



VASCULITIS **UK**
NEWSLETTER JOURNAL



AUTUMN 2023 ISSUE 66

The last few weeks have been very Difficult for Vasculitis UK. If you're not already aware we lost John Mills MBE. He took over a small charity Stuart Strange and in 2009 became chair of Vasculitis UK.

I first met John at the AGM held in Long Eaton 2010. He had such a passion talking about the future of Vasculitis UK. Everyone was listening including me. He had one of those voices that you had to listen to and very good at telling anecdotes. I spoke to the lady at the back of the hall, on the stall. This I later discovered was Susan Mills. I asked her was there a local support group. No! would you like to start one?

Chatting further they found I had fundraising experience. That was it hooked! I became a trustee and the fundraising coordinator. I knew very little about vasculitis but I listened to both John and Susan who were so knowledgeable. He had so many ideas of where he wanted the future of the charity. He wanted us to become a CIO (Charitable Incorporated Organisation) equivalent to a limited company. The lead trustee left and I was asked to take over and complete the change. The new CIO was born in October 2018. I was very surprised when John asked me to take over as chairman, he said it was because "I was very good at the boring stuff." Still not sure if that was a compliment. He has left us with a great legacy in Vasculitis UK and we will miss him.

The work of the charity continues, our fundraisers have been involved some very strange activities. Who would think that driving an old red Fiat Panda to various parts of Europe is a good idea. Well, that is what team Bamboo did. We've also had two fundraisers climbing to Everest base camp. One of

them was our Treasurer Heidi. She also did the Great North Run. I was very disappointed with the numbers this year. Normally we fill all our places and have a reserve list. It was the same

for the Great South run. So, for next year we will reduce the numbers we book. We also have a deal with a Skydive company. Contact me if anyone fancies doing it, they can do groups too!



Chairman's Report

Zoi, our Director of Operations, and only employee has been incredibly busy, her report comes later. We've had stalls at the BSR conference (Manchester), The RCN (Brighton) and at UKIVAS in Cambridge. I'd like to thank the Trustees (Charlotte, Susan and Charlie) and volunteers (Tony, and Giles Hart, Shanali Perera and Helen Cornish) who helped with these events. If you would like to help with the stall the please contact zoi@vasculitis.org.uk. Next year the RCN is in South Wales on the 2nd to 5th of June. We've produced some new posters and artwork for these events.

Our research is finally back on track after covid. The 2019 deferred grants are now completing. We have a new research policy which is more patient focussed, thanks to our awards administrator Laura Whitty. Zoi will present this in her report. We have made the call for next year's grants.



We are still actively involved in covid antibody research, this is outside of our normal grants. During the covid pandemic we found it beneficial to work closely with several smaller charities. Often led by Kidney Research or Blood Cancer UK.

By joining them we were able to persuade government that half a million immunosuppressed patients should be considered priorities when vaccinations started. More recently we've persuaded them to keep the

antivirals like sotrovimab, for our members with renal involvement so they don't end up in hospital.

Covid is still with us. I think we're all used to zoom calls now. There's a new variant doing the rounds. So please keep your vaccinations up to date. Should you test positive it's now your local Integrated Care Group (GP practice) who should prescribe the antivirals. Treatments for COVID-19 - NHS (www.nhs.uk) The group of small Charities have written to the ICGs reminding them that it is now their responsibility to provide treatment to our members.

The AGM was held by zoom on the 24th September. We had 70 requests to join and around 50 attendees. The first speaker was Prof Raashid Luqmani talking about the "Classification of vasculitis." The second Dr Rosemary Hollick her presentation was "recommendations from the VOICES study using care experiences to improve care." The feedback has been very positive from those that attended.

The trustees are mostly unchanged Chairman Dorothy Ireland, Acting Secretary Susan Mills, Treasurer Heidi Pollard, Shop Jen Harper, Fundraising Charlotte Smith, Young Adult group Charlie Harper, and Advisor Peter Rutherford. We welcomed a new Trustee at the AGM Jane Edwards and she will be on the Scientific Advisory Board.

If you would like to join the trustees and help us move forward. Then please email me dorothy@vasculitis.org.uk with a letter stating what you could offer the trustees and the charity.

Finally, I'd like to thank the wonderful volunteers not already mentioned, who work in the background but help us to keep the charity working. Our Webmaster John Geddes, our Newsletter editor Kevin Soper, and the Scientific Advisory Board; Prof Charles Pusey, Prof David Jayne, Prof David Scott and Prof Richards Watts.

Take Care

Dorothy Ireland

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Diagnosed with **VASCULITIS?**
 Living in the **UK?**
 Aged **18 to 39?**

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

Join the community:
<https://www.facebook.com/groups/vasculitisukyoungadult>
 Email: Charlie@vasculitis.org.uk



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



Dear Reader

It is only right that this feature I dedicate to our former chairman and vasculitis advocate John Spencer Mills MBE. It was so sad to have received the news from Susan on John's passing, and my heartfelt sympathy goes to Susan and all the family, and to all our fellow Vasculitis UK & Worldwide family.

It was an honour and a privilege for both my wife and myself to attend John's Memorial celebrations recently, and was so wonderful to hear of how he had impacted on other people's lives, for me his stoic attitude and dedication to helping others via this charity as well as many locally will always set the bar.

When coming up against certain situations during the development of this newsletter, John was always there to encourage and support me and to help find solutions to those situations and I will forever cherish the the words he gave us as a family when we first met both him and Susan after the passing of my dear sister, which is the reason I get involved with this newsletter still today.

John's input into making this newsletter work has always been forever present, and even leading up to the days before his passing he wrote both book reviews by hand for this edition....stoic to the end, he will be truly missed but will always be remembered.

Thank You John.

Kevin Soper (Editor)

A festive advertisement for Christmas cards. At the top, there's a decorative border with pine branches, red berries, and ornaments. Below this, the text "Christmas Cards Available Soon" is written in a bold, red, serif font. Underneath, two sample cards are shown: one with green and blue ornaments, and another with a snowy landscape and a Christmas tree. At the bottom, it says "Place your Order via The VUK Shop" and provides the URL "https://vasculitisuk.myshopify.com".

Christmas Cards Available Soon

Place your Order via The VUK Shop
<https://vasculitisuk.myshopify.com>



Help Advice & Support

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

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

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

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

15 months and 29 days working for VUK



In 2012 my son and I took the big decision to move to the UK from Greece. I sold my small company, gave away most of my stuff, packed the rest and off we went. Two years later my son is doing well at school, the cat has adjusted well (yep, we brought our cat with us) and I am volunteering full time at a secondary school. Then I got severely ill and was diagnosed with GPA vasculitis. My doctor – thank you Dr Jon King – introduced me to Vasculitis UK and I have been involved with VUK for almost 9 years now.

From a member to a volunteer to a trustee to an employee, what a journey! John (my mentor who I will miss so much), Susan, and Dorothy were with me every step in the way. My life path would have been so different without them in my life.

