



# VASCULITIS UK

## NEWSLETTER JOURNAL



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## Chairman's Report

**W**e, at Vasculitis UK, have a really good relationship with all the leading medical vasculitis professionals in England. This enables us to advise, guide and act as advocate for many patients who do not seem to be getting a proper diagnosis or effective treatment. I must emphasise that most vasculitis patients get excellent care; it is the handful of cases which "fall through the cracks" where we find the need to advise and intervene.

However, in Wales it is a different situation. So many vasculitis patients, especially those with rarer types of vasculitis, seem to struggle to get the care they need. Most of the expertise and experience is concentrated on the South Coast, around Cardiff & Swansea. In some parts of Wales there is little or no provision for rare diseases like vasculitis.

With a population of only 4 million, the patients in Wales with very rare types of vasculitis – such as Takayasu arteritis – could probably all fit in one taxi. So there's not going to be much practical experience of treating Takayasu in Wales. No problem – Professor Justin Mason at Hammersmith Hospital in London is a leading world expert on diagnosing and managing Takayasu. But getting a cross-border referral to England seems to be impossible, so those who are desperate for a diagnosis or proper treatment end up paying privately to see him. But it doesn't stop there.

You might expect that having

## What's up with Wales?

been to see a leading world expert on vasculitis, such as Justin Mason or David Jayne at Addenbrookes, for example, and having been given a diagnosis and a treatment plan, that the Welsh patient could go back to their consultant and hospital in Wales and be given that treatment prescribed by someone with extensive knowledge and experience. Sadly not so. The advice of the expert "over the border" seems to be resented and ignored, so much so that one very young patient who managed to get a referral to Addenbrookes, was given a carefully considered treatment plan, which she took back to her consultant in Wales, who ignored and over-rode the plan and instigated his own treatment plan. She died shortly after!

There are various natural problems in Wales for people with rare diseases, associated with the small population and geographic distribution of patients and providers. Recruitment of doctors in Wales is even more difficult than in England. Politics plays its part – the Welsh government chose to offer free prescriptions, but there's no such thing as a "free" prescription, so other services pay the price and rare diseases are a soft target for cuts.

There seems to be a last-century attitude in Wales, that patients should know their place and never question Doctor, who always knows best. Consequently, with the odd exception, we find that GPs and consultants actively resent patients consulting the VUK website or any intervention by Vasculitis UK. There seems also to be a general culture of hierarchy and closed ranks, which prohibits anything that might imply criticism or offend another GP or consultant. One gets the impression that in Wales the self-esteem of the doctor is more important than the health and welfare of the patient.

The recent case of an 8 year old boy in South Wales – let's call him "B" – has prompted me to write these comments. The story began last September when B's mum took him to see a local paediatrician because he had a rash, tummy pains, sickness & nose bleeds. He had previously suffered from regular nose bleeds since the age of three and had an episode of high temperature and rash in April 2015.

A biopsy of the rash was done and possible vasculitis was mentioned. However before the biopsy results were returned his mum found it necessary to take him to the local A&E in Newport, because he had a very high temperature, was vomiting and had more nose bleeds. He was admitted overnight but discharged the following day with an appointment to see the paediatrician two months later, in December.

In mid October, after contacting Vasculitis UK for advice, B's mum asked her GP for a referral to Birmingham Children's Hospital where they have a wealth of experience in treating paediatric vasculitis and similar rare diseases. The GP was supportive but said this was not possible due to cross-border funding issues. In mid November the biopsy result was returned marked "inconclusive". I wrote to a senior consultant in Cardiff who has experience of vasculitis but they would not see him as he was a paediatric case, so he was given an appointment to see a paediatric rheumatologist on 7<sup>th</sup> December.

He saw this consultant who reviewed the case, said he thought that it was probably urticarial vasculitis and that there was no need for a further appointment but he should return to the dermatology department in Newport. At a GP visit on 25<sup>th</sup> January, the GP expressed concern about the lack of any treatment plan. B's school was concerned because



the boy looked so ill and his attendance over 3 months was only 75%. Social Services were called in but they confirmed that his mum was doing everything possible within her power for her child.

On 27<sup>th</sup> January mum took him to the GP with high temperature and pain in his chest and legs. They found traces of blood & protein in his urine and a very high pulse rate. The GP wanted him to go to the local A&E, but in the light of past experience it was agreed that he should be taken to another hospital at some distance. There, he was admitted overnight and was seen the following day by a paediatrician who simply discharged him, with an out patient appointment in 8 weeks. That night he suffered a massive nose bleed.

At this point mum contacted us again and on her behalf, we contacted the wonderful Dr Larissa Kerecuk at Birmingham Children's Hospital. She suggested that the only way of overcoming the resistance of the Welsh system to a cross-border referral was for the GP to write a private referral, which he duly did.

In mid February all the symptoms returned and mum contacted Birmingham who said that an appointment would be sent by post. On 1<sup>st</sup> March, B's eye became bloodshot & painful. We advised she should take him to A&E immediately, but rather than take him to local A&E, mum took him to the nearest English A&E just over the border in Hereford. He was immediately give blood & urine tests and he was seen by the ophthalmologist on the following day. As his sight was at risk, steroid eye drops were prescribed immediately. A renal ultrasound was booked and B was seen by the dermatologist. The following day, 3<sup>rd</sup> March, a paediatrician from Birmingham Children's saw him and he was allowed home until a bed became available at Birmingham Children's.

"B" was admitted to BCH on 6<sup>th</sup> March. There he was subjected to a battery of tests including heart and kidney investigations, which suggested kidney involvement. He was also found to have fluid around his left hip. By this time he had suffered massive weight loss. As I write, he is still in hospital awaiting a kidney biopsy and no diagnosis has yet been made, but he is under the care of one of the UK's leading experts on rare paediatric diseases. Had it not been for the bureaucratic obstacles imposed by the Welsh Health Authority, he could have been referred there 4 months earlier, before his condition had deteriorated.

I know for sure that there are some caring, knowledgeable and experienced vasculitis consultants in Wales, but they seem to be very thin on the ground and the Welsh system seems to impose additional obstacles to best standards of care. The problems are not confined to vasculitis and Vasculitis UK has been working over the past year with Emma Hughes of Genetic Alliance UK to bring pressure on the Welsh Government to adopt a more enlightened attitude to patients with rare diseases.

#### **Vitamin D**

We all know that vitamin D is essential for healthy bones and muscles but a recent major, 14 country study, funded by NIHR (National Institute for Health Research) has shown that vitamin D also has an important protective effect against respiratory infections, something very significant for people who are immune suppressed. Vitamin D is present in some foods and the body makes its own vitamin D when the skin is exposed to natural sunlight; but for people on immune suppressing drugs, like azathioprine, they are advised to limit their exposure to sunlight due to increased risk of skin cancer. Foods such as cod liver oil, dairy products and oily fish can provide you with vitamin D and of course you

can take supplements in tablet form. Perhaps the importance of vitamin D supplements for people with vasculitis or are immune suppressed is something that deserves further investigation.

#### **ERNs Launched**



I wrote in the Autumn newsletter about the new European Reference Networks for Rare Diseases. This is an EU initiative intended to ensure that even those with a rare disease living in a remote area can have access to the best available expertise and experience, with "virtual" consultations and multidisciplinary clinics via the internet. There are 300 hospitals with 900 healthcare units involved. There are 24 networks dedicated to different groups of rare diseases such as rare cancer or rare heart diseases. Vasculitis falls under the "Rare auto-immune, auto-inflammatory and immune deficiency network, known by the acronym "RITA".

The Network was launched on 9<sup>th</sup>/10<sup>th</sup> March at a conference in Vilnius, Lithuania, which unfortunately I was not able to attend, due to ill health. As this venture is funded by the EU it is not yet clear if the UK will be able to continue as members of the ERN post-Brexit

#### **Quotable Quotes.**

I like collecting apposite phrases and quotations.

Here are two which I acquired at the patient symposium in Manchester:-

*"To err is human, to cover up is unforgiveable, to fail to learn is inexcusable"*  
(Sir Liam Donaldson, former Chief Medical Officer – quoted by Dr Peter Lanyon).

*"Art washes away from the soul the dust of everyday life"*  
(Pablo Picasso - quoted by Dr Shanali Perrera.)

*John Mills*

# Vasculitis Patient Symposium & Charity Ball 2017



Anne & Gareth

The Vasculitis Patient symposium was a truly an amazing day with an overwhelming feeling of people coming together to support each other, from professionals sharing their knowledge and expertise on the disease to patients sharing their personal journeys and families who have a loved one with the disease.

My son Gareth had the privilege of being asked to do a presentation about Goodpastures (anti GBM disease), which he was diagnosed with at the age of 16, ( 6 years ago ) after becoming critically unwell.

He spoke very bravely and poignantly about his battle with the disease and how it affected his teenage years. He also talked about the difficulties he had coming to terms with living with a chronic disease and having to give up his active lifestyle at such a young age.

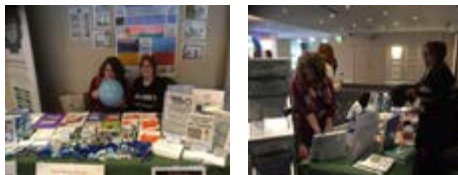
I was really worried about how I would hold it together listening to him speak out about what was a devastating time for us as his family, but I can safely say it was the one of the proudest moments of my life.

The final part of his portrayal was a positive and uplifting one and focused on what he has achieved despite his battle with the illness. I was so overwhelmed by the reaction he received afterwards with people visually moved by his presentation or wanting to shake his hand and telling him how inspirational he is, but what really touched my heart was the mother of a young child who was too unwell to be there, telling me, Gareth had given her hope that her child will one day tell his own story, for me this is why events like this are so important.

13 year old Emily and 12 year old Keira were also amazing talking about their journey with Henoch Schonlein Purpura (IgA vasculitis) and how

it has impacted on them and their families but the positivity from the girls was amazing. I thought Gareth, Emily and Keira certainly made an impact that day. Their courage and resilience was admirable and inspirational for young people struggling with Vasculitis.

All the presentations were extremely informative and so interesting, who



Kelly Jefferies and Kath McIntosh manning the VUK Stand

would have thought that something as simple as a zebra would explain very clearly, the sometimes very difficult journey we go through prior to diagnosis, which I thought was superbly done by Lynn Laidlaw.

From my perspective as the mother of a son who has vasculitis and a sufferer myself, the information and professional expert information shared that day was invaluable.

**Anne Sweeney**

I attended the recent Vasculitis Ball with my wife along with over 100 other guests and was welcomed with drinks served in the International Terrace at the Mercure Manchester Piccadilly Hotel and had the chance to mingle with the stars.



(left) Jean Luc Picard (aka) Derek Wheatland and fellow trekkie



(right) The UK Ghostbusters

Many took up the opportunity to purchase a gift box, inside the box

was some scrumptious chocolates and the lucky ones had a raffle ticket which related to a prize, this was a great idea and raised a lot of money for the charity.

Our compare for the night Paul Crone introduced us to the nights events, he started of with a game of heads and tails which also helped raise around £130 within the first 15mins which I thought was a great way to get the ball rolling.

As we tucked into a lovely 4 course dinner we were entertained by Andy Powell, singing some great classic songs and even did a duet with Paul Crone, he then asked a member of the audience if they would join him and Stacey Hayes kindly obliged, she was a great sport and did a fantastic job entertaining us all.

