



# VASCULITIS UK

## NEWSLETTER JOURNAL

*Celebrating 10 Years*



*Thank You Both*

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Member of  
**EURORDIS**  
Rare Diseases Europe



## Chairman's Report

It's been a very busy few months behind the scenes at Vasculitis UK.

The four professors (who form our Scientific Advisory Board) met and approved only four of the research applications. We will make the call again this autumn for research applications. They are a tough group to please and go through every finite detail to make sure our money is used in the best possible way. John Mills will go through the details of the awards.

I have been dealing with HMRC to sort out our Gift Aid and, after numerous phone conversations, have come to know some of their staff very well. We are now, hopefully, back on course thanks to the assistance of Ian Kayes. It seems strange to say but HMRC were easier to deal with than PayPal. I can now understand PayPal's claims that it's a safe way to make payments! There were so many forms to complete and, at every level completed, more details were required. Eventually, we completed everything, and we are now set up to receive payments through PayPal. Not just PayPal Giving, which links to Facebook, but through the online shop too. For instance, if you order something from the online shop part of the website, it allows you to pay through PayPal and Kelly gets an email to tell her what has been ordered.

There is also a donate button which, again, takes you to our PayPal page. Setting this up was not easy and it's thanks to John Geddes that it works. Those of you who are active on the Facebook support group will know that they have a donate button so that people who want to raise funds for a charity on their birthday can do so. This, again, links to PayPal Giving. Just make sure that you select Vasculitis UK.

We are currently upgrading the website. The team have it almost ready to go live. It will then be compatible with smartphones and tablets meaning access should be a lot easier. I am told it will also have a search facility and a translate button. We get a lot of "hits" from around the world and we are a recognised site which gives accurate information.

For those of you who rely on the written word, all this will be meaningless, but we must move with the times. We also need to update the information leaflets. Not just changing the charity details but give them a facelift! Those of you who attended the AGM in May will know that we surprised my predecessor, John Mills, and of course, Susan Mills with a tribute and some crystal wine goblets. I first met John and Susan a few months after being diagnosed with vasculitis, eleven years ago and he had just been elected chairman. It was still the Stuart Strange Vasculitis Trust then and the main discussion was about whether we should change our name and get rid of the light bulb logo; I thought we should. When they realised I lived locally and wanted to set up a local support group, I found myself taking on my things. They can both be very persuasive! Over the years I have worked

very closely with Susan, particularly on the fundraising side. She does so much that doesn't get seen behind the scenes as well as caring for John.

I got to know John when we were struggling to change the charity and I (foolishly) admitted I was good at form filling. It seems it was a good job I was as I've needed those skills a lot recently. This charity owes a lot to John and Susan. I will just say, thank you!

We have two new trustees elected at the AGM. Many of you will recognise the name Martin Makin. He's taken part in many marathons and half marathons, while still undergoing treatment for GPA. He's joined the fundraising team and is organising the runners for this year's Great North Run. He lives in Leicestershire and is a member of the East Midlands Support Group.

The second new trustee is Zoi Anastasa also diagnosed with GPA. She is a member of the South West Support group. She has become our representative on EURODIS. She is also an admin on the facebook support group and Health Unlocked. We're also very excited that the Vasculitis UK website is being updated in mid October.

It will be much more smartphone and tablet friendly and will have a fully functioning search facility but, as with anything new, there may be a few teething problems at first so please bear with us in the first few weeks and if you have any problems at all, please contact us using the "contact us" facility or by email.

*Dorothy*



## The Blame Game.

We get many phone calls and emails from members/patients wanting help & advice. Sometimes these calls are from lonely unhappy people who just want somebody sympathetic to talk to, someone who understands their situation. We do understand and try to give them the time and attention they deserve.

Often the calls are from people who feel they are not getting proper care from their existing doctors. That is fine – that’s what we are here for & we do our best to help. In these cases, sometimes it’s just a matter of reassuring them that they are already getting an appropriate standard of care; but sometimes we suggest that they seek a second opinion and “signpost” them to a consultant/institution where we know they will

get good care.

Other times we suggest that they should talk to their consultant, (who is probably very nice concerned & caring, but maybe out of their depth in this complex & variable disease).

Doctors can and should consult their colleagues when in doubt there are networks for this purpose. Sometimes we are as baffled as the doctors clearly are!

Unfortunately, some people seem to be less interested in getting better than in blaming doctors from their past history. We, the unpaid volunteers who “man” the helpline, get very frustrated when our valuable time is taken up by lengthy stories about how Dr X did or did not do something for them. We see our role as being about helping people to move forward & improve their quality of life, not wallow in past injustices. Once they have got their health back on track, that’s the time when one can review what might have been done wrong or could have been done better.

### Leading horses to water....!

Another grumble, especially from those who take care of the Vasculitis UK online support groups is that sometimes a person joins the group complaining of a problem. Lots of people come up with helpful recommendations – usually the advice is very similar – such as seeking a referral to Dr X or Dr Y.

But the helpful advice is ignored, or excuses given why they cannot follow the advice given . Then they just keep complaining of the same problem, as if they are just waiting for the piece of advice that suits them or fits their preconceived ideas. These people are few. Most listen to the advice from those of their peers who have knowledge experience and benefit accordingly.

## UKIVAS

UKIVAS is the term usually applied to both the UK & Ireland Vasculitis Registry and the Vasculitis Study Group (formerly known as the “Lockwood Club). Ideally, UKIVAS should be the UK equivalent to EUVAS, with similar aims & objectives. The UKIVAS registry has been highly successful, as was the trial Vasculitis Education Day held at Salford Royal Hospital in May, organised by Drs Nina Brown & Fiona Pearce. There is so much scope for UKIVAS to develop further as the UK’s foremost vasculitis organisation which is patient centred but led by doctors.

## GIRFT.

The Getting it Right First Time (GIRFT) programme is an NHS England initiative. We at Vasculitis UK are very familiar with the inconsistencies in diagnosis and treatment of vasculitis around the country. The scheme has two very laudable linked aims. By improving the overall standard of diagnosis and treatment (standards of care) and improving consistency the Outcome for patients will be greatly improved and the NHS will save money. For example, many of our members will recall the “diagnostic odyssey” being passed from department to department. This is frustrating for patients & wasteful of NHS resources. Similarly, identifying the optimum treatment plan can reduce relapses and hospital admissions & bed occupancy whilst at the same time, improving patients’ quality of life.

## Scottish National Systemic Vasculitis Network.

This is an initiative of the Scottish Health Board. Led by lead clinician Dr Nick Fluck of Aberdeen, with support from many others such as Dr Neil Basu, the network is intended to offer advice and support to all clinicians treating patients with vasculitis with a view to delivering high quality care for all

The formal launch of the network will take place on 12<sup>th</sup> December.

*John Mills*





## FROM THE EDITOR

As we approach the end of another year wondering where that time went, it's time to pop that kettle on, maybe a biscuit or two or a slice of cake and see what's been happening since springtime within the world of VUK.

As you can tell from the front cover this edition as a special feel about it as we celebrate 10 years with John and Susan Mills and thank them for everything they have done and continue to do for Vasculitis UK.

Yes they are backed up by a fantastic group of people but the success of this charity to date is in my opinion built on all their endeavours over the last ten years, even through some tough times due to ill health.

They truly deserved the surprise they received from the trustees at the AGM back in May. On behalf of myself and my family I would like to thank them both, for giving me the opportunity to be involved with this fantastic charity, it has helped and continues to help me honour my sister Clare, who was taken from us with this cruel disease, it has also helped us grieve and understand so much about vasculitis over the last nine years.

Thank you Both so much. XX

*Kevin*

## Vasculitis UK AGM May 2019

The Vasculitis UK AGM and Support Meeting took place in May earlier this year. The guest speaker was Dr Chetan Mukhtyar, Consultant Rheumatologist Norfolk and Norwich Hospital. His story, talking about his own personal journey, vasculitis presentation and Q&A session was one of the best. The meeting was attended by 68 members, it was great to meet up with old friends and make new ones. Here are a few photos of the day.

Susan Mills



Photos courtesy of Zoi Anastasa



Surprise presentation from all the VUK trustees - John and Susan celebrating 10 years with VUK.



Dr Chetan Mukhtyar





In April 2013 I had just completed the London Marathon in 2:52:08, and came 3rd in the Leicestershire Road Running League Winter series. I was looking forward to the Summer league ahead, and more pb's. My body had other ideas, I spent most of the summer in and out of the doctors, and hospitals.

It wasn't until I lost my hearing, and became very ill that I was admitted to hospital where I was scanned, drugged, and tested for everything, until one doctor who had come across Vasculitis before, diagnosed me with Wegeners Granulomatosis, (GPA).

I have had the best help and advice from vasculitis UK, and want to carry the good work that my fellow trustees, and volunteers of Vasculitis UK, have done so before me.

I feel it is a great source of information for newly diagnosed patients, and doctors alike.

**Martin Makin**



My name is Zoi and I was diagnosed with GPA vasculitis in November 2014. I was lucky to get an early diagnosis and react well to the treatment. However, Vasculitis has changed my life.

I have been a member of Vasculitis UK almost since diagnosis. I am one of the admins in the Facebook Support group. Some of you may have met me online. I have recently become an admin in the HealthUnlocked community. I am honoured to represent VUK in EURORDIS as an ePag in the RITA ERN. I am also active in our local vasculitis support group. Additionally I am a member of the Patient Participation Group of our local GP surgery.

I live in Plymouth, Devon, with my partner, Jim, my son Panteli and our cat. I am half Greek, half Swedish and I am fluent in both languages. I work at a secondary school, where I support children coming from abroad, helping them to adapt to the school system and aid them to follow the curriculum.

In my free time I like to do craft workshops with friends and their children, read books, bake cakes, and appreciate and photograph nature with my camera.

**ZOI ANASTASA**

## SUPPORT GROUP NEWS

I had the pleasure to attend the 2019 meeting of the Vasculitis Support Group West Midlands in Bromsgrove. As always, I enjoyed both the educational and social aspect of the meeting.



After a short introduction from the group's leader, David Sambrooks, and a report from the treasurer Judy Ross there were two very interesting presentations.

Anjali Crawshaw, a Consultant Respiratory Physician from UHB (Queen

Elizabeth Hospital) talked to us about the potential effects of vasculitis on the respiratory system. She explained how difficult it can be to pin down diagnosis, what treatments are available and how we can help ourselves. Her advise to vasculitis patients with lung involvement was to stop smoking, keep active and get vaccinated.