So how is it working for VUK? Challenging, exhausting, wonderful! If there's a fine line between working and volunteering, I haven't found it. It is not a 9-5 job, but sometimes I only have me to blame for working late in the evenings, I get so engrossed in what I am doing so time just flies. From answering emails, organising participation in events like conferences and educational days, creating and sending materials out, collaborating with clinicians on research projects, being on the board on RAIRDA, UKIVAS, Vasculitis International and the ERN RITA patient council to travelling giving presentations, supporting a VUK stand or representing you, the patients in meetings, my life is full in a way I never anticipated. I wouldn't be able to do this though without being part of a team, the support of the trustee board is what makes this possible and this is what makes this working position one of the best I have ever had. Teamwork in Vasculitis UK is actually teamwork, you get help, you can ball ideas, you are appreciated!

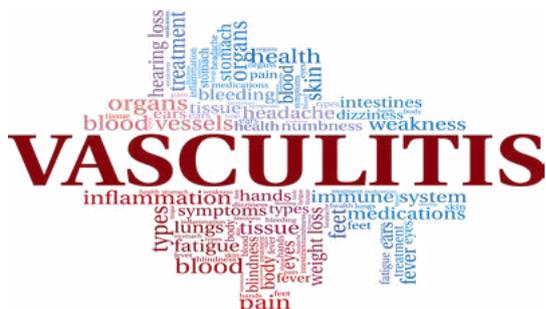
It has been a busy period, these almost 16 months I have been working for VUK. You will find separate articles about events I have been to in the last 6 months like the BSR and RCN conferences and lately to the Vasculitis Awareness and Patient Educational Day in Manchester. There's a lot coming up as well, the UKIVAS educational days for clinicians, a meeting in London about paediatric rheumatic diseases, EURORDIS patient representatives annual meeting, preparation for the Vasculitis International Workshop and many ongoing projects we support.

Vasculitis UK is as busy as ever and so am I! Here's to another amazing 16 months!

Zoï Anastasa

EUVAS MEETING IN SWITZERLAND

The European Vasculitis Society Educational Training Course for doctors who have a special interest in vasculitis met on 30th September 2023 in Switzerland, the meeting was held on the exact same day as John Mills memorial service, and he was honoured in memory.



UKIVAS (Vasculitis Rare Disease Working Group of the UK & Ireland) meeting Glasgow 25th May 2023

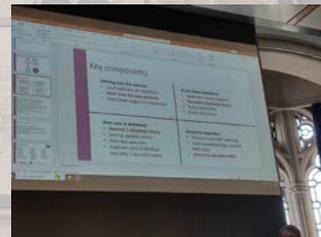


This time the UKIVAS board met in the beautiful building of Glasgow university. The meeting was chaired by Prof Neil Basu and Dr Stephen McAdoo and although there were some apologies the meeting was well attended. The positive feedback from the UKIVAS educational course in Cambridge last December was discussed and so was the upcoming educational course in Manchester this year. Vasculitis UK will have a stand and we will open the event with a presentation about the unmet needs of the vasculitis patients. Furthermore, VUK will fund the registry of around 15 junior doctors, doing our bit to help young doctors learn more about vasculitis.

We are working closely with the communication workgroup in UKIVAS to support them update their website with the view to make it the virtual place for clinicians to get information about vasculitis, guidelines, new research projects etc.

Prof Neil Basu stepped down from the rheumatology co-chair position, the board thanked him for his efforts over the last 10 years. Dr Jo Robson was elected to replace him as a co-chair.

Zoi Anastasa



British Society of Rheumatology Annual Conference Manchester 24th-26th April 2023



I will start by saying that this was a hugely successful event for Vasculitis UK. Our stand was buzzing with visitors taking material, asking questions, and getting to know VUK better. A very good opportunity to show what we are doing and for the clinicians to find out how we can support them and their

patients.

Having a stand at a conference is fun, but it is hard work too. The materials had been sent to the venue a few days earlier, so we didn't have to carry heavy boxes to the venue, we only had to open them and set up the stand. Of course, an adventure was in the cards! I managed to get lost walking from my hotel to the venue and to top this up it started pouring with rain. A soaked Zoi arrived 30 minutes late to the venue, but my dear Shanali was waiting for me there with a big smile! Shanali Perera, a vasculitis patient from the area, volunteered to help manage the stand for all the days and she also designed the background poster for our stand. Thank you Shanali, I wouldn't have done this without you!



The BSR conference is a busy event, rheumatologists, nurses, trainees, and students attend to learn the latest news in the rheumatology world. Usually, we try to attend as many sessions as possible, this year it was impossible as we were busy almost all the time. Shanali and I did a short presentation about the vasculitis patient's journey



and the challenges we face, on the last day of the conference. It was in an open stage and the audience had to wear headphones to hear us. We had such a big audience that the organisers had to find extra headphones from other

stages in the venue. What an applaud we got! As a result of our successful presence in the conference we were asked to participate in updating the British Society of Rheumatology Guidelines for ANCA Associated Vasculitis, take part in an Open Day organised by a hospital, support a study for Giant Cell Arteritis (GCA) amongst other things.

I was very glad to see my nurses and some clinicians from the rheumatology department in Plymouth attending. It was a very nice surprise!

Shanali said: *It was 'game on' spreading vasculitis awareness at the BSR alongside Zoi. A great opportunity it was, to share insights on what the lives experience looks like with health care professionals who attended the conference. For me, to do so with my colleagues from day when I was on the other side, practising Rheumatology was an added bonus.*

Next year the BSR conference will be in Liverpool, and we are already working on it! We hope it will be as successful, if not even more!

Zoi Anastasa



Zoi at the ERN RITA General Assembly Utrecht 15th -17th June 2023



Vasculitis UK is a member of Rare Diseases Europe (EURORDIS). Over 300 patient representatives from 28 European countries, the European Patient Advocacy Groups (ePAGs) represent the patient voice in the European Reference Networks (ERNs) and I am one of them.

In case you have never heard of ERNs and ePags, let me introduce you to them. An ERN is a network of healthcare providers that connects doctors and researchers virtually across borders, so that expertise travels rather than the patient. ERN RITA is the European Reference Network that aims at improving the care of patients with Rare Immunological Disorders. ERN RITA includes 4 disease streams: Autoinflammatory Diseases, Primary immunodeficiency, Autoimmune diseases and Paediatric rheumatology. Julie Power from Vasculitis Ireland and I are patient representatives (ePags) in the autoimmune stream. Complex cases are sometimes discussed in a "virtual" panel of medical experts from across different disciplines and countries at the request of the treating physician.



This way, the treating physician can benefit from the collective input of experts from different EU countries and improve diagnosis,

treatment, or care for an individual patient. Imaging how this will improve diagnosis!

