



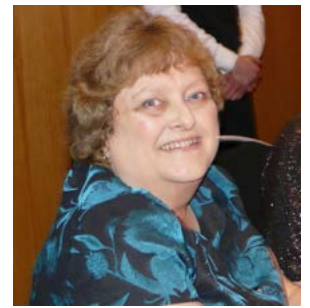
# VASCULITIS **UK**

## NEWSLETTER JOURNAL



**AUTUMN 2024 ISSUE 68**

It's been a very busy Summer for Vasculitis UK. We've attended many conferences and a lot of Zoom/TEAMS meetings. Our fundraisers, as always have been magnificent. When deciding on a Face2Face AGM, the trustees were worried about the rise in covid cases so have decided that the AGM will be via Zoom again. Date the 27<sup>th</sup> October 2024. Please email [agm@vasculitis.org.uk](mailto:agm@vasculitis.org.uk) to register.



## Chairman's Report

Just to prove the point I am currently recovering from Covid and needed Paxlovid antivirals. What I did discover is how poorly organised the local GP and 111 are. I was sent to A&E and not isolated for the first 5 hours! Then they didn't stock the drug.

Many will know from our Facebook support group that Susan Mills has decided to step down as a trustee. I can't imagine VUK without her but I understand her decision. She has a formidable knowledge of the vasculitis specialists and of the individual diseases. This has meant many changes to the charity, probably for the best as we have been growing in recent years. As Susan is also leaving Winster we've had to find a new registered Office. All our details on forms and books need changing. If you need to send us anything then please use the new address of Vasculitis UK, Victoria Court, 17-21 Ashford Road, Bournemouth, ME14 5DA.

Also stepping down are Charlie and Jennifer Harper. They have a very young family and new increased work commitments. We thank them for their work with the young members and the shop, respectively. The remaining trustees are Dorothy Ireland (Chair and Fundraising Team), Jane Edwards (Media Team and Deputy Director of Operations), Peter Rutherford (Advisor), Charlotte Smith (Fundraising Team and Events), and Heidi Pollard (Treasurer). Our Treasurer has not only kept her eye on the finances, she has again run the Great North Run and Climbed Mt Kilimanjaro.

We've restructured the trustees so that we work in teams. That way we hopefully will never be in a position of one person doing all the work and others not being able to step in. We have three co-opted Trustees seeking approval at the AGM. These are Diana Shonfield, Claire Tolliday and Maxine Wright. Plus, two new applications from Anthony Hart and Giles Hart.

Our Director of Operations Zoi Anastasa has been very busy representing Vasculitis UK and assisted by other trustees and volunteers. In April she attended the 21<sup>st</sup> international Vasculitis Workshop in Barcelona with Diana.



Also, the British Society of Rheumatology Conference in Liverpool with Susan Mills and Laura Whitty. In June, the Royal College of Nursing Conference in Newport with Jan Fisher, Richard Foster and Mandie Pontin.

We welcome the volunteers helping with the stand and talking to health professionals. Zoi's reports are later in the newsletter. If you would like to volunteer to help with a stand then email [zoi@vasculitis.org.uk](mailto:zoi@vasculitis.org.uk)

Earlier this year we had a very interesting request for funding from Alice Muir. It was to look at using Guided Imagery as a way to help with fatigue, sleep and pain management. I decided to join the group. It was a truly fascinating experience. We jelled as a group and are still meeting. We now know a lot about each other and were very supportive. Not everything worked for everyone and some of what we experienced; we still can't explain! I think Alice learned as much as we did.

Her article is in this edition and some of the sketches are mine, I'm not saying which. We hope to run other sessions.

We were invited by Imperial College London to join their Science in Medicine Schools Team competition. This is the first time for us and Jane became the trustee lead. The teams are asked to develop an eposter to explain vasculitis. The results and presentation are the week before the AGM, and Prof Dorian Haskard will be one of our speakers. We are all looking forward to seeing the entries.

Our other speaker this year is Dr Jo Robson from Bristol talking about the effects steroids have on our quality of Life. Something many of us can relate to.

I would like to thank all those volunteers who have helped with stands, and those who work behind the scenes to keep things running smoothly.

Take care  
**Dorothy**



**Visualising Vasculitis**

Scan to support



**VASCULITIS UK**

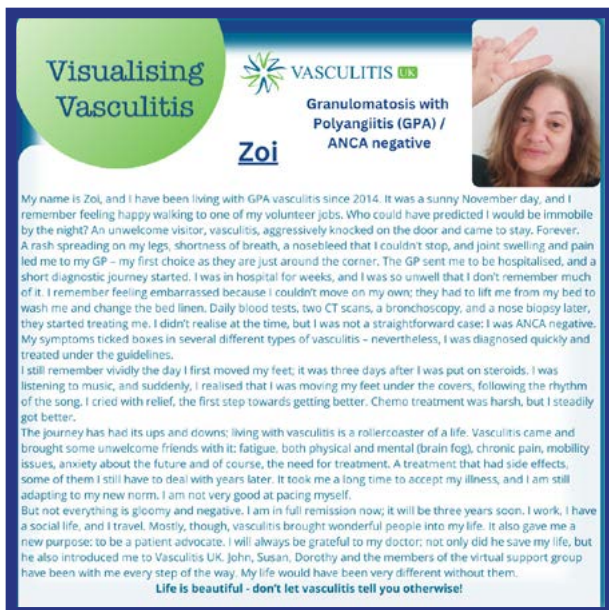
**Susan**

A diagnosis of vasculitis for a family member also has consequences for the family. Carers also face difficulties and problems. These vary depending on the stage at which the patient is at any particular time.

At the diagnosis stage the carer often feels as bewildered and frightened not sure where to go for support for their loved one or themselves.

The treatment for vasculitis can be aggressive and scary, so being strong is so important to help them through the treatment.

Just being there with unconditional love and support gives strength to those with a diagnosis of vasculitis.



**Visualising Vasculitis**

**VASCULITIS UK**

**Zoi**

**Granulomatosis with Polyangiitis (GPA) / ANCA negative**

My name is Zoi, and I have been living with GPA vasculitis since 2014. It was a sunny November day, and I remember feeling happy walking to one of my volunteer jobs. Who could have predicted I would be immobile by the night? An unwelcome visitor, vasculitis, aggressively knocked on the door and came to stay. Forever. A rash spreading on my legs, shortness of breath, a nosebleed that I couldn't stop, and joint swelling and pain led me to my GP - my first choice as they are just around the corner. The GP sent me to be hospitalised, and a short diagnostic journey started. I was in hospital for weeks, and I was so unwell that I don't remember much of it. I remember feeling embarrassed because I couldn't move on my own; they had to lift me from my bed to wash me and change the bed linen. Daily blood tests, two CT scans, a bronchoscopy, and a nose biopsy later, they started treating me. I didn't realise at the time, but I was not a straightforward case: I was ANCA negative. My symptoms ticked boxes in several different types of vasculitis - nevertheless, I was diagnosed quickly and treated under the guidelines.

I still remember vividly the day I first moved my feet; it was three days after I was put on steroids. I was listening to music, and suddenly, I realised that I was moving my feet under the covers, following the rhythm of the song. I cried with relief, the first step towards getting better. Chemo treatment was harsh, but I steadily got better.

The journey has had its ups and downs: living with vasculitis is a rollercoaster of a life. Vasculitis came and brought some unwelcome friends with it: fatigue, both physical and mental (brain fog), chronic pain, mobility issues, anxiety about the future and of course, the need for treatment. A treatment that had side effects, some of them I still have to deal with years later. It took me a long time to accept my illness, and I am still adapting to my new norm. I am not very good at pacing myself.

But not everything is gloomy and negative. I am in full remission now; it will be three years soon. I work, I have a social life, and I travel. Mostly, though, vasculitis brought wonderful people into my life. It also gave me a new purpose: to be a patient advocate. I will always be grateful to my doctor; not only did he save my life, but he also introduced me to Vasculitis UK. John, Susan, Dorothy and the members of the virtual support group have been with me every step of the way. My life would have been very different without them.

**Life is beautiful - don't let vasculitis tell you otherwise!**

Diagnosed with **VASCULITIS?**

Living in the **UK?**

Aged **18 to 39?**

Vasculitis UK Young Adult Group is a new community aimed at supporting young people living with vasculitis

Join the community:  
<https://facebook.com/groups/vasculitisukyoungadult>  
 Email: [Charlie@vasculitis.org.uk](mailto:Charlie@vasculitis.org.uk)

PAGES	CONTENTS
1	Front Cover Susan Mills
2	Chairman's Report
3	Chairman's Report Cont / VUK Awareness Stories
4	From The Editor
5	Trustee News
6	Patient Awareness
7	BSRA Conference / The Great Exhibition
8	Our Fantastic Fundraisers
9	VUK Support Groups
10	RCN Congress
11	VUK Awareness Month
12	Tell Your Story - Jane Edwards
13	Tell Your Story - Jane Edwards
14	Thank You - Susan Mills
15	Thank You - Susan Mills
16	Research Update
17	Research Update
18	Research Update
19	Research Update
20	Guided Imagery By Alice Muir
21	Guided Imagery By Alice Muir
22	21st International Vasculitis Workshop
23	21st International Vasculitis Workshop
24	Workshop Feedback
25	In Memoriam / Donations
26	Local Support Groups
27	Events
<b>BACK COVER</b>	<b>Official Details</b>



**Visualising Vasculitis**

Scan to support



**VASCULITIS UK**

**Granulomatosis with Polyangiitis (GPA)**

**Sophia**

Eight months ago, I'd never heard of Vasculitis or GPA but soon became acquainted with the chaos, pain and life changes it brings. After multiple surgeries on my sinuses then came with excruciating pain, swelling and constant nose bleeds and crusting, a biopsy confirmed GPA.

Complications associated with the disease put me in hospital with a collapsed lung, pneumonia, respiratory and gastric problems. I felt the rug had truly been pulled from under me having been a fit and healthy person previously. Although I'm undergoing treatment, I'm still not in remission and unable to work, socialise or take part in any activities like before.

The disease has brought isolation, financial troubles and time away from my three daughters, but I'm determined to remain optimistic in the outcome once it's managed. For a while my mental health was greatly affected, as being an invisible illness, I found some friends and family didn't believe or understand the seriousness of living with vasculitis. Anything that brings awareness of the condition will be welcomed by myself and others that suffer from it and am grateful to charities like Vasculitis UK.

This editorial feature is done in loving memory of my dear sister, Clare Grossman, who was sadly taken from us at the age of 38 due to Wegener's granulomatosis (GPA) back in 2010. As a family we had no idea about vasculitis, or how we could support her, or get support for ourselves. By the time we did through VUK, it was too late for Clare but we as a family, and especially for myself in getting involved via this Newsletter have found great comfort, and I am truly thankful for being given the opportunity from VUK, via John and Susan Mills to give something back.



## Dear Reader

Well here we are as I write this, with Autumn certainly starting off with the rain hammering down and a gale blowing, Spring and Summer seems an age away!

So welcome to you all, both new and regular readers, this is our 68th edition as a newsletter and journal, which is again packed with articles and reports.

During May many contributed with our awareness campaign, which was Visualising Vasculitis, the images and background stories which were posted each day throughout May are also shown here for those unable to see them originally, I have spread them out in this edition and there will be some in the Spring edition as well.

There is a special centre page spread with a big Thank You to Susan Mills, who will be stepping down as a Trustee, I will leave it there for now as I owe so much to both Susan and John, since my involvement with Vasculitis UK and let you read the rest.

We have our fantastic fund-raisers still helping our charity, with much needed funds and also to help raise awareness, please get involved if you can as we do look forward to this section which enables our fund-raisers to showcase their achievements.

Zoi our Director of Operations also as a report on page 5, Zoi has been very busy, along with other trustees and volunteers. As I write this, Zoi is emailing me from her holiday, so hopefully she is getting some much needed down time now and enjoying the sunshine, as the rain still beats down here in good ol' blighty.

Remember if you have a story to tell, please get in touch, now it's time to grab your favourite tippie and enjoy!



*Kevin Popper*

**Editor**

## Help Advice & Support

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

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

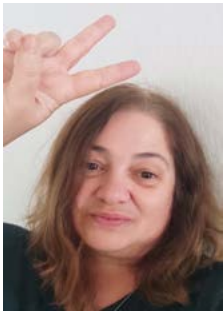
On Facebook you can join all or any of the following Vasculitis UK groups: "Vasculitis Support Group", "Young Vasculitis", "Bereavement", "Pregnancy & Parenting", "Caring for Carers" and the "Healthy Eating" group.

