

## E-NEWSLETTER



## That was the month that was



We are now nearing the end of a fantastic **Vasculitis Awareness Month**.

So many of you have been out there raising awareness in various ways. We can't thank you enough.

There have been newspaper articles and radio interviews galore.- a fantastic way to help raise awareness with the general public. Many thanks to those involved. We have opened a new page on the V-UK website dealing with these interesting media events: [Media Reports V-UK](#)

**Young Vasculitis UK** - To meet the needs of our younger members (16 to 30ish age group) a new V-UK Facebook site was opened during May. This is a "closed" group for young patients to express themselves in a safe environment.. You can join at: [Young Vasculitis UK](#) Mums please note, the Young Vasculitis UK Facebook site is administered and monitored by a V-UK Trustee.

What else has been happening? Well lots. UK vasculitis patients have certainly been doing their part to raise awareness during this month long international event. There was a new V-UK 2013 t-shirt designed by Jim Bornac in the USA which is still available in our [Shop](#). 40 Route Maps have been posted to Ireland to raise awareness with GPs in the Emerald Isle, and lots of fundraisers have been entering events or opening pages on [JustGiving](#)

## V-UK is supporting the MYPAN research project



Vasculitis UK are proud to be helping fund Dr Paul Brogan's research into the use of mycophenolate mofetil, rather than cyclophosphamide, in children with Polyarteritis Nodosa. Dr Brogan is based at Great Ormond Street Hospital for Children.

For full details about this exciting project visit: [Vasculitis Research](#)

## Interesting snippets

### ANCA Conference Paris

In April John Mills attended the 16<sup>th</sup> International Vasculitis and ANCA Workshop at the Institute Cordeliers (which is part of the Paris School of Medicine).

It was a full few days of lectures and poster displays. 350 different pieces of vasculitis research were presented, .

There will be a full report of the meeting in the Autumn Newsletter/Journal.

### Fundraisers for V-UK

There are 50 fundraisers who are raising money for V-UK. You can read their individual pages at [Just Giving](#). Here are just four we have selected for mention in this issue.

**Karen St Ledger** - Karen is one of the happy band of wanderers who will be undertaking the [Thames River Walk](#) on 22 June. Some of her companions are Giles Hart and his family and our new Trustee Jacqui Moran.

**Linda Flegg** - Linda is taking part in the 85 mile Manx Telecom Parish Walk in the Isle of Man on 22<sup>nd</sup> June.

You will also find details on the Research page of other projects which V-UK has recently funded, including a student bursary into Takayasu Arteritis at the Hammersmith in London. Also there is the Cytomegalovirus research at Birmingham University Hospital and, of course, the Vasculitis Registry.

## The Yorkshire Dales Walking Festival



As announced at the AGM, the Lakes Walking Festival was cancelled by the Jane Tomlinson charity.

However, we have now arranged to partner Jane Tomlinson's on their Yorkshire Dales Walking Festival.

We'll be looking for fundraisers and volunteers to join us on Sunday the 18<sup>th</sup> August for a great day out in the Dales and hopefully to help raise some awareness and money for Vasculitis UK.

The Dales Walking Festival takes place around Settle in the Yorkshire Dales. There will be three walks:

- \* A 5 mile walk through the heart of Attermire Scar
- \* A 14 mile walk through Malhamdale including a climb up Malham Cove
- \* A 28 mile challenge taking in Ingleborough and climbing Pen-y-Ghent.

Why not check out the [Jane Tomlinson](#) site:

This will be a great opportunity for us to raise both funds and awareness for Vasculitis and Vasculitis UK. So with your help we're hoping to make it a really memorable day. You can read more about V-UK's involvement in Dales Walk under [News](#) on the V-UK website.

If you'd like to take part and raise funds or even just volunteer to help please contact [Richard Eastoe](#) for further details.

## V-UK Annual General Meeting



The V-UK AGM was held on 12<sup>th</sup> May. There were over 90 members and family present.. Our Guest Speaker was Dr Andrew McClean of Birmingham University Hospital.

Andrew gave an excellent presentation which was based on his current research at Birmingham "Why are people with ANCA associated vasculitis fatigued"

**London 10K** - The London 10K will take place on 14 July, and there will be at least 12 participants representing Vasculitis UK.

Team Clare will be out in force, running in memory of Clare Grossman

**Kilimanjaro** - V-UK sends all good wishes to Tara Gami and the Fab 5 who will shortly be venturing up Kilimanjaro to raise funds for V-UK

### Kira Conroy's Blogspot

Kira is 9 years old and has had HSP since she was 4. She recently took part in the Great Manchester Run to raise funds for Vasculitis UK. See [Kira's JustGiving page](#)

Kira has also opened her own Blogspot so please read her story at :[Kira's Blogspot](#)

### Innov8 Conferences

Vasculitis UK would like to thank [Innov8 Conferences](#) for their support during Vasculitis Awareness Month May 2013

### Donate Mobile

Don't forget that you can raise money for V-UK simply by using your mobile phone. If you would like further details there is a 90 second introduction to Donate Mobile - how it works, how you can join, and how you can support Vasculitis UK - [Donate Mobile](#)

A full report on the AGM will be included in the Autumn 2013 Newsletter/ Journal, but meanwhile a brief account can be found under News at the : [V-UK website](#)

As many of you will know, Susan Mills decided to hang up her Hon Secretary shoes at the AGM. We are, of course, sorry to lose Susan from our fold, although she will remain active in the background as John's secretary - trying to keep him in order !! Unfortunately, Martin Thomas resigned due to ill-health and we wish Martin better health in the coming months.

Three new Trustees were appointed: Danni Brunwin, Dorothy Ireland and Jacqui Moran. Each of the Trustees - new and no so new - introduce themselves and tell of their hopes and plans for the future of V-UK at [Meet the Trustees](#).

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