The last General Assembly was in Utrecht in January 2020, just before the pandemic made face to face meetings impossible, 3 years later we meet again in the same city to celebrate the work that has been done and to collaborate for a better future. The attendance from both clinicians and patient representatives was high. The ERN has a lot of working groups, and I had the pleasure of presenting in the educational group. The whole event was patient-centric, and it was amazing to hear the patient's voice everywhere. A lot of work is done in Europe now to improve the care and the quality of life for rare disease patients and being part of a patient group assisting these changes is a privilege but also a responsibility.



We, patient representatives, are part of different working groups. I had the privilege to present in the education working group, for me education of clinicians and patients on rare diseases and specially in vasculitis is the fundamental step to go forward, to improve the care. Collaboration between clinicians and between clinicians and patient representatives is also important.

We must always remember, together we are stronger!

Zoi Anastasa

Royal College of Nursing Congress Brighton 14th -18th May



Vasculitis UK had a stand in the RCN Congress last May. A big thank you to the Hart family for their help to set up the stand and for Tony and Giles coming to support it. It was a relaxed event and Vasculitis UK had a raffle that was very popular.

A lot of nurses had never come across vasculitis – remember this event was for all nurses so not only specialist nurses. Many of them approached us just to enquire about the raffle, but they got a short presentation of vasculitis while registering their name. Some had a lot of questions, and some had heard about the most common type of vasculitis, GCA. Two had vasculitis themselves and we had a couple of nurses asking for support of family members who were just diagnosed with vasculitis.

Most of these nurses may not see vasculitis patients often, but at least they know that they can approach vasculitis UK for information and advice when needed. Not one leaflet/booklet was left at the end of the event and many nurses asked for posters to put in their offices so colleagues could find our website by scanning the QR code. A thank you to Helen Cornish who saw our post on the Facebook group and volunteered to come and help pack up!



The message was: **If you hear of vasculitis, think of Vasculitis UK** and we really hope they got it!

Zoi Anastasa

Our Fantastic Fundraisers



Neil ran the Manchester Marathon this year raising £584 for Vasculitis UK.

Neil says "For over 20 years this chronic illness has been a part of my mums life and we see first hand the struggles and pain it causes."

Bex Morgan and team pictured ritgh rode 100 miles in May. They raised £705.



Kate Cleary above ran the London Marathon to raise money for vasculitis as her cousin had recently been diagnosed with GPA. She raised £616.

Edinburgh to Grangemouth 29th March 2023 - Vasculitis UK



Alan Armstrong Walked 27.1 miles in one day in memory of his nephew Aaron, who sadly passed aged just 23. so far he has managed to raise £1360 for Vasculitis UK.



Chris Searle pictured right ran the Brighton marathon in 3 hours 52 minutes raising £518 for Vasculitis UK



Bailey Bamforth and Team Bam Boo's



Team Bam Boo have raised over £2000 by competing in The Poles of Inconvenience Rally which started and finished in the Czech Republic, travelling through Romania, Hungary, Slovakia and Poland.



"The annual golf society match at the Earl of Enderby. They raised over £1410."



Above In the picture Left to right are: Phil Sedwill, Co-organiser
Mark Yeates - Winner of the golf competition
Sam Sedwil, Co-organiser
Jane Edwards, Vasculitis sufferer.



Phoebe Leighton and her friends raised £185 doing a 6 mile Mud run. All in memory of Debbie Gregson



150 Miles in May by Rosa The dog!

I am Rosa Eliza Whitesocks and I am a dog! My human mum has GPA vasculitis and many times cannot take me out for walks. I will walk, run and swim 150 miles during May, the vasculitis awareness month.

I will do it for my mum Zoi, and all others suffering from vasculitis. My mum says that living with vasculitis is a rollercoaster of a life, but we don't have a rollercoaster at home. Vasculitis UK is part of my mum's everyday life. They support people with vasculitis, create awareness and fund research. Help me raise funds for them. By the way, the lazy cat will not do anything.

Rosa has raised £540 for Vasculitis UK.



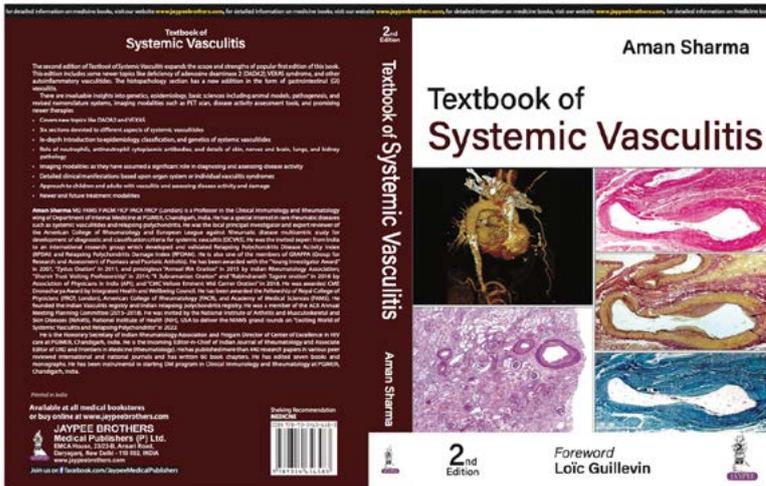
All fundraising photos can be found on the website <http://www.vasculitis.org.uk/about/fundraisers-photo-gallery>

BOOK REVIEWS - John Mills MBE



Textbook of Systemic Vasculitis 2nd Edition Aman Sharma - Professor Clinical Immunology & Rheumatology Postgraduate Institute of Medical Education & Research Chandigarh, India

Systemic vasculitis is a rare disease which for classification purposes is considered as twenty separate disease according to the blood vessels as involved.



This textbook addresses the challenges involved for the classification and understanding all the clinical and academic aspects of these similar diseases by bringing together the knowledge and experience of systemic vasculitis in diagnosing and treating the individual vasculitis diseases as carried out by almost 100 of the leading clinicians around the world - mainly from India but also from Europe and the US.

The first edition published in 2015 provided essential and an invaluable resource for those wanting to expand their understanding of systemic vasculitis. It was not only

comprehensive and accessible in its coverage, but available at a budget price when compared to other similar textbooks on the subject. In this second edition, important areas covered are manifestations according to organ involvement, imaging modalities, principles of management and individual vasculitis syndromes.

This book is a comprehensive composition of the complex management of vasculitis from diagnosis and treatment including care of the patient.

John Mills MBE July 2023

Finding Me Beyond Illness

My Creative Story: Exploring art, illness and Identity - Dr Shanali Perera

This book covers none medial aspects of living with a chronic disabling disease - expressing overall feelings of coping with a chronic disease through art, colour, poetry and conversations.

