

British Society of Rheumatologists - Guidelines

V-UK chairman John Mills recently attended a meeting at the headquarters of the British Society of Rheumatologists in London. This was a meeting of the "ANCA Vasculitis Adult Treatment Guidelines" Working Group which is reviewing the current guidelines that were published by the BSR in 2007.



The top names in UK vasculitis treatment are part of this group, including Vasculitis UK trustee Professor Lorraine Harper, Dr David Jayne, Dr Raashid Luqmani, Dr David D'Cruz, Dr Mike Venning and Dr Richard Watts, who chaired the meeting. It is worth noting that although the guidelines are published by the British Society of Rheumatologists, the working group includes top kidney doctors.

The process of making amendments to the guidelines is very rigorous and every change has to be shown to be clearly evidence based. The suggested changes to the guidelines are quite radical, but it will probably be another year before they are published as they have to be approved at several stages before being adopted. It is possible that they might eventually be published jointly with the British Society of Nephrologists.

These guidelines only refer to ANCA vasculitis - Wegener's Granulomatosis (GPA) and microscopic polyangiitis (MPA). Churg Strauss Syndrome (EGPA) was not included. But plans were made to have another meeting to incorporate CSS and it was agreed that the Vasculitis Rare Disease Working Group (which meets next month) should consider producing guidelines for all the non ANCA types of vasculitis.

Rituximab - We need your help

Many readers will be aware that the National Institute for Healthcare and Clinical Excellence (NICE) is currently examining the role of Rituximab in the treatment of Vasculitis.



Vasculitis Meetings

Beds, Bucks & Herts VSG meeting

Join Chris, Janaine & friends for an informal lunch on Sunday 4th November.

Merseyside, Cheshire & Wales VSG meeting

The 2nd meeting of the group will be held at the Royal Liverpool Hospital on 6th November.

Lancashire & North West VSG meeting

The next meeting is scheduled for 3rd March 2013.

Oxfordshire Vasculitis Seminar

The next Seminar will be held on 17th March 2013.

Cambridge VSG meeting

The next meeting will be held on Saturday 23rd March 2013.

Vasculitis UK AGM

The 2013 AGM will be held on Sunday 12th May.

Full details about all the above meetings, including contact details, and for information on other events visit the [Vasculitis UK website](http://www.vasculitisuk.org)

At present, Ritux is not approved for use in treating vasculitis, so it is used "off label" and every time it is used, the treatment has to be approved by the hospital trust or the PCT for each individual patient.

If NICE approve its use, this will change. NICE have all the research evidence about Ritux and evidence from doctors like David Jayne, who has been a pioneer in the use of this drug. Almost everyone who has been treated with it thinks it has been life-changing for them.

With NICE, the views of patients count for far more than we patients realise. So we are looking for people who have been treated with Rituximab to tell their stories to NICE. **If you have experience of being treated with Ritux (be it good or bad) please contact [John Mills](#)**

All Aboard for the Little T Ball



All Aboard for the Little T Ball an Evening of Nautical Fun and Games at Ickworth House, Bury St Edmunds. Tracy Martin held a ball on the 20th October in memory of her partner Gordon Mott who died in 2006. Gordon suffered with Wegener's Granulomatosis (GPA) for over 10 years but lived life to the full even after being diagnosed.

The evening was opened by the "Captain" Dr Matthew Lockyer, Gordon's GP and a few words were spoken about Vasculitis by guest speaker Dr Richard Watts Consultant Rheumatologist, Gordon's consultant and co-author of "Vasculitis in Clinical Practice". The delightful jazz band consisted of Tracy's friends and vocalist Lydia who is Dr Lockyer's daughter.

Over 130 of Gordon and Tracy's friends attended the ball. Fancy dress was worn by some brave souls including Susan (the girl pirate) and John (Captain Pugwash) Mills.

25 Raffle prizes were donated by local businesses, including a weekend break and a pamper spa day. An official photographer was on hand to take photos. Prizes were awarded for the best fancy dress and the

Publications

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Kind to Kidneys' Recipe Collections
- [Food for Thought](#)

Recipe book published by the UK Kidney Federation. A printed copy can also be obtained for £1.50 from: The National Kidney Federation, The Point, Coach Road, Shireoaks, Worksop, Notts. S81 8BW



winner of the Nautical quiz. A full article about the ball will be in the Spring 2013 Newsletter plus more photos.

Christmas cards



Christmas is fast approaching. Why not take the opportunity to raise awareness of vasculitis and raise some funds for Vasculitis by sending our quality Christmas cards to your family and friends? Each pack contains 10 cards of one design. They are reasonably priced at £3.95 per pack and that includes p&p.

You can see further details about the cards at our [Shop](#) on the Vasculitis UK website. You can download an order form there or, if you prefer, e-mail [Susan Mills](#)

Fabulous Fundraisers



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

Recently **Catherine Fowler** completed the Brighton Undercliffe Run. As Catherine commented, she is more used to running a bath than an 8K run.

Then there's **Martyn Wells** who will be walking the Worcestershire Way in June 2013.

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