VASCULITIS UK

NEWSLETTER JOURNAL

AUTUMN 2025 ISSUE 70

‘View from the Chair’

I was elected as Chair of VUK in May this year and so it is with great pleasure, and a little trepidation that I am writing this, my first article for the newsletter.

As a group of Trustees most of us are all relatively new in post, and so this year has been very much about finding our feet and getting to grips with all of the things that go on in this wonderful charity. I have been struck, in particular by the high regard in which Vascultis UK is held both by the medical profession and those research teams who are working tirelessly to advance knowledge about and treatments for vasculitis and other rare auto-immune diseases. Much of this is the legacy that has been left by John and Susan Mills, and the work that has been picked up by Zoi, who is currently the only person employed by VUK. The collaborative relationships that have been built over the years and that continue to evolve are critical to the standing of VUK in that wider community.

The key role that VUK plays as part of a number of other groups and alliances including Vasculitis International, the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) and EURORDIS rare diseases Europe enables our involvement in the development of greater understanding of, and treatments for this group of Vasculitis conditions that we all have lived experience of.

What is also obvious is that the other significant asset we have are the members and supporters of VUK. I have been struck by what a professional, knowledgeable and supportive peer group there is out there. The role that you all play on a day to day basis supporting and informing each other and running informal and more formal groups and networks ensures that those of us working at the heart of the charity can focus on those other things that enable the work to continue.

Since May this year we have undertaken a review of the work that we are doing and we have highlighted some areas that have needed our more urgent attention. We have accepted that the Trustees as a small group of people, all of us living with vasculitis and many of us with other commitments on our time, need to ensure that we have efficient systems in place to ensure that the charity is able to function effectively. It would be true to say that we have identified that some of these require an urgent overhaul. The charity sector has become increasingly professionalised and regulated over the past few years, and we have not always kept up with these developments. We have therefore started with focusing on a few key areas:

- We have welcomed five new volunteers to the helpline, and have invested in them not only with our internal training but with external CPD accredited training from the Helplines Partnership. We have developed recording systems and quality assurance processes for advice provided.

- We have taken the decision to recruit a part time fundraising lead. Fundraising is a critical part of what we do as a charity and we have some amazing people out there who continue to support us. However, we recognise that we need to be more proactive in our approach to fundraising to create opportunities and sustainable funding streams.
- The new fundraiser will also be responsible for undertaking a review of our membership/supporter structure, including how we can maximise donations made to VUK using Gift Aid

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- We are also in the process of reviewing the VUK 'shop' and have two new volunteers who are going to take on this role in the coming months. Amongst other things the shop provides promotional material to our volunteer fundraisers and we want to be able to expand these offers.

- Over the next 12-18 months we will be reviewing all of the our activities and continuing to identify our strengths, weaknesses and gaps

We will continue to keep you all updated, and we would welcome any suggestions that you would like to make. Please email me on Claire@vasculitis.org.uk if you have anything that you would like to see us consider.

Finally it is with great pleasure that I thank our retiring Chair, Dorothy Ireland for her work over the past few years, most notably in leading VUK to becoming a 'Charitable Incorporated Organisation'. Dorothy is standing down as a Trustee in a couple of months and will be very much missed for her extensive knowledge and huge dedication. We wish her and her family all the very best for the future.

Vasculitis UK will have their AGM on Sunday 30th November online

Your attendence is invaluable as we need to have a quorum

Please,confirm your attendance so we know if we have enough number of attendees

Email us at agm@vasculitis.org.uk

More information will follow on our website

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This editorial feature is done in loving memory of my dear sister, Clare Grossman

Hello, I'm Kevin, and I volunteer with VUK as the editor of our biannual newsletter.

My journey with VUK began after the loss of my sister, Clare, who was diagnosed with an aggressive form of Wegener's Granulomatosus at just 38. At the time, my family knew very little about the disease. Through VUK we found information, guidance, and support, and we wanted to help raise awareness so that other families wouldn't feel as lost as we once did.

Soon after, with encouragement from John and Susan, I became involved in the newsletter. It gave me the chance to do something positive and contribute to the charity's work in a way that felt meaningful.

In 2025, vasculitis touched our family again when my granddaughter was diagnosed at the age of 14. The condition affected both her kidneys, and once more, the knowledge, advice, and kindness we received from VUK—especially from Susan Mills—made a world of difference. I'll always be grateful for that, and it's why I continue to stay involved with this amazing charity.

Dear Reader

Welcome to this Autumn edition of your charities Newsletter/Journal, which covers much of the work done by supporters, volunteers, trustees and medical professionals helping to both raise awareness and fundraising for this wonderful charity.
As we say good bye to our previous Chair (Dorothy) and thank her for all she has done to help grow this charity over the last 15yrs we welcome Claire Tolliday whose report ' View from the Chair' is on Page 2. We also have an insight of how much work is carried out by all of those previously mentioned and especially Zoi, who has been waving the Vasculitis Flag across the nation and beyond. I make no apologies for the front page image as this is my Granddaughter helping family and friends raising awareness and funds for this fantastic Charity. So Grab your favourite brew and enjoy.....

Kevin Soper

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.

Vasculitis UK Support Meeting - Radisson Hotel East Midlands

Extremely interesting Vasculitis UK support meeting May 18th 2025
We were introduced to Dwayne (a vasculitis chat bot) - all thanks to David O'Regan. You can meet Dwayne via the Vasculitis All Ireland website.
vasculitis-ia.org/ask-dwayne
My sister, Janice, came with me to the meeting for extra support, we sat at the back of the room and she was having a little sketch while she was listening.

Nurse Alice's presentation was so good she sent me drifting off to dream land. "Imagery Techniques For Those Living With Vasculitis", coping strategies in imagery.
To be honest Alice's presentation has the potential to help anyone living with a long term health condition.
I also wanted to say it was lovely to see and chat to old friends I had not seen for a few years.

Susan Mills

Director of Operations Report By Zoi

Hello everyone,
I hope you've been coping with the strange weather we've had lately – jumping from heatwaves to storms. Personally, I find the heat quite exhausting (which always makes my friends laugh, since I grew up in Greece!).
It's been a very busy few months for Vasculitis UK, and for me too. Since April, I've been travelling a lot for conferences, meetings, and research projects. In May alone, I was away for 13 days – my dog was so happy when I came home that now she follows me everywhere!
We've attended our regular events such as the British Society of Rheumatology Annual Conference and the Royal College of Nursing Congress, as well as some new ones, including the Scottish Systemic Vasculitis Network meeting, the BSR Patients' Voices meeting, and the first UK Child Health Research Collaboration event. I would like to take the opportunity to thank our trustees Tony, Giles and Diana and our research coordinator Laura for supporting stands at events!

My work at Vasculitis UK has helped me grow my knowledge about vasculitis, patient care, and research. Recently, I supported two appraisals for NICE (the National Institute for Health and Care Excellence), which looks at which treatments can be approved for use in the NHS. I'm pleased to share that one of these appraisals had an excellent outcome: the medicine benralizumab can now be prescribed to treat patients with EGPA vasculitis, without the need for them to be under an asthma clinic. This change will make treatment easier to access for many people. A special thank you goes to patient advocate Lev Ariel, who spoke powerfully at the committee meeting and helped make this possible.
I had the honour of being the patient with lived experience working alongside a dedicated group of healthcare professionals to update the ANCA-associated vasculitis (AAV) guidelines for the British Society of Rheumatology (BSR). This project took many months and an incredible amount of work from everyone involved. The new guidelines were officially published in June 2025, and you can read more about them in a separate article in this newsletter.I want to acknowledge two important things. First, these guidelines were created through the collaboration of many healthcare professionals from different specialties – rheumatology, kidney care, respiratory medicine, ENT, and more. Remarkably, much of their work was done in their own free time, motivated purely by a shared commitment to improving patient care. A very special thank you goes to Professor Loraine Harper, who led the clinical side of the project with dedication and expertise. Secondly, I would like to recognise Jayne Hardman, who I affectionately call our "nose ambassador." Jayne has campaigned tirelessly against the misleading term limited vasculitis, which can understate the serious impact of disease affecting the sinuses and nose. I have been one of her biggest supporters in this effort. While changing entrenched medical language takes time, I'm pleased to share that these new guidelines take the first step – recommending the use of terms like ENT-localised GPA or sino-nasal GPA instead.
In May, we had an important change within Vasculitis UK. Dorothy Ireland stepped down as Chair, and the trustees voted for Claire Tolliday to take over the role. I still work closely with Dorothy and hope she'll continue to advise us after leaving the trustee board at our next AGM. Dorothy has been a huge support to me personally, and her leadership has taken Vasculitis UK to new heights.
When I first joined Vasculitis UK, I was amazed by the hard work and dedication of everyone involved. Years later, I'm still inspired by the teamwork, collaboration, and trust within our organisation. I'm especially excited about the new volunteers who have joined us recently – fresh ideas and energy help us grow and improve. If you'd like to volunteer, whether to help at events, join research advisory groups, or support our online communities, please get in touch with me at zoi@vasculitis.org.uk.
Finally, I want to thank all of you – our members, supporters, and fundraisers. You are the reason we exist, and your generosity keeps our work going. I'm also grateful to the medical professionals who partner with us and share their expertise through our expanding Scientific Advisory Board, which now includes eight specialists in vasculitis.
I hope the rest of 2025 treats us all kindly. We're already looking forward to the start of 2026, which will bring an exciting international event – the International Vasculitis Workshop in Melbourne, Australia.
Take care and thank you for being part of our community.

Zoi Anastasa has raised £512 reflecting on her Vasculitis journey.

New 2025 Guidelines for ANCA-Associated Vasculitis (AAV)

Helping patients get the right care, at the right time

ANCA-associated vasculitis (AAV) is a rare and complex condition that can affect many different organs in the body. Because it's so complicated, people with AAV are often cared for by a team of specialists – including rheumatologists, kidney doctors, lung specialists, and ear, nose, and throat (ENT) experts.

Over the past few years, medical societies have been working to update advice on how best to treat AAV. The **British Society for Rheumatology (BSR)** has now released brand-new recommendations for 2025, building on their last guidelines from 2014.

A group of experts – including doctors, nurses, and a person with lived experience of AAV – reviewed the latest research and advice from around the world. The result is **26 clear recommendations** to help healthcare teams deliver the best possible care for people with AAV.

What's New in the 2025 Recommendations?

The new guidelines cover:

- Treatment for Granulomatosis with Polyangiitis (GPA) and Microscopic Polyangiitis (MPA) – including starting treatment (remission induction) with medicines such as cyclophosphamide, rituximab, glucocorticoids, or avacopan, and advice on long-term maintenance treatment.
- ENT Symptoms and Subglottic Stenosis – guidance for managing throat narrowing and other ear, nose, and throat problems linked to AAV.
- Nomenclature in sino-nasal GPA – terms such as ENT-localised or sino-nasal GPA are preferred as the term limited vasculitis may underestimate the disease burden and Integrated multi-disciplinary assessment in sino-nasal GPA should be offered to the patients
- Treatment for Eosinophilic Granulomatosis with Polyangiitis (EGPA) – with specific advice on medicines and monitoring.
- Service Design – recommendations on how care should be organised, such as specialist clinics with input from several types of doctors and nurse-led services.
- Patient Education and Support – making sure people have the information they need to understand their condition, treatment options, and where to find help.

Why This Matters for Patients

- Faster Diagnosis & Treatment – Early recognition of AAV and quick treatment can save lives and prevent long-term damage.
- Joined-Up Care – Encouraging clinics where specialists work together so you don't have to keep repeating your story to different doctors.
- Focus on You – Supporting people to understand their condition and continue living life as fully as possible, including staying in work where possible.
- Evidence-Based Advice – All recommendations are based on strong medical research, reviewed using the internationally recognised GRADE system.
- Ongoing Improvement – The guidelines also highlight areas where more research is needed, so care can continue to improve.

The full paper is available here.

The **BSR guideline process** is accredited by NICE (the National Institute for Health and Care Excellence), meaning it follows strict standards to make sure advice is based on the best available evidence.

These updated recommendations give healthcare professionals a clear roadmap for managing AAV – but they're also important for you, the patient. They help make sure you're receiving up-to-date, consistent, and high-quality care wherever you are in the UK.

You can ask your healthcare team if the care you're getting follows the new 2025 BSR AAV recommendations – and where to find more information or support.