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



# Trustee News

## Director of Operations Report By Zoi



Dear members of Vasculitis UK,

This last year has been challenging for me as I lost my safety blanket, my mentor John. It would be impossible to fill in his shoes and I have accepted that it shouldn't be my aim. My focus is to do

the best I can for Vasculitis UK and the vasculitis community and to respect the legacy he left to us. With Susan Mills stepping down this of vital importance. They both worked so hard to bring Vasculitis UK where it is and we have to continue evolving the charity, but keeping its heart where it has always been; in supporting the vasculitis patient. Sometimes we have to think a bit out of the box and make decisions with our heart having always in mind how our members could benefit.

The last 6 months have been busy, much more than expected. Conferences, meetings, events, surveys, supporting research, updating material and many other things keep me occupied.

My last article for the spring newsletter was written in Barcelona where Diana Shonfield, one of our new trustees, and I attended the Patient Event organised by Vasculitis International and Vasculitis Foundation and the International Vasculitis Workshop. It was a strange experience to have a poster in the exhibition area with my name on it - it was the 'Small Vessel Vasculitis Patient Journey', a collaborative project between patient representatives and clinicians in ERN RITA (a network we participate in Rare Disease Europe). You will find more information about the workshop in the newsletter - keep reading!

Of course, just because I could, I tested positive when I arrived back in the UK and it is clear that COVID and I don't get along.

It took me almost two weeks to recover and just in time to travel from the southwest to northwest for the British Society of Rheumatology (BSR) annual conference. Susan and I had a good time there creating awareness of vasculitis. We met an old friend of mine and his partner one evening, they took us to a very nice restaurant. As we were spoiling ourselves after a tiring day and talking about this and that - I hadn't seen my friend for over 10 years- we discovered he

had been diagnosed with vasculitis. What are the chances of that?

RAIRDA launched the patient survey at the BSR conference, one we shared with our online groups and through our website. The results will be out shortly, an article about it will be on our next newsletter.

May was Vasculitis Awareness Month and Jane Edwards did such wonderful work collecting patient stories to share in our social media and our online groups. The personal stories were so powerful. ERN RITA had a series of webinars about vasculitis, you can watch them here:

<https://ern-rita.org/webinars/>

June found me in Wales, to manage the VUK stand at the Royal College of Nursing (RCN) Annual Congress, a very successful event. I had some wonderful volunteers supporting the stand and it was a pleasure to hear them telling their stories and creating awareness. After the event a few of the branches of RCN have asked us to share more information about vasculitis and educate their nurses in various different events.

We are at the end of September now and I am looking forward to a whole week of holidays, my first this year. I will recharge my batteries as October and November will be very busy.

Following my visit to Brighton to be at the local support group meeting there, I am going to attend the Birmingham local support group meeting on the 6th of October and then go to Swansea to attend the Conference and official launch of the Musculoskeletal Network in Wales. Towards the end of October Vasculitis International has organised a Patient Summit. Patient representatives, vasculitis doctors and specialist nurses from different countries will come together to discuss, what else, vasculitis!

UKIVAS is having their 3rd vasculitis educational course for clinicians in November and it is almost fully booked so more clinicians will be updated on the latest in research and vasculitis care.

Working for Vasculitis UK is certainly keeping me on my toes and I enjoy it very much! Enough from me, enjoy reading our newsletter and 'see' you again in the Spring!




**Visualising Vasculitis**

Scan to support



**VASCULITIS UK**

**Granulomatosis with Polyangiitis (GPA)**




**Wendy**

I was diagnosed with GPA in December, just before Christmas 2023. I woke up one day with painful, sore eyes and light sensitivity. I was sent to the hospital ophthalmology dept, and after six days of tests, I finally got the diagnosis from the rheumatology consultant.

I'd never heard of vasculitis before this. Symptoms leading up to this were neuropathy on top of my left foot for a year, alongside severe leg cramps and pain. I had suffered with sinus issues for a couple of years, but in July 2023, I started to get really sore patches inside my nose. I was given a cream which worked, but it kept reoccurring. I lost weight easily and had little appetite. I felt exhausted every day, but I just put it down to getting older.


On diagnosis, my consultant started me on a high dose of prednisolone, which took away the pain overnight. I've since had two rituximab infusions and yesterday started on methotrexate. I've also started to lower the pred slowly.

My life has changed massively but I have a massive faith and this gives me the strength to remain positive no matter what this illness throws at me.




**Visualising Vasculitis**

Scan to support



**VASCULITIS UK**

**Granulomatosis with Polyangiitis (GPA)**



**Helen**

My story seems to be about numbers:

- Six body parts are affected, starting with the skin and moving on to eyes and ears, nose, lungs and finally kidneys.
- Two hospital stays resulting in seven weeks as an inpatient.
- Five years to get a diagnosis.
- Countless (thirty, just in the last six months) outpatient appointments.
- Remission for two years, now back waiting for remission again - the second time.

I'm doing well, but early diagnosis is key. I didn't have that. If we can raise awareness, future sufferers may not need hospitalisation. I'm doing well; life is virtually normal, apart from the immunosuppression necessitating care to avoid infection.

# Lancashire and the Lakes Vasculitis Patient Awareness Evening - March 2024

For the first time in Lancashire and the Lakes, Vasculitis patients had the benefit of a local evening to talk through the implications of living with Vasculitis. The evening was organised by Renal consultants from Preston Royal Hospital with support from two charities, Kidneys for Life and BK's heroes. The evening was hosted at the newly built Lancaster University Medical Innovation Campus.



The event was well supported with around 45 patients and families who were welcomed by Dr Dhaygude, a Renal consult with expertise in Vasculitis based in Preston. Dr Dhaygude gave an overview of the evening and described the central role Royal Preston played in a network of local hospitals in supporting Vasculitis patients' treatment requirements. This means essential drugs local hospitals were not licenced to use could still prescribed by Preston and administered locally to stabilize difficult conditions.

It was reassuring to learn that staff from Preston were involved in joint research projects. The strength of the research is evidenced with papers jointly published with other institutions.

Dr Morris, a Consultant at Preston, described ANCA Vasculitis and explained the latest developments in the treatment of the disorder. This involved targeting cells within the body to stabilise the condition.



As patients, we all know Vasculitis can attach any part of the body and Dr Gatheral, a respiratory consultant and Dr Maskery, a neurology specialist provided insight into their respective disciplines.

But the evening was not all about the medical aspects of treating Vasculitis. One patient provided an account their experience of being diagnosed, their treatment and how they have learnt to live with it.

Managing Boom and Bust behaviour cycles was the theme of the final presentation of the evening. A clinical psychologist, Dr Rozwaha's description of a cycle of often intense activity followed by lethargy or even exhaustion was recognised by most patients present. They also welcomed his suggestions of how to live with the chronic condition and minimise the peaks and troughs of the cycle.



A mid evening break allowed attendees the opportunity to meet and share their experiences other patients.

Many thanks to the Doctors involved who provided useful insights for the patient community. It is hoped other Patient Awareness events can follow.



Scan to support



**VASCULITIS UK**

Granulomatosis with Polyangiitis (GPA)

**Emma**



**VASCULITIS WARRIOR**

Outwardly, I look well. I've lost lots of steroid weight. My skin looks better. I appear cheery most days. Some days I can walk for miles.

But... there are dark days...

It's hard losing the weight. I have to be careful what I eat and drink to protect my kidneys and liver. I still need high-factor skin protection all year round due to the high cancer risk. Small stresses can cause huge issues due to reduced cortisol production, thanks to steroid use. A long walk one day can be followed by a day not being able to leave the sofa the next day.

And people forget... we don't recover. We often hide issues, and we cope, we put on a brave face, and we have the vasculitis shadow hanging over us forever.



Scan to support



**VASCULITIS UK**

Granulomatosis with Polyangiitis (GPA)

**Maddie**



2016 what a year! I went from fitness queen to sleeping queen.

I was finally diagnosed in December 2016 with GPA after 7 blood transfusions, 3 weeks in hospital and not knowing if I was going to survive.

Here I am 2024 surviving with active disease being helped with Rituximab. Living with this disease on a daily basis is like playing Russian Roulette, you never know if it is a good day or a bad day, but we soldier on. I still try to live my best life as I can making memories. I am grateful for everyday.

# The British Society for Rheumatology Annual Conference 2024

This year I attended along with Zoi Anastasa and Charlotte Smith, the British Society for Rheumatology Annual Conference. This was to be my last medical conference, as I retire from Vasculitis UK, after 15 years as a trustee, in October of this year.

The venue on Liverpool Docks is unique and the area is beautiful, the sun was shining and it promised to be an exciting few days.

Over 1200 medical professionals signed up to attend the conference, some travelling from as far away as Northern Ireland and Scotland.



On the evening before the conference Zoi and I set up the VUK stand along with other support charities, including SRUK and RAIRDA.



The following three days were not going to disappoint, many doctors, specialist nurses and physios came to our stand and were so interested in what our stand had to offer but also interested and appreciated Zoi and Charlotte's own personal stories, actually living and coping with vasculitis.



Zoi was also asked to speak, as part of one of the break out sessions, about Vasculitis UK and the research we support. Her presentation was very well received.

Some types Vasculitis were also included in the full BSR programme. Guest speakers included Dr Louise Oni - Children Get Vasculitis Too

Dr Rosemary Hollick - Voices of Vasculitis

Dr Neeraj Dhaun ( Bean ) - Updates in Imaging in Large Vessel Vasculitis



It was great to catch up with old friends and meet new people too. But one important observation I did bring home with me was that the path for those diagnosed with vasculitis is improving, better outcomes for patients seem closer than ever. Diagnosis and treatments have definitely improved over the past 23 years and with improved national and international collaboration in research. I hope this continues in the future.



**Susan Mills**

## The Great Exhibition Road Festival 2024



The Great Exhibition Road Festival returned to London on the weekend of 15th-16th June 2024 bringing hands-on science, art, music and food together.

Dr Shanali Perera and the team at Imperial College also collaborated to "Make the Invisible Visible" including Vasculitis.

The sun shone and a great weekend was had by all!

# Our Fantastic Fundraisers



Molly Bostock along with family and friends joined together for a house fundraiser for Vasculitis UK. They shared, food, cake and lots of catch ups and have raised over £600 so far.

A massive thanks to my Nephew Ryan, Brother Jim and my Son Ollie, who accompanied me on the great north run for Vasculitis. U.K.

The atmosphere was electric, the local people were amazing and despite the lousy weather, it was worth doing.

I have to admit, I struggled to finish (the others left me well behind) I just kept thinking about my time in hospital and the people who didn't give up on me. It kept me going.

I limped to the finish line and paying for it today but It was worth it. **Steve Bryan**



Brandon Braun successfully completed the Great North Run 2024 in support of Vasculitis UK fundraising £300



Katrina Rodden completed the Great North Run for VUK and has so far raised £368



Matt and Târana Allen are taking part in sponsored #parachute jump on 20th July 2024 in memory of Martin Allen who very sadly lost his life to #Vasculitis. Take a moment to read their story. <https://t.co/he4Q8A48AV>

Vasculitis - In memory of John Mills MBE

I'm doing a couple of half marathons this year in support of Vasculitis UK. My mum was diagnosed with a form of vasculitis (called GPA) around 20 years ago and has been living with it since. It would mean the world to me to raise some money to support her and others going through similar experiences, and I really appreciate anyone who can spare a few pennies for the cause.

The two runs I'm doing in aid of this (and in spite of my own knees) are the Mud Master in Weston Super Mare and the Great Western Run in Exeter.

<https://mud-master.co.uk/>

<https://thegreatwestrun.co.uk/the-event/>

[https://www.justgiving.com/page/andrew-meggs-1707479196475?utm\\_medium=fundraising&utm\\_content=page%2Fandrew-meggs-1707479196475&utm\\_source=copyLink&utm\\_campaign=pfp-share](https://www.justgiving.com/page/andrew-meggs-1707479196475?utm_medium=fundraising&utm_content=page%2Fandrew-meggs-1707479196475&utm_source=copyLink&utm_campaign=pfp-share)



All fundraising photos can be found on the website <http://www.vasculitis.org.uk/about/fundraisers-photo-gallery>





# SUPPORT GROUPS



Vasculitis in general is a rare disease and some types are extremely rare. People with vasculitis often feel very alone and isolated because few people properly understand their problems and they know nobody else with vasculitis. Local groups provide an opportunity for people to meet and share knowledge and experiences.

