Cavernoma Alliance UK - July 2015 e-mailshot

Note that as of February 2011 mailshots are personalised for each member so the personalisation has been replaced with "XXX" where appropriate.

Welcome from all the team

This month's bumper e-mailshot from CAUK includes news on:

- Tenth Anniversary Launch
- New Logo and Website
- The Ninth Annual International CAUK Forum
- Annual General Meeting
- Tenth Anniversary Launch
- Upcoming Events
- Media Enquiries
- Review other several exciting events in May and June
- Fundraisers

TENTH ANNIVERSARY

Many of you will be aware that CAUK has been in existence since 2005. Ian Stuart, founder and co-ordinator created CAUK from his bedroom in Dorchester and has overseen the development from humble beginnings all of those years ago to date.
In 2013, CAUK received a grant from the National Lottery for £193,000. This enabled CAUK to launch the 'Big Step' project. This grant has given CAUK the resources to develop its membership from 600 to in excess of 950.

Get Involved

CAUK is planning an action-packed year and is encouraging members and supporters to join in and raise awareness and funds. You may be interested in helping with:

- Christmas Appeal to be launched in November.
- Organising a local event, such as walks or tea parties
- We are naming March 2016 as Cavernoma Alliance UK month, to run alongside Brain Awareness Week
- 10th Anniversary reception, Friday 10 June 2016
- Attend the 10th International Forum, Saturday 11 June 2016

Please get in touch with a member of the team if you would like to be involved and volunteer for any of the above events. If you have any ideas of your own, then please let us know and we will be happy to support you. Contact David Scott, Volunteer Co-ordinator, Paul Cooper, Fundraising and Development Manager or Angie Yeomans, Community Worker.

CAUK would like to thank all its members, some of whom have been here from the beginning and some as recent as this month. Without you there is no CAUK; please keep sharing and raising awareness of cavernoma. It would be fantastic if this cavernoma was a more 'known', than unknown condition.

NEW LOGO AND WEBSITE

To coincide with the launch of the Tenth Anniversary celebrations, CAUK is pleased to officially introduce our new logo and website.

The updated logo is still recognisable as CAUK, with a modern look and will gradually be applied to all new merchandise and literature over the next few months.
Feedback from the External Review we had in 2014 and our members confirmed that our current website was very useful and had excellent content but also that CAUK needed a more modern look website that connected people more to CAUK. We teamed up with Richard Smith at Computersmiths and have produced a website with a fresher look while still keeping aspects of our original identity. We hope our members will find it engaging and supportive. It will be launched soon after testing. Here is a sneak preview of the homepage.
THE NINTH INTERNATIONAL CAVERNOMA ALLIANCE UK FORUM 2015

The Ninth International Cavernoma Alliance UK (CAUK) Forum was exciting for a number of reasons. The Forum brought together members from all over the country enabling them to exchange valuable information and ideas in a unique and safe environment. The Forum hosted a range of important speakers as well as launching its tenth anniversary year - CAUK was founded in 2005 as a result of insufficient information among both the general public and medical community.
Our keynote speaker was a leader in clinical genetics from Dundee, Dr. Jonathan Berg, who discussed in easily-understood terms the complex role of genetics in clinical management.

Dr Berg was a guest speaker at our very first Forum in 2007.
For the first time this year, CAUK ran two parallel sessions: on "PGD, Pregnancy and Cavernoma" and "The Psychological Effects of Living With a Cavernoma" (this session was broadcast live throughout the world using Periscope - a secure service only available, at the moment, through Apple's iPhone).

This year, we held the AGM in the middle of the Forum, after the two sessions above, and a report on the AGM follows.

After lunch, CAUK members participated in two of the six workshops available with topics including Mindfulness, Cavernoma Surgery and a talk on the Expert Patient Programme.
The final talk was given by Dr Tim Wehner, a consultant neurologist, specialising in cavernoma and epilepsy. With the exception of Dr Wehner's talk, much of the Forum was recorded and will shortly be made available for those members unable to attend, on the CAUK website.

The Annual General Meeting saw the election of trustees.

Tim Millward FCA retired as a Trustee from the date of the Forum, having seen CAUK from a small
organisation run entirely by volunteers, to a much larger body with with two offices and four full and part-time employees, and Ian Stuart paid tribute to the immense amount of time Tim had devoted to us over that time, keeping us on the straight and narrow, not just financially but with a host of other advice. He had also been the acting Secretary.

The meeting re-elected the other Trustees: Roxanna Dixon, Anna Farrar, Emily Fletcher, Simon Temple, Ahmed Toma and David White, and elected David Scott and Karen Bennett as new Trustees, with Karen becoming our new Secretary.

