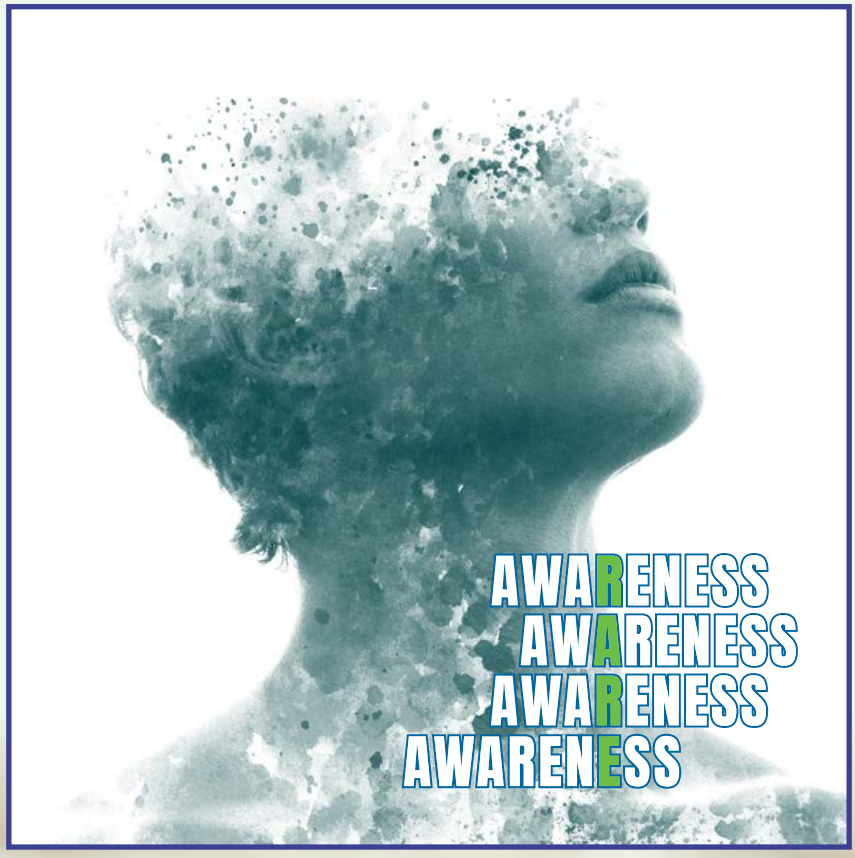
VASCULITIS UK

NEWSLETTER JOURNAL



SPRING 2026 ISSUE 71

‘View from the Chair’

I would like to use my column this month to celebrate our fantastic fundraisers who are the backbone of the income that we generate in Vasculitis UK.

I have been struck by the incredible commitment and passion of all of those people who take time to raise money for our Charity. From raising a few pounds from a plant sale to climbing mountains or taking part in endurance events, everything that you do is really appreciated and reinforces what a great community we have.

Some of you may be raising money in remembrance of a loved one; some of you may be living with Vasculitis and some of you may be family, carers or friends of a person who has been affected by Vasculitis. Whatever your motivation, we want you to know that the money that you raise goes straight into funding much-needed research and supporting our Vasculitis community. We also fund Vasculitis specific training for our medical professionals, and this year we were able to provide funding towards the travel costs of eight UK based health professionals attending the International Vasculitis Workshop in Melbourne. You will be able to read some of their stories in the newsletter. We want to extend the bursaries that we are able to give over the coming year or so, to ensure that we have a cohort of professionals who remain committed to working to address the needs of Vasculitis patients.

Our funds also enable us to create specialist materials and hold stalls at key national and international events so that we can engage face to face with our professional colleagues to increase their awareness of Vasculitis and to ensure that the patient voice is put at the centre of their work. At the time of writing this article, Laura, Diana and Zoi are getting ready to go to Glasgow for a few days to have a stall at the British Society of Rheumatology conference.

We always try to acknowledge our fundraisers in this newsletter, although occasionally we don’t get all of the information that we need from some of the smaller fundraising platforms, so if we don’t mention you by name, please be assured that you still have our sincere thanks for all that you do. Especial thanks though do have to go to the Pittacchio family who continue to raise substantial funds for the charity through their activities – including having climbed Mount Kilamanjaro! Also to Nic Rotton from the Midlands who is currently part-way through completing the equivalent of a triathalon a day for 30 days. I am hoping to record an interview with Nic for our website once he has recovered!
Although much coveted sponsored places for the London Marathon still elude us, we have a number of people, including Heidi, our Treasurer, who have got ballot places and are choosing to run for Vasculitis UK this year.

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We are able to offer places in certain events to our fundraisers including the Great North and Great South runs. Alongside this we can provide running vests/t-shirts and fundraising packs and promotional materials for any events that you may be organising. Please email me on claire@vasculitis.org.uk if you are arranging or taking part in an event and would like some materials to use. At the moment our Vasculitis UK flags are proving very popular!

So sincere thanks are given to everyone who has either raised funds for us or have donated to the fundraising efforts of others. In these difficult times for so many, your generosity is acknowledged with thanks and love.

VASCULITIS UK

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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 Spring newsletter, slightly delayed so that we could deliver another packed edition. There is one very special thank you to go out to Dorothy Ireland who recently retired as chair of our charity, look out inside for those special tributes!
As I write this we are 8 days into our annual awareness month of May, this year the focus is "Move your way in May".
On a personal note the next few months will be one of excitement along with some anxiety, both as a parent and grandparent as our granddaughter will be having her kidney transplant and our Son is the donor this is due to take place in early June.

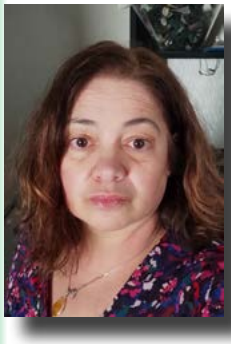
As I have said on many occasions that without this charity and those involved we as a family would not be able to pass on information and guidance and we will always be grateful for the support and advice that we have been given via support groups and those involved with this fantastic charity.

Time to grab your favourite brew and enjoy!

Kevin Soper

Director of Operations Report – Spring Edition

By Zoi Anastasa



Spring has finally arrived, and even the sun seems to have remembered its job. The winter that was grey, wet, and determined to chill us to the bone, but the work carried on — as it always does. Over the next pages you'll read the official version of what we've been up to these past seven months but allow me to lift the curtain and share a few behind-the-scenes moments and hints of what's coming next.

UKIVAS in Bristol — A Bright Start

The UKIVAS course in Bristol was a triumph. Seeing so many healthcare professionals gathered to learn about vasculitis felt like watching awareness bloom in real time. I was especially delighted to see nurses in attendance. For them, attending educational events often requires Herculean effort: time off is scarce, grants are rarer than unicorns, and travel and accommodation costs are… well, let's just say they don't come with a fairy godmother.

This year also saw the first **John Mills Educational Award**, it went to nurse consultant Sarah Hardy for her outstanding commitment to nurse education. A well-deserved honour.

A Prague Adventure — With Plot Twists

November brought me an unwelcome guest: a fierce fibromyalgia flare. For the first time in four years at VUK, I had to take sick leave. By the time I travelled to Prague for the Vasculitis International Patient Summit, I realised I couldn't manage alone. In ten years of living with vasculitis and fibromyalgia, I've only needed support once — so this was not in the script. Enter Irene, my guardian angel from Greece, who flew to Prague to help me pace myself and sprinkle a bit of magic on the trip. I'm also deeply grateful to Vasculitis International for covering the cost.
The summit itself was a joy — reconnecting with old friends in advocacy and meeting new ones just beginning their journey. Prague was breathtaking, freezing, and full of Christmas charm. My new waterproof boots earned their keep, and evenings spent with friends warmed the soul, if not the fingers.

Budapest — Guidelines, Christmas Markets, and a Walking Stick

A few weeks later, I found myself in Budapest, invited through ERN RITA — the European Reference Network for Rare Immunological Disorders. A dedicated group of healthcare professionals had spent a year working on developing guidelines for paediatric CNS vasculitis, and I was genuinely inspired by their commitment. The meeting took place in a hotel overlooking the Danube, and the organisers treated us to evening meals and cultural events. Budapest, dressed head-to-toe in Christmas lights, was irresistible. The city has more Christmas markets than seems strictly necessary — two large ones and countless smaller ones. Even with a walking stick, I explored as many as I could. I love Christmas, and Budapest clearly does too.

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London — Panels and Prime Ministers

January took me to London for the Glomerular Disease meeting at the Royal Society of Medicine. I was honoured to serve on the patient panel — a role that always reminds me why advocacy matters.

With a day to spare, I visited Hughenden Manor, once the home of Prime Minister Benjamin Disraeli. To my astonishment, I learned that during the Second World War its basement served as a secret intelligence base known as "Hillside." History always has its surprises.

Melbourne — The Journey of a Lifetime

And then came the biggest trip of my life: the International Vasculitis Workshop in Melbourne, Australia. Until now, I had never travelled more than five hours in one go. So yes — exciting, terrifying, and requiring a visa process that felt like auditioning for a medical detective series. Finding a local appointment for the required medical exam was a challenge, and the scrutiny was… thorough.
I met Inge from the Netherlands during a layover in Dubai, and Isabelle from France joined us later in Melbourne (after a missed flight — the joys of international travel). We were representing Vasculitis International, and I was the only one with partial funding from my own organisation, Vasculitis UK.
Our accommodation was a glass building that made us feel like decorative fish. The venue was a 15-minute walk away, so we earned our daily steps whether we wanted to or not.
The workshop itself was extraordinary: a patient conference followed by four days of intense learning, global collaboration, and the shared passion of clinicians, researchers, and patient advocates. I met colleagues from Canada, Japan, the US, and Ireland — though I missed my partner-in-crime, Julie Power.
I returned home with new knowledge, new connections, and — most importantly — Mr Peter Kitching, my new fluffy companion. He even wrote an article. You should absolutely find it.
We stayed an extra two days to rest and explore. Fatigue limited us, but we managed a beautiful west-coast tour. And then reality struck: a war broke out, disrupting flights and sending our plans into chaos. My flight was cancelled. For ten anxious hours we debated whether to stay longer, whether accommodation would be available (Formula 1 was arriving in Melbourne), and how long our medication supplies would last. With support from our families and reassurance from Peter Verhoeven, chair of Vasculitis International, we made the decision to return to Europe as soon as possible.
Inge's family came to the rescue, booking us flights via Shanghai to London. From there, Inge and Isabelle continued home, and I took the train to Plymouth. I will be forever grateful — they lifted a heavy burden that day.
What an adventure.

What's Next

After a blessed seven-week pause, the travel begins again. The British Society for Rheumatology conference is next week, followed by the Royal College of Nursing Congress in May. Between these events, Vasculitis UK will be appraising two medications for the Scottish Medicines Consortium.

And of course — May is Vasculitis Awareness Month. Spread the word, share the stories, and let's keep pushing for better care.

Thank you to everyone who continues to support our work, our community, and our mission.

Join our team as a volunteer!

Vasculitis UK is looking for volunteers to strengthen its team – you may be that person!
We're seeking enthusiastic volunteers to help in three areas:

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

Please, contact **zoi@vasculitis.org.uk** to register your interest or to ask questions.