2025 BSR Management recommendations for AAV

British Society for Rheumatology

Striving to improve care for people living with AAV

(1) Management of GPA and MPA

- All people with active (newly diagnosed or relapsed) GPA/MPA should be considered as having potentially life or organ-threatening disease
- Treatment should follow 2 paradigms: Remission induction and remission maintenance
- CYC or RTX are recommended for induction remission. RTX is preferred in those with active relapsing disease
- Reduced dose GC tapering regimens are recommended.
- Avacopan should be considered in active disease to reduce GC-related morbidity
- Adjunctive plasmapheresis should be considered in cases of severe kidney involvement but NOT pulmonary haemorrhage alone

(2) Management of SGS and ENT disease associated with GPA

- Both subglottic stenosis and sino-nasal disease are challenging disease manifestations that require expert management by an ENT ± specialist with expertise in vasculitis
- The term 'limited GPA' may underestimate disease burden; terms such as 'ENT-localised GPA' or 'sino-nasal GPA' are preferred
- Systemic therapy with CYC or RTX can provide early disease control, delay need for recurrent dilatations in SGS, and limit morbidity in ENT disease
- Care is required to identify potential sino-nasal disease mimics, including recognition of cocaine-associated vasculitis conditions

(3) Management of EGPA

- EGPA should be considered in anyone with asthma, rhinosinusitis and an eosinophil count ≥1 x 10^9/L
- Treatment should follow 2 paradigms: Remission induction and remission maintenance
- Anti-IL-5/5R biologics are recommended (if available) in non-life and non-organ-threatening disease to reduce glucocorticoid-related morbidity
- Life-threatening disease should be treated with CYC or RTX, if there is intolerance or contraindication to CYC

(4) AAV Service specification

- Specialist vasculitis review within 7 days for people with new suspected AAV is associated with fewer serious infections, hospital admissions and reduced mortality
- Nurse-led components of care, specialist vasculitis MDT meetings and cohorted clinics are associated with improved health outcomes

(5) Patient education and support

- All adults, children and young people with AAV (and their families and carers) should receive ongoing, tailored information and education about AAV
- People with AAV should be empowered to collaborate in shared decision making with their healthcare team to reach a joint decision about their care

- AAV = ANCA-associated vasculitis
- Anti-IL-5/5R = anti-interleukin 5/5 receptor
- CYC = cyclophosphamide
- EGPA = eosinophilic granulomatosis with polyangiitis
- ENT = ear, nose and throat
- GC = glucocorticoid
- GPA = granulomatosis with polyangiitis
- MDT = multidisciplinary team
- MPA = microscopic polyangiitis
- RTX = rituximab
- SGS = subglottic stenosis

Scan the QR code for the full guideline or visit rheumatology.org.uk/guidelines

Manchester and Region Vasculitis Patient Awareness and Education Day Sunday 20th July 2025

After the inaugural event in 2023, we were pleased to hold a second Patient Day, organised by Dr Brix from Manchester Royal/Foundation Trust and supported by Vasculitis UK, Kidneys For Life, with sponsorship from MRI/MFT and Vifor CSL.

The agenda was derived from discussions within Greater Manchester Vasculitis Support Group.*

With just under a hundred attendees, we had presentations by Doctors from several hospitals across the region, supported by Specialist Nurses and with patients telling their own stories of how Vasculitis has impacted their lives.

The clinical presentations focused on Kidneys and Lungs, with supporting sessions including "How to eat to help your kidneys", "Self-Compassion and Coping with Fatigue" , and "Treatments for Vasculitis".

Interspersed with ample refreshment breaks, it was a great opportunity for patients and their families and friends to chat about their personal journeys.

We all agreed this was a great success, socially as well as educationally, and are looking forward to making this an annual event.

* Greater Manchester Vasculitis Support Group is very much at the embryonic stage! However, if you are interested in joining us for occasional "tea and biscuit" get-togethers, you can contact us by email at greatermanchestervasculitis@gmail.com

Dean Lane

TELL YOUR STORY

Send your story to kevin@vasculitis.org.uk

FINDING MY VOICE WITH CNS VASCULITIS: SPEAKING UP WHEN THE SYSTEM DOESN'T SEE YOU

Before I became a nursing student, I was an art student—someone who processed the world through creativity, colour, and expression. Five years later, I found myself in a very different space: training to become a nurse while living with a rare neurological condition that few people, even in healthcare, had heard of.

Central nervous system vasculitis (CNSV) is a rare autoimmune disease that affects the blood vessels in the brain and spinal cord. It's difficult to diagnose, poorly understood, and often invisible in medical records. My journey to diagnosis was long and confusing. I experienced neurological symptoms that were dismissed or misattributed. Even after being diagnosed, I found myself explaining CNSV to professionals who had never encountered it before.

As a student nurse, I've had to learn how to advocate for myself while also learning how to care for others. CNSV hasn't significantly affected my ability to learn my role, but the transient ischaemic attacks (TIAs) have caused memory issues, and my neurodivergence adds complexity to how I process and retain information. These challenges aren't always visible, and that invisibility can be isolating.

There's an expectation in healthcare education that students should be resilient, adaptable, and able to "push through". But rare conditions don't follow the rules. They disrupt routines, challenge assumptions, and expose the gaps in our systems. I've had to navigate those gaps while trying to build a career in a system that doesn't always recognise my condition—or me.

Systemic Invisibility and the Search for Data

Rare diseases like CNSV often fall through the cracks. They're underrepresented in data, misunderstood in practice, and overlooked in policy. That invisibility affects access to care, eligibility for support, and the ability to advocate for change.

In an effort to understand how CNSV is recognised nationally, I submitted a Freedom of Information request to NHS England. I asked for data on the number of patients diagnosed with CNSV or related ICD-10 codes (such as I67.7 – 'Cerebral arteritis, not elsewhere classified') from 2017 to the present, including annual and regional breakdowns, diagnostic coding practices, and whether the data covered inpatient or outpatient settings.

The response was simple: **NHS England does not hold this information.**

This confirmed what I had already experienced as a patient—CNSV isn't just rare, it's **invisible** in the system. Without data, we're not counted. And if we're not counted, we're not considered in service design, research, or policy.

Reclaiming Visibility

Writing has helped me find my voice. It's a way to reclaim visibility, connect with others, and challenge the silence around rare diseases. I've met people who feel similarly unseen, and together we're building a collective voice that says: we exist, and we matter.

I believe stories like mine can help bridge those gaps. Whether you're a patient, a carer, or a healthcare professional, your experience is valid. Your voice is part of the solution. CNS vasculitis may be rare, but we are not alone. And we deserve to be seen.

VASCULITIS UK

Helen Hosick
BSc (Hons) Nursing (Adult) Student

CNS vasculitis – a call to increase collaborative working to facilitate clinically-relevant research and improved outcomes for patients

Claire M Rice, Associate Professor in Neuroinflammation and Honorary Consultant Neurologist, University of Bristol and North Bristol NHS Trust, Bristol, UK

Central nervous system (CNS) vasculitis is inflammation and damage to the vessels of the brain and spinal cord. It may occur in the context of vasculitis affecting other organs or may occur in isolation, when it is known as primary CNS vasculitis. It occurs when the immune system is misdirected to attack the blood vessels; sometimes the cause for this can be identified e.g. after certain infections but, more commonly, the reason why this happens is not known.

Although vasculitis affecting the brain and/or spinal cord is relatively rare, it causes a range of symptoms which can include headache, seizures, changes in thinking and personality, limb weakness, problems with control of bowel and bladder, as well as difficulties with vision and/or hearing.

The many different ways in which CNS vasculitis can affect patients makes pattern recognition harder, and this may delay the diagnosis. Furthermore, investigation results are rarely specific to the condition i.e. they can be mimicked by many other neurological conditions. Like other forms of vasculitis, the most accurate way of making the diag-

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nosis is by sampling (biopsy) affected tissue and examining it under a microscope. The threshold for biopsy of the brain or spinal cord is, understandably, relatively high due to the risk of causing neurological injury during the procedure which may add further delay. Furthermore, there is no guarantee that active vasculitis will be demonstrated at the site of biopsy, so false negative biopsies are possible.

However, once the diagnosis of CNS vasculitis is established, some treatments are available and these can be very effective. At present, all the available treatments aim to dampen the overactive immune system.

Due to the rarity of the condition, clinical trials have not been done in CNS vasculitis, and the treatments are often based on those for which there is a stronger evidence base in more common forms of vasculitis e.g. that affecting the kidneys rather than the CNS. These treatments themselves carry risks of side effects, including infection and increased risk of some cancers.

The combination of a rare condition that can present in many different ways, together with treatments that are considered relatively high risk, means that neurologists often find the diagnosis and treatment of CNS vasculitis challenging. There is a clinical need for them to work together with research scientists to find ways of improving the rapidity and accuracy of the diagnosis of CNS vasculitis, as well as access to treatments, including new, less toxic therapies. Given the rarity and complexity of the condition, this can only be done by establishing national/international networks of interested neurologists and researchers, and by pooling of clinical data and expertise. Although overdue, we are currently working towards the establishment of a formal UK neurovasculitis network which will include interested professionals with relevant expertise in the diagnosis and management of vasculitis, CNS disease and clinically-relevant research. They will work together with patients and their representatives to identify the most pressing research priorities, increase awareness of CNS vasculitis amongst clinicians, produce guidance for investigation and management of CNS vasculitis and work towards improving outcomes via high quality research studies.

'Low density neutrophils in ANCA-Associated Vasculitis' student abstract award BSR 2025

Author: Abigail Nutley *PhD Student, Centre for Inflammatory Disease*
Department of Immunology and Inflammation Imperial College London

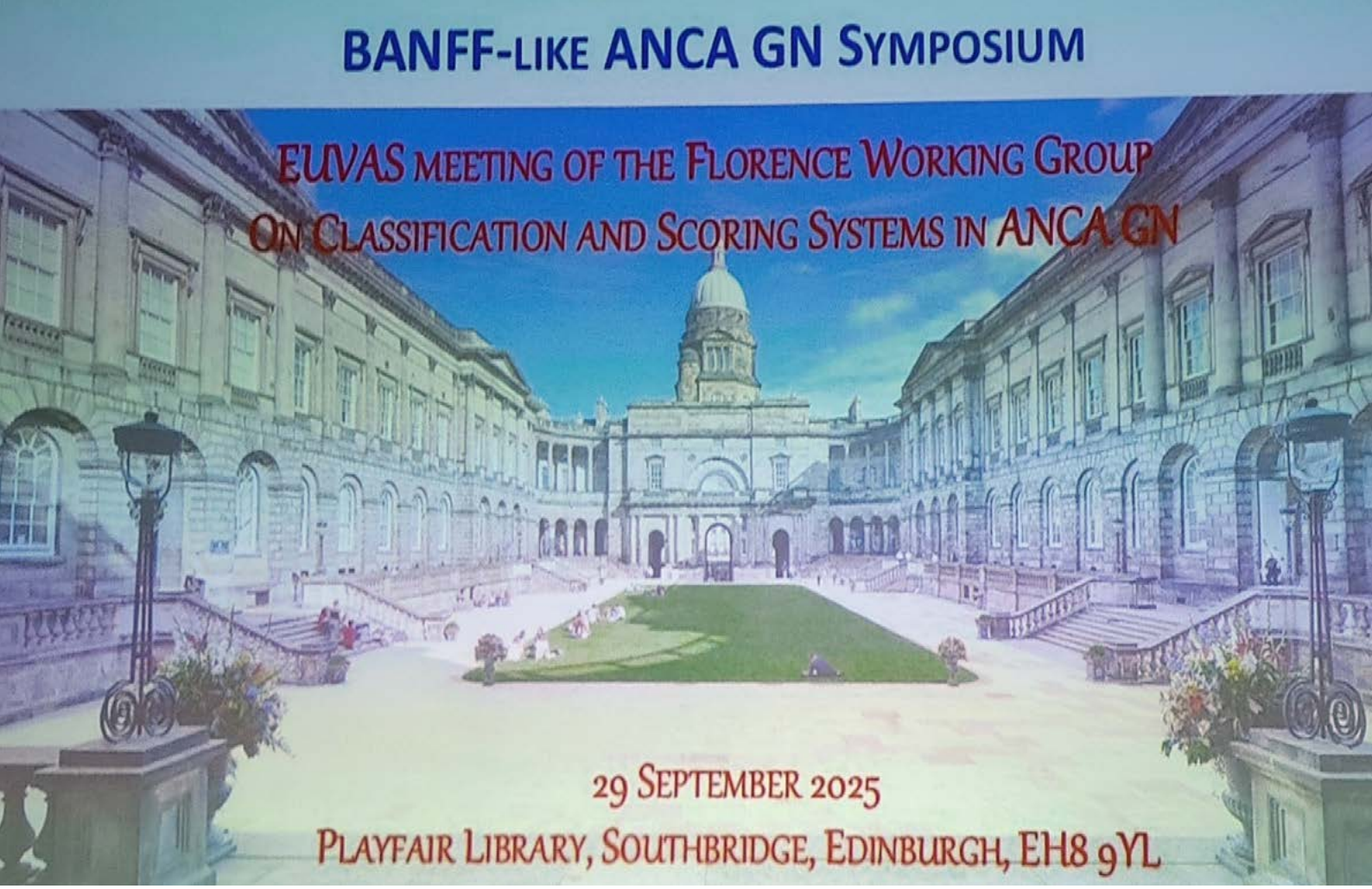
The BSR (British Society for Rheumatology) holds annual Abstract Awards at its conference for top-scoring abstracts in different areas. This year Abigail won one of the student abstract awards with her poster on low density neutrophils in ANCA-Associated Vasculitis. She has kindly shared her experience with us!