After the formal business, the AGM also saw an introduction by Paul Cooper, CAUK's fundraising and development manager, who discussed his role with members and fundraising strategy. David Scott, recently appointed CAUK trustee and volunteer coordinator, spoke of the charity's need for help in all aspects of CAUK's work and David White, CAUK's chair, discussed the Priority Setting Partnership with its selection of cavernoma research questions submitted by members and clinicians coming to a conclusion in September.

Although the section on the new website, shortly to go into its testing phase, was introduced by David White, most of the work on the website was undertaken by Sophie Eldridge, CAUK's part-time administrator. With its new logo and easy-to-follow sections including pictures of members' fundraising, the exciting new website is a fitting tribute to a great start of an exciting tenth anniversary year.

THE CAUK RE-ELECTED BOARD OF VOLUNTARY TRUSTEES AND STAFF
GATHERING FOR A RECENT BOARD MEETING IN DORSET

UPCOMING EVENTS

Liverpool CaverCentre

You are invited to attend CAUK's second CaverCentre meeting on Saturday 25 July 2015, 11.00 - 14.30 at Neosupport, Norton Street, Liverpool, L3 8LR. As many of you already know, CAUK's first CaverCentre meeting in November 2014 proved very popular and was a great success. Please join CAUK for this free event - tea, coffee, juice and a light lunch will be provided. Many thanks to Clare Prince and Rachel Edwards, CAUK's part-time administrator. With its new logo and easy-to-follow sections including pictures of members' fundraising, the exciting new website is a fitting tribute to a great start of an exciting tenth anniversary year.

https://member.cavernoma.org.uk/opus1085.html
COULD YOU HELP WITH MEDIA ENQUIRIES?

Thanks to the kindness of CAUK members, the charity now has five volunteers who would be willing to talk to the local and national media regarding cavernoma and the effect the condition has had on their life. CAUK would still like a few more members to come forward, particularly from Wales, the Midlands, North England and Scotland. Contact: Paul Cooper, Fundraising and Development Manager, fundraising@cavernoma.org.uk

REPORT ON EVENTS IN MAY AND JUNE

North East Development

At the beginning of June, Angie travelled to the North East for five days. The purpose of this journey was to raise awareness, encourage more members and build stronger relations with other neurological charities. CAUK is underrepresented in the North East in comparison to the rest of England.

Angie met with Jo Cole, Head of Operations, Tees Valley, Durham and North Yorkshire Neurological Alliance (TVDNY), at the Gateway neurological centre in Middlesbrough. Jo was keen to assist CAUK with raising awareness and has kindly agreed to work in conjunction with more closely in the future. The Gateway is a possible venue for future CaverHub and CaverCentre meetings in the north East.

Nitin Mukerji, consultant neurosurgeon, James Cook Hospital, has offered to speak at the next Brain Awareness Week meeting in March 2016, more details nearer the time.

Angie also travelled to Newcastle and met with Jo Ede and Kate Bowman, Northern Neurological Alliance, Dr Ann Fitchett, Events and External Liaison Co-ordinator, Institute of Neuroscience, Newcastle, Helen James, Manager, Chase Neuro Park, Gateshead and Alistair White, Network Support Manager, Headway, at the Gateway. Everyone was welcoming and willing to assist CAUK to raise awareness of cavernoma.

In the trip's assessment, Angie reported "I suspect that there are many more people diagnosed with cavernoma in the North East, but because of associated symptoms the focus is on the larger charities like the MS Society, Parkinson's UK, the Epilepsy Society and Stroke Association, which may have people diagnosed with cavernoma, but are unable to signpost to CAUK because we are not well-known enough”.

If you would like to get involved and help raise awareness of CAUK, particularly in Middlesbrough, Darlington, Durham and Newcastle, please get in touch: community@cavernoma.org.uk.

FUNDRAISING

The trustees and staff would like to say thank you too all the members and supporters who have raised funds for CAUK.

Steve Burton, Peterborough

"The Wensleydale triathlon is a 2000 metre lake swim, 42 mile hilly bike ride and 20 km run. The run course takes competitors up the Great Shunner Fell the third highest mountain in the Dales. Hurricane Bertha decided to show her face that weekend. The Swim took place in the beautiful sometimes temperamental glacial lake Semer Water. On this occasion the rain fell so heavy and the wind was blowing a gale.

A tough start to the bike route as still exhausted from the swim and to be honest at this point I was ready to quit, faced with the steep accent 1:4 (25%) climb just 500 meters into the ride. This is where I focused on the task ahead and put Babs in my mind and all she’d been through. Also I could hear messages of support from all the great people that sponsored me for the Cav Alliance UK. I started the run I felt good and still smiling I passed more competitors. Then as the path got rocky and steeper I was nearly at walking pace then Bang! My old quad muscle strain came back to say hello. Ouch.