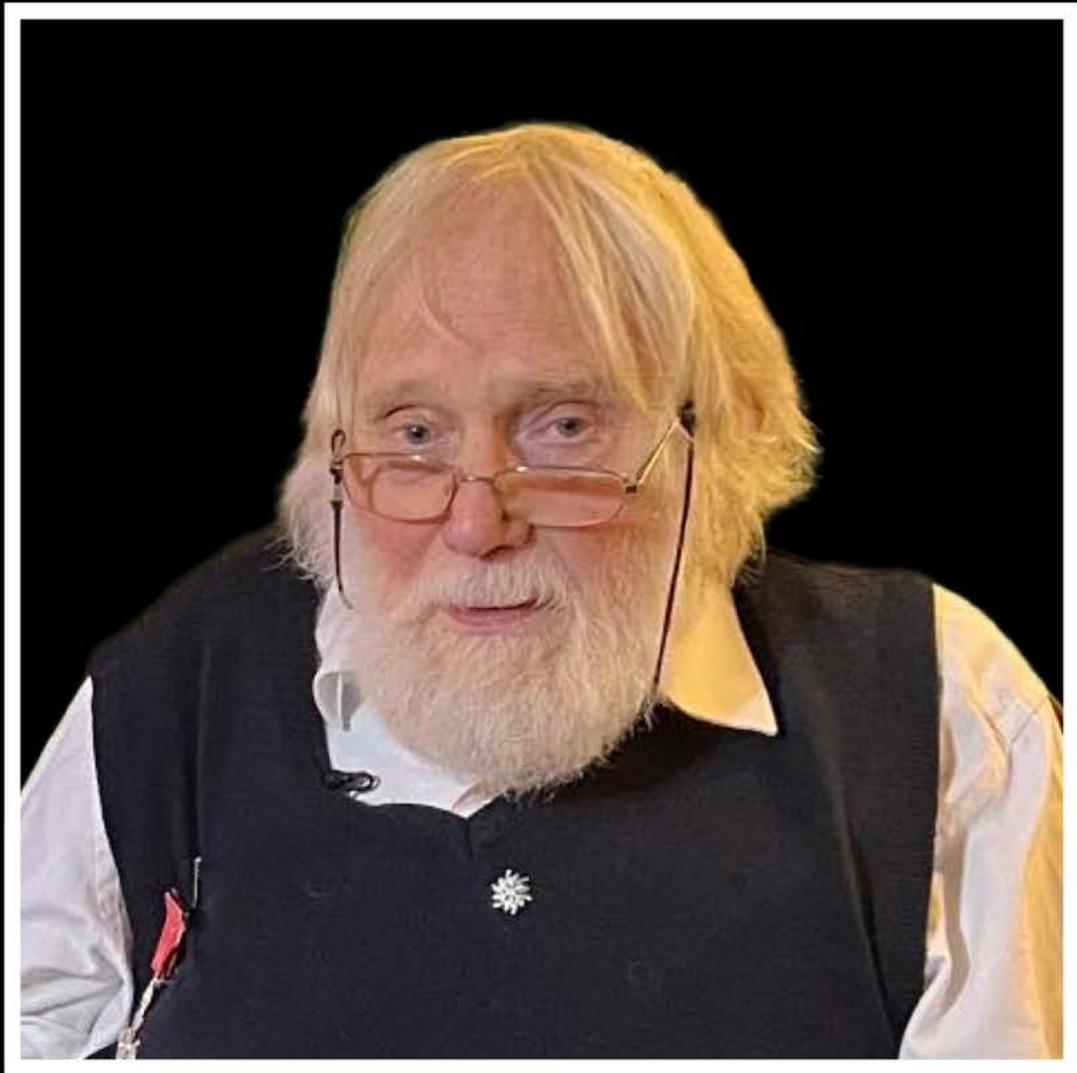
Shanali's book is thought provoking but also enables me to take a look at myself, to re-evaluate to how I am feeling and what I am going through personally. A book to refer to over and again and again.

Susan, my lovely wife, curls up on her favourite chair, picks Shanali's book up from time to time and loses herself within the stories, poems and art. Definitely a book to have by your bed, on your coffee table or on your book case.

John Mills MBE June 2023



JOHN MILLS MBE



1943 - 2023





John Mills MBE

Died peacefully in his sleep in the early hours of Monday 28th August. John lost his life to metastatic prostate cancer. He was diagnosed with advanced prostate cancer in 2016 and had coped very well with the cancer and the aggressive treatment for five years but for the last two years became very unwell.

A private family cremation was held in early September, a memorial service was held for John at the end of September at his local village church.

John worked as a NHS dentist in Bakewell, Derbyshire for 40 years, 1966–2006. He founded the Vasculitis UK charity in 2009 and worked as Chair for almost ten years and continued as a volunteer for a further three years, up until December 2021 when he became too unwell to carry on.

In January 2023 John was awarded the MBE in the New Year Honours, for services to people with rare diseases. <https://www.bbc.co.uk/news/uk-england-derbyshire-64341107>

I Just wanted to thank everyone who donated in John's memory for Vasculitis UK , the total so far has reached £1746 <https://www.vasculitis.org.uk/news/john-mills-mbe-donate-in-memory>

On Saturday September 30th we held a memorial service for John , a celebration of John's life, as he called it. All planned by John, the hymns, music, speakers and poem were all chosen by John. I want to thank those who did make the journey, some travelling a long distance. Over £800 in donations for Prostate Cancer UK were collected at the service.

Thank you for all the lovely messages, memories and condolences <https://www.remembr.com/john.mills> and welcome any new messages and memories.

John will be remembered in so many ways by so many people and he will also be missed by so many people. As a family, John was our guiding force and we will miss him so very much, but as Tim (John's son said at the service) said "We are all the poorer with his passing, but so much richer for the time we've had"

I thought I would also share John's chosen poem, read at the close of his memorial service.

Speak of me as you have always done.
Remember the good times, laughter, and fun.

Share the happy memories we've made.
Do not let them wither or fade.

I'll be with you in the summer's sun
And when the winter's chill has come.

I'll be the voice that whispers in the breeze.
I'm peaceful now, put your mind at ease.

I've rested my eyes and gone to sleep,
But memories we've shared are yours to keep.

Sometimes our final days may be a test,
But remember me when I was at my best.

Although things may not be the same,
Don't be afraid to use my name.

Let your sorrow last for just a while.
Comfort each other and try to smile.

I've lived a life filled with joy and fun.
Live on now, make me proud of what you'll become.



Susan Mills



Professor David Jayne, Director of the Lupus & Vasculitis Services, Cambridge University Hospitals September 30 2023

I knew John as Chairman of Vasculitis UK a patient charity focused on improving lives for patients with vasculitis.

Vasculitis UK grew out of an earlier charity, the Stuart Strange Trust - Stuart had been a patient in Cambridge - and John with others, such as Pat Fearnside, developed in 2008 what had been a small charity finding difficulty continuing to a National patient organisation that has become widely influential both in the UK and elsewhere dedicated to improving the lives of vasculitis patients.

Vasculitis, not a term widely known or understood, even in the medical world, presents mainly challenges to patients and John whose diagnosis with Wegener's granulomatosis, now GPA, was in the early 2000s appreciated only too clearly problems with delayed diagnosis and access to appropriate health care.