The second speaker of the day, Caroline Cox who is a Clinical Psychologist also from UHB made a presentation about "Managing / Living with Vasculitis", focusing on how to manage fatigue. Living with a chronic illness is stressful itself, having to manage other stressors too can be very hard. Fatigue affects a lot of vasculitis sufferers and can impact on their quality of life. Pacing, rest and relaxation, mindfulness and asking for help were recommended.

I would like to take the opportunity to thank David, Judy and everyone else involved in organizing this successful meeting.



**ZOI ANASTASA**



Beds Bucks Herts Support Group

North East Vasculitis Support Lunch





**The Dunkirk - Huddersfield**

We'd like to say a big thank you to everyone that came along to support our charity golf day to raise money for Vasculitis UK. We raised a fantastic £1640!



Sarah and Mark Griffiths Chicago 10k



Inga Bennet walked 25k on behalf of her brother and for VUK, raising £665



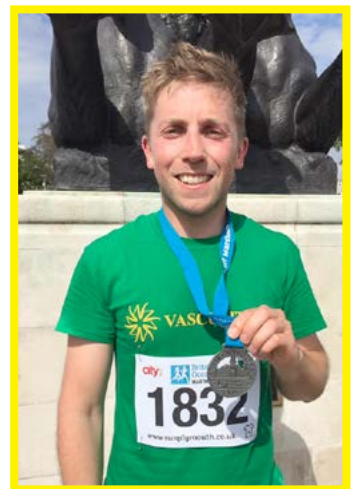
Jayne Cowgill walked 32 miles in 11 hours in memory of Sarah Pierce and Vasculitis UK, on her own, in the rain and wind, raising over £650



Alexandra Bavey was diagnosed vasculitis in 2015 She been in and out of hospital for 4 years. Alexandra completed the 2019 Edinburgh Marathon Festival with the support of her dad. Up to date she has raised over £500 for VUK.



(Left & Below) Table Top Sales for Vasculitis UK Helen and Simon, Claire and Andrew Janice, Audrey, Isobel and Harriet took part in two table top sales for Vasculitis U.K.



Liam's Nichols Ocean City Half Marathon for Vasculitis UK



(Left) Sarah and Jeanette both completed the Sheffield 10k fundraising for VUK



## Bear - Necessities

Colin Ransom of the Rheumatology Department, Addenbrooke's Hospital in Cambridge got a Vasculitis UK bear last year at the British Society of Rheumatology Annual Conference. In his office the bear had many admirers (mostly female!) so Colin decided to ask for another bear at this year's conference and raffle the second bear in aid of Vasculitis UK. 26 boys names went into the raffle and each raffle entrant had to choose a name for a donation of £2 - thus raising £52 for our charity. The winning name, as drawn out of a hat, was 'Valentino' and the winner was Sue Sriskandan, a Musculoskeletal Physiotherapy Specialist at Addenbrooke's. Sue was very happy to win teddy as she said that he will go to Reuben, her great nephew who is 12 weeks old and has been in hospital most of his life. Congratulations to Sue and Reuben!



Congratulations and thank you to Lewis and Jordan skydiving for VUK raising an amazing total of £1436 through JG and sponsorship. Lewis's mum has a rare type of Vasculitis called Takayasu Arteritis.



Team Jiggle: 5K Obstacle Colour Rush at Newbury raising awareness for VUK

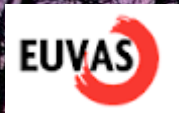


Pete, Steve and Sean completed their Coast to Coast walk on the 5th September 2019, covering 120 miles and over 240,000 steps in just 5 days! It was truly a challenge, but we have raised an amazing £3,099.16. They work at the Olympus Print Group and were Fundraising on behalf of Emma Smith who has EGPA



Denise Johnson  
London Marathon  
2019





## Third EUVAS three day residential educational course, Downing College, Cambridge. 23<sup>rd</sup>-24<sup>th</sup> September 2019.

**UVAS is the European Vasculitis Society. Founded 30 years ago it is a multi-disciplinary collaboration of doctors with a shared interest in achieving the best for their patients and with a mutual respect for members' differing skills & level of experience. The degree of interaction between European Centres over the past 30 years is most notable and is represented by EUVAS and by the European Reference Network – the ERN.**

**EUVAS was created in 1989 by the Dutch vasculitis pioneer, Fokko van der Woude, in an EU funded trial to determine the diagnostic role of ANCA in vasculitis. This involved 14 EU countries and was followed by other investigations and trials.**

### The objectives of EUVAS are:-

- 1) To further scientific development in the field of vasculitis.
- 2) To widen the knowledge and to assess the practical implementation of technical & scientific developments in this field.
- 3) To encourage the development of the discipline in regard to prevention, treatment and rehabilitation of vasculitis patients of any age.
- 4) To encourage continuing education of vasculitis researchers and clinicians through the organisation of conventions, meetings, courses & workshops.

Vasculitis UK is very proud to be closely associated with this powerful and effective doctor-led, but patient-focused organisation and is proud to help in sponsoring this 3<sup>rd</sup> EUVAS Education course.

The first residential Education course (led by Prof. David Jayne) was held at Clare College, Cambridge, in 2017. Last year the course was in Florence, Italy, but in 2019 it has returned again to Cambridge.

Next year will take place again in Florence under the leadership of Dr Augusto Vaglio, "Il Illuminare" (as he is popularly known in Florence) who also played a major role in this year's conference.

The structure of the conference was that each morning & afternoon (starting at 8.30 & finishing at 18.30) there would be a series of presentations by leading experts on selected topics. This was then followed on each occasion by a choice of 3 breakout sessions on specific cases related to the topic under consideration – such as Large Vessel vasculitis, Behcet's Disease or EGPA, where the real cases

are discussed by experts in the specific type of vasculitis. These cases are always extremely challenging and it's fascinating to hear the experts discussing the possible diagnosis & treatment. They don't always agree entirely! But that only illustrates how complex vasculitis can be!



The meeting commenced with opening addresses by John Mills and Prof David Jayne. Topics covered in the lecture sessions included: Large vessel vasculitis, Takayasu Arteritis, Small vessel vasculitis, Organ Involvement in vasculitis (Nervous system, eyes, skin, lung & ENT), Management of ANCA vasculitis, EGPA (Churg Strauss) Auto-inflammatory syndromes,

Paediatric vasculitis, Behcets Disease, IgG4-Related Disease, Improving the Quality of Life in Vasculitis Patients and a session on Genetics in Vasculitis delivered by Prof. Ken Smith.



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The meeting closed with a final address by Prof. Peter Merkel of Philadelphia on the theme "What's coming up in vasculitis".

The takeaway message was that "there is more vasculitis research taking place today than ever before". For me the most interesting point I learned is that in Peter's vasculitis clinic in Philadelphia, part of the routine testing procedure for new patients is for traces of "recreational drugs" – such as cocaine – as this plays an increasing role in the causative factors of ANCA vasculitis.

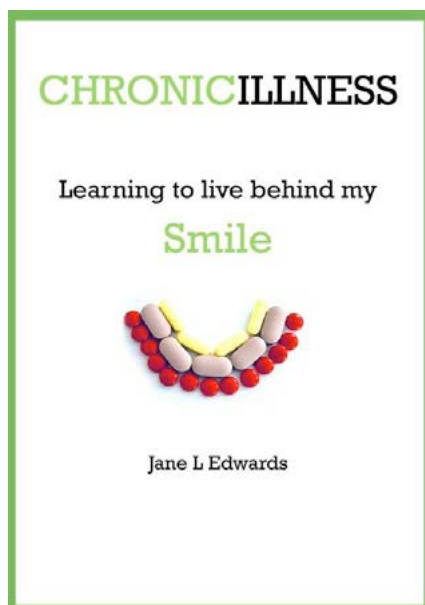
The whole course is so busy that it's not possible to attend all the lectures and breakout sessions. There were so many excellent presentations, many delivered by members of the Cambridge team. It is difficult to choose a favourite. However those which stick in the mind were those by Prof Benjamin Terrier from Paris (on Rare vasculitis; PAN & Cryoglobinaemia), Christina Ponte from Lisbon; Pasupathy Sivasothy from Cambridge (on Vasculitis & the lung) & Prof Cord Sunderkotter from Halle in Germany (on "Vasculitis & the Skin").



We are hoping that Cord will write an article for a future newsletter on this very relevant topic. Dermatologists in Germany seem to adopt a much more proactive & "holistic" approach than do those in the UK.

**John & Susan Mills**

## Chronic Illness: learning to live behind my smile



The problem with a long-term chronic illness is that it isn't a quick fight, taking a few drugs and having a couple of weeks in bed will not cure it. It isn't ever an out and out win, you never beat the illness forever. It is a long-term war, some battles you lose and some you win: It is an on-going campaign. It is a chronic illness, after all. In the end, the struggle is about getting to a place where you can live together, the illness and you, and trying to make the most of the environment you share, an attempt to make it a positive life.

This book is a collection of experiences I have faced living with a chronic illness, experiences I am still learning from and having to deal with every day. It is like living in no man's land, somewhere between feeling ill and feeling healthy, but not really being healthy or ill. I hope, by sharing my experience, I can help you with your journey, dealing with your chronic illness or give you some tools to help you make some sense of living with a chronic condition.

Please note: small sections of the book are only relevant to the UK NHS system.

New Book available through Amazon: [https://www.amazon.co.uk/Chronic-illness-learning-behind-smile/dp/1075727863/ref=sr\\_1\\_fkmr3\\_1?keywords=chronic+illness+janet+edwards&qid=1562694249&s=gateway&sr=8-1-fkmr3](https://www.amazon.co.uk/Chronic-illness-learning-behind-smile/dp/1075727863/ref=sr_1_fkmr3_1?keywords=chronic+illness+janet+edwards&qid=1562694249&s=gateway&sr=8-1-fkmr3)

**Jane Edwards**

## Zoomy Zoo take on the the Surf Coast Century

Conner, James and Viv completed a 100km ultra marathon across Victoria's Surf Coast for VUK raising over \$2000 Conner's sister Kath has a particularly rare type of Vasculitis.



## Vasco da Rhino and the Vasculambers

Vasco da Rhino and the Vasculambers completed their trek of 134 miles around Anglesey in memory of Lydia Moxley.

Thanks to all 56 who walked and all who have supported and donated, over £1500 raised for VUK.

*Tim, Jamie, Ellen And Dan*



(Left) Jenny Fulford-Brown accepting a cheque for £1600 on behalf of Vasculitis UK from Phil Gardner who was representing Whitechurch Golf Club, at the Wales vasculitis support meeting.



(Above) Former Members of Her Majesties Royal Navy Submarine, HMS Torbay held a reunion at the Wheelers Bar in Devon. They held a fundraiser on behalf of Phil Eddy, who has vasculitis and who is also an old shipmate of the organiser Mark Mytton. They raised an amazing £500.