You will find details of support groups throughout England and Wales on page 22, Some groups are large, holding formal meetings with invited speakers, others are very small, perhaps meeting for coffee in someone's house, or at a cafe or pub. The most important part of any meeting is the sharing of experience.

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

## Sussex By the Sea Support Group

Thank you to those that have responded - I hope to get an email list together to notify you of our regular meeting

We hope to move them around both East and West Sussex

We have planned:

- 19th October Brighton (same venue as last time)
- 16th November Hastings (probably the Fisherman's Club)
- 21st December TBC

These will be informal meetings with all family members and supporters welcome  
Liz Wilson will be your host.



The wonderful NE Vasculitis Support Group welcomed new members at The Mill, Rainton Bridge, Houghton-le-Spring recently.



**Takayasu Arteritis**

**Sarah**

I was a healthy (or so I thought) person loving life working as a nanny when, one day, I collected my nanny child from school on the bike and couldn't catch my breath. I was rushed to hospital with oxygen of 71 and a pulse of 220. Tests later showed I had a rare form of vasculitis: Takayasu arteritis.

It was so scary not being able to breathe, and I have narrowing in my arteries by my heart and by my kidneys as well as one in my neck, which made my heart not beat properly and my lungs fill up with fluid. I have gone from being super active to struggling to walk a few feet, I get out of breath so quickly. I am on a cocktail of medications.

I'm only two weeks into my diagnosis, so I'm still getting my head around it all. I have found all the groups on social media very helpful. My diagnosis means doing the job I love; the job I trained for so long is going to be difficult as I will have a suppressed immune system. But I refuse to let it get me down. I get out of bed every morning ready to take on the day's challenges.

**Granulomatosis with Polyangiitis (GPA)**

**Jane**

2 years ago I ended up in Intensive Care for 3 weeks after a bout of Covid with a kidney function of 7% and lungs 90% full of blood.

Welcome to GPA.

After lots of oxygen, a plasma exchange and buckets of steroids and immunosuppressant drugs, I am now free of meds (just 1 more Rituximab infusion hopefully) and feeling pretty good all things considered.

The road ahead is unclear, but it helps feeling like I am part of a family. Who knows what's in the future for us - hopefully some miracle drug to rid us all of this nasty condition!

# RCN Congress 2024, what a success!

This year the Royal College of Nursing Congress was in Newport Wales. Five days full of educational sessions, networking and nurses visiting the exhibition. The Vasculitis UK's stand was one of the most successful booths and we had a lot of nurses coming to speak with us.

A few had vasculitis knowledge, some had heard of it, but most had no knowledge at all. But, that's ok we cannot expect the average nurse to know about vasculitis - it is a rare disease after all.

I think though, that most of our visitors now have a basic knowledge of what vasculitis is and how severe it can potentially be. Furthermore, they know about Vasculitis UK, what we do and how we can support them to support their patients.

The success of our exhibition stand has translated to invitations to speak to nurses about vasculitis. I have already made a short online presentation to RCN West Midlands and it was nice to see questions coming up at the Q&A that followed. A planned presentation for the RCN Devon branch had to be postponed because of technical issues, but it will be rescheduled. I am off to London to speak at the Autumn Learning 2024 event organised by RCN South West London and Outer Branches and we will do an online presentation for the RCN Birmingham and Solihull branch in January.

Awareness of vasculitis amongst clinicians is very important as it makes a huge difference in patient care.

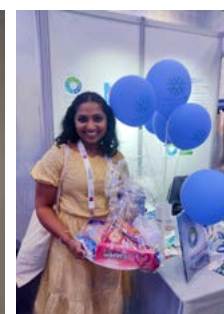
I couldn't have managed the stand on my own and I cannot thank enough the volunteers who came to support the VUK stand. Jan, Richard and Mandie we really appreciate your time and effort and I must thank you for the companionship and the laughs. Everyone of you has your own style and approach and that makes a difference when you are approaching professionals to educate them about a rare disease. Being yourself and sharing a bit of your story is getting them interested.

Jan said: "I found the RCN Congress very interesting as it gave me an insight into the vital work you do, with such positivity and attention to detail. The vasculitis stand was by far the most attractive and you certainly attracted lots of people to come and chat to us. Yes, chocolates and

a free raffle helped (!) but they meant that we could spread the information to so many people. A number of delegates clearly knew you from previous years and spoke to you with such warmth and respect."

If you are reading this and considering that you would like to volunteer for Vasculitis UK, please send me a line at [zoi@vasculitis.org.uk](mailto:zoi@vasculitis.org.uk), then we will have you in mind and ask if you are available when an opportunity arises. It is not only conferences and events, but also supporting the VUK fundraising team or the VUK media team.

**Zoi Anastasa**



## Meeting Nurses at the RCN Annual Congress 2024

What a great experience to attend this conference as a first-time volunteer for Vasculitis UK. To give some context, the Royal College of Nursing (RCN) Congress is their key event and main opportunity for nurses to network with their peers, hear key speakers and debate the critical issues affecting nursing. The event this year was held from 2 - 6 June in Newport, Wales at the International Conference Centre, where they were expecting more than 2,000 delegates. The programme included well being and learning opportunities and a range of exhibitions. Vasculitis UK made the most of the opportunity to exhibit and over 4 days, reached a wide audience of nurses from across the UK.

I was quite nervous before the event. I had replied to an email looking for volunteers and it seemed a good opportunity to help now that I was feeling able to. The charity, especially the helpline, has been a lifeline for me and my family, especially when I was first diagnosed with EGPA in 2017.

When I arrived at the event it was huge! There were hundreds of people milling around, I think that was how I managed to walk into the exhibition hall first and right past reception. The first person I then saw was Gareth Thomas, a former Wales rugby captain, LGBTQ+ and HIV advocate and now RCN speaker and perhaps most importantly for our family, unique

Cardiff pantomime star, seeing him made me smile and helped calm some nerves.

The Vasculitis UK exhibition was co-ordinated and led by Zoi Anastasa, Director of Operations. She not only has experience as someone with GPA vasculitis, she has an extensive knowledge of vasculitis, including the specialist treatment centres across the UK. Zoi was friendly and welcoming as I arrived to help on the final day, steering me back to reception for my identification badge so that I was less likely to be picked up by security. Zoi had been at the event all week, with support from local volunteers Richard Foster and Jan Fisher who each helped for a day. Even though she must have been tired, Zoi was enthusiastic, with groups gathering around her chatting and asking questions.

I think a lot of my nervousness before the event was thinking about how I could possibly talk to medical professionals about vasculitis? I followed Zoi's lead and with her support, I realised that what I could do was talk about my own experiences. I shared how the charity supported me, about its aims, both to support and educate individuals and their families and to raise awareness amongst professionals and the wider public. It had been a while since I had visited the Vasculitis UK website and looking again before the event was invaluable, it had been updated with


even more useful and insightful information. I made a mental note to visit more often as its regularly updated!

We spoke to so many people, of those, only two nurses had direct experience of treating patients with vasculitis, albeit that they were aware of, as this disease and symptoms make it such a 'shapeshifter'. The majority of delegates either had no idea or misunderstood what vasculitis is and that there are different types of vasculitis and varied symptoms. Most delegates who passed by took literature and many came back with questions, about vasculitis, about the charity, specialist treatment centres and our own experiences, when they realised that we both had vasculitis. A few delegates made arrangements with Zoi for future presentations to local and specialist groups that will be great opportunities to make connections and share information. As the day went on, conversations became easier and when it came time to pack away, I realised that even though I was tired, time had passed so quickly. I learned so much volunteering at the event, by spending time with Zoi and listening to her sharing information. I would recommend volunteering to anyone who might have the opportunity and perhaps feels nervous or hesitant - and just to give some early notice, next year's event is in Liverpool!


**Amanda Pontin**

**Visualising Vasculitis**

Scan to support



VASCULITIS UK  
Granulomatosis with Polyangiitis (GPA)  
ANCA




**Gemma**

In April 2023 two very scary things happened to me, my nose collapsed and a wound appeared on my leg. The nose began to close up and my leg wound grew from the size of a golf ball, until it covered the front of my leg. The pain was unbearable and I was admitted to hospital. I was told I would die without surgery but due to extreme fear of needles I declined. I didn't die and was discharged into community care to get myself in a position to have blood tests.

After months of hypnotherapy I finally had a blood test and was found to have PR3 indicators. This changed everything. I now have an explanation for my face and leg but there isn't enough understanding about what this meant for me longer term. Due to delays with other specialists such as ENT I've had to start treatment without their data. I'm now on chemo and steroids and feel that I have more questions than ever than my GP alone can't help with. More awareness of this systematic critical illness is so necessary and I'm grateful for the charity!


**Visualising Vasculitis**

Scan to support



Granulomatosis with Polyangiitis (GPA)

VASCULITIS UK



**Caryn**

I was diagnosed with GPA Vasculitis in May 2020. This time, four years ago, I had been ill for almost three weeks with no improvement, dismissed as having had COVID by my GP and was told to ride it out. It would take a further two weeks & further decline in my health. I could barely get out of bed, chronic muscle pain, coughing up blood, ear ache, and sinus pain. I was in respiratory failure and fighting for my life before I was diagnosed with GPA VASCULITIS.

I didn't realise at the time how life-changing vasculitis would be. The side effects of the drugs completely changed my appearance, my weight, and me mentally. It became a HUGE battle!! I could moan about vasculitis and how it's left me with nerve damage in both feet, the ongoing ear issues, the tingling and numbness in fingers which come and go, the scarring in my nose, the damage it caused my lungs, being immune suppressed and more likely to pick up infections etc etc.

You know what? I am lucky!! I am lucky and grateful that even after all that vasculitis has given me and done to me. I am here, I am alive, I am fighting, and I am strong!! I have now managed to be steroid-free for almost 17 months and have lost majority of the weight I gained. My consultant has been amazing and got me on the right treatment plan quickly.

I have a positive mindset and ready for whatever comes my way!!

## VASCULITIS AWARENESS MONTH 2024

Throughout the month of May many contributed to the VUK awareness month campaign, **Visualising Vasculitis**, by sharing their stories, these will be spread across this edition and will continue the spring edition.

Others contributed by sharing these stories via social media which is a great way to help raise awareness, many other individuals contributed by creating their own.

VASCULITIS UK

May is Vasculitis Awareness Month.

We have a month of fundraising planned.

We need you to be involved with helping people to visualise what it is like to live with vasculitis.

Watch out on Social Media and [www.vasculitis.org.uk](http://www.vasculitis.org.uk) for all the information.

Search Facebook for "Vasculitis Support (UK)"

Or "Vasculitis UK" on [HealthUnlocked.com](http://HealthUnlocked.com)

**Visualising Vasculitis**

Getting involved in this campaign during May each year is growing in momentum and I am sure 2025 will generate more interest and hopefully more of our readers will join in. Look out for more information on next year's campaign both via social media, the VUK website and also in our spring edition of this newsletter.

Thank you to all those who contributed their stories and to those that shared them.

**Visualising Vasculitis**

Scan to support



VASCULITIS UK  
Microscopic Polyangiitis (MPA)



**Dorothy**

I'm now entering my 7th decade. So, it's time to reflect.


Sixteen years ago, I had a routine blood test. The GP called, "I've got a bed for you on renal. Go now!" My kidney function was 18. I had the biopsy and started chemo.

Like everyone, I'd never heard of Vasculitis. I had to adapt to the number of tablets I needed to take. It really made me stop and think, how could I help spread the word? I'm now in full remission but have to take tablets for the damage done by Vasculitis and prednisone.


I joined VUK 14 years ago to help with fundraising and became a trustee. In 2018, I became the chairman of the new Vasculitis charity. The charity is moving forward into a new era with a group of very capable new trustees.

**Visualising Vasculitis**

Scan to support



VASCULITIS UK  
Behcet's Syndrome



**Helen**

I have fought vasculitis in the form of Behcet's Syndrome for nearly 2 decades. My symptoms started after the birth of my second child. I was young, healthy and very active until suddenly I developed strange lumps on my shins that were painful and caused me to have a fever. Then my eyes became blurry, joint pain, oral ulcers and fatigue began soon after.

It took 2 years to get a diagnosis and I was hospitalised for 14 days for multiple rounds of intravenous steroids which caused Cushing syndrome but thankfully saved my sight. Guys and St Thomas's in London looked after my care but local doctors and even some rheumatologists were unsure how to treat my vasculitis as my type is rare and, in some cases, have never met a Behcet's patient in their career.