He took on the challenge at a time of considerable change, both to the way the Health Service approached vasculitis and the way the diseases were managed, and as a representative of the patient voice he made key contributions in many, many areas.

I would like to emphasise a few,

In 2012, rare diseases such as vasculitis became a focus of the NHS and John was a member of a specialised rheumatology initiative which defined specifications for how patients with vasculitis should be cared for within the NHS. This required frequent trips to London and many long meetings in somewhat drab NHS offices. It has been very influential, I was fortunate to work with John on an earlier mission statement for rare immune disease that became an advisory document for this process.

Medical guidelines to help doctors treat vasculitis were being formulated at this time, led by David Scott and Richard Watts for the British Society of Rheumatology and John naturally slipped into the membership of the writing committees imbuing some common sense and vital patient perspectives into the deliberations. This resulted in John joining an International guideline process in 2016 led by Chetan Mukhtyar and many of us remember working with John at a beautiful house on the banks of Lake Zurich a short walk from the large Lindt Chocolate factory. Indeed, I returned last night from a European Vasculitis Society meeting close to Zurich where many physicians from all over Europe and America wanted to pass on their grateful memories for John's contributions and appreciation memories of working with him. I could mention many names but Mara Cid from Barcelona, who had her own health problems was very much helped by her conversations with John and Peter Merkel from Philadelphia who leads the North American vasculitis network remembers John's valuable contributions.

John led the development of both fund raising and medical research spending for Vasculitis UK, assembling administrative support within the charity, helped by Mike Patnick and a Scientific Advisory Board to advise on how the money was used. This involved detailed patient surveys of what topics were important to patients, and any funded research needed to have a direct line of sight through to improving patient care. He joined in large government funded medical research projects in vasculitis both as a co-applicant and steering committee member

Around 2013 we were trying to persuade the NHS through NICE - the National Institute of Clinical Excellence - to pay for a newer expensive drug for vasculitis patients - rituximab. They declined our initial approach but John was not to be deterred and understanding the power of patient opinion he wrote a superb statement of need supported by testimony from many patients who had already received rituximab and won the day to the benefit of hundreds of patients in the UK subsequently, rituximab is now routine care for many

Education, with annual patient symposia were a central activity of Vasculitis UK, but John also engaged with medical education and helped organise the first European vasculitis course in 2017 and I have a wonderful

photograph of John giving the address at the gala dinner during the meeting. He was one of the early members of the UK and Ireland Vasculitis network and its current chair, Neil Basu from Edinburgh also wanted me to make special mention today of his support for this organisation over many years

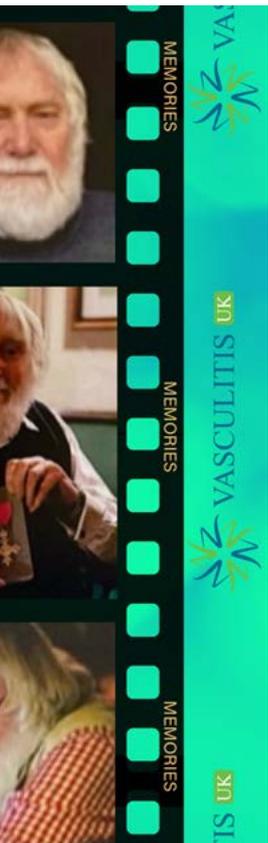
My personal experience of John the man was as a committed, hard working and pragmatic man, typically with Susan at his side, who could be relied on to give sensible informed advice and was the most effective patient advocate I have ever worked with in this and other countries.

His medical background made him relaxed and effective in medical discussions and he always knew the direction he wanted these to go.

He railed against the high salaries of employed directors of large charities and was determined that the most should be made of the funds the charity raised.

He was contacted by patients from throughout the world wanting advice and was truly innovative with many of his ideas - I can think of his advice and guidance to the organisers of the 2015 International vasculitis workshop in London, his enthusiasm for information technology, social media and promotion of virtual consultations well before Covid made this routine practise and his drive to understand and minimise the impacts of Covid on patients through the pandemic.

It has been an honour to have shared so many experiences with John over the last 15 years, his work has directly accelerated improvements in care and will be long remembered by patients, their families and us on the medical side throughout the UK and beyond.





*Thank You
John*

Living with Vasculitis

Regional Vasculitis Awareness and Patient Education Day Manchester 10th September



A very successful day at the Museum of Science and Industry in Manchester, organised by the local Vasculitis clinic. I don't think I have ever seen so many vasculitis patients gathered in a room! The day had everything, presentations for different specialists, 2 presentations from patients, and stands from VUK and Kidneys for Life.

"How does vasculitis affect my body?", we know very well that it does affect our body, our emotions, our mental health. From the diagnostic odyssey to living with a chronic illness. From the pain to physical and mental fatigue (brain fog). From change in appearance to living with the damage vasculitis have caused. We can only try our best, we have to accept and love ourselves, find joy where we can and live. Life is beautiful even you live with vasculitis!



Shanali presented "Art, Vasculitis and the lived experience."

"We strive to be the best we can be amidst the challenges we face..." is a sentiment that most of us going through the vasculitis journey try to hold on to. I got the opportunity to share the importance of and unmet need for psychological support and self-management tools at #vascnorthwest patient education day. It is not just about managing symptoms, but also about improving quality of life addressing every facet of the lived experience.

Psychological support and self-management can play an integral part in the healing process - something we don't address as much as we perhaps should? This question was put to the 100 plus attendees at the event and to perhaps think on widening psychological support and holistic solutions that improve quality of life. I personally think this is an important area in long-term management of Vasculitis that warrants further attention.



Finding mechanisms to go forward can be a challenge, but expressing yourself through art is one both Shanali and I recommend!

We are looking forward to seeing more events like this through the UK. The patients definitely need them, but we think the clinicians benefit as well from hearing the patient's voice!



by Shanali Perera and Zoi Anastasa

Thank you Manchester City Supporters Club – Alkington Branch!



At the Vasculitis Awareness day in Manchester we were presented a cheque of £1,000 by Mr Denis McMahon.

The cheque was from the Manchester City Supporters Club – Alkington Branch. Each year they nominate two charities they fundraise for and last season their two charities were Royal British Legion and Vasculitis UK, both charities received £1,000.

Denis is the secretary of the branch and has GPA vasculitis, so the members supported his nomination that Vasculitis UK would be one of their charities.

Thank you very much for fundraising for VUK!



The MELODY Study



Ipsos MORI



Imperial College
London



Blood and Transplant

Dr Fiona Pearce said: COVID-19 can be a serious infection that can lead to treatment in hospital or even death. We know from previous research that people who have a weakened immune system were more likely to catch COVID-19.

The MELODY study aimed to find out how well vaccines protect people who have a weakened immune system from COVID-19. We invited people who have had transplants, people with certain types of blood cancer and people with rare autoimmune rheumatic disease to take part.

We found that about 4 in 5 people that took part in MELODY had had antibodies after having 3 or more vaccines. People who had more doses of vaccine were more likely to have antibodies.