I was very grateful to attend the annual British Society for Rheumatology conference 2025 as the winner of a student award. I am a PhD student in the Prendecki/McAdoo lab at Imperial College London and our research focuses on understanding vasculitis and improving treatment options. This award was in recognition of my work so far during my PhD.

My PhD project explores the role of neutrophils in ANCA-Associated Vasculitis – neutrophils are a type of cell in the immune system responsible for causing much of the damage that occurs during vasculitis. With the kind support of vasculitis patients at Hammersmith hospital, I obtain neutrophils from patient blood samples and perform various tests to see what they look like and how they are behaving. If we are able to identify how patient neutrophils are different, this could enable the design of better treatments for vasculitis.

The conference was held in Manchester this year and had so many great talks covering advances in various rheumatic diseases. This included updates from doctors on their guidelines for treatment of ANCA-Associated Vasculitis. The enthusiasm of the participants created an exciting and welcoming atmosphere. I was given the great opportunity to present my research in the format of a digital poster and a short talk. It was rewarding to have audience members asking questions and engaging with my work. Much of the research presented at the conference was related to clinical trials and disease management, so it felt especially gratifying to share my lab-based research. I am thankful to the BSR for organizing such an insightful event and for inviting me to be a part of it!

I would also like to extend my thanks to Vasculitis UK and its supporters. The hard work of this charity and the generosity of those supporting make our research possible. Thanks to the support of Vasculitis UK at the conference, my work has the chance to reach beyond the scientific community and connect with patients living with vasculitis. A huge thank you for the continued encouragement of Vasculitis UK!



Ingeborg Bajema and Silke Brix held a first BANFF-like symposium for ANCA GN classification and scoring systems on behalf of the recently formed Florence Working Group.

The event was endorsed by EUVAS and the Royal Society of Pathology and took place in Edinburgh on September 29. Adult and paediatric nephrologists, pathologists, rheumatologists and immunologists came together to discuss kidney biopsies, standardisation and prognostic tools. In a hybrid format, 35 participants locally and 65 people online spent the day evaluating the benefits and risks of using classifications and scoring systems in assessing kidney disease in ANCA vasculitis.

One aim is to recommend a standard reporting that allows the comparison of treatment responses and patient outcomes. Another aim is to establish clinico-pathological prediction tools that support patient and physician education, predict outcomes and maybe assist in guidance of treatment in the future.

The initiative is to hold regular consensus meetings on classification and scoring systems for the implementation in clinical practice and guidelines.

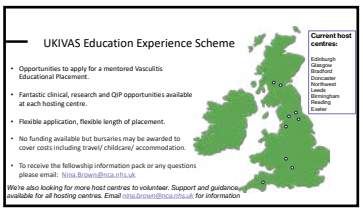
Following on to this meeting of healthcare professionals, the working group will hold a meeting for patients and relatives to discuss the results and incorporate the patient's perspective into the agenda with the goal to improve the management of ANCA associated kidney disease.

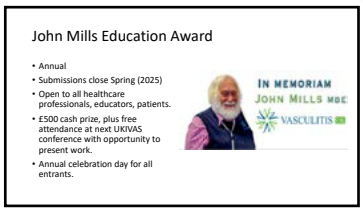
Dr Silke Brix

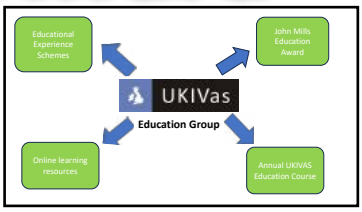
I was honoured to be invited to the recent face-to-face meeting of the EUVAS Florence Working Group in Edinburgh. This group brings together clinicians from around the world who are dedicated to improving the care, prognosis, and quality of life for vasculitis patients with kidney involvement. As patients, we don't always see the important work happening behind the scenes, so it's inspiring to know that our voices will be included. Patient feedback and opinions will play a key role in ensuring that the patient perspective is part of this project.

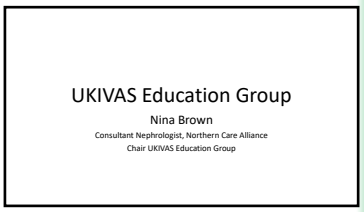
Zoi Anastasa

John Mills MBE Vasculitis Educational Award









Background

Dr John Mills was a Bakewell dentist who was diagnosed with Granulomatosis with Polyangiitis in 2001. Following his diagnosis, he undertook many roles including becoming a member of the British Society of Rheumatology (BSR) and British Health Professionals in Rheumatology (BHPR) guideline panel, Member of the Board of Trustees at the Genetic Alliance UK and Rare Disease UK, and a patient representative for vasculitis for European Organisation for Rare Diseases (EURODIS)-Rare Disease Europe.

In 2009, John became the Chair of the Stuart Strange Vasculitis Trust (SSVT), which became Vasculitis UK in 2010. Since then, John served as Vasculitis Patient Representative for the UK and Ireland Vasculitis Study Group (UKIVAS) and European League Against Rheumatology (EULAR).

John was the Patient Public Voice for NHS England Specialised Rheumatology Services for 6 years and was also part of the NICE appraisal for Rituximab in ANCA vasculitis.

In 2023 John was awarded an MBE for services to People with Rare Diseases through his role as Chair and Director of Operations of Vasculitis UK in recognition of his tireless work for the vasculitis community.

John worked unremittingly to improve vasculitis patient care, championing education of both healthcare professionals and patients and supporting vasculitis research across centres in the UK. His undoubted achievements and successes were enhanced by the devotion and dedication of his wife Susan who continues to champion this cause.

In recognition of the legacy left by John "The John Mills MBE Education Award" seeks to recognise innovative educational projects which have made a difference to those living with or caring for people with vasculitis.

The Award

£500 will be awarded to the prize winner alongside the opportunity to attend the annual UKIVAS training course to present this educational work. The award winner will be posted on the Vasculitis UK website together with a summary of their project.

Application criteria

This award is open to applications from any healthcare professional or non-professional (e.g. patient/carer) who has undertaken educational projects or educational initiatives in the field of vasculitis. Applications will be considered from groups or individuals. Projects can be nominated for this award by others.

Applications with the following aspects will be viewed favourably:

Completed projects (or those with significant progress underway)
Collaborative projects e.g. multi-disciplinary involvement, cross centre collaboration
Ability to demonstrate positive impact of the educational activity on vasculitis patient care.
Projects not previously presented or published elsewhere.
Examples of educational projects that might be eligible include: –

Creating training programmes, workshops or meetings for clinical staff managing vasculitis.
The design of disease specific educational documentation or information leaflets for staff and / or patients.
Hosting or facilitating a dedicated vasculitis fellowship or trainee opportunity for any clinical discipline.
Designing an online/remote access or interactive training platform.
Hosting patient education days

Review and selection process

Applications will be reviewed annually in September by:

- Vasculitis UK representative(s)
- UKIVAS Education committee

As this year's applications deadline has passed, please watch this space for next year's applications!

VASCULITIS UK

Introduction

On Monday 30th June 2025, the United Kingdom and Ireland Vasculitis Society (UKIVAS) held its Summer Meeting at the Francis Crick Institute in London. This was a special setting - the Crick is Europe's largest biomedical research centre, home to cutting-edge discoveries in immunology and genetics - and it provided the perfect backdrop for a day focused on new advances in vasculitis research and care.

The meeting brought together clinicians, researchers, and patient representatives from across the UK, with many talks illustrating how laboratory discoveries may translate into real improvements for people living with vasculitis. Invited speakers presented on topics ranging from the biology of IgA vasculitis in children and adults to the challenges of relapse in giant cell arteritis, and from innovative clinical trials in Kawasaki disease to the development of national research platforms in neuro-vasculitis. Other sessions highlighted the role of neutrophils in ANCA vasculitis, the hidden risk of heart disease in patients with autoimmune diseases, and the unmet needs in conditions such as aortitis. Equally important were discussions about improving the patient experience, including the RAISE project on self-management and psychological support, and calls for a national vasculitis audit to ensure that new service standards are delivered fairly across the country.

Throughout the day, a strong theme emerged: science and patient priorities are increasingly aligned. Researchers are not only mapping disease pathways with the latest technologies but also co-designing studies with patients, ensuring the questions asked really reflect their priorities.

Louise Oni – Update on IgA Vasculitis Research

Dr Louise Oni (University of Liverpool & University College London) spoke about IgA vasculitis (formerly Henoch–Schönlein Purpura), the most common vasculitis in children but also affecting adults. Most children recover quickly, but a proportion develop kidney inflammation (nephritis), which can cause lasting problems. In adults, the disease is rarer, but kidney outcomes are often worse. Despite this, there are almost no proven treatments, making IgA vasculitis arguably one of the most neglected forms of vasculitis.

Her team has been tackling key barriers to research. First, existing scoring systems don't measure organ involvement very well. They developed a new disease-specific tool (the IgA-VAS score), validated in over 150 UK children, and now being tested in French adults. This will help doctors track disease consistently and test whether new treatments work. Second, there are no agreed diagnostic criteria or treatment recommendations for adult IgA vasculitis. A European study group is finalising the first consensus guidelines, which will support future trials. Third, her lab in Liverpool is studying the biology of the disease. It looks very similar to IgA nephropathy (a much more common kidney-limited condition currently studied in over 100 clinical trials), raising the exciting possibility of repurposing treatments for the treatment of IgA vasculitis. Next, Dr Oni highlighted the SISTA study, where patients post urine samples from home for early biomarker analysis. This could allow doctors to predict who will develop kidney disease and target treatment more precisely.

Finally, international efforts are now underway to design age-inclusive trials that bring together children and adults, making studies more feasible. A French team is preparing a trial of rituximab, and studies of other therapies (such as atacicept) are starting to include IgA vasculitis patients.

Overall, Dr Oni's message was one of cautious optimism: by repurposing drugs, building trial infrastructure, and listening to patients, researchers hope to transform care for this under-researched disease.

Paul Brogan – Kawasaki Disease and the KDCAAP Trial

Professor Paul Brogan (Great Ormond Street Hospital) discussed Kawasaki disease (KD), which affects young children under the age of 5 years, and can lead to coronary artery aneurysms. These aneurysms are dangerous swellings of the heart's arteries, and if untreated, up to 25% of children develop them. Since the 1980s, intravenous immunoglobulin (IVIG) has been the main treatment, thought to reduce this risk to about 4%. However, new UK and international data show aneurysm rates remain much higher than the textbooks suggest – closer to 20%, and even ~40% in babies under one year old.

This led to the KDCAAP trial, designed to test whether adding steroids (prednisolone) to IVIG would protect children more effectively. While Japanese studies suggested clear benefit, the European trial led by Prof Brogan told a different story. Among 103 children recruited across 35 sites in 10 countries, aneurysm rates at three months were 23–24% in both groups - no difference. Steroids did, however, shorten fever by a day, reduce hospital stays, and cut the need for extra IVIG or other "rescue" treatments.

The trial faced challenges – particularly the COVID-19 pandemic, and the emergence of COVID-related inflammatory syndrome in children which mimics the clinical features of Kawasaki Disease - but successfully delivered useful results. Steroids did not prevent aneurysms, and the trial has clarified treatment in Europe: steroids cannot be recommended universally.

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Importantly, biobanked samples from the trial will now be used to search for biomarkers and genetic clues to identify which children are at highest risk of aneurysm formation and to help identify new treatment targets.

Maria Prendecki – Biophysical Properties of Neutrophils in ANCA Vasculitis

Dr Maria Prendecki (Imperial College London) shared new insights into the role of neutrophils, a type of white blood cell, in ANCA-associated vasculitis (AAV). Neutrophils normally patrol the bloodstream and can squeeze through tiny vessels to fight infection. In AAV, however, they become stiffer and less flexible, particularly in patients with lung disease, making them more likely to clog blood vessels and damage tissues.

Her team used real-time deformability cytometry, a cutting-edge technique, to measure neutrophil stiffness. They found that patients with active vasculitis had the stiffest neutrophils, which correlated with disease activity scores. This stiffness was linked to changes in the cells' internal (actin) skeleton and signalling pathways.