Andy Powell duets with Paul Crone and Stacey Hayes



Paul Crone then returned to do a live auction and prize give-aways, he did a fantastic job helping those funds to rise to over £4000 which was brilliant.

As the coffees were being served we were then entertained by VibeTown our resident band for the night and danced the night away.



VibeTown

Both these events were organised by Emma from Innov8 Conferences. You can view their website at: <http://innov8-conferences.co.uk/> Emma along with everyone else who made both events possible should be proud of themselves, it was a pleasure to be part of it. There will be more about the symposium in the Autumn Newsletter.

**Kevin Soper**

## From The Editors

Welcome to this Spring edition, there are many interesting stories and features that you will all hopefully enjoy reading.

It always amazes me how many of you our readers who also have Vasculitis or care for those that do are able to still manage to help fundraise and raise awareness, this is particularly highlighted in Andrew Robertson's article Part 1 "How do you eat an elephant" Part 2 will be in the Autumn edition.



Kevin Soper

Recently my wife Lesley and I attended the charity ball in Manchester and were both amazed of the positive attitude and commitment of everyone we met, reading some of the comments on social media it also highlighted that many of those who attended had learnt a lot from the Symposium and Education Day which was held earlier in the day.

The images on the front cover of this edition from left to right Motivation "Up the Tempo" collection March 2017 and Collective Power "Take A Bow" collection March 2016 were created by Dr Shanali Perera, Shanali had some of her

images on display at the symposium.

If you would like to see more of Shanali's work please visit <http://shanaliperera.wixsite.com/digitalart>



Graham Baker

Many of you recently participated in Rare Disease Day on the 28th February using the graphics created by Kelly Jefferies whom I had the pleasure to meet at the ball, hopefully there will be more to come from Kelly during Vasculitis UK's Awareness month in May this year so watch out via social media for more details.

Fundraising and awareness is a key part of Vasculitis UK as this helps generate funds for research into the various types of Vasculitis.

Thank you for everything you do to aid this you truly are an inspiration to all.

*Happy Reading*

*Kevin & Graham*

## Donating To VASCULITIS UK

*The charity is **entirely** dependent on voluntary donations  
Just £8 a year will pay for the printing and posting of both your  
Spring and Autumn Newsletters*

Without your financial support we could not meet our aims of supporting patients, raising awareness and funding Vasculitis research here in the UK.

There are easy ways to make a voluntary donation by cheque, standing order (donation forms enclosed with this Newsletter) or by card via donations at JustGiving.com, VirginMoneyGiving or by PayPal.

Please remember that **Gift Aid** can increase your donation by 25 per cent at no extra cost to you. For Further details about donating to Vasculitis UK, please contact the Treasurer, contact details on page 28



**For all the latest information and news,**

**visit the Vasculitis UK website <http://www.vasculitis.org.uk/>**



## Some of Our Fantastic Fundraisers



### Annalise is a cut above

Annalise had her hair cut in aid of Vasculitis UK she also kindly donated her plaits to make wigs for children diagnosed with cancer.

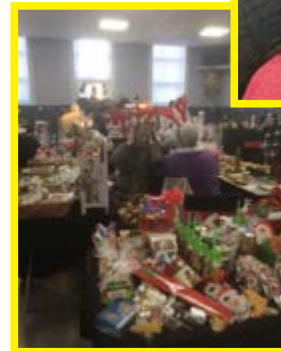


### Father Christmas makes a visit to Winster village shop

Over 50 children came to visit Vasculitis UK's very own Santa aka John Mills and Elf, Winster Village Shop Manager, on the 10th December 2016. Donations were made to VUK, VUK Christmas cards were also on sale and a total of £150 was raised.



Megan's Christmas Fare, West Lothian, raised an amazing £2000



Julia Glenny's Big Heart Bike Ride raising over £1600



Maxine and Michael 100 mile challenge for VUK 2016



James Allen and James Martin Folkestone Boxing Day Dip



David Pinckney HSBC Triathlon



Paula Barnett and family - Coffee Morning - Rare Disease Day 2017



Kyri Colette and Tillypops, fundraising at Heanor Craft Fair

## Dry January



Instead of raising glasses during January Jane Edwards & friends were raising £2763 for Vasculitis UK



Sami Burgess and Amie Skydive for Vasculitis



Nicola Morgan Cardiff 10k 2016

## Some of Our Fantastic Fundraisers



Sharon Elliott competed in the Skipton Triathlon as well as holding an Afternoon Tea in memory of her mum



Liz Taylor In The Great North Run



Janine Osbourne who has WG (GPA) with her medal

### Team Franklin & Bailey



Rich, Harrison & Emma running on behalf of Harrison's Mum Loretta raise over £1000 for VUK



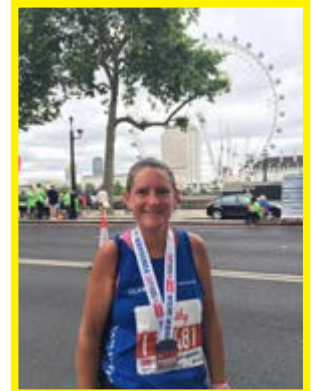
Jackie Natalie & Ryan Mouldale held a Fancy Dress Party in memory of Jackie's husband Neal.



Elaine, Sarah & Susan Bakewell Christmas Tree Festival 2016



Nicci Hall after completing her triathlon on behalf of her nephew 18 year old Aiden Richards, raising over £2555



Claire Holland London 10k 2016



Winster Guisers - £100 Donation



Derek Wheatland presented a cheque for £200 on behalf of the Rogski Group to VUK at the 2017 Patient Symposium & Charity Ball in Manchester



# EUVAS – European Vasculitis Study Group

## Introduction to EUVAS

The European Vasculitis Society (EUVAS) was established in May 2011. It is an open collaboration of physicians interested in research and education in vasculitis and includes representatives across many medical specialities, not only in Europe but the globe.



EUVAS Study Group Meeting Netherlands June 2016

The first EUVAS vasculitis course was held in January 2017, in Cambridge and over 100 doctors with an interest in vasculitis attended the 3 day course. (The course was heavily over subscribed)



Keynote speakers from the UK, France, Germany, Sweden, Netherlands, Switzerland, Prague and Denmark were invited to share their knowledge, experience and to discuss case studies.

John Mills Chairman of Vasculitis UK was asked to speak as the after dinner speaker as a vasculitis patient representative and chairman of Vasculitis UK. Dr David Jayne Course Director and EUVAS president says



John Mills

“The idea for a dedicated course has been incubating for some time as interest in vasculitis has grown, the science and treatment have evolved and more health professionals are interested in developing expertise in this area.”

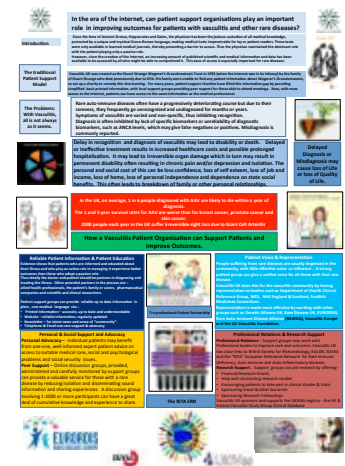
The second EUVAS research and education meeting will be held in Florence, January 2018.



EUVAS Vasculitis Course - David Jayne



EUVAS Education Day group photo



The Poster (above) was designed for the VUK information stall at the EUVAS Vasculitis Course which was very well received by medical professionals

## RESEARCH

- Do you suffer with Fatigue?
- Are you aged 18 or over?
- Do you have a Diagnosis of vasculitis?
- Are you in remission?

Would you be willing to take part in a trial of physical activity and behaviour change support versus standard care?

The FAB-V trial team at the University of Birmingham and University Hospital Birmingham are actively seeking participants willing to take part.

All volunteers will need to attend the clinics at the Birmingham QE hospital but travel expenses will be paid.

If you are interested or you need more information, please contact Hollie Caulfield on 0121 414 8582 or email [fab-v@trials.bham.ac.uk](mailto:fab-v@trials.bham.ac.uk)





# EUVAS First Educational Course

## *A personal perspective*

I felt greatly privileged to be invited to take part in the first ever Vasculitis Education Course in early January, organised by Dr David Jayne and his Cambridge team on behalf of EUVAS – the European Vasculitis Society.

The aims of the course were to allow delegates to gain in-depth specialist knowledge of vasculitis, with a view to earlier diagnosis, more effective disease management and improved patient care as well as offering an opportunity to network with world-leading experts in vasculitis and gain greater understanding of research into this rare disease area.

This was about education for consultants and senior registrars, not junior doctors and it attracted delegates from all over Europe and beyond – even one from Brazil. Despite the delegate fee of £750, the course was very heavily oversubscribed.

The speakers were of a correspondingly high calibre – the best and most knowledgeable to be found in Europe and beyond.

The course was 3 days residential in the prestigious environment of Clare College, Cambridge – the undergraduate students were still on vacation. Organisation was with meticulous attention to detail, largely thanks to Maria King and her administrative team. As always with these international events, I feel humbled by the fact that everything is conducted in English, regardless of the native language of speakers and delegates.

The course was certainly rigorous, covering all types and all aspects of vasculitis in detail. The sessions started at 8.30am and closed at 6.10pm, with additional interactive lunchtime and evening sessions. There were interactive case presentations where delegates were invited to contribute their ideas on management of complex cases.

My turn to sing for my supper came at the Gala Dinner, held in the magnificent Great Hall of Clare College. The atmosphere was made complete by the choir singing in the gallery. I was invited to speak after dinner about the patient's perspective of vasculitis. I certainly felt greatly honoured to be speaking to all the vasculitis experts on behalf of all the vasculitis patient community.

Sadly, the three days of the course came to an end all too soon. I had been made most welcome by all the professional participants, many of whom I already knew. I had learned a lot, contributed a little and had been able to do so much invaluable networking. It is difficult to describe the "buzz" that comes from being in such a stimulating environment.

The second EUVAS education course is scheduled to take place next year in Florence. I'm not likely to get a free pass to attend on that occasion, but for me it's not to be missed, so I'm saving up in readiness!

**John Mills**

## Arthritis Research UK Clinical Study Workshop February 2017

John Mills chairman of VUK was invited to the Arthritis Research UK Clinical Study Workshop for Improving Clinical Research in Rare Musculoskeletal Diseases. (Including Vasculitis). 60/70 enthusiastic and passionate doctors attended this workshop, all listening to other dedicated doctors speaking about the challenges of research, clinical trials and finding better and more effective treatment and care for their patients.



Dr Kassim Javaid  
Oxford – RUDY study



Dr Peter Lanyon BSR –  
Integrating Research



Dr Bridget Griffiths – NHS England  
Rheumatology Specialised Services



Dr Peter Lanyon – Discussing  
RAIRDA Alliance

British Society for Rheumatology  
**AUTUMN CONFERENCE**  
**Case-based discussions**  
13-14 October 2016 | Bath Assembly Rooms



John Mills, Lynn Laidlaw & Susan Mills represented Vasculitis UK with the VUK stand.

Two Days of presentations from some of the world experts, including Dr David Jayne and Prof Robert Moots, plus doctors from all over the UK taking part in lively debates & discussing research studies and complex & rare cases. Full programme also included Vasculitis, Raynauds, Spondyloarthritis and Infection & Arthritis.



The VUK stand attracted much attention!!



