VASCULITIS UK

NEWSLETTER JOURNAL

SPRING 2025 ISSUE 69

Chairman's Report

This will be my last report as Chairman. I've decided to step down and let the younger trustees take their turn. I will be 71 at the next AGM. The new Chairman will be Claire Tolliday. The other trustees are Heidi Pollard, Jane Edwards, Diana Shonfield, Peter Rutherford, Athony Hart, Giles Hart and Maxine Wright. I've been a trustee for 15 years and Chairman for 6. So much has changed in those years. The first meeting I attended was at the Novotel Long Eaton. John Mills had just taken over as chairman and we still had the "light bulb" from the Stuart Strange days. The formidable Pat Fearnside seemed to run most things and kept a very tight eye on the finances. John and Susan did everything else. I was asked to take over fundraising, this was new to me. I'd raised funds through Government and lottery funding but never with people doing events for the charity.

Over the years I've had the chance to talk to and meet some incredible fundraisers. Whether that's running the London Marathon or the Great North Run. Climbing Everest, Kilimanjaro, or Scafell Pike. Driving across Europe in a very dodgy panda. Many Sky Dives and wing walking. Cycling both East-West or North-South across the UK. Swimming incredible distances. Concerts and sleep overs. Then coffee and cake sales. Nothing surprises me now. I thank all of you and I'm sure you will recognise some of the events.
Also, some very sad moments. We feel every loss as a personal loss because we are a small vasculitis family.

Since taking over from John we became a very different type of Chairty a CIO (Charitable Incorporated Organisation). We moved into the digital age. Meetings held online; we were doing this before Covid. A new registered office and business line. We have our first employee Zoi Anastasa Director of Operations. We are invited to attend more and more professional conferences. The message about Vasculitis is reaching more Doctors and nurses than ever. The Charity is growing and our voice is being heard. We need more volunteers to help with the stands.

Research is also moving into new areas. Partly thanks to work done during covid. The future could be so different if those looking into the genomics of our DNA can find the trigger and switch it off. New medicines are becoming available and some we have been asked to appraise by NICE. They could make as big an impact as Rituximab and Avacopan.
And yet we still hear of those who are diagnosed too late or on the wrong treatment. Plenty of work still to do. I hope I will see a lot of faces I recognise at the AGM. Its on the 18th May starting 12.30 at the Radissons East Midlands Airport. We will get to meet Dwayne an AI bot developed by David ORegan and Ciara Coady from Vasculitis Awareness Ireland. Then a good friend Alice Muir will talk to us about Guided Imagery. I did the trial with her and 12 others. We all came away with a good feeling of healing and pain management. I hope you will too. Please email agm@vasculitis.org.uk to book a place.
As always, we need volunteers to help with stands, fundraising and run support groups. Please contact Zoi@vasculitis.org.uk if you think you could help.

Take care
Dorothy Ireland
Chairman 2019-2025

VASCULITIS UK

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

A few spaces left for the 2025 GNR

run one of the most famous half Marathons in the world and fundraise for Vasculitis UK

Contact Vasculitis UK
or
scan the QR code

SCAN ME

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" ,"Pregnany & 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/

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

Welcome to our Spring edition of our newsletter, it only seems like a few weeks since the Autumn edition. Firstly I would like to pay tribute, and give thanks to Dorothy who has been a trustee for the last 15yrs and our Chair for the last six year. Without those of you within the Vasculitis community stepping up to volunteer our charity would not be here, or able to support and give advice to those diagnosed with vasculitis or their carers, family and friends.

Dorothy, is stepping down so that, in her words, "to let the younger trustees take their turn".
As with any organization having the younger generations coming through and getting involved is very much needed to keep up with our ever changing world and especially to be able to support and give advice to others.

Talking of the youth, with my granddaughter having been diagnosed with vasculitis back in Feb 2024, and whilst round Granddads for after school tea, my Grandson Louis (Macy's Brother) aged 12 and my Granddaughter (Macy's Cousin) Alexa aged 9, were asking what I was doing on my computer?
I said I was working on the newsletter for the charity, they then asked if they could design a poster?
Of course my response was a yes!
They used a design app and AI tools to help them get the information and produced this poster.

I may have lost my role as editor now ha-ha! Seriously though it does make me feel happy just knowing that the younger generations want to get involved. This also rings true with many of our fantastic fund-raisers, who get involved with raising much needed funds and awareness for our charity.

So now it's time to grab your cuppa and read the articles within this Spring edition, and I'll start preparing for the Autumn edition!!

Kevin Goper

Editor

Director of Operations Report By Zoi

Dear Readers,
The past six months have been incredibly busy for Vasculitis UK! It has been a pleasure to participate in various events, attend meetings, and collaborate both nationally and internationally.

Our packed schedule kicked off with the West Midlands local support group meeting, followed by a project organized by Vasculitis International in Amersfoort, Netherlands. Amersfoort is a beautiful town, and we managed to squeeze in a short 20-minute walk near the venue. A special thank you to Ron Hendriksen, who took great care of all the participants and proved to be an excellent guide. You can find a detailed article about the event in this newsletter. I flew back just in time for the VUK AGM.

In October, I received the heartbreaking news that my dear friend Michelle had lost her battle. Although she had been unwell for quite some time, her passing still came as a shock—I had held onto hope that she would recover.
I was devastated that I wouldn't be able to attend her funeral due to a prior commitment abroad. However, fate intervened. As I was at the airport, preparing to board my flight, I received a message that my meeting had been moved online due to flooding in the area. If you've ever tried to leave an airport after checking in, you'll know it's not as simple as turning around—you have to be escorted out and go through passport control again! But this unexpected turn of events meant I could attend Chelle's funeral and pay my respects.

November and December flew by in a blur of meetings with industry partners, educational events with nurses, the UKIVAS educational course for healthcare professionals, and an RAIRDA board meeting in London.

With the arrival of the New Year, I expect 2025 to be just as busy as 2024! Local support group meetings have resumed, new groups are forming, fundraising efforts are thriving, and we've introduced new promotional materials to boost vasculitis awareness.

Spring and summer promise even more activity. In April, we'll be attending the British Society of Rheumatology Annual Conference, followed by the Scottish Vasculitis Network meeting in May. We'll also be in Liverpool for the Royal College of Nursing (RCN) Congress, and this year, our AGM will be held in person.

May is Vasculitis Awareness Month, with May 15th marking Vasculitis International Day! Please help us spread the word and raise awareness.
Take a deep dive into this newsletter and enjoy reading it!

Zoi Anastasa

As part of my company's annual cycle event, we raised funds for Vasculitis UK - my wife has a lived with TA for 17 years.
I'm delighted to confirm that our fund-raising for the charity is now finalised, with a donation amount of £16,946!

The Prologis 100 includes a range of physically challenging events, with some riders participating in a 100-mile or 100-kilometre bike ride and others showing support through a 100-furlong hike, which was introduced for this year and saw around 40 participants hike through the Oxfordshire countryside. The new addition to the challenge also allowed challengers of all skill levels to get involved and push their limits for a good cause.

Cyclists pedalled through scenic routes, facing varying terrains, testing their stamina and determination. For those who preferred a different kind of challenge, the 100-furlong hike (roughly 12.5 miles) provided an excellent opportunity to take in the beauty of the outdoors.
The collective effort and camaraderie on display throughout the challenges highlighted the spirit of the Prologis 100.
This year's event was particularly special, as it celebrated 15 years of making a tangible difference to those in need. The proceeds, which were gathered through donations, sign-ups for the event and by taking part in a raffle and auction on the evening, will be spread between three incredible charities: LandAid, Molly Olly's, and Vasculitis UK.
LandAid works tirelessly to provide safe spaces for young people facing homelessness, Molly Olly's supports children with life-threatening illnesses, and Vasculitis UK funds research and offers support to those affected by vasculitis, a rare autoimmune disease.

Tom Osbourne

VASCULITIS UK

Join our team as a volunteer!

Vasculitis UK is looking for volunteers to strengthen its team – you may be that person!

We're seeking enthusiastic volunteers to help in three areas:

- Our Online Groups
- The Helpline
- The Vasculitis UK Online Shop

More information about the roles can be found on the website.

Visit https://www.vasculitis.org.uk/ or scan the QR code

You can also volunteer to support a stand when we are participating in events in your area. Please read the role descriptions and contact zoi@vasculitis.org.uk to register your interest or to ask questions.

Research results show the importance of COVID vaccination and a personalised approach for RAIRD patients

A study published in the Lancet on Thursday has revealed that blood tests can predict the severity of Covid-19 infection in Rare Autoimmune Rheumatic Disease (RAIRD) patients, which could lead to individualised approaches to vaccination.

The MELODY study was supported by a collaboration of research charities and medical funders including RAIRDA member charity Vasculitis UK, to ensure better representation of at-risk groups in pandemic research.

MELODY is the largest research study to date in people with rare diseases, including 6,516 people living with a RAIRD.

Key findings from the study:

- COVID-19 antibodies provide strong protection for people with RAIRDs.
- Regular vaccinations are crucial for people living with RAIRDs to maintain immunity.
- Antibody tests can guide personalised prevention plans.

How COVID-19 vaccines helped people with RAIRDs during the Omicron wave: the MELODY* Study

Background on the study:

People with RAIRDs, like lupus, vasculitis, scleroderma, and myositis, are more likely to get seriously ill from COVID-19. This is because their immune systems don't work normally, and people with these conditions often take medications that weaken their immunity.

In the UK, people living with RAIRDs were offered three initial COVID-19 vaccine doses and regular boosters. The MELODY study looked at whether people with RAIRDs who didn't develop detectable COVID-19 antibodies after receiving three or more vaccines were at a higher risk of catching the virus or experiencing more severe illness, during the Omicron wave.

How the study worked:

From February to June 2022, 6,516 people with RAIRDs across England joined the study. They had all received at least three COVID-19 vaccine doses. Participants did at-home antibody tests, filled out health surveys, and their health was tracked for six months using NHS records for COVID-19 infections, hospitalisations, and deaths.

What the study found:

- Out of the 6,516 participants with RAIRD, 37% had lupus, 21% small vessel vasculitis, 13% systemic sclerosis, 9% large vessel vasculitis, and 7% had myositis. 13% did not specify which RAIRD they had.
- Many (71%) were on treatments that suppress their immune system, and 42% were on steroids.
- After at least three vaccine doses, 86% of participants had COVID-19 antibodies.
- People on certain medications—like anti-CD20 drugs (e.g. rituximab), cyclophosphamide, or mycophenolate—were less likely to have antibodies. Steroids also reduced antibody levels, but methotrexate and azathioprine didn't seem to affect them.

