




VASCULITIS **UK**

NEWSLETTER JOURNAL

 VASCULITIS **UK**

VASCULITIS AWARENESS MONTH

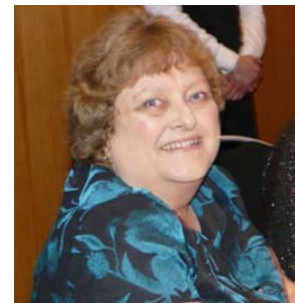
MAY 2024

VISUALISING VASCULITIS

<https://www.vasculitis.org.uk>



The trustees have continued to meet via Zoom. With us being so spread across the country and occasionally further away, it has made sense to continue. Plus, those living with vasculitis are still cautious of being in enclosed spaces with other people. The AGM for 2024 will be in October and we are considering the possibility of it being a Face2Face meeting. Our officers for 2024 are; Chair Dorothy Ireland, Vice-Chair Susan Mills, Secretary Vacancy, Treasurer Heidi Pollard, shop manager Jennifer Harper, advisor Prof Peter Rutherford, The fundraising team Charlotte Smith, Jane Edwards, and Claire Tolliday. Other trustees are Charlie Harper and Diana Shonfield.



Chairman's Report

Volunteers; Awards Admin Laura Whitty, and Auditor Duncan Chochrane-Dyet. Our one employee Director of Operations Zoi Anastasa.

We co-opted two new trustees who came forward after the AGM, they will need approval at the next one. First is Diana Shonfield a Biochemist by training and works within a medical diagnostics and clinical trials company. She is attending the Vasculitis International Conference in Barcelona in April with Zoi. She has been helping with the preparations for the conferences in the north west where she is based. She will probably join the Scientific Advisory Board.

The second new trustee is Claire Tolliday who has experience with adult social care and welfare rights. She is updating the pages on our website. She has joined the fundraising team and will also attend the Scientific Advisory Board at its first Face2Face meeting since Covid. I am always amazed by our fundraisers. During the summer our treasurer went to Everest base camp. Followed by Matt Smith from Derbyshire who went in October. He has raised almost £11,000, a phenomenal amount in memory of his mother-in-law. I attended his return party and meet his amazing wife Louise and lovely group of friends. I was invited to give a talk about Vasculitis and what we do with the donations.

Charlotte Smith now deals with the events. Claire Tolliday with the fundraisers and I have the Great North Run. After 2023 being a disappointing take up, the 2024 places flew. I am keeping a reserve list and, in the summer, may see if I can buy from another charity. Jane Edwards sends out the Thank You and condolence cards.

In the autumn we were invited by Imperial College to join their education prize. The aim is to encourage more students into STEM (Science Technology Engineering and Maths) subjects. For us, the school teams are asked to produce an eposter about vasculitis, Jane Edwards took the lead in this and worked with Imperial on what we hoped the outcome would be; more in the next edition!



Thanks to Laura Whitty for introducing the new Grants Procedures which focus more on the needs of Vasculitis patients than an academic study.

We make the "call" in the autumn, on our website and various professional sites. These are then peer reviewed before going in front of the professors. They score each grant on the merits they see. It then comes to the trustees who also score the grants. The top scorers receive funding under the new criteria. Each grant is worth £50,000, and can be for a year or two years. We still have

some that were delayed by covid yet to complete. The details of previously funded grants are on our website.

We are attending more conferences usually with a stand. These always need people to help. Whether its sitting at the stand or talking to the attendees, or simply helping to bring the boxes. Its always appreciated. There are separate reports about these.

Vasculitis UK agreed to give a bursary of £400 to all the 22 UK Junior Doctors attending the Vasculitis International in Barcelona. We will appear as a funder on all documents. In return we ask for an article for the Autumn Newsletter. Zoi and Diana are attending for Vasculitis UK.

We also agreed to continue with our support for RAIRDA (Rare Autoimmune Rheumatic Diseases Alliance) for the coming year. We work with Forgotten Lives to ensure that immunosuppressed patients voices are heard. With the UKIVAS (United Kingdom and Ireland Rare Disease Group) conference, we will again provide a travel bursary to enable Junior Doctors to attend.

We have also agreed to set up an educational award in the name of John Mills MBE. Susan Mills is working with the organisers to ensure it is properly spent and through her an equivalent amount is available from John. He very much wanted to spread the knowledge and understanding of vasculitis to improve the treatment and outcomes in the future.

May is Vasculitis awareness month. Jane Edwards is looking for something that visualises vasculitis. She wants to put patient stories on the website and link to a Just Giving page. The stories would change daily. The 31st is a Friday so we are hoping that people will organise coffee mornings, or craft days. Something to bring people together. Zoi's story would be on the 15th which is World Vasculitis Day. Theme "**Visualise living with vasculitis.**" Please contact Jane@vasculitis.org.uk if you want your story adding.

Take care

Dorothy Ireland
Chair Vasculitis UK

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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

Well what can I say other than 2024 is proving to be a testing one straight off the bat! My mum of 81yrs took a fall and broke her hip, luckily she was able to have a hip replacement the very next day and I’m glad to say after 5 weeks of both hospital and at a rehabilitation centre is now on the road to recovery. Also on top of that my eldest granddaughter aged 13 was admitted into Evelina Children’s Hospital around the same time with kidney failure, caused by Vasculitis.

The one thing we did not want to hear, especially after our experience as a family with vasculitis previously, but since her diagnoses and by having a good support network through VUK of which I am truly grateful, I am sure this is a battle we can and will win, albeit a life changing time especially for my granddaughter and family, thankfully so far after a couple of re-admissions they have got things under control and she will at some stage in the future go on the list for a transplant, hopefully as we are about to step forward into spring and look forward to what that brings we can only hope that better days are ahead for us all, with bright mornings and hopefully some longer sunny evenings as summer approaches.

Talking of spring and positive thinking, in this edition we have new trustees to meet along with some inspiring fundraisers as always and some great feedback from Zoi, Susan, Jayne and others. Vasculitis awareness month is in May, so look out on how you can get involved in Visualising Vasculitis via social media and other ways of raising awareness and fundraising.

I created this image of a Vasculitis Warrior recently whilst my granddaughter was taking on her recent battles!



Enjoy and don’t forget if you have a story to tell contact me on how you can get it submitted into the next edition in Autumn.

Kevin Soper (editor)



Help Advice & Support

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

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

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

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



Trustee News

New Trustee's Jane, Diana and Claire



Jane Edwards was diagnosed with Microscopic Polyangiitis in 2012, involving her nose, kidneys, and fluid buildup around her heart. The diagnosis was later changed to EGPA/Wegeners when she transferred her care to Addenbrookes. At the same time, a scan found inflammation in her aortic arch affecting the blood flow to the body. Over the years, she has tried many treatments but has struggled to find a lasting remission.

Professionally, Jane holds a BSc in Chemistry and a Master in Business Administration (MBA) from Durham University. She has over 20 years of experience in the medical device industry; these roles included detailed medical knowledge and working with the NHS. Her current position at BSI oversees the EU and UK Medical Device Notified Body's internal and external communications.