Reflections on the Patient Panel at the RSM Glomerular Disease Meeting Royal Society of Medicine, January 2026 *by Zoi Anastasa*

Taking part in the patient panel at the RSM Glomerular Disease meeting was a meaningful and humbling experience — one that reminded me how powerful patient voices are in shaping the future of care, research, and understanding in glomerular disease.

Although I do not have renal involvement myself, I had the privilege of representing the experiences of many within our community who do. Before the event, several of our members generously shared their stories with me their challenges, their hopes, and the realities of living with glomerular disease. Their openness allowed me to step into the panel with a deeper sense of responsibility and a clearer understanding of what truly matters to patients navigating these complex conditions.

The session, chaired by Dr Haresh Selvaskandan and Dr Katie Allen, created a rare and valuable space where lived experience guided the conversation. Patients spoke candidly about their diagnostic journeys, the treatments that shaped their lives, and the emotional and practical hurdles they faced along the way. Their reflections grounded the meeting in the real world beyond test results, beyond protocols, and into the day-to-day realities of life with a rare kidney disease.

Listening to the panel, several themes stood out:

- **Navigating the healthcare system** can be overwhelming, especially when care is fragmented or communication is unclear.
- **Good days and bad days** are shaped not only by symptoms, but by support, stability, and the ability to plan life around treatment.
- **Clinical research** offers hope, but only when it is accessible, well-explained, and integrated into routine care.
- **Support groups** remain a lifeline offering community, shared understanding, and a sense of not being alone in a rare journey.

These insights are not abstract. They are lived truths, and they carry weight.

I want to extend my heartfelt thanks to the Vasculitis UK members with renal involvement who took the time to share their experiences with me ahead of the meeting. Your honesty and trust allowed me to represent your perspectives with care and accuracy. Although I do not walk this path personally, your voices guided me, and I carried them with me into the discussion.

Your stories, your resilience, frustrations, humour, and determination shaped the contribution I was able to make. This panel was not about one person speaking; it was about a community being heard.

The patient panel was a reminder that progress in rare disease care depends on partnership. When clinicians, researchers, and patients come together with openness and respect, we create a stronger, more compassionate foundation for the future.

I left the session encouraged not because the challenges are small, but because the commitment to listening and improving is real. And that commitment grows stronger every time patients share their stories.

VASCULITIS UK

Consensus meeting for childhood CNS vasculitis

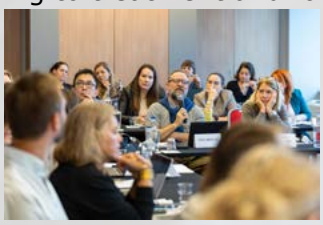
A major international effort to improve the diagnosis and treatment of childhood CNS vasculitis took place in Budapest on 12–13 December 2025, bringing together experts from paediatric rheumatology, neurology, neuroradiology, and adult rheumatology. The meeting was organised by the Semmelweis University Pediatric Center, with Dr. Tamás Constantin, paediatric rheumatologist, serving as lead organiser. Supported by ERN-RITA, the meeting aimed to build the first evidence-based, globally agreed recommendations for this very rare condition, which affects around three in every million children each year.

Of course the project had started much earlier, and a lot of work has been done behind the scenes. Ahead of

the conference, the Semmelweis University Paediatric Rheumatology Working Group conducted a comprehensive systematic literature review across four major databases screening 7,842 publications and identifying approximately 200 relevant studies through independent dual review. Uniquely, this process was supported by AI-assisted tools. Parallel AI and expert analyses of the selected literature enabled a comparative evaluation of human and AI-generated conclusions — a level of AI integration that, to the organisers' knowledge, represents a first in paediatric clinical guideline development.

Over two intensive days, the conference brought together 54 international experts from 18 countries — spanning Europe, North America, and the Middle East across 7 medical specialties, including paediatric rheumatologists, neurologists, neuroradiologists, immunologists, a neurosurgeon, a haematologist, and a patient representative.
I had the privilege of attending as the patient representative, and being part of this process meant a great deal to me. It was important to ensure that the patients voices were included alongside the scientific evidence.

The final recommendations will include statements covering all key aspects of care, from diagnosis and imaging to treatment and follow-up. They will also introduce new tools, such as clearer definitions of remission and



relapse, a child-specific guide for interpreting vessel wall imaging, and a system to help assess risk at the time of diagnosis. Importantly, the group also identified areas where research is still urgently needed.

The outcomes of the meeting including consensus-agreed diagnostic pathways, imaging assessment criteria, and treatment algorithms will be published in international peer-reviewed journals and will serve as official ERN-RITA recommendations across Europe. These recommendations are expected to harmonise care across centres, reduce variation in practice, and ultimately improve outcomes for children and families affected by CNS vasculitis.

This work is still ongoing, and we look forward to sharing a clear, patient-friendly lay summary once it is published.

We want to thank everyone for sharing their expertise and for working together with such commitment to improving care for children and families affected by CNS vasculitis.

Tamás Kecskés and Zoi Anastasa

On a personal note, spending two days in such a beautiful city made the experience even more memorable—although staying focused was sometimes a challenge with the stunning views just outside the window. I am deeply grateful to the clinicians who took the time to explain complex concepts and who listened when I spoke about the importance of education and support for patients and families.
Our evening quiz hunt was an unexpected highlight and the most fun I've had in ages—a reminder that collaboration can be both meaningful and joyful.

Zoi Anastasa

Walking the Journey Together: Reflections from the Helpline

I first started taking calls on the helpline more than 10 years ago. I had very good mentors in John and Susan Mills. Like many people, I knew my own condition of MPA and the other AAV forms, but not much about the rest. Even though I'd attended meetings and listened to the professors, there was still so much to learn. I was very thankful to have John and Susan at the end of a message whenever I got a call about something unfamiliar.
The route map was fairly new on the website then, and I made good use of it. Later we produced the book with most of the conditions included, although it does need regular updates.
I actually enjoy taking the calls. It's mostly people who've never met another "vascie". When they realise you also have Vasculitis, they're so thrilled. Like them, I remember when I was first diagnosed — all the new terminology, the medications, and the shock of learning you're on a chemo drug. It was overwhelming. So callers are relieved to speak to someone who truly understands this rare disease.
Sometimes we get callers who've been on US websites. It really is a different world, especially if you can't afford treatment. That's often why people turn to strange diets or herbal remedies.
We don't give medical advice; instead, we signpost people to the growing number of Vasculitis specialists throughout England. Wales is a different story. There's also a Vasculitis network in Scotland with a few specialist centres. Mostly, people want reassurance that they're on the right treatment and to understand that treatment better — something doctors should ideally be explaining. Others are unhappy with their treatment, or lack of it, and want to know where their nearest specialist is.
Very occasionally we receive a sad call from someone who has lost the battle. The family often wants to raise awareness and fundraise for us. I've had a couple of these calls and will never forget them.
Now we have some volunteers to help with the calls. They have all completed formal helpline training, as well as Trust training with Zoi and me, and they are now very competent. We still have a message group to ask questions and support one another. We always welcome anyone who feels they could cope with a few days a month.

Dorothy Ireland

Behind the Helpline: A Volunteer's Perspective

It will soon be almost eight months since I began volunteering for the Vasculitis UK Helpline. Before I started, I was quite anxious that I would be more of a hindrance than help, as I have no medical/clinical qualifications or experience and I couldn't see what I could bring to the table that would be of benefit to Vasculitis UK and the callers to the helpline.

The initial course provided was very helpful, but even more useful was the warm and ready-made support provided by the very experienced guidance of the other volunteers and the almost encyclopaedic knowledge of Zoi and Dorothy!

Once I got started, I came to realise that I did have one important quality that was appreciated by callers to the helpline. That is, I listen. I listen to the whole story, how symptoms first manifested themselves, how they were diagnosed, how their lives have been turned upside down and how infuriating it is for other people to have no understanding of what Vasculitis is and how serious it can be.

During the past few months, working on the helpline has proved to be a most satisfying and rewarding way to help others and in the process of doing so, I find that it does also help me in having a much deeper understanding of what the illness is and how it can be managed.
If anyone is thinking of becoming a volunteer, I would say that please do try it and I feel sure that you would also find it a most productive way of using up some spare time.

Robert Tunick

European Vasculitis Patient Summit 2025

Prague, Connection and a New Chapter for Patients Across Europe

A Warm Welcome in the Heart of Europe

In mid-November, patients, caregivers, clinicians and experts from across Europe gathered in Prague for the third European Vasculitis Patient Summit. Some familiar faces and a lot of new people joining for the first time. For me personally it was a joy to meet Greek and Swedish patient/patient representatives there!
A simple opening slideshow — listing the names and organisations of all participants by country — set the tone. No photos, no videos, just names. Yet this personal touch made everyone feel immediately connected. Badges showing each person's name, country and role helped conversations flow smoothly throughout the event.

This year's location was chosen to celebrate the launch of **VASKULITIDA.CZ,** the new Czech vasculitis organisation supported by Vasculitis International.

In a video message, Professor Onno Teng (ERN RITA, autoimmune stream lead) highlighted the importance of such gatherings, noting that rapid advances in treatments, digital tools, and AI make shared learning and knowledge exchange essential — a core mission of Vasculitis International.

The scientific programme offered a hopeful look at how vasculitis care is changing for the better. Treatments have come a long way — from early steroid therapies to today's more precise and safer options — bringing care closer to each patient's individual needs. New possibilities, such as CAR T-cell therapy, once imagined as science fiction, are now showing encouraging results for some people living with autoimmune diseases. At the same time, digital care tools are helping patients stay connected with their care teams, making support more responsive, reducing unnecessary hospital visits, and allowing care to fit more easily into everyday life.

As conversations explored the growing role of artificial intelligence in healthcare, one example showed how technology can truly support patients. "Dwayne," the VIA chatbot from Vasculitis Awareness Ireland, demonstrates how AI can be used safely and responsibly — offering friendly, reliable information at any time, based only on trusted sources. While experts reminded participants that AI should never replace medical advice, tools like Dwayne can make it easier for patients to find clear answers, feel supported between appointments, and stay connected to their community whenever they need guidance.

The programme also explored the ongoing challenges of living with ANCA-associated vasculitis (AAV). Experts explained that diagnosis can still be complex, as symptoms vary widely and no single test provides clear answers, highlighting the need to combine medical findings with patients' own experiences.

Just as importantly, discussions reminded participants that remission does not always mean feeling fully well. Fatigue, pain, and emotional challenges may continue, making continuity of care, access to specialist nurses, and trusting relationships with healthcare teams essential for helping patients live well beyond remission.

Key Messages from the Summit

- Treatments are improving — but personalised care remains the goal.
- Digital tools can reduce unnecessary clinic visits and support safer monitoring.
- AI offers opportunities, but must be used responsibly.
- Remission is not the end of the journey — quality of life matters.
- Stronger patient networks across Europe are essential.

I would like to extend my sincere thanks to Peter Verhoeven and Inge Lynn-Mess from Vasculitis International, and the entire team at VASKULITIDA.CZ for their exceptional organisation and hospitality throughout this event.
My thanks also go to all the speakers and attendees whose contributions enriched the discussions and strengthened the sense of community across borders.

A special note of appreciation is due to our two colleagues from the UK — Dr Rosemary Hollick and vasculitis specialist nurse Georgina Ducker — who generously travelled to join us and offered thoughtful, patient-centred perspectives on vasculitis care. Their insights added real depth to the programme and were warmly received.

