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January 2013 e-News

What is your rare disease experience?

Genetic Alliance UK and Rare Disease UK are working with Shire Human Genetic Therapies to help to identify and bring increased awareness to the myriad of issues facing the rare disease community.



The more information which can be gathered can only help to bring the problems associated with diseases such as vasculitis to the attention of a much wider audience.

Please spare 10 minutes to complete the questionnaire on the [Genetic Alliance UK website](#). You will then find the appropriate link under the heading "What is your rare disease experience?"

Vasculitis UK Chairman, John Mills appears on BBC television

A BBC crew recently descended on West Bank House and recorded an interview with John. He spoke of his journey with vasculitis, about Vasculitis UK and about his hopes for the future for vasculitis patients.



You can view the video on the Trust's website: [Tackling the disorders that destroy blood cells](#) or go directly to the [BBC link](#).

Lake District Walk For All

V-UK are excited to announce that we've just signed up to partner the [Jane Tomlinson "Walk For All"](#) fundraising festival in the Lake District. We'll be looking for fundraisers and volunteers to join us on **Sunday 8th September 2013**.



New and updated pages on the Vasculitis UK website

Have you seen our new and amended pages?

1. [Urticarial Vasculitis](#)
2. [Vasculitis and the Eyes](#)
3. [Benefits - PIPs](#)

Coming soon - Housing Benefits and Council Tax Benefits

Events Diary

Charity Ball - York - 16th March 2013

To raise funds for V-UK and York Against Cancer see full details at: [Charity Ball](#)

V-UK Annual General Meeting

The 2013 AGM will be held on **Sunday 12th May** at the Novatel, Long Eaton. Further details from: [John Mills](#)

Vasculitis Support Group Meetings

February:

SE London/NW Kent - Saturday 23rd

Beds, Bucks, Herts informal lunch - Sunday 24th

March:

Lancashire & NE - Sunday 3rd

Oxfordshire Annual Seminar - Sunday 17th

Cambridge - Saturday 23rd

Lincolnshire - Saturday 30th

April:



Walk For All caters for walkers of all abilities and offers three different walks that take in the wonderful views of Lake Windermere and the beautiful Cumbrian Lakeside towns of Newby Bridge, Ambleside and Windermere itself.

We want this to be a really special event to raise both awareness and funds for Vasculitis UK. With your help we can make it a really memorable day. So if you'd like to take part and raise funds or even just volunteer to help please contact [Richard Eastoe](#) for further details.

Your Rituximab Experiences

As reported in earlier e-News issues, during February Vasculitis UK will be presenting written evidence to NICE (National Institute for Clinical Excellence). This submission will contain the personal experiences of those who have been prescribed Rituximab for their vasculitis.



This is an extremely important submission in the decision making process as to whether Rituximab should be prescribed for the treatment of vasculitis. If you haven't already done so please contact [John Mills](#) who will give you full details.



Exciting new DNA research at Cambridge

- Is there more than one person in your family with ANCA Associated Vasculitis?
- Were you 16 or younger when diagnosed with ANCA vasculitis - WG (GPA), CSS (EGPA) or MPA?
- Do you have ANCA vasculitis?

Please see [DNA Analysis Research](#) for further details, or e-mail: [John Mills](#)

Interesting article for Behçet's patients
[Symptoms of Behçet's Syndrome in a Representative Group of Adults in the UK](#)

Vasculitis UK

North Yorkshire - Sunday 21st
May:
Surrey - Sunday 5th
June:
Oxfordshire lunch - Sunday 2nd
October:
West Midlands - Sunday 13th

For full details of the above please visit: [Events](#)

Fundraising Events

To read about over 40 of our fundraisers please visit their fundraisers pages at [Just Giving.com](#).

In this issue we are highlighting

[Martyn Wells](#) and his friends who are walking the Worcestershire Way in June, and



[Aimee Morrison](#) who is hoping to raise £1000 for the Trust - see Aimee's [video](#)



Vasculitis UK New Website



Our new website has now been operational for almost five months. We are thrilled that the site is proving to be a huge hit with vasculitis patients not only here in the UK but all over the globe.

The site has had over 22,000 visits with over 35% returning on at least one occasion. On these visits over 117,000 pages have been viewed. The most visited pages are, of course, those concerning vasculitis. There have been visits from 119 countries including Mongolia, Cote d'Ivoire and the latest one Zimbabwe.

The Trust is grateful to our web designer/host, Paul Townend of [OnScreen](#), for his hard work, professionalism and expert guidance.

Supporting patients with vasculitis, helping raise awareness
and funding vasculitis research since 1992

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