Jane lives in Lincolnshire with her husband, two teenage daughters and two excitable dogs. In 2019, Jane published a book about her journey with vasculitis and how to maintain a positive life. She has received overwhelming feedback and believes providing information to people can significantly impact their lives. She feels communication is one of the critical strengths of Vasculitis UK, sharing information and supporting those who feel vulnerable.



I am Diana Shonfield and I live in the North-West with my husband and have two young adult children. I have worked in various positions in quality, within pharmaceuticals, medical diagnostics and clinical trials – being a Biochemist by training.

So, when I was diagnosed with GPA (ears, lungs, joints, kidneys) in August 2020, during Covid lockdown, it was a huge shock to find myself as a patient & to be on 'the other side of the fence'.

I utilised my background to press for diagnosis and I am grateful for the support from VUK and the multidisciplinary medical team in Manchester to get me to clinical remission – though it has taken longer than expected.

I have adjusted to living with a chronic condition and I hope I can help support others in finding their pathway to get best medical and mental-health advice, and live the best lives they can.

Hi, I am Claire and I am delighted to be joining Vasculitis UK as a trustee. I was diagnosed with large vessel vasculitis in 2021 and found the information available on the website (and from John Mills directly) was so helpful as a reliable source that I could have confidence in. I have worked in health and social care for four decades and had never come across anyone with vasculitis in all of that time. I am one of those people who likes to take control of my situation by being as well-informed as I can possibly be.



I still work full time in adult social care as a local authority Head of Service and my professional background is mainly as a welfare rights/housing rights and debt advice worker. I have found that the ability to work at home full-time has been invaluable to enable me to remain working which is something that is important to me. I am also a volunteer for a local Credit Union and our allotment committee as well as a local environmental group.

In my spare time my passions are my garden and my allotment, which although they now take me much longer to do and I need some help, are really big parts of my life. The current trends in no-dig gardening and re-wilding are also very helpful! I live in Suffolk with my husband and our rescue Bedlington terrier, so getting out to the countryside and our beautiful coast is also something that we enjoy together.

Claire Tolliday



In November 2023, UKIVAS held a two-day educational course on vasculitis for clinicians. It was very successful, and every single space was booked months ahead of the event.



Vasculitis UK had a stand there and our trustee Charlotte Smith made a tribute to John Mills MBE and spoke about the unmet need of vasculitis patients. As a vasculitis patient myself, it warms my heart seeing new clinicians showing an interest in vasculitis.

You, who know me, are aware that I am half Greek, and it was a pleasant surprise to meet a young doctor from Wales who

also had family connections to Greece. Furthermore, he has a special interest in vasculitis! It cannot get better! I asked Dr Jones to share how he sees his future and the care of vasculitis patients in Wales.

Zoi Anastasa

Providing excellent care for those with rare autoimmune rheumatic diseases, such as vasculitis in a rural context has always been challenging. The nature of the beast is that you need a critical mass of patients and expertise to make services work. Over the course of my training in North Wales, I have been very lucky to work with multiple excellent clinicians with understanding of these diseases, who have taught me a great deal. However, it has always been a challenge to reconcile ideal pathways, with that which is practicable in our context.

I am now a final year rheumatology registrar with an

interest in vasculitis, who is looking at applying for a substantive consultant post in North Wales and I am excited about the future of this area of medicine in our locality. When I started my registrar training in North Wales, I was the only rheumatology registrar and we had 3 substantive rheumatology consultants, with 1 at each site. It was very hard work to maintain the most basic of services for rheumatology patients. As I am about to finish, we are likely to have 7 substantive consultants by the end of this year and we have a North Wales based rotation for registrars (which includes a 9-month block in Liverpool with LUHFT) with 4 registrars at present. With better staffing comes the opportunity to look at providing more diverse services. We have also benefitted from having closer relations with our nearest tertiary centre in Liverpool, who are a valuable source of expertise. We have better access to PET-CT these days, despite being a long way from the nearest cyclotron (these particle accelerators make the radioisotopes required for the scans. With every hour further away you live from the cyclotron, the amount of active ingredient that gets to your scanner diminishes exponentially!). Going forward we are looking at how we can improve our access to US Doppler across the patch, so that we can create a clear pan -Betsi pathway for Giant Cell Arteritis modelled on what we have seen work elsewhere, and we are looking forward to working with other specialties in providing more specialist care in areas such as interstitial lung disease. My major ambition would be for there to be a robust North Wales Vasculitis MDT in the next 5 years, with an option to discuss with Liverpool in selected cases. I am optimistic for the future.

Giorgos (Alex) Jones
ST7 Rheumatology registrar

The UK and All Ireland Vasculitis Rare Disease Group (UKIVAS) held their recent educational Vasculitis Course in Manchester November 2023.

The course was attended by around 70 attendees including junior doctors, registrars and specialist nurses. All thanks to Dr Nina Brown and her team in organising the delivery of this highly regarded annual event which included expert presentations and intensive interactive sessions.

Members of Vasculitis UK were also asked to take part - Zoi Anastasa, Operations Manager for Vasculitis UK gave an excellent presentation discussing “The Patient’s Perspective on Medical Research”. Charlotte Smith, trustee for Vasculitis UK gave an excellent presentation discussing “The Unmet Need for Patients Diagnosed with Vasculitis”.

Charlotte and myself were also part of a panel along with a specialist nurse practitioner Georgina Ducker (Norfolk & Norwich) answering questions and giving our personal experience/opinion on the subject of “ Difficult to Manage Symptoms”:- this included fatigue and mental health.



The full programme included talks from clinical experts about the different aspects of vasculitis. Tributes were also made to ex chair of Vasculitis UK, John Mills MBE, for being a huge voice for Vasculitis patients for the past 15 years.

The next UKIVAS Vasculitis Educational Course is already in the planning for Autumn 2024



RAIRDA is the Rare Autoimmune Rheumatic Disease Alliance. We are the first alliance linking clinical and patient organisations to campaign for improved care for people living with RAIRDs in the UK. RAIRDA is comprised of LUPUS UK, Vasculitis UK, Scleroderma and Raynaud's UK, and the British Sjögren's Syndrome Association.

RAIRDA is pleased to announce that in April, we will be launching a survey, looking at the key features of care and treatment which lead to satisfaction for people living with rare autoimmune rheumatic diseases, as well as which issues and gaps in care are leading to low satisfaction. We will use the results of the survey to inform and support our policy and campaigning work, to drive change in the areas which really matter to people living with rare autoimmune rheumatic diseases. We are encouraging all members of the Vasculitis UK community to complete the survey when it is launched – if you are able, please complete the survey, to share your experiences with us and make sure we can best represent you in our work. The survey will be shared on RAIRDA's website and social media.

In other RAIRDA news, to coincide with Rare Disease Day, RAIRDA held its first parliamentary event, in the Senedd. The event in the Welsh Parliament was sponsored by Joel James MS, whom RAIRDA met with in December. The event was really successful, with representatives from all four of RAIRDA's member charities attending the event and sharing their stories with MSs, including someone with lived experience of vasculitis. It was great for MSs to have the opportunity to hear from people living with RAIRDs, to outline the challenges they face and the solutions which would be most meaningful to them.

On Rare Disease Day itself, RAIRDA launched its 2024 manifesto, which makes three main calls:
 Making sure that rare diseases remain a priority for health policy in the UK
 A quality standard for rare disease
 Support and funding for the development of specialised networks.