They also discovered that oxygen levels affect neutrophils. At low oxygen (similar to levels seen in inflamed tissues), neutrophils became even stiffer, released more damaging enzymes, and were more likely to cause blood vessel injury. At near-normal oxygen levels, healthy neutrophils resisted these changes – but vasculitis neutrophils still behaved abnormally, suggesting a built-in disease defect.

Importantly, the team tested a drug targeting these changes in the internal cell skeleton. In a rat model of vasculitis, this reduced lung haemorrhage and inflammation, though effects on kidneys were mixed.

These findings point towards new, precise therapies. Current treatments suppress the whole immune system, causing many side effects. Drugs that specifically target neutrophil stiffness might stop the damaging behaviour while leaving useful immune responses intact. This research is still at an early stage, but it offers a hopeful path towards safer, more effective treatments for ANCA vasculitis.

Maria Karabayas – Defining the immuno -stromal biology of relapsing giant cell arteritis

Dr Maria Karabayas (University of Aberdeen) focused on giant cell arteritis (GCA), the most common vasculitis in older adults and a leading cause of preventable blindness. While steroids and newer drugs like tocilizumab have transformed treatment, around half of patients relapse, often when medications are tapered or stopped. This shows that current therapies may not fully control the underlying disease.

Dr Karabayas compared biopsies taken at diagnosis and at relapse using cutting-edge single-cell analysis. They found that disease "onset" and "relapse" are biologically distinct – both in the composition and in the signalling of cells in affected vessels. At relapse, for example, biopsies showed more fibroblasts, the supporting cells in the artery wall, which may sustain chronic scarring and vessel narrowing, keeping inflammation "smouldering" even when patients seem better.

These findings are important because most trials treat relapse as just a return of onset biology. In fact, relapses may need different drugs. For example, JAK inhibitors, which target specific inflammatory pathways seen in relapse cases, could be more effective than standard approaches. Her research highlights the need to design trials that reflect this biology, not assume all GCA is the same. By mapping the immune "ecosystem" in arteries, researchers are getting closer to targeted therapies that can reduce relapses, minimise steroid side effects, and improve long-term outcomes for people living with GCA.

Taryn Youngstein – The UK Cardio-IMID Network

Dr Taryn Youngstein (Imperial College London) introduced the UK Cardio-IMID Network, an ambitious new collaboration between rheumatologists, nephrologists and cardiologists. Its aim is to tackle the hidden burden of cardiovascular disease (CVD) in people with vasculitis and related autoimmune conditions such as lupus and rheumatoid arthritis. Patients with these immune and inflammatory diseases (IMIDs) face a higher risk of heart attacks, strokes, arrhythmias and heart failure. This is partly due to the diseases themselves and partly due to treatments, such long-term steroids.

The network has already signed up 42 NHS trusts across the UK. Its priorities include:

1. Building a national registry linking autoimmune disease with heart imaging and outcomes.
2. Standardising advanced imaging (MRI, CT, PET) to detect heart inflammation earlier.
3. Identifying biomarkers that predict cardiovascular risk.
4. Creating joint training and education so rheumatologists and cardiologists learn to manage IMID-related CVD together.

Dr Youngstein emphasised that current cardiology guidelines rarely address patients with autoimmune diseases, meaning risk factors are often missed or under-treated. The new registry will generate evidence to change practice, ensuring earlier diagnosis and prevention of heart disease in these high-risk groups. The initiative has already planned its first educational conference and hopes to expand into Europe.

For patients, this is an important cultural shift: care will no longer stop at controlling inflammation but will also focus on protecting long-term heart health. By bringing specialities together, the Cardio-IMID Network hopes to close the gap in cardiovascular care for people with vasculitis and related diseases.

Claire Rice – Establishing a Platform for Research in Neuro-Vasculitis

Dr Claire Rice (University of Bristol) spoke on the challenge of neuro-vasculitis, where blood vessel inflammation affects the brain, spinal cord, or nerves. Though rare, it is one of the most severe forms of vasculitis, leading to strokes, seizures, cognitive problems, and disability. Because cases are rare and often misdiagnosed, there is very little research to guide treatment.

To address this, Dr Rice and colleagues are developing a

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national clinical research platform. This will collect cases of neuro-vasculitis across the UK into a single resource, recording clinical details, imaging, biopsy results and outcomes. By pooling this data, researchers hope to establish clearer definitions, identify diagnostic pathways that work best, and set the stage for future clinical trials.

Importantly, the project is co-designed with patients, who help prioritise research questions and shape study design. Patient involvement ensures the platform does not just generate data for scientists but also produces outputs directly relevant to people living with the disease, such as information leaflets, care guidance, and decision-support tools.

Long-term, the vision is a UK-wide "learning health system" for neuro-vasculitis, where every patient contributes to and benefits from research. This could also link with European efforts, strengthening the evidence base internationally.

Neuro-vasculitis has been neglected, but with this platform, diagnosis should become faster, treatment more consistent, and knowledge of outcomes far stronger.

James Lee – Functional genomics to investigate shared disease mechanisms in IMIDs

Professor James Lee (Francis Crick Institute) gave a fascinating overview of how genetics and genomics are transforming our understanding of autoimmune conditions, including vasculitis. For years, researchers have known that some inflammatory diseases tend to run in families, suggesting a genetic component. Large studies have now identified hundreds of genetic "risk variants", but most sit in parts of the DNA that do not directly code for proteins. Instead, they act like switches, controlling how and when genes are turned on or off.

The challenge has been to link these genetic switches to the behaviour of specific immune cells. Professor Lee's team is doing this using functional genomics - combining cutting-edge tools like CRISPR gene editing, single-cell sequencing, and high-throughput screening with large patient biobanks. By studying immune cells from patients with different autoimmune diseases, they can see how risk genes alter cell function in practice.

The results are striking: many apparently separate diseases actually share overlapping biological pathways. For example, changes in immune cell signalling that increase the risk of Crohn's disease can also be found in certain types of vasculitis. This raises the exciting possibility that drugs developed for one autoimmune condition could be repurposed for others, greatly speeding up the development of new treatments.
Professor Lee also stressed that these advances are only possible because patients volunteer samples for research. Every donated blood tube helps connect the dots between genetics and disease. For patients, this work is laying the foundations for a new era of precision medicine, where therapies are tailored not just to the disease label, but to the underlying biology driving inflammation.

Jo Robson – The RAISE Project

Dr Jo Robson (University of West England, Bristol) spoke about the RAISE project, which aims to improve self-management and psychological support for people living with rare autoimmune diseases including vasculitis. While much research focuses on drugs and inflammation, patient surveys consistently show that daily life challenges – uncertainty, isolation, anxiety, fatigue – have just as much impact on quality of life.

The RAISE team has worked closely with patients to co-design solutions. These include digital tools and apps to help track symptoms, access reliable information, and link with peer support networks. They are also developing educational resources for both patients and healthcare professionals, to improve understanding of the emotional burden of vasculitis. Another strand is training clinicians in communication and shared decision-making, so that care better reflects patient priorities.

Dr Robson emphasised that building confidence in self-management can reduce stress, improve wellbeing, and even lead to better medical outcomes. Early results suggest patients using RAISE resources feel more empowered and connected, reducing the sense of being "alone" with a rare condition.

A key message is that healthcare teams increasingly recognise that living well with vasculitis requires more than just controlling inflammation. Supporting mental health, resilience, and self-management is an essential part of modern care. The RAISE project is pioneering this approach, ensuring the patient voice is heard at every stage.

Shirish Dubey – Aortitis: Clinical Patterns and Unmet Needs

Dr Shirish Dubey (University of Oxford) discussed aortitis, inflammation of the body's largest artery, which can occur in vasculitic conditions such as giant cell arteritis (GCA) and Takayasu arteritis (TAK). Aortitis is often difficult to recognise because symptoms are vague - fatigue, pain, fever - and may mimic other illnesses. Advanced imaging (CT, MRI, PET scans) is usually required, but timely access is inconsistent across the UK.

Dr Dubey explained that untreated aortitis can cause serious complications, including aneurysms (artery ballooning), dissections (tears), and rupture, all of which can be life-threatening. Even when inflammation is controlled, patients remain at risk of long-term vascular damage, highlighting the need for ongoing surveillance.

Treatment currently relies heavily on steroids, but relapse is common and steroid side-effects are burdensome. Biologics like tocilizumab and rituximab may help some patients, but evidence remains limited. There have been very few clinical trials focused on aortitis, and most management strategies are borrowed from related vasculitic conditions.

Dr Dubey called for dedicated research to understand the natural history of aortitis, identify biomarkers that predict progression, and test new treatments. He also emphasised the importance of multidisciplinary care, involving rheumatologists, cardiologists, vascular surgeons, and radiologists.

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Peter Lanyon – New insights into AAV care and outcomes in England from process mining of whole population data

Dr Peter Lanyon (Nottingham University Hospitals NHS Trust & National Disease Registration Service, NHS England) introduced a technique called process mining, which uses large-scale NHS data to map how patients with vasculitis move through the healthcare system. By linking hospital, GP, and prescribing datasets, researchers can reconstruct the "patient journey" from first symptoms to diagnosis, treatment, and outcomes.

Early work shows that patients with ANCA-associated vasculitis often experience delays in diagnosis, with repeated GP and out-patient clinic visits before a diagnosis is made. After diagnosis, Dr Lanyon was able to describe variations in specialities where patients are treated (e.g., rheumatology, renal, respiratory). In the future, this data could be used to assess variations in how quickly treatment begins, and in what drugs are chosen, and if this is influenced by geography.

The advantage of process mining is that it uses data already collected by the NHS, meaning insights can be generated at whole-population scale without extra burden on clinicians. It also makes it possible to identify "bottlenecks" in care, measure inequalities between regions, and monitor whether new guidelines are being followed. Professor Lanyon suggested that process mining could underpin a national vasculitis audit, ensuring accountability and continuous improvement. Patients would benefit from more consistent care no matter where they live, and services could be benchmarked against best practice.

For patients, the significance is clear: your experiences are not invisible to the system. By harnessing NHS data intelligently, researchers can highlight where care falls short and push for changes that ensure timely diagnosis, equitable treatment, and better long-term outcomes.

Rosemary Hollick – Towards a National Vasculitis Audit

Dr Rosemary Hollick (University of Aberdeen) closed the meeting by making a powerful case for a national audit of vasculitis outcomes and services. While new guidelines (such as the recently published BSR recommendations for ANCA-associated vasculitis) set out what care should look like, there is currently no way to measure whether patients actually receive it.

She presented results from a recent survey of 65 UK services:

1. Most centres could see suspected vasculitis patients within a week, a major strength.
2. Around half ran multidisciplinary clinics, but only a third had access to specialist vasculitis nurses.
3. Even fewer offered nurse-led clinics or dedicated advice lines.
4. Psychological support was available in under half of services, despite clear patient demand.

Currently, the UK has multiple registries that may include patients with various forms of vasculitis (such as the UK Renal Registry, UKIVAS, and the severe asthma registry), but each covers only part of the patient population and uses different methods, meaning that a joined-up, comprehensive view of vasculitis care or outcomes is very challenging.

Dr Hollick argued that a national audit could highlight inequalities, improve accountability, and drive service improvement. Challenges include sustainability, avoiding excessive bureaucracy, and ensuring funding. But in other disease areas (like rheumatoid arthritis) have shown audits can transform standards of care.

She asked the community to consider: do we want a vasculitis audit, and if so, what should it look like? For patients, the answer is important: an audit would mean services are measured against the same yardstick, ensuring that everyone – wherever they live – can expect high-quality, timely, and equitable care.

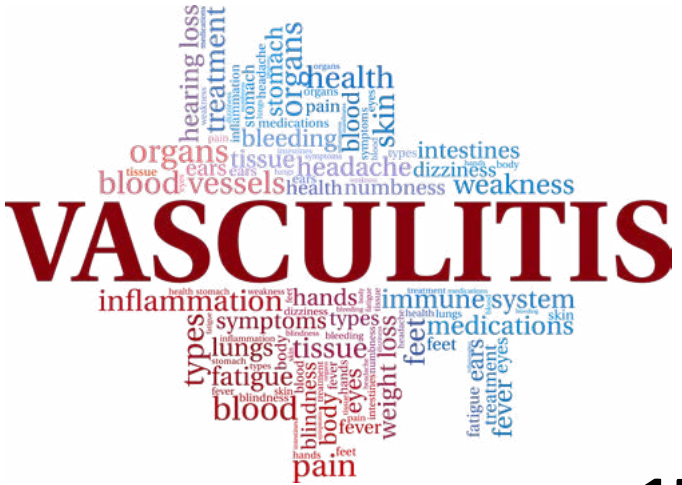
Conclusion

The UKIVAS Summer Meeting at the Crick demonstrated the breadth and variety of vasculitis research in the UK. What stood out was not only the scientific progress but also the range of perspectives represented – from laboratory studies and clinical trials to service organisation and patient support.