* Mass Evaluation of Lateral Flow Immunoassays for the Detecetion of SARS-CoV-2 Antibody in Immunosuppressed People Study

Over six months:

- 1,024 participants caught COVID-19. Younger people and those living with children had more infections.
- Having COVID-19 antibodies reduced the risk of infection by 43%.
- 140 participants were hospitalised with COVID-19. Antibodies lowered the risk of hospitalisation by 68%.
- Older participants and those with other health issues were more likely to be hospitalised, but antibodies still helped protect them.
- There were only four COVID-19-related deaths.

What does this show us?

COVID-19 antibodies provided crucial protection for people with RAIRDs, reducing their chances of getting infected or seriously ill during the Omicron wave.

COVID antibodies decrease over time since your last vaccine; and the study shows that having antibodies reduces your chance of infection with COVID by half, and of hospitalisation with COVID by two-thirds.

Therefore, it is key that people with RAIRDs get their booster COVID vaccines, to increase their chances of having COVID-19 antibodies.

Further, we know that some people who are immunosuppressed remain at risk of serious illness from COVID-19. The study shows that a simple blood-test which can be deployed at scale, would enable those at greater risk to be identified, and have individual support directed to them, to protect them from COVID-19.

This is a summary of the results relevant to rare autoimmune rheumatic diseases from **Impact of SARS-CoV-2 spike antibody positivity on infection and hospitalisation rates in immunosuppressed populations during the omicron period: the MELODY study**

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(24)02560-1/fulltext

Mumford, L., Hogg, R., Taylor, A., Lanyon, P., Bythell, M., Sean McPhail, Chilcot, J., Powter, G., Cooke, G. S., Ward, H., Thomas, H., McAdoo, S. P., Lightstone, L., Lim, S. H., Pettigrew, G. J., Pearce, F. A., & Willicombe, M. (2025). Impact of SARS-CoV-2 spike antibody positivity on infection and hospitalisation rates in immunosuppressed populations during the omicron period: the MELODY study. The Lancet, 405, 314-328.

RAIRDA is the Rare Autoimmune Rheumatic Disease Alliance.

We are the first alliance linking clinical and patient organisations to campaign for improved care for people living with RAIRDs in the UK. RAIRDA is comprised of Lupus UK, Vasculitis UK, Scleroderma and Raynaud's UK, and Sjögren's UK.

Since our last update, RAIRDA has been focused on developing a report, based on the findings of our 2024 survey. The survey report will be released in early April 2025, and will provide RAIRDA with fresh evidence to inform and drive forward our calls for change.

RAIRDA has also supported the work being carried out by the quality statements for rare disease project. The next stage of the project is a second consensus survey round, for members of the rare disease community to review a revised set of statements. The survey has just been launched: if you would like to complete it, or to find out more about the project, please visit rarediseaseqs.org.

Rare Disease Day took place in February, and RAIRDA co-Chairs Sue Farrington and Peter Lanyon attended the Westminster reception. It was great to hear RAIRDA's work referenced by Genetic Alliance in their interim CEO's speech, and the next day, we were really pleased to see the England Rare Diseases Action Plan 2025 reference both the quality statements for rare disease project, and RAIRDA's work securing a Westminster Hall debate on RAIRDs.

In Westminster, RAIRDA has recently met with several MPs, including Peter Dowd MP (Chair of the APPG on rare, genetic and undiagnosed conditions), Kevin McKenna MP and representatives from the office of Margaret Mullane MP. It's been great to get their support for our calls, and RAIRDA looks forward to working with them to drive change for people living with RAIRDs.

Finally, the RAIRDA member organisations have come together to offer a prize for the Science in Medicine School Teams Prize 2025. The challenge is run by the National Heart and Lung Institute, and the British Heart Foundation's Centre of Research Excellence at Imperial College London. It asks teams from schools within the UK to design an ePoster which illustrates an idea for combining science and technology with health research, to improve lives. RAIRDA's challenge asks students to design an innovative, non-pharmaceutical solution based on science/technology to help improve the quality of life and wellbeing of people with RAIRDs. The prize is open until 30th June 2025.

Melanie Sloan

'I still can't forget those words': mixed methods study of the persisting impact on patients reporting psychosomatic and psychiatric misdiagnoses

A research team in Cambridge conducted a study to better understand the lasting effects of patient-reported psychosomatic and psychiatric misdiagnosis on individuals with systemic autoimmune rheumatic diseases (SARDs).
Vasculitis is a rare condition that can be challenging to diagnose. Its symptoms often overlap with those of other autoimmune diseases or even cancer, yet many patients are frequently told their symptoms are psychosomatic. This misattribution can lead to delayed diagnosis and treatment, affecting a patient's prognosis. But what impact does it have on their mental health and their trust in healthcare professionals? This study sought to explore these critical questions.
We extend our gratitude to Dr. Melanie Sloan and her team for their ongoing efforts to investigate mental health and healthcare inequalities in systemic autoimmune rheumatic diseases like vasculitis.
Follow the link for the published paper:
'I still can't forget those words': mixed methods study of the persisting impact on patients reporting psychosomatic and psychiatric misdiagnoses. https://academic.oup.com/rheumatology/advance-article/doi/10.1093/rheumatology/keaf115/8042899

Key message from latest Cambridge research study - Research team highlights the power of doctors saying "I believe you"

My Experience of MDT Meetings – A Patient Perspective – Molly Bostock

I was first informed my case was being brought up at an MDT (Multi-Disciplinary Team) meeting after my first scans/blood tests came back, suspecting EGPA Vasculitis. Within the talk I gave at the 3rd UKIvas Conference on 25th November 2024 alongside a consultant and specialist nurse, I explained more about my experience of this and how MDT meetings are important to ensure that the patient feels safe, listened to, and an active part of their treatment plan.
I explained during my talk that the respiratory consultant I had initially seen explained they suspected I had this rare disease, but they only had learnt about it years ago at University. By raising my case at their weekly MDT, he wanted to ensure he was right with his suspicions. By chatting about my presentation to his colleagues, the respiratory consultant explained to me that he would then have the right knowledge to refer me to the right specialist. In my talk, I explained his willingness to ask for help with gaps in his knowledge and ultimately admit he needed to gain more advice was what made me feel reassured and safe. Explaining what he was planning to do and why he was doing it gave me autonomy as a patient and kept me informed of the process.
Discussing my case with other consultants and specialists ensured that if I needed follow-up emergency appointments, the other respiratory consultants would already be aware of my case. This avoided confusion and offered continuity of care. By the time I had my second asthma attack, they could then diagnose EGPA Vasculitis, due to my case being raised in an earlier MDT meeting. By this time, I had been referred to a Vasculitis specialist, and tests had already been performed to confirm the diagnosis.

UKIVas Education Course 2024

Zoi Anastasa

The 3rd UKIVas Educational course was held in Birmingham on the 25th and 26th of November 2024. Being a patient representative, it warms my heart to see so many clinicians wanting to improve their knowledge in vasculitis.
As the previous courses, it was well attended. Dr Nina Brown, who is organising these events for UKIVAS with the support of local clinicians, did a brilliant work and so did Dr Dimitri Chanouzas from the Birmingham vasculitis team.
There were a lot of presentations about the management of different types of vasculitis, the updated ANCA-associated vasculitis guidelines (more about this on our next newsletter, after they are published), research, and a very interesting presentation about how to use new Model Health System metrics to benchmark care in England.

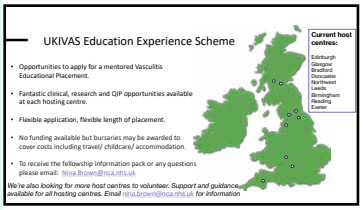
Two sessions were very close to the patients' needs:

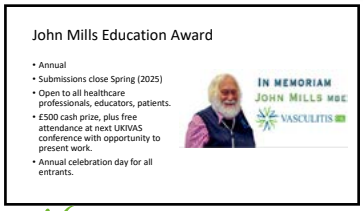
- **Service considerations, patient perspectives and the role of the MDT,** Molly shared her patient experience with the clinicians and her words touched them deeply. Dr Rosemary Hollick and a specialist nurse, Sarah Hardy, were the presenters.
- **Vasculitis Specialist Nurse/MDT Session**
  It was the first time a session about vasculitis specialist nurses was included in the educational course, and I think it was very successful. They discussed the need of specialist nurses, their role and training, and the impact they have on patient care. Rheumatology research nurse Alice Muir shared the Guided Imagery for Managing Vasculitis programme, we had an article about it in our Autumn Newsletter.

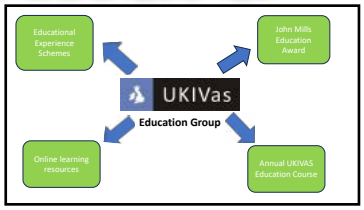
At the UKIVAS Educational Schemes Launch session, the John Mills Education Award was presented. The award is supported by a bequest left to UKIVAS from John Mills and Vasculitis UK. We are looking forward to seeing this year's entries!

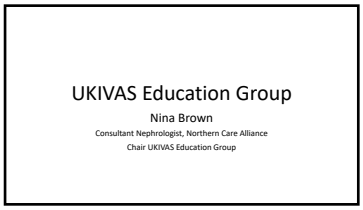
The event closed with the presentation of 5 clinical cases presented by Vasculitis UK bursary recipients.