Regarding the quality standard for rare disease, it is also exciting to announce that a project is now underway looking at developing quality statements for rare disease. The results of this project will then be looked at by NICE, who will consider them when looking at developing a quality standard for rare disease.

RAIRDA's parliamentary event in the Senedd

Vasculitis UK is a member of RAIRDA (Rare Autoimmune Rheumatic Disease Alliance). For those who are not familiar with RAIRDA, it is an alliance bringing together patient organisations (Vasculitis UK, Lupus UK, Scleroderma & Raynaud's UK and the British Sjögren's Syndrome Association) to campaign for improved care for people living with rare autoimmune rheumatic diseases in the UK.



On the 27th of February we supported RAIRDA's first parliamentary event, a drop-in event in the Senedd. The event was sponsored by Joel James MS.

The event was really successful. It was the first time I saw RAIRDA in action and it was obvious to anyone in the room that our combined voices were reaching the audience. There were representatives from all four charities and four patient representatives from Wales who shared their lived experience with the 17 MSs who dropped in during the event.

All agreed that the care of patients with rare rheumatic diseases in Wales must improve. RAIRDA is advocating for a quality standard for rare rheumatic diseases and specialised networks in Wales.



This successful event is the first big step in raising awareness of RAIRDs in Wales.



I would like to take the opportunity to thank Tim Roberts, a vasculitis patient from North Wales who attended the event. Tim was absolutely brilliant! Furthermore, I would like to thank each patient from Wales who took the time to contact me and share the challenges they face locally. You gave the insight needed to represent you at the event, your words travelled to the Senedd!

Zoi Anastasa

Our Fantastic Fundraisers



Keith Prior (above) recently successfully nominated Vasculitis UK to receive a charitable payment from his Masonic Lodge, Zetland Lodge, Guisborough. A cheque for £500 cheque was presented to Dan Hughes, from the North East Support Group, at their charity evening.



Jack Strong ran the Bath Half in March this year in memory of his dad Jason, raising £665. Sadly, last Spring, Jason became seriously ill, after suffering difficulties in breathing, he was admitted into ICU. He was eventually diagnosed with Vasculitis. He very sadly passed away in the Summer.



So proud of my husband Sam Edwards and his two colleagues Scott Fawcett and Jack Clarke. They completed the great north run 2023 in blistering heat and then torrential rain.

They raised £3696 directly from friends and family and their company Essentra matched the donations and so the final amount was £7392.

Amazing achievement, considering Sam has not run a race since he was at school.

Photos of Jack, Sam and Scott before the race and then Sam and Scott in the rain after the race, enjoying a pint!

Jane Edwards

Martyn Hill's fundraiser for Vasculitis UK



Martyn Hill will be running in the London Marathon this year in support of his wife who has vasculitis, you can read his story here: <https://www.justgiving.com/page/mick-merry-1705575384905>

Matt Smith Climbs Mount Everest



"Climbing Mount Everest was a dream come true, but wasn't without dedication and motivation. After 10 months of training in the gym morning and night and 5 months of a strict diet but no regrets. The experience was unforgettable and views were breath taking and I met some amazing people along the way. The adventure was all in memory of my mother in law Janice Stevens and I'm so proud to raise just shy of £11,000 for Vasculitis UK and shared awareness of the disease."



Vasculitis UK Christmas trees were set up at both Littlehampton golf club pictured left and Winster Church below.



Chris Foster is running the London Marathon for the first time to raise awareness of Vasculitis. His niece was diagnosed at the age of 11 and is waiting a kidney transplant take a moment to read their story: <https://2024tcs londonmarathon.enthuse.com/pf/chris-foster>

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

Vasculitis UK Supports Imperial College

“Science in Medicine School Teams Prize”

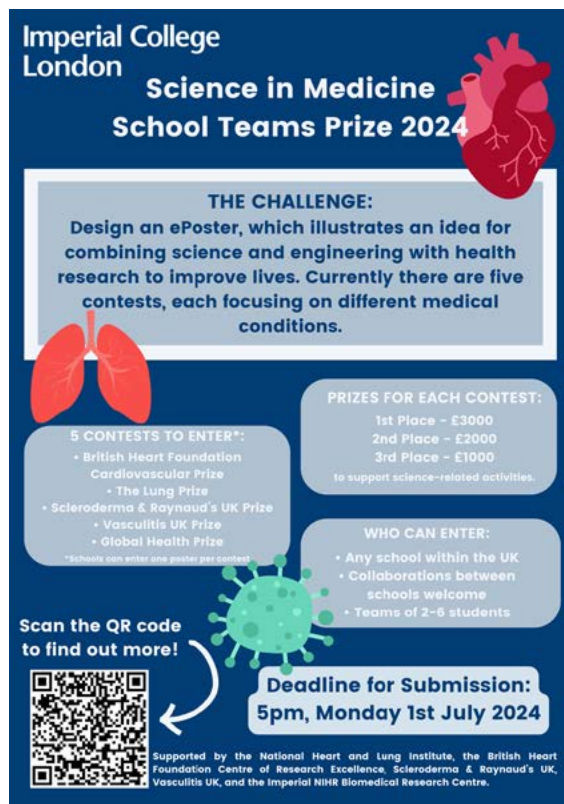
Inspiring the scientists of tomorrow

Vasculitis UK is pleased to announce that we have co-sponsored the 4th Annual “Science in Medicine School Teams Prize” to engage sixth-form school students with science in medicine. The [National Heart and Lung Institute](#), the [British Heart Foundation’s Centre of Research Excellence](#) at Imperial College London, offers the annual prize, and we are so glad to be involved in the 2024 competition.

The aims are to encourage students to:

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

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



Imperial College London
Science in Medicine
School Teams Prize 2024

THE CHALLENGE:
Design an ePoster, which illustrates an idea for combining science and engineering with health research to improve lives. Currently there are five contests, each focusing on different medical conditions.

PRIZES FOR EACH CONTEST:
1st Place - £3000
2nd Place - £2000
3rd Place - £1000
to support science-related activities.

5 CONTESTS TO ENTER*:
• British Heart Foundation Cardiovascular Prize
• The Lung Prize
• Scleroderma & Raynaud’s UK Prize
• Vasculitis UK Prize
• Global Health Prize
*Schools can enter one poster per contest.

WHO CAN ENTER:
• Any school within the UK
• Collaborations between schools welcome
• Teams of 2-6 students

Deadline for Submission:
5pm, Monday 1st July 2024

Scan the QR code to find out more!

Supported by the National Heart and Lung Institute, the British Heart Foundation Centre of Research Excellence, Scleroderma & Raynaud’s UK, Vasculitis UK, and the Imperial NIHR Biomedical Research Centre.

The Vasculitis UK prize. The challenge is to provide a novel vision of how science can improve the health and wellbeing of patients with vasculitis. The focus can be on a particular subtype of vasculitis or on vasculitis in general. There is no fixed topic, but suggestions include: helping earlier diagnosis; providing effective disease monitoring; managing the problem of physical and mental fatigue; reducing infections and/or improve patient response to vaccines whilst on drugs that suppress the immune system.