## Vasculitis Education Days for Professionals 2019

On 16th May representatives from Vasculitis UK were invited to the United Kingdom & all Ireland Study Group ( UKIVAS ) Vasculitis Training and Education Day at Salford Royal Hospital Manchester. The day was attended by around 130 medical professionals from all over the UK. This was the very first training day of this type in the UK.

On July 17th representatives from Vasculitis U.K. were invited to join 100 doctors, on a Vasculitis Renal and Respiratory Training Day at Imperial College in London. It's the the first training day of this type to be held in London.

The medical speakers were all leaders in their field.

Topics included :-

All types of ANCA Associated Vasculitis including EGPA & Anti GBM Goodpastures, Respiratory complications of GPA including ANCA negative GPA and the role of Steroids for treating Vasculitis, Ear Nose and Throat, Behçet Syndrome, Large Vessel Vasculitis, IgA Vasculitis, Skin involvement and Nerve involvement in Vasculitis.

Jayne Hardman who has Granulomatosis with Polyangiitis ( GPA ) was asked to speak on both education days and Emma Smith who has Eosinophilia Granulomatosis with Polyangiitis ( EGPA ) was asked to speak at the Imperial College education day. Hopefully this will be the first of many. Both Jayne and Emma were amazing and were thanked by the doctors who organised the training days for being there. See below their own personal accounts and photos.

Jayne

Over the last six months, I have been lucky enough in my position as patient advocate for Vasculitis UK, to give two speeches to medical professionals. The first one was in Manchester and the second in London. In compiling the speech, I had to find some photographs that detailed my progress from over the years. This was actually quite upsetting to see how bad I was - compared to now. But this I feel is very important; to show the absolute WORST of what ANCA Positive Vasculitis can do. I'm on a mission. To ensure nobody else ever goes through what I went through. The speech in Manchester, I made notes for and prepared, but once I stood up, my words went off script and came organically. I also spoke very quickly and didn't let people absorb what I was saying before I moved on.

My speech in London was far better because I kept to my script, I was measured, I was calm and I said everything I wanted to. The speech in Manchester was slotted during the afternoons events. Therefore, there were a lot of people listening. Sadly, the speech in London was at the end of the day and some people had left. On both occasions, I was asked questions at the end of my speech. I was touched in Manchester, when someone asked if I was offered any counselling, due to what I had been through.

In London, the doctors had a conversation between themselves regarding my life-long Rituximab treatment. I was given excellent feedback at both events and I truly believe in my heart they are not going to forget my nose in a hurry. After all, who sees someone take their nose off when they give a speech. I can't wait for the next opportunity to talk to another group of medical professionals and doctors and to give them a patient's perspective.



Emma

On the 17th July 2019 I boarded a train from Leeds, to travel down to Hammersmith Hospital in London, to spread my story of living with Vasculitis, in particular EGPA.

The event that took place was a Vasculitis Training Day with the speakers being the leaders of their medical fields. I was one of the people asked to represent Vasculitis UK which I jumped at the chance of doing. The education day was a full day event, with around 100 doctors attending. It was at the end of the day that I got my opportunity to tell my story.

I'm not going to lie and say it was easy, as it was one of the most nerve wracking things I have ever done in my life and this was the first time I have presented in front of anybody, let alone 100 doctors!

I managed to conquer my fears and nervously stepped up to take my position to lead my PowerPoint Presentation. I started with a very shaky voice.



Knowing that you are talking to doctors who have been medically trained for years and I'm just an account manager from Leeds is a very scary thought. But then again who knows

Vasculitis more than somebody living with it everyday for the past 10 years. I might not be medically trained but nobody can know what I've been through more than myself.

Thankfully my presentation was a success! I managed to get through the whole thing and by the end I was ecstatic that I had faced my fears and hopefully educated the doctors a little bit more on EGPA. Once my presentation was complete it was followed up by a Q&A, there were lots of questions which goes to show that everybody was actually really paying attention to what I had to say.

It was a fantastic opportunity to be part of this day which will hopefully lead to more Vasculitis Training days in the near future.

Thank you to John and Susan Mills for giving me the opportunity to take part and present.

If my story impacts just a handful of the doctors and then in turn helps patients, then it was 100% worth taking the journey to London and facing my fears.



# Conference Round Up

This year, Vasculitis UK attended two medical conferences. The British Society for Rheumatology Annual Conference and the Royal College of Nursing Annual Conference.

The BSR 3 day conference was held in Birmingham in May. It is attended by about 1200 Rheumatologists and Specialist Nurses.

This year, 4 national rare-disease charities joined forces with RAIRDA (Rare Autoimmune Rheumatological Disease Association) to form a "RAIRDA village" within the conference. The other rare disease charities who took part were Scleroderma Raynauds UK, Lupus UK and Behçets UK.

It was an interesting and informative 3 days and John and I were joined by Jayne Hardman and Martin Makin, both who have Vasculitis themselves and work as volunteers for VUK.

Many doctors and nurses came to the VUK stand to talk to Martin, Jayne and John. One doctor dropped by and left his details with an interest to start a new Vasculitis Support Group in his area. Hopefully this new group will be launched this Autumn.



Martin giving out information and talking to the doctors.



Jayne talking and sharing her experience living with Vasculitis

The RCN 3 day conference was held in Liverpool, also in May, and was attended by around 5,000 nurses. This was the first year VUK had an information stand at this conference.

Our stand was so busy and so very popular, so much so, that by the end of the second day we were afraid we were going to run out of information booklets and leaflets!

We met some very interesting people including 3 nurses who actually had been diagnosed with Vasculitis. They were so pleased to see Vasculitis represented at the conference. In fact one of them said "I am so pleased to see you here, I was diagnosed in 2008".

VUK will definitely be attending next years RCN Annual Conference.

In the photos you will see John with 2 of the nurses who actually have Vasculitis. At one point they came to help on the stand and talk to other nurses.

*Susan Mills*



Kelly's "Fact a Day About Vasculitis" was very popular.



# Research Funding Autumn/Winter 2019

Each autumn, the Vasculitis UK Board of Trustees meets to discuss if there are sufficient funds available to launch a “call” for applications for awards to fund research projects. These awards are usually up to £50,000 each and a budget of £100-150 thousand is usually allocated.

The “call” is made through the UKIVAS mailing list, so it reaches as wide a range of clinicians, academics & researchers with an interest in vasculitis as possible. For administrative reasons, applicants must operate from institutions based in the UK or Irish Republic. The Awards process is administered on behalf of Vasculitis UK by Laura Whitty.

The call in November 2018 resulted in 8 excellent applications. These were then subject to a rigorous peer review process by members of our international panel of independent reviewers. The results of the review process were then considered by the members of the Vasculitis UK Scientific Advisory Board (Professors Scott, Jayne, Pusey & Watts) at a meeting in Cambridge in mid July.

**Three projects were totalling £147,405 approved for funding, as follows:-**

## 1. **TARGET Consortium: GCAT Biobank - £49,473**

**Team:** Professor Ann Morgan (Leeds) on behalf of Target Consortium. Co-applicants; Dr Sarah Mackie (Leeds), Dr Charlotte Harden ) Leeds & Prof. Raashid Luqmani (Oxford).

This three year project brings together the University of Oxford and Leeds Institute of Cardiovascular & Metabolic Medicine. They plan to launch a dedicated biobank for the GCAT (Giant Cell Arteritis Tocilizumab) Registry and to conduct preliminary investigations using these samples, taken from up to 1000 patients. The Registry is funded by Roche Products. By taking the opportunity to collect and store samples taken from participants in this unique and timely Registry, they will have access to tissue for ethically approved pathogenesis and personalised medicine studies of GCA, making research faster and more cohesive, and bringing greater benefits to patients.

## 2. **Investigation of ANCA-driven Pro-Inflammatory Signalling in Human Monocytes - €49,936**

**Team:** Dr Gareth Brady and Prof. Mark Little (Both of Trinity College, Dublin).

This one year project based at St James’ Hospital, Dublin, will seek to understand how MPO autoantibodies drive the complex, tightly regulated signalling pathways leading to IL-1 $\beta$  release and to develop inhibitors of its release, to provide an exciting window into the ways antibodies can drive the pathology of autoimmune vasculitis, whilst offering new tools for therapeutic intervention in a specific, targeted manner without the current requirement for global immunosuppression.

## 3. **Utilising a novel data source and national registration to improve patient care, outcomes, and enhance clinical research in Takayasu’s arteritis - £47,996**

Dr Fiona Pearce (Nottingham), Dr Matthew Grainge (Nottingham), Prof. Justin Mason (Imperial College, London), Dr Peter Lanyon (Nottingham).

Bringing together the University of Nottingham, Imperial College London and Nottingham University Hospital, this one year project looks at utilising a novel data source and national registration to improve patient care, outcomes, and enhance clinical research in Takayasu arteritis. the award will allow them to employ a research manager for 1 year to undertake the research.

Laura Whitty ( Awards Administrator )

# Manchester Workshop



A workshop was recently held in Manchester by pharmaceutical company Vifor Pharma Group / Vifor Fresenius Medical Care Renal Pharma Ltd to develop resources for both health professionals and patients with ANCA associated vasculitis (AAV) and raise awareness of the disease.

The aims for the day were for the Vifor team to gain a deeper understanding of the patient journey and find out about any of their needs which are currently not being addressed; test creative visuals which will be used as branding for new websites; discuss how patients and carers with vasculitis could be better supported through resources, information and networks and create video footage to help support patients and improve awareness of the disease.

Four patients and a carer took part in the event: -

- Shanali – a former specialist trainee in rheumatology and now a vasculitis patient who is also an artist
- John Mills– chair of Vasculitis UK and patient with his wife and carer Susan
- Cath and Jeremy, both vasculitis patients.

The workshop started with a discussion about a patient journey map, developed by Vifor based on market research findings, and participants were invited to share their experiences over three key phases: initial presentation, diagnosis and treatment – covering intensive care stays, going home on treatment and finally any relapses or flares.

Some of the key findings were:

- The path to diagnosis is highly variable between patients and the journey can be long
- Uncertainty of the symptoms can create fear and concerns that they were “just imagined”
- GPs often don’t link symptoms together, leaving diagnosis down to luck
- The relief of getting a diagnosis and a name for the disease is seen as the beginning of the road to recovery
- Following diagnosis, the information about vasculitis available online can be scary, resulting in a feeling of uncertainty; more information about what to expect is needed and patients often struggle with knowing what happens after they are diagnosed with a rare illness and where they fit in.

The treatment experience is also different for each patient including their response to high dose steroids which can make people feel agitated or elated but usually makes you feel better.