John Mills MBE Vasculitis Educational Award









LONG-TERM STEROID USE RESEARCH

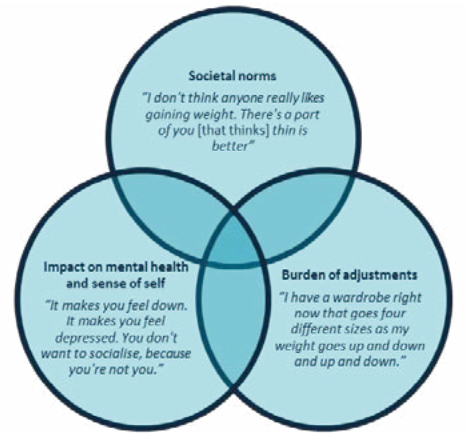
Perspectives on the impacts of appearance and weight changes due to long-term steroid use

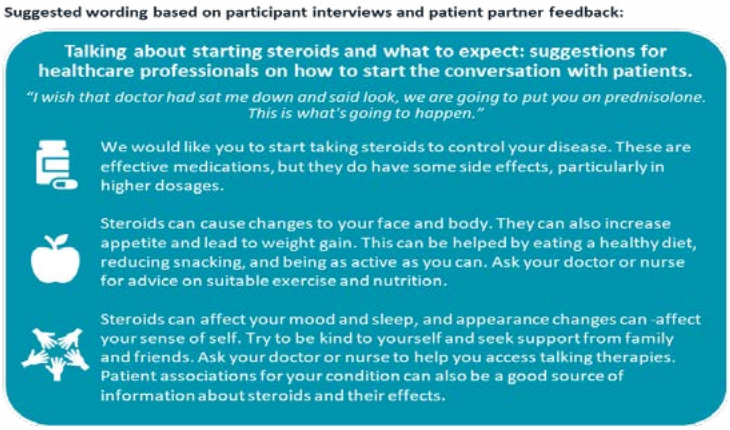
I'm Stephanie Lax, a researcher from the University of Nottingham alongside Dr Fiona Pearce and Alice Muir in the RECORDER team. You might remember Alice's lovely double pager in the Autumn 2024 newsletter about her Guided Imagery project. Her YouTube resources on the Vasculitis UK website here: https://www.vasculitis.org.uk/imagery-techniques-for-people-living-with-vasculitis.

It's also been my pleasure to join Dr Jo Robson at UWE Bristol and colleagues on a project about the impacts of appearance and weight changes due to long-term steroid use. Previously, Jo's team had interviewed 60 patients with lots of different rheumatic conditions, including vasculitis, about the general impacts of steroids on their lives. I looked at the original interviews with fresh eyes and pulled out everything participants said about how steroid-related appearance and weight changes affected them.

Three main issues came out. Firstly, participants shared the pressures they felt about their appearance because of cultural expectations and unhelpful comments received from others when their appearance changed. This was across weight, skin, and hair changes. Secondly, participants explained how appearance changes had a negative impact on their mental health and sense of identity.

Thirdly, we drew up a list of all the adjustments people said they had to make to cope with steroid-related appearance changes. They included changes to diet, physical activity, and social interactions. We realised many were associated with increased financial costs, which some people would find easier to afford than others.





Something that surprised us was the mention of hair thinning. That's because doctors and researchers typically think of steroids as causing hair gain, rather than loss. It's an area that needs further work to fully understand.

Some participants indicated more support and information about steroids would have helped them prepare themselves better, which is something the patient partners on our team agreed with. Drawing on the research, we came up with some advice for healthcare professionals talking to patients who are starting to take steroids. A postcard is available to print from https://www.nottingham.ac.uk/research/groups/recorder/documents/steroid-project-20250313-updated-postcard.pdf.

If you have any comments about this work, would like to hear more about our research, or live in the East Midlands and would be interested to join our Public Partnership, please email RECORDER@nottingham.ac.uk. Please also contact Jo Robson at UWE Bristol for further information about the original Steroid PRO project (Jo.Robson@uwe.ac.uk).

Suggested pictures:

Images are from our paper: Lax SJ, et al. Patient perspectives on the impact of appearance and weight changes attributed to systemic glucocorticoid treatment of rheumatic diseases, Rheumatology, 2025; https://doi.org/10.1093/rheumatology/keaf121.

Stephanie Lax

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.

West Midlands Group meeting

6th October 2024

It is always a pleasure to go to the annual meeting of the

West Midlands vasculitis support group. The meeting was hugely successful from every aspect. The room was full, and I met people that had travelled from further away to participate in a face-to-face support group meeting. It was nice to meet ''old friends'' too, Jayne Harman- our nose ambassador- being one of them!

The two presentations were

well received by the audience and a lot of questions were asked.

Dr Azm Ulhussain, a renal registrar at UHB talked about new medicines for inducing remission in ANCA associated vasculitis and avoiding the use of steroids.

Linda Coughlan, a renal research nurse at UHB spoke about what being a part of research into ANCA related Vasculitis involves and gave information about current and past studies.

Thank you David and Margaret for organising this and for inviting me.

As the group meets annually on the first Sunday of October, I hope to be able to join them again next year!

Coffee & Chat

North Derdyshire and South Yorkshire Group met for a coffee and a chat in the Peak District Derbyshire.

Catching up with old friends and also making a new friend.

Susan Mills

Hastings/Brighton

VASCULITIS AWARENESS MONTH 2024 & 2025

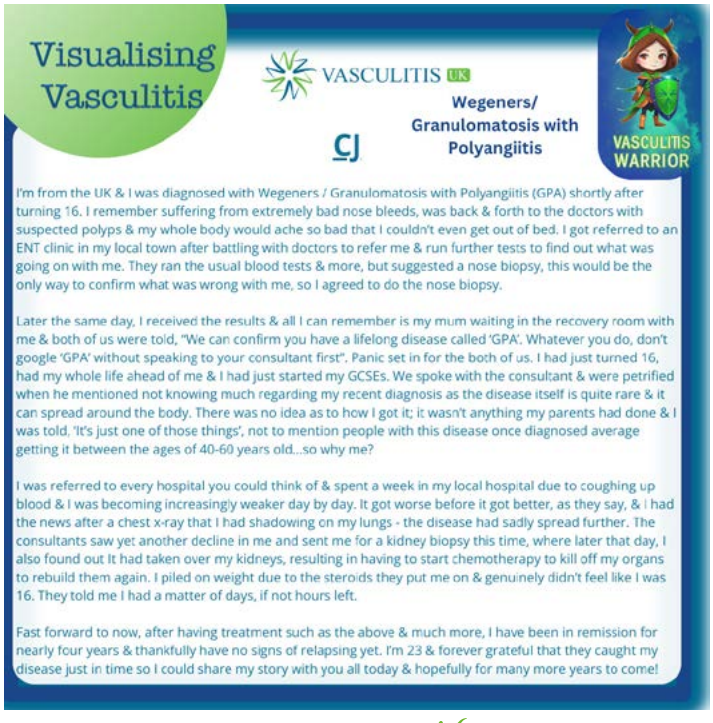
Throughout the month of may last year many contributed to the VUK awareness month campaign, **Visualising Vasculitis,** by sharing their stories, those in this edition are the remaining images.

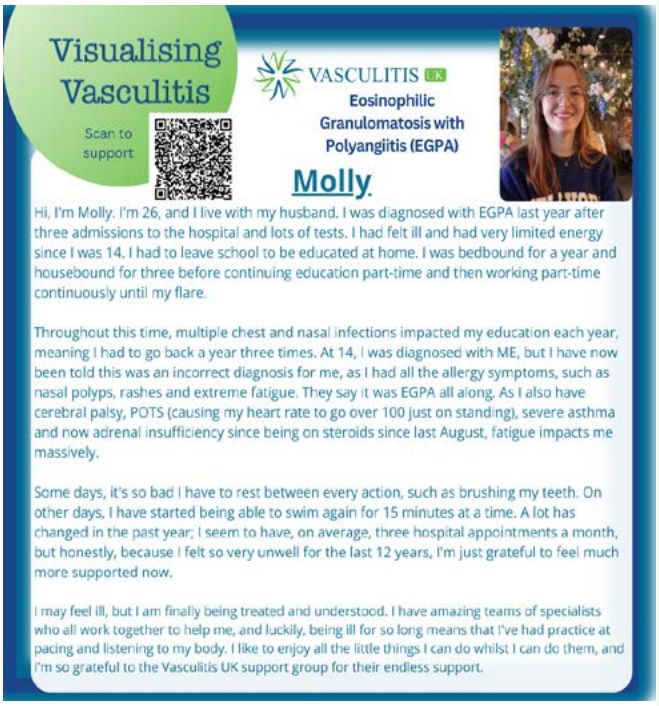
Others contributed by sharing these stories via social media which is a great way to help raise awareness, many other individuals contributed by creating their own.

Rare Disease Day was on 28th Feb and Jane Edwards created the image above and many others which were used throughout the month on social media, you will see them in this newletter as well. Many thanks to Jane and anyone else who shared them to help raise awareness.

Getting involved in this campaign during May each year is growing in momemtumn and I am sure 2025 will generate more intrest and hopefully more of our readers will join in. Look out for more information on this years campaign both via social media, the VUK website.

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





TELL YOUR STORY

Send your story to kevin@vasculitis.org.uk

My name is Kirsty and I'm 39 years old. I was diagnosed with GPA vasculitis on 15th May 2023, National vasculitis day 🎉.

My symptoms started in 2022 after having COVID-19. At first, the symptoms were mild but got more severe very quickly. I experienced lots of different symptoms but at the time I didn't realise that they were all linked.

It started with pains and swelling in my joints. Especially elbows, hips, knees and ankles. It was so painful some days I could barely walk and couldn't lift my arms. My fingers swelled so badly on one occasion I couldn't hold a pen.

I also developed Episcleritis which is an inflammatory disease of the eyes. Rashes and blisters took over my legs and feet. I suffered breathlessness and walking up a flight of stairs was exhausting. There were nights I would crawl up the stairs because the pain of walking on my feet was excruciating. On other nights I couldn't get up the stairs because it was too painful to move and I would sleep on the sofa. Carry out daily tasks on some days was impossible. I knew something wasn't right and contacted my GP.

After blood tests I was referred to a rheumatologist. Many more tests later I was told that my Kidneys were failing! They believed that I had Vasculitis, but I would need to have a kidney biopsy to confirm to the diagnosis. It was all very scary. I had never heard of vasculitis and had no idea at the time how serious it actually was.

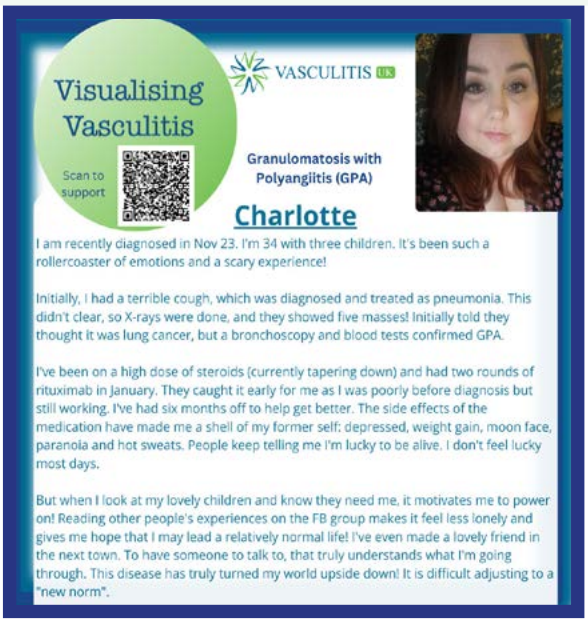
Biopsy completed and diagnosis confirmed. I was started on an aggressive course of treatment straight away. I received a course of Cyclophosphamide infusions over a three-month period along with Rituximab infusions. High doses of Prednisone and other prescription medications got my condition under control.