There was also a strong sense of connection between disciplines and between professionals and patients. Talks highlighted collaborations that cut across traditional boundaries: cardiologists working with rheumatologists, data scientists with clinicians, and researchers with patient partners. These links are helping ensure that new discoveries are relevant to everyday care.

The meeting also underlined how much can be achieved when people with rare diseases are brought together in national networks. Registries, audits, and shared research platforms are beginning to generate the critical mass needed for meaningful insights into rare disease and fairer access to high-quality care across the UK and Ireland.

Many challenges remain, but the research community is active, imaginative, and increasingly focused on outcomes that matter to those living with vasculitis. By combining rigorous science with strong patient involvement, we hope that the UKIVAS community is helping to shape a future where care is not only more effective but also more consistent and supportive.



Our Fantastic Fundraisers

TEAM MACY

Macy's Story

In February 2024 Macy was rushed to Evelina children's hospital after recurrent bouts of nausea and sickness which turned out to be end stage kidney failure with both kidneys only working at 4% . This meant that she now has to have daily dialysis every night for a 10 hour program that does the job that her kidneys cannot do along with numerous medication and hospital appointments.

What a sudden turn of events for a 14 year old girl. After weeks of testing Macy was diagnosed with having ANCA vasculitis.
In the last year Macy has undergone numerous blood tests, X-rays, CT/MRI and heart scans, a blood transfusion ....the list goes on. She currently getting herself physically and mentally prepared for a kidney transplant.

The amount of strength, courage, determination and patience Macy has showed throughout this whole process has amazed us and she is an inspiration to us all. She took part in the army assault course and did very well We are all extremely proud of her.

The event was held during June at an army assault course in Kent. Team Macy consisted of family and friends and our fundraising has raised over £4073 for Vasculitis UK, we all had a fun day. Although aching a bit now..

Josie Coglan

Our Fantastic Fundraisers

The Mackays Get Tuff

The Mackays done the MacTuff to help raise awareness in memory of their Dad Paul King raising £300 for VUK.

Sarah Sainsbury has completed the 25km Jurassic Coast Challenge, to raise awareness of vasculitis in memory of her mum. She has raised £373.

Prof Ann Morgan and her family and friends from Leeds ran the GNR 2025. They have a so far raised over £2000. Those attending her clinics over the next few months may be treated to cake sales to increase that money.

Craft and Jam Stall held at Winster Wakes raised £100 - Susan Mills & the Vasculitis Green Fingers, Food & Fun, Hobbies FB Group.

Jessie Barden pictured right decided to do 100k throughout July to continue to raise awareness of Vasculitis. His dad Wayne sadly passed of the disease in 2021.
He raised £194

Matthew Denniff (above) was diagnosed with EGPA in early 2025. He was always a runner including ultra marathons. He has an ongoing challenge to complete 33000 miles in a decade! So far he has raised nearly £900.

Anne Huckvale family and friends have raised £776 in memory of Moira Fahy.

Jane Edwards was raising awareness during May by selling cakes and chatting at her house. She raised over £800.

Laura Elson walked from Dover to Deal in May. She raised £738 to raise awareness of vasculitis.

Cal Lloyd completed the Manchester Marathon and raised £1896. Her mum and best friend both have vasculitis.

Martin Swainson has completed the Ullswater Epicman Triathlon and raised £1352. He was competing in memory of his dad Chris Swainson and Kathryn Rigg

Lisa Hurley has completed the Great Birmingham Run and raised £602.

Jo Gambi and the Eton Family did a family Triathlon in July. In memory of Delfi who died from TA. They have raised over £1200.

Christin and Clare jumped out of an airplane in May. A close family member had been diagnosed with GPA. They raised £1559.

Dean McMackin cycled 150 miles to raise awareness of vasculitis. This was in memory of his father in law John. He has raised £667.

Kate Hersey has climbed Snowdon after being diagnosed with EGPA. She wasn't alone she had Claire Kimber and Charlie Hockin joining (and probably dragging her up the steeper bits), and of course, Alfi the spaniel. She has raised nearly £3370.

Katie Williams raised £4016 by running for 24 hours straight. This was in memory of her friend Loretta.

Declan Howells took part in the Ultra White Collar Boxing at Preston in July and has raised £255.

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

33000 miles for Vasculitis UK

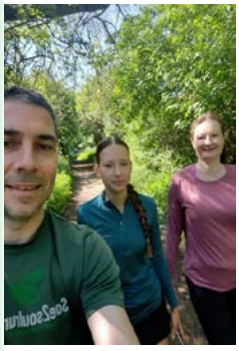
Hi, my name is Matthew. I'll never break any records, but I do like a challenge.

Early in 2025 I was diagnosed with an autoimmune disease, a type of vasculitis, Eosinophilic granulomatosis with polyangiitis (EGPA).

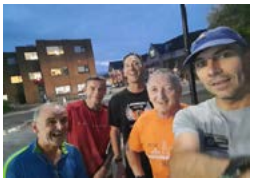
While 10% of the population suffer from autoimmune diseases like the often mentioned, type 1 diabetes, celiac or psoriasis, the many forms of vasculitis are considered rare diseases. EGPA itself has an estimated prevalence of 2–38 per 1,000,000 people in Europe.
EGPA (former Churg-Strauss), who's ever heard of that?

Before EGPA I loved to run. People recognised me as a runner first and foremost. If in conversation, running would be what people would ask me about. I have completed many races in my time as a runner including ultra-marathon events up to 100 miles and 24-hour challenges, and I love a challenge.

My symptoms I'm sure sound familiar. They snuck up on me over a few months, maybe half a year as I transitioned from the eosinophilic phase to the vasculitic state. I had no energy. I needed sleep all the time, but sleep didn't help, this was pure and debilitating fatigue! My muscles ached. What was once easy now took time or was impossible. Elevated heart rate, night sweats, extreme limb swelling and a loss of sensation in my feet and hands were all exhibited. The GP investigated the most likely options. No cancer, maybe chronic fatigue or a deep-seated viral infection. It might go away on its own. Give it time.



I am grateful that an angel was watching me and guiding me. My angel sped up my diagnosis considerably. I fall considerably short of the mean, mode and median times for diagnosis of this thing. Thank you.



Ultimately, EGPA stole my running identity from me for many long and painful months. My running shoes laid under the bed unused. I could hardly move some days.
My body ached like I had run a marathon, but I had done nothing.

There is hope.

I have medicated with the expected daily hand full of pills and irregular infusion dates. I have struggled with the highs and lows of the drugs I am taking to the point where I am now in remission. Mononeuritis multiplex (MNM) still lingers. Everything else feels 8 out of 10 (I like to nap now if I can get away with it), but the MNM causes ongoing pain in my feet and hands. I try not to let it bother me.

I have learnt to run again. I've paid my dues and plodded through the coach to 5k programme. Learning to run again was a tear inducing, humbling experience. I have progressed a little with time but running is now a slower and harder process than it was before. 80, 90 or 100 miles a week are now a distant memory. Running hurts to the point of pain because of vasculitis but for many reasons I am compelled to push on passed the points of physical, mental and emotional discomfort.

I need to build up more mileage again if I am to achieve my next challenge. Can I be bold enough to say EGPA won't stop me?

It's time for a new challenge.

In September 2020 (Covid), I ran 630 miles in the month. In 2023 I ran 4169 miles in the year. Now I want to know how far I can run in a decade. I challenge myself to see if I can make 33,000 miles. I won't let vasculitis stop me.

My first race was on March 5th, 2017, a local half marathon. By March 4th, 2027 I want to have run 33,000 miles.

That's 3,300 miles a year, or 275 miles a month if you prefer.
If you say 9.1 miles a day for 3652 days, it doesn't sound that far.

What remains of this running task is detailed on my justgiving page. I am now challenged on behalf of Vasculitis UK.

Can I complete this challenge? I don't know! 25% of this challenge will be undertaken while suffering with vasculitis.

Will my body let me down? I hope not! I will run with the ones I love the most. They are my greatest inspiration.

Please cheer me as I try to complete this challenge!

https://www.justgiving.com/page/matthew-denniff-3

A Clinical and Research Vasculitis Nurse Training Course

To promote the value of the specialist nurse role

Cambridge Vasculitis & Lupus Research and Training Centre
Understanding Autoimmunity for better patient care

Cambridge Vasculitis Team delivered their first vasculitis hospital based nurse training programme in June 2025 which had a clinical and research focus.
The 3-day course was initially advertised earlier this year and was immediately met with a high level of interest. Specialist nurses in rare disease typically receive very limited on the job training. Sharing of nursing expertise is highly desirable, however there is a lack of opportunities for specialist vasculitis nurse training across the UK. This course is particularly timely to develop this service as nurses from 19 Trusts across UK and Northern Ireland expressed an interest in visiting and attending the course.

The team of 4 clinical nurses and 10 research nurses at Cambridge University Hospitals NHS Foundation Trust have a deep experience in supporting the management of patients with Vasculitis: streamlining transitions in care from inpatient to the community setting. The nursing team co-ordinate 3 outpatient clinics per week and research trial visits as well as providing valuable support, education and counselling to patients. The vasculitis nurse-led advice line provides direct access for patients to contact the team for treatment advice outside of scheduled appointments. The wealth of experience at CUH provides an ideal setting to deliver a hospital-based nurse specialist training course aimed at specialist nurses across the UK with an interest in vasculitis, seeking to develop the role in their respective units.

Aims of the Vasculitis Training Course

- Share clinical nursing expertise with other nurses and promote a deeper understanding of the multi-professional approach to vasculitis
- Provide educational resources to increase theoretical knowledge based on Vasculitis.
- Promote the role of the vasculitis research Nurse by sharing how we manage practical care for patients with vasculitis
- We hope we can inspire other nurses to develop practice locally
- To encourage exploration of best practice for numerous aspects of care such as treatment options and patient education

By limiting the spaces to a small group each participant had the opportunity to visit patients on the wards, observe infusions and attend a vasculitis clinic. Participants joined the vasculitis research nurses during a research trial visit and attended a research education forum. Throughout the course there were presentations by the medical and nursing team. The nurses also had an opportunity to meet and chat to a patient expert panel.

The first cohort of three specialist nurses had different backgrounds- Specialist Nurse in Nephrology, a Rheumatology Specialist Nurse and a Renal Research Nurse. This broader range of experiences and backgrounds led to lots of opportunities for interactive discussions.

Feedback

"The sessions were exceptionally well-balanced, combining interactive elements with classroom-based learning, which made the experience both engaging and informative. I particularly valued the chance to gain insight into how other trusts operate, especially regarding their clinical guidelines".
"This experience prompted me to return with several questions for my medical team, particularly regarding our guidelines for treating vasculitis patients."

The first small group of nurses came from Leeds, Leicester and Bristol and we have just invited four more nurses to the October 2025 training course who come from Stevenage, London, Hull and Plymouth. We have a further 21 on a waiting list.

Improvements for the next Vasculitis Nurse Training Course planned for October 2025 include extending the number of participants to 4, pre-course video introductions, increase content on lifestyle and pregnancy advice and include ENT topics.

Our plan is to offer the Cambridge Vasculitis and Research Nurse Training Course three times a year for up to four participants. It is hoped that nurses attending this course will form strong links across the vasculitis UK nursing community that can enhance patient care on a national level.

CSL Vifor has supported this course with the provision of an educational grant. However, they have had no input into the content of this training programme.

Pictured below are clinical and research nurses:
Daniele Arcoria, Maria Bernadette Laforteza, Viola Ricci, Senior Research Nurse Carlotta Soave, Nanditha Peedikayil Mani, Vasculitis Lead Nurse Stella Burns, Nithya Kollannur.

Vasculitis UK has been busy creating awareness, educating patients and professionals. We have been travelling around the UK, taking every opportunity to spread the word about vasculitis!
So, where has Zoi and VUK been over the last few months?

Zoi Anastasa

April 2025

A month of preparation! Multiple visits to our storage unit preparing boxes for different events. Getting the logistics right is the first step for having a stand at events. And towards the end of the month, off we went!

Greater Manchester Local Support group meeting – Manchester 27th April

Travelling with 2 suitcases on the train can be challenging, thankfully patients' assistance was very good and the journey from Plymouth to Manchester went smoothly.