Beyond the formal programme, the summit revealed how strong — and how diverse — the European vasculitis community has become. Discussions highlighted a shared truth: in many countries, patient support remains fragmented. Stronger cooperation will be essential in the years ahead.

Participants left Prague with energy, hope and a shared belief that this is the beginning of a new chapter. New organisations. New therapies. New technologies. And most importantly, new connections between people who truly understand one another.

The most important lesson of all: we do not move forward alone — we move forward together.

Zoi Anastasa

John Mills MBE Vasculitis Educational Award 2025

The UKIVAS (United Kingdom & All Ireland Vasculitis Society) annual Vasculitis education event was held in November 2025. It's a 2 day event open to those medical professionals with a special interest in vasculitis. The course focuses on all aspects of vasculitis including guideline updates, challenging vasculitis phenotypes and holistic symptom management. It is usually well attended by around 150/200 medical professionals from all over the UK.

The Award was created to honour John's remarkable legacy and his lifelong commitment to improving care, understanding, and support for everyone affected by vasculitis. The award recognises educational projects that make a real difference to patients, families, and the professionals who care for them.

This was the very first year UKIVAS included the "John Mills MBE Vasculitis Educational Award"

There were quite a few applications, but only one overall winner followed by 3 highly commended. The criteria to be met was for originality and to benefit vasculitis patients.

I was asked to be part of the review panel along with three vasculitis specialist doctors. All of the applications were excellent and it was really difficult to select an overall winner.

I'm delighted to share that the very first winner is Sarah Hardy, Nurse Consultant at Aintree Hospital. Sarah has spent over 15 years supporting people with vasculitis and has developed a national training programme to help nurses safely deliver key treatments such as intravenous cyclophosphamide and rituximab. Her work strengthens confidence and consistency in vasculitis care across the UK.

(see Sarah's article below)
Dr Nina Brown presenting Sarah with her award.

Highly Commended were :-
10 Things to Know about Vasculitis Educational Video - Patient & Public Involvement within the ERA PerMed Paradise Project

Guided Imagery for Coping with Vasculitis Specialist Nurse Alice Muir

The Manchester Regional Vasculitis Awareness & Patient Education Days - Dr Silke Brix
Delepoing novel methods for co-production of clinician & patient education within the PMR Parodix Project

Susan Mills

John Mills MBE Education Award Winner
Sarah Hardy Nurse Consultant Aintree Hospital Liverpool

It was an absolute honour and delight to receive this award. I have been working with vasculitis patients for over 15 years and for the past decade have worked hard to support the education of nurses to facilitate the use intravenous cyclophosphamide and rituximab.

These two medications are classified as hazardous and harmful to man and therefore health care workers exposed to the drug during preparation and through the many stages to administration require sufficient information, instruction and training as mandated by the Health & Safety Executive (HSE).

Access to appropriate training in the safe administration of these drugs for non-cancer conditions in the North West of England was non existent and thus I designed an innovative specific training program that supports nurses with the knowledge, understanding and compassion to deliver these evidence based treatments. It also allows those experienced in the care of patients with vasculitis to take full responsibility for these treatment modalities and regimens within professional boundaries. The course design delivers a robust curriculum which fulfils fundamental HSE legislative requirements and Care Quality Commission (CQC) standards. It also meets the 'Getting Right First Time' NHS improvement program training standards.

The course includes a study day introducing all aspects of cyclophosphamide and rituximab delivery including the pharmacodynamics, pharmacokinetics, management of side effects and the health & safety requirements for handling these therapies. This is delivered by a small, dedicated expert team.

Certification is awarded once delegates have accurately completed a detailed workbook which tests and challenges their knowledge to safely deliver these medications for autoimmune disease and when practical drug handling and patient management competence is gained in the workplace.

Up to four training days are held every year and to date over 140 nurses have attended. Vasculitis nurses from 5 neighbouring Trusts have also attended as they too had no local training. To date there has been no health & safety issues reported following the delivery of these medications' and urgent treatments are now delivered promptly throughout the Trust. Course evaluations have consistently rated 'excellent or above average'.

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Understanding Vasculitis Today: Highlights from the 4th UKIVas Course

A patient-friendly look at two days of learning, collaboration and hope

In November 2025, clinicians, nurses, researchers and patient advocates gathered in Bristol for the 4th United Kingdom and Ireland Vasculitis Society (UKIVas) Educational Course. Over two full days, experts from across the UK shared the latest knowledge on vasculitis care from diagnosis and imaging to treatment updates, pregnancy, mental health and long-term management.

For patients and families living with vasculitis, events like this matter. They help ensure that the people caring for you stay up-to-date, connected and inspired. Here's a friendly guide to what was covered, why it matters, and how it shapes the future of vasculitis care.

The course opened with Dr Nina Brown and Dr Jo Robson, setting the tone for two days focused on improving patient outcomes.

ANCA-Associated Vasculitis (AAV): What's New?

Experts including Dr Fiona Pearce and Dr Dimitrios Chanouzas explored:

- How common AAV is and how it affects different groups
- Updates to the 2025 British Society for Rheumatology (BSR) guidelines
- New approaches to treatment
- How services across the UK are adapting to meet patient needs

A key message: **care is becoming more standardised, more evidence-based, and more patient-centred.**

Large Vessel Vasculitis (LVV): Imaging, Treatment & Real-World Cases

Talks on Takayasu's arteritis and Giant Cell Arteritis (GCA) highlighted:

- Advances in imaging that help diagnose disease earlier
- New therapies and how they're used in practice
- Real patient cases showing the complexity of LVV
- How multidisciplinary teams (MDTs) improve outcomes

For patients, **this means faster diagnosis and more personalised treatment plans.**

Nurse Education: The Heart of Holistic Care

A dedicated programme for vasculitis nurses focused on the issues patients often feel most strongly about:

- Person-centred care
- Contraception and reproductive health
- Adrenal insufficiency
- Steroid-related weight changes
- Fatigue
- Communication barriers in clinical care

Nurses shared practical strategies to support patients through the emotional, physical and social challenges of vasculitis. This session reinforced the vital role specialist nurses play in day-to-day wellbeing.

Organ Involvement in Vasculitis: Understanding the Whole-Body Impact

Experts covered how vasculitis can affect:

- The heart
- Lungs
- Eyes
- Skin
- Ears, nose and throat

Real case presentations helped bring these topics to life, showing how symptoms can vary widely and why early recognition is so important.

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Justin Mason Memorial Lecture

Professor Neil Basu delivered a thoughtful lecture honouring the late Professor Justin Mason, a pioneer in vasculitis research. His legacy continues to shape modern care and inspire new generations of clinicians.

Inflammatory Disorders: VEXAS, Neurovasculitis & IgG4 Disease

Day two opened with sessions on complex inflammatory conditions that overlap with vasculitis.
Speakers explored:

- vEXAS syndrome
- Neurological involvement in vasculitis
- IgG4-related disease
- Behçet's syndrome

These talks emphasised the importance of **specialist expertise and tailored treatment.**

Psychosocial Aspects: The Human Side of Vasculitis

One of the most powerful sessions featured **patient perspectives**, including lived-experience talks from Zoi Anastasa and Julie Power.

Topics included:

- The emotional impact of vasculitis
- Navigating uncertainty
- How a chatbot called Dwayne van support patients
- The importance of being heard
- How psychological support can transform coping and quality of life

Clinicians also discussed patient-reported outcomes—tools that help measure what really matters to patients.

Pregnancy, Paediatrics & Transitional Care

This session focused on:

- Safe pregnancy planning
- Managing vasculitis during pregnancy
- Paediatric vasculitis
- Supporting young people as they move from children's to adult services

The message was clear: **with the right team, pregnancy is possible and safe for many people with vasculitis.**

Renal Vasculitis, Classification & Future Therapies

The final scientific block covered:

- Long-term kidney outcomes
- Updated classification systems
- Risk stratification
- Emerging therapies and clinical trials

These advances are paving the way for **more precise, less toxic treatments.**

Why This Course Matters for Patients

Although the event is aimed at healthcare professionals, its impact reaches far beyond the lecture hall. Courses like this help ensure:

- Faster, more accurate diagnosis
- Better access to modern treatments
- More consistent care across the UK
- Greater understanding of the emotional and practical challenges patients face
- Stronger collaboration between doctors, nurses, researchers and patient organisations

Most importantly, they reinforce a shared commitment to **improving the lives of people living with vasculitis.**

Our Fantastic Fundraisers

Kayleigh Morris Completed the Great Eastern half marathon run in October and raised £1520 + gift aid for Vasculitis UK. Kayliegh took on this challenge for her mum who was diagnosed with GPA in 2023.

Kayleigh said, "I am so proud of how strong my mum has been throughout her diagnosis and how strong she continues to be having to live with this condition. By raising funds for vasculitis along with others I hope that one day they will understand the causes for the disease, develop new treatments and be able to improve the quality of life for those affected"

Winster Village Christmas Tree Festival was held December 2025. Susan Mills on behalf of Vasculitis UK displayed a Vasculitis Awareness tree and raised £50. Many thanks to Maria Williams and Littlehampton golf club for the lovely decorations.

Kate Hersey Raised £2775 by climbing Snowdon. Here she is at the summit!

Heidi Pollard (Trustee) run her very first London Marathon raising over £2000 in Memory of her sister Sarah pictured below.

John Mills MBE Vasculitis UK Memory Stone

Susan Mills and her local church have laid a memory stone for John Mills MBE, in the grounds of their local church in Winster, Peak District, Derbyshire.

Kate Gorwits Raised £749 by running the Great North Run in memory of her Dad, Michael Gorwits

Mark Pitaccio Raised £13, 275 by climbing Snowdon and Kilamanjaro.

Pictured here with his daughter on her graduation day

Lorraine Oakley raised £209 by running the Great North Run

Laura Pearce raised £1412 by running a half marathon around Dorney Lake

Kaye Gordon raised £60 by holding a lady's night

Kayleigh Morris raised £1520 by running the Great East Run

Kate Morris raised £250 by running the Great North Run

Jess Wilford with a team of 11 staff members from Butterfly Data took part in thr Cardiff Half Marathon, and raised £543.27 for VUK.

Our Fantastic Fundraisers

We are so grateful to all of our fundraisers, but we are occasionally not able to publish their names as we don't get this information from some of the fundraising platforms. Please know thought that every penny raised is appreciated.

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

Imperial College Science in Medicine School Team Prize 2025

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) Prize was one of the five national contests within Imperial College London's prestigious Science in Medicine School Teams Prize 2025. Now in its fifth year, the competition continues to inspire sixth-form students across the UK to think boldly about how science and engineering can improve health.

RAIRDA is a coalition of UK charities representing people living with rare autoimmune rheumatic diseases (RAIRDs), including lupus, scleroderma, Sjögren's disease and the various forms of vasculitis. Vasculitis UK—one of RAIRDA's founding members—plays a central role in advocating for earlier diagnosis, better care pathways and improved quality of life for people with these complex, often misunderstood conditions. The RAIRDA Prize reflects this mission by challenging students to design innovative, non-pharmaceutical solutions that could meaningfully support the wellbeing of people living with RAIRDs.

This year's competition saw record participation, with 198 schools entering and more than 1,600 students involved. Against this highly competitive backdrop, the RAIRDA Prize judges awarded **Joint First Prize to St Olave's Grammar School , to The Tiffin Girls' School and the Wallington County Grammar School.** Their work stood out for its scientific insight, creativity, feasibility and clarity of communication—qualities that lie at the heart of RAIRDA's vision for patient-centred innovation.