I was officially in remission by November 2023. Thank you to all the team at Hammersmith Hospital, you saved my life ❤️.

Having just finished a second dose of Rituximab, one year later. I continue to live a pretty normal life.

I hope my story helps others with Vasculitis, you are not alone. Anyone reading this who is experiencing similar symptoms or knows someone who is experiencing these symptoms, please don't ignore them.

K Barton is fundraising for Vasculitis UK So far Kirsty has raised over £100 please follow this link to donate.



"After VUK"

On the 27th October 2024, the very exact day, I stood down, after 15 years, as a trustee for Vasculitis UK I became extremely ill. I started suffering with extreme nausea, diarrhoea with no sensation of wanting to go to the toilet and lower back pain.
After 4/5 days of this plus my weight dropping dramatically I made an appointment to see my GP. They asked all the usual questions regarding my symptoms, took the "usual" blood, urine and poo tests. All returned normal. But in the meantime my nausea and diarrhoea continued and my lower back pain increased plus my weight continued to drop. My GP told me they would refer me to a gastroenterologist but I would not be guaranteed an appointment and if I received an appointment it might be a long wait.

By the end of November after suffering for 4 weeks and my weight was less than 48kg, I collapsed, I was so weak, the diarrhoea was uncontrollable, so I contacted 111 but they told me because I was not considered an emergency I would probably have to wait hours for an ambulance. So I contacted my son, who took me to A&E.
I was immediately admitted and over the next 4 days I was attached to a drip because I had become so dehydrated. I had CT, MRI and Ultrasound scans, blood tests, urine tests and umpteen poo tests.
I was eventually diagnosed with EPI - Exocrine Pancreas Insufficiency (the part of my pancreas which produces enzymes to break down my food into nutrition for my body had stopped working). I was in danger of dying from malnutrition.
I was immediately prescribed Creon (an enzyme replacement drug) , I have to take with absolutely everything I eat or drink.

I was then told by the gastroenterologist that EPI doesn't normally happen in isolation, there is usually an "underlying condition" behind the problem. So I was admitted into hospital the middle of December for a colonoscopy and multiple biopsies of my colon.
Earlier this year, late January, I was diagnosed with MC - Microscopic Colitis (severe inflammation of the colon). I was immediately prescribed steroids to bring down the inflammation. These I will take for 3 months with a view to another taking them for a further 3 months plus adding an immune suppressant further down the line, depending on how the inflammation responds to the steroids.

Early February I also started with very strange symptoms involving my fingers and toes, my fingers became intermittently white and frozen and my big toe became blue and I started suffering with chilblains on my toes. I then started suffering with chilblains on the knuckles of my fingers on my left hand. I was diagnosed with Raynaud's Syndrome.
So I had reached the age of almost 72 years with nothing more serious than having a cold, then suddenly, I was having to deal with 3 chronic health conditions all involving my immune system.

I am now a few weeks on with taking the steroids, my nausea has stopped and also my diarrhoea, although not totally back to normal. I struggle to put weight on as I have had to cut out full fat dairy (milk, cheese, butter, cream), fried food, soluble fibre and vegetables such as onion, garlic and cabbage from my diet because of the EPI and MC. I just weigh 51kg today which is a slight improvement but still low for my height. I have been prescribed food supplement drinks which I try to drink every day but they are not really very appetising.

Our family have been in shock, just can't quite believe that this is happening to me after years of supporting John and all those diagnosed with autoimmune diseases.
But, it has really helped me, all those years of working for VUK and living with my John who had GPA vasculitis, to understand what is happening to me and also help me cope with my condition, the drugs and adjust to living my "new and very different " way of life.

I am very lucky to have such a supportive family and friends, I walk our dogs everyday, I have started pilate classes and I am playing pickle ball again but have not dared to resume swimming yet, but I am hopeful. I have joined an on line support group because I know no one else with either EPI or MC. I have also joined the charity, Crohn's & Colitis UK, who have been so very helpful with information and support.

So 4 months on, I can now see the light at the end of a very a dark tunnel, I just wish my John was here to chat to about it all. He would have said "I am so sorry you have these heath conditions Susan, but they are all just so very interesting!" I do miss him so much!

Susan Mills (retired trustee for Vasculitis UK)

I am a 63-year-old male diagnosed with EGPA in late 2020, still working full-time in a job I enjoy with no immediate plans to retire. This has all been made possible by the amazing support I have had from my wife and my employer, together with finding the right combinations of drugs (thanks to the team at Addenbrookes). I chose to be completely transparent with my employer about my illness, which made managing my condition easier.

Coping immediately after diagnosis was all about keeping myself occupied, having a positive outlook, and living life day to day whilst celebrating any small victories. At first, there were so many drugs that I lived life in divided segments, filling up the time between doses. At work, I drew up enormous lists – actions for the current day and actions for the next day and documented all possible outcomes, who to call, and situations to manage, all prioritised as I couldn't rely on my memory. Finally, working from home (my employer gave me a home-based contract shortly after diagnosis) meant I could schedule lunchtime naps, rest periods really, as tiredness was and remains an issue.

I feel I have been more fortunate than most who have vasculitis. My wife researched and wouldn't accept any pushback from the system, which led to me having a relatively fast diagnosis. I realise not everyone will have such understanding employers. I feel for everyone who has not been so fortunate.

This year, my employers have embraced Rare Disease Day to raise awareness of Vasculitis through my journey. I work for a large organisation and I hope next year they will agree to do more.

I would like to finish with a short message about my current drug regime should anyone from NICE happen to be reading these words. Benralizimab has been life-changing for me both at home and work – it has enabled me to function without the nasty side effects of immune suppressants, which we are all familiar with. I have a working immune system (save Eosinophils), and the biggest victory of all is as of late February this year, I have finally managed to taper off pred completely.

Lev Ariel

Our Fantastic Fundraisers

Members of Littlehampton Golf Club have raised £20,000 to support Vasculitis UK as their charity of the year.

Various fundraising events have taken place throughout the year including a 'Capers Day' and a 'Drive in Day'.

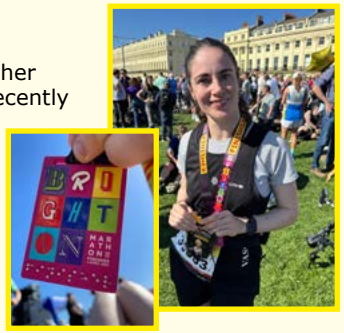
Please join us in expressing our thanks for their generosity.

Our daughter Ellie was sadly diagnosed with tak age 21 in 2023.
My husband Rob, Ellie's brother Oli and friends Tony and Trevor walked from Middlesbrough to Scarborough a total of 54 miles for funds for Vasculitis UK to raise much needed awareness for this very rare disease.
So far they have raised over £11,000

Vicky Sugget

Liz Wilson took part in the South Coast Ultra Challenge 2024, on 7 September 2024. She was Diagnosed with GPA in April 2024. She raised £618 including gift aid, through her Just Giving page
Her wife Dee-Dee Wilson also did the South Coast Ultra and raised £473.

Emma McKinney completed her first marathon in Brighton recently raising a massive £1364 for Vasculitis UK.



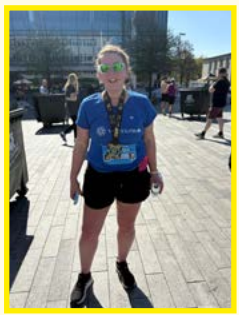
Augusta Eagleton competed in the Larkin Gowen Norwich Half marathon in November 2024.
She was diagnosed with GPA a few months after giving birth, in 2021.
She raised £2218 including Gift aid

Hackney Half Marathon 19th May 2024

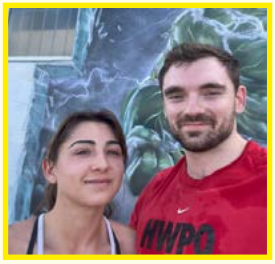
Rory Mosseveld ran the Hackney Half marathon to raise awareness and help a close family member diagnosed with GPA. To read his full story and to make a donation please follow the link:

Rory Mosseveld is fundraising for Vasculitis UK (justgiving.com)

Route of Hackney Half Marathon



Francesca Goldstraw pictured left proudly wearing her VUK T-Shirt has so far raised £210 for Vasculitis UK.



Mini and Junior Great North Run 7th September 2024
Henry and Eli fundraising for Vasculitis UK because a good friend has EGPA.
Please follow the link to donate:

Catherine Reay is fundraising for Vasculitis UK (justgiving.com)

Great North Run 8th September 2024
Asley Wilde ran to raise awareness of Vasculitis.
Please follow the link to donate;
Vasculitis UK: Ashley's page (enthuse.com)

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

Our Fantastic Fundraisers

Bath half Marathon 17th March 2024
Jack Strong ran in memory of his dad Jason who sadly passed after a diagnosis of vasculitis. Please read his full story by following the link;

Jack Strong is fundraising for Vasculitis UK (justgiving.com)

Edinburgh Marathon 26th May 2024
Christian Lloyd ran the Edinburgh Marathon to support and fundraise for Vasculitis Uk.
Please follow the link to donate;

Christian Lloyd is fundraising for Vasculitis UK (justgiving.com)

Our Amazing Treasurer Heidi Pollard climbed Kilimanjaro in August 2024. She continues to raise money in memory of her sister Sarah Pierce. This time she raised £3396.
Rather than putting her feet up she then did the Great North Run a few weeks later and raised a further £578.

Well Done Heidi

Running for Mike

On September 9th 2023, Mike George Harris was suddenly and tragically taken from his friends and family after enduring years of living with vasculitis. A cheeky bear of a man, Mike was a genuine example of one of those people that no one has a bad thing to say about. His close friend, Max Wilshaw, was one of many that Mike had previously helped in some way, and he was inspired to show what he could endure in an effort to raise money for Vasculitis UK, a charity dedicated to researching and treating the disorder.