Our trustee Diana Shonfield and I attended the meeting – Diana as a local member and I as an invited VUK representative.
Dean Lane was the lead for this local meeting and Dr Brix kindly found space in the hospital for it to be hosted. As she had her birthday that weekend, her supporting the arrangement and participating in the meeting was extra special. We took the opportunity to thank her for her work and support. Diana gave her some lovely flowers on behalf of VUK.
It was lovely to meet fellow vasculitis warriors and to spend some relaxed time chatting about vasculitis and not only!

I hope we will see this local group growing over time and we look forward to advertising their next meetings!

British Society of Rheumatology Annual Conference – Manchester 28th to 30th April

The biggest awareness event for Vasculitis UK. The place where we meet a lot of rheumatologists, trainee doctors, medical students, rheumatology nurses, allied healthcare professionals and of course colleagues from other patient organisations.

As of last year, VUK was part of the RAIRDA ''village''. All 4 patient organisations, Vasculitis UK, Lupus UK, Scleroderma and Raynaud's UK and Sjögrens UK, have their stands together and create awareness of RAIRDA (Rare Rheumatic Disease Alliance) alongside promoting the work of their own organisation. We must remember that together we are stronger.

Our stand was very busy and at times it felt like the 3 of us – Laura, our research coordinator, Diana, one of our trustees and I – were not enough. As always, we had the pleasure to be visited by clinicians that are well known in the vasculitis community, but this year we met a lot of new faces; the interest in vasculitis is increasing and that can only lead to better care for us, the vasculitis patients.
Just behind our stand was the poster area where the abstracts that were chosen by BSR were shown. Amongst them the work of Abigail Nutley, a PHD student at Imperial College, about ''Low Density Neutrophils in ANCA-Associated Vasculitis. You will find an article by her in this newsletter.
A lot of sessions were focused on rare rheumatic diseases and vasculitis. Up to now we had two Special Interest Groups, the GCA & PMR group and the Vasculitis group.

From this year onwards we will have one; the Vasculitis & PMR SIG. In this year's session we saw three presentations:

- A typical presentation of GCA – Dr Chetan Mukhtyar
- Use of biologics in the management of eosinophilic granulomatosis with polyangiitis (EGPA) - Dr Allyson Egan
- What should secondary care provide for PMR – Dr Max Yates

As we were so busy I didn't attend as many sessions as I would like – thank goodness for the on-demand option- but here are some highlights:

Renal Disease in Rheumatology, not uncommon in vasculitis patients especially in ANCA associated vasculitis and IgA vasculitis patients. Pain, Participation and Progress, we all know how much pain impacts our life and prevents us from doing things we took for granted prior our diagnosis, now clinicians are looking at this aspect as well. Cardio-Rheumatology is an emerging new sub-specialty and Dr Taryn Youngstein from Imperial College spoke about Identification and Management of Pericarditis

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and Myocarditis. The session about Specialised Rheumatology Networks was very interesting. Time to find ways for the knowledge to travel instead of the patient! The patient's voice was loud and clear in this session, your voice as well. If you remember last year, we asked you to participate in a survey from RAIRDA about your care. In April this year they published the results, Rare Care Matters: The struggle to access diagnosis and care for rare autoimmune rheumatic disease patients. Sue Farrington, the chair of RAIRDA, informed us of what the networks can learn from the RAIRDA study.

This year attending the BSR had a personal reason as well as representing Vasculitis UK, I was invited to co-chair a session, Roundtable: How can we promote inclusion of people with rare rheumatic diseases in interventions to support them?
It was a huge honour to be co-chairing with Dr Peter Lanyon who got the Heberden's Award this year – a legend, a doctor who has been working hard to improve the care of patients, an amazing person! I cannot thank him enough for the support, being a newbie chair was a bit overwhelming, and huge thanks to Dr Jo Robson, Dr Yuzaiful Md Yusof and Dr Ilhem Berrou for their trust and for treating me as an equal in the team!

The Vasculitis UK's short talk presentation was focused on patient education this year. Our trustee, Diana Shonfield, and I co-presented ''Educating patients. When & why. The role of a patient organisation in educating patients.'' A subject that gave a lot of food for thought and we have been asked to talk about it in a few roundtables next year! A success!

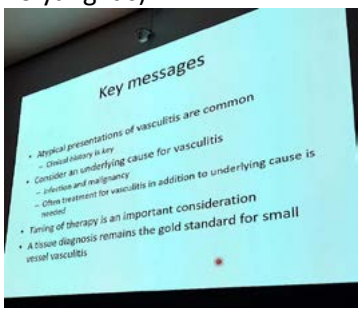
After a few busy days in Manchester it was time to pack and travel north to attend the next event.

May 2025

Scottish Systemic Vasculitis Network meeting, hosted at the Scottish Thoracic Society's annual meeting, Edinburgh, 2nd May

Back in 2019, the Scottish Systemic Vasculitis Network (SSVN) was created to make sure patients in Scotland could get better, more consistent care. Vasculitis UK was proud to be there right from the start – our founders, John and Susan Mills, even travelled north to attend the very first meeting and show their support.
Then, like so many things, the pandemic put those plans on hold. Meetings were cancelled, and the NHS had to focus on other urgent challenges. Now, with face-to-face events starting up again, the SSVN is finding its feet once more – and we're delighted to be part of it.
When the invitation came to attend their latest meeting and host a Vasculitis UK stand, we didn't hesitate – even though it wasn't the easiest trip to organise! A big thank you goes to my partner Jim, who drove all the way from Plymouth to Manchester to pick me up, before heading to Edinburgh with all the banners and leaflets packed in the car. Without him, it just wouldn't have been possible.
The event took place at the Royal College of Physicians of Edinburgh, a beautiful old building (though parking was definitely tricky!). We were the only patient organisation with a stand, which meant lots of opportunities for conversations. Many respiratory consultants came to speak to us – they were there to learn more about vasculitis before moving on to the second half of the meeting, which focused on their own specialty.

The programme was both engaging and eye-opening.
Dr Rosemary Hollick opened with an overview of the network's work so far.
Dr Rona Smith spoke about how vasculitis can first appear in patients – often in very acute and worrying ways.
Dr Benjamin Sutton explained how asthma biologics can play a role in treating EGPA (Eosinophilic Granulomatosis with Polyangiitis).



The highlight of the day was a series of difficult case presentations, showing just how serious and challenging vasculitis can be for both patients and doctors.
It was inspiring to see so many clinicians eager to learn and improve care. For us, it was also a great chance to raise awareness of Vasculitis UK and remind professionals of the importance of patient voices in shaping services.

We look forward to watching the SSVN grow and thrive – and to being there alongside them, making sure that people living with vasculitis in Scotland and beyond get the best possible care.

Royal College of Nursing Annual Congress, Liverpool 12-15 May

Liverpool welcomed us with sunshine – the perfect start to this year's **Royal College of Nursing (RCN) Congress**!
Our trustee, **Antony Hart**, deserves a big thank you for driving almost 300 miles with boxes full of materials for our stand. I was lucky enough to travel by train with just one large suitcase. We'd also managed to find a small flat close to the venue, which made everything much easier. Having worked together before, Antony and I had the stand set up in no time.

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I still remember my very first RCN Congress – I was amazed at how different the levels of knowledge about vasculitis were among the nurses. That experience made us rethink how we present our information. Over the last couple of years, it's paid off: more and more nurses have been stopping by, eager to learn and ask questions.

This year, the **first day was the busiest** we've ever seen. We barely had a moment to sit down – let alone enjoy a cup of tea! The second day, which we had expected to be even busier, was a little calmer. That gave us the chance to look around, meet other exhibitors, and share ideas. We were also joined by **Diana Shonfield**, whose help meant we could take short breaks without leaving the stand unattended.

One of the highlights was our **raffle**. To get a ticket, attendees first listened to a short talk about vasculitis and Vasculitis UK – then answered a question to show what they had learned. It was a fun and engaging way to raise awareness, and it worked really well.

Best of all, we left Liverpool with invitations to speak at future **nursing education events**. It's so encouraging to see such strong interest from nurses, who play a vital role in caring for people with vasculitis.

We're already looking forward to next year's Congress – and to keeping the conversation about vasculitis going!

Vasculitis UK – members and supporters meeting 2025 , Radisson Blu Hotel, East Midlands Airport 18th May

On **18th May**, we gathered at the **Radisson Blu Hotel, East Midlands Airport** for a **Members and Supporters Meeting**. What was planned to be our AGM did become a friendly and welcoming day where we met face to face, shared updates, and learned from each other.

It was wonderful to see so many familiar faces, catch up with old friends, and welcome new ones. Almost all of our trustees were there in person too, which made the day extra special.

The meeting began with a warm welcome from our **new Chair**, followed by an update on what Vasculitis UK has been doing over the last seven months. Then we moved on to our guest presentations:

1. **David O'Regan** travelled from Ireland to introduce us to *Dwayne* – an AI chatbot created to support patients through Vasculitis Ireland.
2. As **Jason Whittaker** was unable to join us at the last minute, **Claire** kindly stepped in to share his presentation on the *Impact of PIP reform*.
3. Finally, our Vice Chair **Dorothy Ireland** presented a project funded by Vasculitis UK on *Imagery Techniques for people living with vasculitis*. We watched a recorded session led by research nurse **Alice Muir**, who gently guided us through one of the relaxation exercises. Everyone in the room joined in – and enjoyed the calm moment it brought. (If you'd like to try it yourself, the techniques are available on our website!)

Of course, no meeting would be complete without good food and good company – and we had plenty of both. After years of online events, it was a real joy to come together again in person.

Look for our online AGM date in this Newsletter!

RaDaR 15 years celebration- London 22nd May

The invitation came as a bit of a surprise since Vasculitis UK only joined RaDaR earlier this year! (You'll find a separate article about that elsewhere in this newsletter.) The event itself was really well organised and gave us plenty of chances to network. It's always inspiring to see what other organisations are working on, pick up new ideas, and find ways to collaborate – all for the benefit of patients.

June 2025

Patient voices in rheumatology course – London 27th June

In June we were part of something new and refreshing – the **Patient Voices in Rheumatology course** in London, an initiative from the British Society for Rheumatology (BSR). What stood out right from the start was how clearly they made it: the **patient voice matters**.

The day was led by a mix of experts – both healthcare professionals and patients – and the programme covered some really important ground: communication, shared decision making, self-management, disability and diversity, and how patients can be genuine partners in service design and research. At the heart of it all was person-centred care.

Giles Hart, one of our trustees, and I set up our Vasculitis UK stand and it was great to see other patient organisations there too. There was a real community feel and a positive buzz in the room.

The morning kicked off with a welcome and an introduction to the day, followed by sessions on communication, how to engage patients in their care, and the power of collaboration with patient partners. We also heard moving patient stories – and they really were empowering. It was encouraging to see the audience nodding along, recognising just how vital it is to keep care patient-centred.

One downside though: attendance by rheumatologists was disappointingly low. The people who did come were already convinced about the importance of listening to patients, so in a way it felt like preaching to the converted. The challenge now is how to reach the wider group – the clinicians working in rheumatology clinics every day – so that real change can happen.

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On the brighter side, we had some really engaging conversations at our stand. Visitors were keen to learn more about Vasculitis UK and the work we do, which was fantastic to see. All in all, it was a good initiative and a step in the right direction. We'll be keeping an eye on what comes next – because if we want true person-centred care, the patient voice has to be heard loud and clear.

UKIVAS board meeting and research presentations – London 30th June

After missing out last year, I was very happy to finally make it to the **UKIVAS Summer Meeting** this time around. And let me tell you – it was worth the wait!

We kicked off with the **steering committee meeting**, where there was plenty of discussion and planning. I can't reveal too much yet (I'd have to swear you to secrecy), but let's just say **UKIVAS is evolving** – so keep your eyes peeled for news of what's coming next.

The afternoon was packed with presentations (you'll find the details in a separate article). What really struck me was how often the **priorities of clinicians, researchers, and patients lined up**. It feels like we're moving into an era where everyone's rowing in the same direction – and that can only mean a brighter future for patient care.

And the cherry on top? A quick dinner with some of the clinicians afterwards. With the science part done for the day, the conversation turned more personal – and it was lovely to see the people behind the stethoscopes.

So, in short: steering, sharing, learning, and a bit of eating. Not a bad day at all!

July 2025

UK Child Health Research Collaboration (UKCHRC) Networking Event on Inflammation and pain, London 1st July

Vasculitis UK was honoured to be invited to the very first **UKCHRC Networking Event** in London, focused on *inflammation and pain*. This inaugural gathering provided a valuable opportunity to connect with others who share the same passion for improving patient outcomes, while also opening the door to potential collaborations in future research.

The event was expertly chaired by **Professor Paul Dimitri**, who created a welcoming and engaging atmosphere throughout the day. Patient organisations, including Vasculitis UK, were given the opportunity to introduce themselves, share their aims, and present their ongoing work. This not only highlighted the important role of patient groups in shaping research but also sparked meaningful dialogue with fellow participants.