I got used to feeling alone and grieved for the person I was before vasculitis, until I found a group on social media who helped me feel like I was part of something bigger, our combined knowledge was powerful and helped me in so many ways. Vasculitis challenges me every day, mentally and physically but I am a stronger person for it.



Tell your story

Send your story to [kevin@vasculitis.org.uk](mailto:kevin@vasculitis.org.uk)

## Fighting for Her Future

*Diagnosed with ANCA-associated vasculitis, Jane Edwards has learned that the right attitude is everything in managing this chronic disease.*

**Updated Jul 9, 2024**

**By: Claire Gillespie  
Medical Reviewer Harley Cohen, M.D.**

When Jane Edwards was exhausted and having frequent nose bleeds, vision changes, and tingling toes and fingers, she and her doctor put it down to the pressures of an intense part-time job and two young children. But in fact, this was where her vasculitis journey started, 12 years ago.



"My wisdom teeth became infected, and after removing all four of them and taking lots of antibiotics but still not being able to get rid of the infection, my dentist suggested that something was seriously wrong," she says. This prompted Edwards, now 50, to push for blood tests from her doctor, which showed inflammation in her body. However, it still took a while to get a diagnosis.

Months later, she was at the point where she couldn't walk up a few steps without having to stop. "My legs felt like I'd run a marathon and I was covered in sweat from pure exhaustion," she recalls. Edwards was finally admitted to the hospital, where she endured two weeks of tests, including blood cultures, blood tests, echocardiograms, CT scans, and electrocardiograms.

Multiple medications and more tests later, Edwards received a diagnosis: granulomatosis with polyangiitis (GPA), a type of ANCA-associated vasculitis formerly known as Wegener's granulomatosis. The effects are wide-ranging. "GPA, which affects my small blood vessels, has left lasting damage to my kidneys, eyes, nose, and ears," she says. Complicating matters, Edwards was also diagnosed with large vessel vasculitis, chronic periaortitis, hypothyroidism, and adrenal insufficiency (due to receiving many steroid doses over years of illness).

### Knowing Is Half the Battle

Getting diagnosed with GPA was a big turning point, says Edwards: "I felt so relieved that I could identify a cause for how I felt and glad that I had something I could finally fight." But her journey has been far from straightforward, despite what her health care team initially hoped. "My doctor told me that I would have three to six months of high-dose steroids and immunosuppressive drugs, and after that I would reach remission and could lower my dosage," she says. "I promised myself I would fight hard and beat it in three months."

But so far, remission has remained elusive on these treatments. "I still haven't reached a meaningful and lasting remission," Edwards admits. "And I've never managed to reduce my steroids below 7 milligrams a day, which is too high to maintain long-term."

There's no way to sugarcoat the daily reality of Edwards' disease. "I take between 15-20 tablets a day, plus a couple of vitamins, and have terrible side effects from the steroids: puffy face, weight gain, mood swings, and bone damage," she reveals. "I worry my reliance on steroids now may be permanent as the adrenal glands have stopped producing cortisol, so I must carry injectable steroids around with me as an alternative if I can't get my tablets down, or I vomit."

## Struggling With Fatigue

Edwards worries about the bone deterioration caused by steroids, so she does "load bearing" exercise daily—typically a dog walk with her Labrador George and spaniel Burt. "We go slow and on the flat, but moving helps me," she says. "I try to do some yoga, but I'm still weak after catching COVID-19, which turned into pneumonia, 16 months ago. It hit me hard, and it's taken over a year for my lungs to show real improvement."

A constant fight with exhaustion means Edwards finds it hard to start anything—and if she does, she fades quickly and needs rest. "Rest and sleep don't stop the fatigue—this is not just feeling tired," she explains. "The blood flow around my body is restricted, which means I struggle to walk up any incline—even a gentle slope stops me in my tracks. I am currently on long-term sickness from work as I don't have the energy to get through the day."

Simply being with people can also be draining. "The noise, the focused conversations, and staying upright all leave me shouting out for a dark room with a big bed," Edwards says. "My friends now laugh when my eyes start dropping, and within five minutes, I need to excuse myself. So nights out and social events are minimal."

## A Mission to Help Others

Where some might be tempted to give in, Edwards has doubled down on her efforts to work with her ANCA-associated vasculitis, not against it. "I found it helpful to document the ups and downs of my story," she says. "At first, this was just to help me get my head straight, but I thought it would be good to share what my family has learned with others." What started as journaling about her personal experience eventually became a book, *Chronic Illness: Learning to Live Behind My Smile* (available on Amazon). Edwards says feedback from readers has helped keep her health challenges in perspective. "I'm so proud that I could turn something rubbish into a positive outcome," she says.



Edwards credits the nonprofit patient organization Vasculitis UK ([vasculitis.org.uk](http://vasculitis.org.uk)) for helping her move forward. "It's an incredible charity," she says. "Vasculitis is rare and it's often not possible to have a face-to-face meeting with other patients, so an active social media group really helps." Her advice to other ANCA-associated vasculitis patients is simple: "Try and stay positive."

Easier said than done, but Edwards believes in trying to live with the disease in a way that works for you, rather than questioning it and fighting against it—that approach will only leave you even more exhausted and frustrated, she says. Her other advice? If you don't trust your doctor, keep looking until you find the right one. A strong doctor-patient relationship is key with a disease like this one.

Above all, be your loudest advocate. "Learn about your condition, be an informed patient, and be an active partner when it comes to managing your health," Edwards says. "And please be kind to yourself; you don't have to be superhuman every day. We are all allowed to crumble sometimes."

This article was originally published June 24, 2024 and most recently updated July 9, 2024.  
© 2024 HealthCentral LLC. All rights reserved.

# Thank

*After 15 years of supporting her late husband John Mills MBE, and them both taking Vasculitis UK charity to where it is now, Susan Mills will be stepping down as a Trustee.*

Susan's dedication and commitment during this period can only be an inspiration to others, although many of Susan's contributions have been at the forefront of Vasculitis UK along side John, there has been so much more done behind the scenes which have had major effects positively for both those she has helped or for Vasculitis UK as a whole.

Throughout all this time Susan has been the backbone of our charity and has helped many patients, carers and often been the link to medical professionals, which has enabled her to advise them directly or via the helpline.

Much of Susans hard work has been more visual, from helping set up and arranging support groups events, fundraising events or more often setting up a stand at a medical event to help raise awareness to the medical professionals.

Susan has been raising awareness locally, to all areas of the UK and internationally via the autoimmune communities for the last fifteen years and is hugely respected by all that have crossed paths with her.

Professor David Jayne said "Vasculitis UK has had a unique and important place in the development of vasculitis as a disease area of direct benefit to patients and their carers. For many years now, Susan Mills has made a central contribution to the running and building of Vasculitis UK both as an individual herself, and as an enormous support to her late husband John. Many will have been touched and helped by her emails and phone calls. Susan, this is a big thank you from my side of the consulting desk, you have been wonderful."

Our Chair, Dorothy said " My Friend Susan, I first met Susan 15 years ago at the Novotel in Long Eaton. It was the first AGM of Vasculitis UK that I attended. I spoke to Susan who was manning the information stand, we started chatting and she found out we were both interested in forming a local support group. I had recently been diagnosed and it was before online group had started.

I was then introduced to the speaker, John. Who'd been talking about the "lightbulb". Older members will remember it was the logo of Stuart Strange. Susan and I seemed to get on straight away and with Lisa Raynell we started the East Midlands Group. We organised

events together for the group and slowly I was brought into the charity. Susan found out I'd been involved in fundraising for my local park, including successfully applying for lottery money. I then became a trustee with a remit for fundraising.

We started meeting for coffee in Belper about equal distance between us. Plus trying out different venues for future use by the local group, they had to be tested!

The Belper meetings became lunch and following this we ended up shopping together. The main purpose was to hand over stock to Susan. It was Susan, who organised the fundraising packs which we tried to tailor to each event. She also posted out all the T shirts and leaflets that people requested. We chatted online too.

Then Covid arrived and John's health started to deteriorate the "meetings" were more spread out. I'd been carer to my husband so I knew how much time and effort it was taking for Susan. But she seems to have endless energy. I said to her a few times could she bottle some of it up to share. I still don't know how she didn't catch covid from me last year, when we were travelling to a vasculitis event together.

As she leaves the charity its in a much better place than when we met. She has done so much work that never got mentioned, to keep things running smoothly. She also has an encyclopedic knowledge of the vasculitis doctors and the individual diseases.

I wish her every success in the future. I, personally and the charity will miss her.

Shanali Perera said " Susan, has been, is and will always be a pillar of strength to me going through the Vasculitis journey. I first met her at the BSR in 2016 and since then have personally witnessed her compassion and commitment to the Vasculitis community. A massive thank you goes out to her for all the support she has given me and the Vasculitis community."

Zoi Anastasa Said "I was walking in the park early this morning when I saw a leaf dancing in the air before joining other autumn-coloured leaves on the ground. A beautiful moment full of tranquillity! It transported me almost ten years ago; I was walking, enjoying the day and life, but before the end of the day, vasculitis was there to change everything. As we all know, the first part of our journey with vasculitis,



# You Susan



while we wait for every piece to fall in place so we can get a diagnosis, is challenging, but the part after diagnosis is not easier. As many other newly diagnosed patients, I made the mistake to google the outcome of my condition. Not one of my best moves! I got terrified, angry, sad, and had a thousand emotions altogether. My lovely consultant suggested getting in touch with John Mills, and that's how the Mills family became a part of my life.

Susan and John were there for me when I tried to accept my new life. Susan became a friend; she opened her home to me, and I have spent some wonderful times there. I even took my friends to visit.

When a person takes you under their wings and shares their love, passion and knowledge, they affect your life in multiple ways, and Susan has been and is that kind of person in my life. Her knowledge about vasculitis, specialists, and research has been a drive for me. Susan has the most amazing memory and remembers journeys of so many vasculitis patients she has helped over the years, and when it comes to advice for vasculitis, she is my go-to person. We share a passion for supporting patients, a love for dogs, travel, and watching good TV shows!



As we both are strong personalities, we have had a few tense moments, but what would life be without some sparkles in our relationships with other people? I respect Susan and will certainly miss working with her in Vasculitis UK. If John was VUK's public face, Susan has made the charity work as a well-oiled machine. Although I have learned

a lot working with Susan for so many years, I will miss the safety of having her advice.

But, I am lucky as I consider Susan more than a colleague; she is a friend and will still be part of my life. We have

things to look forward to; we can meet in our travels and go for mouthwatering meals and chat and share news of our families. This is the beginning of a new chapter in our friendship, but I will never forget that Susan and John changed my life path.

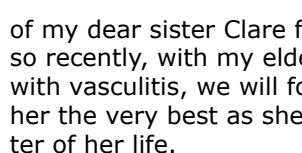
I know that a lot of other members of our vasculitis community share these feelings of gratitude and admiration towards Susan. She has advised and supported so many



people over the years!  
Susan, thank you! Thank you for all the support through the years, thank you for all the advice and knowledge I got from you, but mostly, thank you for being part of my life and letting me be part of yours!"

I am sure that Susan has been there for many of our readers over the years, and these personal thanks are very much relatable to you all.

For me as editor, Susan has not only been a great help over the years with my involvement in putting this newsletter together which goes back to the Autumn of 2015 to where it is today, some 18 editions later. But even more so on a personal note, with Susan, who I will always consider a true friend, and will never forget the support and advice she has given us as a family since our first introduction after the passing



of my dear sister Clare from Vasculitis in 2010, and more so recently, with my eldest Granddaughter being diagnosed with vasculitis, we will forever be thankful to her and wish her the very best as she moves forward into the next chapter of her life.

# RESEARCH UPDATE

Vasculitis UK aims to spend at least 50% of annual income on supporting research. We are a small charity depending entirely on donations. As such we must ensure that any research we fund will provide tangible outcomes for our community of vasculitis patients and their families.

## Chetan Mukhtyar wins top award



**Chetan Mukhtyar, Consultant Rheumatologist, has won a prestigious award from the British Society for Rheumatology (BSR) for research into vasculitis.**

He leads the service for patients with giant cell arteritis (GCA), a form of vasculitis, which is inflammation of the blood vessel, for which we're a specialist centre. The disease is typically found in women over 50, although men can also be affected, and requires urgent treatment with steroids and if untreated the disease can have serious consequences

such as loss of vision or stroke.