In May 2024 Max raised a staggering £4428 for the charity, after taking part in the Bristol Half Marathon, but this was just the beginning of his ambitions.

Starting from October 1st last year, Max committed himself to competing in four running events with the goal of donating £12k over a twelve month period. Having already completed two of his challenges, the next event on the calendar is the TCS London Marathon on April 27th, when Max will be running 'virtually' with a route mapped out across Bristol. Then, on the 10th of May, he'll be taking part in 10YFAN, the annual Brecon Beacons test of climbing to the top of Pen Y Fan ten times within a twenty-four hour window!

"Shevington Sharks have played all year wearing vasculitis UK logo shirts.
They have raised over £4300 in memory of their former chairman Ian Robinson, who died a year ago from Vasculitis."

Pic Right Mathew Halton wearing the new match day tops with the Vasculitis logo on for Shevington Sharks ARLFC

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

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.

Blood protein profiles provide new insights into large-vessel vasculitis – February 2025

Large-vessel vasculitis (LVV) is the name for a group of diseases that cause inflammation and damage to arteries (the blood vessels that carry blood away from the heart).

LVV affects medium- or large-sized arteries and can lead to serious complications following blood vessel narrowing or damage, such as sight loss, stroke, or aortic aneurysms. LVV is most often caused by giant cell arteritis (GCA) or Takayasu arteritis (TAK).

These autoimmune diseases have traditionally been classified as separate diseases due to differences in the age of patients and the location of the blood vessels affected. However, some experts have recently suggested that GCA and TAK might be variations of the same disease given the difficulty in telling them apart in certain patients.

This question has important implications for clinical care and for the design of trials testing the effectiveness of new treatments.

Last month, Vasculitis UK funded investigators from Imperial, University of Leeds and the University of Oxford published new research addressing these questions in the most extensive study of its kind.

The team used new 'proteomic' technologies to measure the levels of hundreds of blood proteins in nearly 300 patients with GCA or TAK, and a comparison group of unaffected individuals.

Proteins play a critical role in most biological functions, and proteomics can provide a powerful snapshot or profile of a person's or group's biological state. The team found that the protein profiles in GCA and TAK arteritis were surprisingly similar, indicating significant overlap in the biology of these diseases.

Notably, the shared profiles emphasised the important roles of macrophages—key immune cells—and structural cells of the artery in LVV. Deeper investigation revealed that the overactivity of these two cell types is interconnected, suggesting that their communication is likely central to the progression of LVV.

In the article, the authors propose that the disruption of key proteins involved in this communication could be a promising strategy for new LVV treatments. The study's lead author Dr Robert Maughan (Imperial) said: "The most severe damage to tissues is often caused by the body's response to persistent inflammation. In LVV, the response of arterial structural cells leads to the affected vessels becoming stiff and narrow. Our work identifies a protein communication network that is likely to be involved in this process and we believe that the targeted manipulation of such networks would be an effective treatment strategy. Of course, further research will be required to develop this concept."

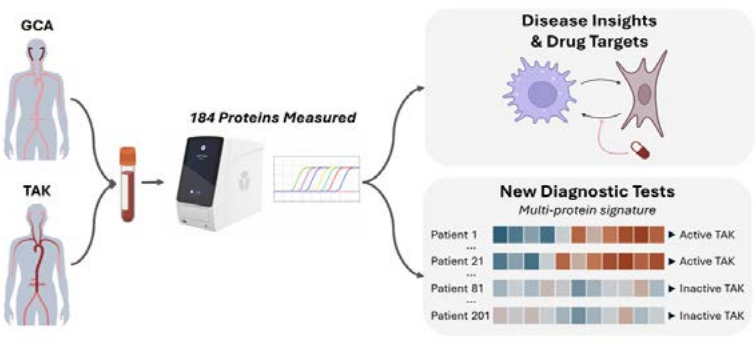
The team's study may also help in the development of better blood tests for diagnosing and monitoring LVV diseases. Patients with GCA and TAK require regular monitoring to identify relapses i.e. a return of disease activity that can cause further arterial damage. Unfortunately, the currently available blood tests for diagnosing and monitoring disease are inaccurate. Using their proteomic data, the team identified multiple proteins that could be used to monitor disease activity in in TAK. Importantly, they showed that these tests could be combined to form 'multi-protein signatures' which provide significantly improved diagnostic accuracy compared to current tests. Dr Maughan noted: "With advances in technology, it is now easier to measure multiple proteins in the blood simultaneously, which is helpful for research and for the development of better blood tests. In this study, we found that multi-protein signatures consistently performed better than single protein tests. More accurate blood tests have the potential to benefit both patients and hospital services by speeding up diagnosis and by reducing the number of other examinations required to monitor disease activity." The authors emphasised that while this approach has great potential, it is still in its early stages and requires further rigorous testing and development before clinical implementation.

This study was initiated through an MRC TARGET Partnership award leading to an ongoing collaboration between the Imperial, Leeds and Oxford NIHR Biomedical Research Centres with additional funding from NIHR, Vasculitis UK, the Medical Research Foundation and UKRI.

Links to the paper:

https://acrjournals.onlinelibrary.wiley.com/doi/10.1002/art.43110

https://pubmed.ncbi.nlm.nih.gov/39817309/



IgAVworkshop

On 13th & 14th February 2025, Zoi from Vasculitis UK attended the above workshop to gather multi-professionals together to help create a pathway for kidney involvement in patients with IgA vasculitis. The meeting was chaired by Dr. Louise Oni, a children's kidney doctor working in London and Liverpool, and Prof. Alan Salama, a kidney doctor for adults, based in London.

58 professionals from across the world, including coming as far as Australia and Brazil, joined the session. The meeting started with Dr. Oni highlighting that nothing has changed for patients for over 20 years yet other rare diseases have seen major improvements. It included discussions about why there has been very little research into this condition and what may be holding it back. The group agreed that the kidneys, gut, Skin, and joints were important organs in this condition and research would work through this list to try to improve the outcomes for everyone. An overview of all the drugs available for other forms of vasculitis and other conditions such as IgA nephropathy was discussed. The group had discussion about new

LifeArc Centre
Rare Kidney Diseases
In partnership with Kidney Research UK

'A Pathway to a clinical trial for IgA vasculitis nephritis'

A collaborative workshop

13th &14th February 2025

types of clinical trials that can assess drugs in a quicker way that may be helpful for this disease. There was an overwhelming agreement to work together to get high quality evidence for patients. The meeting was a great success and further steps will include publication of the meeting report into a medical journal and applications for funding to help move this forward. The lead investigators will be holding a patient involvement event online in April to gather ideas from patients who have lived experience of this condition, either as a parent or experienced the condition themselves, if you have had IgA vasculitis (also known as Henoch Schonlein Purpura) and would like to help with this event then please email Kelly (UKKidneyEcosystem@liverpool.ac.uk).

Louise Oni, 22nd February 2025

Nurses, the spine of our healthcare system, and vasculitis

Every year, Vasculitis UK attends the Royal College of Nursing (RCN) Congress. Last year's event was a tremendous success for the VUK stand, leading to invitations to speak about vasculitis at various RCN branches.

We delivered three presentations and engaged with nurses at different levels of vasculitis knowledge. Some were specialist nurses working in departments that care for vasculitis patients, while others were based in A&E, GP surgeries, and community nursing. The enthusiasm and interest from the nurses were truly heartwarming.

We would like to extend our gratitude to:

Abé Golamaully, Local Learning Events Lead/Coordinator with the North Staffordshire Branch of the RCN, for visiting our stand and inviting VUK to speak at their online educational event.

Maria Ponto, a member of the RCN South West London Inner Branch, for hosting us at the face-to-face RCN Inner and Outer South West London Autumn of Learning event at St. George's Hospital in London.

Christopher Barber, Interim Chair of the RCN Birmingham East, North, and Solihull Branch, for organizing an online session focused on vasculitis. We would also like to thank Dr. McAdoo for presenting at this educational event.

One nurse expressed a sentiment that resonated deeply with us:

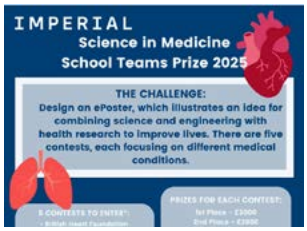
"I want to know more about this and be able to recognize the signs so I can suggest to the doctor that the patient may have vasculitis. I want to help patients get diagnosed as early as possible."

We understand how vital early diagnosis is for vasculitis patients, and we remain committed to raising awareness and supporting healthcare professionals in this effort.

Zoi

Science in Medicine School Teams Prize 2025

Vasculitis UK is pleased to announce that as part of RAIRDA we have co-sponsored the 5th Annual "Science in Medicine School Teams Prize" to engage sixth-form school students with science in medicine.
The National Heart and Lung Institute, the British Heart Foundation's Centre of Research Excellence at Imperial College London, offers the annual prize, and we are so glad to be involved in the 2025 competition.



The aims are to encourage students to:

- stretch beyond the school curriculum, think outside the bubble of traditional biomedical fields, and learn about the excitement of research.
- consider how trends in science and technology will impact on health and medicine in the future.
- understand the importance of a multidisciplinary approach and teamwork to effective research and development for improvements in public and individual health.
- forward think realistically by realising the importance of affordability, availability and acceptability in translating inventions towards a reduction in inequality-related poor health outcomes.
- appreciate the importance of effective communication in rolling out scientific developments, via the use of art and design.

We are proud to be involved with this amazing challenge to spread the word and encourage new ideas in rare rheumatic diseases research.

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) Prize

Rare autoimmune rheumatic diseases include Lupus, Scleroderma, Sjögren's disease and Vasculitis. Patients often face common challenges which impact their quality of life, such as fatigue, consequences of immunosuppressant treatment, and navigating life with a fluctuating and often invisible chronic illness. Non-pharmaceutical approaches like nutrition, psychological support, and exercise can support people to improve their quality of life, but testing and researching these solutions can be difficult in traditional clinical trials.
Your challenge is to design an innovative, non-pharmaceutical solution based on science/technology to help improve the quality of life and wellbeing of people with RAIRDs. You should consider how to assess the effectiveness and promote the implementation of such intervention.