Teams should research the disease using reliable sources. Help understanding the patient’s perspective can be gained by visiting [Vasculitis UK](#). This prize is supported by the [Immunology Theme of the Imperial NIHR Biomedical Research Centre](#) and sponsored by Vasculitis UK.

For more information, please follow the link below. We would love it if you could share with any contacts who have school connections and would be interested in joining a team.

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

If you have any questions, please email Jane@Vasculitis.org.uk

<https://www.vasculitis.org.uk/news/schools-prize-science-in-medicine>



Feedback from previous years:

An absolutely amazing opportunity - the students were so grateful and learnt so much from the experience. I watched the team grow in confidence and develop their teamwork and communication skills, all whilst learn about how to do scientific research and presentations. Thank you for contributing so much to their futures.

The competition was a fantastic opportunity to give older pupils more maturity and exposure to science in the real world, as well as getting the group together as a team.

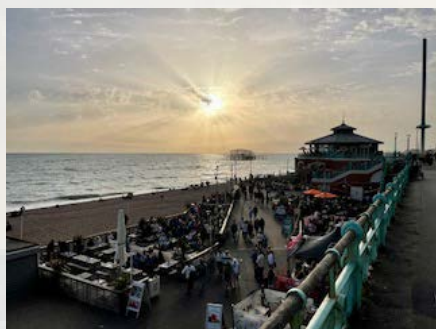
An absolutely fantastic competition. An opportunity for students to engage with academic literature of their own accord and gain insight into what scientific research is really like. The students who got involved really developed their collaborative working skills and ability to write and present.

Thank you again for running this competition. It was useful and valuable for my students and every one of them has mentioned our personal statement applications to university, so it certainly does have benefit.

Students saw the benefit of working with others with different academic strengths, this will help them as undergraduates and future research. An incredibly worthwhile project which has inspired and motivated the students who are now applying for a wide range of courses at university.

Email: school-teams-prize@imperial.ac.uk

Dorothy and Susan Road Trip to Littlehampton - Representing Vasculitis UK.



Dorothy and Susan Road Trip to Littlehampton - Representing Vasculitis UK. October 2023 Dorothy and myself were invited by Littlehampton Golf Club by new Captain Adie and his wife Sarah, to their annual Captains Day Sunday event. Adie and Sarah had chosen Vasculitis UK to be the charity they will fundraise and support, for the year October 2023/October 2024. Dorothy and I were a little nervous setting off on the 250 mile trip on our own but nevertheless we set off planning to stay over for 2 nights in Brighton just a few miles from Littlehampton.



Our journey was uneventful but long, we were grateful to arrive in time for tea and a stroll/ride on Brighton promenade in the evening. It was beautiful evening and an amazing sunset.



On the Sunday after a relaxing breakfast we set off for Littlehampton Golf Club arranging to meet our good friends and fellow VUK volunteers Sally and Antony Hart at the golf club. It was a beautiful sunny warm day and when we arrived we were all made very welcome. Good food and lovely company.

As the afternoon progressed everyone was asked to stand on the balcony of the club house as we watched a stream of motorcyclists drive over the green towards us with the

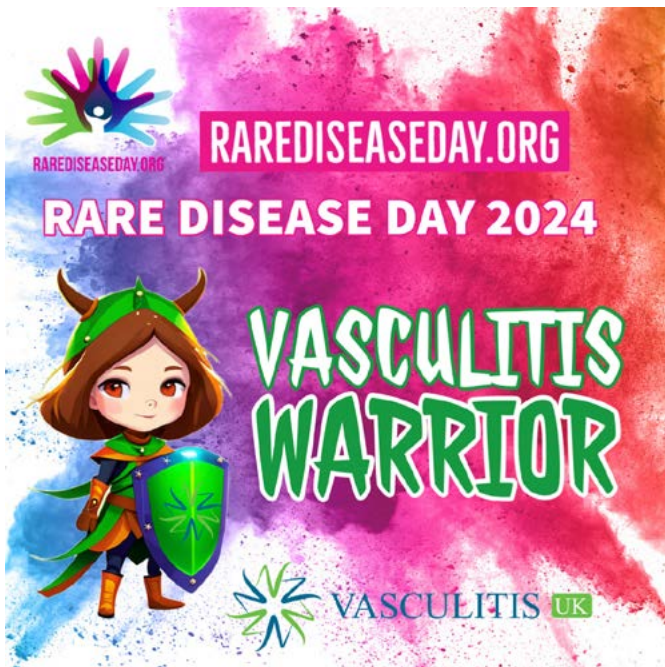
new club captain taking the lead. Paragliders also flew above. This was then followed by the new captain's drive in. A fantastic sight!

The whole day was exciting and fun and we were all so pleased to be involved. I believe over £2500 was raised on the day for VUK.

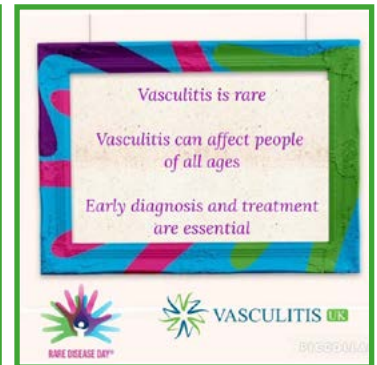
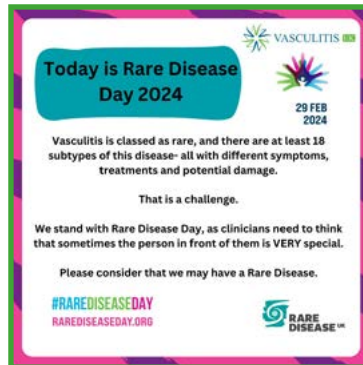
We look forward to hearing more about the ongoing fundraising for the remainder of this year and we want to thank Sarah, Adie and Littlehampton Golf Club for such a wonderful day.

Susan Mills and Dorothy Ireland





Rare Disease Day 2024 was held on February 29th this year, Zoi our Director of operations posted daily throughout the month via social media to help raise awareness. These are just a few that were posted, many of you helped by sharing or reposting so thank you to those that participated.



You can get involved in this year Vasculitis Awareness Month! Jane Edwards is looking for something that visualises vasculitis. She wants to put patient stories on the website and link to a Just Giving page. The stories would change daily. The 31st is a Friday so we are hoping that people will organise coffee mornings, or craft days.

Something to bring people together. Zoi's story would be on the 15th which is World Vasculitis Day. Theme "**Visualise living with vasculitis.**" Please contact Jane@vasculitis.org.uk if you want your story adding.

VASCULITIS AWARENESS MONTH 2024

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VASCULITIS UK

May is Vasculitis Awareness Month.

We have a month of fundraising planned.

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

Watch out on Social Media and www.vasculitis.org.uk for all the information.

Visualising Vasculitis

Search Facebook for "Vasculitis Support (UK)"

Or "Vasculitis UK" on HealthUnlocked.com

VASCULITIS AWARENESS MONTH 2024

VASCULITIS AWARENESS MONTH 2024



Shevington Sharks Charity of the Year



<https://www.justgiving.com/campaign/shevingtonsharkscharityoftheyear>

<https://www.shevingtonsharks.co.uk/> Charity Registration No. 1185238

STORY

In memory of our former Chairman Ian Robinson who sadly passed away in April 2023 we will each year in conjunction with Ian's family, chose a charity which the Sharks will support annually through fundraising, whilst at the same time raising awareness. This year we will be supporting Vasculitis UK a disease from which Ian suffered in the 12 months before he died.