Dr Peter Lanyon  
BSR President



Dr David Jayne  
Keynote Speaker

### Lupus East Anglia Information Day October 2016 – Susan Mills

John and I were invited to this event by Lupus UK, not only to attend the meeting but to have a Vasculitis information stand along with Scleroderma & Raynauds UK, British Sjogrens Association, Patient-Led Research Hub (Cambridge) and Alliance for Independent Living and Health Watch.

We did not think we would be able to go as we were supposed to be travelling down to France on that same day. But we decided to postpone our travelling date by one day and called in on the way en-route to catch the ferry.

The information day proved very popular, with 240 attendees. The event was officially opened by Heidi Allen MP for South Cambridgeshire. A number of excellent speakers had been arranged from Addenbrookes Hospital to discuss various "Lupus related" topics. Speakers were Dr Natasha Jordan, Dr Frances Hall, Dr Lisa Willcocks and Dr Thomas Hiemstra.



Heidi Allen MP Cambridgeshire



We met lots of very friendly people who were very interested in the Vasculitis UK stand and we also met a few people who had lupus & vasculitis crossovers or a member of their family had vasculitis.





# V-PREG VUK

**I was impressed with the V-Preg study when I attended the Vasculitis Investigators meeting that was held in Washington on Saturday, 12<sup>th</sup> November 2016. I would like to draw it to the attention of all female VUK members, 18 years of age or older, currently pregnant, and who have one of the vasculitic diseases detailed at the end of the article.**

One of the most common questions women with vasculitis ask is how the disease may affect their ability to have children. Unfortunately, there is limited reliable information regarding pregnancy and women with vasculitis. This is a great concern for both patients and physicians.

The Vasculitis Patient-Powered Research Network is pleased to partner with Megan E. B. Clowse, MD, MPH from Duke University Medical Center to launch the Vasculitis Pregnancy Registry (V-PREG). V-PREG is an electronic, patient-reported prospective pregnancy registry. Every woman who enrolls will bring knowledge and better understanding one step closer. We recognize that many women with vasculitis want to participate in research but cannot because of a variety of

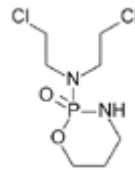


barriers. That is why V-PREG and the V-PPRN have made it easy for women to participate in this important research online.

V-PREG will consist of several on-line surveys to understand pregnancy characteristics and outcomes. The secondary objective is to assess the impact that vasculitis activity and medical therapy has on pregnancy outcomes.

The reproductive health of women with vasculitis has not been extensively studied. For example, we do not know if there is a higher than expected rate of infertility, early menopause, or pregnancy complications. Many patients with vasculitis are treated with cyclophosphamide (CYC), an alkylating agent that causes increased infertility in 30-50% of treated patients. The rate of infertility, however, has not been measured in the same cohort

of patients. A recent online survey of 450 vasculitis patients (sponsored by the VF and the VCRC, found that pregnancies conceived by women following the diagnosis of vasculitis had a higher rate of pregnancy loss compared to those conceived prior to diagnosis. Vasculitis was not worsened during 82% of pregnancies conceived after diagnosis. V-PREG will help investigators learn what specific complications of pregnancy and vasculitis



are experienced by women who become pregnant following a diagnosis of vasculitis. This registry is important because it will provide new, needed, clinical information and guidance to patients with vasculitis and to physicians.

Together, we can help expectant mothers with vasculitis. Clinical research can help answer the most important questions, and is a critical tool to improve outcomes for expectant mothers with vasculitis.

Who can participate?

You can participate if you are a woman, 18 years of age or older, currently pregnant, and have one of the following diseases:

- Behcet's disease
- CNS vasculitis
- Eosinophilic granulomatosis with polyangiitis (Churg-Strauss)
- Granulomatosis with polyangiitis (Wegener's)
- IgA vasculitis (Henoch-Shoenlein purpura)
- Microscopic polyangiitis
- Polyarteritis nodosa
- Takayasu's arteritis

***It is easy to enroll and easy to participate!***

[www.vpprn.org/vpreg](http://www.vpprn.org/vpreg)

**Caroline Savage**

## TRAVEL INSURANCE

**Vasculitis UK have a comprehensive list of companies who provide travel insurance for patients with pre-existing conditions.**

**Details are available on the VUK website:**

**[www.vasculitis.org.uk/living-with-vasculitis/insurance](http://www.vasculitis.org.uk/living-with-vasculitis/insurance)**

**or contact John or Susan Mills details on page 28**

## Volunteer News

*Vasculitis UK needs more volunteers if you are interested or know someone who would like to become a volunteer please email: [susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)*



## Support Group Meetings

<http://www.vasculitis.org.uk/about/find-a-local-group>

### Merseyside, Cheshire and North Wales Vasculitis Support Group Meeting

Speaker John Mills discussing the latest developments in vasculitis research, European vasculitis and rare Disease collaboration plus the latest news regarding Vasculitis UK. The meeting was followed by a fantastic Chinese Christmas buffet.



### East Midlands Vasculitis Support Christmas Party.

On December 10<sup>th</sup> 2016 the EMVSG held their annual Christmas party at the Mill House, Belper. 32 out of 40 members enjoyed a lovely Christmas lunch and the highlight of the day was a visit from VUK's very own Father Christmas who drew the raffle and gave Joe and Max an early Christmas Present.



Plymouth Vasculitis Support Coffee morning



Beds Bucks and Herts Vasculitis Support Group



North East Support Group lunch February 2017



Vasculitis Support Leaders Meeting October 2016



New VUK support meeting, Hastings Pier attended by 30 and sponsored by D.C Mercer & Son



There are Vasculitis Support Groups in a number of regions in the UK. Please see the Support Group list on page 26. If there isn't a group in your area you might like to consider starting one. You don't have to start big with a venue and speaker, it could be a small gathering at home or in a local pub. This is an excellent way to meet and support other vasculitis patients, and starting small is much less stressful for the organisers.

the Support Groups.

All the Support Groups mentioned in the Support Group list are autonomous in that they are not "administered" by the Trust. However, it is one of the aims of the Trust to help and support

We, at Vasculitis UK, do our best to ensure that support group meetings are well attended by advertising them in the "Dear Diary" section in the Newsletter, the e-News, on our Facebook and Health Unlocked discussion groups, and here on our website.

For new groups the Trust will advertise your endeavours by checking our main database for all members in your area and writing to them with details of the meeting. We can supply you with posters for your local hospitals/GP clinics etc, and send loads of "goodies" - balloons, pens, stick-it notes, car stickers etc. We also have a leaflet available to give you ideas about how to set up a Group.

We do not believe that anyone setting up a group should be out-of-pocket if they are willing to organise and run support group meetings. The Trust can offer some financial assistance towards funding at least the initial meeting.

Why not check the Support Groups. If there isn't a group in your area then email John Mills to discuss setting up a group.



## VASCULITIS SUPPORT GROUP WEST MIDLANDS (VSGWM )



### FIRST STEPS

When I was diagnosed with systemic vasculitis 1990 there was very little information or support available for patients, however I was lucky to be looked after by Dr Rashid Luqmani, registrar, to Professor Bacon at Birmingham Q.E. Rheumatology Research Dept.(R.R.D.) DrLuqmani was very enthusiastic about having a local support group. 1991-ish he gave me a great deal of help and encouragement, until when he left 1993/4, I had gained enough knowledge and enthusiasm to gradually gather together a small number of patients with Systemic Vasculitis, the start of VSGWM! Our first meeting was organised with Dr Exley when he became Registrar (R.R.D.). The speakers at that meeting 1996 were Professor Caroline Savage and Dr. Exley.

Eventually the Vasculitis Support Group West Midlands was set up 1993 (first meeting 1996) simply to help patients, and was the only Regional group for several years.

The Stuart Strange Trust, a national vasculitis group started a little earlier concentrating on obtaining funding for research and information, patient care was included later.

Searching for others with vasculitis I contacted Arthritis Care who referred me to a Mrs Braithwaite who kept lists of people with rare illnesses. This lady sent me a list of anyone with vasculitis (about 25). With my newly acquired Computer I sent a letter to all, and received back about 20 answers.

I took over care of the vasculitis list directly from Arthritis News, who included us in their Newsletters this brought me many enquiries over the years. Vasculitis Foundation USA were also very helpful and put our details in their Newsletter.

### EARLY MEMBERS

VSGWM had a nucleus of founder members who worked hard and remained very loyal, Judy Ross looking after finances (non existent for some time) and David Sambrooks joined a little later and who has gradually taken over the organization of members and meetings, (my deafness and age ( 88 yrs old ) making it necessary to step aside.). Unfortunately many of those members from the early 1990s are no longer with us, not unexpected as on the whole we are an elderly group.

### AIMS

The aims for VSGWM were to provide knowledge of vasculitis, and to give support to members and carers. The knowledge was well covered by

our speakers at the meetings and distributed to all members by reports in Newsletters. In the early 1990s the Newsletters were extremely important as information was so difficult to find.

They were discontinued in 2010 but by then information was more easily available.

The early years were very hard and we had so many enquiries I eventually had to produce an explanatory leaflet for new members. Probably because VSGWM was the only Regional group for some years, databases throughout the UK were asking for our details, again leading to further enquiries.

It was also important for members and carers to meet and support each other. All members were given a Contact List giving them the opportunity to talk to each other throughout the year, not just at the meetings. Names were only included on this list if they gave their permission.

### MEETINGS.

We have had tremendous support for many years from vasculitis specialists with the majority from Birmingham, most speakers would cover basic facts for new attendees and also up to-date information would be covered including the latest research programmes. I have already mentioned Caroline Savage, Paul Bacon, David Carruthers even Professor Raashid Luqmani who has visited to talk to us twice since he came to Oxford. My apologies for not mentioning all speakers, there have been so many and they have helped us to understand a great deal. It was very reassuring to realise how much was being done for vasculitis patients even as far back as the early 1990s.

There was always time allowed at the meetings for members to meet each other. Numbers of patients and carers attending varied from about 24 in the beginning, up to 50 when we had to find another venue, there were just a few years when over 70 people attended but numbers dwindled as more regional groups were being set up to look after their members.

At first we held 2 meetings per year but in 2003 we decided to have just 1 meeting per year.

### CONCLUSION

Many members have said how helpful they found VSGWM, and I also think it helped in my own recovery.

Enough of the past, I now look forward to future years with more Regional/ Local Groups being set up and our voices being channelled via Vasculitis UK to make official organisations more aware of vasculitis and its affects and how they can improve patient situations.

**Margaret Gentle 2017**

## Help Advice & Support

For help advice and support or just a chat about your problems, join the Vasculitis UK online discussion groups on Facebook and HealthUnlocked. Look in the top Right corner of any page on the website and click on the small icon marked F or HU.

These groups each have about 3000 members, all living with some type of vasculitis, or they may be partners, carers or family members of people with vasculitis. There's a lot of collective knowledge & experience there!

On Facebook you can join all or any of the following Vasculitis UK groups: "Vasculitis Support Group", "Young Vasculitis", "Bereavement", "Pregnancy & Parenting", "Caring for Carers" and the "Healthy Eating" group.

**For all the latest information and news,  
visit the Vasculitis UK website <http://www.vasculitis.org.uk/>**

## How do you eat an elephant?

## Part 1



"A small piece at a time." That's what I was told back in 2008 when I was first diagnosed with Wegener's Granulomatosis (WG). The date was the 1<sup>st</sup> October (the anniversary of an infamous

cyclist who was stripped of 7 Tour de France wins; however he was diagnosed with cancer that day).