Teams should research the disease using reliable sources. Help understanding the patient's perspective can be gained by visiting RAIRDA, Vasculitis UK, Lupus UK, Scleroderma and Raynaud's UK and Sjögren's UK. This prize is supported by the Immunology Theme of the Imperial NIHR Biomedical Research Centre and sponsored by RAIRDA. For more information, please follow the link below. We would love it if you could share with any contacts who have school connections and would be interested in joining a team.

https://www.imperial.ac.uk/bhf-research-excellence/community/

National Musculoskeletal (MSK) Network

On Tuesday the 8th of October 2024 the first National Musculoskeletal (MSK) Network was launched in Wales.
I attended the event, with other representatives of RAIRDA (The Rare Autoimmune Rheumatic Disease Alliance, which Vasculitis UK is part of). It was very interesting to see many healthcare professionals from different departments (rheumatologists, nurses, physiotherapists, occupational health therapists, mental health supporters etc) discussing how they can improve the care of people living with MSK conditions in Wales.

The focus was on people living with arthritis, but RAIRDA's co-chair, Sue Farrington gave an excellent presentation where she raised the barriers that we, patients of rare rheumatic diseases, come across.
Living with arthritis and musculoskeletal conditions in Wales:

A framework for the future 2024 to 2029 that describes an all-Wales vision, mission, and approach for improving services for people with, or at risk of developing, musculoskeletal (MSK) conditions in Wales. This high-level guidance will sit as part of a suite of resources, including future development of service specifications and clinical pathways.

This is the start of something that could be very beneficial, but it is in its early stages and it will need a lot of work. The most important thing is that we were asked to be there, to be involved and to continue collaborating with the network.

Zoi Anastasa

AAV patient summit 2024 – organised by Vasculitis International

The second AAV patient summit was held on October 24th and 25th, 2024, in a beautiful city in the Netherlands, Amersfoort, and it followed the first one in Madrid in 2022 that was organised by the CSL Vifor pharmaceutical company.
It was awe-inspiring to breathe in the atmosphere of the event. Patients, doctors, and specialised nurses from 11 different countries participated in the two-day meeting organised by Vasculitis International. A patient-centred event!

The summit focused on the need for specialised nurses in the care of vasculitis patients.
The two-day event consisted of presentations, plenary sessions, and workgroups; Patients', nurses' and doctors' groups, then country groups and mixed groups. Barriers were explored, downsides were found, but the benefits triumphed. It was evident that everyone agreed on the need for awareness and how having specialist nurses would enhance patient care.
I have never been in a meeting where every single person agreed on something so enthusiastically. The willingness to work together and find ways to improve the care of vasculitis patients warmed my heart. As I always say, together we are stronger!

Dr Rosemary Hollick and Vasculitis consultant nurse Georgina Ducker were there. Dr Hollick's work provided the data to support the call of specialist nurses. The feedback we got has been excellent ***Thank you so much for sharing these valuable resources and for all the effort that has gone into this important initiative. Thank you also for your dedication and commitment to advancing vasculitis care,*** was the comment from Dr Padoan, Italy.
Georgina Ducker said: ***Thank you for arranging such a wonderful meeting in Amersfoort. I feel very privileged to have been able to take part. It was very satisfying to see such enthusiastic patients and health care professionals.***

My favourite quote comes from a patient, Inge Lin-Mess, from the Netherlands:
What I would like to add is that I was surprised, astonished, in short, super flabbergasted by the enthusiasm and boundless positive energy that the doctors and nurses from all participating countries shared to discuss this idea.

A big thank you to the organising committee:
The organising committee
Peter Verhoeven – Chairman, Vasculitis International
Dr. Hilde Remmelts – Nephrologist Meander Medical Center
Anneloes Cirkel – Vasculitis Nurse Meander Medical Center.

The Welsh Parliament Health and Social Care Committee has published their report titled "Supporting people with chronic conditions".

Supporting people with chronic conditions
Welsh Parliament Health and Social Care Committee January 2025

Link to report here

Key people involved

Members of the committee	Other members involved during the inquiry
• Russell George MS (Chair) • James Evans MS • Lesley Griffiths MS • Mabon ap Gwynfor MS • John Griffiths MS • Joyce Watson MS	• Gareth Davies MS • Sarah Murphy MS • Jack Sargeant MS • Mark Drakeford MS • Sam Rowlands MS

The overall message

The inquiry highlights a lack of focus on people with chronic conditions who rely on regular healthcare access. Despite the Welsh Government's vision of integrated, person-centred care, many patients experience fragmented treatment, with services operating in silos and lacking shared decision-making.

While prevention is key in the long term, immediate improvements are needed to ensure proper support for those already living with chronic conditions. The report makes several recommendations, stressing that systemic funding and service delivery issues must be addressed to achieve truly person-centred care.

The inquiry
The inquiry was conducted in two stages:

- In stage one, stakeholders identified key themes, highlighting the need for holistic, person-centred care for those with multiple chronic conditions.
- Stage two focused on improving services for people with multimorbidity, tackling inequalities, promoting best practices, supporting self-management, and strengthening prevention efforts.

Evidence was gathered through written submissions, discussions with stakeholders, oral evidence sessions, and interviews with individuals with lived experience.

Below is an overview of the different areas of the inquiry, focusing on the analysis done by the Committee and relevant recommendations.

Person-centred approach

The committee acknowledges the growing prevalence of chronic conditions and the need for a person-centred approach in healthcare. While the Welsh Government has recognised this need, implementation has been inconsistent and slow. Achieving true person-centred care requires long-term systemic changes, strong leadership, and investment.

In the short term, more must be done to ensure that people with chronic conditions are partners in their own care. Individual care plans should be reviewed to ensure consistency, and patients should have time to discuss treatment options with healthcare professionals. Self-management support, including awareness of charities and digital tools, should be enhanced, though digital solutions should not replace community-based support.

Unpaid carers play a vital role and need greater recognition and support. The committee is concerned about the impact of funding cuts on respite services and will consider this in the upcoming Welsh Government budget review. Additionally, while quality statements set care standards, there is a lack of clarity on their implementation and accountability, with best practices not being widely shared across Wales.

continued on page 21

Relevant recommendations

Recommendation 1. The Welsh Government must take urgent action to ensure a renewed focus on the delivery of person-centred health and care services that are designed around the individual, not their condition. In its response to this report, the Welsh Government should set out the work it is doing to implement its refreshed actions to support its 'A Healthier Wales' strategy. This should include specific milestones for delivery of the refreshed actions and an assessment of how they will improve care and services for those living with chronic conditions.

Recommendation 2. The Welsh Government should work with health boards to explore reorientating services to 'wrap around' patients living with chronic conditions, providing 'one-stop-shop' clinics that combine different services and medical professionals in one place. In its response to this report, the Welsh Government should provide details of current work to provide services in this model, and then provide an annual update to us with examples of new services that are being developed

Recommendation 3. The Welsh Government should review, as a matter of urgency, the use of individual care plans for patients with chronic conditions to ensure that all eligible individuals are offered a plan as a matter of course and to ensure consistency of practice. It should report back to this Committee with the findings of this review 12 months after the publication of this report

Interaction with healthcare professionals

The committee emphasises the critical role of primary care and strong patient-GP relationships in managing chronic conditions, highlighting concerns about limited consultation times and the need for healthcare professionals to better understand patient experiences through improved training.

They stress the importance of multidisciplinary teams, including Allied Health Professionals, in providing comprehensive care and reducing hospital admissions. However, they note a preference among some patients to see GPs even when other professionals might be more suitable, calling for better public understanding of these roles.

The committee also notes the need for enhanced collaboration and communication across healthcare services to avoid delays and confusion, particularly during hospital discharges. They advocate for centralised sharing of best practices and express frustration over the short-term nature of pilot project funding, which often leads to the loss of valuable innovations. Additionally, they highlight the urgent need for digital transformation in healthcare systems to improve record-keeping and information sharing, expressing concern that Wales is lagging in this area.

- **Relevant recommendations**

Recommendation 6. The Welsh Government should work with NHS Wales to improve public understanding of the different roles of members of the multidisciplinary team in primary care and ensure that direct referral services provided by allied health professionals are clearly signposted to encourage their greater use.

Recommendation 7. In its response to this report, the Welsh Government should provide an update on the review of the All-Wales communication protocol between primary and secondary care, and set out how it is going to work with NHS Wales to improve communication between primary and secondary care.

Recommendation 8. In its response to this report, the Welsh Government should set out its approach to ensuring that good practice for supporting those living with chronic conditions is shared across health services in Wales so that pockets of good practice become disseminated across the system. The Welsh Government should clarify the role the NHS Executive and clinical networks play in this work.

Recommendation 9. It is important that successful pilot projects which deliver improvements for patients are identified so that good practice and innovation can be shared across Wales. Within 6 months of the publication of this report, the Welsh Government should set out clearly its own expectations of how the success of individual pilot projects should be evaluated by Regional Partnership Boards to encourage improved collaboration between services.

Workforce

The health and social care workforce faces significant challenges, worsened by the pandemic, with high levels of stress, burnout, and low morale among staff. Addressing recruitment and retention is crucial to effectively supporting those with chronic conditions. While the Welsh Government's investment in training healthcare professionals is welcomed, there is a pressing need for more specialist nurses, particularly in deprived areas. The lack of centrally held data on specialist nurses in Wales is concerning, and an urgent audit is needed to assess current numbers and future requirements. Witnesses emphasised the importance of workforce planning based on population health needs, which is not consistently happening. Greater clarity and strategic planning are essential to meet these demands.

continued on page 22

- **Relevant recommendations**

Recommendation 11. The Welsh Government should collect and publish data on specialist nurses working in Wales, including the number of specialist nurses and their locations. The Welsh Government should provide an update on the progress of implementing this recommendation to this Committee within 12 months of the publication of this report

Recommendation 12. The Welsh Government should develop a workforce plan for specialist nurses to ensure the future sustainability of the services they provide, with an emphasis on ensuring equal access for those living across Wales.

Mental health

There is a strong link between chronic conditions and mental health issues, with at least 30% of people with chronic conditions also experiencing mental health problems. Conversely, mental health issues can hinder self-management and engagement with healthcare, worsening physical health. Despite this, mental health support is often not signposted at diagnosis, even though a chronic condition diagnosis can profoundly affect mental wellbeing.