All of the school teams delivered outstanding work this year. Their creativity, scientific curiosity and thoughtful presentations enriched the judging panels and demonstrated just how powerfully young people can engage with complex health challenges. We are deeply grateful to every team that chose to explore the RAIRDA Prize and to spend time learning about rare autoimmune rheumatic diseases. Your commitment to understanding these conditions and to imagining new ways to support the people who live with them embodies the very spirit of this competition.

The following article showcases one of these winning projects, offering a glimpse into the thoughtful, multidisciplinary approach that earned the team top honours. Although the students worked on Sjögren's disease, the project is transferable to other rare rheumatic conditions, vasculitis included.

Daniya, Jasmine and Ritu describe what it was like to take part in the Imperial College Science in Medicine School Teams Prize 2025 and to work on their award-winning RAIRDA project.

As part of the Imperial RAIRDA competition, we developed NeuroZen, a project exploring an alternative approach to managing Sjögren's syndrome. Sjögren's syndrome is a chronic autoimmune condition that mainly affects women over the age of 50 and can cause symptoms such as fatigue, inflammation, and severe dryness. During our research, we were surprised to discover how limited current treatment options are. Most rely on long-term medication, which can be expensive and often comes with side effects that reduce the quality of life of patients. This helped us to understand the need for a safer, non-invasive way to support patients by working with the body rather than against it.

Research:

Our research led us to focus on the vagus nerve, a key component of the nervous system involved in regulating inflammation and immune responses. Our idea, NeuroZen, is based on a pair of wearable earbuds called NZ Buds, which gently stimulate the auricular branch

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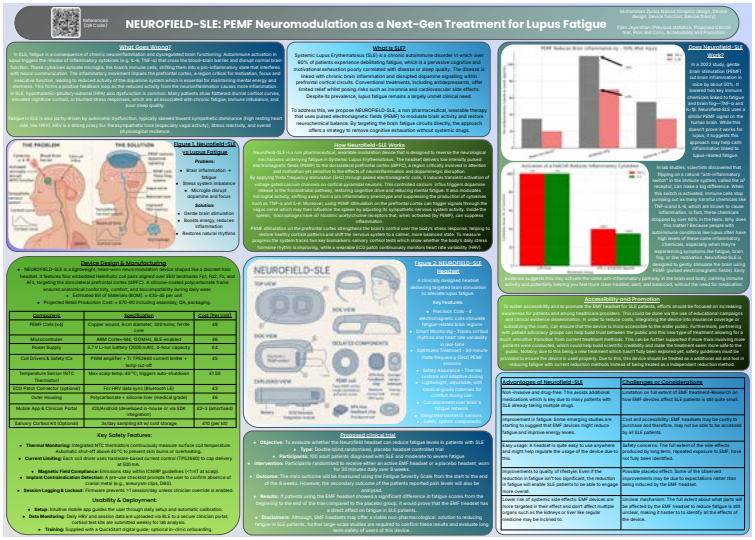

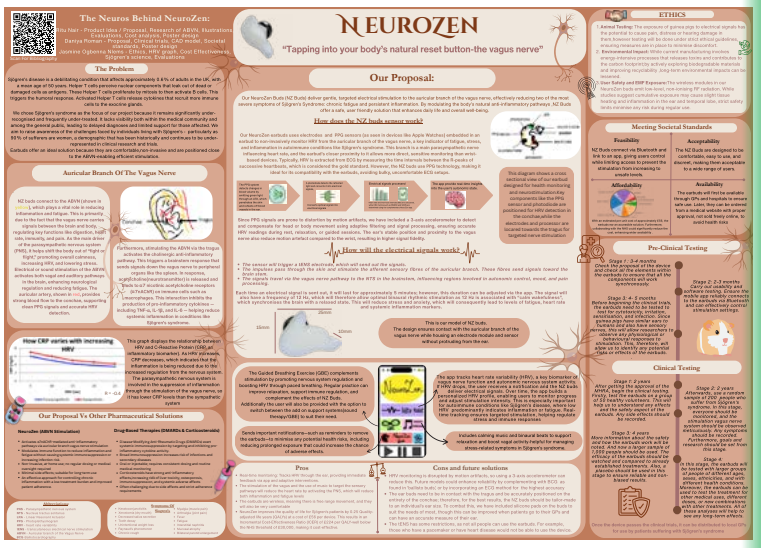

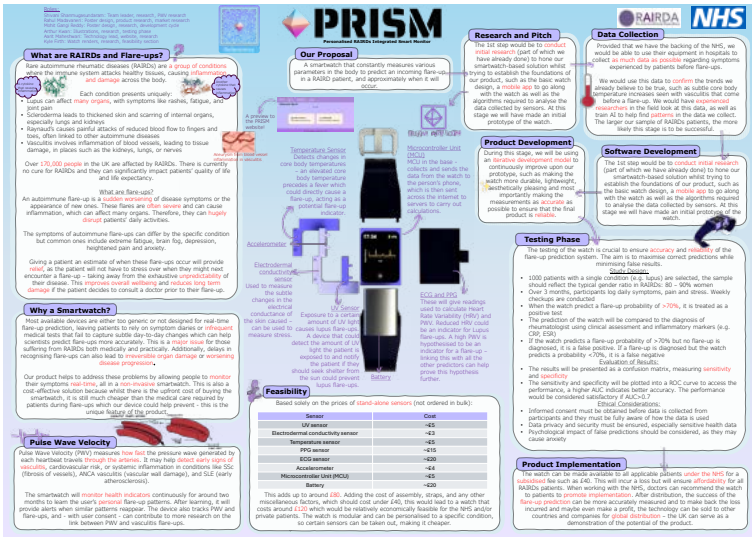

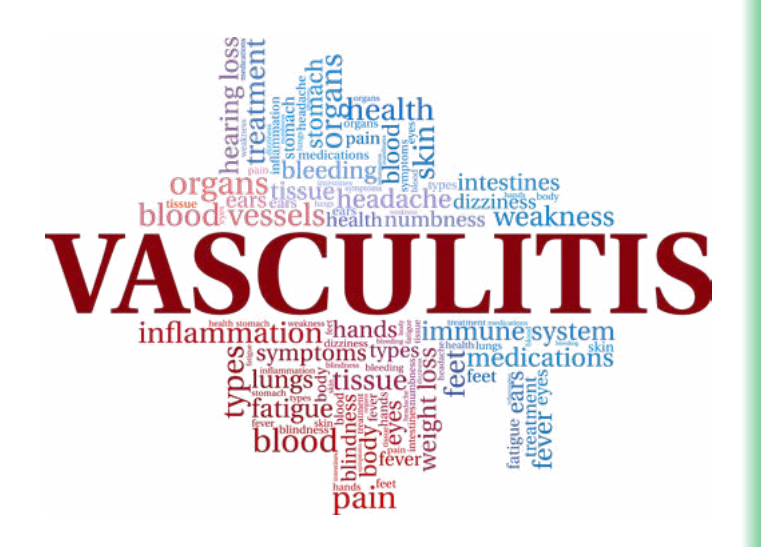

of the vagus nerve through the ear using electrical stimulations. Instead of suppressing symptoms with drugs, this stimulation aims to activate the body's natural anti-inflammatory pathways through the parasympathetic nervous system. We also designed an accompanying app that monitors heart rate variability (HRV), a measure of how well the body copes with stress. By tracking HRV, the app can suggest short stimulation sessions - around five minutes - either at set times or when stress levels drop. Through developing this idea, we learned a lot about neurobiology, wearable medical technology, and the importance of designing solutions that are both scientifically feasible and realistic for everyday use.

Our Experience:

Equally important was the experience of working as a team throughout the competition. We had to divide tasks based on our strengths, whether that was researching the medical background, designing the device concept, or planning testing and future development. Combining our work into a single poster challenged us to communicate clearly and make complex scientific ideas accessible. Presenting our project also pushed us out of our comfort zones, especially when answering questions from judges, as it required us to think critically and defend our ideas confidently.

Overall, this competition was a valuable learning experience that went far beyond creating a poster. It taught us how collaboration, creativity, and scientific research come together in real-world problem solving. NeuroZen represents not just a potential solution for Sjögren's syndrome, but also what we gained from the process: a deeper understanding of science, improved teamwork skills, and greater confidence in turning ideas into meaningful innovations.

Dorothy Ireland Retiring Chair of VUK

Susan Mills

Dorothy was diagnosed with Microscopic Granulomatosis in 2008 and had joined the old Stuart Strange Vasculitis Trust charity (SSVT) almost immediately after being diagnosed.

John and I first met Dorothy a few months after we, ourselves, had taken the reins of the SSVT charity in 2009.

At that same time I was also keen to start an East Midlands local Vasculitis Support Group along with a good friend called Lisa, so we asked Dorothy, as she lived locally to us both, for her help and support with the group, she was only too pleased to help. The support group was just so popular, thirty members, just in our local area, we would meet twice a year and also celebrate Christmas with a special Christmas lunch. Sadly the Covid Pandemic put a stop to these meetings in 2020 which was a real shame as these face to face support groups were invaluable.

After chatting to Dorothy about our local support group, I very soon came to realise she had experience of fundraising along with many other charity voluntary roles. I passed this very important information onto my John who immediately approached Dorothy and before she had time to refuse, was appointed as a trustee and fund-raising coordinator for the SSVT charity. Dorothy also instigated the trustee job role descriptions by initially writing her own first!

Dorothy later supported John, along with Patricia Fearnside and myself to change the name of the Stuart Strange Vasculitis Trust to Vasculitis UK. Dorothy was also part of a small team who successfully changed the logo of the charity from a light bulb to a circle of V's which was taken from the filament of the original lightbulb logo. The Stuart Strange Vasculitis Trust became Vasculitis UK in 2010 and the new Vasculitis UK logo was launched in 2012.

Dorothy and I worked very successfully together for over 12 years, supporting all VUK's fundraisers by putting together a fundraising package for each fundraiser which would include a VUK T shirt. We would occasionally attend fundraising events together. The one event I remember most was a golfing fundraising event held near Brighton where the new president of the golf club, who was also hosting the fundraising event made an extraordinary entrance over the slopes of the green, with around thirty Hells Angel Bikers. A truly amazing sight to behold, Dorothy and I were completely speechless.
Dorothy also coordinated the Great North Run runners, Great South Run runners and a few half marathons, sometimes managing up to twenty fundraising runners just for one event.

Dorothy very soon became an invaluable member of the VUK team on so many levels, Dorothy's skills, which included being part of the Helpline Team, giving one to one support either by telephone or email, becoming an admin for both the online Vasculitis UK Support communities, taking part in Vasculitis Research projects but most important of all was her ability to to understand and complete difficult forms and legal processes which led to Vasculitis UK being upgraded to a Charitable Incorporated Organisation (CIO Charity).
After many false starts, Dorothy finally, after months and months of incredible hard work completed the application and VUK were finally accepted as the new Vasculitis UK CIO Charity in October 2018. An amazing achievement by Dorothy.
Dorothy's commitment and dedication to Vasculitis UK never wavered even through personal relapses and flares of her own vasculitis, she would always be there supporting others.