The discussions that followed were both open and constructive, offering space to exchange ideas, perspectives, and experiences. The workshop element of the day was particularly valuable, enabling participants to explore opportunities for joint working and to consider how research could be shaped around the needs of patients.

Overall, it was an inspiring and thought-provoking event. We look forward to hearing which research topics UKCHRC will prioritise next – and very much hope there will be future opportunities for Vasculitis UK to contribute again.

Living with Vasculitis Regional Vasculitis Awareness and Patient Education Day – Manchester 20th July

On **20th July**, Manchester hosted the *Living with Vasculitis Awareness and Patient Education Day*. The event was organised by **Dr Silke Brix** and her team, with support from a patient committee – and it was a great success.

It wasn't all smooth sailing. The venue, a stunning listed building, was a little tricky to find as signs weren't allowed. Luckily, some helpful patients stood outside to guide people in. A small technical issue also delayed the start, but once that was fixed, the day flowed wonderfully.

The programme included a mix of **presentations from patients, doctors, and nurses** – giving a full picture of life with vasculitis. The **patient stories** were especially moving and set the tone for the whole event.

There was plenty of time to chat, share experiences, and connect with others living with vasculitis. The day ended with **roundtable discussions**, each led by a specialist and a patient, encouraging open and supportive conversations.

Events like this mean a lot to patients. They provide:

1. Education about vasculitis
2. Support from healthcare teams
3. The chance to meet and connect with fellow "vascies"

The good news? This will now be an **annual event in Manchester**. So, if you missed it this year, keep an eye out for the next one!

A big thank you to **Dr Brix** for involving **Vasculitis UK** in such a valuable day. Here's to many more successful open days ahead!

RAIRDA Summer Update: Progress, Partnerships, and Planning Ahead

For those who are not familiar with RAIRDA: The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) is the first dedicated body linking both clinical and patient organisations, providing a strong voice to campaign for improved care for people living with rare autoimmune rheumatic diseases. Vasculitis UK is an active member of the alliance.

From refining our Quality Standard for Rare Disease project to engaging with Parliament and responding to England's 10-Year Health Plan, the past few months have been both busy and productive for RAIRDA.

Driving Forward the Quality Standard

Our core focus this summer has been on the **Quality Standard** work.

In June, we held a **Steering Group meeting** to refine the draft statements following feedback from the second community survey. This process reduced the number of statements to 13, which were then discussed and ranked at a **Consensus Workshop on 15th July**. Attendees from across the rare disease community provided valuable input, helping us move closer to a final set of recommendations.

Our next milestone: finalising the statements ahead of our **November meeting with the NICE Quality Standards Committee.**

Parliamentary Engagement

We've been active in building connections and strengthening advocacy across the UK:

- **Met with Genetic Alliance UK** to explore collaboration through the APPG on Rare, Genetic and Undiagnosed Conditions. A joint session is planned for discussion in September.
- Attended the **June APPG session** on the Rare Disease Framework, highlighting the importance of its continuation beyond 2026.
- Held meetings with **Jim Shannon MP** (sponsor of December's Westminster Hall debate) and **James Evans MS** (Conservative Health Spokesperson in Wales), and are arranging a session with **Lord Kamall.**
- Met with **DHSC** to discuss the Rare Care Matters report, our Quality Standard progress, and how best to achieve improved outcomes for people with RAIRDs.
- Developed **Parliamentary Questions for Wales** following the launch of *Rare Care Matters*, with similar lists in progress for other nations.

Other Key Activities

- Submitted RAIRDA's response to the **DWP Pathways to Work** consultation, shaped by feedback from a dedicated workshop.
- Continued work on **high-cost drugs and specialised networks** with Dr. Shouvik Dass (National Specialty Advisor for Specialised Rheumatology) and Dr. Frances Hall (Consultant Rheumatologist).
- Progressed the **RAIRDA Schools Prize**, with Imperial College reviewing submissions. Shortlisted posters will be shared with member organisations in October for the final judging round.

Responding to the 10-Year Health Plan for England

Following the plan's release, RAIRDA published a statement outlining the opportunities and concerns for people with RAIRDs. While there are positive commitments—such as earlier diagnosis, personalised care plans, and mental health investment—there are gaps in addressing non-genetic rare diseases and risks in shifting to community-led care without clear specialist pathways.

Key points from our comparison with the Rare Care Matters recommendations include:

- **Early diagnosis:** Must include non-genetic conditions, with investment in methods beyond genomics.
- **Care plans:** Strongly welcome, but patients must be actively involved.
- **Digital tools:** Potential benefits in centralised patient data and remote care, but risk of confusion without clear referral pathways.
- **Community-based care:** Could reduce pressure on hospitals, but requires robust specialist links to avoid gaps.
- **Mental health:** Encouraging funding, but psychological support must be embedded in RAIRD care pathways.

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Our Key Recommendations

1. **Renew the Rare Disease Framework** beyond 2026 to sustain progress, particularly for predominantly non-genetic conditions like RAIRDs.
2. **Invest in specialised networks** (including rheumatology) to expand clinician expertise, improve access to specialist input, and deliver more care locally.

Looking Ahead

- **Jim Shannon MP** will send letters to Ashley Dalton and Wes Streeting after summer recess, incorporating RAIRDA's reaction to the 10-Year Plan.
- We'll contribute to **James Evans MS' Welsh Health Manifesto** later this year.

RAIRDA remains committed to ensuring people with RAIRDs receive timely, coordinated, and specialist care—wherever they live.

RaDaR – celebrating 15 years!

In February this year I attended a meeting about IgA vasculitis in Liverpool and I was approached by Prof. Allan Salama who asked if I could be a patient representative in RaDaR supporting the vasculitis workgroup.
What is RADAR you will ask. With over 35,000 patients recruited from 109 sites across the UK, RaDaR is the largest rare kidney disease registry in the world and it supported by the UK Kidney Association.
A good registry is a tool for researchers, especially when it comes to rare diseases where identifying patients to support research can be challenging.
I am not a renal patient so over the last 6 months I have studied a lot about renal disease and renal involvement in vasculitis. I admit that glomeruli are not only fascinating, but also beautiful (under the microscope).
Being a newbie in RadaR it was a privilege to be invited to the 15 years celebration in London. A good opportunity to meet people from other organisations and healthcare professionals, a space for networking and sharing ideas.
If you would like to learn more about RaDar and watch the presentations of the day please visit The UK Kidney Association website at
https://www.ukkidney.org/rare-renal/events/radar-15-year-celebration

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Vasculitis UK Grant Awards and SAB Update 2025

A year of progress and change

The past year has been an important one for Vasculitis UK as we continue to build on our work supporting patients, funding research, and raising awareness of vasculitis across the UK and beyond. Our annual grant call once again brought forward a wide range of high quality applications, each offering new ideas and approaches for improving patient outcomes. Thanks to the hard work of applicants and our peer reviewers, as well as the expertise of the Scientific Advisory Board, we are delighted to announce four new projects that will be funded in 2025.

Alongside these exciting research awards, this year also marks a change within the Scientific Advisory Board (SAB). The SAB plays a vital role in guiding our decisions on research funding and helping us ensure that every project we support has the greatest possible chance of making a difference. The addition of four new members, each bringing considerable expertise and perspective, represents an important moment in the continuing growth of Vasculitis UK.

Welcoming new members of the SAB

We are especially pleased that all four of our new SAB members reflect the breadth of expertise and leadership among women in vasculitis research and care. Their arrival strengthens the SAB and gives us an even broader base of knowledge to draw upon.

Dr Silke Brix is a highly respected renal consultant and honorary lecturer at the University of Manchester. Based at the Manchester University Hospitals NHS Foundation Trust, she divides her time between front-line clinical work and cutting edge research in nephrology and clinical immunology. Dr Brix's insight into both patient care and scientific discovery makes her a valuable addition to the SAB.

Dr Rachel Jones is an Associate Professor and Consultant Nephrologist with a specialist focus on vasculitis, lupus and immune mediated renal disease. Her clinical role focuses on management of the Cambridge vasculitis and lupus service, which supports more than 1,800 outpatients, alongside a dedicated inpatient service. Dr Jones has a strong background in clinical trials, having led numerous international studies that bridge both academia and industry. Her experience of translating research findings into patient benefit will be a great asset.

Georgina Ducker is the Vasculitis Specialist Nurse at the Norfolk and Norwich University Hospital. Since 2020, she has been part of a large multidisciplinary team working to improve outcomes for people with vasculitis. She runs nurse-led clinics that provide education, monitoring and support for patients across all types of vasculitis. Her published work includes studies on ultrasonography training for specialist nurses, quality standards in Giant Cell Arteritis (GCA), and practical improvements in GCA patient care. Georgina is also part of a European taskforce contributing to the development of EULAR recommendations for large vessel vasculitis (LVV) and polymyalgia rheumatica (PMR).

Dr Jo Robson is an Associate Professor in Rheumatology at Bristol Royal Infirmary. She specialises in systemic vasculitides, with a particular focus on ANCA associated vasculitis and Giant Cell Arteritis. Dr Robson's clinical and research portfolio is built on patient centred approaches, with a strong emphasis on outcome measures that reflect what matters most to patients. Her commitment to research that translates into better quality of life for those affected makes her an important voice on the SAB.

The addition of these four new members ensures that the SAB continues to reflect a wide range of perspectives, from laboratory research and clinical trials to patient care and service development. Their contributions will help shape the direction of Vasculitis UK research funding for years to come.

Research grants awarded in 2025

This year we received ten applications covering a wide spectrum of research topics. Each was reviewed by external experts before being discussed at the SAB meeting in June 2025. The SAB's recommendations were then carefully considered by the Board of Trustees, who made the final funding decisions. We are pleased to announce the following four successful projects:

1. A prospective trial emulation study comparing the effect of standard versus minimal glucocorticoid exposure on renal outcomes in ANCA associated vasculitis patients treated with avacopan.

Lucy Francis at Addenbrookes (£12,500)
This study focuses on improving kidney health in patients with ANCA-associated vasculitis (AAV), an autoimmune disease that can lead to severe kidney damage. A newly approved drug avacopan may help improve kidney function in AAV, however the best way to combine it with steroids to achieve the best kidney health remains unclear. The study will compare two treatments: one using standard steroid doses with avacopan and another using little to no steroids with avacopan, to see which approach better protects kidney function. The optimal strategy for steroids is an important question as it can have several side effects such as weight gain, high blood pressure, mood changes, weakened bones, increased infection risk.

Researchers will aim to recruit 100-150 kidney AAV patients not receiving avacopan, and 350-400 kidney

AAV patients receiving avacopan from across the UK. Patients' outcome data will be collected in a registry database for up to 24 months by accessing medical records data including monitoring for kidney health, vasculitis remission and relapse, medications and adverse events. Patients will be asked to complete quality of life questionnaires. The main question being addressed is whether steroids are needed with avacopan to optimise kidney function recovery, or whether steroids are not required with avacopan.

2. Frailty in Vasculitis – Investigating the Influence of Different Elements of Frailty Screening on Patient Outcomes in ANCA Vasculitis.

Dr Silke Brix at Manchester Royal Infirmary (£46,818)
This project will investigate patients with small vessel vasculitis whose disease is associated with anti-neutrophil cytoplasmic antibodies (ANCA).

Age, other health conditions and growing weaker and dependent, so-called frail, seem to affect the risk of suffering complications from treatment. There is an urgent need to develop tools in vasculitis to measure the risk of failing treatment and suffering complications.

In this Vasculitis UK project, researchers will try to understand the different aspects of frailty that are the reason why patients with vasculitis fail treatments. They will use the funding to study a large data set of linked data from primary and secondary care. Will examine the data in a confidential manner, and search for the responsible aspects in frailty screening that associate with patients dying and requiring hospital admission. Identifying the risks for bad outcomes, patients, nurses and physicians will have a better understanding of the benefits and risks of vasculitis therapy when making treatment decisions together.

3. Impact of Fc-Glycosylation on relapse risk in ANCA-associated vasculitis (GLYCOVASC study).

Professor Mark Little at Trinity College Dublin (£49,378)
ANCA-associated vasculitis is a rare autoimmune disease that tends to recur (or relapse). Predicting in which people this will happen is a major unmet need with the potential to greatly improve patient quality of life. For example, if we could identify people with a very low risk of disease recurrence, these individuals could be spared the side effects of ongoing medications.