Prior to this date I was fairly fit and active I had completed several 10K road races about 3 half-marathons and ran 3 times a week. The fitness was lost as a result of the WG, I could barely walk, I had lung damage and then the depression kicked in, which was harder than dealing with the WG. At the time I had a lot going on in my life: a disease, mother-in-law in intensive care, 2 houses to fund and I wasn't working. So I had a big elephant to eat and the only way I could do it was a small bit at a time.

My consultant said getting back to exercising would start to chase the depression away. So I did a small piece at a time but often as I was having cyclophosphamide at the time. Eventually I built up enough fitness to race again. Then I went onto to do a marathon which I never dreamt of doing prior to WG. An ankle injury resulted in me taking up swimming then I decided to start cycling to work, this is when I caught the triathlon bug!

In 2014 I had a flare up which resulted in a blood clot in my internal jugular vein, which meant more treatment and warfarin for life (only 4 units of alcohol allowed -Booo), I kept my training up through cyclophosphamide.

Fast forward 2016, my fitness was good (remember I got here by just doing a small bit at a time). I decided to do 10 events for Vasculitis UK in 6 months, this consisted of 2 duathlons and 8 triathlons. For those that don't know a duathlon is run bike run event and a triathlon is a swim, bike then a run.

So this is how the year of events panned out with a bit of chemo chucked in for good measure:

### **20<sup>th</sup> March 2016: Sun City Duathlon**

This was an 8am start at Roker which is on the North East coast so as you can imagine it's not going to be warm! I picked my Mam up (A member of the #TeamHag) at 6am as you need to register prior to the race. Team Hag consists of Mrs Hag (Ali), Mother Hag and Dad Hag. The name Hag comes from my nickname Haggiss (no we are not all ugly, well some might be, I'll let you decide!). I arrived at The Seaburn Centre at Roker in good time, collected my race numbers filled up with coffee, and then racked my bike with my bike shoes. The 1<sup>st</sup> run was 5K which went well at one point I had to actually slow down as pacing is the key in these events otherwise you run the risk of bonking!! (See Jonathan Brownlee

in Mexico, now that was a classic bonk! I know what you were all thinking; this is a typical triathlon term). In from the run you head into Transition 1 (T1). In T1 you change out of your running shoes put your bike helmet on then your bike shoes, collect your bike for 4 laps around Roker. All I can remember about the bike is that it was cold windy and a competitor crashed into a public cyclist and broke his collar bone! On completing the 4<sup>th</sup> lap I hopped off the bike into T2 and changed back into my running shoes, then headed off onto the run, bang wobbly legs if you ever have tried running whilst coming off a bike it's the closest thing to looking drunk if you have never trained for it. Even the fittest person in the world would struggle if they don't include it in their training. After around 200m I was ok, 5k later I crossed the finish line so that was the start 1 out of 10 completed. Whilst I was racing my Mam who's not that shy was talking (no) to a man about what I was doing this year and he donated some money for Vasculitis UK, so the first event was worthwhile after all.

### **April 2016:** I won the Sunday Post family hero award in Glasgow. Judy Murray and Lorraine Kelly presented the award to me.



Looking back at the photo of the night my wife (Mrs Hag) noticed that my left eye was starting to protrude forward again. I also started getting facial pain. The Scans showed that the WG was coming back. The prednisolone was increased then the plan was to stick me back on Cyclophosphamide. I was gutted as I thought that's the end of the other 9 events and the fundraising for Vasculitis UK.

Eventually it was decided I would have Rituximab this was planned for May. I was only kept in hospital for a day, phew as I was racing on the Sunday at Stockton.

### **24<sup>th</sup> April 2016 Stockton Duathlon:**

After no training all week, an increase in Prednisolone it wasn't the best preparation for this event. I went swimming the Friday before with my eye still protruding the goggles being tight had caused the white in my left eye to go red; being on warfarin it made the eye look worse. It must have looked bad as I got plenty of sympathy off my club mates.

It was Mrs Hags turned to get up early for the start. We got there in good time did the usual register, coffee and racked the bike. There was also a few other Durham Tri Club members there as Stockton Duathlon is a really big event as it's usually a British qualifier. If you are good enough you can qualify to represent Britain for

your age group. Durham has quite a few "Age Groupers". The 1<sup>st</sup> run was quick, the bike was really windy and I was quite pleased because I passed a Durham age grouper and took 4 minutes out of him on the bike. (At the finish he was complaining that he selected the wrong bike for the course!!!). Coming onto the final run I was a bit angry with the WG coming back so I decided just to go for it, plus I knew the Age Grouper was chasing me down low and behold I beat him. I was delighted especially after the week I had. Once I received my medal I went straight over to the podium and posed for a photo before the actual winners were presented with their prizes. Now that was 2 down 8 to go. Plus the prospect on 2 infusion of Rituximab.

**May 2016:** Prior to the increase in steroids I had terrible double vision so I use to keep one eye closed whilst cycling, I know the steroids were working as the double vision was going - there was only 1 Mrs Hag. Now it was time for the Rituximab I had the 1<sup>st</sup> infusion on the 5<sup>th</sup> May, this went ok but I had an irritating cough that started. It was that bad Mrs Hag chucked me in the spare room!

### **15<sup>th</sup> May 2016, the Cleveland Sprint Triathlon:**

This was a 400m swim, 20K bike followed by a 5K run. Mrs Hag and I stayed in the camper van overnight at Stokesly so I would be there in good time. I did the usual register, rack the bike and then loaded up with coffee. The swim was a pool swim and it was only 16 lengths. The thing is with sprint triathlons, that's what you do throughout the race "sprint". The swim I hardly breathed, I coughed throughout the bike and the run was pretty good considering the previous legs. I finished in a reasonable time 3 down 7 to go; now it was time for my 2<sup>nd</sup> infusion of Rituximab.

**18<sup>th</sup> May 2016,** I went for a swim prior to my 2<sup>nd</sup> infusion of Rituximab. This made me late for the appointment so I ran up from the baths to the hospital trying to eat a flapjack and drink a coffee at the same time. By the time I got there I was sweating buckets. The nurse was concerned about the sweating; I still had the irritating cough and my temperature was low!!! She said she would have to take a blood test prior to starting the infusion. Anyway I got the go ahead to proceed and a blanket to warm me up!!!

**June 2016:** Now the Triathlon season really kicks in. Open water swimming is now the norm for Triathlons. I was warned by my consultants not to take necessary risks whilst swimming in open water (not to swallow the water) as there was an increased risk of catching an infection as my immune system was suppressed with all the medication I was on.



I still had the irritating cough it was that bad I was sleeping now sitting up as the consultants thought it was reflux, a side effect of the prednisolone. I was booked in for a chest scan and a barium meal. However, whilst at work a Queen Bee landed on our factory wall and it attracted over 20,000 Bees, I had to organise a Bee Keeper to come out and take her away. He heard me cough and he said it's hay fever (I never realised he was an expert in WG). He said natural honey would get rid of it; I was that desperate I decide to start taking it daily.

**19<sup>th</sup> June Kielder Olympic distance Triathlon** – this triathlon was probably the hardest of them all as the distance doubles: 1.5Km swim, 40Km bike (England to Scotland) and then a 10Km trial run. I thought with the cough, lack of open water swimming (one swim prior to the event), being eaten alive throughout the night by midges and the terrain I would just be glad to finish in one piece, I was generally worried!

With us camping I could register the night before, this would give me an extra 30 minutes in the van the day of the race. I racked the bike next to a friend of mine who helped me on with my wet suit. I was nervous about the swim as I knew the cold water would start the cough again, this is why I wanted to get in the reservoir and "warm up". Once in you have to let the cold water in via the neck, its freezing believe me, your body then heats the water trapped between you and the wetsuit to keep you warm. I did this no coughing, a great mental boost! The hooter went and we were off you couldn't see a thing as the water was brown off the peat.

Kielder Reservoir is a man-made reservoir, the largest in Europe! Half way through the swim I was making good progress I was in the middle of the reservoir and then bang my arm caught something it was I though a log! In fact it was an old tree that hadn't been removed prior to the land being flooded (I know there was an old village beneath us). At this point I had to climb on top of the trunk. It was so funny as everyone swimming around me thought I was walking on water, the guide in the boat wanted to know what I was standing on, I explained he tied a buoy to it and I was on my way.

I exited the water on about 32 mins, stripped off the wet suit and then headed off onto the bike route. This was windy, cold (yes I know it's June but we are on the border with Scotland here) and it was full of cattle grids ( a recipe for bad backs). The route took you into Scotland with a great sign saying "Welcome to Scotland" I know why it was downhill for approx. 3 miles to the turnaround point. Then I realised I had

to climb that hill on the way back no wonder the return sign just said "England" – no welcome here then! The run I was knackered and you could tell the lack of running and possibly the infusion of Rituxamab, the cough was taking its toll oh and those bloody midges. I know I can run quicker and it wasn't flat! However the plan was to finish it and raise money for Vasculitis UK. I did finish received my medal and then drank about 2 litres of coke (I never drink coke, so that was bizarre).

**July 2016** – I had the chest scan then the barium meal, the result showed everything was ok, so they were puzzled where the cough was coming from. I was that desperate now I was taking 2 spoonfuls of honey a day, one was for the cough the other was because I like the taste.

Anyway low and behold prior to the Ripon Triathlon, the cough disappeared. Now reading the comments online about Rituxamab I think it might have been a side effect.

### **9<sup>th</sup> July 2016 – Ripon Olympic**

**Distance Triathlon** (1m swim, 40Km bike followed by a 10Km run) – this is a massive triathlon (4000 people in attendance over the weekend) and it was based at Ripon Race course. The swim believe it or not is in the middle of the race course, watch out for it next time you are watching at the races!!" Team Hag travelled down on the Friday in the Camper Van. We managed to get a good spot next to the Lake. On the Saturday the race started at 2pm. With having over 2000 competitors you were split into 10 waves for the swim (no pun intended). I was in Wave 5, each wave was set off every 10 mins so I wasn't actually off until 2.50pm. This gave me time to cheer the leaders in from the swim and there were 2 Durham lads in the top 10 out of the first wave.

My mate Bally was in the same wave as me and we can both talk so the 50 minute wait with wetsuits on soon passed by quickly. So in the water we went, the plan was to go to the far end of the line up to the deepest point but at the front. We wanted to get ahead of the pack so Bally was going to swim like mad for 400m and I would follow, then I would take over. After the 1<sup>st</sup> 10 metres I lost him but stayed with a pack all the way round the lake to the exit point, I swam behind them to conserve energy for the bike. Quick change out of the wet suit and onto the bike, this again was wet and windy an out and back route along the old A1. I was caught up by a club member whilst on the bike, he said he was delighted that he managed to have a pee whilst on the bike, I couldn't stop laughing thinking about the damage he would have done to his "cogs" (steady bike cogs I mean).

Into transition then a quick change of shoes and onto the run. I was knackered however, I managed to pass a few and it was great at the finish to see all the Durham Triathletes cheer me home. That was it 5 done 5 to go for Vasculitis UK.

### **17<sup>th</sup> July 2016 Northumberland**

**Sprint Triathlon**, now the races were coming thick and fast if I wasn't racing I was training. Every Tuesday I would head off to the lake near where I work to swim with another Durham Triathlete "Yoda" he's a British Age Grouper and my "mentor", well he keeps me right!!!. Yoda is a great swimmer I'm sure he is half fish! He was doing Northumberland with me, again Mrs Hag and myself kipped over night in the camper of the hotel car park whilst Yoda had all the luxuries of a bed and bog!