It was highlighted that: -

- In some cases, the treatment options are not made clear and the purpose of the drugs are not always explained properly
- It is challenging having to deal with the physical side effects of the drugs as well as the emotional trauma around recent diagnosis
- Patients can feel powerless as the disease takes control and completely changes your life. There is no stability as life becomes a lot more unpredictable
- Some patients have no communication with healthcare professionals about how life could be different and return home having little support with adapting to a complex drug regime other than from family and friends which can lead to anxiety
- Patients are anxious about the possibility of a relapse which they fear when dosage is reduced
- Mentally, a relapse is often worse than the initial onset due to fear of losing control again and an expectation of what’s to come.

Catherine told the group: “I kept going back to the GP and they just said oh it’s a viral infection. It was a year from when I started having symptoms and went to the GP to when I eventually ended up in A&E. I remember when I was first diagnosed, one of the nurses said to me ‘you’ve just got to change the whole way you live your life.’”

Jeremy said: “The total time taken to identify that I had vasculitis was about 10 months. That wasn’t because of any confusion or any doubt about what I might have, it was simply the time delays that are built in to see a consultant. It was not a problem in my case, but I was lucky there. It could easily have been in a more serious case that actually could have been the difference between a good outcome which I’ve had and a much more serious outcome if things had gone wrong.”

Shanali said: “I was in my second year as a rheumatology specialist trainee doctor, when I embarked on an unexpected journey by becoming a patient in my own specialty. The uncertainty with management decisions and ‘not so straightforward’ presentation was an overwhelming experience for me, and I felt powerless to control the direction my life was heading. The day I had to give up my specialist training post, I felt robbed of all my dreams and life expectations, career gone out of the window.”





During the next session, the group were asked to discuss and rank four creative designs for a patient web platform designed to raise awareness, increase understanding and support patients with vasculitis. This was followed by a discussion about what resources the group though would be useful to help patients manage and understand different aspects of their journey.

Some suggestions were:

- animated material, videos and infographics aimed at patients
- individual leaflets – to be available online but also printed by the doctor for patients
- more patient-friendly information about treatment options (immunosuppressant, cyclophosphamide, steroids etc) and the condition and support material to help patients with what to ask during visits to their consultant
- help health professionals realise the importance of patient organisations to support their patients - make sure they are aware of Vasculitis UK, Health Unlocked etc.



We then moved on to a creative session 'Art and Voice' with Shanali, who invited everyone to have a play with pixels to find out what creating a digital canvas feels like. Initially it involved getting used to the sketch app, having free hand movement with colours and exploring brush options. Everyone was then asked to sum up their journey with AAV in one word leading to the following digital art exercises:-

- putting a colour and shape to humour
- the patient's perception, the carer's perception and the clinician's perception of what pain, fatigue, change and support looks like in colour and shape using the iPads provided.

The aim of the session was to attempt to capture and portray the subjective experience of illness, pain, fatigue in colour and shape using art as a way of voicing some of the 'difficult to articulate' emotions and experiences. It was also to make sure the participants had fun and gave them a chance to explore art as a way to communicate to health teams the impact illness can have on identity, image and lifestyle.



During the day each of the participants was recorded on video sharing their personal story and these are available on a website for health professionals created by Vifor to raise awareness of the disease. There is also a video about the day. The plan is to create a web resource for patients which is currently being developed which will also feature these videos. You can catch a sneak preview by visiting [https://www.understandaav.com/patient-experience/index.html?mc\\_phishing\\_protection\\_id=28632-bksaptse2is86cl9c70](https://www.understandaav.com/patient-experience/index.html?mc_phishing_protection_id=28632-bksaptse2is86cl9c70)

## Interviews



The insights from the group were shared with an EU workshop in June and the Pan EU patient association shared the views of the Manchester group about the creative concepts for the digital patient platform. Vifor Fresenius Medical Care Renal Pharma Ltd who are creating the resources gave a donation to Vasculitis UK for their help with the project.

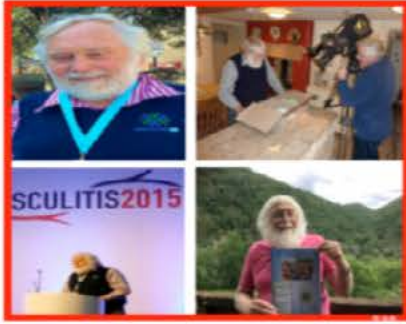
Dijana Krafcsik, marketing director with Vifor, who looked after participants at the workshop, said: "Thank you to all workshop participants for taking the time and the great insights you provided us with. What I learned I could not have learned from books, so I am so grateful. We are looking forward to producing these vital resources to help raise awareness of ANCA-associated vasculitis."

Cath added: "It was a really enjoyable day and work while experience to be involved in research and developing tools to hopefully help more vasculitis patients in the future. We were very well looked after by the Vifor team, I really felt that my experiences mattered, and they did everything possible to make us feel at ease throughout the day, in particular when making our videos."

Shanali commented about her experience: "I am really grateful to have had the opportunity to work with the Vifor team organising the workshop and being able to take part as a patient as well as a digital artist. It was an amazing journey leading up to it and day itself was made a real success by everyone who participated, so a big thank you to all."

# 2009 CELEBRATING 10 YEARS CELEBRATING

In 2001, John was diagnosed with GPA (Granulomatosis with Polyangiitis - formerly known as Wegener's Granulomatosis). Susan researched it & found the information & support from the Stuart Strange Vasculitis Trust (former name of Vasculitis UK). Thus began their journey with Vasculitis UK.



John became Chairman in 2009 with Susan taking on many roles. John was particularly keen on raising awareness amongst medical professionals of vasculitis to help patients get a more rapid diagnosis, with correct treatment but it wasn't all plain sailing & he

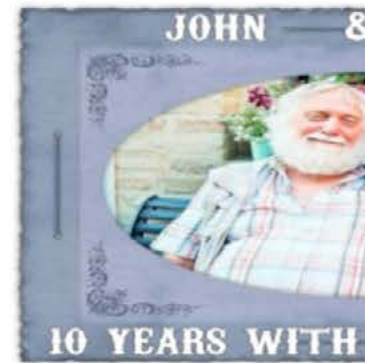
worked tirelessly to achieve this.



Vasculitis UK has gone from humble beginnings to the UK's leading vasculitis support charity & is now a Charity Incorporated Organisation (CIO) thanks to John & Susan with some help from a few dedicated volunteers (especially Dorothy). They're good fun to be around too!



## JOHN & SUSAN THANK YOU FOR



They've met hundreds of vasculitis patients & their family members from all over the UK. John was also instrumental in co-funding Vasculitis Europe & helping to set up the rare Autoimmune Rheumatic Disease Alliance (RAIRDA).

After 10 years, John is stepping down as Chairman but will be continuing as the Vice Chair & Director of Operations. They are by no means leaving Vasculitis UK but we wanted to thank them both for all their dedication & hard work over the past 10 years.



# 2009 CELEBRATING 10 YEARS CELEBRATING



Here are a few messages from a select few people they have encountered on their journey:

John has made many contributions on national & international committees aiming to improve the health of patients with vasculitis & has engaged in a unique way with other patients & healthcare professionals. His understanding of the medical issues have made him well placed to effectively present the patient's voice in these discussions. Many patients & their carers will have appreciated his advice on how best to access care within the NHS. Patient support groups such as Vasculitis UK provide an essential support for patient's with vasculitis at the personal level as well as being an advocate in health policy development at the National level. John & Susan's selfless contributions to these roles provide a wonderful example of what patient activism can achieve & have placed the charity in a strong position for the future.

*Professor David Jayne - Consultant Nephrologist & Vasculitis UK Scientific Advisory Board*

I don't think I would be here if you hadn't persuaded me to get a second opinion! Since then, through working together for Vasculitis UK, we have become friends & I can't tell you how much your friendship means to me. You are both the kindest, most caring & inspirational people I've ever met & I'm incredibly grateful for all you have done for me, countless others & the vasculitis community. You're my heroes!  
Kelly Jefferies - Vasculitis UK Secretary & Trustee

When you get diagnosed with a rare, chronic illness your life changes. Mine did in many ways. Thanks to John & Susan, I found a new path in my life. Being part of Vasculitis UK is very important to me. I cannot thank them enough for their support & trust.  
Zoi Anastasa - Vasculitis UK Trustee & EURORDIS representative

John has made an unprecedented contribution to improving the lives of people living with vasculitis by being a passionate & effective advocate at all levels within & outside of the charity. He has directly influenced the design of standards of care through his role as an author of the BSR guidelines for vasculitis treatment. John has relentlessly driven the voice of people with vasculitis into the heart of NHS decision making, through his work with NICE and NHS England that enabled access to Rituximab. There is so much more he has achieved such as successfully championing the need for better education of health professionals - an essential starting point for good care - within many organisations including NHS England's Clinical Reference Group, the United Kingdom and Ireland Vasculitis Group, the British Society for Rheumatology (BSR) & the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) amongst others.

In addition, John himself is a great teacher, not just of his own story but sharing with fellow professionals the enormous in depth knowledge, through the charity, of where the real needs lie, for people living with vasculitis. Crucially, John has, on occasion, successfully challenged some of the traditional ways of thinking and working amongst the medical profession, inspiring them to see things, for want of a better way of putting it, "in a different light", & always from the patient's perspective. So many of us, across the whole vasculitis community, are incredibly fortunate to have benefitted from so many things - his leadership, wisdom, friendship, but also supportive challenge, that have been components of his relentless, effective & successful drive to improve the lives of people living with vasculitis. John has also been a very strong supporter of the next generation of doctors, encouraging their early research & nurturing them to lead improvements in the medical aspects of vasculitis care. It has been a privilege to work with him over the past six years.

*Doctor Peter Lanyon - Consultant Rheumatologist*

## SUSAN MILLS FOR EVERYTHING!



I found the Vasculitis UK website & Facebook support group about a year into being ill, when the word vasculitis was first mentioned. When it became clear my treatment plan was below standard, Susan & John gave me invaluable advice & support. The helpline meant I had somewhere to go when I needed a point of contact &, having met them both, they were as friendly & full of character as I had imagined. What a cracking team!  
Kath McIntosh - Moderator in the Facebook support group

I am very happy to add my huge support for John & Susan who have been so effective in raising the profile of vasculitis in the UK and, with the support of their trustees, provided much needed funds for research. They have worked tirelessly & always enthusiastically & cheerfully in not always the easiest circumstances.

The vasculitis community owes them a huge debt of gratitude & hopes that they will be able to take life a little easier in the future. Can I also add that they have been great fun to be with & always helpful in every way to support us all in the interest of promoting & supporting vasculitis patients & researchers.