We now know that most immunosuppressed people make antibodies after having a COVID-19 vaccine. We also know that the more vaccines you have, the more likely you are to have antibodies. Therefore, we recommend that people have vaccines and booster doses as offered by the UK vaccination programme.

Here's the lay summary of our findings:

Plain English Summary: Antibody levels after 3 or more COVID-19 vaccine doses in 23,000 immunosuppressed individuals: first results from MELODY.

Short summary

COVID-19 can be a serious infection that can lead to treatment in hospital or even death. We know from previous research that people who have a weakened immune system were more likely to catch COVID-19. The MELODY study aimed to find out how well vaccines protect people who have a weakened immune system from COVID-19. We invited people who have had transplants, people with certain types of blood cancer and people with rare autoimmune rheumatic disease to take part.

We found that about 4 in 5 people that took part in MELODY had had antibodies after having 3 or more vaccines. People who had more doses of vaccine were more likely to have antibodies.

We now know that most immunosuppressed people make antibodies after having a COVID-19 vaccine. We also know that the more vaccines you have, the more likely you are to have antibodies. Therefore, we recommend that people have vaccines and booster doses as offered by the UK vaccination programme.

Why was the MELODY Study undertaken?

This research was done in response to the COVID-19 pandemic.

COVID-19 can be a serious infection that can lead to treatment in hospital or even death. We know from previous research that people who have a weakened immune system were more likely to catch COVID-19. They were also more likely to need to go into hospital for treatment or die from COVID-19.

Antibodies protect people by fighting the infection and preventing serious illness. Vaccines trigger the immune system to make antibodies. If your immune system is weak, you may not respond well to the vaccine and produce enough antibodies.

The MELODY study aimed to find out how well vaccines protect people who have a weakened immune system from COVID-19.

We did this first part of the study to find out:

- i) how many people in the study have antibodies after having at least 3 COVID-19 vaccines,
- ii) what common factors are present in people who don't have antibodies.

This information will help plan better care, treatment and services for people living with these conditions.

There is a second part of the study that aims to find out if the presence of antibodies reduces the chance of having COVID-19 and becoming very ill with it. This part of the study is on-going. We will report these results as soon as they are available.

Who undertook this research?

A team of doctors and researchers from many organisations carried out the MELODY study. These organisations include Imperial College London, The Universities of Nottingham, Southampton, and Cambridge, Nottingham University Hospitals NHS Trust, NHS Blood and Transplant, the National Disease Registration Service at NHS England, and IPSOS MORI (an independent research organisation).

Funding for the MELODY study came from the Medical Research Council and health charities. The charities include Kidney Research UK, Vasculitis UK, Blood Cancer UK, and Cystic Fibrosis Trust.

How was this research done?

We invited three groups of immunocompromised people to take part in MELODY. People who:

- i) Are living with a solid organ transplant, or
- ii) Are living with a type of blood cancer affecting



the lymphocyte blood cells or

iii) Are living with a rare autoimmune rheumatic disease such as lupus, vasculitis, myositis or scleroderma.

Participants were recruited between December 2021 and June 2022.

We invited people who were 18 years or older from the three groups listed above to take part. We identified these people using national patient registers. These registers included the UK Transplant Registry (UKTR), the National Cancer Registration and analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). We sent letters to invite 101,972 people to take part. Participants could choose to enrol if they had received at least 3 COVID-19 vaccine doses. Some people who had transplants signed up to take part in the study before invitations were sent out.

Participants gave consent and completed questionnaires on a web portal. People answered questions about themselves like their age, gender and ethnicity. They were also asked about their diagnosis, medicines and their physical and emotional health. People's COVID-19 history, including infection, shielding and vaccination was also collected.

Participants received home blood finger-prick antibody tests with instructions by post. We asked people who had 3 or more COVID vaccines to self-test for antibodies. They reported their test result on the portal system. We used this data to see what factors might be linked to having antibodies, or not having antibodies, after having at least 3 doses of COVID-19 vaccine.

What did we find?

Main results

- About 4 in 5 people with a solid organ transplant, rare autoimmune disease or blood cancer affecting lymphocytes had antibodies after having 3 or more vaccines.

- People who had more doses of vaccine were more likely to have antibodies.

More detailed results

- Of 101,972 people invited to take part in the study, 28,411 enrolled and 23,036 provided their result of the finger prick blood test.

- 9,927 participants had a solid organ transplant, 6,516 a rare autoimmune disease and 6,593 a blood cancer affecting the lymphocytes.

- 29% of participants had 3 vaccines, 62%, 4 vaccines and 10%, 5 or more vaccines at the time of their test.

- Antibodies were found in 77% of people who had a solid organ transplant, 79% of those with a blood cancer, and 86% with rare autoimmune disease.

- People were more likely to have antibodies if they were younger, had more vaccine doses and had previously had COVID-19. Some medications that weak-

en the immune system reduced the likelihood of having antibodies.

How will these findings help us?

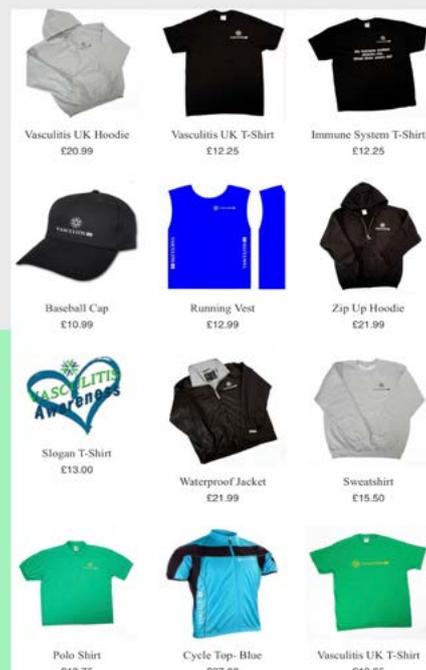
We now know that most immunosuppressed people make antibodies after having a COVID-19 vaccine. We also know that the more vaccines you have, the more likely you are to have antibodies. Therefore, we recommend that people have vaccines and booster doses as offered by the UK vaccination programme.

Taking part in the study provided people with real-time information on their antibody status. In the future, a blood finger prick test may be a useful tool to quickly identify people who have no protective antibodies. This could enable them to have quick access to treatments to prevent infection and if they have a COVID-19 infection.