Of 486 papers submitted to the BSR, Chetan received the "Paul Bacon Vasculitis award" for the best vasculitis abstract at the national conference last week, on behalf of his co-authors Shruti Alanoor and Georgina Ducker. The conference is one of three annual international rheumatology conferences.

His paper, "Giant cell arteritis relapses occur in a different arterial territory as compared to diagnosis" shows the changing nature of the disease when patients relapse.

We've used ultrasonography rather than biopsies since 2017 as this technique is faster, less invasive and significantly reduces the cost of diagnosis. Chetan's team found that most patients tend to relapse in a different arterial system. The disease usually presents in the branches of the external carotid artery, but the relapses were seen to be more likely in the subclavian arterial system.

"We've become a pioneering centre for treating GCA, and using ultrasonography to diagnose the condition," he said. "We wanted to see if relapses occurred in the same artery that was originally inflamed, or another. This question is important because if it's in a different artery, the symptoms will be different. We now know it can manifest in a different way and we should scan other arterial territories. It's a completely new finding that we would like to share with the rest of the world."

Georgina Ducker, Vasculitis Specialist Nurse, added: "Dr Mukhtyar works tremendously hard supporting the junior doctors, nurses and admin staff in the department. It is great to see his work recognised by his peers. This really puts our clinic and Dr Mukhtyar on the map and could change treatment pathways for patients across the world."

Earlier this month, he was invited to speak at the world's biggest vasculitis conference, attended by the most prominent international researchers in the field, about our experience of running the ultrasonography service.

Bernard Brett, Interim Medical Director, said: "I am delighted to see Dr Chetan Mukhtyar receive such important recognition for his work. As a Trust, we want to encourage more staff to engage with active research to improve the care we deliver for our patients. Congratulations Chetan and your whole team."





**Mary for Vasculitis UK, July 2024**  
**by Dr Stephen McAdoo, Imperial and Dr Jo Robson,**  
**UWE Bristol Co chairs of UKIVAS.**

In July this year, the UKIVAS registry and community held a successful research meeting at Imperial College London, Hammersmith. Researchers and clinicians working within vasculitis from across the UK met together to share updates and opportunities to collaborate. Here are some updates from some of the key projects discussed. **UKIVAS Sum**

**The RACEMATE Trial: Tezepelumab in EGPA was presented by Dr Harry Wilson-Morkeh From Imperial College London**



**The RACEMATE Trial: Tezepelumab in EGPA was presented by Dr Harry Wilson-Morkeh From Imperial College London**

The **RACEMATE trial stands for: A RA**ndomised Placebo **C**ontrolled Trial – to **E**xplore the Efficacy and **M**echanism of **A**ction of **T**ezepelumab in **E**osinophilic Granulomatosis with Polyangiitis. It is open to people with a diagnosis of Eosinophilic Granulomatosis with Polyangiitis (EGPA) who are taking regular maintenance oral steroids (at least 5mg od prednisolone daily).

Tezepelumab is a biologic medication that is given as a monthly injection under the skin. It targets a protein called TSLP found in patients with EGPA. This protein is also found in patients with asthma and tezepelumab is already used in patients with severe asthma to reduce asthma exacerbations, improve symptoms and quality of life. Currently, this trial is now open at Imperial College Healthcare NHS Trust, the co-ordinating centre, with more centres across the UKIVAS and UK Severe Asthma Registry (UKSAR) networks due to start recruitment in the coming weeks. So far, 5 patients have already had their 1<sup>st</sup> trial visit and there are plans to enrol a total of 66 patients over the course of this rare disease trial. Please speak to your local vasculitis/asthma specialist or email [racemate@imperial.ac.uk](mailto:racemate@imperial.ac.uk) to find out more.

**STERoid Reducing options for ReLapsING PMR – The STERLING-PMR Trial, presented by Dr Max Yates, Norfolk and Norwich University Hospital NHS Trust.**



Polymyalgia Rheumatica (PMR) is a condition affecting approximately 278,000 people in the UK, causing pain, stiffness, and limited mobility. The standard treatment involves the steroid prednisolone, gradually reduced over 12-18 months, but half of the patients experience relapses and can develop side effects from prolonged treatment.

The STERLING-PMR trial is investigating whether adding disease-modifying antirheumatic drugs (DMARDs) to the usual steroid treatment can reduce the need for higher steroid doses in patients with relapsing PMR. DMARDs, such as methotrexate (MTX) and leflunomide (LEF), have shown promise in reducing inflammation and helping patients taper off steroids. In this large-scale study, 200 patients from across 20 secondary care sites will be randomly assigned

to receive either DMARDs alongside their usual steroid treatment or just the steroid treatment alone. The trial will measure various outcomes including symptom severity, time to achieve steroid-free remission, and overall quality of life. Researchers hope to identify if the addition of DMARDs can make a significant difference in managing PMR. If successful, the STERLING-PMR trial could revolutionise the way PMR is treated, offering patients a more effective and safer way to manage their condition.

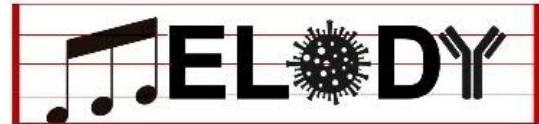
**PRISMA: Precision Medicine Using a Risk Stratification in the Management of ANCA Glomerulonephritis presented by Dr Silke Brix, University of Manchester**

Patients with ANCA vasculitis often suffer infections and are now three-times more likely to die of infections than from vasculitis itself. The infection risk seems to increase with age, frailty (a term used to describe ageing patients not being able to bounce back and recover from illness) and comorbidities (having other health problems).

We created a working group to explore frailty and infection risk in ANCA vasculitis. Our aim is to develop a risk stratification for infection risk in addition to the existing tool for disease severity, the ANCA Kidney Risk Score, AKRIS. The project is called Precision Medicine using a Risk Stratification in the Management of ANCA vasculitis, **PRISMA**.

We will find out how vasculitis patients and healthcare professionals use kidney failure and frailty screening in daily practice. We will study data on what influences the risk of infection in vasculitis and use the information to build a tool to measure it. We will create a guide on how best to use prediction tools so the right patient receives the right care at the right time adjusting treatment in ANCA vasculitis to the individual patient.

**Rare autoimmune rheumatic disease in the MELODY study presented by Dr Fiona Pearce, University of Nottingham**



Dr Fiona Pearce presented the MELODY study, which recruited more than 35,000 immunocompromised people in 2022 to determine their immune response to the Covid-19 vaccination and assess future risk of infection, hospitalisation and survival. The main results will be available soon. The talk focussed particularly on the 2,407 people with vasculitis who chose to take part, and what we can learn from their survey responses about current treatment of vasculitis in the UK.

continued on page 18



**Clothing**

Check out our online shop

<https://vasculitisuk.myshopify.com/collections/clothing>



The main paper from the VOICES study was published in The Lancet Rheumatology in June 2024. It is the first study to identify the key parts of health care services that improve experiences of care and health outcomes for people living with vasculitis. UKIVAS were a key collaborator in this project. Findings from the study are already influencing several national initiatives:

- 1. British Society of Rheumatology (BSR) recommendations for the management of ANCA vasculitis update**
- 2. NHS England Rheumatology specialist commissioning service specifications**
- 3. National Services Scotland commissioned Systemic Vasculitis Managed Clinical Network (SSVN) Strategic plan 2024-2027**
- 4. Scotland Rare Disease Implementation Board priorities for 2024/25 - building upon the VOICES study to improve care for people with non-genetic rare diseases.**
- 5. Recent presentation at the Department of Health and Social Care – England Rare Disease Framework Delivery Group – with focus on non-genetic rare diseases.**

We have also created [online resources for people with vasculitis](#). As of January 2024, this has been used over 10,000 times since launch (September 2022). Sections include:

- \* Living with the financial impact of systemic vasculitis
- \* Living with the practical impacts of systemic vasculitis
- \* Treating systemic vasculitis
- \* Side effects of steroids and other systemic vasculitis medication
- \* The damage that systemic vasculitis does to the body

The vasculitis community have also highlighted the importance of being able to use the VOICES study data to support the case for local and regional service development. We are currently in discussions with Versus Arthritis about in-kind support from their website team and have secured a small amount of resource from the University of Aberdeen to fund additional research fellow time to develop this.

### **BSR AAV management recommendations**

Several UKIVAS members sit on the BSR AAV guideline committee. For the first time this will include evidence-based service specifications and audit recommendations.

As an output of discussions within the guideline committee, we put forward a proposal to the UKIVAS steering group to collaborate in conducting a short national audit of vasculitis services using the BSR service audit recommendations. This would provide an up-to-date assessment of current access to key service components, pre-introduction of BSR AAV service recommendations, which would be repeated post-introduction (and on rolling basis going forward) to assess the impact of the recommendations and inform targeted support for implementation.

### **Steroid PRO paediatric version presented by Dr Jo Robson, UWE Bristol.**



Researchers from UWE Bristol have developed a patient reported outcome measure questionnaire to measure the impact of steroids on health-related quality of life in patients with inflammatory conditions, particularly vasculitis and giant cell arteritis.

<https://innovation.ox.ac.uk/outcome-measures/steroid-pro-glucocorticoids/>

We are now collaborating with paediatricians and researchers from Alder Hey, at the University of Liverpool, to develop and validate a new version for use with children and young adults. This new project will explore if similar outcomes are relevant across the lifespan, or if adaptations are needed so that patient and carers' topics of key importance are included and measured.

### **The ObiVas Trial: Obinutuzumab in ANCA vasculitis presented by Dominic McGovern, University of Cambridge**



Obivas is an ongoing randomised trial in PR3 ANCA-associated vasculitis (i.e., GPA). Rituximab – the current gold standard therapy for ANCA-associated vasculitis – works by removing B cells that act as “factories” to produce ANCA antibody “missiles”, which are sent out to promote inflammation in small blood vessels across the body. Rituximab is effective, but as some patients will know – its effects wear off and we need to give it every 4-6 months. Obinutuzumab is a newer version of rituximab. It has the same target as rituximab (a protein called CD20 on the surface of the factory B cells) but has been

shown to be more effective than rituximab in other diseases where removing B cells is helpful (e.g. blood cancers). For this reason, we think obinutuzumab could be more effective than rituximab in treating ANCA-associated vasculitis – potentially offering patients longer, deeper periods of remission and reducing the need for repeat infusions.

ObiVas is aiming to recruit 26 patients and has currently recruited 19. Our primary assessment is the difference between rituximab and obinutuzumab to remove factory B cells from the tissue, so all patients have a biopsy of their nasal tissue before they receive treatment and after 6 months, so we can see the differences over time between the two drug groups. We are recruiting both newly presenting and relapsing patients and hoping to finish recruitment by the end of 2024. Patients must have active disease (i.e. a flare) and have not had rituximab for at least 1 year. Patients outside of the East of England must be willing to travel for regular follow up in Cambridge for 18 months (travel expenses can be covered). If interested, we suggest local vasculitis team can liaise with Dr Rachel Jones and the Cambridge vasculitis team. We hope to have results to share with the vasculitis community before the end of 2026.

Ultrasonography-led multimodal diagnostics for GCA presented by Dr Chetan Mukhtyar Norfolk and Norwich University Hospital NHS Trust

There have been huge advances in the way that Giant Cell Arteritis (henceforth termed GCA) can be diagnosed. Temporal artery biopsies are key in the diagnosis of GCA. Imaging technologies like ultrasonography, magnetic resonance imaging (MRI) and positron emission tomography (PET scan) have now also entered common use. Current European recommendations offer ultrasonography as a valid bedside diagnostic tool. We presented our experience of the first 1000 referrals to the Norfolk and Norwich University Hospitals NHS Foundation Trust GCA diagnostic service.

In Norwich, the patient journeys of all patients with suspected GCA flow through the rheumatology or ophthalmology departments. If the reviewing doctor feels that GCA is a possible diagnosis, they commence treatment for it and request ultrasonography. If the ultrasonography was negative, a second test was added if the suspicion remained high. We tested the sensitivity (the probability of a positive test result when the condition is present) and the negative predictive value (the ratio of those who truly do not have GCA to the number of negative tests) of our pathway. Typically, the higher these values are, the more reliable the test (or combinations of tests).