*Professor David Scott - Consultant Rheumatologist & Vasculitis UK Scientific Advisory Board*

All the work you have put into Vasculitis UK has gone on to help numerous people, from patients like myself, to families & their carers that are also affected. I have only ever heard good words about you both & you're always available with helpful information or just a reassuring smile. I'm not sure we'll know how many of us have survived this dreadful disease because of your selfless drive to promote & educate those in the medical profession. From myself & Andrea, thank you from the bottom of our hearts for the 10 years you have given to Vasculitis UK!

*Martin Makin - Vasculitis UK Trustee & "green haired" fundraiser*

This year marks the end of an era, since John is stepping down as Chairman of Vasculitis UK. I have known John for most of the 10 years he has served as Chairman & during which time he has developed what was formerly the Stuart Strange Vasculitis Trust into the much larger, more widely represented & highly respected organisation that Vasculitis UK has become. To many professionals, John has become the "face" of Vasculitis UK, since he attends such a large number of research & educational meetings. He has done a tremendous job in raising the profile of vasculitis nationally & in fundraising to support patients, researchers & trainees. The help & advice he gives to so many patients with vasculitis is legendary. He has been ably assisted in this work by his wife, Susan, who has served as Web Administrator for the charity. I was delighted to learn that John will be continuing, for the time being, as Vice Chair & Director of Operations, since he still has a vast amount to contribute to patients & professionals in the field of vasculitis.


*Professor Charles Pusey - Consultant Nephrologist & Vasculitis UK Scientific Advisory Board*




# Small Vessel Vasculitis Poster. (Mariam al Attar)

Whilst on a rheumatology placement, medical student Mariam al Attar produced this poster on small vessel vasculitis for a Rare Disease Event organised by "Medics4Rare Diseases".

It is an unusual presentation in that it shows the secondary vasculitides associated with Irritable Bowel Disorder, cancer, rheumatoid arthritis, Sjögrens & lupus, which we don't usually list as individual types.



## Small Vessel Vasculitis



*Part of the M4RD Rheumatology For Finals revision series*

**What is small vessel vasculitis?**

- ◆ Inflammatory disorders predominantly affecting small blood vessels
- ◆ May be primary or secondary
- ◆ Effects may be transient, but usually result in long-term damage

**What is ANCA?**

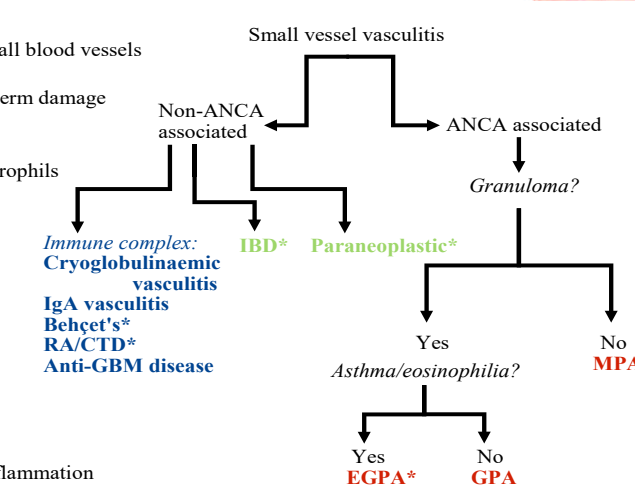
- ◆ Anti-neutrophil cytoplasm antibodies targeting neutrophils
- ◆ Two relevant types:
  - c-ANCA [new terminology PR3] = shows cytoplasmic granular fluorescence
  - p-ANCA [new terminology MP0] = shows perinuclear staining

**What is an immune complex (IC)?**

- ◆ Type III hypersensitivity
- ◆ Formed from antibody-antigen binding
- ◆ Deposit on organs causing inflammation

**What is a granuloma?**

- ◆ Mass of granulation tissue formed in response to inflammation



```

graph TD
    A[Small vessel vasculitis] --> B[Non-ANCA associated]
    A --> C[ANCA associated]
    B --> D["Immune complex:  
Cryoglobulinaemic vasculitis  
IgA vasculitis  
Behçet's*  
RA/CTD*  
Anti-GBM disease"]
    B --> E[IBD*]
    B --> F[Paraneoplastic*]
    C --> G[Granuloma?]
    G -- No --> H[MPA]
    G -- Yes --> I[Asthma/eosinophilia?]
    I -- No --> J[GPA]
    I -- Yes --> K[EGPA*]
    
```

**JBD**

Vasculitis associated with Inflammatory Bowel Disease

**Presentation:**  
Variable  
Cutaneous vasculitides reported, but could be any type including medium/large vessel

**Paraneoplastic**

A non-malignant manifestation of a neoplasm

**Presentation:**  
Variable  
Cutaneous and CNS vasculitides reported, but could be any type including medium/large vessel


**Cryoglobulinaemic**

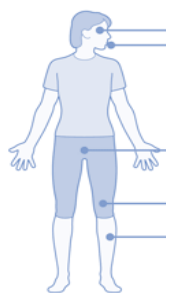
Cryoglobulins = IC  
Precipitate at < 37°C, deposit on vascular endothelium

**Presentation:**  
Purpura, Weakness  
Arthralgia (=Meltzer's triad)  
Glomerulonephritis  
Raynaud's

**IgA Vasculitis**  
AKA Henoch-Schönlein Purpura  
Self-limiting. 90% occur in childhood.

**Presentation:**  
Skin purpura on back of legs and buttocks, abdo pain, arthritis, GI bleed, orchitis, nephritis  
Preceding URTI





**Behçet's**

Multisystem disorder w/ strong genetic association. Often in younger males.

**Presentation:**  
Recurrent oral ulceration  
Genital ulceration  
Uveitis/eye lesions  
Erythema nodosum

**RA/CTD**

Secondary to RA or Connective Tissue Diseases

**Presentation:**  
Any size vessel could be involved.  
Commonly reported: systemic, cutaneous, renal, peripheral nervous system

**Anti-GBM dx**

Old name: Goodpasture's disease

**Presentation:**  
Pulmonary haemorrhage with haemoptysis  
Crescentic glomerulonephritis with haematuria

**EGPA**

Eosinophilic Granulomatosis with Polyangiitis [formerly Churg-Strauss]  
~40% ANCA +ve.

**Presentation:**  
Asthma, paranasal sinusitis, pulmonary infiltrates, histological vasculitis  
eosinophilia > 10% neuropathy

**MPA**


Microscopic Polyangiitis  
Usually MP0 positive  
No granuloma/ eosinophilia

**Presentation:**  
Renal, GI, cutaneous, and peripheral neurological manifestations  
Fatigue & arthralgia

**GPA**

Granulomatosis with polyangiitis [Formerly Wegener's]  
Usually PR3 positive  
Granuloma on CXR

**Presentation:**  
ENT, Lungs, Renal  
Ulcers around nose  
Destroyed cartilage = saddle nose  
Haemoptysis  
Haematuria



**Resources**

<https://patient.info/OxfordHandbookofRheumatology>

Developed for M4RD by  
Dr Mariam Al-Attar  
Foundation Doctor  
with special thanks to  
Dr Chetan Mukhtyar  
Consultant Rheumatologist

\* Not exclusively affecting small vessels



## Leicester Hospital Vasculitis Patient Engagement Day

This was organised by Leicester University Hospitals, back in March. John Mills, Susan Mills, Dorothy Ireland and Martin Makin attended on behalf of Vasculitis UK. It was very well attended with around 45 patients.

Leicester Hospital are working towards a multidisciplinary rare disease clinic and wanted to share best practice and research.

The day included talks and presentations discussing large and medium cell vasculitis, ANCA associated vasculitis, IgA vasculitis and also the use of social media.

The speakers were from both Rheumatology and Renal - Dr Reem Al jayyousi, Dr Kenny Sunmboye, Professor Jonathan Barratt, Dr Matt Graham-Brown and Professor James Burton

The day was enjoyed by everyone with a wealth of knowledge and good practice.



*Dorothy Ireland/Susan Mills*

## New Look & Updated Vasculitis UK Website

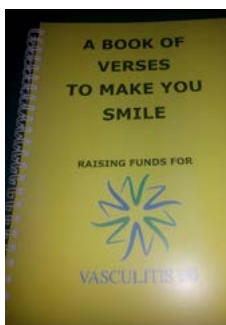


As Dorothy has mentioned in her Chair's report, the new look and updated VUK website was launched in October of this year.

The new look website is now mobile and iPad compatible, complete with a new search icon to help direct you to the pages you want to read. The news and events pages will stay on the home page but are more obvious and much more accessible. All "Individual disease" pages will updated over the next few months.

Thank you to John Geddes and Susan Mills for all their dedicated and hard work this last few months and special thanks to Paul, the website master from On Screen. <https://www.vasculitis.org.uk/>

## A Book of Verses to Make You Smile



The Book Of Verses To Make You Smile It is still going well. I have just received another batch having sold just under 200 and raising more money to have these further books printed. Up to date it has raised over £1,300. If you would like a copy of the book the cost is £6.50 plus £2 p+p.

I can be contacted via email:- [mgtrib@talktalk.net](mailto:mgtrib@talktalk.net)  
I also now give talks, I have three to do this year and bookings are coming in for next year. I have recently added another talk on to the one I usually give called "Andrew's Journey." I now also do "45 Minutes Of Fun And Laughter," and bookings have started to come in for that one for next year, with the fees going to Vasculitis UK.

Margaret Robertson

## 19<sup>th</sup> International Vasculitis & ANCA Workshop, Philadelphia: April 7<sup>th</sup>-10<sup>th</sup> 2019



Wow – my inaugural ‘Vasculitis’ conference is over in a flash, and what an experience it was! The few days kicked off with the very informative ‘Cutting Edge: Vasculitis’ course, which was an excellent overview of the key areas, by some of the world’s experts in the field. The panel discussions were of particular interest to me and I particularly enjoyed how the evidence was presented in a clinical context, with the patient at the forefront.

The meeting proper then proceeded. It was great to meet the vasculitis community – young and old - share ideas, discuss potential future collaborations and gain new knowledge and perspective. To meet and chat to experts who’s papers I read and reference was very inspiring!