The race format was 750m lake swim 14 mile bike with a 6Km run. For the swim Yoda always tells me to start as far left as I can, so we can avoid the masses, this is so we don't get a couple of kicks or left/ right hooks. For once I listen to him, the hooter went then the washing machine of swimmers starts, we headed for the 1<sup>st</sup> buoy. I came to the first buoy at angle joined a pack of about 8 swimmers drafted off them to the exit ramp. I started running up the bank whilst stripping the wetsuit off, glanced to my left and noticed Yoda alongside me; I couldn't believe I actually came out of the water ahead of him!!! After the race he said he was sick during the swim (yeah right).

I was out of transition and onto the bike a minute ahead of him now, well he does have to put a hair band in!!! The bike was so windy and I'm quite a thickset lad and sure enough he passed about 5 miles later. Yoda went on to overtake 75 people to get a place on the podium. Another age grouper passed me from Durham who also went on to win his age group. As the norm I got off the bike and imploded I might as well have walked I was that slow, but it was all about the finishing, which I did that was the 6<sup>th</sup> one out of the way, 4 to go – momentum.



By Andrew Robertson

**To be Continued  
in the Autumn Edition...**

## A Vasciprincess Road Trip

Hello, I am Zoi Anastasa and I live in Plymouth, and guess what? I am diagnosed with vasculitis, a journey that started more than two years ago in a hospital bed with me unable to walk, suffering from a bad rash and in tremendous pain.

Living with vasculitis is like being on a roller coaster ride all the time. The impact of the illness in my everyday life was big. I cannot remember spending so much time indoors in my life and I can tell you I am not born to be a housewife...household chores are last on my list!

My rheumy introduced me to Vasculitis UK website. I am also a facebook fan (I found my long lost love there but that's another story!) I joined the Vasculitis UK fb support group and it became my second family. I have "met" so many lovely people there and I have made some new friends. A very special "web" friendship bloomed up.

I wanted to meet my internet friend and since her condition doesn't allow her leave her bed it was all up to me, but she lived in the North of England! Twice I cancelled my visit because of medical problems. But I was determined to show vasculitis, it does not control my life!

Almost two years after my diagnosis, I am off for my first ever road trip in UK on my own. Knowing my limits I planned three overnight stops.

Over, a 200 miles drive got me from Plymouth to Birmingham and by coincidence another vasculitis web friend Jayne, (who

introduced to me by my special friend Chelle) was hospitalised there for a few days, so there was an opportunity to meet Jayne and chat for a few hours.



**Me and Jayne Shaw**

The following day and another 100 miles in the car, with my favourite music on, brought me to Rochdale, near Manchester, where I made a surprise visit to my Vascie princess Chelle Taylor.

I cannot describe the joy I felt walking in her room and seeing her sparkling beautiful eyes when she realised who I was. I have to thank her mum Marilyn for helping me organise it. Meeting Chelle was big for me, she had been virtually holding my hand for 18 months, even though she has to fight hard for her own life.



**Me and Chelle**

(I still think I dreamt of our meeting sometimes!)

Day three: On my return journey, I had the opportunity to attend the Birmingham vasculitis support group annual meeting. David Sambrook, his wife and all

the members made me feel very welcome (I plan to attend next year's meeting as well).

There were two speakers, two wonderful doctors. Professor Lorraine Harper spoke about fatigue and vasculitis. Unfortunately I live too far away to be part of her new study.

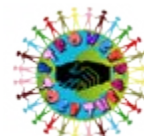
The second speaker I must admit was one of the reasons I attended the meeting, Dr. Dimitrios Chanouzas. A lovely young Greek doctor that introduced me to the CANVAS study. It feels good to know that doctors are trying to find ways to help us fight this disease that sneaked in to our lives.



**Dr. Dimitrios Chanouzas and Professor Lorraine Harper**

More than 600 miles on the road made me feel I was finally on top of my illness. My life will not be any less than it was before diagnosis, just a bit different. I want to thank my family, my rheumatologist, Dr. King and my GP, Dr Gastone for being there for me on this new journey but most of all I want to say thanks to Vasculitis UK for all the information and support. Last but not least thank you my awesome vascie family for being here for me.

**Zoi Anastasa**



**For all the latest information and news,  
visit the Vasculitis UK website <http://www.vasculitis.org.uk/>**



## **A Vasculitis Patient Support Presentation Evening with RD&E Exeter Consultants**

On 9<sup>th</sup> February the West Country Support Group organised an event at the RD&E Hospital, Exeter. Approximately 35 people attended a presentation by RD&E consultants Dr Lucy Smyth (renal) and Richard Haigh (rheumatology), followed by a Q&A session (which also included Dr Catherine Gwynne, rheumatology, Torbay hospital).

Dr Smyth began with a presentation called "Everyday Vasculitis (or what questions do we get asked most)".



She discussed the definitions and symptoms possible causes/triggers, remission induction and maintenance drug options and guidelines, causes of fatigue, blood test results, preventing and managing relapse and how we can be proactive in our ongoing health. Of course much of this information is available online (via the invaluable Vasculitis.org.uk website) but I found it extremely helpful to have a clear and accessible summary of current understanding from someone who has experience of scientific research and medical trials as well as expertise with several current patients.

Dr Haigh spoke next on "What's New In Vasculitis", which looked in more detail at the science of the causes, actions and effects of vasculitis, and how understanding the precise mechanisms of the disease at genetic and microscopic levels is informing research into effective treatment. A potentially bewildering subject was brought to life with talk (and pictures!) of zombie policemen, rioting crowds and striking binmen, as well as use of the technical term "gubbins"!

Dr Haigh talked of a new possible alternative drug to steroids for those with ANCA vasculitides (called CCX168, a C5aR inhibitor) for which the RD&E will be participating in a future trial.

He conveyed a great sense of enthusiasm about the progress being facilitated by research, but finished by acknowledging that there was still much to learn and improve upon, highlighting some challenging areas such as treatment of asthma in EGPA, treatment of continually relapsing disease, mitigation of organ damage, etc.

In response to an audience question about alternatives to standard medicines, Dr Haigh observed that little was known about what other complementary/alternative medicine (CAM) therapies vasculitis patients used. He showed the results of a US study in which 81% of patients used CAM (eg. Prayer, massage, exercise, homeopathy, mindfulness/meditation etc) but only 24% discussed this with their doctors.



Cultural differences such as healthcare insurance vs NHS mean the results don't necessarily translate to the UK situation, and Dr Haigh

suggested that Vasculitis UK conduct a survey on complementary therapy use in UK patients treated for vasculitis.

His final suggestion very much encapsulated an underlying theme of both presentations, namely that while science has over time established many answers to the difficult questions posed by vasculitis, there are still many unknowns and variables in this rare disease, that each patient is an individual, and that doctors and patients must work together for the best possible outcomes.

**Article by Lesha Farrar**

*A member of the West Country Vasculitis Support Group. For more information about the group visit [www.vasculitiswest.wordpress.com](http://www.vasculitiswest.wordpress.com)*



**VASCULITIS  
AWARENESS MONTH  
IS MAY 2017**



# Travel Bursaries

## The 18<sup>th</sup> International Vasculitis & ANCA Workshop

Tokyo, Japan 25th-28th March 2017



The 18<sup>th</sup> International Vasculitis Conference and ANCA Workshop took place on 25-28 March at the Ito International Research Centre in Tokyo, Japan. This is the showcase where researchers present their papers, abstracts and posters to a wide audience of medical and scientific experts on vasculitis. Many of the speak-



ers are eminent in their field, but others are young, up and coming researchers, some of whom will perhaps become the experts of the future.

Tokyo is a long way from here and an expensive city. Conference delegates have to pay their substantial registration fee, air fares and hotel accommodation. For a junior doctor on a modest salary, wanting to present a paper or a poster in public, these costs can be daunting. So this year, Vasculitis UK invited junior doctors and other trainee professionals to apply for one of five travel bursaries worth up to £1000 each.

We were fortunate in receiving just five very suitable applications for the five grants on offer. The applicants varied from a final year medical student to Specialist Registrars.

**Dimitrios Chanouzas** is a clinical lecturer and Specialist Registrar at Birmingham University Hospital. He was to present an abstract from his paper on the "Reactivation of cytomegalovirus and its association with cardiovascular disease" This study was part funded by Vasculitis UK and Dimitri presented his findings at the Vasculitis UK AGM last year.

**Alex Harper** is a final year medical student at University College London who does extracurricular work with the Institute of Child Health at Great Ormond Street Hospital on vasculitis and autoinflammation. He was to present an abstract on ANCA vasculitis in children, with an investigation to establish if disease activity scores were predictors of outcomes.

**Pani Gopaluni** is a Research Fellow and honorary Clinical Fellow at Cambridge University Hospital Trust, with a strong track record in research, including



investigations into the effectiveness of alemtuzumab in treating vasculitis, a study to which Vasculitis UK contributes some modest funding. He was to present an abstract on a retrospective study to establish if patient data at six months after diagnosis

could be used as a predictor of mortality and end stage renal failure.

**Sarah Moran** is a final year Nephrology Specialist Registrar in Dublin, doing a PhD in Personalised Medicine in ANCA vasculitis. She has a list of published papers to her name.



Sarah was to present an abstract on the value of urinary soluble CD163 and urinary MCP-1 as indicators of mild renal flare.

**Jeremy Royle** is a Rheumatology Clinical Research Fellow at Queen's Medical Centre in Nottingham, working with Dr Peter Lanyon and Dr Fiona Pearce. He was to present an abstract on a study comparing the long term effects of daily oral versus pulsed intravenous cyclophosphamide treatment.

We hope that Dimitri, Alex, Pani, Sarah and Jeremy will offer us their impressions of the Tokyo conference in a future newsletter and maybe share the results of their research at support group meetings and through the newsletter. These are the rising stars of the vasculitis world. Remember, you first read about them in the Vasculitis UK newsletter.



# IgA vasculitis (HSP) patient and parent focus group

A successful focus group was held on Sunday 5<sup>th</sup> March 2017 in Manchester for patients and parents of children who have had IgA vasculitis (formerly known as Henoch Schonlein Purpura). The meeting was hosted by Dr. Louise Oni.

The aim of the group was to gather ideas from those who have experienced this condition with a focus on how we can improve clinical care and to explore



priorities for future research. The focus group consisted of 8 families, and included children as young as 3 years old. Teenagers attended and the young people were actively involved in

the session and were each rewarded with a gift bag. Representatives from Vasculitis UK attended the meeting too and were extremely useful at describing the typical enquiries that they receive from patients across the country.

It was an excellent event and raised many interesting

areas for us to drive forward. We discussed what differences in care matter the most to patients, the many ways that parents knew the condition was improving (as a measure that could be used for possible studies), they formulated an ideal care pathway for patients and brainstormed ways to reach out to patients with any further events (eg: facebook, instagram, twitter).

All attendees were keen to be part of a disease registry and we discussed that we are trying to include children with IgA vasculitis in the UKiVAS.



The meeting was funded by a Public engagement grant from the University of Liverpool and the Wellcome Trust Research Charity. I would like to thank all of those who attended for helping with such an important piece of work. Due to its success, we hope to hold another event in a different location in the near future.