Because of the success of the CIO Charity status, Dorothy became Chair of Vasculitis UK in 2019, John became Vice Chair or Director of Operations as he called himself. Dorothy and John would work together until 2022, when John finally had to take a back seat due to his failing health. Dorothy, with a group of new trustees Chaired Vasculitis UK until 2025 when she decided it was time to step down and let younger trustees take the reins. But most important of all Dorothy was to become a grandmother for the very first time. Dorothy's daughter gave birth to a daughter, Lily, just before Christmas 2025.

On a personal level Dorothy and I became good friends, every couple of months or so we would meet for lunch in a small town quite near to us both, to discuss fundraising but we also managed to squeeze in a little shopping too. Dorothy was very supportive to me after John became so very poorly in 2022, always there to lend a friendly ear.

So I just want to wish Dorothy all the best for the future and to enjoy her new granddaughter, grandchildren are just so precious and are such good fun, I am sure she will enjoy every minute.

Dorothy Ireland – Not Only Good at the "Boring Stuff"

If you ever attended a Vasculitis UK AGM and spotted a woman with a notepad, taking meticulous notes with the focus of a headteacher during Ofsted week… that was probably Dorothy. When I first met her, I'll admit I was a little wary. She had that air of someone who gets things done — and expects the same from everyone else. Little did I know that not only would we end up working closely together, but she would also become one of my closest friends.

Dorothy was already a pillar of Vasculitis UK when I joined, and she became Chair around the time I became a trustee. She often jokes that John Mills gave her the role because she was "good at the boring stuff" — meaning admin. And yes, she was good at it… but she was also good at absolutely everything else.

Our real partnership began during the pandemic. Along with Susan, the three of us became a sort of Vasculitis UK triad — answering helpline calls, running online groups, creating materials, debating vasculitis (endlessly), and juggling projects, education, and information. Eventually it became just the two of us, and I'm fairly sure we spoke almost every day. Some days we solved big organisational challenges; other days we solved small ones. All of them mattered.

We met in person a few times a year — usually when I travelled her way — and once when she and her daughter were holidaying in Cornwall. But most of our teamwork happened through screens and phone lines, and somehow that never made it feel distant.

I've watched Dorothy's knowledge grow enormously, especially over the last few years. She is a steady, reassuring presence on the helpline, and callers often tell me how grateful they are for her support. She was also my manager when I started working for Vasculitis UK in 2021, and I always joked that I was her best personal assistant. (Not entirely untrue.)

Her communication was the best I've ever experienced in my working life. Even when she was very unwell, she never disappeared — she cared too much about the people and the work.
Although Dorothy has stepped down as a trustee, she continues to volunteer on the helpline, so we still get to work together. These days, though, our conversations are less about vasculitis and more about her beautiful granddaughter and my nephew — both born in the second half of 2025 and both currently running the show in their respective households.

I'm looking forward to visiting her soon: seeing the updated garden, meeting the new cat, and taking photos of birds and squirrels while we drink tea and put the world right. Some people come into your life and stay. Dorothy is one of those people for me.

Our birthdays are only a few days apart, so soon we'll be celebrating together — probably over a video call, a cuppa, and a good laugh about the memories we've collected.

Dorothy worked incredibly hard for Vasculitis UK and helped the organisation evolve. She took her responsibilities seriously, brought structure where it was needed, and supported countless people along the way. I miss working with her in the old way, but I treasure the new way too.

I learned a lot from Dorothy — though I will never master the serious admin wizardry she handled so effortlessly.

So, happy sort of second retirement, Dorothy! Keep drawing, painting, knitting, and enjoying your well-earned personal time.

Thank you for everything.
With love, Zoi

The 22nd International Vasculitis Workshop, Melbourne 2026: A Landmark Global Gathering

The 22nd International Vasculitis Workshop (IVW) took place in Melbourne from 21–25 February 2026, marking a historic milestone as the first time this prestigious meeting was held in the Southern Hemisphere. Hosted by the Australia and New Zealand Vasculitis Society (ANZVASC), the workshop brought together more than **1000 clinicians, researchers, trainees, laboratory scientists, and patient representatives from 43 countries,** making it the largest vasculitis workshop ever held.

Over **507 scientific abstracts** were presented across oral sessions, debates, mini-workshops, and 11 themed poster categories, covering the full spectrum of vasculitis—from ANCA-associated vasculitis (AAV) and large-vessel vasculitis to Behçet's disease, IgA vasculitis, EGPA, and rare paediatric vasculitides. The programme reflected the field's rapid scientific evolution, with strong representation from immunology, genetics, imaging, clinical trials, health systems research, and patient-centred innovation.

Scientific Highlights from the Workshop Programme
Opening Day – Sunday 22 February

The meeting opened in the Goldfields Theatre with a Welcome to Country and the **Fokko van der Woude Lecture,** delivered by **Professor Ken Smith,** exploring the genetic architecture of vasculitis and how susceptibility extends "beyond genes" into immune regulation and environmental triggers. This was followed by the **Young Investigator Award Plenary,** showcasing cutting-edge translational and clinical science from emerging leaders.

Poster tours began that evening, covering epidemiology, diagnosis, classification, treatment of AAV, and early translational research—setting the tone for a week of intense scientific exchange.

Monday & Tuesday: Deep Dives into Mechanisms, Treatment, and Innovation

Early-morning case-based breakfast sessions tackled challenging real-world scenarios, including IgG4-related disease vs AAV overlap, anti-GBM disease, Takayasu arteritis, Behçet's disease, and polyarteritis nodosa.

Plenary lectures featured world-leading immunologists such as **Laura MacKay** (tissue-resident memory T cells) and **David Tarlinton** (plasma cell longevity), followed by highly ranked abstract presentations.

Across the parallel sessions, themes included:

- **Stratifying AAV** through regional signatures, developmental immunology, and classification frameworks
- **Emerging therapeutic mechanisms** in large-vessel vasculitis
- **Genetics and –omics,** including CHIP (clonal haematopoiesis) and precision medicine
- **Kidney-focused discovery science** in ANCA-associated glomerulonephritis
- **Disease assessment and imaging,** including debates on optimal imaging modalities
- **Clinical trials,** including concept development workshops and late-breaking abstracts
- **Patient-centred research and health systems innovation,** reflecting the growing emphasis on lived experience and real-world outcomes

Poster tours continued each lunchtime, with categories spanning organ-specific manifestations, outcomes, biomarkers, health systems, and fundamental research.

Wednesday: Looking Ahead to the Future of Vasculitis Care

The final day opened with a plenary on **ANZDATA's 49-year legacy** and a forward-looking talk on **innovative trial methods for rare diseases** a critical topic for vasculitis research. Sessions explored long-term management of AAV, GCA, and PMR, paediatric vasculitis trial networks, and the evolving implications of therapies such as **avacopan,** five years after the ADVOCATE trial.

The workshop closed with a plenary session reflecting on the week's achievements and the future direction of global vasculitis collaboration.

A Global Community United for Progress

Beyond the scientific sessions, the workshop emphasised community, collaboration, and shared purpose. More than **160 patients and carers** attended the Community and Patient Conference, organised with support from the Vasculitis Foundation. Additional satellite events included the Vasculitis Education Course and the ANCA Laboratory Testing Workshop, bringing total attendance to over **1300 participants.**

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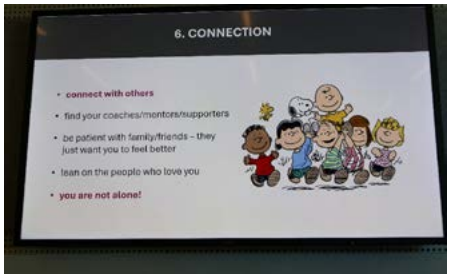
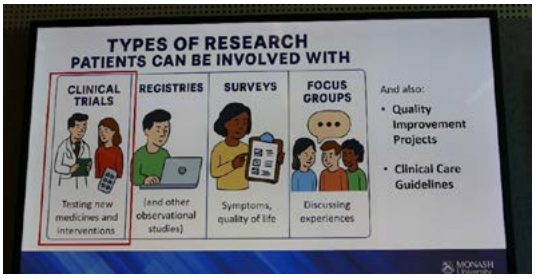
The organisers—Prof Richard Kitching, Prof Catherine Hill, and Dr Vicki Quincey—highlighted the workshop's spirit of openness, collegiality, and scientific rigour, noting that the ideas and partnerships formed in Melbourne will shape future research and improve care for people living with vasculitis worldwide.

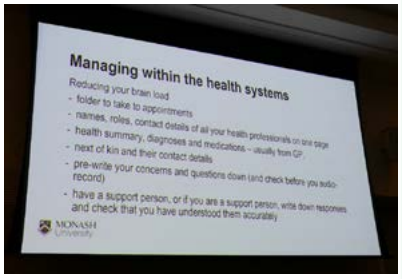
Why This Workshop Matters

For patients, families, and clinicians, the IVW is more than a scientific meeting—it is a catalyst for progress. As Vasculitis International noted, hosting the workshop in Melbourne reflects the growing strength of vasculitis research in the Asia-Pacific region and the importance of global collaboration to improve diagnosis, treatment, and long-term outcomes.

With the next workshops scheduled for **Istanbul (2028)** and **Montreal (2030),** the momentum generated in Melbourne will continue to drive innovation and international partnership.

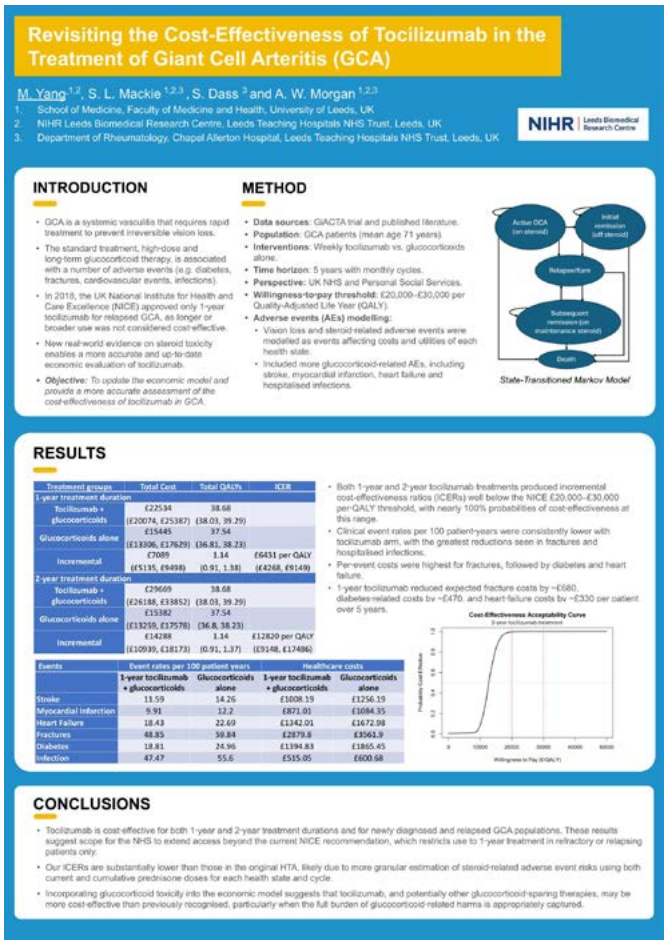






International Workshop Insights: Updated Model Shows Greater Cost-Effectiveness of Tocilizumab in GCA

I'm a health economist specialising in the cost-effectiveness of health technologies for the NHS. At the International Vasculitis Workshop 2026 in Melbourne, I presented a poster examining the cost-effectiveness of tocilizumab for the management of Giant Cell Arteritis (GCA). Our revised model incorporated additional steroid-related adverse events, including myocardial infarction, heart failure, fractures, and hospitalised infections, and applied more granular, time- and dose-dependent estimates of steroid toxicity. The results suggested that tocilizumab is more cost-effective than previously estimated in the health technology assessment report.