The sensitivity of ultrasound scanning the superficial temporal artery alone is 62%. This rises to 79% when we add ultrasound scanning of the axillary artery. Scanning more arteries in the head and neck based on the symptoms of the patient (for example, scanning the maxillary artery if the patient complains of difficulty in chewing their food) improves the sensitivity to 86%. Performing either a temporal artery biopsy or a PET scan when the ultrasound scan is negative improves the sensitivity to 96%. This means that our pathway picked up 310 patients out of 324 with a final diagnosis of GCA. Likewise, the negative predictive value of adding a second test (biopsy or PET scan) to ultrasonography provides a negative predictive value of 98%. This means that of the 690 patients that journeyed through this pathway with negative test results, 676 actually did not have GCA. Of the 14 patients missed by our pathway, 7 dropped out after a negative ultrasound scan and did not want a second test and were treated as if they had the condition. The other 7 all contacted the vasculitis advice line when their symptoms returned and were diagnosed quickly either with a biopsy or a repeat ultrasound scan without

suffering any deleterious effects.

Our combination of tests and the manner in which we stratify them provide a high degree of confidence in our ability to diagnose or rule out GCA, thus setting out a potential low-cost pathway that could be emulated in the NHS.

### Micro sampling for rare disease biobanking presented by Dr Louse Oni, University of Liverpool

Dr. Louise Oni presented work on the role of dried blood spot samples that is a project initially funded by a Med-Tech grant from Kidney Research UK. The work is looking at whether tiny finger prick blood samples that have been left to dry can be posted for discovery science. The presentation showed the laboratory data to optimise this for proteomics and plans to apply for MRC grant funding to take this work further for which any collaborators are welcomed.

### What to do about toxicity from steroids in clinical practice: VAS-UP: An implementation science project presented by Dr Vasilis Vasiliou, University of Oxford and Royal Holloway, London on behalf of the VAS-UP team.



Patients on steroids often experience significant glucocorticoid (GC) toxicity. However, current methods to track and assess this toxicity are inadequate. The VAS-UP study addresses this gap by exploring how both patients and clinicians measure and respond to steroid toxicity in clinical practice.

#### Preliminary Findings:

##### 1. Patients' Perspectives:

- **Challenges:** Patients often struggle with self-assessment due to a lack of knowledge and understanding of toxicity symptoms. Weight gain and mood changes are commonly noted side effects, yet many patients are not adequately informed and cannot easily track changes.
- **Barriers:** Memory issues, lack of time, and psychological resistance to focusing on toxicity symptoms.
- **Facilitators:** Digital tools (like apps), routine reminders, and supportive healthcare providers can aid effective self-assessment of steroid toxicity

##### 2. Clinicians' Perspectives:

- **Challenges:** Time constraints and a primary focus on disease control rather than toxicity management during appointments.
- **Barriers:** Lack of structured methods and adequate training to assess and explain toxicity symptoms.
- **Facilitators:** Pre-visit assessments by patients, simple and efficient assessment tools, and better training for clinicians.

#### Moving Forward:

The VAS-UP team is committed to refining these insights into practical, evidence-based interventions that can be easily integrated into clinical practice. We will use modern frameworks from behavioural and clinical science to identify what would support you and your clinicians in the assessment and management of steroid toxicity and improve quality of life.

#### Join the Study:

We are in the final part of VAS-UP phase 1 study and are looking for clinicians participants! If you are interested in contributing to this vital research, please register at VAS-UP Registration. Thank you for your ongoing support and participation in these groundbreaking initiatives. Warm regards, The VAS-UP Team.

# A programme of Guided Imagery for managing Vasculitis.

## A new Vasculitis UK initiative By Alice Muir



*"This is how I pictured my Vasculitis. I don't know why this came to mind; it is a pig in a kayak. It is just the most ridiculous thing I can think of. During the week I kept seeing it and once I stopped laughing, I was thinking it is quite a good thing to watch it disappearing off into the distance, so it's not as prominent (given that it represents my ailments). I imagined it moving*

*away into the distance making it less important."*

At the beginning of this year Vasculitis UK and the RECORDER Team from Nottingham University joined forces to work together on a project to develop an online programme to help people understand and use guided imagery to cope with and manage Vasculitis.

We used the work by Martin Rossman published in Guided imagery for self-healing (reference below) to make and run a 10-week programme via YouTube and Microsoft Teams for eleven people from around the UK with Vasculitis who kindly volunteered their help to test it and give us feedback of their experience.

We started with an introductory meeting to explain guided imagery and the evidence to support it and ended with a "tie up loose ends", feedback and closure session.

The programme included eight different guided imagery exercises. These were written to allow people to form and work with their own imagery and chosen to show the range of ways in which guided imagery might help. They included exercises to explore one's own imagery ability, develop basic relaxation skills, better understand thoughts and feelings about illness and treatment, find and trust one's own answers to difficulties and make and create positive thoughts and changes. Participants could access the recordings on YouTube whenever they wished and were encouraged to use a reflective diary and/or artwork to keep a record of their experience. We met online for an hour each week to discuss this.

At the end of the programme all eleven who took part felt guided imagery would help others living with illness. Overall, they gave the programme a rating of 8.5 out of 10 and made many positive comments. For example, one person said: "I can refer to my relaxation skills learnt from the sessions and use them instantly to great benefit; I did not have these skills before. It makes me feel a bit more empowered to handle this illness." Another highlighted the advantages of running the programme online saying, "being immunocompromised it felt safe staying at home, it was affordable (no bus, petrol or parking!) and when feeling below par I could still take part with my camera switched off whilst resting on the sofa in pyjamas." A third mentioned how helpful it was to meet other people with Vasculitis "The group came together well. Sharing our experiences was enlightening and fun. We were so diverse, and at different stages of treatment, so we helped each other."

By exploring the exercises with participants and getting their feedback we have gained invaluable experience to run, and made a number of changes to improve the programme. For example, recording a further 5 guided imagery exercises to help with pain, anxiety, aid relaxation and sleep and to think positively about treatment.

If you are interested in using guided imagery to help cope with and manage Vasculitis, then we are pleased to say we

now have a product for you to try. For further information about guided imagery, how it might help you and peoples experience of the programme, please read on!

### What is guided imagery?

Guided imagery is a complementary mind/body therapy that can be explained by scientific (psychoneuroimmunology) and psychological (cognitive/behavioural) theories. It involves using your imagination to form pictures, sounds, smells, tastes, and sensations in the mind. There is evidence to show that it can be a useful self-help tool which can be safely used alongside standard medical care to cope with and manage illness. It has been reported to be helpful in promoting wellbeing, managing anxiety, depression, pain, fatigue, speeding up recovery from illness and changing behaviour to improve health. If you would like to try a guided imagery exercise to see what it involves then at the end of this article there are some instructions and link to a short exercise to help with sleep.

### People's experience of using the programme

These are just a few examples of people's experience of using the exercises and the artwork they shared with other members of the group.



#### Imagery Exercise: Exploring your imagery ability

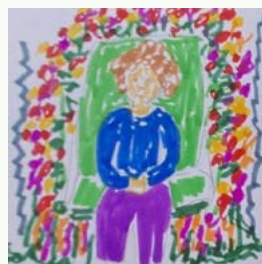
*"I truly felt relaxed and nearly went to sleep. The beach scenario took me straight back to when I went to Tobago, and this is my picture showing my feet feeling really hot on the sand and that is the water. The guided imagery*

*took me straight back there and I could feel the sensations, it was strange because I didn't think I would feel any sensations."*



#### Imagery exercise: The body scan to relax

*"As you were going up and down the body, as you came up I could feel light going in and out, and I think it is green the good coming in, and red the bad going out. As your voice took us up through the body this is what was happening, it was sparkling around me."*



#### Imagery exercise: Going down a staircase to a beautiful place

*"I ended up on a seat surrounded by all the plants, and the smells, the beauty of the birds singing, the whole lot. I was just sitting there loving it. Yes, I certainly didn't want to come back up the steps. I felt quite cosy down in my little flowery den. It was quite comfy."*

*I could have spent another hour there."*

### Imagery exercise: Your healing imagery

"I was thinking of a path leading up and being hopeful as part of the imagery guidance. I painted this from a photo I took a year ago and it was what I was imagining in the sessions, skies and the dark, and light of them. This shows the power of light can peek through, showing hope and warmth. I relate to that about my vasculitis."



"When you mentioned the inner advisor I got an image of my late father. He comes in my dreams and he kind of advises me and shows me what to do to get through a situation, and there was this beautiful white light behind him."

Three months after the programme "I so wish this had been around when I was diagnosed, it would have helped so much. The doctors were amazing but there was no other support. To have just had some support, something to fall back on. I am still using the guided imagery; I still walk my grassy path and with a little research beforehand I have now almost completed the Pembrokeshire coastal path. What a wonderful experience."



**Imagery Exercise: Your healing imagery** "When I was diagnosed they kept saying it is rare and I felt quite isolated, quite detached from everybody, quite detached from society. The picture on the left, they are all sort of lonely, alone, isolated images that struck me, and then the other image on the right, in my medication induced insomnia, I had this feverish need to find out as much as I could about everything, and this second picture shows me and my little dog all through the night just sitting reading and researching and wanting to find answers."



**In Conclusion**  
Overall, the project has been a positive, enjoyable, and fruitful experience for everyone involved. Whilst not a

panacea, we have found that Guided imagery is a skill that can be learnt and a helpful tool to navigate the many challenges of illness. The author would like to say thank you to Vasculitis UK for their support and funding and also to all the participants who generously gave their time and shared their experience and insights to help us learn more about guided imagery and develop a programme that we all hope might be helpful to others living with Vasculitis. We aim to make the Links to the exercises (with instructions on how to use them) available for individual use on the Vasculitis UK website and we hope to secure further funding to run the programme again and also start an ongoing guided imagery "club."

### Imagery exercise making positive changes

"And the picture of me is how I was probably about 10 years ago. I had come off the steroids and lost a lot of weight and felt that I was actually getting a life back. I think COVID has a lot to answer for! Being immunosuppressed, I was stuck and not able to go out, so the boredom, the eating, not getting exercise, I used to walk miles, now I can barely get down the street."



An example of a guided imagery exercise to try if you wish.

"Sleep well tonight – cottage by the sea,"  
(Taken from the book "The healing waterfall" by Max Highstein reference below)

### Three months after the programme

"The sessions encouraged me to join a health programme through the GP/Council and I also have Bowens therapy .....which is helping too. I have lost half a stone in weight and am walking more easily."

Before you start the recording, make yourself comfortable. As you listen, close your eyes, and allow yourself to relax, focus on and immerse yourself in the story. In your imagination, use all your senses e.g. feel the sand beneath your feet, hear the waves, smell the flowers, see the colours of the sea and sky. Do not worry if you find your mind wondering, this is normal! Just notice it and gently bring your mind back to focusing on the exercise again. When you are ready just click the following link and enjoy!:

<https://youtu.be/W2bPZ1-scfU>



**Imagery exercise: Your wellness imagery**  
"This took me to the beach with my dogs, and what wellness means to me – space, freedom, having fun, being in the moment. When I tried to visualise myself as an image of wellness, I saw a beautiful Afghan hound running free in the wind and playfully chasing seagulls (not to catch them) but just for fun and to see them fly and make glistening shapes and pretty patterns against the sand and the sky."

### References

Rossman M 2000 Guided Imagery for Self-Healing: An Essential Resource for Anyone Seeking Wellness. Pub. New World Library.

Highstein M 2016 The Healing Waterfall: One Hundred Guided Imagery Scripts for Counsellors, Healers and Clergy. Pub. Desert Heat Multimedia.

### Imagery exercise: Your inner Advisor

**We have no pictures for this exercise but these are two examples of people's experiences**

"I had a strong visual image and a sense of presence. I asked the best way to solve my issues, the response I got were wise answers.....good advice. The image was male with long wavy hair like a pandit - Indian holy person."



# 21st International Vasculitis Workshop

21<sup>ST</sup> INTERNATIONAL  
**VASCULITIS** BARCELONA  
WORKSHOP 7 - 10 APRIL 2024

What a privilege to be able to participate in the biggest vasculitis event worldwide! I didn't manage to attend the 2022 one in Dublin as I had covid and because covid and this event seems to be associated in my body, I tested positive the day I came back from Barcelona. I was very happy that my travel companion on the way back, Dr Jo Robson was lucky not to catch it from me!

A big event, with clinicians, researchers and patient representatives from 50 countries, I think we were just over 800 people there. As the change of name suggests (from International Vasculitis and ANCA Workshop) it is not focused on ANCA associated vasculitis. It is now the top specialised in vasculitis academic meeting where researchers from around the world share data and research projects, and clinicians can discuss clinical care.