*Dr. Louise Oni, NIHR Clinical Academic Lecturer in Paediatric Nephrology, Alder Hey Children's NHS Foundation Trust Hospital, Liverpool*

## RARE DISEASE DAY February 28th 2017

Rare Disease Day is an international event to raise awareness of all rare diseases and their impact on patients. Rare Disease UK promoted an on line photo challenge, open to all those diagnosed with a rare disease to share photos for all of the month of February. Many of those diagnosed with vasculitis took part in this challenge. Here is just a small selection of photos.





A new App called patientMpower is available for Vasculitis patients. It offers personalised tips on staying well, help with medication adherence, a place for storing health data (such as blood pressure, blood results) and a means of enhancing



patient-physician interactions.

There are versions for both iOS (iPhone, iPad etc) and Android, and while the features vary a bit (step-counting is

only applicable to mobiles, not tablet devices, for example - and for the moment only on iOS), it is still well worth exploring.

The developers write:

*"We also envisage it as supporting vasculitis research, by allowing direct recording of patient reported outcomes and linkage of relapse events to environmental factors. Ultimately, we aim to provide a personalised tool to assist you and your doctor in getting the dose of immunosuppression right and in predicting relapses before they occur"*

## Well-being

Some great tips for being well

When registering, selecting "Vasculitis" in the condition field. If your hospital is not present in the registration options, email [support@patientmpower.com](mailto:support@patientmpower.com) with the name of your hospital and they will get it added.

After registering, you can select the type of Vasculitis you have in the "profile" section.

If you need any help getting registered, setup or want information on compatible devices which work with the app, please email [support@patientmpower.com](mailto:support@patientmpower.com)

As this is the first release of the app - the team would love your feedback on how to make it better. Please email [support@patientmpower.com](mailto:support@patientmpower.com) with any suggestions or improvements or content you would like to see included.

At a later stage the team will look for your consent to have your (anonymised) data included in the AVERT research program, being run by Prof Mark Little of Trinity College Dublin and Prof Alan Salama at University College London.

## Chronic pain- What can I do to help myself?

The following is an extract from the booklet "Managing Chronic Pain" produced by the Scottish Intercollegiate Guidance Network (SIGN).

The booklet covers many topics to help you understand your pain, covering issues such as how it is assessed and how to manage your pain, including complementary medicines.

You can view the booklet at: [www.vasculitis.org.uk/living-with-vasculitis/dealing-with-pain](http://www.vasculitis.org.uk/living-with-vasculitis/dealing-with-pain)

Nobody else can understand your experience of pain or what it feels like to live with it every day. You are the best person to understand your pain and the best to manage it.

**You can try to "self-manage" your pain. This could include:**

- Formal self-management programmes (group-based, individual or online); or
- Informal self-management (for example, learning about pain management by reading about it).

Learning about your pain and understanding it can help you manage it well.

Healthcare professionals can help you find a self-management programme that suits you.

**Take medication regularly:** To achieve good pain control, it is usually important that you take your medication every day, as guided by your healthcare professional, even if your pain doesn't feel as bad. You should not change the dose of the medication or when you take it until you have discussed this with your healthcare professional.

**Exercise:** Staying active can help to improve your pain in the long term. If you are not sure what exercise is best to do with your pain, discuss this with a doctor or physiotherapist.

It is important that if you are experiencing pain you should discuss this with your GP or consultant and follow the regime suggested by your healthcare professional.





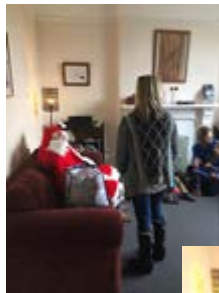
## Young Vasculitis Weekend Winter 2016

Emma Smith



In November 2016 we held our very first Young Vasculitis support weekend which was located in the lovely little village of Hathersage in the Peak District.

A number of people attended including Fiona a Vasculitis Doctor and Alice a Vasculitis Specialist Nurse. From the moment we arrived on Friday evening the atmosphere was relaxed and chilled (which we all need sometimes) and the night was spent eating pizza and sharing our Vasculitis stories. Saturday morning Fiona gave a presentation which included information on ANCA Positive Vasculitis and Vasculitis research that she is involved in. Throughout the day we were left to our own devices, some visiting the village or like me using the time for an extra nap.



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## The Finnish Vasculitis Association

Our national organisation Suomen Vaskuliittiyhdistys ry (The Finnish Vasculitis Association) was founded in November 2013. At the beginning of 2014 we had 6 members. At the end of 2016 we had 111 members, of which 100 have vasculitis living all around the country. Annual membership payment is 17 € (2017).



Secretary Mailis Suhonen  
Chairman Daniel Segerlov

We have a board of 5 members and we work at home, all of us being volunteers. The board has its meetings in skype, except at the annual meetings, where we meet live and rent the place in different cities.

We are a member organisation of Suomen Reumaliitto ry (The Finnish Rheumatism Association)

<https://www.reumaliitto.fi/en>

### ACTIVITIES 2017

March - Areal meeting for members and other vasculitis and other people with vasculitis in Turku patients from eastern Finland in Kuopio

March - Annual meeting and event for all the members

November - Areal meeting for members and other vasculitis patients from northern Finland in Oulu

We publish "member letters" monthly with information of the Vaskuliittiyhdistys, vasculitis, rehab etc. These letters are mostly emailed to members except a few posted.

Our website is [www.vaskuliittiyhdistys.fi](http://www.vaskuliittiyhdistys.fi)



Finland's population is about 5,5 million. In each of the 5 university hospitals in Finland, there is a department for rare diseases to get the best knowledge in those places. Otherwise mostly rheumatologists treat vasculitis patients.

Suomen Vaskuliittiyhdistys ry had an areal member meeting in Helsinki October 15th 2016

In the Helsinki meeting there were 15 members listening to psychotherapist Saana Janhunen's lecture about how illness effects your mind, and how to find your own assets. Meeting many equals face to face was very fruitful and important.

## Southampton Children's Hospital Renal Paediatrics and the Transition to Adult Services Conference



John Mills & Lynn Laidlaw  
VUK Stand



Keynote Speaker  
Dr David Jayne





## Anti-neutrophil cytoplasm antibodies (ANCA)

Mark E. McClure (left), Vasculitis Research Fellow, Addenbrooke's Hospital, Cambridge  
Rachel B. Jones (right), Consultant in Nephrology and Vasculitis, Addenbrooke's Hospital, Cambridge

For all references for this article please visit the VUK website <http://www.vasculitis.org.uk>



### ANCA-associated vasculitis

If a patient has ANCA-associated vasculitis, he or she may have one of three different vasculitis conditions: 1. granulomatosis with polyangiitis (GPA), previously known as Wegener's granulomatosis, 2. microscopic polyangiitis (MPA) and 3. eosinophilic granulomatosis with polyangiitis (EGPA), previously known as Churg-Strauss syndrome (1). These three conditions are grouped together under the umbrella term 'ANCA-associated vasculitis' because they are all associated with a key protein factor in the blood called 'ANCA' and because they all cause inflammation or damage to small blood vessels. Small blood vessels are found all over the human body, so any part of the body can be affected, but most commonly the kidneys, lungs, joints, ears, nose, and nerves. Because the kidneys and lungs are vital organs, early treatment for ANCA-associated vasculitis is very important to prevent serious organ damage.

### Antibodies and autoantibodies

The human body is well designed to fight infections and prevent the development of cancers using the white blood cells and protein factors that comprise a healthy immune system. A key element of our immune system is its ability to distinguish between the human body's own cells (referred to as 'self') and foreign cells e.g. bacteria and viruses ('non-self'). Each cell carries protein markers called antigens that allow it to be identified as 'self' or 'non-self' by the immune system. Antibodies (also known as immunoglobulins) are important blood proteins in the immune system that are produced by a type of white blood cell called B cells. Antibodies naturally develop during exposure to infection and by binding to foreign antigens, help neutralise and eliminate the particular 'non-self' bacteria or virus that caused the infection. Antibodies are especially helpful when a particular type of bacteria or virus is encountered for a second time. In this situation antibodies already present in the blood against the particular bacteria or virus, prevent infection from developing. Stimulating the formation of antibodies against potentially serious infections by exposure to a mild or killed version of a bacteria or virus is the principle of vaccination. Antibodies against foreign 'non-self' cells are therefore very useful.

Autoimmunity is a failure of the immune system to always correctly recognise 'self'. As a result, the body's own immune system attacks part of the human body. Autoimmune conditions are often characterised by the production of antibodies against one type of human cell (so called auto-antibodies). Autoantibodies may directly cause harm, by binding to their specific cell type, causing the cell to malfunction.

### What are ANCA?

Anti-neutrophil cytoplasm antibodies (ANCA) are autoantibodies that target a type of human white blood cell called neutrophils, which are important for maintaining good health by fighting infection, partly through the release of toxic substances that destroy bacteria. In ANCA-associated vasculitis, ANCA specifically bind to two proteins that are normally found in the fluid within the neutrophil cell (cytoplasm). The two proteins are called proteinase

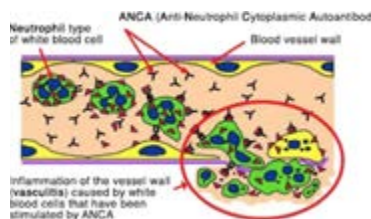
3 (PR3) and myeloperoxidase (MPO). Patients with ANCA-associated vasculitis usually have autoantibodies against proteinase 3 (PR3-ANCA) or myeloperoxidase (MPO-ANCA) but not both. In granulomatosis with polyangiitis (GPA, Wegener's) 95% of patients are ANCA positive at diagnosis, and GPA is most commonly associated with PR3-ANCA (~65% patients). In microscopic polyangiitis (MPA) 90% of patients are ANCA positive at diagnosis, typically with MPO-ANCA (~55% patients) (2). However, in eosinophilic granulomatosis with polyangiitis (EGPA, Churg Strauss) only 40 % of patients are ANCA positive at diagnosis, usually MPO-ANCA(3).

### ANCA contribute to blood vessel damage

ANCA are not only a measurable blood marker in patients with ANCA-associated vasculitis but are also harmful autoantibodies that are directly involved in small blood vessel damage. The binding of ANCA to neutrophils in the blood results in: 1 the release of toxic substances from neutrophils causing damage to small blood vessel walls, 2 neutrophil movement through blood vessel walls causing inflammation in surrounding tissues, 3 release of signalling factors that attract more neutrophils, perpetuating the inflammation and destruction of small blood vessels (4). ANCA alone are capable of causing vasculitis, as observed in a baby who developed lung and kidney vasculitis after birth, because MPO-ANCA had crossed the placenta from the mother(5). Furthermore, medications including propylthiouracil, hydralazine and penicillamine have been associated with the development of ANCA and vasculitis. Stopping the medication usually results in improvement in symptoms and the disappearance of ANCA from blood (6).

Figure 1 (below)

Diagram showing ANCA-induced 'activation' of neutrophils causing inflammation of the blood vessel wall



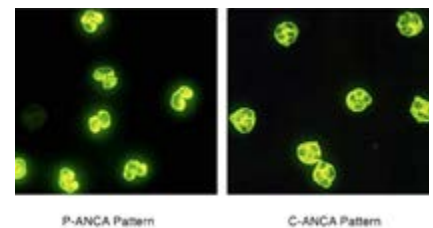
### Where do ANCA come from?