During the conference, I engaged with researchers, clinicians, and industry representatives to discuss the potential implications of our modelling approach, particularly its potential to improve the estimation of cost-effectiveness of steroid-sparing therapies. This work has important implications for patients with GCA, as it supports broader access to effective treatments that reduce reliance on high-dose steroids and risk of associated side effects.

Presenting this research at an international conference provided a valuable opportunity to share insights, receive expert feedback, and contribute to ongoing discussions that shape our research. It was particularly useful to gain feedback into the real-world implications of our findings and how this evidence can inform healthcare decision-making.

Dr Miaoqing Yang

Images from the Workshop

The Adventures of Mr Peter Kitching

(As told by a small but mighty Kiwi bird)

You may be wondering who I am and what on earth my adventures have to do with you and vasculitis. Fair question. I am a Kiwi bird — yes, the fluffy, flightless kind — originally from New Zealand. My journey began when Dr Tze Goh from the local organising committee of the International Vasculitis Workshop chose me to be one of the event mascots.

Australia, here I come, I thought. And off I went.

When I arrived in Melbourne, I found myself in excellent company: a koala and a crocodile were already on mascot duty. That was only the beginning. I was hugged, photographed, squeezed, admired — my 15 minutes of fame stretched into hours. And now here I am in the UK, talking to all of you. Honestly, what a ride.

Welcome and acknowledgement of Country: Prof. Catherine Hill

A Workshop to Remember

The workshop kicked off with a brilliant initiative: a twoday vasculitis course for 500 local clinicians. Using the event's speakers to train so many healthcare professionals was inspired — and I'm sure patients across Australia and New Zealand appreciated their doctors returning home with sharper knowledge of this rare disease.

Speaking of patients, I met quite a few. Zoi Anastasa (Vasculitis UK), Inge LinnMes (Vasculitis Netherlands), and Isabelle SteinlSthal (Vasculitis France) — representing Vasculitis International — were frequent visitors to my corner. They filmed interviews, discussed sessions, met people from around the world… it was fullon, I tell you.

The Community/Patient Conference, organised by the American Vasculitis Foundation, was held on Saturday 21 February and was a huge success, with 160 patients attending. The pace was patientfriendly, and the themes were shaped with help from local patients. The day began with the basics of vasculitis and management strategies, followed by breakout sessions on infections, vaccinations and travel, advocacy, pain and fatigue, emotional support, diet, exercise, steroids, medication management, paediatric vasculitis, and diseasespecific discussions.

Living with vasculitis is clearly challenging — and the message was loud and clear: doctors should see the whole person, not just the disease.

Prof. Richard Kitching opening the main workshop

The Patient Representatives

Around 20–30 patients stayed on for the main workshop, but let me tell you about the patient representatives — experienced advocates respected across the vasculitis community. You already know Zoi, Inge, and Isabelle, who travelled from Europe. They were joined by Jon Stewart from Canada, Noriko Okochi from Japan, and two representatives from Vasculitis Ireland Awareness David and Ciara O'Regan, who even presented their own chatbot, "Dwayne". The Vasculitis Foundation team, led by Joyce Kullman, were also there throughout.

From my table, I watched people arrive to register for the main workshop on Sunday. More than 1,000 attendees. A record 507 abstracts. The Vasculitis Lund team had so many posters it must have taken them hours to set up. Everywhere I looked, people were greeting each other, hugging, catching up, and talking vasculitis — and plenty of other things too. The buzz was incredible.

And did you notice? Prof Richard Kitching and I share a surname. Intriguing, isn't it? I'll come back to that…

Celebrating Research and Collaboration

One of the first sessions was the Young Investigator Award presentations. One of the winners, Michal Zulcinski from the Leeds team, came over to chat with the Vasculitis International representatives during the break. He presented work on steroid treatment effectiveness and biopsy differences in GCA patients requiring tocilizumab.

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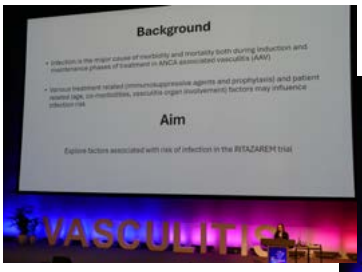
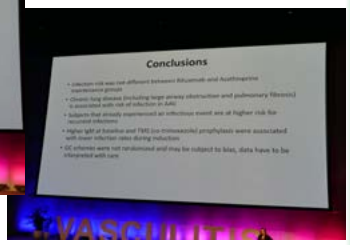
Dr Michal Zulcinski presenting his research and receiving his award





Dr Rona Smith - conclusions

There were so many UK teams and young researchers presenting abstracts, winning awards, or showcasing posters. Vasculitis UK supported several of them with bursaries (selected with the workshop committee and EUVAS):

- Dr Nishant Chaudhari – University Hospital Birmingham
- Dr Michael Chen Xu, Dr Romain Guitton, Giorgio Trivioli – University of Cambridge
- Miss Abigail Nutley, Yasmin Kassir – Imperial College London
- Dr Maira Karabayas – University of Aberdeen
- Dr Gavin Chapman – University of Edinburgh

Zoi and Inge with Mr Koala

Seeing so many dedicated clinicians and researchers gives real hope for the future. Vasculitis may be rare and complex, but behind the scenes there is a global community working tirelessly to improve diagnosis, treatment, and quality of life.

A Workshop Full of Energy

Patients, carers, families, and friends shared their journeys — and what mattered to them was genuinely heard.

My friends Zoi, Inge, and Isabelle were recognised as patient representatives and welcomed into the poster area, normally offlimits to patients. The welcome ceremony was held there, and the giant koala quickly became the most photographed creature in the building. (I wasn't jealous. Much.)

Monday to Wednesday were packed: sessions, discussions, poster tours, and constant movement.

- Monday and Tuesday focused on real patient cases, cutting edge science, and new research on diagnostics, imaging, treatments, and patient centred care.
- Each lunchtime, poster tours showcased the breadth of work happening worldwide.
- Wednesday looked to the future: long term management, rare disease trial design, paediatric research networks, and how emerging treatments are reshaping care.

More than 1,300 attendees from 43 countries took part — and left ready to share what they'd learned.

A New Name and a New Home

And then, just like that, the workshop was over. But my adventure wasn't.

Someone whisked away the crocodile (I hope he found a good home). Then Prof Richard Kitching picked up me and the koala — and in a moment that changed my life, he handed me to Zoi as a thankyou for her support and work.

I gained a new owner and a new name: **Mr Peter Kitching** — "Peter" from Peter Verhoeven, Chair of Vasculitis International, and "Kitching" from Prof Richard Kitching.

I was meant to travel home with Zoi via Dubai, but the war changed our plans. Instead, we flew to London via Shanghai. Quite the detour for a small bird. I now live in the southwest of England, still learning new things about vasculitis every day.

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I hope my adventures have entertained you. Thank you to Zoi for helping me type my story and to Inge and Isabelle for being wonderful friends.

Mr Peter Kitching

Inge, Jon, Zoi and Isabelle

P.S. Some of the young doctors/researchers that received bursaries from Vasculitis UK to attend this wonderful workshop would like to share a few words with you.

Dr Gavin Chapman: I found the conference very engaging. It was wonderful to have experts from all across the world meet in one place and led to lots of positive discussion and new ideas for research that we are hoping to take forward locally. Melbourne was a fantastic city and the organisers were wonderful hosts. Thanks again to Vasculitis UK for supporting my travel to Melbourne.

Giorgio Trivioli: I am very grateful to Vasculitis UK for the generous support that allowed me to take part in the 2026 International Vasculitis Workshop, which was held in Melbourne in February 2026.
The program of the meeting was high-quality, and the beautiful congress venue allowed plenary lectures, as well as breakout sessions with opportunity to engage in deep discussion and a large hall to take a look to over 300 posters.

We have lived four intense days sharing ideas and comments and immerse ourselves in the notable progress that care and research in vasculitis is making.

One good example for me was the many flavours of genetics: from the opening lecture of Prof Ken Smith on genetic susceptibility of ANCA-associated vasculitis, which largely based on seminal work done in early 2000, to the update of this projects (a new GWAS study) illustrated by Dr Paul Lyons, to the new applications of genetics in defining acquired genetic forms of vasculitis (such as VEXAS) discussed by Dr Peter Grayson and the clonal haematopoiesis of indeterminate potential (CHIP), which was lectured by Prof Melissa Southey.

I have had the privilege to contribute three presentations on eGFR decline, vaccine response and kidney transplantation, which made my attendance also an excellent.

Maria Karabayas MD,PhD, (left) Honorary clinical lecturer, University of Aberdeen:
I am greatful to Vasculitis UK for funding my attendance at IVW26. This experience has inspired my research, particularly in advanceing our understanding of these rare yet often under-recognised disease groups. It has also further motivated me to explore how we can work collaborativelyu to addresdsd the existing treatment inequalities.

David and Ciara O_Regan - Vasculitis Ireland Awareness

Dr Jo Robson

Dr Louise Oni

Dr Mukunthan Srikantharajah with Zoi

Miss Abigail Nutley: I found the sense of community with the patients to be very inspiring at the IVW26 - as a scientist, it was great to meet patients and carers and see how parts of the conference were hosted for them too. It felt amazing to see how my project fits with all the amazing research going on.

Dr Michael Chen-Xu: It was inspiring to see colleagues from across the breadth of the vasculitis community — from patients to basic scientists and clinicians — all gathered together for the same goal: to further vasculitis research and the care of patients living with vasculitis. There was a great mixture of basic science through to translational and epidemiologic presentations, which really illustrated to me the process from how discoveries at

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Continued from p22

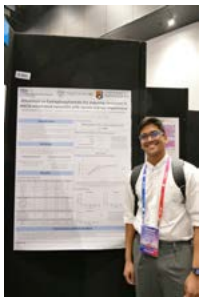
the laboratory bench can lead to new and/or improved treatments for patients. Additionally, the “Young Investigator Award: Translational Science and Clinical Science Presentations” was another highlight, as it showcased the high quality of research early career investigators are capable of achieving — which I found inspirational!

I am very grateful to all those living with vasculitis who have given their time to be participants in and drive clinical research — without you, we would not be able to advance the field of vasculitis research.

I really enjoyed the plenary presentation by Dr Harry Robertson, a bioinformatician, on how using AI/machine learning techniques on genomic and transcriptomic data from blood and tissue samples across different organs can be used to improve disease phenotyping in patients. This felt like a concrete use of AI/machine learning to potentially help improve patient outcomes, and Dr Robertson explained these in such a way that someone such as myself, with only a rudimentary understanding of AI/machine learning, could easily understand them.

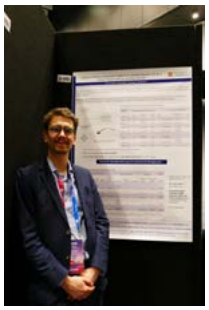
It felt wonderful to attend the IVW not only to present some of my work but also have the opportunity to learn from experts in their respective fields within the vasculitis community, and I am very thankful to Vasculitis UK for the support to do so.