The committee stresses the need for better integration of mental and physical health services and calls for healthcare professionals to have a basic understanding of mental health support. Social prescribing can significantly improve wellbeing for those with chronic conditions, but limited link workers and community resources hinder its effectiveness. Additionally, people with severe mental illness often face the worst health outcomes and struggle to access services. While the Welsh Government's draft Mental Health and Wellbeing Strategy aims to address this, the committee urges more urgent action, including regular physical health checks for those with severe mental illness.

- **Relevant recommendations**

Recommendation 13. Mental health support should be signposted for all at diagnosis with a chronic condition. In response to this report, the Welsh Government should set out how it plans to implement this and should then provide an update to this Committee in 12 months on progress made.

Recommendation 14. The impact on well-being and mental health of being diagnosed with a chronic condition is well documented. The Welsh Government should ensure that, as Quality Statements are developed for chronic conditions, this impact is recognised and the need for mental health support to be available is included.

Recommendation 16. In its response to this report, the Welsh Government should provide the Committee with an update on the implementation of the social prescribing framework, with a particular focus on how the needs of those living with chronic conditions are being met.

Prevention

The NHS in Wales is struggling to meet current demands, and the rising number of people with chronic conditions will only increase the pressure. A shift towards prevention is crucial for sustainability, but lengthy waiting times and limited resources often sideline preventative efforts. While the Welsh Government's A Healthier Wales strategy promotes collective responsibility for health, clear actions and targeted interventions are needed to address the growing prevalence of chronic conditions. Tackling health inequalities is vital, as people in deprived areas are more likely to have multiple chronic conditions and shorter life expectancies. Chronic conditions are also more prevalent among ethnic minority communities, who are less likely to engage with screening and preventative programmes. Building on pandemic-era community engagement, tailored support and cultural awareness training for NHS staff are essential.

Prevention cannot rely solely on the NHS; wider determinants like education, housing, and employment play a significant role, requiring collaboration across local authorities, the private sector, and the third sector. The third sector is crucial in supporting those with chronic conditions but faces financial pressures and short-term funding, hindering long-term planning. Preventative programmes like Healthy Weight: Healthy Wales and Smoke Free Wales are welcome, but greater efforts are needed to encourage participation. Improving health literacy is also key, empowering people to make informed health choices and reducing reliance on health services.

- **Key recommendations**

Recommendation 19. The Welsh Government should work with partners, including local authorities and third sector organisations, to improve the connections between different sources of support for people living with chronic conditions to address broader issues beyond health, including housing, debt, and employment.

Recommendation 20. In response to this report, the Welsh Government should provide an update on the introduction of cross-governmental health impact assessments and outline how they will guide policy making to address health inequalities.

Experimental Arthritis Treatment Centre for Children Showcase Event

Liverpool 22nd March 2025

The EATC4Children Showcase Event was an inspiring and impactful day at the Institute om the Park at Alder Hey Children's Hospital. From young people sharing their research journeys to groundbreaking scientific discussions, charity partnerships, and hands-on lab experiences – it truly showcased the power of collaboration.

The round table discussions at the Showcase were dynamic and insightful, bringing together young people, researchers, clinicians, and charity representatives to explore the big questions in paediatric rheumatology research.

Key themes that emerged:

- Unmet needs in paediatric research – Participants highlighted gaps in early diagnosis, treatment personalisation, and transition care for young patients. There was strong agreement on the need for more patient-led research and a life-course approach to treatment, with the Voice of the Child always at its heart.
- What matters most to young patients and families – Discussions emphasised mental health support, better communication between doctors and families, and ensuring that young people are not just subjects in research, but active contributors in shaping studies.
- How EATC4Children can address these challenges – Ideas included expanding patient and public involvement (PPI) initiatives, strengthening international collaborations, and increasing awareness of paediatric autoimmune diseases to improve funding and research opportunities.
- Closer partnerships with patients and charities – Many partners, including Vasculitis UK, Versus Arthritis, LUPUS UK, RAiISE, LifeArc agreed that stronger collaborations between researchers, patients, and advocacy groups are essential for translating research into real-world impact.

I received a warm welcome & had successful day in Liverpool. It was a unique opportunity to meet the dedicated clinical & research staff of the Institute, meet and hear from young people and their parents & have a tour of the research labs - fabulous high tech facilities.

I was particularly moved to hear the stories of the young people living a range of rheumatic diseases – often having similar struggles to those we know when diagnosed with Vasculitis, having fatigue, pain, feelings of loss of previous life, isolation & fear of future. But I also saw a lot of hope & support & normalisation- a few teens meeting & enjoying having peers & lots of positivity in the research to better manage their conditions; said Diana Shonfield, a trustee of Vasculitis UK, who attended the event and manned the VUK stand.

RACEMATE

Do you have a diagnosis of Eosinophilic Granulomatosis with Polyangiitis (EGPA) and take regular maintenance oral steroids (at least 5 mg of prednisolone daily)?

If so, you may be eligible to take part in the RACEMATE trial: A Randomised Placebo Controlled Trial – to Explore the Efficacy and Mechanism of Action of Tezepelumab in Eosinophilic Granulomatosis with Polyangiitis. This exciting trial opened for enrollment in June 2024.

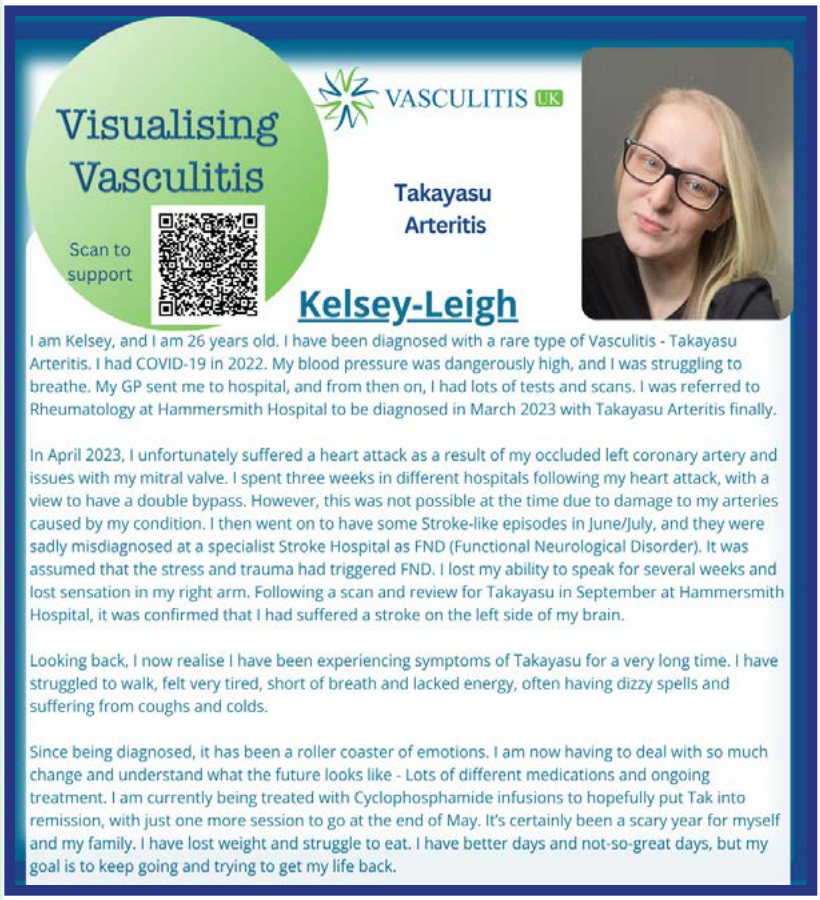
Tezepelumab is a biologic medication that is given as a monthly injection under the skin. It targets a protein called TSLP found in patients with EGPA. This protein is also found in patients with asthma, and tezepelumab is already used in patients with severe asthma to reduce asthma exacerbations and improve symptoms and quality of life. Recently published trial data has also shown very promising results in patients with severe sinusitis and nasal polyps. We have focused on tezepelumab as we believe it may help to increase the likelihood of achieving and maintaining remission in patients with EGPA whilst allowing patients to reduce their daily oral steroid dose.

Currently, this trial is open in 10 centres across the UKIVAS and UK Severe Asthma Registry (UKSAR) networks. So far, 26 participants have successfully been enrolled, and there are plans to enroll a total of 66 patients throughout this rare disease trial.

Please speak to your local vasculitis/asthma specialist or email racemate@imperial.ac.uk to find out more.

Tributes

Kelsey-Leigh



Kelsey-Leigh fought hard against Vasculitis. Unfortunately, the damage was too significant, and she passed away at Hammersmith Hospital on 12 March 2025. She had amazing strength in fighting this battle and will be missed by many.

Vasculitis UK would like to send love and condolences to her Parents, Nadine and Darren, and sister, Taylor, and all her family at this difficult time. Kelsey-Leigh and her family and friends have raised significant amounts to support VUK in such a selfless manner during highly challenging times; we will forever be grateful. Sleep well, Kelsey-Leigh, you were incredible.

Michelle Wood

Dear Chelle, Fly high!
When I was diagnosed with vasculitis in 2014, I realised it would affect my life in multiple ways. I hadn't realised the amazing people it would bring into my life. I said goodbye to a very special lady a few months ago.
Let's travel 10 years back, when a friendship flourished in Vasculitis UK's online support group. Chelle was an ''expert'' and I was a newbie. She supported me during the difficult first part of my journey. We cried, laughed, and made big dreams about travelling to fabulous places.
We wanted to donate our bodies to a project called Body Worlds at the Institute for Plastination in Heidelberg, Germany. When we got a big fat no, thank you – we saw that reading between the lines of the very polite email they sent, we were very disappointed, and a lot of words that I am not going to repeat here were screamed loud enough for them in Germany to hear us!

Chelle had a magic power; she could bring people together. She created online groups and was the connection between strangers. When the friendships flourished, she usually left the group. I will mention one very special group she created in 2015, the Vascie Princesses. To start, there were 8, but now only 5 of us are still here. But the group is still going and has been the place for strong friendships to grow and a sanctuary for every one of us. Our journeys would have been different and much more difficult if Chelle hadn't brought us together.
I remember when I convinced myself that I was well enough to travel around 300 miles to go and see her in Rochdale. It was a surprise visit, and I will never forget her smile when she realised that I DID it. I managed to get myself there to meet her in person. Over the years, she was very ill, and many times we thought she wouldn't make it, but she did. Somehow, it made me believe she could beat anything. When her brother contacted me in the middle of October to inform me of her passing, I found it hard to believe. We said goodbye to Chelle on the 7th of November, just a few weeks from her 51st birthday. It was a small ceremony, full of colour, tears and laughter; the revenant was also a magician, Chelle would have loved him! Thank you, Marilyn, Jasmine, and Lee, for making me feel like one of the family!
Chelle, we used to say this to each other: I met you as a stranger. Now I have you as a friend. I hope we meet in our next walk of life where friendship never ends. Until we meet again, keep sending me glitter!