@ShevingtonSharks

Ian as a club chairman, we could not have wished for anything more – he represented our club and our village so so well, everyone loved Ian he never had a bad word to say about anyone he will be sadly missed but never forgotten.- his legacy will live long in our hearts.

International Vasculitis Patient event Barcelona 6th April 2024

I am writing this sitting at a desk in a hotel in Barcelona. Today was the first day of the International Vasculitis Workshop, but you will have the opportunity to read about it in our next newsletter.

This article is a reflection of the patient event that was held yesterday (6th of April). A hugely successful event, from every aspect. Buzzing



with patients, great speakers and a very tasty lunch! There were mostly patients from Spain, but also patient representatives from all around the world, Australia, Japan, Colombia, the States and of course Europe. A patient with GCA vasculitis and PMR, Dianne, travelled from London only to come to the Vasculitis Patient event. A short 24 hour trip, but what an experience!

Dr Maria Cid, the organiser of the Vasculitis International Workshop, welcomed us and promised us a very exciting day- and YES! It was an exciting, informative, emotional and full of hope day.

Carmen Moreno Herencia, the president of the emerging Spanish Vasculitis Patient organisation AVESI, a patient with GPA vasculitis, opened the event. Her quote: "I live with vasculitis, so what?" will stay with me forever. We live with vasculitis, it doesn't define us.



There were a lot of presentations. New therapies in GCA, Takayasu Arteritis, GPA, MPA and EGPA vasculitis. The therapies have advanced a lot in the last 10 years. Managing steroid toxicity, the impact of steroids and living with a rare rheumatic disease on the quality of life of the patient and the link between frailty in vasculitis patients and their wellbeing were of high interest to the patients attending. The impact of steroids on appearance and the self-image of the patient should be acknowledged alongside the health related side effects of steroids.



Furthermore, there were presentations about the importance of clinical trials and how patients can be involved, patient journeys and patient registries and their role. The most powerful session was the patient session. Patients were asked to share their personal journey. A lot of emotion, quite a few tears, but much hope!

The last presentation of the day was about "Exciting Research Advances on the Horizon" and I will leave you with this: **THERE IS MORE RESEARCH BEING CONDUCTED IN VASCULITIS NOW THAN EVER BEFORE.**

A big shout out to the speakers from all around the world and the people behind this event.

Dr Maria Cid and Dr Georgina Espígol-Frigolé, the organisers of the Vasculitis International Workshop who kindly supported the patient event and went above and beyond to make this happen.

The patient committee who organised the patient event: Vasculitis International (Peter Verhoeven from Netherlands, Julie Power from Ireland and myself) and Vasculitis Foundation (Joyce Kullman and Beth Westbrook from the States).

I would like to add a personal thank you to Diana Shonfield, one of Vasculitis UK's trustees who is with me in Barcelona.

Zoi Anastasa



Vasculitic neuropathy-related disability, pain, quality of life, and autonomic symptoms: a survey of 312 patients

Lay person summary, for *Vasculitis UK*

By Michael Collins, Rob Hadden, Zoi Anastasa, Raashid Luqmani

Background, Vasculitis is a chronic autoimmune illness that causes inflammation in the blood vessels and can affect any part of the body. Peripheral nerves are like electric telephone wires which send messages up and down the arms and legs, down to the muscles and up from the skin. Vasculitis affecting the peripheral nerves is called vasculitic neuropathy. It typically causes pain, numbness, weakness and clumsiness of the feet and hands.

Most research in vasculitis has focused on its life-threatening aspects, such as when it affects the kidneys, lungs and heart. Neuropathy rarely kills people, but it can be disabling. Only very limited research has been done into vasculitic neuropathy. Therefore, we do not know if it should be treated differently from vasculitis affecting other organs. With current treatments, most people affected by vasculitis survive, but many still suffer long term disability and pain. We wanted to find out if the presence of vasculitic neuropathy was linked to any long-term symptoms.

Method, We designed an anonymous online survey to evaluate symptoms of pain, quality of life and disability. We used questionnaires previously developed by medical experts to reliably measure these problems. Vasculitis UK charity distributed the link to this survey to its members, who are people with vasculitis mostly living in the United Kingdom. Because this survey was anonymous, no personal data was collected, and all our information came from the people with vasculitis who participated. We could not and did not get any additional information from their doctors or hospitals.

Results. 312 people with vasculitis completed the survey. Most people were of middle or older age, and their vasculitis had not changed much for several years. People had many different types of vasculitis, most commonly ANCA-associated vasculitis (especially granulomatosis with polyangiitis, GPA).

Symptoms of numbness, pain, difficulty walking, or weakness were each reported by around half of the group (Figure 1). Symptoms differed between people, so those reporting numbness did not necessarily also report pain, difficulty walking or weakness. We concluded it was likely that someone had a vasculitic neuropathy if they answered "yes" to any of the following three questions:

1. Do you have constant numbness (loss of feeling) in hands or feet? OR
2. Do you have persistent weakness in hands or feet, such as foot drop? OR
3. Have you been told by your vasculitis team that you have damage to peripheral nerves (neuropathy)?

By this composite definition, 242 people completing the survey (78%) had neuropathy and 70 (22%) did not. We compared the survey findings in those who had neuropathy with those who did not.

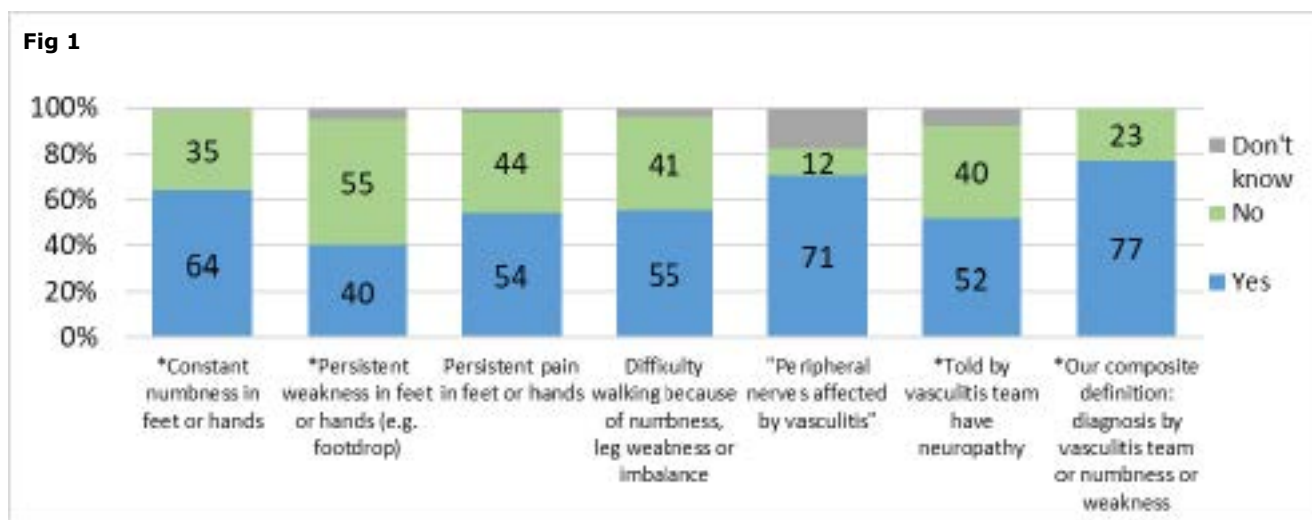


Figure 1. Patient-reported indicators of neuropathy. This graph shows two different things. The first four bars (from left to right) show percentages of people who reported four symptoms which suggest they have neuropathy. The last three bars show the source of the diagnosis of neuropathy: identified by the patient, diagnosis by the vasculitis team (patient recalls being told by their clinician), and our composite definition of neuropathy.