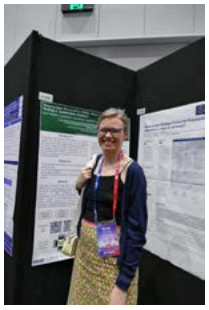
Dr Michael Chen-Xu with Mr Peter Kitching!



Left - Dr Nishant Chaudhari – University Hospital Birmingham

Right - Dr Romain Guitton - University of Cambridge





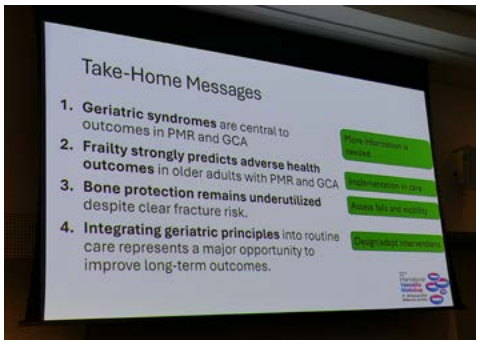
Dr Sarah Mackie

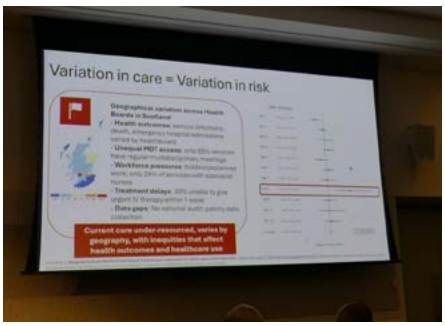
Dr Taryn Youngstein

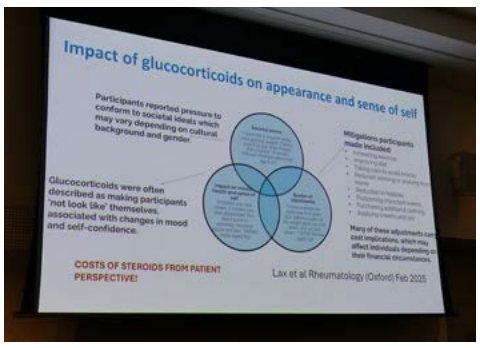
Isabelle Steinl - Sthal, Dr Benjamin Terrier, Prof. Neil Basu and Zoi Anastasa

Images from the event

The RAISE Study Poster







Justin Mason Travel Award A brief report

My reflections on the 22nd International Vasculitis Workshop

I am deeply grateful for the support of the Justin Mason Memorial Fund, which enabled me to attend the 22nd International Vasculitis Workshop in Melbourne, Australia from February 21–25, 2026. I presented my intercalated BSc project, awarded First Class Honours, titled "Impact of immunosuppression on collateral formation in Takayasu arteritis". This opportunity proved to be a profoundly enriching experience, both personally and professionally, and I am honoured to share this report with Professor Mason's family.

I never imagined that my journey as a medical student would take me across the world, and visiting Melbourne for the first time was a highlight. In my short time there, I experienced the unique beauty of Australia, from kangaroos and koalas to witnessing the little penguins native to Melbourne's Phillip Island. This vibrant setting made the professional milestone even more memorable.

This conference marked my first oral presentation at an international meeting, representing a pivotal moment in my academic journey. Having dedicated the past year to my research, often working in isolation and sharing updates mainly with my supervisors, I found it both daunting and exhilarating to present my findings to a global audience. I remember taking a deep breath before looking out at the room of over a hundred attentive faces. Their encouraging smiles and photographs they took of my slides felt like a validation of the work's significance, strengthening my confidence not only in public speaking but also in the academic rigour of the project itself.

After the presentation, clinicians from around the world stood to offer their perspectives, sparking thoughtful discussions that broadened my understanding of a subject I had previously considered niche. It was remarkable to see how my work resonated with others and stimulated meaningful academic dialogue. I was also honoured to contribute to a subsequent panel discussion among leading researchers in the field.

The opportunity to meet and learn from renowned experts, many of whose names I recognised only by their publications, was invaluable. It was a privilege to speak with several of Professor Mason's colleagues and friends, who fondly recalled his character and expressed admiration for his contributions. Similarly moving was the connection with patient representatives from Vasculitis UK, who emphasised the real-world impact of our research. These conversations echoed my experience the previous year at Hammersmith's Large Vessel Vasculitis clinic, where I had met many patients who had been under Professor Mason's care.

I remain especially thankful to Professor Mason, whose legacy endures through the mentorship of my supervisors, Dr Taryn Youngstein and Dr Andrew Porter. Their guidance, which began during my BSc project and continued through this presentation, has been foundational to my development. I am certain that their supportive and insightful approach reflects Professor Mason's own dedication to teaching and nurturing future clinicians and researchers. This generous travel grant, awarded in his name, covered essential costs including flights, accommodation and conference registration.

This experience has inspired me and solidified my desire to pursue a career in academic medicine. The encouraging reception of my work has further motivated me to continue this project and pursue its publication as my debut first-author paper. Being exposed to leaders across rheumatology, vascular medicine, cardio-immunology and other specialties highlighted the vital role of interdisciplinary collaboration and provided much to reflect on as I weigh my future specialty path. Above all, it renewed my belief in the importance of remaining curious, engaged and dedicated to research that tangibly improves people's lives.

Sincerely,
Annie Alocious
Fifth Year Medical Student, Imperial College London

RAIRDA update: January - March 2026

It has been a busy first quarter of the year for RAIRDA, with the publication of the **Rare Disease Quality Standard**, alongside our **RAIRDA** workshop in February, where priorities for 2026 were identified.

Quality Standard for Rare Diseases

Work on the Quality Standard has been one of our focuses at the start of the year. While publication sat with NICE, we worked closely with the NICE team on communications planning around the release of the statements. The Rare Diseases Quality Standard was published on 27th February 2026 in time for Rare Disease Day. This quality standard marks the first developed collaboratively between NICE and the patient community. The development was led by the rare disease project group, coordinated by RAIRDA. The process has centred the voices of those with lived experience throughout the process. You can find out more here.

Rare Disease Day

For Rare Disease Day on **28 February,** much of our engagement and communications activity focused on the Quality Standard. Sue Farrington, Co-Chair of RAIRDA, attended the Genetic Alliance reception in Parliament, where she gave a short speech on the Quality Standard and its contribution to improving equity for the rare disease community. You can see our LinkedIn post about the event here.

Conferences in 2026

RAIRDA members will be present at the **BSR conference** in April this year, helping to raise the RAIRDA profile across individual stands. Additionally, RAIRDA has been successful in securing a not for profit complimentary booth in **EULAR** 2026 - it will be the first time RAIRDA has presence in this conference. For both events, we're preparing briefings on RAIRDA's work and the Quality Standard for members to distribute.

Priorities for 2026

At our February workshop, we discussed key areas of focus for 2026. Key areas identified included:

- Addressing inequalities in care through a strong focus on specialised networks.
- Exploring barriers faced by RAIRD patients in accessing primary care and achieving timely diagnosis.
- Ensuring that the Quality Standard is implemented and leads to better outcomes for people with RAIRDs
- Understanding progress against our recommendations in Rare Care Matters.

Placebo: it's not nothing

Why making a placebo can be as complicated as building a toaster

By Dr Sarah Mackie — simplified for patients

I want to share a story that might help explain why some clinical trials are harder to run than they look. It's about giant cell arteritis (GCA), a treatment many patients rely on, and a clinical trial that never quite made it off the ground. And at the heart of it all is something surprising: the humble placebo.

Why this trial mattered

GCA is a serious condition. Without treatment, it can cause blindness or stroke. Steroids help, but they come with many side effects, especially when used long term. Tocilizumab, a weekly injection, has been a huge step forward because it reduces the need for steroids.

But the NHS only funds one year of tocilizumab. After stopping it, about half of patients relapse and need more steroids. Doctors and patients have been desperate to know: **should some people stay on tocilizumab for longer?**

So when a national research funder asked for a trial to answer this question, we were excited. We designed a study where some patients would continue tocilizumab for another year, and others would stop and receive a placebo injection instead.

Why a placebo was needed

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Continued from p25

Relapse in GCA is partly based on symptoms like headache or jaw pain. These can be influenced—without anyone meaning to—by whether people think they're still on treatment. To get a fair answer, neither patients nor doctors could know who was getting the real drug. That meant we needed a placebo injection that looked and behaved exactly like tocilizumab.
And that's where everything became unexpectedly difficult.

Why a placebo isn't "nothing"
A placebo sounds simple—just salty water, right? But it must be made, packaged, labelled, sterilised, stored, and delivered to the same strict standards as the real drug. And because tocilizumab is a complex biologic given in a special injection device, the placebo had to match that device perfectly.
The problem? The original drug's patent had expired. The company making the new, cheaper biosimilar had no reason to produce a placebo for a small academic trial. So we had to build one ourselves—piece by piece.
We contacted manufacturers of syringes, plastic casings, labels, sterilisation services, and specialist drug-handling companies. Many wouldn't work with us.

Others could, but at enormous cost. Every step required regulatory approval. Every component had to be sourced, tested, and assembled under strict conditions.

By the time we added up the costs, the placebo alone came to nearly **£1 million** for just 72 patients.

Why the trial couldn't go ahead

The funder was supportive, but they had to consider value for money. Spending almost a million pounds on placebo manufacturing simply wasn't feasible. The trial was stopped before it began.

What I learned

I used to think of a placebo as "nothing". But it isn't. It's more like trying to build a toaster from scratch—something that seems simple until you realise how many hidden parts, processes, and technologies go into making it work.
For tablets or IV infusions, placebos can be easier. But for modern biologic drugs given by injection, especially when the drug is near the end of its commercial life, creating a matching placebo can be almost impossible for academic researchers.

Why this matters for patients

Patients often ask why certain trials don't happen, or why answers take so long. Sometimes the barrier isn't the science—it's the practical reality of making a safe, regulated placebo that matches a complex medicine.
A placebo is not nothing. And understanding that helps explain why some important questions in rare diseases like GCA remain unanswered longer than any of us would like.

SUPPORT GROUPS

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

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

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

West Midlands Vasculitis Support Meeting October 12th 2025

Susan Mills

West Midlands Vasculitis Support Group held their annual Vasculitis support meeting in October 2025 at the Bromsgrove Hotel Birmingham. It was well attended by around 40 members.

Speakers were:-

Specialist Nurse Alison Moore UHB Queen Elizabeth Hospital
Vaccines and their importance to vasculitis patients

Dr Iwan Raza Academic Renal doctor UHB Queen Elizabeth Hospital
Rituximab maintenance therapy, patient perspectives on treatment continuation and withdrawal.

Dr David Carruthers, Consultant Rheumatologist at City Birmingham Hospital
Environmental Factors and Disease

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Vaccines and the Importance to Vasculitis Patients

The key points I learnt from Alison's presentation were that vaccines work by imitating an infection to engage the body's natural defences, they help the body learn how to defend itself from disease without the dangers of a full-blown infection.

The Flu and Covid vaccine roll out began for all eligible people from October 1st 2025 to help and support those who are most vulnerable and of course to support the NHS (to reduce hospital admissions) amid new variants which had been recently recorded. Vaccination teams across England were working to protect those who are most at risk of getting seriously ill during the winter by building immunity ahead of December and January, when hospitalisations for respiratory viruses usually rise. There already had been early signs of an increase in flu cases, and COVID-19 cases, they had been steadily increasing for a few weeks, with increasing hospitalisations. The increase was thought to have been driven by the return of schools after the summer break.