Zoi

Bequests - In Memoriam Donations & Fundraising

John Harrison kindly donated £100, for the hard work the charity does.

A Donation of £316 was made in memory of a beloved mum Maureen Ann Harris

Louise Poole donated £10.00 in meomory of her Dad xx.

£357.75 in lieu of festive gifts from Rachel Marsh's friends. This is to mark having GPA for thirty years.

A donation of £50.00 to acknowledge our thanks for a beautiful musical gift. Thank you Jo for entrusting us with the piano loved so much by your mum xxxxxx

Janet Marriage much loved and will always be remembered. Raised £1214

Susan Mist, who was born in Dover. A wonderful wife, mother, grandma and a friend to so many. She is much loved and will always be remembered. Raised £300

Adam Morgan is much loved and will always be remembered. Raised £120

Dave Howard much loved and will always be remembered. Raised £441

Andy Narramore from Northampton. He is much loved and will always be remembered. Andy was diagnosed with vasculitis in 2004 and survived this little-known disease for 20 years. Raised £468

Michelle Wood, who was born in Pool in 1973. She is much loved and will always be remembered. Raised £158

George Jefferson, who was born in Little Downham. He is much loved and will always be remembered. Raised £187

£50 was kindly donated in memory of Dr Rosemary Nash by Victor Schrieber

Donations in total of £440 via Memory Giving was made by various donors to the Henery Watmough-Cownie Fund Page

Donations in total of £2825 via Memory Giving was made by various donors to the Elizabeth Ann Perry Fund Page.

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**

VASCULITIS UK

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.

Virgin money giving Donate here

Donate with JustGiving

PayPal MasterCard VISA

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
Christine Lee - 01480 869162 - chrislee0307@btinternet.com

Cambridge Group
Lesley Noblett - 0776 5897780 - 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
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

Lincolnshire Group
Sandra Lee - 0754 514 4777 - sandylee777@hotmail.co.uk
Caroline Meyrick - 01780 460354 - cmmyerick@gmail.com

London
North London Group
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

Northampton Group
Mel Alexander - 07884257123 - northants-vsg@outlook.com

Norfolk Vasculitis Support Group
Mark Sayer - msayer1502@gmail.com

The North West Group
TBA

Oxfordshire Group
Sue Ashdown - 07817303625 – vsgoxford@gmail.com

Plymouth Group
elaine203@live.com

Solent/Portsmouth Group
Julie Ingall - Julie.ingall@porthosp.nhs.uk

Surrey Group
Peter surreyvsg@gmail.com

Sussex by the Sea Vasculitis Support Group
Antony Hart - Antonyghart@outlook.com

Swindon Support
Wendy and Lisa swindonvsg@mail.com

West Midlands Group
David Sambrook – davsamuk@yahoo.co.uk
Margaret Gentle - 0121-243-5621 - mgentle128@gmail.com

West Country Group
Website https://vasculitiswest.wordpress.com/
Charlotte Stoner - 01626 872420 - westcountryvasculitisgroup@outlook.com

West Sussex Group
John Bailey - 07752 122926 – johnbee4@googlemail.com

North and West Yorkshire Groups :
TBA

East Yorkshire Group :
Rachel Weeks - 07968 959 850 email rachel@yorkshirevasculitis.org.uk

North East Yorkshire Support Contact :
TBA

South Yorkshire Social Group Contact :
Jenny Gosling - email jenny@yorkshirevasculitis.org.uk

WALES

North Wales - (Contact Person)
Pat Vernalls - 01766 770546 - patvernalls@btinternet.com

North Wales Group

TBA

South Wales Group
Jenny Fulford-Brown - 029-2021-8795 - jenny.fulford-brown@ntlworld.com
Ryan Davies – ryan@wegeners-uk.co.uk
Angharad Jones - Angharadjones.vas@gmail.com

SCOTLAND

Edinburgh and Lothian (Contact Person)
Jimmy Walker - 07725 770103 - jamzywalker@gmail.com

Republic of IRELAND

(Contact Person)
Joe O'Dowd - 00353 (086) 2345705 – dwodo@iol.ie

Ireland - Vasculitis Awareness Ireland
Vasculitis Awareness Ireland Website http://vasculitis-ia.org/
Julie Power - 028 44 842889 - vasculitisireland10@gmail.org.uk

VASCULITIS UK

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

Visualising Vasculitis

Scan to support

VASCULITIS UK

GPA/ANCA associated vasculitis

Wendy

There are many ways you can look at vasculitis.

I've had GPA for nearly eight years now, and it's amazing that I can look back on so many years of ups and downs. Life was very bleak for the first two years. Currently, I've got problems with my eyes and digestive system. You can't see the problem with my eyes in the photo because I've been putting steroid eye drops every hour for the last five days. With another five weeks of eye drops (slowly decreasing them), I hope to see the back of that particular problem, but my digestive issues seem more difficult to solve.

Most of all, I'm hoping that the monoclonal antibody infusion I had in March will give me a boost very soon. It wears off quickly, so I'll have another one in August. I can't visualise what lies further ahead, but I'm always hopeful of discovering new solutions to the ongoing challenge of living with vasculitis.

Visualising Vasculitis

Scan to support

VASCULITIS UK

IgA Vasculitis

Kelly

I've had IgA Vasculitis for the past fourteen years. It has been life-changing for me, and I often still grieve the old healthy me. I look well from the outside, which adds to my feeling of isolation.

I've developed many other conditions since my original vasculitis diagnosis, some as a direct knock-on effect, such as fibromyalgia. I've found that it's had a negative impact on each area of my life - career, relationships, & friendships. I have found spirituality and meditation somewhat comforting, and I love being around animals.

My mum has been my number one support throughout this tough journey, for which I'm incredibly grateful. Some days are better than others, but it isn't just the physical limitations and pain - it can be as equally as hard dealing with the acceptance of this new way of life.

It has taught me resilience and that, above anything else, health is the most important thing.

Visualising Vasculitis

Scan to support

VASCULITIS UK

GPA with Sinus and Lung involvement

Amanda

My husband and I tried for a baby for many years, and when I fell pregnant, I started getting strange symptoms... it was all put down to pregnancy related. After my son was born, the symptoms got worse: Sinus pain, Headaches, Joint pains – I couldn't bend my legs or fingers.

GP was perplexed and had no idea what was going on as my blood tests were OK!

My nose then collapsed, and I started coughing up blood. I was taken into hospital, where they found lung lesions and diagnosed me with GPA. I started my treatment with Rituximab, and I was then diagnosed with Subglottic Stenosis and Asthma. I must have Dilatation every six months on my windpipe. I was also suffering from a blocked tear duct and have just had Lester Jones tubes fitted in my eyes.

Every day is a struggle mentally, but I still try my best to go to work and look after my son. I hate attending my local hospital as no one knows what to do with me, and I get pushed between hospitals. I just hope I get into remission soon!

Visualising Vasculitis

VASCULITIS UK

GPA with MPO ANCA

Sian

In the middle of September 2022, I did my third triathlon of the season. I'd been losing weight successfully, and apart from feeling really tired, I was kind of okay. I'd been to the doctors / minor injuries unit far more in the previous six months than ever before for a variety of reasons but didn't really think much of it. By the final week in September, I was in so much pain I was struggling to move, and then I started coughing up blood.

I was so very lucky to be taken to an intensive care unit where there was a consultant on shift who was a Vasculitis specialist. He looked at my history, did lots of tests, and I was diagnosed within 48 hours. Then followed high flow oxygen, lots of sessions of chemo, many plasma exchanges, steroids, rituximab, and other medications. After eight days in ITU, I went to a ward for a week before going home. That was when I had to begin to learn to adjust to my 'new normal'.

Nearly two years on from my diagnosis, I am so much better than I was but still constantly frustrated with all the things I can no longer do. It affects me both mentally and physically, and I just keep going as much as I can. On my bad days just walking even a few steps hurts so much, and the fatigue exhausts me. I am constantly scared of whether there are new symptoms that are related to the vasculitis.

I found the Vasculitis UK group soon after being diagnosed when everything was new and terrifying. I am so grateful for the people there who understand what I'm going through, who can offer advice and support, and who are just 'there' for you when you're having a rubbish day and have had enough of it all, or when you have a question which seems so trivial.

EVENTS

VASCULITIS UK

AGM 2025

Sunday May 18th 2025

Radisson Blu Hotel - East Midlands Airport, Derby, DE74 2TU

13:00 - 15.30

Registration and light buffet 12.30

Speakers:

David O'Regan - Meet Dwayne

Alice Muir, research nurse - Imagery techniques for people living with vasculitis.

Jason Whittaker - Impact of PIP reform

This is an in-person only event and will not be recorded. to confirm attendance please email:**AGM@vasculitis.org.uk**

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:

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

Independent Advisor:
Duncan Cochrane-Dyat

Medical Advisors & Scientific Advisory Board
Prof David Scott
Prof David Jayne
Prof Richard Watts
Prof Charles Pusey
Dr Joanna Robson
Dr Rachel Jonea
Dr Silke Brix
Consultant Nurse Georgina Ducker

Research Awards Co-Ordinator:
Laura Whitty

Trustees:
Dorothy Ireland
Jane Edwards
Peter Rutherford
Heidi Pollard
Diana Shonfield
Claire Tolliday
Maxine Wright
Antony Hart
Giles Hart

Volunteers:
Kevin Soper
Shanali Perera
Vivienne Dunstan
Janice Mather
Kath Macintosh
Jayne Hardman

The VUK Shop Manager:
shop@vasculitis.org.uk

Web Admin:
Zoi Anastasa

CONTACT US

Helpline:
0300 365 0075

Website:
www.vasculitis.org.uk

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

Phone:
0300 365 0070

Published by:
VASCULITIS UK

Member of EURORDIS Rare Diseases Europe

Printed by: Whittington Moor Printing Works Ltd, Stonegravels Lane, off Sheffield Road, Chesterfield, S41 7LF
01246 221892 studio@WMPW.co.uk