



by Will Sears (thank you)

15th Cavernoma Alliance UK International Annual
Forum
Saturday 26th June 2021

Welcome

A very big welcome to our 2021 Annual Forum. This is a virtual meeting again, but closer to the format of our normal in-person Forums.

We have arranged it so that you can come and go as you like - to return simply use the access link that you have been sent. If you have problems please phone me or David White on our CAUK number 07775 194042.

In addition to three Keynote Speakers and our Annual General Meeting we have created a set of Breakout Rooms similar to the Pods of earlier years - these are described elsewhere in this leaflet.

I look forward to seeing you on 26th June.

Jo

The Forum

This year's forum is an all-day Zoom meeting, with three very interesting main talks, a number of 'breakout rooms' and our Annual General Meeting.

You can come and go as you please, so you can leave the meeting and rejoin using the link that you were given when you registered whenever you wish.

The 'breakout rooms' will be open between midday and two o'clock. You can join and leave them as you wish. Some will be devoted to particular topics, with a host to can lead the discussion. One will be a 'chat room' for people to meet others informally. In addition, you can book your own room to meet a group of friends on your own - just let us know, even on the day itself.

The Annual General Meeting (AGM) is an important part of the day, and is a chance to hear what CAUK is planning for the future and to feed your own ideas into this.

Biographies



Professor Rustam Al-Shahi Salman

Professor of clinical neurology, clinical director of Edinburgh Clinical Trials Unit at The University of Edinburgh

Professor Salman has been CAUK's advisor on neurology for many years. He has authored many of the pivotal papers on cavernoma and has had a long interest in obtaining high-quality evidence for the optimal treatment of cavernoma. This has culminated in the CARE Study, the subject of his discussion with Mr Kitchen at this meeting.



Mr Neil Kitchen

Consultant Neurosurgeon, National Hospital for Neurology and Neurosurgery, Queen Square, London

Mr Kitchen has been CAUK's advisor on neurosurgery for many years. He has long experience of the neurosurgery and stereotactic neurosurgery of cavernoma. He is currently the immediate past President of the Society of British Neurosurgeons, and is the co-chief investigator of the team running the CARE Study.



Mr Bassel Zebian

Consultant Paediatric and Adult Neurosurgeon, King's College Hospital NHS Foundation Trust

Mr Zebian is a consultant neurosurgeon specialised in the management of brain and spine lesions and malformations, including cavernomas, in both adults and children. He is a leader in the field of minimally invasive neurosurgery, with approaches that have allowed access to previously inaccessible lesions and their removal.



Dr Lina Nashef

Consultant Neurologist and Reader, Kings College Hospital NHS Foundation Trust

Lina Nashef co-authored the Oxford Specialist Handbook on epilepsy and has co-edited a textbook on Neurology and Pregnancy. Her research field included mortality and sudden death in epilepsy. She was previously a trustee of Epilepsy Research UK and has served as a council member of the Association of British Neurologists.

Program

10:00	Mr Neil Kitchen and Professor Rustam Al-Shahi Salman <i>Cavernomas: A Randomised Effectiveness (CARE) Study</i> There is insufficient evidence to inform everyday decisions in clinical practice about whether to treat cavernoma with or without surgery. This can leave doctors and patients uncertain about whether to use surgery. Answering this uncertainty is the top priority for research into cavernoma and the subject of the pilot CARE Study which has just started recruiting patients.
11:00	AGM
12:00 - 14:00	Breakouts
	» Brainstem Cavernoma Host: Ian Stuart
	» Cavernoma Genetics Host: David White
	» CaverFamilies Host: Ann Atkins
	» Epilepsy Host: Katrina Bottle (specialist epilepsy nurse)
	» Just Chat Host: Tracey Hammond
	» International Collaboration Host: Jana Bergholtz (CASE and ECA)
	» Book your own room If you would like your own room to chat with friends, let us know
14:00	Mr Bassel Zebian <i>Minimally invasive approaches, cavernomas and decision making in neurosurgery</i>
15:00	Dr Lina Nashef <i>Cavernoma and epilepsy</i>

Annual General Meeting

There is a separate leaflet for the AGM with a separate file for the draft of the new Constitution



ANNUAL GENERAL MEETING 2021

SATURDAY 26th June 2021

11:00 a.m. to 11:45 a.m.

1. Minutes of the Annual General Meeting 2020
2. Matters Arising
3. Report from the Chair – Mark Farrar
4. Report from the Treasurer – Joe Freeman
5. Report from the CEO – Jo Noakes
6. Report from the Scientific Advisor - David White
7. Change from a Charity to a Charitable Incorporated Organisation
8. Election of Trustees
9. Any Other Business
10. Close of Formal Business

Breakouts

We are making use of Zoom's 'Breakout Rooms' facility to enable there to be several simultaneous things happening between the AGM and the first of the afternoon's important talks.

They build on the Pods we introduced in 2019. Each of one group of rooms will be dedicated to a particular topic, with someone familiar with that topic acting as a host. You may come and go between topics at will and take part in the discussion as you wish. This worked amazingly well when face-to-face, and we expect it will do so again.

One room is given over to a general chat.

Also, if you wish to have your own room so as to get together in a group of your own, please let us know and we can set up a Breakout Room for you.

To enter a Breakout Room, use the 'Breakout Rooms' button on your Zoom Screen. You can move from one room to another or back to the main meeting using this button.