of the CAUK Advisory Board, and appointment will be at the discretion of the CAUK Advisory Board Chair and the CAUK Charity Manager. There will be two formal roles within the CAUK Advisory Board, namely that of Chair and Secretary.



The Chair will be responsible for setting the agenda oversee the running of each meeting, ensuring they run to time. The Secretary will be responsible for circulating papers in advance of the meeting, taking minutes and assisting with any other administrative requirements.

#### **4. Frequency of meetings and availability**

Meetings will take place twice a year in the months of April and September. Meetings will be held virtually using Zoom and will typically take place on a Wednesday or Thursday evening from 5pm to 6pm. Papers will be sent at least 2 weeks in advance of each meeting. In order for the meeting to be conducted in the time available it will be essential for board members to pre-read the papers.

At the end of each meeting the date for the next meeting will be set. Members are expected to attend a minimum of one meeting a year. If a member is unable to attend a meeting then apologies should be sent to [admin@cavernoma.org.uk](mailto:admin@cavernoma.org.uk). If a member doesn't attend two consecutive meetings then a discussion will be had about their commitment. If a member doesn't attend three consecutive meetings then their membership will be rescinded and a replacement identified.

#### **5. Working practices**

From time to time through-out the year CAUK may contact members of the CAUK Advisory Board asking them for comment on information resources, inviting them to speak at a CAUK event, or aiding with a CAUK helpline enquiry. These communications will be infrequent and will never involve asking the member to provide clinical advice in respect of an individual patient.

If a communication is addressed to all members of the CAUK Advisory Board, then it is at the discretion of each member as to whether or not they reply unless there is a stated requirement for all members to reply. If a communication is addressed to individual member then it would be much appreciated if a response could be sent within 5 working days, excluding holidays.

#### **6. Conflicts of interest and confidentiality**

Members will be required to disclose conflicts of interest at the start of each meeting. Members will also be expected to maintain strict confidentiality, and not disclose information shared during the meeting without the prior consent of the Chair unless the information is already in the public domain. Any questions or concerns in respect of this should be addressed to [admin@cavernoma.org.uk](mailto:admin@cavernoma.org.uk).