For the first time, those eligible for winter vaccines have been able to book since the 1st September to allow more people to book their flu or COVID-19 vaccine appointments well in advance. Regional teams across the country had been working to make it as easy as possible for people to receive their vaccines such as introducing mobile vaccine services, community drop in centres and using pharmacy services.
Flu vaccines are available for everyone aged 65 and over, under 65s in clinical risk groups, care home residents and carers, close contacts of those who are immunosuppressed, frontline health and social care workers, as well as children and pregnant women.
Following advice from the Joint Committee on Vaccination and Immunisation (JCVI), COVID-19 vaccinations are only available to adults aged 75 and over, older adult care home residents, and people who are immunosuppressed including those diagnosed with vasculitis.

For those having Rituximab the advice ideally was to have the Flu or Covid vaccine 4 weeks before infusion (but 3 weeks is ok) OR 4/6 months after infusion.

Alison also touched on the subject "no live vaccines" for those who have vasculitis and are immunosuppressed but also about living in the same household as those family members who do have live vaccines eg:- the live flu vaccine available for young children.
The take home message for me was to show common sense, practise good cross infection control, when being immunosuppressed and living with those who do have live vaccines. The risk is low for those who are immunosuppressed. But to be very aware of those who are severely immunosuppressed or considered very vulnerable. As Alison stated, it's difficult for parents to avoid children and also those who are immunosuppressed who are teachers.

There didn't seem to be any obvious reason why there was a difference between flu and COVID vaccines for eligibility to me initially, (carers and family members are not included in the COVID vaccine eligibility but are included in the Flu vaccine eligibility) but after some research I found that the Joint Committee on Vaccination and Immunisation's (JCVI) annual advice said Covid-19 was now a "relatively mild disease for most people", with rates of hospitalisation having "reduced significantly" unlike Flu which had increased BUT also the cost between the two vaccines is around £80 difference per vaccine. The Flu vaccine being much less expensive

The JCVI also advised "By focusing on the oldest adults and individuals whose immune systems are compromised as the two groups who continue to be at higher risk, is based on "a standard cost-effectiveness assessment, in line with other routine vaccinations".

The general advice from NHS England for those in remission, is that while vaccination may not completely prevent infection, it is highly effective at reducing the risk of severe illness, which are higher in vasculitis patients.

Alison also discussed the Shingrix vaccine (none live vaccine) to prevent shingles offered to those who are 18 years and older with a severely weakened immune system from September the 1st 2025. It is given in 2 doses 4/6 months apart.
According to GSK, recent research shows Shingrix Vaccine efficacy remains high at 82.0% at year 11 after initial vaccination.
It was surprising how many in the group had not had their Shingrix vaccine including myself. I have to confess it had not even crossed my mind. Something I decided I must rectify!

Rituximab maintenance therapy, patient perspectives on treatment continuation and withdrawal.

Iwan began his presentation by discussing what Rituximab is - Rituximab is a targeted monoclonal antibody therapy used to treat some types of vasculitis. It works by targeting and destroying CD20-positive B-cells, helping the immune system eliminate these cells.

Dr Iwan Raza

He also discussed the new British Society for Rheumatology guidelines for treating and managing AAV Vasculitis, published June 2025.
Rituximab is the first choice of induction in AAV related vasculitis In most cases but not all. Cyclophosphamide is still given where appropriate. Cyclophosphamide acts faster than Rituximab and is used if the vasculitis is particularly aggressive.
In managing AAV Vasculitis, it's crucial to balance controlling the disease with avoiding treatment-related side effects.
Iwan also discussed the Pros and Cons of Rituximab:-

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Pros - Early Rituximab Intensive induction regimens have shown rapid remission induction and longer disease free status. In most cases Rituximab is more effective than other treatments
Cons - Increased risk of infection (so Rituximab is not used if it's not needed)

Growing evidence suggests that, at least in MPO-AAV, "Rituximab maintenance therapy" may not be needed but in some cases of PR3 - AAV maintenance therapy may be needed. In EGPA, Rituximab can be given in some cases but there are alternatives for EGPA to target the eosinophils.

At this moment in time there is no absolute prediction of relapse in any type of ANCA associated vasculitis, the patient is in the best place to know if they are flaring/relapsing. The patient's perspective is essential. But there is still clinical research ongoing and some research completed.

Those on Rituximab maintenance "for life", it is essential the medical team along with the patient will weigh up pros and cons, this will include the number of flares and relapses, time scale in-between relapses/flares, tried all other available drugs eg:- Methotrexate, MMF, Azathioprine etc before a decision is made for "life long" maintenance of Rituximab.

Rituximab recovery - immune recovery is about 6 months but it is possible for it to be 18 months after the last infusion. The patient will never be "fully back to normal" after having Rituximab infusions and will still have to be fairly cautious.

Most of those on Rituximab infusions for life have them every 6 months but have regular monitoring and blood tests. (one or two patients may have infusions every 4 months but that's extremely rare) it's all about balancing disease activity and side effects of the Rituximab.

A friend of mine has been having Rituximab every 6 months for almost 20 years. They were told they had refractory vasculitis (failed to respond to standard immunosuppressive treatments) So my friend embraces and loves life and lives every day to the fullest, because nearly 20 years ago they came so very close to losing their life to GPA vasculitis and every day since then has been so very precious.

On the other hand I actually sat next to a gentleman at the meeting, he told me he stopped Rituximab infusions 11 years ago and "touch wood" has been in full remission ever since but even so, he is still seen by his vasculitis team once a year.

Environmental Factors and Disease

David's presentation and discussion was incredibly complicated and complex and at times difficult to understand but the key point I learnt was that every human has some baseline genetic risk of developing a given disease. Extensive research has been performed to both understand and learn how to respond to these risks.

Our genomes play an important role in our health but so do environmental factors. These factors can lead to epigenetic change modifications that alter gene expression without changing the DNA sequence. Some people can be more at risk from environmental factors and autoimmune diseases, known as a predisposition.
While environmental factors, which can include personal, external and biological responses account for roughly 70% of autoimmune disease risk, these factors often require a susceptible genetic background to trigger disease onset. These include chronic physical or psychological stress or trauma, infections, viruses, smoking, exposure to toxins, air pollution, even poor diet which can lead to an imbalance of gut microbes which in turn can trigger chronic immune-mediated inflammation (IMIDs)

David discussed identical twins where one might be diagnosed with vasculitis and the other not? While identical twins are often called "identical," it is more accurate to say they have a "shared genetic blueprint" that drifts apart over time due to environmental factors and small, unique genetic mutations.
This particularly interested me as I know identical twins personally, both are my age 72 years old.
One was diagnosed with GPA vasculitis almost 20 years ago. The other has no disease involving their immune system. Both qualified as teachers one taught and lived in a rural environment the other lived and taught in an urban area, a city. I am not sure of their hobbies but I know they both liked to do a lot of walking. Did one twin have a more stressful job than the other? Did the environment they lived and worked in make a difference? Did one have a predisposition but the other did not? There have been studies on identical twins and autoimmune conditions but to date I don't think the results were conclusive but I am sure there is ongoing research.


Dr David Caruthers

Genomic research will transform healthcare from a "standardised approach" to a personalised, proactive approach by analysing a patient's entire DNA set. Future health improvements will focus on predicting diseases before symptoms appear, enabling highly targeted treatments, and tailoring medication to a patient's genetic makeup.


David Sambrooks

All in all it was an extremely interesting and informative day, as always, thanks to David and Diane Sambrooks and of course all the speakers.

It was also lovely to catch up with a few old friends too. I was so pleased I made the 160 mile round trip.

Susan

Donations & Fundraising Bequests - In Memoriam

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

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

£20.00 Was recieved in support of Vasculitis UK by Nils Clemmetsen In memory of Steve Shaw.

£210.00 Was recieved in support for Vasculitis UK from Robert Dennis.

£50.00 Was recieved in support for Vasculitis UK by Ann Mc-Farlane for Muriel.

G & H Courts donated £50 Hazel Courts said "My Husband has suffered with Vasculitis for 20 years and we are grateful for all the help he has received in that time and wish to help in future research into the disease".

Paul Smith and family donated £200 to VUK along with the following Message:
As usual, and now for twenty years, the family give to VUK as Christmas gifts.

Kerry and her brother John made a donation of £145 in memory of their beautiful Mum, Elizabeth Bonnar, her wish was a cure may be discovered, as she has Takayasus Arteritis.

Elaine Harris made a donation of £150.00 to Vasculitis UK. She has been teaching Indian Block Printing at a couple of workshops and managed to raise this money in memory of our son Mike. Elaine said "hopefully throughout the year I can raise a bit more awareness and cash in this way".

£2798 raised in memory of Paula Cleworth

£895 raised in memory of Dave Wood

£610 raised in memory of Colin Skinner

£656 raised by Cameron Lees by running the Loch Ness Marathon in memory of Marion – apparently he was attacked by a dog en-route but still finished his run.

VASCULITIS UK

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 Chaplin – 07736 795637 surreyvsg@gmail.com

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

West Country Group
West Country Vasculitis Support website
Charlotte Stoner – 01626 872420 – westcountry-vasculitisgroup@outlook.com

Yorkshire Group
Rachel Weeks – 07968 959 850 – rachel@yorkshi-revasculitis.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-TBA

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

VASCULITIS UK

We are very excited to announce our Vasculitis UK patient day and Annual General meeting (AGM)

Wednesday 23rd September 2026, Cambridge (venue to be confirmed)

Morning session from 10.30am

- In-person patient, carer and supporter session
- 'Living well with Vasculitis'
- Feedback sessions and speakers will be recorded and available online after the meeting (no live participation)

Afternoon session 2pm

- AGM with key note speakers (to be confirmed)
- Hybrid meeting: live participation face-to-face and on-line
- Meeting will be recorded and available online

Buffet lunch and refreshments during the day provided for those attending in person.

Registration for the meeting(s) will be open in June 2026

VASCULITIS UK

Would you be interested in becoming a Trustee of Vasculits UK?

You don't need any qualifications, just an understanding of Vasculitis or other auto-immune conditions and/or the charity sector.

You would be part of a supportive team who meet monthly on-line

Tasks are shared, and any training needed is provided.

If you'd like to find out more, contact Claire at chair@vasculitis.org.uk

Clothing

Check out our online shop

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

We can supply flags and fluffies and other goodies for your fundraising events

Just contact us at: fundraising@vasculitis.org.uk

VASCULITIS UK

HONORARY LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

Established in 1992 by the family and friends of Stuart Strange,
In his memory.
Formerly known as the Stuart Strange Vasculitis Trust
Registered Charity No. 1180473

Officers, Trustees and Volunteers

Chair:
Claire Tolliday
chair@vasculitis.org.uk

Vice Chair:
Vacant

Director of Operations
Zoi Anastasa
zoi@vasculitis.org.uk

Secretary:
Vacant

Treasurer:
Heidi Pollard - Director of Finance

Fundraising Co-Ordinators:
fundraising@vasculitis.org.uk

Independent Advisor:
Duncan Cochrane-Dyat

Medical Advisors & Scientific Advisory Board
Prof David Scott
Prof David Jayne
Prof Richard Watts
Prof Charles Pusey
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