I was there wearing three hats: A patient representative from Vasculitis UK, a board member of Vasculitis International and an ePAG from ERN RITA.

The venue was buzzing and I saw a lot of familiar faces from the UK, some clinicians I met in European events and of course representatives from vasculitis patient organisations from across the world. Some of them are now considered not only colleagues, but also friends, some I had never met before like the Japanese group of patient representatives. It was very disappointing that networking between medicals and patient organisations was difficult as patients were not allowed in the poster area, or the break area

for academic and clinical researchers and medicals. The reason behind this was the law in Spain about patients and industry being in the same space is very strict and when they organised the space they didn't think

about it, so we were allowed in sessions, but then had to be in the hallway outside the exhibition and poster area. I must say that I was devastated that I couldn't visit the poster area as Vasculitis UK had granted awards to all junior clinicians and nurses with successful poster applica-

tions. It would have been nice to be able to go and congratulate them, especially those we have never met before. Furthermore, me and Julie Power had to 'sneak in' to put up the poster Julie was presenting, the patient journey we created in ERN RITA.

It was a full on event and it was very difficult to choose which breakout sessions to go to. Furthermore, it was draining as we had to focus so we could follow the presentations that were for clinicians. I admit that some of the more complex scientific presentations were beyond my ability. I wish it was a hybrid event and we could watch the sessions again and be able to see them all.

The first day started on Sunday afternoon with the FOKKO VAN DER WOUDE lecture where the evolving landscape of vasculitis management was presented and we heard about past, current and emerging therapies. A positive message was shared:

"We have gone from an era of high mortality rates to remission rates of 70% to over 90%  
Relapse rates from 0% to 50%"

In the evening at the welcome reception we had the opportunity for networking and a chat with some of the top vasculitis specialists from all over the world.

The next two days were very hectic. Sessions started at 8:00 in the morning and finished around 7:00 in the evening. Two 20 minute coffee breaks and one hour lunch break are really not enough when you are a patient - but we have to remember that this event is aimed at clinicians. An intensive vasculitis course! The last day was less busy, we just finished a couple of hours earlier! Vasculitis International had organised an interview at the end of every day where clinicians and patient representatives attending the workshop discussed the highlights of the day. Links will be available on Vasculitis UK website and will be shared in the online groups.

A lot of research trials and studies were shared over the days - it is absolutely amazing how much research is done in vasculitis these days! CAR/CAAR-T cell research is emerging and a lot of biomarkers are investigated to help the diagnosis and monitoring of the disease.

All types of vasculitis were discussed, from the most common (GCA) to rare types like DADA2.

Some of the key messages were:

- Treatment strategies that maximise efficacy
- Safeguard cardiovascular health in vasculitis patients
- Reduce kidney and lung scarring
- Advance sinusitis care
- Be aware of increased risk infection in patients receiving steroid treatment
- Glucocorticoid sparing is important
- Fatigue, underlying causes should be investigated and there's a need to find effective strategies to ease the effect on quality of life

The list is endless, really. I loved the debates and the case presentations (in some I made the correct diagnosis from the first slide! I was chuffed.), I found the monogenic vasculitis very interesting. I had almost no knowledge of DADA2, a monogenic vasculitis affecting children. They have a genetic vasculitis that is hereditary, ADA 2 deficiency. The VEXAS syndrome information was another surprise. When we first heard of VEXAS it was thought that it was extremely rare and definitely fatal Five (5) years later we know it is a monogenic vasculitis disease in adulthood, it is much more common than they thought and treatable! It affects 1/14,000 people and 1/4,000 males.

Some information from the pediatric session:

0.45-6.4 cases/million children/year are diagnosed with ANCA associated vasculitis (AAV)

39.7% of pediatric onset Behçet's patients still have active disease symptoms in adulthood and kidney transplantation in childhood onset AAV showed good rates of graft survival and low risk of relapse. More research needs to include children as there is not much data available to support enhancing the care.

The highlight for me was the trainee session where these young doctors had 3 minutes to present their research projects. I can say that the future looks brighter for vasculitis patients thanks to so many young talented people showing a special interest in vasculitis!



I'm Diana – a newish trustee of VUK & was privileged to be invited to represent Vasculitis UK, along with Zoi, at the 21st International Vasculitis Workshop in Barcelona early April 2024.

**This was promoted as 'Come and hear from world renowned Clinicians and Researchers about the latest developments in Vasculitis'**

It was a conference attended by over 800 people clinicians, researchers & patient representative bodies, from 50 countries. It had an expanded remit from previous workshops the conference would now cover all types of Vasculitis, whereas previously the emphasis was on ANCA Associated Vasculitis (AAV).

I will try to give an overview of the experience, and hopefully some key points I filtered out of the huge amount of complex information that I heard & saw during the week.

As a person living with GPA, in clinical remission but with low immunity, the challenge of travel & insurance & potential infection was a consideration; but I decided to take the risk to attend. Naturally I was bestowed with a cold & sinus infection during my stay (and for a few weeks after!), but I was in the right place to get advice! (Though not the antibiotics I needed – a whole other story)

The conference for us had 2 key elements – the Patient Day & the 4 day Workshop (ie the medical professionals conference).

**The Patient Day** for me, that was almost useful opportunity for my role with VUK; meeting with the patient attendees who are my peers in disease & with the representatives of Vasculitis Patient Advocacy Groups (PAGs) worldwide.

The sessions were mainly presented in Spanish, with simultaneous translations to English – I felt as if I was at the United

Nations with my little headset! I chatted with & learnt from these attendees: - the patients & the PAGs: - Ireland – Julie Power, Spain – Juliana Bordignon, supported by medics Maria Cid & Georgina Espigol-Frigolé, US – Vasculitis Foundation – Joyce A. Kullman & Beth Westbrook, Canada – Jon Stewart, Australia – Rob Edwards, Netherlands – Peter Verhoeven, and Japanese & Colombian peers.

Most of these PAG reps remained throughout the whole conference, which gave us further opportunities to collaborate. On a personal level and on behalf of VUK. I was able to:

- gain understanding of other patients' journeys – both those diagnosed recently & those living with a vasculitic condition long term
- hear the difficulties encountered in obtaining clear diagnosis & timely treatment
- ask PAGs about best practices learned to support you, the patient & stories of the emotional & informational needs for each individual with the challenges they encounter
- identify the type of advice / peer solutions & signposting that are possible, without overstepping the VUK remit to support the person, but not give medical advice.

The main event – the Workshop, over the next 4 days, was a hugely successful gathering of experts from around the globe – many of them eminent in their fields of disciplines - Rheumatology, Renal, Immunology, ENT, Neuro, Dermatology, Cardio etc & included many interested junior medics, whom we hope will leave with a greater understanding range of vasculitic disorders & hopeful-

ly will become be our future specialists. Other disciplines covered were laboratory & clinical researchers, diagnostics and pharm companies.

The conference was held in a spectacular events building, overlooking the ocean, sessions were run like clockwork from morning till early evening – mainly presented in English. Zoi & I dashed from room to room covering topics that we found of interest & those that might be of interest to you. Worth a note however, that a patient body, we were unable to attend any session or display in the pharma arena and therefore we unable to see posters on some niche research.

As the clinical information will come, I understand, from the official slides & some of the sessions were beyond my capacity, I'm only going to give an idea of some sessions below.

- There were a plethora of sessions, but these topics were mentioned regularly:
- Future licencing of Avacopan beyond 12mth
- Tapering & stopping steroids – recommendations v reality in prescribing
- Potential new research streams & the potential treatments (and the difficulties find target markers for these rare diseases – although EGPA is seemingly treated by target biologic)
- BVAS & the trials to utilise 2022 version
- Patient Registers & patients' participation in research

But in summary – our presence gave the medical attendees opportunity to speak to us about the patients we support and we in turn, hope we gave insights to the challenges & queries our members have in managing their lives, living with these conditions.

**Diana Shonfield**

**Georgina Ducker  
Specialist Vasculitis Nurse**



Julie and Zoi setting up the poster they created for ERN RITA

Attending a conference specifically for Vasculitis with other like-minded professionals is always an exciting opportunity. I was delighted to re-

ceive support from Vasculitis UK to attend the 21st International Vasculitis Workshop in Barcelona, 7-10 April 2024. Having our posters displayed for others to see was a huge honour.

The 4-day event provided many opportunities for meeting old and new acquaintances sharing their expertise in vasculitis. The range of oral presentations highlighted a variety of data from clinical trials to patient reported outcomes giving food for thought on

what could possibly be introduced into current practice such as the data on optimising pneumococcal vaccination in vasculitis patients receiving rituximab. It was interesting to learn about vasculitis teams' experiences of therapies such as avacopan being used in real life outside of clinical trials including efficacy and side effects. The presentations also provided information on possible future developments as well as reporting the outcomes of negative trial results, demonstrating that not all clinical trials have a positive outcome. Patient perspectives always make for powerful reading and listening. The negative impact of medications, in particular steroids, which may cause weight gain, changes in mood and sleep disturbances reinforces the importance of patient support and education. Having access to specialist clinicians and patient groups such as Vasculitis UK is vital for patients living with vasculitis.

Our team works incredibly hard to run our vasculitis service including our GCA

fast-track pathway. Attending conferences such as this is hugely important for developing our knowledge base but also learning from other centres to look at ways we can continue to develop our service to make it better for our patients.



Vasculitis International Representatives



Patient representatives from Canada, Ireland and UK



Continued on P24



## Some feedback from trainees who attended the workshop

### Dr Isabelle Nicholls

I wanted to share my learning points from Dr Catherine Sim's lectures:

Dr Catherine Sims presented her work from Duke University in the United States which looked at reproductive outcomes of women with vasculitis and the experience of pregnancy in this cohort. The insights from patients were very interesting and a key take home message from her presentation was that family planning should be approached early by clinicians for women of child bearing age as the necessary switches to medication can take time to facilitate. Also women may need additional support and a good multi-disciplinary team (MDT) approach to their care during this period. I think these insights can also be translated to other patients living with vasculitis, not just those considering pregnancy - a good MDT approach and clear communication between specialties is often beneficial.

### Dr Arslan Ather

It was a wonderful experience to attend this highly informative workshop in vasculitis. It has broadened my perspective regarding vasculitis, providing me useful knowledge which is going to improve/change my practice while looking after vasculitis patients.

Some talks introduced me to whole new concepts include; IgG4 disease course and its management  
GCA -PMR spectrum disorder (GPSD)  
eGPA disease course and management.

### Dr Lauren Floyd

Feedback from the 2024 ANCA workshop  
Key talk

- Some vasculitis patients may be aware or have even been involved in the PEXIVAS trial. It was one of the largest international trials in vasculitis looking at the effects of steroid dosing as well as the role of plasma exchange in improving outcomes. Whilst the findings have resulted in a clear change in the dose of steroids we use, opting for a lower dose than previously felt was needed, the use of plasma exchange is still debated. Dr Balazs Odler from Austria presented data from further PEXIVAS analysis which looked at the impact of plasma exchange on early renal improvements. It showed that tailored and personalised management is always needed, as some treatments such as plasma exchange may be more or less beneficial than others in specific cases.

Key learning points

- Dr Benoit Brilland presented 2 great talks on outcomes

following kidney transplantation in anti-GBM disease and ANCA vasculitis. The work from the French vasculitis registry showed that the relapse risk is very low in both conditions but currently there is no consensus on the ideal time to kidney transplant. This was highlighted in the Q&A as something that needs further research to better understand and optimise for patients with end stage kidney disease.

- Professor Specks presented interesting work looking at intestinal lung disease (ILD) and vasculitis and the different ways to categorise, investigate and treat patients with ILD. There is more and more research going on looking at how to improve outcomes and better treat patients with ILD.

Exciting prospects for the future

- Dr Kim O'Sullivan from the centre for inflammatory disease Monash Health in Australia delivered a great talk on the effect of the gut biome on vasculitis in mouse models. Her team found that high resistant starches were beneficial in MPO vasculitis. Dietary resistant starches increased growth of some bacteria which were associated with reduced neutrophil recruitment and inflammation. More research is needed but the effect of the gut biome is a really interesting area of future research.

**Visualising Vasculitis** **VASCULITIS UK** **Granulomatosis with Polyangiitis (GPA)**

**Ali**

My route to diagnosis was scenic, to say the least. It took two years of sinusitis, chest infections, nose bleeds, frozen shoulder, ankle pain, via diagnoses of whooping cough, adult-onset asthma and menopause - I kid you not.