The most important result was that people with neuropathy had more difficulty doing everyday activities and suffered more pain than people without neuropathy (Figure 2). People with neuropathy also had worse health-related quality of life. Most individuals with neuropathy indicated that their neuropathy was frustrating, painful and tiring and that it affected everyday activities, walking, sleep and mood. Anxiety and depression were equally common in those with or without neuropathy.

Fig 2

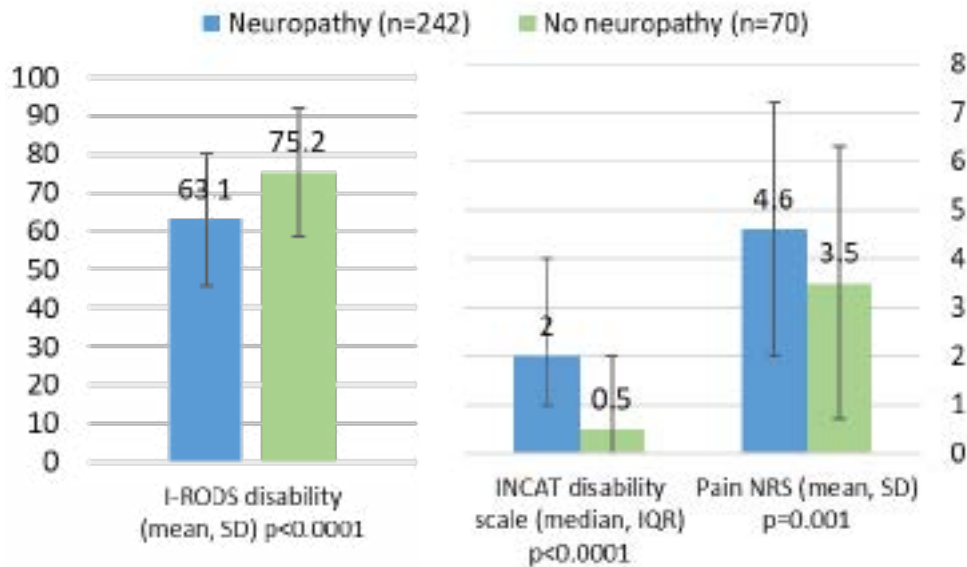


Figure 2: Vasculitis patients with neuropathy (blue) had worse pain and worse disability than those without neuropathy (green). Coloured bars show the “average”, vertical lines show the spread of results among different people. The I-RODS is a disability scale measuring activity and social limitations, developed in patients with other inflammatory neuropathies; the centile-transformed score ranges from 0 (worst) to 100 (best). The INCAT scale is a measure of arm and leg disability, developed for patients with chronic inflammatory demyelinating polyradiculoneuropathy (CIDP); scores range from 0-10 (0 best, 10 worst). Pain was measured by a 0-10 numeric rating scale (NRS).

Many said that their vasculitis also affected other parts of the body. Joints, muscles and nose/sinuses were each affected by vasculitis in over half of the people who replied to the survey. Autonomic nerves are those controlling internal body functions. Many people with vasculitis reported experiencing faint/dizzy sensations when standing, increased sweating, dry gritty eyes, stomach bloating or constipation. However, these symptoms were equally common in people with or without neuropathy, suggesting that they were probably not caused by vasculitis affecting autonomic nerves, but rather by vasculitis affecting other body parts, by medications, poor physical fitness or other diseases. Other studies have shown that when vasculitic neuropathy causes numbness or weakness in the feet, legs or hands, it often also damages autonomic nerves to the skin in the same areas of the body, resulting in abnormal sweating or blood circulation, but our survey did not include questions about these symptoms.

In conclusion, among people with vasculitis, those with neuropathy suffered more disability and pain than those without neuropathy. Neuropathy seems to be one of the most disabling aspects of vasculitis. Some people may have vasculitic neuropathy that is unrecognized by their doctor. The major strength of this study was that it included more people and asked more questions than any previous survey of vasculitic neuropathy. In contrast, standard rating scales for vasculitis include relatively little information about neuropathy. However, our results may have been biased towards people with more severe neuropathy who may have been more likely to reply. Another limitation was that we received very few responses from people whose vasculitis affected only nerves and not other body parts.

We are very grateful to Vasculitis UK and to everyone who responded to this survey. By showing how much suffering continues despite current treatments, we hope that this survey will encourage more research into vasculitic neuropathy.

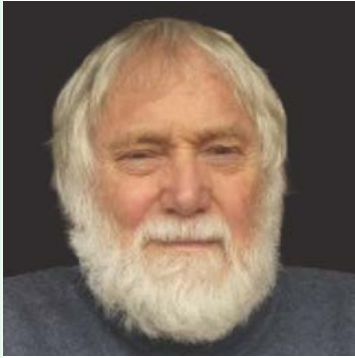
Key messages

- People with systemic vasculitis often have long-term symptoms.
- On average, those with neuropathy have worse long-term disability, pain and health-related quality of life than those without neuropathy.
- Doctors do not always recognise when someone is suffering from neuropathy.

For full details see the published scientific paper <https://academic.oup.com/rheumatology>

“Neuropathy in vasculitis is linked with worse pain, disability and quality of life. We thank Vasculitis UK members for contributing to the world’s biggest survey of these long-term symptoms”

John Mills MBE Vasculitis Educational Award



Vasculitis UK and UKIVAS (United Kingdom & All Ireland Vasculitis Study Group) have joined forces to create the "John Mills MBE Vasculitis Educational Award" in memory of John to recognise and remember all he has done for raising awareness of vasculitis within the medical profession and for supporting patients diagnosed with vasculitis from 2009 to 2023.

This award will be an annual award given to the overall prize winner for vasculitis research/study/project at the annual UKIVAS Educational Event for medical professionals.

Further details will be published in the Autumn 2024 Newsletter.



Advancing Research & Clinical Practice in Glomerulonephritis Royal Society of Medicine Nephrology Section & Kidney Research UK GN clinical Study Group Collaboration. January 22nd -23rd 2024

On January 22nd and 23rd, a two day meeting was held at the Royal Society of Medicine which was a collaboration between Kidney Research UK Glomerulonephritis (GN) Clinical Study Group (CSG), co-chaired by Dr Rachel Jones, and Professor Jonathan Barrett and the Royal Society of Medicine, Nephrology Section chaired by Dr Allyson Egan.