This is the plain English summary of: Pearce FA, Lim SH, Bythell M et al. Antibody prevalence after three or more COVID-19 vaccine doses in individuals who are immunosuppressed in the UK: a cross-sectional study from MELDY, The Lancet Rheumatology 2023, 5(8) e461-e473
Link to journal paper: [https://doi.org/10.1016/S2665-9913\(23\)00160-1](https://doi.org/10.1016/S2665-9913(23)00160-1)



Clothing



Check out our
online shop

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



Tell your story

Meggie's Story

Send your story to kevin@vasculitis.org.uk

I have always been a poorly child. I had constant upper tract infections: ear infections, tonsillitis, colds and lots of time off school. One day when I was 9, I woke up with a very swollen and discoloured right eyelid which I couldn't open. My mum took me to my GP who prescribed me some antibiotic eye drops for conjunctivitis. After a week, the swelling was no better and we returned to the GP who then suspected orbital cellulitis, and I was given a course of stronger antibiotics. After 2 weeks, my eye was still no better which is when my GP then referred me to my local hospital. At A&E, I was seen by a junior doctor who told my mum it was an allergy and sent me home. I was referred to the Hospital again by my GP who requested that I would be seen by an ophthalmologist. I was seen by the same Junior Doctor again who still persisted that it was an allergy. My mum says she refused to leave until someone took me seriously. After a second and a third opinion by ophthalmologists, I finally had an Anca blood test and a CT scan. My mum received a call the same week by a consultant who had seen my results and told my mum that I was being referred to Great Ormond Street Hospital (GOSH).

A week later I had a biopsy taken of my eye at GOSH, where I stayed for 2 weeks. I received IV pulse steroids during my stay and was sent home on steroids, antibiotics and eye drops. Once home, my mum got a call from Professor Paul Brogan. 'Well do you want the good news or the bad news?' He asked my mum. 'Good news is it's not cancer, but the bad news is its GPA'. That week I was seen as an outpatient at GOSH where I had photos taken of my saddled nose which they had noticed at this time showed nasal septum collapse. I then took part in an 18 month clinical trial called the MYCYC trial in which I was randomised to Mycophenolate mofetil with Prednisolone, followed by Azathioprine. I then became in remission after my treatment. I was able to go back to school, but I looked different. Having been on IV and oral steroids, I had become quite cushingoid, and I had what they call a moon face. I did hear the word 'fat' thrown around a few times at school, but I knew what I had been through and how special I was.

It was during this time that my mum received a call from the Junior Doctor who misdiagnosed

me in A&E who apologised profusely and asked if he could write a journal on my GPA diagnosis to teach others about how GPA can present in different ways.

Within 18 months I had relapsed. I had constant nose bleeds and was admitted into hospital on New Years due to low platelets and E-coli in my urine. I was still on the MMF and steroids for a further year. I relapsed again when I was 12. It was Easter and my mum was unable to get hold of anyone at GOSH for advice, so my GP had to prescribe me some MMF and Steroids to get me through Easter. I had a short stint on treatment, and was able to stay in remission for a long time.

I was discharged from GOSH as an Outpatient when I was 16 and then was under the Royal free London. When I was 18 I was able to have reconstructive surgery to fix my saddled nose. This improved my breathing and my confidence a lot and I was also able to lose my steroid weight I had carried with me through my teens.

In January 2021 (When I was 21) I got covid. I was in remission from the GPA and wasn't on any medication at the time. I did not have any symptoms of the covid at all. However, around May 2021 I started to become very breathless and had a sharp pain in my chest when I breathed. My GP saw me and was shocked how ill I was. I went straight to A&E where a CT scan picked up that I had suspected hypersensitivity pneumonitis. After learning of my history of GPA, the Respiratory consultant was convinced it was pulmonary vasculitis, meaning that the GPA had spread to my lungs. I had a 10 day stay in Hospital as I needed pulse steroids and oxygen. When I was well enough, I was referred to the Royal Brompton Hospital as an outpatient where they re-started my mycophenolate mofetil and oral steroids.

This leads me to now, 2023. I am able to live a normal life and I work full time as Pharmacy Technician in a busy Hospital in West Sussex. Unfortunately, I have not lost the weight I have gained since my most recent flare-up but I am working on this and am just glad that I am happy and (at the moment) healthy.

Meggie

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 27. 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.

We, at Vasculitis UK, do our best to ensure that support group meetings are well attended by advertising them in the “Dear Diary” section in the Newsletter, the e-News, on our Facebook and Health Unlocked discussion groups, and here on our website.

For new groups the charity will advertise your endeavours by checking our main database for all members in your area and writing to them with details of the meeting. We can supply you with posters for your local hospitals/GP clinics etc., and send loads of “goodies” – balloons, pens, stick-it notes, car stickers etc. We also have a leaflet available to give you ideas about how to set up a Group.

We do not believe that anyone setting up a group should be out-of-pocket if they are willing to organise and run support group meetings. The charity can offer some financial assistance towards funding at least the initial meeting.

Why not check the Support Groups? If there isn't a group in your area then email Susan Mills to discuss setting up a group.

West Country Vasculitis Support Group

On the 29th April the West Country Vasculitis Support Group met in Dawlish for lunch. The group is now only meeting socially so they decided to donate the money they had in their account to Vasculitis UK.

Charlotte Stoner, the leader of the group, presented a cheque for £516.

Thank you so much for the donation!





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

In loving memory of our uncle and great uncle Philip Morris. £120 from Robin, Luke, Alfie and George Morris.

Funeral Donations of £115.08 were made in memory of Jane Adamson of North Devon

Funeral donations of £96.10 were made in memory of Malcolm Swift of Devon

Funeral Donation of £50 was made in memory of Ronald John Morris of Windsor

Funeral Donations of £70 were made in memory of Josie Seaman of Shoreham by Sea

Funeral donations of £60 were made in memory of Judith Ann Pashley

Funeral Donations of a total of £1375.45 were made in memory of Penny Bailey of Warwick

Donations have been received of £283.90 in memory of Francis Michael Hoskin of Mullion

Donations & Fundraising

David and Marilyn Bentley, Bowling Green Pub, Winchester made a £200 donation.

Donation of £100 was made by the Nondescripts Golfing Society of Belfast

David Walter made a donation of £100

Donation of £40 received in memory of Hilda Fairer

Donations received of £260.00 in memory of Julie Shorrocks of Blackburn

Donations of £191.49 were made in memory of Philip Morris of Windermere

Donations received of £236 in memory of Josephine Robertshaw of Warrington

Donations received of £500 in memory of Jacqueline Adie of Kent

£70 donation through our just giving page in memory of Bernard Farrington.

Donation received of £50 in memory of John Mills

Donations received of £1761 via Just Giving in memory of John Mills

Reg Lowe made a donation of £100

Yvonne Nicholson made a donation of £200

Leah and Freddie Wren raised £616 completing a Marathon in May. She was celebrating 3 years in remission.

Donating To



VASCULITIS UK

*The charity is **entirely** dependent on voluntary donations
Just £8 a year will pay for the printing and posting of both your
Spring and Autumn Newsletters*

Without your financial support we could not meet our aims of supporting patients, raising awareness and funding Vasculitis research here in the UK.

There are easy ways to make a voluntary donation by cheque, standing order (donation forms enclosed with this Newsletter) or by card via donations at JustGiving.com, VirginMoneyGiving or by PayPal.

Please remember that **Gift Aid** can increase your donation by 25 per cent at no extra cost to you.