The organisation of the meeting was second to none, and the organisers should be highly commended for their excellent execution. A few features of this meeting that particularly stood out to me were:

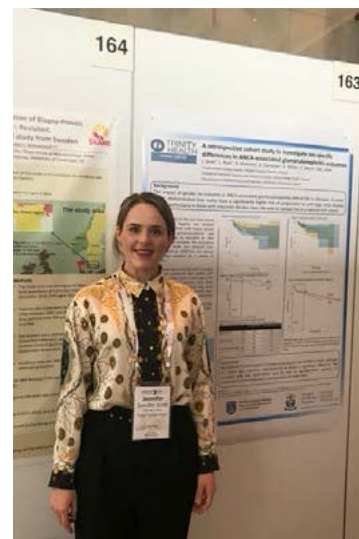
- i) The mix of early and more experienced investigators on the panels, as well as the strong female representation.
- ii) The moderator’s introduction and summaries for all sessions was a novel and very beneficial addition to proceedings.
- iii) The trainee speed dating was an imaginative way to get juniors to mingle with senior investigators and gain valuable insight and advice.



The recurring theme of personalised medicine was notable throughout the meeting. Perhaps one of the highlights was a keynote session by Dr. David Fajgenbaum, who told his very moving personal story of ‘curing’ his own Castleman’s disease. His approach to investigation and rigorous science definitely set my mind thinking about my own projects and how I could apply his advice.

Finally, a review of the meeting would not be complete without mentioning the fabulous social highlights.

The exclusive viewing of the ‘Reading Terminal Market’ and the gala dinner at the incredible Barnes Foundation were unforgettable nights. We have a lot to live up to for Vasculitis 2021 in Dublin – I eagerly look forward to it!





The 19th International Vasculitis & ANCA Workshop took place in April of this year in Philadelphia, USA. The Workshop brings together scientists and clinicians from all over the world to share news and insights into mechanisms of disease and novel approaches to treatment in vasculitis. This meeting is the biggest forum for discussion of advances in pathophysiology, genetics/genomics, biomarkers, outcomes, and therapies for vasculitis, with the ultimate aim to improve the outcome of patients with these conditions.

Event organiser Dr. Peter Merkel opened the conference by welcoming the 550 attendees from 40 countries, which included the recipients of the Vasculitis UK travel bursaries. We then heard from the Director of the US National Institutes of Health Francis Collins, who introduced a talk from Dr. Carl June about novel T-cell-based treatments for autoimmune disease. Francis later performed with his band – “The Affordable Rock’n’Roll Act” – at a social event in Reading Terminal Market where we got a taste of some Philadelphia delicacies. Before that we had presentations from the Early Investigators

Award-Winning Abstracts, which included travel bursary winner **Maria Prednicki**. Drafts of new classification criteria after AAV and Large-Vessel Vasculitis diagnosis were also discussed.

Our first full day of the conference focussed on diagnosing and understanding the development of vasculitis. The first session focused on treatment of MPA and GPA, where results of a number of ongoing clinical trials were

presented including RaVer and ALEVIATE. We learned about the role of non-ANCA antigens and the role of histopathology in diagnosis of vasculitis, and there were dedicated sessions to EGPA and Behçet’s Syndrome. The poster viewing opened up and attendees were free to browse the 360 posters from international research groups. This research was also published in a special edition of the journal [Rheumatology](#).

As well as the exciting research and clinical trial updates we had the privilege of hearing the unique and extraordinary story of Dr. David Fajgenbaum, Co-Founder and Executive Director of the Castleman Disease Collaborative Network (CDCN). While in medical school David developed Castleman’s Disease – a rare disorder of the lymph nodes which causes organ failure and currently has no cure. David has dedicated his life to understanding his disease and discovering new treatments and cures for deadly disorders like Castleman’s Disease. His powerful and inspiring take-home message was that despite the advances in treatments and hard work put into research, his disease could return at any time and – “we are all in overtime” – and should live life to the fullest.

The exciting opening session of day 3 was focussed on the innate immune system and how the pathways and processes involved in vasculitis development can potentially be targeted for treatments. Dr. Rae Yeung presented some fascinating work on the complex roles of genetics and the environment in Kawasaki disease, including links to wind direction. We were introduced to some new biomarkers of vasculitis such as sCD163, interleukin-27 and calprotectin. We also learned how novel imaging techniques can be used for diagnosis and to monitor treatment responses. After a busy lunchtime session



and some more dynamic and informative poster viewings, attendees had the opportunity to attend an event at the Barnes Foundation with some great food, good music and impressive artwork.

The final day of the workshop focused on new and existing treatments for small and large vessel vasculitis. This included the results from PEXIVAS, that largest AAV trial to date, which found that a reduced dose of glucocorticoid had similar efficacy to standard treatment regimens and led to reduced incidence of infection. Different combinations of traditional and novel therapies and the sensitive issue of funding these treatments were also discussed.

Dr. Peter Merkel closed the meeting by thanking all attendees and commending our extreme coffee consumption during the last 4 days. We are very grateful to Vasculitis UK for allowing us to experience the conference, network with other researchers, and present our data to the world. The next Vasculitis Workshop will take place in Dublin in 2021 – we look forward to seeing you there!

*Emma Leacy*



I had a wonderful time at the *19th International Vasculitis & ANCA Workshop* in Philadelphia. The term 'workshop' somewhat undersells the scale of the event which felt more like a full-blown conference. It was attended by over 500 delegates from over 40 countries.



Cutting edge research ranging from basic and translational science to clinical trials was discussed through a combination of formal scientific sessions, interactive breakout sessions and social events. The organisers had cunningly set up the coffee and refreshments stands in the poster hall. This served as a hub for interaction around the 300+ posters that were displayed throughout the conference.

Key themes emerging from a range of impressive presentations included: 1) lower steroid doses can be used, and 2) we are moving towards an era of 'personalised medicine', in which rather than adopting a 'one shoe fits all' approach to treating patients with vasculitis, patient-specific factors (e.g. blood levels, genetic profile, imaging techniques) will be used to determine treatment decisions and predict prognosis.

Many thanks to Vasculitis UK for providing me with the generous travel bursary. I promise it did not all go towards the many '*Philly cheese steaks*' that were enjoyed over the course of the week!

Mark



I am an NIHR academic clinical lecturer in Nephrology, currently working in the renal lab at Imperial College London. I also completed my PhD in this lab investigating a role for P2X7 in autoimmune vasculitis and glomerulonephritis.

One of my presentations at vasculitis 2019 was 'Leucocyte Syk activation in ANCA associated vasculitis'. Spleen tyrosine kinase (Syk) is a molecule that has been shown to be important in the responses of cells to antibodies.

Previous work done in our lab has shown that Syk is present in renal biopsy tissue from patients with AAV and in an animal model of AAV, Syk inhibition was effective at treating disease. I isolated neutrophils from the blood of patients with AAV and active disease, in remission and from healthy controls. I showed that the neutrophils from patients with active disease contained more active Syk than the other groups and that the levels of Syk activation decreased when those patients went into remission. I also stimulated neutrophils with MPO-ANCA isolated from patients and showed that also resulted in Syk activation.

When neutrophils are stimulated with MPO-ANCA they produce pro-inflammatory cytokines and other substances which could be causing damage to blood vessels in patients with AAV. In the lab, when we incubated neutrophils with a Syk inhibitor before stimulating them with ANCA lower levels of these substances were released. Finally, following from our previously published work showing that Syk is present in renal tissue from patients with vasculitis, we showed it is also present in non-renal sites of inflammation such as gut, ENT, lung and skin biopsies. This work, which was funded by a grant from Vasculitis UK, is one of many projects we are undertaking investigating Syk in vasculitis and we hope that there may be a role for Syk inhibition in patients with AAV.

**Kavita**



**Imperial College London at Vasculitis 2019, Philadelphia**

By Kavita Gulati (Academic Clinic Fellow) and

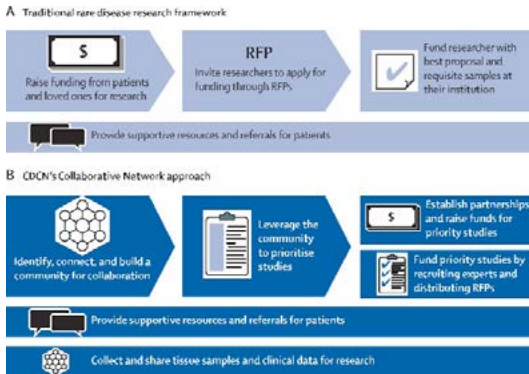
Maria Predecki (Academic Clinical Lecturer)



Photo 1 View from Loews Hotel, Philadelphia

We were both fortunate enough to be supported by Vasculitis UK to present our work at Vasculitis 2019. The conference had a strong focus on the importance of multi-centre collaboration in rare disease and patient-led research questions.

Particularly fascinating were the plenary sessions with invited speakers from related auto-immune diseases. Dr Yeung described collaboration with different disciplines helping direct investigations in Kawasaki disease, including input by climate scientists.



One of the most inspiring talks, which even received a standing ovation, was by David Fajgenbaum, who spoke about his experience as both a patient and leading researcher in Castleman's disease. His talk really emphasised the importance of patients being the centre of developing collaborative networks.

Incredibly, there was a lot of encouragement given to junior researchers with prizes for winning abstracts, mentoring events and trainee poster tours.

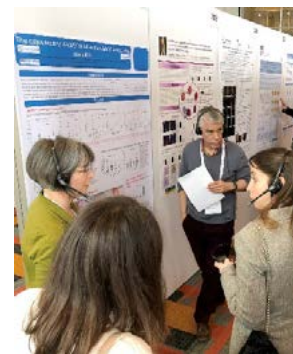


Photo 3 Trainee Poster Tour

Further analyses were also discussed from the PEXIVAS trial, the largest randomised control in ANCA associated vasculitis. The most important learning point from this was that larger trials are possible, and are necessary even in rare disease to ensure the benefits and risks of treatments are understood.

Philadelphia really was a great setting for team bonding, developing partnership and future direction for ANCA associated vasculitis research. We were also informed that all this was fuelled by over 400 gallons of coffee during the workshop.



Photo 4 Award for Imperial researchers Dr Predecki & Dr McAdoo



Photo 5 Imperial Rheumatology & Nephrology

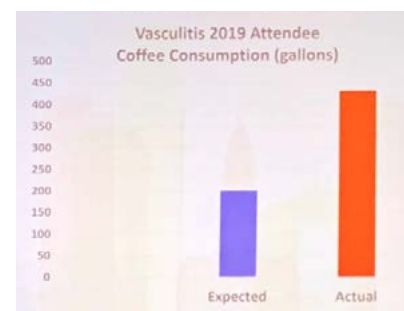


Photo 6 Coffee Consumption



Maria Predecki



Photo 7 UK & Ireland Researchers in Vasculitis

# Healthcare Moore Blatch Solicitors.



Tim Spring

**When things go wrong with your healthcare.**

**(Advice on Patient Safety & your options when making a formal complaint and pursuing a claim for compensation when you have suffered injury).**

## **VASCULITIS CAN BE A SERIOUS CHALLENGE FOR CAREFUL CLINICIANS TO DIAGNOSE AND TREAT; SO WHAT ARE THE OPTIONS WHEN PROPER STANDARDS ARE DEPARTED FROM?**

The overwhelming majority of patients are happy with the healthcare they receive, but that is not the case for a significant minority. For many, an appropriate and timely diagnosis could, and should have led to problems being avoided.