The meeting showcasing developments in the field of inflammatory renal disease, through the lens of patient experience, clinical trials, newer therapeutics, scientific and clinical research. Representing the field of Vasculitis Ms Zoi Anastasa was an active participant in the two-day programme and joined the panel discussion sharing patient experience and focusing on priority areas moving forward.

The program highlights the importance of collaborative networks between patient partners, academia, clinical medicine, and pharm. Advancements in science, registries, therapeutics, clinical trials were celebrated within lectures,

case presentations, and panel discussions by international experts in the field. The meeting exemplified strong collaborations and advancement in the field of autoimmune disease.



RESEARCH UPDATE

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

Important research papers can be found in the Professionals section of our website.

The most recent research information can be found at the following sites:

Clinical Trials
www.clinicaltrials.gov/

European League Against Rheumatism [EULAR]
www.eular.org

European Vasculitis Study Group [EUVAS]
www.vasculitis.org

Vasculitis Clinical Research Consortium [VCRC]
www.rarediseasesnetwork.epi.usf.edu/vcrc/

We are committed to ensuring that researchers incorporate the views of people with lived experience into their research; ensuring patient & public involvement (PPI) in the design, production and dissemination of their studies.

We are keen to be part of training and retaining the best minds in vasculitis research and actively encourage early career researchers from all fields of health care to apply to our grant call. By nurturing the next generation of talent, we aim to bolster the depth and breadth of vasculitis research.

We continue our support for studies into the causes of vasculitis, early diagnosis and better treatments whilst being mindful that the funding we provide will generate tangible outcomes for our community.

Our new 5 year strategy, with a fresh new direction and updated priorities it is our hope that the research we fund will provide direct patient benefit, finding ways to improve the quality of life for people with vasculitis.

We are committed to ensuring that researchers incorporate the views of people with lived experience into their research; ensuring patient & public involvement (PPI) in the design, production and dissemination of their studies.

<https://www.vasculitis.org.uk/wp-content/uploads/2023/09/VUK-Research-Strategy-2023-2028.pdf>


Guy's and St Thomas'
NHS Foundation Trust

Are you living with ANCA Vasculitis?

Are you interested in taking part in the HAVEN Trial?

The HAVEN trial is looking to find out whether a drug used in Lupus can also treat Vasculitis.

You may be eligible if:

- You're aged 18 or over.
- You've been diagnosed with GPA, MPA or EGPA.

If you're interested, please contact the HAVEN trial team:

Chief Investigator: Prof David D'Cruz

Email Address: haventrial@gstt.nhs.uk



Raise donations when you shop online

You shop

6,000 retailers donate

Your cause receives donations for free

<https://www.easyfundraising.org.uk/causes/vasculitisuk/>

Total raised so far

£3213.91

Clothing



Check out our
online shop

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

Paediatric Rheumatology

Unmet Needs



At the end of November 2023, I attended a face-to-face event in London. It was about addressing unmet needs in paediatric rheumatology.

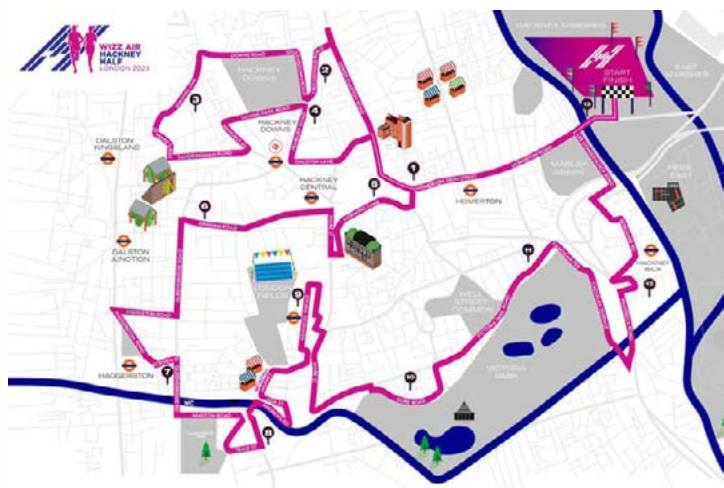
We all know the barriers patients with rare rheumatic diseases face, for children there are many more. Less specialists in the field, less specialist clinics and no therapies specially for their age group.

Transition is another big issue as it must be tailored to the patient, not all children mature the same and some need bigger transition periods.

Academia, patients, the NHS and industry must work together to give a better future to all children suffering from rare rheumatic diseases like vasculitis.

Zoi Anastasa

Hackney Half Marathon 19th May 2024



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

<https://www.justgiving.com/page/rory-mosseveld-1707486305008>

INSPIRING THE SCIENTISTS OF TOMORROW.



Vasculitis UK Supports
Imperial College
"Science in Medicine
School Teams Prize"

Imperial College London
Science in Medicine
School Teams Prize 2024

THE CHALLENGE:
Design an ePoster, which illustrates an idea for combining science and engineering with health research to improve lives. Currently there are five contests, each focusing on different medical conditions.

PRIZES FOR EACH CONTEST:
1st Place - £3000
2nd Place - £1500
3rd Place - £1000
10 support prizes/runner-up prizes.

5 CONTESTS TO ENTER:
- British Heart Foundation Cardiovascular Prize
- The Lung Prize
- Science & Technology UK Prize
- Global Health Prize

WHO CAN ENTER:
- Any school across the UK
- Collaborations between schools welcome
- Teams of 2-6 students

Scan the QR code to find out more!

Deadline for Submission:
5pm, Monday 1st July 2024

Supported by the National Heart and Lung Institute, the British Heart Foundation, Centre of Research Excellence, Science & Research UK, Vasculitis UK, and the Imperial Well Biomedical Research Centre.

www.vasculitis.org.uk/news/schools-prize-science-in-medicine

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.

Margaret Gentle (Vasculitis Support Group West Midlands)



Anyone who may have gone through a difficult time before being diagnosed with systemic vasculitis will have many questions. How will this disease affect me in the future? Will I survive this disease?

(Systemic vasculitis is an immune disease of the blood vessels, symptoms vary in individuals according to which blood vessels are affected)

I was diagnosed in 1990 with WG (Granulomatosis with Polyangiitis) a type of ANCA associated vasculitis, at the age of 62.

Up to 20 years before my diagnosis patients were only expected to survive around 5 years as the only treatment, at that time, had been steroids.

There was big change in the early 70's when a chemotherapy type drug could be added to the treatment, as steroids alone were not affective enough.

I was very lucky as I was given the steroids and chemotherapy, I am still surviving at the grand age of 95 and live on my own in my semi detached house.

I have just started to have help in the house for an hour, once every 2 weeks, plus a gardener cuts my grass in the summer.

Looking back on my life it would seem that I do not hold any secrets of living a long life, apart from following a normal healthy life style.

The researchers, doctors and all other health care professionals, with all their hard work, have made great changes and continue to improve treatments. Work with your medical team, keep positive and you may also reach a comfortable old age.

Margaret



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 Ian £50 from Eric.

Funeral Donations of £614.42 received in memory of Michael George Harris

A total of £2216 raised in Memory of John Mills via Just Giving

Funeral donations of £315 in memory of Annette Straight. Loving mum to Leanne and family.

Collection of £300 in memory of Don Matthews, chosen charity as his son Ian Matthews has had vasculitis for over 20 years"

Funeral donations of £547 received in memory of Micheal George Weaver



£50 was kindly donated in the memory of Martin Georgiades from the Gergiades family in Cyprus.