For someone who played sports regularly, I found the fatigue and infections really hard. I stopped going to my GP as I didn't feel any better when I did, and I felt a bit of a nuisance going so often. Finally, in August 2019, I was admitted to hospital with suspected pneumonia. I was discharged two days later but called back the next day and diagnosed with GPA.

I spent ten days in hospital, undergoing biopsies, scans, and endless blood tests, all to try to determine the level of damage and confirm the diagnosis. It was in my sinuses, chest, small bowels, kidneys and skin. At first, I was so pleased I finally knew what was wrong with me. However, I was really unwell at this point and was heading for organ failure. My consultant told me that without treatment, I would probably have died within six months. That still rocks me. With kidney function at 23%, I began high-dose steroids, followed by cyclophosphamide six days later. After 16 weeks, I moved to maintenance therapy. I started on azathioprine, but my liver didn't like that, so I switched to methotrexate, moving from tablets to injections quite quickly. For someone who used to panic at the thought of needles, I've had to face that tear over and over again.

I fully expected to pick up my life afterwards but soon realised it's not that simple. Managing recurrent infections and flares, trying to hold down a demanding full-time job that I worked hard for and love, crushing fatigue, and serious weight gain have taken their toll physically and emotionally. I've lost some of the steroid weight but still have lots to go. I'm probably going to be on them for life now, at various doses, depending on how stable I am. I'm also going through the menopause, which adds another dimension. I'm still working full-time, but I have to pace myself. I regularly finish work and go straight to bed. I don't drink anymore, as my blood tests always seem to suffer from even a small amount. When people see me, they tell me how well I look, and if you met me, no doubt you wouldn't have a clue how hard I sometimes find it doing everyday things.

Having family and friends who understand vasculitis really helps navigate the ups and downs. It's a journey I never asked to go on, but I'm still here. That's something to be very grateful for.

**Visualising Vasculitis** **VASCULITIS UK** **MPA - with MPO and pr3 antibodies**

**Emma**

My story is unusual in that I first presented with a hard bit under my skin, which originally, the surgeons thought was an infection. Quickly after this, "Bertha" grew and continued up one side of my spine, and at the same time, I got more and more fevers, hip pain, a relentless cough and terrible sickness.

I was in the hospital overall for three months and deteriorated quickly in this time until dermatologists and renal specialists diagnosed me.

That was four years ago.

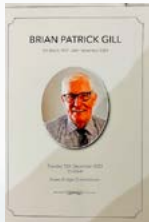
Now, I am in clinical remission and able to walk small distances. I have to plan my energy spend but I'm thankful I am still here.



# Bequests - In Memoriam Donations & Fundraising



£360 received at a Thanksgiving Service in memory of George Jefferson of Cambridge



Donations of £220 in memory of Brian Gill who was an Electrical Engineer and was also a landscape Artist. Brian beloved husband, to Marie, dearly loved Dad to Geoff & Tony, and a very good

friend to many.

Donations of £300 in memory of Jackie Flanagan, Rotherham who sadly lost her battle with Vasculitis earlier this year.

Christine and John raised £3000 (including gift aid) from requesting donations in lieu of gifts at their Golden Wedding celebrations.



In memory of Alan McLeod - by Stuart McLeod  
"Through taking part in Tough Mudder in the grounds of Drumlanrig Castle and a combination of sponsorship and donations from our employers, Howden, we were able to raise an additional £2166 was raised for each - Vasculitis UK and Maggie's Cancer Care."

£125 was donated by Elaine H along with golfing partners and friends in memory of her son Mike who sadly passed away in September after suffering GPA Vasculitis for many years.

£25 was donated by Mick Groom in memory of Pat Harris who passed recently of complications due to vasculitis. I shall always remember you. All my love Bruno.

£30 was donated by Mr David G Robinson in memory of his dear friend Chris Lawrence, Colden, Hebden Bridge.

£260 was donated by Catherine Listeri in memory of her Mum who lived with vasculitis for 16 years until she died in February aged 90. Catherine said "She was absolutely amazing & only stopped driving last year. We asked for donations to be sent to you & also had a collection at her funeral". Thank you for all that you do.

Susan Graham recently collected £120 in memory of her late father John C Storrier.

£360 received at a Thanksgiving Service in memory of George Jefferson of Cambridge

Donation of £1000 made by Barry Coulson in memory of his wife Mary.

Garage Sale / Tea & Scones raised £50 - held by Margaret Playfoot

Funeral donations were made totalling £265 in memory of Mr John Banks from Southport.

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)

## 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 back page.



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)

### East Midlands Group

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

### Lincolnshire Group

Sandra Lee - 0754 514 4777 - [sandylee777@hotmail.co.uk](mailto:sandylee777@hotmail.co.uk)  
Caroline Meyrick - 01780 460354 - [cmmyerick@gmail.com](mailto:cmmyerick@gmail.com)

### London

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

### Merseyside, Cheshire and North Wales Group

TBA

### North East Group

North East Support Group  
Co-leaders Dan Hughes and Claire Phillips  
[vasculitusne@gmail.com](mailto:vasculitusne@gmail.com)

### Northampton Group

Mel Alexander - 07884257123 - [northants-vsg@outlook.com](mailto:northants-vsg@outlook.com)

### Norfolk Vasculitis Support Group

Mark Sayer - [msayer1502@gmail.com](mailto:msayer1502@gmail.com)

### The North West Group

TBA

### Oxfordshire Group

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

### Plymouth Group

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

### 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 - [mgentle128@gmail.com](mailto:mgentle128@gmail.com)

### West Country Group

Website <https://vasculitiswest.wordpress.com/>  
Charlotte Stoner - 01626 872420 - [westcountryvasculitisgroup@outlook.com](mailto:westcountryvasculitisgroup@outlook.com)

### West Sussex Group

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

### North and West Yorkshire Groups :

TBA

### East Yorkshire Group :

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

### North East Yorkshire Support Contact :

TBA

### 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 - [jamzywalker@gmail.com](mailto:jamzywalker@gmail.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/>  
Julie Power - 028 44 842889 - [vasculitisireland10@gmail.com](mailto:vasculitisireland10@gmail.com)

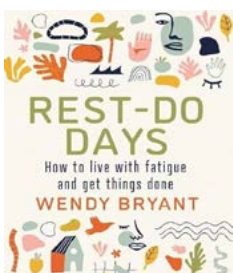


<http://www.vasculitis.org.uk/about/about/find-a-local-group>

# EVENTS



## PRESS RELEASE



### REST DO DAYS

HOW TO LIVE WITH FATIGUE AND GET THINGS DONE

Dr Wendy Bryant

\*Print ISBN: 978-1781612316  
\*Dimensions of print: 221 x 176 mm  
\*Price print: 19.99  
\*Pub date: 17th October 2024

\*PR Contact: [grace@readmaxwell.co.uk](mailto:grace@readmaxwell.co.uk)

*Life doesn't stop when you have a chronic illness. After the shock of being diagnosed with vasculitis, Dr Wendy Bryant searched for satisfying ways of living with fatigue. In this practical guide, she shares what she has discovered...*

Facing debilitating fatigue and numerous other symptoms, Wendy had to rethink her approach to rest while reacting to demands from work and home. Her everyday life became more satisfying as she explored how to balance resting and doing. She is continuing to receive life-saving treatment and find creative ways to thrive.

Rest-do days are not a quick fix, but draw on Wendy's personal and professional experience of concepts from occupational therapy. Dr Bryant pushes back against the idea that rest is only sleeping or doing nothing. Life doesn't stop when you have a chronic illness. *Rest Do Days* offers creative, flexible and sustainable ways of resting while adjusting the demands of daily activities.

*Rest Do Days* is a practical guide with many ideas and tips to inspire and encourage readers who want to take a positive approach to their life with fatigue. By rethinking their most important and satisfying activities, readers can explore how to develop their own rest-do days. In the book, examples, suggestions and worksheets help them along the way.

The book is essential for anyone living with a degenerative disease that involves fatigue, such as multiple sclerosis, rheumatoid arthritis, stroke, lupus and Parkinson's. It will also help readers who know someone living with fatigue to understand and become more aware of how to support them in everyday life.



Dr Wendy Bryant is a retired occupational therapist, who lives in Essex. She is a Fellow of the Royal College of Occupational Therapists and Honorary Professor at the University of Essex. She is the co-editor of two standard textbooks on occupational therapy and mental health and continues to write academic papers. Since becoming seriously ill with vasculitis, she has learned how to crochet. She has more time to spend in her garden but also has frequent contact with health professionals to keep the vasculitis under control. Living with fatigue, she developed rest-do days to make her life more satisfying.

## Visualising Vasculitis

VASCULITIS UK  
Microscopic Polyangiitis (MPA)

Gemma

Scan to support



Hello, I'm Gemma, and I am 32. Married with two children.

For the past few years, I have struggled with fatigue and frequent chest infections. I was back and forth to my GP for blood tests. Always seemed to be that my iron levels were low, etc.

Then, in September 2023, I coughed up blood and was hospitalised for eight days. I was discharged and told my ANCA levels were raised, but possibly a false positive caused by suspected Pneumonia. Then, my kidney function dropped to 54, and I had a kidney biopsy in February. On 25th March, it was confirmed I've got MPA Vasculitis.

Nobody I know has vasculitis, so it has been a very lonely time as you feel like it's just you! But reading other people's stories on Facebook has been therapeutic, and you feel like you belong.

I have good days and bad days. It's been quite scary for me and my husband, as it's the unknown. Luckily, the staff at St. James in Leeds have been a godsend and have always put my mind at ease.

## 22<sup>nd</sup> International Vasculitis Workshop Convenors Melbourne, Australia: 21<sup>st</sup> - 25<sup>th</sup> February 2026



Richard Kitching  
Nephrologist and  
Paediatric Nephrologist  
NHMRC Fellow, Monash  
University, Melbourne



Catherine Hill  
Rheumatologist, Adelaide  
Past President, ARA  
Co-Chair OMERACT GC Impact and  
PMR Groups



Vicki Quincey  
Head Rheumatology, Waikato NZ  
Clinical Informatics Lead NZ  
President NZ Rheumatology Association



Christmas cards!

For sale soon at the VUK shop

[vasculitisuk.myshopify.com](http://vasculitisuk.myshopify.com)



Join us for VUK's AGM  
on Sunday 27th October  
at 1:00 pm GMT  
on ZOOM

### Speakers



Dr Jo Robson: Impact of steroids and having a rare rheumatic disease on quality of life



Prof Dorian Haskard: The Imperial College Science in Medicine Schools Team Competition and this year's Vasculitis UK prize

email [agm@vasculitis.org.uk](mailto:agm@vasculitis.org.uk) to register



## 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. 1180473**

## Officers, Trustees and Volunteers

### Chair:

Dorothy Ireland  
Dorothy@vasculitis.org.uk

### Vice Chair:

Susan Mills  
susan@vasculitis.org.uk

### Director of Operations

Zoi Anastasa  
zoi@vasculitis.org.uk

### Secretary:

Vacant

### Treasurer:

Heidi Pollard - Director of Finance

### Fundraising Co-Ordinators:

Dorothy Ireland  
dorothy@vasculitis.org.uk

Charlotte Smith  
charlotte@vasculitis.org.uk

### Independent Advisor:

Duncan Cochrane-Dyat

### Medical Advisors & Scientific Advisory Board

Prof David Scott  
Prof David Jayne  
Prof Richard Watts  
Prof Charles Pusey

### Research Awards Co-Ordinator:

Laura Whitty

### Trustees:

Dorothy Ireland  
Susan Mills  
Jane Edwards  
Charlotte Smith  
Charlie Harper  
Jennifer Harper  
Peter Rutherford  
Heidi Pollard  
Diana Shonfield  
Claire Tolliday

### Volunteers:

Kevin Soper  
Shanali Perera  
Vivienne Dunstan  
Janice Mather  
Kath Macintosh  
Jayne Hardman  
Antony Hart  
Giles Hart

### The VUK Shop Manager:

shop@vasculitis.org.uk

### Web Admin:

Susan Mills

## CONTACT US

### Helpline:

0300 365 0075

### Website:

[www.vasculitis.org.uk](http://www.vasculitis.org.uk)

### Address:

Vasculitis UK  
Victoria Court  
17-21 Ashford Road  
Maidstone  
ME14 5DA

### Phone:

0300 365 0075