Crossing the finish line and collecting my cheese was the best thing ever and it all felt worth it to see my friends cheer me in and to know I’d done what I’d set out to do. With the Hurricane hanging over us only 60
people turned up to compete with only 52 finishing, I was one of them in a respectable 39th in a time of 6 hours 23 minutes 59 seconds”.

Lucy Leadbeater, Halifax

Lucy held a pampering event for Mother’s Day and raised funds for CAUK.

Charlotte Brett, Greater Manchester
"I decided to sign up to the Greater Manchester Marathon last July. I decided I wanted to honour my friend Anyta who had been diagnosed with cavernoma and try and raise some money for Cavernoma Alliance UK. Training for the marathon certainly was a personal challenge. I had to get used to running 4 times a week.

Running the marathon was great - I felt prepared, and I knew that Anyta and her family would be there when I finished. It was tough going but there wasn't a point where I thought about giving up. We started and finished from Old Trafford - Manchester United's football ground. The spectators all along the route were amazing. There were bigger crowds when we ran through towns, but even on long stretches of road there would still be people cheering, offering sweets or sliced oranges.

I completed the marathon in 5:12:27 which meant I achieved my silver - that'll do for me! Anyta and her family saw me cross the finish line, and her daughter presented me with a poster that said 'Well Done Charlotte' - I think that was better than my medal!"

Karen Winterflood, Wigan

Karen organised a Family Fundraising Evening in Wigan to raise money for CAUK and Diabetes UK, with help from Michelle Taylor and Alison Glover. Karen is in the middle of the picture.

Matt Bessey, York

Matt entered the City of York Triathlon in April and advised "Thoroughly enjoyed the triathlon and somehow managed to come 4th in the super sprint distance". 
Dave Pinner, Huntingdon

David entered the Cambridge 100 mile cycle ride to raise funds for Zane and CAUK.

"I completed the ride in 6hrs 35mins at an average 15 mph, 25 minutes quicker than planned in the worst weather I have ever ridden in, torrential rain for 80 miles and 20mph heads winds for the last 30 miles. Training for this event meant riding 30 to 40 miles two or three times a week and one ride of 60 miles to prepare me for the final 100 mile event. The thought of raising money for such a worthwhile cause spurred me on through training and the actual event. I feel proud to have achieved my goal knowing the money I have raised will go towards making the lives of the sufferers of CAUK a little happier".

Adele Sharp, Kent

Adele achieved the National Three Peaks challenge in May, climbing the three highest mountains Ben Nevis, Scafell Pike and Snowdon, reaching the final summit in just 24 hours and 25 minutes.
"I have never attempted a challenge like this before. There was a total of 6 in our team and I only knew 2 members before the event. I think I found the first part of the (Ben Nevis) climb the toughest as I realised I had such a long way to go but thankfully because I had trained I think my body just took over. The paths you clamber up are not just at an obvious incline but are covered in rocks and boulders. When we got to the snowline the wind was viciously attacking us with the snow. It felt like sharp needles consistently poking our faces. I found the steeper inclines, albeit less rocky, really worked my calf muscles and found this quite painful.

We started Scafell Pike in the dark. If I was to describe Scafell Pike it is like someone has picked up an enormous skip of rubble and thrown it all over the mountain. This is where trouble began for 2 of our team Lindsey and Tash. Lindsey was getting severe pain in her knee while Tash was in agony with her hip. But still they ploughed on through.

Snowdon is beautiful but for me I thought it was the toughest of the three. We climbed a trail called the Pyg track. Boy I was not expecting what we would have to climb! Some of the pathways at first are quite pleasant and then we were climbing, what seemed to me, almost sheer rock faces and trying to make a stairwell out of the crevices within it.

We reached the summit in 24 hours and 25 minutes. I felt this was a fantastic achievement but it didn't feel like the right time to start high fiving the team considering two of us were suffering! One of the best parts of the experience was the unexpected intense connections you make within your team. It really is like being in a bubble and time just blurs into one. We all got on fabulously including our guide who just felt like one of us. I now know that this is just as important as having a certain level of fitness”.

Sally Mead, Cambridgeshire

Sally had her hair shaved in May for Zane, aged six, who has a rare genetic form of cavernoma and for CAUK.
Sally said “It was an honour and a pleasure to do this for an awesome lil lad Zane and for this great charity. I hope to have raised the awareness of this great cause by doing what I done”.