In that context vasculitis poses a particular challenge due to the variety of related symptoms, their insidious onset, and the rarity of the condition. Pattern recognition is a reflexive way of thinking we all apply, including the healthcare professional, but how useful is that facility in the case of a rare condition that may manifest itself in a plethora of symptoms over a lengthy period of time.

A clinician's ability to diagnose is central if effective treatment is to be delivered in a timely fashion. A sequential approach involving history taking, examination, differential diagnosis and eventual final diagnosis is part of basic training, but in a pressured environment a clinician may arrive at a diagnostic hypothesis that is adopted and stuck to for too long.

A proper approach when a diagnosis by exclusion is the only correct route may take too long, or not occur at all with serious consequences.

So what are your options if you suspect you have come to harm as a result of poor care? My 35 years as a healthcare lawyer enable me to say with some confidence that patients ordinarily want an explanation, an apology, knowledge that lessons will be learned and fair compensation. We all want the NHS to be the best it can possibly be. All of us, at some point, will be NHS patients. The NHS belongs to us all and making a complaint, or bringing a clinical negligence claim for compensation, has two important potential outcomes. Firstly appropriate redress but secondly, the creation of data and information from which our NHS can learn.

If you are unhappy about an aspect of your care, the first step should always be to raise your concern with those treating you. In 2014 a duty of candour was imposed on the NHS and you are entitled to a frank explanation if anything has gone wrong. There is a Patient Advice & Liaison Service (PALS) at most hospitals, and this is usually open during normal working hours. They can assist with any issue including helping you frame a formal complaint.

If you make a complaint your letter should be polite, focused, succinct employing numbered paragraphs to make it obvious if a particular point you raise is not properly replied to. You should also make sure that you request a written reply to your letter even if you are offered an opportunity for a meeting to discuss your complaint.

I recommend that any letter of complaint should be directed to the Chief Executive of the Trust. The Chief Executive might not be the person who investigates and provides you with a reply, but by directing your complaint to the most senior person, you have made that person responsible for the process.



Learning from errors and complaints has, in recent years, taken centre stage in the drive to improve patient care and patient experience. Learning from error is something our Health Secretary has made a key objective. The complaint process may result in an understanding of what went wrong. However, immediately seeking legal advice may be the appropriate action when substandard care has resulted in serious harm, warranting financial redress that can only be achieved through making a claim for compensation.

Many patients worry about whether or not pursuing a clinical negligence claim might adversely affect the care they will continue to need. It is a common fear, but I can honestly say that in all the years I have undertaken clinical negligence work, this is something I have never encountered. Healthcare professionals chose their profession wanting to do the best they possibly can, but they work in very difficult and demanding circumstances, and much is expected of them. To err is, as the cliché goes, to be human, and it would be unrealistic to expect a healthcare professional to get through a career without, at some stage, making a mistake.

Choosing the right solicitor to look after you when you need one is of key importance. Do not hesitate to ask questions about the solicitor's experience of investigating a case just like yours. Do not be frightened to ask about the firm's success rate. Competent and confident solicitors are familiar with medical experts with a national and often international reputation, and it is they rather than the solicitors themselves, who will identify and frame the specific criticisms they consider can fairly and properly be made of professionals in their own discipline.

Successfully pursuing a clinical negligence claim is dependent upon proving two things. Firstly, that care fell below an acceptable standard and secondly, that in doing so, injury or a delayed recovery resulted. A key first step is to obtain all medical notes and records and a careful account from you as the patient. Next comes the instruction of independent experts, and based on what they say, the preparation of a Letter of Claim to which a defendant is expected to respond within four months. Only after this is there any question of commencing legal proceedings.

Most cases are settled without going to court. However, the best guarantee of success is careful preparation relying on the best available expert opinion. Cases settled when it is clear to all that the ultimate outcome is inevitable.

Cases have to be properly funded and most are pursued by clients with the benefit of a Conditional Fee Agreement

( no win, no fee ). This arrangement ensures that patients of ordinary means are on an equal footing when it comes to financial and medical resources.

There are time limits that must be met to bring a claim.

Though there are some exceptions, generally a claim should be issued within three years of the date you knew, or ought to have known, that an injury, or poor outcome, might be attributable to an error. Time does not run for those lacking mental capacity and in the case of a child, time does not start to run until the age of majority at 18. However it is better to consult a solicitor before memories fade and any documentary evidence is lost. Do not be frightened about approaching a solicitor. A good solicitor will happily provide free advice as to your likely options.

*Though Tim has worked exclusively for patients and their families over the last 20 years, he spent 10 years investigating clinical errors for the NHS so has a comprehensive understanding of the problems facing both patients and medical professionals."*

## Little T's Holiday Cottage



The detached brick and flint cottage was built in approximately 1882. It stands with others in a private square in the centre of the picturesque Georgian town of Holt. Usually, there is off road parking for one car outside the cottage in the square. Approx. 50 yards away, there is a public car park. Free overnight parking is often available in nearby streets.

The cottage, in the centre of Holt, is an ideal location for a self catering holiday. Within easy walking distance there are several cashpoints, newsagents, supermarket, bakery and a range of interesting shops. In addition, the attractive town centre boasts several pubs and coffee/tea rooms. Take away food outlets include fish & chips, Indian and Chinese.

At any time of year, Holt is a town full of charm and character. At Christmas, festive lights and decorations make it especially pretty.

A short drive from Holt are the picturesque coastal villages Blakeney and Cley. The seaside resorts Sheringham and Cromer are nearby. The city of Norwich is also well worth a visit. The surrounding area is ideal for birdwatching and walking. There are many places of interest including: Felbrigg Hall, Blickling Hall and Holkham Hall. The North Norfolk steam railway runs from Holt to Sheringham. Good road links exist from Holt to Swaffham, Norwich, Ipswich and Bury St. Edmunds.

The fully double glazed cottage sleeps four people. With the exception of the kitchen and a small area in the dining room and shower room, the cottage is carpeted throughout, free wifi access during your stay.

Upstairs there are two bedrooms. The larger one (at the front) has a double bed, bedside tables, dressing table, wardrobe, clock radio, TV (Freeview), DVD player and hair dryer.

The smaller back bedroom sleeps two people.

Early 2019: 2'6" single bed beneath which there is another pull out same size trundle bed (together they make a double or twin beds). There is also a small wardrobe, small chest of drawers and clock radio. (Note: a single airbed is also available, please ask when booking).

Downstairs: front living room, separate dining room with breakfast galley, kitchen and bathroom.

- Shower room: toilet, wash basin, electric shower unit, extractor fan and shaver point.
- Kitchen/breakfast galley: cooker/oven; dishwasher; fridge (with small freezer); combi microwave: oven & grill; crockery, glasses & cutlery.
- Living room: two settees (one is a double bed settee for those who prefer to sleep downstairs), footstool, coffee tables, lamps, colour TV (Freeview). DVD player, dvds, books and games are available for use.
- Dining room: gateleg table (chairs available for six people), CD player/radio, 2 x lap trays and breakfast galley, guest information and leaflets about the local area.

Heating is by way of gas central heating. Radiators with adjustable thermostats are in each room. There is a multi fuel burner in the living room (coal supplied).

A fire guard is available, but you may wish to bring a child proof guard.

Outside at the back of the cottage: a small private enclosed courtyard with a table and two chairs, coal bunker and washing line.

Included in hire: hot water, electricity, central heating & coal/wood. A Hoover, iron/board and basic cleaning materials are available.

Summer and winter bedding is available i.e. single duvets, double duvet and pillows. Plus, bedding for the sofa bed and air bed.

You will need to take: bed linen\* (i.e. pillow cases, sheets for mattresses, duvet covers), towels and food.

### VERY IMPORTANT!

The stairs are steep and narrow. There is no telephone or washing machine. Please: no deep fat frying or smoking.

*I hope you will enjoy staying in Holt and exploring the surrounding area as much as I do.  
This advert is in memory of my late partner Gordon Mott 'Motty' 29th July 1940 — 13th April 2006.  
Gordon loved this cottage, Albert's fish & chips and the North Norfolk Coast.*

*Celebrating 20 years!*

*For more information, prices and availability please Contact Tracy:*

*Email: [tmlittle1@gmail.com](mailto:tmlittle1@gmail.com)*

*Tel: 01359 - 233343 Mob: 077*

*Visit the website: [www.littletscottage.co.uk](http://www.littletscottage.co.uk)*



VASCULITIS UK

Raising awareness about Vasculitis: [www.vasculitis-uk.org.uk](http://www.vasculitis-uk.org.uk)



VASCULITIS UK



## In memory of Leanne Henzel



Leanne sadly lost her battle to PNS, Vasculitis and Lupus on the 4th of May 2019. She was only 30 years old. Sometimes people come to our lives and make them brighter. Leanne was a bright sunbeam, a beautiful person, her humorous way of dealing with whatever life threw at her and her courage being admirable. She was a great mum, constantly thinking of her beautiful girls. She always talked about her family, making us part of her everyday life. Leanne loved porcelain mugs with Disney characters on and always was so happy and excited even in situations you wouldn't expect it; when she had her wheelchair, for example.



Martin Jayne Zoi Leanne Angharad - Vasculitis UK AGM 2018



Leanne and the UK Ghostbusters - Vasculitis UK Charity Ball 2019

It was a pleasure to meet her, in person first at the VUK AGM May 2018 and then again at Vasculitis Charity Ball earlier this year. What an evening and what great memories we made! I think of Leanne very often and she always brings a smile to my face – and a tear sometimes.

A brave warrior was taken early. Our unique unicorn zebra may not be with us anymore, but she will always be in our hearts.

*Zoi Anastasa / Susan Mills*



# Merry Christmas!

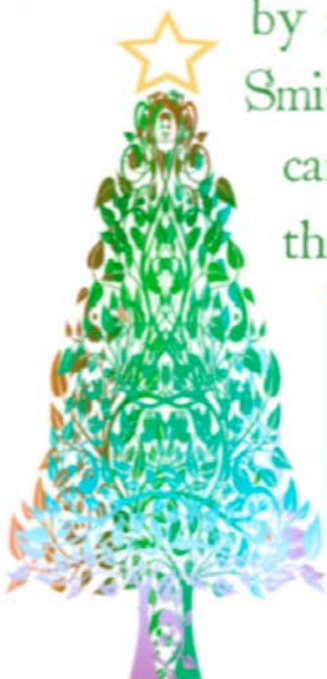


We are very pleased to announce that this year our Christmas cards have been hand drawn by a member of Vasculitis UK, Su Smith, who has previously sold other card designs in aid of the charity that were sold in a local art gallery.