The GLYCOVASC project will test whether changes in the sugar molecules on the antibodies that cause vasculitis can predict future relapse risk. They will achieve this by bringing together several large groups of patients (in Ireland, Spain and Czechia) who have agreed to share information about their disease history (including relapse events) and their biological samples. The antibody sugar patterns will be measured using advanced techniques in Leiden, Netherlands and the results will be linked to the clinical information to determine the link between sugar patterns and the occurrence of relapses. This analysis will be fed into a larger European programme which aims to build an AI tool for relapse prediction, with the potential for direct impact on patient care.

4. Cell Free DNA as a Biomarker for Primary Angiitis of the Central Nervous System.

Dr Claire Rice at University of Bristol (£48,740.61)
Vasculitis - inflammation of the blood vessels – can affect any organ in the body. When the vessels of the brain and spinal cord are inflamed without other organs being involved, the condition is referred to as primary angiitis of the central nervous system (PACNS). People with PACNS have varied neurological symptoms which may include headache, visual problems, confusion, bowel and bladder disturbance and limb weakness. These symptoms, and the associated abnormalities seen on scans, may be caused by many other neurological diseases and there is no blood test which can confirm a diagnosis of PACNS. As with other types of vasculitis, the diagnosis can be confirmed by seeing vessel inflammation in tissue examined under the microscope. However, getting samples (biopsies) of brain and spinal cord involves a neurosurgical procedure which may itself contribute to neurological damage. These factors delay the diagnosis of PACNS which, in turn, exacerbates damage to the brain and spinal cord and increases the risk of permanent neurological disability.

In cancer and some types of inflammation, small amounts of genetic material that can be traced to specific cell types can be detected in body fluids such as blood and spinal fluid. This is referred to as 'liquid biopsy'. In this project, they will determine whether liquid biopsies can help confirm a diagnosis of PACNS with the aim of making the diagnosis earlier and monitoring treatment response without the requirement for a neurosurgical procedure, so that neurological disability due to vasculitis can be avoided.

Looking ahead

These four projects highlight the diversity and strength of current research in vasculitis. From optimising existing treatments, to understanding the role of frailty, to developing entirely new diagnostic tools, the work funded this year represents real progress for patients. Each project is grounded in improving outcomes and quality of life, which remains the central priority of Vasculitis UK.
We are also encouraged by the growth and evolution of the SAB, whose members give freely of their time and expertise to ensure our grant funding process is rigorous, fair and progressive. With their guidance, and the continued support of our community, we are confident that the research we fund today will bring benefits to patients for many years to come.

NEWSLETTER

AUGUST 2025

UWE Bristol | University of the West of England

Welcome to our very first RAISE newsletter!

The RAISE patient survey started on 2nd May 2025 and 3 months in, there has been brilliant recruitment activity! So far we have collected over 700 responses from NHS sites and social media adverts/ links.

A total of 22 NHS sites have had the green light and are currently recruiting. NHS sites include England and Scotland so far, but we are hoping to recruit more sites including Wales.

Many thanks to the patient charities Lupus UK, RAIRDA, Vasculitis UK, Behçets UK, Sjögrens UK, Myositis UK, Scleroderma and Raynauds UK who are distributing the online version of the survey via their social media platforms

*We would like to say **thank you** to all NHS sites and patient charities involved for your commitment and amazing work so far, we hope that you continue recruiting more patients in the coming months*

Focus on NHS recruitment

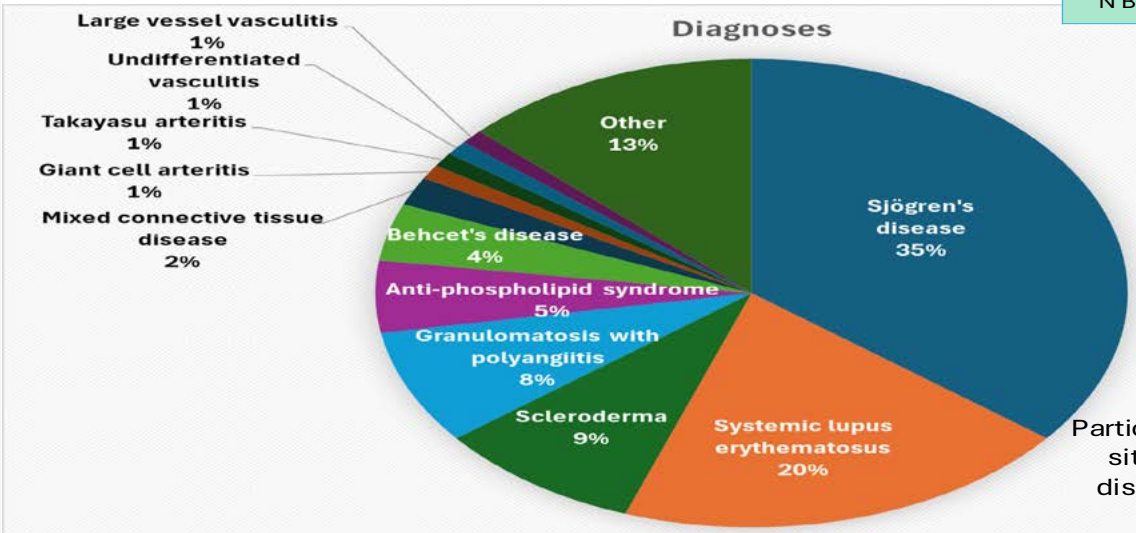
We have received total 151 completed NHS surveys since May (87 online and 65 paper).

Well done to Great Western Hospitals for achieving 25 completed online surveys so far. Dudley group of hospitals and Royal Blackburn Hospital have achieved the highest number of surveys completed on paper, amazing work!

We have found that some sites prefer surveys to be completed on paper rather than online, please continue to follow what is best for your team and patients, keep going!

The survey will continue until at least Dec 2025

Top 5 NHS sites for survey completion			
NHS sites	Online	Paper	Total
Dudley	16	29	45
Blackburn	1	32	33
Great Western	25	3	28
Sandwell & W Birmingham	13	1	14
Maidstone & Tunbridge Wells	12	0	12
N Bristol	0	10	10



Participants recruited via NHS sites: 35% had Sjögren's disease, 20% SLE, and 9% Scleroderma

PARTICIPANTS NEEDED! Please keep recruiting all patients

Specific patients we would particularly like to focus on (but all still welcome) :

- **People with myositis, scleroderma and SLE**
- **Men**
- **People with a range of different ethnic backgrounds**
- **Younger people**

Here is the QR code to access the survey

RAIRDA Rare Autoimmune Rheumatic Disease Alliance

VASCULITIS UK

UNIVERSITY OF LEEDS

FUNDED BY NIHR | National Institute for Health and Care Research
The RAISE project has NIHR portfolio status

Donations & Fundraising Bequests - In Memoriam

Debra Kesby Much loved mother, auntie and nanny. She ran a B&B in Tenby and enjoyed her arts and crafts. She developed Vasculitis in 2019. Donations to Vasculitis £403.75

Adam Morgan much loved and never forgotten. Donations £748.75

Loretta Franklin much loved and will always be remembered.
Loretta was originally diagnosed in March 2008 with GPA. She underwent many medical procedures and endless medications. She tried to live her life even when in pain. Donations to vasculitis UK £1833.75

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**

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.

Donate with JustGiving

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

PayPal MasterCard VISA

Help , Advice & Support

For peer to peer advice and support join the Vasculitis UK online discussion groups on HealthUnlocked and Facebook.

You can find the groups by clicking on the icons HU or F at the bottom of each page on Vasculitis Uk's website

Both groups have around 7,000 members each, and whatever type of vasculitis you have you will find a peer.

For more tailored advice and support contact the helpline at 0300 365 0075

For all the latest information and news visit the Vasculitis UK website https://www.vasculitis.org.uk/

VASCULITIS UK

We need your help to continue the great work of this charity.

This summer, wonderful new volunteers joined our team — and we'd love for **YOU** to be part of it too!

Whether you can give a little time or a lot, your support makes a real impact.

Interested in volunteering?
Contact us today to find out how you can assist and be part of something truly meaningful

email info@vasculitis.org.uk

Join our team

Get in touch with your local Vasculitis Support Groups

England

Beds, Bucks & Herts Group
Janine Davies – 01525 372733 – family.davies@btinternet.com

Cheshire Support Contact
Susan Chance - susanchance53@icloud.com

Gloucestershire Support Group
Sian Green – gloucestershirevasculitis@gmail.com

Hastings/Brighton
Antony Hart and Liz Wilson – antonyhartvuk@outlook.com

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

London Support Group
Roy Seger 0779 974 6268 – roysg296@gmail.com

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

Norfolk – The Ring
support group in Norfolk for RA patients
Judith Virgo – jvirgo@fsmail.net

North Derbyshire and South Yorkshire Support Group
Susan Mills – susan@vasculitis.org.uk

North-East Group
Co-leaders **Dan Hughes** and **Claire Phillips** vasculitusne@gmail.com

Northampton Vasculitis Support Group
Mel Alexander – 07884 257123 – northants-vsg@outlook.com

North-West Group
Jann Landles – 07979 180145 or
Anita Parekh – 07921 682232 – nwvasculitis@outlook.com

Oxfordshire Group
Sue Ashdown – 0781 730 3625 – vsgoxford@gmail.com

Plymouth Group
Elaine Ponsford – elaineponsford1964@gmail.com

Surrey Group
Peter– surreyvsg@gmail.com

West Midlands Group
David Sambrook - davsamuk@yahoo.co.uk

West Country Group
West Country Vasculitis Support website
Charlotte Stoner – 01626 872420 – westcountryvasculitisgroup@outlook.com

Yorkshire Group
Rachel Weeks – 07968 959 850 – rachel@yorkshirevasculitis.org.uk
Mark Widd - vasculitis.yorkshire@gmail.com

Wales

North Wales – Contact Person
Pat Vernalls – 01766 770546 – patvernalls@btinternet.com

South Wales Group
South Wales Support Group website
Angharad Jones - Angharadjones.vas@gmail.com

Scotland

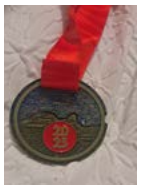
Edinburgh and Lothian – Contact Person
Jimmy Walker – 07725 770103 – jamzywalker@gmail.com

Republic of IRELAND

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

All-Ireland Support Group – Vasculitis Awareness Ireland
Vasculitis Awareness Ireland Website http://vasculitis-ia.org/
Cecil Armstrong, Chair, Vasculitis Ireland Awareness – vasculitisirelandawareness@gmail.com
Tel: +44 78 1587 2010
Julie Power, Patient Contact Officer – vasculitisireland10@gmail.com
Tel: +44 7522 932126

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



great north run

Thank You

To all this year's runners in the Great North Run. You've raised over £9,000 and some of you are still fundraising. This will be my last year as the coordinator for the GNR and Fundraising for Vasculitis UK. I've greatly enjoyed meeting and talking to so many of you. Especially those who come back every year. I've already had the first email requesting a place for 2026. The trustees have decided to employ someone to carry out my role. I don't know who will succeed me. For now, please send your requests to the Chairman claire@vasculitis.org.uk

2025 runners

Jake McMorris, Reece McMorris, Lily Daniels, Jonathan Ford, Katie Morris, Deb Downey, Lorraine Oakley, Kev Heath, Ted Tavendale, Ann Morgan, Tom Morgan, Steph Harrison, Ella Hughes-Reader, Oliver Galotto, Jess Downey, Andrew Sharp, Kayleigh Morris, Zach Simpson, Katie Gorwits-Chapman, Sue Pryke, Heidi Pollard, Vimbai Tungwarara, Peter Stallard and Charlotte Hall.

Thank you for 15 wonderful years of getting to know some crazy magnificent people.

Dorothy Ireland

VASCULITIS UK

Tribute to James (Jimmy) Walker

James Walker was diagnosed with GPA vasculitis in 2007. You can read more about his story here: https://www.vasculitis.org.uk/living-with-vasculitis/jimmys-story

From the moment of his diagnosis, James became deeply committed to supporting others living with vasculitis. Through this work, he formed a lasting friendship with John and Susan Mills and became a dedicated part of the Vasculitis UK community.

James was passionate about helping others. He visited patients in hospital, raised awareness about vasculitis, and fundraised tirelessly for research. In 2014, he took on the role of Vasculitis UK's contact in Scotland, offering advice, encouragement, and understanding to those newly diagnosed.

Despite his illness, James refused to let vasculitis define him. He continued to travel widely, sharing photos of the beautiful places he visited on his Facebook page. That same year, he and his close friend Richard travelled from Scotland to London to take part in the VasculitisUK Thames Walk, raising both awareness and funds for the cause he cared so deeply about.

James was a kind, genuine man who touched many lives through his warmth, humour, and compassion. He will be greatly missed by his family, his friends, and everyone in the vasculitis community who had the privilege of knowing him.

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

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Published by:
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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