Both genetic and environmental factors contribute to the development of ANCA-associated vasculitis in patients (7). However, the precise cause for ANCA arising in individual people at different ages is poorly understood. Infections are one possible trigger; 63% of patients with granulomatosis with polyangiitis (GPA, Wegener's) chronically carry the common bacteria, *Staphylococcus aureus* in their noses, and nasal vasculitis is common in GPA (8). Another proposed mechanism is 'molecular mimicry' between bacterial and self-antigens, when similarities between 'non-self' and 'self' antigens may be enough to activate immune cells (9). Alternatively ANCA may result from defective neutrophil cell death, resulting in abnormal exposure of internal neutrophil fragments (10).

### ANCA testing

ANCA blood tests are performed by two methods: Indirect Immunofluorescence (IIF) and Enzyme-Linked Immunosorbent Assay (ELISA). Indirect immunofluorescence identifies ANCA by staining patterns within neutrophils. ANCA staining throughout the neutrophil cytoplasm (cytoplasm, C-ANCA pattern) usually occurs with PR3-ANCA. Staining around the cell nucleus (perinuclear, P-ANCA pattern) usually occurs with MPO-ANCA. Immunofluorescence testing provides either a positive or negative result. Conversely ELISA is a technique that allows the level of PR3-ANCA or MPO-ANCA in the blood to be measured. Indirect immunofluorescence is often used to screen patients to see if they are ANCA positive, followed by ELISA testing in positive patients to measure the actual amount of PR3-ANCA or MPO-ANCA present (11).

Figure 2. Indirect immunofluorescence of ANCA



### How useful are ANCA blood tests?

Testing for ANCA at the time of diagnosis of ANCA-associated vasculitis is really useful. A positive C-ANCA immunofluorescence test or a strongly positive PR3-ANCA or MPO-ANCA ELISA test result is highly suspicious for the diagnosis of ANCA-associated vasculitis. Provided that a patient has clinical features of vasculitis, the positive ANCA test helps to confirm the diagnosis along with tissue biopsy results. The introduction of ANCA testing across the UK in the 1980s was associated with a significant increase in the diagnosis of ANCA-associated vasculitis, probably because ANCA tests allowed more cases of ANCA-associated vasculitis to be correctly identified.

After a diagnosis of ANCA-associated vasculitis has been made, regular blood testing for ANCA is part of routine clinical care. Importantly patients with PR3-ANCA at diagnosis have a higher long term relapse risk (50% relapse at 5 years) compared to those with MPO-ANCA at diagnosis (20-30% relapse risk at 5 years) which influences treatment decisions. Typically both PR3-ANCA and MPO-ANCA levels fall during treatment, and most but not all patients become ANCA negative over many months. ANCA testing can be very helpful for some individual patients for predicting the timing of a relapse, with a switch from ANCA negative to ANCA positive or a rise in ANCA level predicting relapse. However, these rules do not consistently apply to all patients, making the interpretation of ANCA results less straightforward. For example, a minority of patients suffer relapses when they are ANCA negative, and others relapse without a significant rise in their ANCA level. ANCA test results are therefore always interpreted alongside a patient's symptoms and other blood test results such as inflammatory markers (CRP, ESR), kidney function and urine measurements for blood and protein.

## IN MEMORIAM

Vasculitis UK receives donations from bequests and funeral collections in memory of particular individuals who have suffered from vasculitis, or where vasculitis affects a family member. Our sympathies are extended to the families and friends of those mentioned below.



*The Trust is extremely grateful for families remembering us in this kind and generous manner.*

*All donations received will be used to fund activities of the Trust, especially our research projects.*

Donations totalling £200 were received in memory of Mrs Jean Whybrow of Sowerby, near Thirsk, North Yorkshire.

A total of £320 was donated by her family in memory of Mrs Edith Sproats, who died due to complications of WG in 2014.

Donations totalling £1137 were received in memory of Mr John Day, of Crewkerne, Somerset who sadly died due to vasculitis, aged 73.

A total of £180 was donated in memory of Mrs Ann Brannan who died in August 2016 after suffering from vasculitis for several years.

Vasculitis UK received donations to the value of £75 in memory of Michael James Daniels, who died in July last year, aged 82.

Donations totalling £700 were received from Russ Rigby in memory of his wife, Maureen Rigby, of Preston, who sadly died due to vasculitis.

A donation of £100 was made by Barry Coulson in memory of his wife, Mary Coulson, who died due to vasculitis in 2009.

Donations of £230 were made in memory of Mrs Doris Phillips of Birmingham who sadly passed away as a consequence of WG in September 2016.

A funeral collection in memory of Mrs Susan Jane Ochyra raised donations of over £745 in support of Vasculitis UK. A former PE teacher and mother of two, she was a champion bowls player in Devizes and an administrator for Wiltshire Bowls.

A donation of £50 was made by Bonsall Carnival & Well Dressings committee, in memory of Margaret Lownds of Bonsall, Derbyshire, who sadly passed away in June 2016. Her daughter also donated £20 in lieu of sending Christmas cards. These donations were in addition to the £878

donated last year.

£286 was donated in memory of Mr Frank Wright of Whitchurch, Shropshire who sadly passed away in October 2016.

Donations totalling £85 were made to Vasculitis UK in memory of Avis Clinch of High Wycombe, Buckinghamshire..

A funeral collection for Mr John Bowling, of Scarborough, resulted in donations totalling £160 for Vasculitis UK.

A total of £495 was donated in memory of Mr Alan Cook of Great Harwood, Lancashire, who recently passed away.

A collection in lieu of flowers raised £326 at the funeral of Sam Cann of Newquay, Cornwall, who very sadly



died, June 2016, at the age of 28 due to Wegener's Granulomatosis. Sam left his partner Kat & 3 young children. (above)

Donations totalling £300 in favour of Vasculitis UK were received in memory of Donald Mabey of Pentre, mid Glamorgan, who died aged 65 due to complications of vasculitis.

Donations totalling £125 were received in memory of Jeffrey McDonald of Camberley, Surrey, who suffered from WG..

A funeral collection in memory of Herman Anthony Rex, of Llavanches, Newport, South Wales resulted in donations of £510 for Vasculitis UK. A donation of £400 was made by Lorraine May, in memory of her hus-

band, John May.

Scott Heron of Eastbourne nominated Vasculitis UK to receive £125 from the corporate charitable giving scheme of his employers, Ansvr Insurance. This was in memory of his father, who died as a result of WG.

A donation of £300 was received in memory of Mary Coulson, of Benfleet. Much of this resulted from her cousin, Derek Bleasedale's 70th birthday where he asked for donations in lieu of gifts.

A donation of £50 was made in memory of Mary Coulson's aunt, Doreen Collingridge of Denaby in South Yorkshire, who recently passed away. Mary and Doreen had a very close relationship.

£50 was donated in memory of Lorna Wright, who suffered from vasculitis. She passed away in January 2014.



Chris Potter raised £650 through JustGiving for Vasculitis UK in memory of his father, Richard Potter who died last year due to ANCA vasculitis. A much loved dad and granddad. (above)

Debbie Hewitt raised £600 for Vasculitis UK through Justgiving in memory of Tom Hewitt.

£17 was donated in memory of Barbara Lewtas, who recently passed away.

£100 was donated by his wife in memory of William Henshaw, who passed away in December 2012. A total of £1123 was donated in memory of the late Colin Seddon of Greasby, Wirral, Cheshire who passed away in January.



## Donations & Fundraising

A donation of £300 was received from Malcom Harwood of Thirsk, N.Yorkshire.

A charity event run by the employees of SSP Ltd raised £116.40 for Vasculitis UK.

Ali Marston of Caythorpe Post Office, near Grantham, donated £122.89 which had been collected in the collection box on the P0 counter.

Mona Powell of Kidderminster marked her 90th birthday by donating £25 to Vasculitis UK.

Buckingham Charity Football Cup kindly donated £180 and Buckingham Town Cricket Club donated £50 to Vasculitis UK. This was in appreciation of the support given to them by "Sports Shots" photographer Andy Bone, who was formerly the Vasculitis UK treasurer.

As many readers will know, David and Diane Sambrooks run the West Midlands Support Group. On the occasion of the celebration of their Golden Wedding last September they requested donations to Vasculitis UK in lieu of gifts, raising a total of £500.

Despite having vasculitis, Bill Ingham of Barton, near Preston, made a sponsored walk with his friends to the summit of Skiddaw mountain in the Lake District, raising £438 in support of Vasculitis UK.

Howard and Jenny Franklin celebrated their Golden Wedding last Autumn and the guests at the party made donations to Vasculitis UK in lieu of gifts, thereby raising £150 for Vasculitis UK.

Northumbrian Water donated £50 in support of Andrew Robertson's major fundraising effort for Vasculitis UK.

A coffee morning in Litton, Derbyshire, to coincide with the launch of Charlotte Baker's latest book "Valour Diamond" raised £60 for Vasculitis UK.

May Willavoys very kindly donated £1200 to Vasculitis UK. This was the profit from her catering at craft fairs during 2016.

Craig Martin is an employee of Nestlé UK. He nominated Vasculitis UK to receive £200 through the company's charity support scheme.

Damian Hey has vasculitis so when his grandparents, Jean and Stanley Hill celebrated their Diamond Wedding in December they asked for donations to Vasculitis UK in lieu of gifts. This resulted in a total of £530.

The members of the Newark Spire Club kindly donated £100 to Vasculitis UK.

Swithland Spring Water Limited in Leicestershire very kindly donated £900 to Vasculitis UK in lieu of sending out Christmas cards. One of their team, Martin, has been affected by vasculitis.

Rushden & District Ladies Darts League very kindly donated £180 to Vasculitis UK.

Hopton Primary School in Norfolk once again supported VasculitisUK with a donation of £35

A music event featuring Bernard Hoskins and Crooked Tree at the Gravelly Barn Arts Centre in Essex raised £1000 for Vasculitis UK.

The "Guisers" of the small Derbyshire village of Winster, maintain the ancient folk tradition of the Christmas mime play, performing in disguise in pubs and other venues and raising money for local charities. This year they donated £100 to Vasculitis UK. <http://www.winster.org/pages/winster-guisers.htm>

Joan Westlake of Barnstaple had a birthday bash and asked her friend to donate to charity in lieu of presents. This resulted in a donation of £50 to Vuk from her friend Linda Andrews, who has vasculitis.

Derek Wheatland is a member of the "Rogski" skiing Group. This year they went to Italy. A collection was made among the group resulting in a donation of £200.

Penny Barnett held a Rare Disease coffee morning in February which raised a total of £140 for Vasculitis UK.