Thanks to Rob and Deborah Bailey who gave up their wedding presents to raise additional funds for CAUK in memory of Rob’s sister Jacqui Bailey who died in 2012. Keith Savill from Cambridge who completed the London Marathon in a very fast time of 3 hours 51 minutes and raised funds for CAUK. Steve Wheeler from Essex who entered the Maldon Mud Race in April to raise money for CAUK. Also to Paula Wheeler from Essex who ran in the Great Baddow Fun Run in May to raise funds for CAUK.

Please advise Paul at fundraising@cavernoma.org.uk or telephone on 01305 213876 if you will be organising a fundraising event or taking part in a sports challenge for CAUK.

CAUK will display any photographs and fundraising stories in the members’ e-mailshot and also on our new website which will be available soon.

Please take photographs of your fundraising event. We would be pleased to display your photos and fundraising stories in the e-mailshots and on our new website due to be launched in June.

SOCIAL MEDIA

If you have any ideas or comments regarding CAUK’s use of social media, please let us know. We are always looking for ways to reach a wider community.

CAUK’s Secret facebook Page

https://member.cavernoma.org.uk/opus1085.html
Are you a member of CAUK’s secret facebook page? This enables you to contact other members in your area and share information and stories with a wider audience. All of this is 'behind closed door'.

This is the information new members are sent:

“CAUK would like to invite you to join our secret facebook page. For this page to remain confidential you will need to firstly request Cavernoma Alistair as a friend (this is run by CAUK staff solely) by following this link: https://www.facebook.com/cavernoma.allistair

Please be aware that CAUK takes no responsibility for the content posted on either facebook pages and members do so at their own risk and discretion.

CAUK’s facebook 'like' page

If you are on facebook please follow this link and 'like' our page.

Twitter

Did you know CAUK has a twitter page? If you tweet, please follow us. Together we can make a difference https://twitter.com/CAUK1

INFORMATION

Monthly Direct Debits To CAUK

Our thanks to those members who provide monthly contributions to Cavernoma Alliance UK and to those who give anonymously, to whom we cannot write and express our gratitude. Regular payments enable us to plan for the future and continue to find ways in which to increase awareness of cavernoma and help everyone affected. To assist us with a monthly contribution, go to our JustGiving page.

CAUK Video Library

Paul Oldham, CAUK’s webmaster, has created a library of videos which includes talks from all of the Forums and some of CAUK’s other events. This library is accessible from a Videos link at the top every page on our public website.

Update Your Story

Please would all members take a look at your story and amend any changes that may have occurred since you initially joined CAUK. You can do this by emailing your story to Sophie Eldridge, admin@cavernoma.org.uk. It is good for old and new members to see a true account of your story to date. Thank you.

Travel Insurance

Many of you write to ask us about travel insurance. Despite their cavernoma, many members are successful obtaining travel insurance with cavernoma. (REMEMBER - even those members with an incidental, non-symptomatic cavernoma are legally obligated to inform insurers of all pre-existing conditions). Many members have been successful with Columbus Travel (0845 888 8893 who have indicated that members for whom they do accept the risk (and PLEASE remember it depends on Columbus Travel to determine your insurability), a 10% discount off their premium can now be provided. CAUK members should supply the source code CVRNMA.

Members' Area Password

https://member.cavernoma.org.uk/opus1085.html
One of the commonest queries to our office is from members who have forgotten their password to the Members' Area on our website or indeed have yet to be allocated one. It's easy for you to get a new password by visiting this page and entering the email address you used to register with us (if it's not accepted then you registered using a different email address - more on that below). Then we will email you a password. Once you are logged in then, if you want, you can change your password to something more memorable using the Change Password link in the Members' Area. Please remember that we don't know what your password is so we can't send you a reminder: if you lose it you will have to start over.

For any enquiries, please contact Sophie Eldridge at admin@cavernoma.org.uk

Changes To Your Details

If your details have changed in any way, for example your postal address or your primary email address, then you can please remember to amend your details on our database so we can keep in touch with you. You can do so using this link:

http://www.cavernoma.org.uk/m-XXX-XXX-XXX

The CAUK Team

The CAUK team consists of: Ian Stuart (founder member and co-ordinator), Paul Cooper (fundraising and development manager), and “part-time” staff members Sophie Eldridge (administrator), Angela Yeomans (community worker) and Iris Cassomini. Many of you already know who we are. We look forward to meeting many more of you in the future. Hopefully at some of the exciting events planned for 2015.

The Board of Trustees, who are unpaid and are responsible to the Charity Commission for CAUK are Karen Bennett, Roxanna Dixon, Anna Farrar, Emily Fletcher, David Scott, Simon Temple, and Ahmed Toma, chaired by David White.

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