



## International Cavernoma Alliance UK Forum 2010

Dear Members, Associate Members, Honorary Members, Carers and Friends of Cavernoma Alliance UK,

The Board of Trustees would like to invite you to attend the International Cavernoma Alliance UK Forum on Saturday 5<sup>th</sup> June 2010. It will be held at the Orion Suite, Grange Holborn Hotel, 50-60 Southampton Row, London WC1B 4AR from 09.00 to 17.00. The Grange Holborn's website is <http://tr.im/N0Ip>

- THE COST

Ever since the Forum began four years ago, the Board have always maintained that everyone should have free access to the Forum. So, as always, the event is **free** and includes a buffet-style lunch to all registered participants. To register, please contact [info@cavernoma.org.uk](mailto:info@cavernoma.org.uk)

On an "as needed" basis Cavernoma Alliance UK can also meet UK travelling costs. This concession is available with prior clearance only. Gift-aided, voluntary contributions are always accepted. Please see our Treasurer, Jon Anderson, at break-time.

- SUPPORT

Last year, many more members registered for the Forum than actually attended. Please come along and support our charity. The neurologists, neurosurgeons and geneticists who attend give freely of their time, and we should show our support for them. With little money, the indulgence of the Grange Holborn Hotel, and the support of our sponsors - many of which are you - Cavernoma Alliance UK organises and finances this International Forum. Attendance at this London meeting is essential. Former international speakers have included Professor Awad from America and last year the Alistair William MacQueen Memorial Lecture allowed Professor Dr. Helmut Bertalanffy from Zurich to be amongst us.

(Dr. Bertalanffy's lecture along with other neurologists, geneticists and neurosurgeons from 2007-2009 are available on our website. Please visit <http://tr.im/MgRm> to access these talks.)

- ANNOUNCEMENT

This year the Board is pleased to announce the 2010 keynote speaker is Dr. Amy Akers, Chief Scientific Officer of Angioma Alliance in America. Dr. Akers has been described as "the one person in the world best able to present an overview of research developments across the spectrum".

- THE MORNING

The International Cavernoma Alliance UK Forum 2010 begins with registration at 8.30 on the 1st floor of the hotel, followed at 8.50 by a welcome from me, Ian Stuart, member and co-ordinator.

At 9.00 our first speaker is Dr. Jonathan Berg, Senior Lecturer and Consultant in Clinical Genetics, Ninewells Hospital and Medical School, Dundee.

Dr. Berg will be followed at 9.50 by Dr. Rustam Al-Shahi Salman, Honorary consultant neurologist, Department of Clinical Neurosciences, Western General Hospital, Edinburgh and a Cavernoma Alliance UK medical adviser. Dr. Salman will speak until 10.30, and his talk will be followed by questions.

Morning coffee will be served in the Pegasus Suite at 10.45.

At 11.15 Mr. Neil Kitchen, consultant neurosurgeon, National Hospital for Neurology and Neurosurgery, and senior medical adviser, Cavernoma Alliance UK, will give a presentation on cavernomas and answer members' questions.

Finally at Cavernoma Alliance UK presents a lecture to members from Dr. Amy Akers from North Carolina, USA, followed by questions from the floor.

NB: speakers and timings may be subject to change.

- THE AFTERNOON

Following a one hour lunch break at 13.00 members gather at 14.00 (sharp) for structured but informal workshops. As with previous years' workshops, these occur in the Orion Suite where, during lunch, partitions will have been erected to form break-out rooms. At this point there are four workshops to choose from. These workshops will be repeated twice during the afternoon. Emma Ramsay will facilitate a workshop on living with the impact of cavernoma; Tabitha Bushill will talk about epilepsy and cavernoma (calling upon her recent operation for cavernoma removal by awake craniotomy); Joanne Smith and Adrian will run a workshop on having multiple cavernomas; and Lois will coordinate a discussion for carers. A comfort break for Forum participants occurs between 15.45 and 16.15 during which time tea will be served in the Pegasus Suite.

At 16.15 Members, Associate Members, Honorary Members, Carers and Friends of Cavernoma Alliance UK are invited to discuss the Forum and the charity's work at the 2010-11 Annual General Meeting. The Forum will be finished by 17.00.

- ACCOMMODATION

Reduced-rate accommodation is available at the five-star **Grange Holborn Hotel** (street address above). The normal rate in June is around £275 per night. But for those attending the Cavernoma Alliance UK Forum the figure is reduced to £85.00 plus VAT (17.5%) for Friday 4th June and £90.00 plus VAT for Saturday 5th June 2010. You may want to look at the hotel's **website** for more information (Based on both the 2008 and 2009 Forum, I can recommend the Grange Holborn without hesitation.) Situated in Bloomsbury, the Hotel is five minutes walk from Holborn tube station on the central line. Talk with the hotel about parking.

- BOOKING YOUR OWN ACCOMMODATION

You need to make your own bookings by calling Cavernoma Alliance UK's contact, Nandita Rai, at the Central Reservations Office, telephone 0845 450 4400 quoting reference number 040610N. To hold the room a credit/debit card will be needed. No charge is made against the card until the member leaves the hotel. At that point the cardholder will be able to choose

whether they prefer to use their credit card or pay in cash. Upon calling, members should also state whether both nights of Friday 4th and Saturday 5th June 2010 are required or simply one night. Hotel bookings need to be made **no later than 31 March 2010**. So don't delay; book today. It will soon be March! At the time of booking, please indicate whether a double or twin bedded room is required. NB. The price is for the room NOT the person so you can save money by sharing. Maybe the (under-used) Cavernoma Alliance UK cavernoma-chat mailing list might be a good posting site for members of the same gender wishing to share a room?

- ALTERNATIVE ACCOMMODATION

The Grange Holborn offers exceptional value and it's hard to find good alternatives in London. However, I can recommend [The Crescent Hotel](#), 49-50 Cartwright Gardens, Bloomsbury, London WC1H 9EL. Telephone: 020 7387 1515; Fax: 020 7383 2054. At the time of writing, the Crescent Hotel has rooms from £51 inclusive of cooked breakfast and VAT. The hotel is about twelve minutes' walk to the Grange Holborn Hotel. Also members can look in the London suburbs for less expensive accommodation. (Remember, though, registration commences at 08.30 and you need to allow plenty of time to get to us.)

- CONCESSIONARY TRAVEL TO THE FORUM

If you have difficulty with mobility issues, especially if you are in receipt of disability living allowance (DLA) or can't drive for medical reasons then you should be able to get a disabled person's railcard. The advantage of having this card is that you AND the person travelling with you get a third-off train fares anywhere in the country for one or three years (renewable) at any time, not just off peak. Application forms should be available at your local railway station or [online](#).

Warmest wishes,

Ian

Ian Stuart Ph.D.

Member and Co-ordinator, Cavernoma Alliance UK  
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