### Helpline

for information and advice about vasculitis by telephone or email. If you prefer you can write to us

**Helpline Telephone:  
0300 365 0075**

E-mail  
[john.mills@vasculitis.org.uk](mailto:john.mills@vasculitis.org.uk)  
[lynn@vasculitis.org.uk](mailto:lynn@vasculitis.org.uk)  
 Post: John Mills  
 West Bank House, Winster, Matlock  
 DE4 2DQ

The charity has a simple and sensitive JustGiving page for those who may wish to raise funds for Vasculitis UK by celebrating the life of a loved one. If you would like to remember a loved one in this way to help raise funds for the charity please visit: [www.justgiving.com/VasculitisUK/Remember](http://www.justgiving.com/VasculitisUK/Remember)

**We received many other donations from members and supporters, for which we are most grateful.**

*There are easy ways to make a voluntary donation by cheque, standing order (donation forms enclosed with this Newsletter) or by card via donations at JustGiving.com, VirginMoneyGiving or by PayPal.*



# Get in touch with your local Vasculitis Support Groups

## ENGLAND

### Beds, Bucks & Herts Group

Janine Davies - 01525 372733 - [family.davies@btinternet.com](mailto:family.davies@btinternet.com)  
Christine Lee - 01480 869162 - [chrislee0307@btinternet.com](mailto:chrislee0307@btinternet.com)

### Cambridge Group

Lesley Noblett - 0776 5897780 - [cambsvsg@gmail.com](mailto:cambsvsg@gmail.com)

### Canterbury area (Contact Person)

Margaret McGrath - 01227 638469 - [margaretmcgrathfmsj@yahoo.com](mailto:margaretmcgrathfmsj@yahoo.com)

### East Kent (Contact Person)

Brian Hart - 01227 369774

### East Midlands Group

East Midlands Website Group <https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home>  
Dorothy Ireland - 01332 601303 - [Dorothy@vasculitis.org.uk](mailto:Dorothy@vasculitis.org.uk)  
Lisa Ranyell - 01664 857532 - [lisa.ranyell@ntlworld.com](mailto:lisa.ranyell@ntlworld.com)  
Susan Mills - 01629 650549 - [susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)

### Essex Group

Jules Darlow - 07789 113144 - [jules.essexvsg@googlemail.com](mailto:jules.essexvsg@googlemail.com)

### Lancashire/North West Group

Jann Landles - 07979 180145 - [nwvasculitis@hotmail.com](mailto:nwvasculitis@hotmail.com)  
Anita Parekh - 07921 682232 - [nwvasculitis@hotmail.com](mailto:nwvasculitis@hotmail.com)  
Margaret Robertson - [mgtrob@talktalk.net](mailto:mgtrob@talktalk.net)

### Leicestershire Group

Leicestershire Group Website <https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home>  
Tricia Cornforth - [lvsg@btinternet.com](mailto:lvsg@btinternet.com)

### Lincolnshire Group

Sandra Lee - 0754 514 4777 - [sandraleee\\_506@famail.net](mailto:sandraleee_506@famail.net)  
Caroline Meyrick - 01780 460354 - [cmmyerick@gmail.com](mailto:cmmyerick@gmail.com)

### London

#### North London Group

Dave Newman - 07429137670 - [david.newman@londonvsg.org.uk](mailto:david.newman@londonvsg.org.uk)

#### South East London & North West Kent Group/

#### Bi-Ennial Thames Riverside Walk

Jacqui Moran - 07792 412768 - [jacqui.moran1@ntlworld.com](mailto:jacqui.moran1@ntlworld.com)

### Merseyside, Cheshire and North Wales Group

Susan Chance - 01244 381680 - [susan53@icloud.com](mailto:susan53@icloud.com)  
Dave Birch - 0151 7229049 or 07968226230 - [davebirch@talktalk.net](mailto:davebirch@talktalk.net)

### North East Group

[susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)

### Northumberland and Cumbria (Contact person)

Martin Thomas - 07765 888987 - [nwukvsg@gmail.com](mailto:nwukvsg@gmail.com)

### Oxfordshire Group

Sue Ashdown - 01295 816841 - [vsgoxford@gmail.com](mailto:vsgoxford@gmail.com)

### Plymouth Group

[elaine203@live.com](mailto:elaine203@live.com)

### Scarborough Group

[ruth.newton@york.nhs.uk](mailto:ruth.newton@york.nhs.uk)

### Solent/Portsmouth Group

Julie Ingall - [Julie.ingall@porthosp.nhs.uk](mailto:Julie.ingall@porthosp.nhs.uk)

### Surrey Group

Group under discussion

### West Midlands Group

David Sambrook - [davsamuk@yahoo.co.uk](mailto:davsamuk@yahoo.co.uk)  
Margaret Gentle - 0121-243-5621 - [mgvsgwm@blueyonder.co.uk](mailto:mgvsgwm@blueyonder.co.uk)

### West Country Group

Website <https://vasculitiswest.wordpress.com/>  
Charlotte Stoner - 01626 872420 - [the.stoners@talktalk.net](mailto:the.stoners@talktalk.net)

### West Sussex Group

John Bailey - 07752 122926 - [johnbee4@googlemail.com](mailto:johnbee4@googlemail.com)

### Yorkshire Group

Website [www.yorkshirevasculitis.org.uk](http://www.yorkshirevasculitis.org.uk)

### North Yorkshire Group

Richard Eastoe - 01423 520 599 - [Richard@yorkshirevasculitis.org.uk](mailto:Richard@yorkshirevasculitis.org.uk)  
Lynne Jacques - 01274 412378 - [lynne@yorkshirevasculitis.org.uk](mailto:lynne@yorkshirevasculitis.org.uk)

### York, North & East Ridings Group

Richard Eastoe - 01423 520 599 - [richard@yorkshirevasculitis.org.uk](mailto:richard@yorkshirevasculitis.org.uk)  
Jennifer Wormald - 01937 586734 - [Jennifer@yorkshirevasculitis.org.uk](mailto:Jennifer@yorkshirevasculitis.org.uk)

### Yorkshire (North/West) Group

Lynne Jacques - 01274 412378 - [lynne@yorkshirevasculitis.org.uk](mailto:lynne@yorkshirevasculitis.org.uk)

## WALES

### North Wales - (Contact Person)

Pat Vernalls - 01766 770546 - [patvernalls@btinternet.com](mailto:patvernalls@btinternet.com)

### North Wales Group (group also covers Merseyside and Cheshire)

Susan Chance - 01244 381680 - [susan53@icloud.com](mailto:susan53@icloud.com)

### South Wales Group

Jenny Fulford-Brown - 029-2021-8795 - [jenny.fulford-brown@ntlworld.com](mailto:jenny.fulford-brown@ntlworld.com)  
Ryan Davies - [ryan@wegeners-uk.co.uk](mailto:ryan@wegeners-uk.co.uk)  
Angharad Jones - [Angharadjones.vas@gmail.com](mailto:Angharadjones.vas@gmail.com)

## SCOTLAND

### (Contact Person)

Lynn Laidlaw VUK Helpline 0300 365 0075 - [lynn@vasculitis.org.uk](mailto:lynn@vasculitis.org.uk)

### Edinburgh and Lothian - Contact Person

Jimmy Walker - 07725 770103 - [james-walker@outlook.com](mailto:james-walker@outlook.com)

### Glasgow - Contact Person

Patricia Henderson - 0141 581 1711

## Republic of IRELAND

### (Contact Person)

Joe O'Dowd - 00353 (086) 2345705 - [dwodo@iol.ie](mailto:dwodo@iol.ie)

### Ireland - Vasculitis Awareness Ireland

Vasculitis Awareness Ireland Website <http://vasculitis-ia.org/>  
Julie Power - 028 44 842889 - [vasculitisireland10@gmail.org.uk](mailto:vasculitisireland10@gmail.org.uk)



EVENTS CALENDAR

# RHEUMATOLOGY 2017

25-27 April 2017 ICC Birmingham, UK

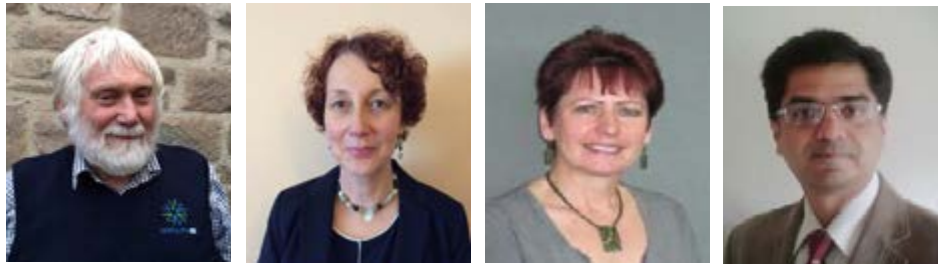
John Mills Chairman of Vasculitis UK will be speaking as a vasculitis patient representative at the Spring BSR Conference.



Rheumatology 2017 brings together over 2,000 delegates (doctors/nurses) from over 50 countries, with interactive sessions, workshops, lectures, poster tours, symposia and more than 50 exhibitors showcasing the latest developments and advances in rheumatology.

## NATIONAL INSTITUTE FOR HEALTH RESEARCH

Wednesday 24<sup>th</sup> May 2017 / NORFOLK & NORWICH UNIVERSITY HOSPITALS  
 "VASCULITIS AND YOU" Patient Conference



**Chair and Speaker - John Mills, Speakers – GCA Vasculitis Study Patient, Lynn Laidlaw, Dr David Scott, Dr Janice Mooney, Your Questions Answered - Dr Chethan Mukhtyar**

See VUK website for contact details [www.vasculitis.org.uk](http://www.vasculitis.org.uk)

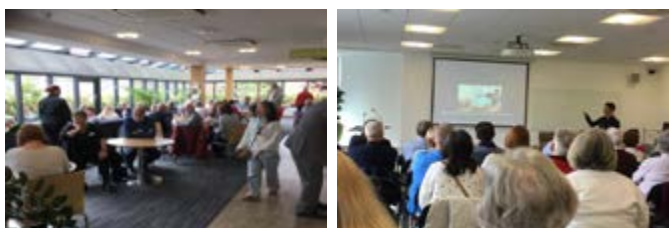


### Annual General Meeting MAY 14<sup>th</sup>

DERBY UNIVERSITY ENTERPRISE CENTRE, DERBY



Speakers to be Confirmed  
 Final details via VUK website  
[www.vasculitis.org.uk](http://www.vasculitis.org.uk)  
 To book a place contact  
[susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)



### LOCAL SUPPORT GROUP MEETINGS

**Lincolnshire Vasculitis Support Meeting**  
 April 8th - Caroline Meyrick: [Cmmyerick@gmail.com](mailto:Cmmyerick@gmail.com)  
<http://www.vasculitis.org.uk/events/lincolnshire-sg-2017-03>

**Yorkshire Vasculitis Support Meeting**  
 Lynne Jacques [Lynn@yorkshirevasculitis.org.uk](mailto:Lynn@yorkshirevasculitis.org.uk)  
<http://www.vasculitis.org.uk/events/yorkshire-meeting-april-2017>

**Cambridge Vasculitis Support Meeting**  
 Lesley Noblett [cambsvsg@gmail.com](mailto:cambsvsg@gmail.com)  
<http://www.vasculitis.org.uk/events/cambridge-support-meeting-2017-06>

# HONORARY LIFE PRESIDENT - LILLIAN STRANGE

Vasculitis UK is the UK's No 1 Vasculitis charity, established in 1992. We are an independent Organisation funded entirely by voluntary contributions from members and supporters.

The main aims of the Trust are:

- To offer support and advice for those with vasculitis, and their families
- To support and promote research into the causes and treatments of vasculitis
- To increase awareness of vasculitic diseases among both the general public and health professionals
- To support the development of local vasculitis support groups

**Established in 1992 by the family and friends of Stuart Strange,  
in his memory.**

**Formerly known as the Stuart Strange Vasculitis Trust  
Registered Charity No. 1019983**

## Officers, Trustees and Volunteers

### Chairman:

John Mills  
john.mills@vasculitis.org.uk

### Chairman Elect:

Caroline Savage

### VICE-CHAIRMAN:

Mike Patnick

### Hon Secretary:

Jann Landles  
secretary@vasculitis.org.uk

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Richard Remorino  
treasurer@vasculitis.org.uk

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Gareth Garner  
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David Newman

### Volunteers:

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Kelly Jefferies  
Lynn Laidlaw  
Janice Mather  
Julie Scott  
Kevin Soper

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