For Further details about donating to Vasculitis UK, please contact the Treasurer, contact details on page 28



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



Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group

Janine Davies - 01525 372733 - family.davies@btinternet.com
Christine Lee - 01480 869162 - chrislee0307@btinternet.com

Cambridge Group

Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

East Midlands Group

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

Lincolnshire Group

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

London

North London Group
susan@vasculitis.org.uk

Merseyside, Cheshire and North Wales Group

TBA

North East Group

Dan Hughes dfhuk@yahoo.co.uk
Claire Phillips clairealps@icloud.com
Val Farnsworth val.f@the-madhouse.co.uk

Northampton Group

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

Norfolk Vasculitis Support Group

Mark Sayer - msayer1502@gmail.com

The North West Group

TBA

Oxfordshire Group

Sue Ashdown - 01295 816841 - vsgoxford@gmail.com

Plymouth Group

elaine203@live.com

Solent/Portsmouth Group

Julie Ingall - Julie.ingall@porthosp.nhs.uk

Surrey Group

Peter.surreyvsg@gmail.com

Sussex by the Sea Vasculitis Support Group

Antony Hart - Antonyghart@outlook.com

Swindon Support

Wendy and Lisa swindonvsg@mail.com

West Midlands Group

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

West Country Group

Website <https://vasculitiswest.wordpress.com/>
Charlotte Stoner - 01626 872420 - westcountryvasculitisgroup@outlook.com

West Sussex Group

John Bailey - 07752 122926 - johnbee4@googlemail.com

North and West Yorkshire Groups :

TBA

East Yorkshire Group :

Rachel Weeks - 07968 959 850 email rachel@yorkshirevasculitis.org.uk

North East Yorkshire Support Contact :

TBA

South Yorkshire Social Group Contact :

Jenny Gosling - email jenny@yorkshirevasculitis.org.uk

WALES

North Wales - (Contact Person)

Pat Vernalls - 01766 770546 - patvernalls@btinternet.com

North Wales Group (group also covers Merseyside and Cheshire)

Susan Chance - 01244 381680 - susan.chance@53@icloud.com

South Wales Group

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

SCOTLAND

Edinburgh and Lothian (Contact Person)

Jimmy Walker - 07725 770103 - jamzywalker@gmail.com

Republic of IRELAND

(Contact Person)

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

Ireland - Vasculitis Awareness Ireland

[Vasculitis Awareness Ireland Website](http://vasculitis-ia.org/) <http://vasculitis-ia.org/>
Julie Power - 028 44 842889 - vasculitisireland10@gmail.com



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

EVENTS

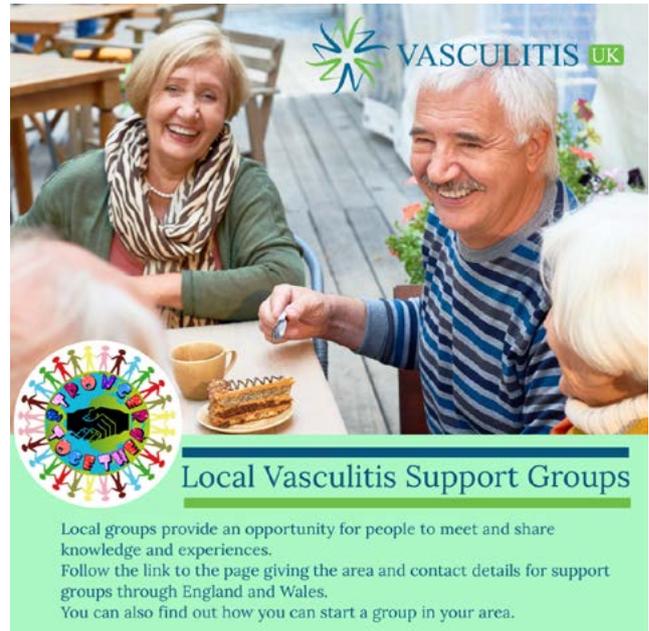


Volunteers Wanted

We are always looking for new volunteers or trustees for VasculitisUK

We need hardworking and friendly volunteers to join our team.

follow this link for more information on our charity.
vasculitis.org.uk/contact



Local Vasculitis Support Groups

Local groups provide an opportunity for people to meet and share knowledge and experiences. Follow the link to the page giving the area and contact details for support groups through England and Wales. You can also find out how you can start a group in your area.

TRAVEL INSURANCE

Vasculitis UK have a comprehensive list of companies who provide travel insurance for patients with pre-existing conditions.

**Details are available on the VUK website:
www.vasculitis.org.uk/living-with-vasculitis/insurance
or contact Susan Mills details on page 28**

Chronic pain- What can I do to help myself?

The following is an extract from the booklet "Managing Chronic Pain" produced by the Scottish Intercollegiate Guidance Network (SIGN).

The booklet covers many topics to help you understand your pain, covering issues such as how it is assessed and how to manage your pain, including complementary medicines.

You can view the booklet at: www.vasculitis.org.uk/living-with-vasculitis/dealing-with-pain

Nobody else can understand your experience of pain or what it feels like to live with it every day. You are the best person to understand your pain and the best to manage it.

You can try to "self-manage" your pain. This could include:

- Formal self-management programmes (group-based, individual or online); or
 - Informal self-management (for example, learning about pain management by reading about it).
- Learning about your pain and understanding it can help you manage it well. Healthcare professionals can help you find a self-management programme that suits you.

Take medication regularly: To achieve good pain control, it is usually important that you take your medication every day, as guided by your healthcare professional, even if your pain doesn't feel as bad. You should not change the dose of the medication or when you take it until you have discussed this with your healthcare professional.

Exercise: Staying active can help to improve your pain in the long term. If you are not sure what exercise is best to do with your pain, discuss this with a doctor or physiotherapist.

It is important that if you are experiencing pain you should discuss this with your GP or consultant and follow the regime suggested by your healthcare professional.



HONORARY LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

**Established in 1992 by the family and friends of Stuart Strange,
In his memory.**

**Formerly known as the Stuart Strange Vasculitis Trust
Registered Charity No. 1180473**

Officers, Trustees and Volunteers

Chair:

Dorothy Ireland
Dorothy@vasculitis.org.uk

Vice Chair:

TBC

Director of Operations

Zoi Anastasa
zoi@vasculitis.org.uk

Temporary Secretary:

Susan Mills
susan@vasculitis.org.uk

Treasurer:

Heidi Pollard - Director of Finance

Fundraising Co-Ordinators:

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Charlotte Smith
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Independent Advisor:

Duncan Cochrane-Dyat

Medical Advisors & Scientific Advisory Board

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Prof David Jayne
Prof Richard Watts
Prof Charles Pusey

Research Awards Co-Ordinator:

Laura Whitty

Trustees:

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Susan Mills
Jane Edwards
Charlotte Smith
Charlie Harper
Jennifer Harper
Peter Rutherford
Heidi Pollard

Volunteers:

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

The VUK Shop Manager:

shop@vasculitis.org.uk

Web Admin:

Susan Mills

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