(Blue border not included)

A pack of 10 cards costs £5.50 including FREE postage by Royal Mail second class post. Payment can be made PayPal, Debit/ Credit card or by personal cheque. Please use the "Pay Now" button at the bottom of the VUK shop page to pay by PayPal or Debit/ Credit card (no PayPal account necessary) or make your personal cheque payable to Vasculitis UK and let Kelly know how you wish to pay when you order. Thank you!





## Bequests - In Memoriam



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.*

### Bequest

A bequest from the estate of the late Miss Anne Lilian Johnson of Hampshire resulted in £5,000 for Vasculitis UK.

### In Memoriam

Linda Andrewes of Barnstaple kindly donated £1000 to Vasculitis UK in memory of her uncle, Herbert John James Andrewes who sadly died in June 2018, two days after his 98<sup>th</sup> birthday.

Donations totalling £217 were received in memory of Frances Audrey Jones of Liverpool, who passed away in February this year as a consequence of GPA.

Philip Iliffe of Market Harborough sadly passed away last February. A donation of £153 was made to Vasculitis UK in his memory by employees at Leicester City Clinical Commissioning Group

At the funeral of Mrs Joan Valerie Martin of Lavenham, a collection in support of Vasculitis UK raised £350 in her memory.

Funeral donations of £30 were offered in memory of Mr Peter Clayton of Huddersfield, who died in the Spring of 2019.

Donations totalling £217 have been received in memory of the late Frances Audrey Jones of Liverpool, who sadly passed away in February of this year as a consequence of GPA.

Funeral Donations totalling £205 were received in memory of the late Phillip Jonathan Callander of Mereworth, Kent, who sadly passed away In February of this year.

A donation of £300 was received in memory of David Vickery of Bebington in the Wirral who died after suffering from GPA for 13 years. He was on dialysis for 10 years.

The husband of Mrs P White, of Sudbury, Suffolk, sadly died last April. Donations in his memory raised £166 in his memory.

James (Jim) Glynn, of St Helens, Merseyside sadly passed away last June due to vasculitis, leaving a widow, Norah. Donations in his memory raised £330 for Vasculitis UK.

The members of St Theresa's Over 50's Group donated £72.00 in memory of Jim Glynn.

Alan Edward Gunn of Holsworthy, Devon, sadly passed away in 2019. Donations to Vasculitis UK totalling £148 were received in his memory.

Joyce Blackwell of Sidmouth, Devon, died aged 93, peacefully at home surrounded by her family.

Funeral donations totalling £210 were received in memory of the late Thomas Curry of Sutton Coldfield.

Funeral donations totalling £63 were received in memory of the late Geoffrey Charles Newman of Coventry.

A donation of £250 was received in memory of Helen Barker who sadly died in August 2019.

Funeral donations totalling £227 were received in memory of Janice Giles of Kidlington, Oxfordshire. Janice left a widower, Sam

Funeral donations in lieu of flowers, totalling £245, were received in memory of Mr John Channon of Fishguard, Pembrokeshire.

## Vasculitis UK AGM 2020 Advance notice.

This will take place on 17<sup>th</sup> May 2020 at the same venue as this year  
The Post Mill Centre at South Normanton, near junction 28 on the M1.  
Full details will be in the Spring Newsletter.



## Donations & Fundraising



Paypal Giving Fund donated £1442 to Vasculitis UK

An anonymous donor kindly donated £200 to Vasculitis UK.

Margaret Robertson of Chester-le-Street donated £206.50. This represented mainly the proceeds of her book of verse "A Book of Verses to Make You Smile", which is still available in the Vasculitis UK online shop.

Frances Hawkins of Ipswich kindly donated £200 to Vasculitis UK.

Once again, Buckingham Charity Football Club, with Buckingham Charity Cup Competition have kindly made donations totalling £160 to Vasculitis UK.

Tracy Martin of Pakenham in Suffolk held a "significant birthday" & retirement party this Spring and invited guests to donate to Vasculitis UK in lieu of gifts.

The total raised was £262. Tracy also lets her holiday cottage (see advt elsewhere) and guests donated an additional £20.

The Home Claims Team at LV Insurance held a Bake Sale which raised £19.77 for Vasculitis UK.

The staff at Boots Chemist at Beeston, Nottingham, held a collection in aid of Vasculitis UK, which raised £50.00

The Hartshead Square Fundraising Group at the Department for Works & Pensions in Sheffield raised £204.99 to support Vasculitis UK.

Paypal Giving Fund kindly donated £1882 to Vasculitis UK.

Vasculitis UK is the current chosen charity of the staff of the Leeds office of Keebles Solicitors. They have so far made donations £170 and £112 – a total of £282 - to this charity.

Suzanne Morris designed and screen-printed a tea towel, sales of which raised £20 for Vasculitis UK.

Margaret Robertson's book of poems, published in aid of Vasculitis UK, continues to sell well. Margaret recently donated over £200 to Vasculitis UK.

Sealy UK Social Club Charity Committee kindly donated £50 to Vasculitis UK.

One of the members of Higham Fencers Bowls Club suffers from vasculitis so the members agreed that their annual President's Day should raise money for Vasculitis UK. This resulted in a cheque for £275.

Helen Taylor of Meltham, Holmfirth, near Huddersfield raised money amounting to more than £500 in support of Vasculitis UK, through a cake sale, raffle, table-top sale & selling CDs & books online. Helen's daughter, Sarah, has GPA.

Lewis Perry & Jordan Brown took part in a SkyDive on 2<sup>nd</sup> June, raising a total of £1436 in sponsorship for Vasculitis UK. Lewis's mum, Emma was diagnosed with Takayasu arteritis in 2007. See photo elsewhere in this edition.

A raffle at "Hairforce" Haidressers in Corton, Suffolk, raised £75 for Vasculitis UK. Thanks also to Rachel Marsh for her support.

Tim Moxley's wife, Lydia, sadly died due to vasculitis a few years ago. In July, Tim with friends Jamie, Dan & Ellen, set out to circumnavigate the island of Anglesey in a "Vasculamble", covering 130 miles in 9 days. Various friends joined them en-route for the day. Sponsorship through Justgiving raised £1512 for Vasculitis UK and a further donation raised this to £1537

The Scott Bader Commonwealth Limited Global Charity Fund donated £200 to Vasculitis UK.

The 2019 Annual reunion of the former serving members of HM Royal Navy Submarine "Torbay" was held at Torpoint, Devon. HMS Torbay was built in 1987 and decommissioned in 2017 after 30 years' service. During that time, over 1000 crew had served onboard.

At the reunion was former shipmate, Phil Eddy, who now lives near Northampton. Phil has suffered from WG for several years. At each reunion there is customarily a fund raiser for a worthwhile charity on this occasion it resulted in a donation of £500, which, at Phil's request is to be split between Vasculitis UK and the newly formed Northampton – based Local Vasculitis Support Group

## 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/>**

# 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 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)

### 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 - [sandylee777@hotmail.co.uk](mailto:sandylee777@hotmail.co.uk)  
Caroline Meyrick - 01780 460354 - [cmmeyrick@gmail.com](mailto:cmmeyrick@gmail.com)

### London

#### North London Group

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

### Merseyside, Cheshire and North Wales Group

Susan Chance - 01244 381680 - [susan.chance53@icloud.com](mailto:susan.chance53@icloud.com)  
Dave Birch - 0151 7229049 or 07968226230 - [davebirch@talktalk.net](mailto:davebirch@talktalk.net)

### North East Group

Margaret Robertson - 07443016665 - [mgtr@talktalk.net](mailto:mgtr@talktalk.net)  
[susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)

### Norfolk Vasculitis Support Group

Mark Sayer - [m-sayer@hotmail.co.uk](mailto:m-sayer@hotmail.co.uk)

### The North West Group

Jann Landles - Anita Parekh [nwvasculitis@outlook.com](mailto:nwvasculitis@outlook.com)

### Northamptonshire Group

Maurice - [northantsvsg@gmail.com](mailto:northantsvsg@gmail.com)

### 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

Peter surreyvsg@gmail.com

### Sussex by the Sea Vasculitis Support Group

Antony Hart - [Antonyghart@outlook.com](mailto:Antonyghart@outlook.com)

### Swindon Support

Wendy and Lisa [swindonvsg@mail.com](mailto:swindonvsg@mail.com)

### 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)

### North and West Yorkshire Groups :

Richard Eastoe - 01423 520 599 email [richard@yorkshirevasculitis.org.uk](mailto:richard@yorkshirevasculitis.org.uk)

### East Yorkshire Group :

Rachel Weeks - 07968 959 850 email [rachel@yorkshirevasculitis.org.uk](mailto:rachel@yorkshirevasculitis.org.uk)

### North East Yorkshire Support Contact :

Jennifer Wormald - 01937 586 734 email [jennifer@yorkshirevasculitis.org.uk](mailto:jennifer@yorkshirevasculitis.org.uk)

### South Yorkshire Social Group Contact :

Jenny Gosling - email [jenny@yorkshirevasculitis.org.uk](mailto:jenny@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 - [susan.chance@53@icloud.com](mailto:susan.chance@53@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

### Edinburgh and Lothian (Contact Person)

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

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



# Diary of Events for Medical Professionals



EUVAS 3rd Vasculitis Course - Master Class

September 23 - September 25

The third European Vasculitis Master Class will return to Cambridge this year!



United Kingdom & all Ireland Vasculitis Study Group

4th December 2019 London



BSR Annual Conference 20-22 April 2020

Glasgow

## Cambridge Vasculitis Support Group Meeting Saturday 2nd November 2019

[NB - this is a change of date, replacing the original date of Saturday 5th October 2019]

We have a bumper line-up for this, our 10th Birthday Meeting. Book now for a special day.

Our speakers:-

Joss Goodchild is an artist (and one of our members), who lost the use of her hands and feet, with the onset of vasculitis.

Kay White is a physical well-being and rehabilitation practitioner with a particular interest in chronic physical conditions.

Dr Rachel Jones is a Consultant Nephrologist with the Vasculitis Team at Addenbrooke's Hospital.

For more details follow this link via the VUK website <http://www.vasculitis.org.uk/events/cambridge-vsg-2019-01>

## ***North East Vasculitis Support Group Meeting***

On Saturday 16th November at the Freeman Hospital Newcastle

For more details follow this link via the VUK website:

<http://www.vasculitis.org.uk/events/nescg-2019-08>

## 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

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