



December e-News

End of the year report from the Chairman

Well, it's certainly been a busy Autumn for me and Susan, with visits to local support groups in Lancashire, West Yorkshire, Merseyside, West Midlands, Cambridge and Lincolnshire. It's interesting to see how each group is quite distinctive and different but all providing essential support for people with vasculitis. Very often it's such a relief to be able to talk to someone else who actually understands the problems of living with vasculitis.

With fellow-trustee Richard Eastoe, we attended an open day for the bio-medical research unit at Imperial College. At the end of October, we went to Suffolk to take part in Tracy Martin's nautical themed Charity Ball in support of Vasculitis UK. This was held at Ickworth House – a very grand National Trust property and was a very splendid affair, raising over £2,500 for VUK.

On the "business" front, I've been to the British Society of Rheumatologists' HQ in London for a meeting to discuss the revision of the Guidelines for the treatment of Adult ANCA vasculitis. The meeting of the UK and Ireland Vasculitis Study Group (UKIVAS) was in Birmingham. This involved discussions about the new Vasculitis Registry (which VUK will be supporting financially), the new BSR Guidelines and the Paediatric ANCA Guidelines. It also gave me an opportunity to press for the development of some non-ANCA vasculitis guidelines.

Next week I will be meeting Professor Charles Pusey of Imperial College Medical School to discuss the planned setting up of a new multi-disciplinary Vasculitis centre at the Hammersmith Hospital.

Many thanks to those of you have contributed your experiences of Rituximab for inclusion in a report for NICE which will be submitted in the New Year. There is still time for you to send your contribution about your experiences (good or bad) if you haven't already done so. Please contact [me](#) for details.

So in conclusion, on behalf of all the Trustees of Vasculitis UK, may I wish you all a very Merry Christmas and a Happy and Healthy New Year.

John Mills



Vasculitis Meetings

West Country VSG informal lunch

The next West Country Support group informal and friendly lunch will be held at The Mill on the Exe, Exeter in mid-January. Full details from [Charlotte Stoner](#).

Beds, Bucks & Herts VSG informal lunch

Join [Janaine Davies](#), Chris & friends for an informal, lunch on Sunday 24th February 2013 at the Inn on the Lake, Bletchley.

Lancashire & North West VSG meeting

The next meeting is scheduled for 3rd March 2013. Details from [Jann Landles](#).

Oxfordshire Vasculitis Seminar

The next Seminar will be held on 17th March 2013. Details from [Sue Ashdown](#).

Cambridge VSG meeting

The next meeting will be held on Saturday 23rd March 2013. More information from [Jenny Fulford Brown](#).

We are looking for participants for vasculitis/DNA research

If you have ANCA associated Vasculitis and have a close blood relative who also has ANCA vasculitis, would you like to take part in a DNA analysis research project?



Also, if you started with ANCA associated Vasculitis below the age of 18 we would like to hear from you.

For further details please contact [John Mills](#).

BBC 2 - See Hear

Jamie Flanagan of Edinburgh, who has raised a considerable amount of money for Vasculitis UK, was left deaf as a result of his vasculitis.



On 7th November Jamie appeared on the BBC 2 programme "See Hear" which is aimed at the deaf community. Jamie described how his life has been transformed by a new type of hearing aid. Jamie will be "test driving" the hearing aid when he undertakes a series of gruelling marathon events in the African desert in 2013. View the [programme](#). Jamie's contribution starts at 5mins 30sec.

Following the programme Jamie received a cheque for £2000 from a kind couple in Scotland to pay for his travel and accommodation. Vasculitis UK wishes Jamie every success in his African adventure.

Santa John

Ho, ho, ho, and Seasons Greetings.

Not satisfied with everything he does for Vasculitis UK, here is Santa John rehearsing in case the proper Santa needs a little help delivering presents to the children of Winster.



Christmas cards

Thank you to everyone who bought our V-UK Christmas cards. We hope that by sending them to your family and friends it will help raise awareness of vasculitis. If you haven't bought your cards there is just time to get yours for posting before the Christmas postal deadline. Please contact [Susan Mills](#).

Vasculitis UK Annual General Meeting



The 2013 AGM will be held on **Sunday 12th May** at the Novotel, Long Eaton, Nottingham. Further details to be announced.

West Midlands (VSGWM)

Preliminary notice of meeting - Sunday 13th October 2013. Details will be available from [David Sambrook](#).

Full details about all the above meetings and for information on other events please visit the [Vasculitis UK website](#)

Fundraisers



Why not visit our [Justgiving](#) page and read about the 40 fundraisers who are helping to raise funds for Vasculitis UK. Here are just two stories:

Natalie's Walk

Natalie Mouldsdale and her friends and family raised nearly £3500 for the Trust when they undertook a walk from St Helens to Stockport (19 miles). The walk was in memory of Natalie's Dad Neale who lost his battle with vasculitis in September 2007 at the age of 46.

Midland Kickboxing

Lindsey Whitehead helped organise an evening of kickboxing at West Bridford, Nottingham in November. The event raised almost £1200 for Vasculitis UK.

Our thanks go to Natalie, Lindsey and all the fundraisers who do so many things to raise funds for the Trust, and to all those kind people who donate to their cause.

Vasculitis UK
West Bank House, Winster, Matlock
DE4 1DQ 01629 650540