Donations in memory of John Mills MBE of £25 by Renee Cohen and £100 by Jean Skyrme

Funeral Donations of £373.10 received in memory of Celia Margaret White

Funeral donations of £200 received in memory of Lily Dunn

Funeral donations of £180 received in memory of Kevin William Debeney, aged 52. Kevin will be greatly missed by all his family and friends.

Donations of £450 received in memory of David Young, devoted husband, father, grandfather and great grandfather. He will be greatly missed by his wife, Margaret and daughters Diane and Alison.

Funeral donations of £245 received in memory of Christine Kenrick



Funeral donations of £82.50 received in memory of Anthony Francis Smith

Funeral Donations of £311.30 received in memory of Derek Tempest, Derek had been a great supporter of VUK after he lost his wife, Joyce, to Vasculitis.

Funeral donations received of £54 in memory of Mary Biggs

Donations & Fundraising

Donation of £40 was received from Culag Lochside Self Catering in support of Vasculitis UK

Susan Mills & The Vasculitis Craft and Green fingers fb group raised £150 - holding a VUK craft stall at various crafting events.

Annette Stait £251.75

Paul Smith donates £150 annually in lieu of christmas presents.

Ian Johnson raised £250 for his 80th birthday celebrations in memory of his wife Barbara who sadly passed away in 2016 from vasculitis & sepsis.

Michael Gebbie A larger than life character £242.30

Donation of £215.00 by Renee Denyer from the Celebrating Our Queen V event in memory of Victoria Blisse for Vasculitis UK.

Much Loved Donations

Michael George Harris £750

Elizabeth Attfield for her husbands 80th Birthday - donations instead of presents raised an amazing £300

Alan Forward Much loved and always remembered £1892.50

Brian Merfield £981.25

Indy Mason Kidd £1732.50

Ian Olive £1176.25

Donating To



VASCULITIS UK

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

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

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

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

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



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



OBITUARY

The international vasculitis community is saddened by the tragic news of Dr Danda's death.



Dr Debashish Danda, ex-professor, the Department of Clinical Immunology and Rheumatology at the CMC, Vellore passed away in a tragic car accident. He retired on 28th October 2023, after 27 years of dedicated service in CMC Vellore, and was working at the Narayana Health Institute, Bangalore.

After completing his M.B.B.S from JIPMER, Puducherry, M.D in Internal Medicine from GSVM Medical College, Kanpur, and 3-year Post-Doctoral degree (DM) in Clinical Immunology from SGPGIMS, Lucknow, Dr. Danda joined as faculty in Medicine-II at CMC Vellore in 1996. He had 3 years of advanced training in Rheumatology at The Royal Adelaide Hospital, The Queen Elizabeth Hospital, Flinders Medical Centre and The Repatriation Hospital, Adelaide from 2001 to 2004. After coming back from Australia, he established the Department of Clinical Immunology and Rheumatology at CMC Vellore in 2004 with out-patient, in-patient, consultations, procedures, teaching programmes, research facilities, faculty positions, basic scientist posts and technicians positions. He also created the infrastructure and services for comprehensive laboratory facilities for autoimmune rheumatic diseases. He introduced a dedicated extremity MRI machine, ultrasonography, nailfold capillaroscopy, real-time PCR and several other advanced techniques within the department. The most important publication with 100+ citations includes his work on designing the disease assessment instrument for Takayasu's Arteritis namely the ITAS (Indian Takayasu's Arteritis Score) 2010 and ITAS- A score.

He started a two-year Post-Doctoral Clinical Fellowship training and Medical Council of India approved 3 year DM programme under the Tamil Nadu Dr. MGR Medical University, Chennai. The department was also recognized by the National Board of Examinations for DNB training in

Rheumatology and the Tamil Nadu Dr. MGR Medical University for Ph.D. programme. Dr. Danda was also a recognized guide for this purpose in the department. Dr. Danda conducted the Annual Conference of Indian Rheumatology Association at CMC in 2011 and the meeting was the first in the history of Indian rheumatology to have the President of the American College of Rheumatology (ACR) as the guest faculty. He also organized a National Level Symposium on 12th December 2015 with the theme "Leaders in Rheumatology". This was a meeting where India's senior-most Rheumatologists were honoured. Dr. Danda served two terms as Editor-In-Chief of the International Journal of Rheumatic Diseases (IJRD) from 2012 to 2018 and was instrumental in bringing up the impact factor of the journal from 0.7 to 2.5.

Dr. Danda was the President of the Indian Rheumatology Association from 2017 to 2019 and he initiated several new initiatives for the cause of Indian Rheumatology including the formation of the education cell, Indian College of Rheumatology, research cell, patient cell, database cell, legal and ethical cell, media and communication cell etc. He was the immediate past president of the Asia-Pacific League of Associations for Rheumatology (APLAR) after having led it from 2021-2023. He had earlier served one term each as Vice-President (2018) and Treasurer of APLAR. Dr. Danda had published over 255 peer-reviewed papers. Dr. Danda has been honoured with several awards all these years. In 2023 he was awarded in the category of Distinguished International Rheumatology Professional Award by the American College of Rheumatology. In 2020, he was honoured with the Guardian of Health award by IHW council, New Delhi and 'Chikitsa Ratna Samman' award by Tripura government. He received the CME Excellence Innovation award in CME Excellence Summit and Awards 2019 presented by IHW council. He was conferred with the "Dynamic Indian of the Millennium" award by the KG Foundation in 2019. He was the Course Director for the PG Certificate Course for Primary Care Rheumatic and Musculoskeletal Medicine being arranged by BMJ.

(Prof John Mathew, CMC, Vellore)



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.org.uk



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

EVENTS

Future events we look forward to

Apparently, spring is here – where? Looking out of my window I see a very dark grey sky and I can hear a thunderstorm approaching. I am glad that I work from my cosy office at home today!

Looking out of the window my eyes landed on this:



*May we always be connected
in our travel journeys.*

Vasculitis UK connects the patient community to the medical and academic vasculitis community. In a way VUK travels to spread awareness, gather information, network with other charities, clinicians, and researchers. So, what are we up to?

April is a busy month. The International Vasculitis Workshop which is held every 2 years will be in Barcelona at the beginning of April. A patient educational event will be held one day before the main event starts. One of our trustees, Diana and I will attend the patient event and the workshop – more about it in the autumn newsletter.

At the end of April VUK goes to Liverpool to attend the BSR (British Society of Rheumatology) annual conference. We will have a stand there and will get the opportunity to talk to a lot of clinicians, inform them about our work and the unmet needs of vasculitis patients.

May is vasculitis awareness month, and our trustee Jane will be behind our campaign. Information will be shared on our website and the online groups.

In June we are off to Wales again, this time to Newport where we will spread the word of vasculitis to nurses attending their annual congress.

More events are planned for the autumn, 2024 will be a busy year for Vasculitis UK!

Zoi Anastasa

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

Fly away!



HONORARY LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

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

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

Officers, Trustees and Volunteers

Chair:

Dorothy Ireland
Dorothy@vasculitis.org.uk

Vice Chair:

Susan Mills
susan@vasculitis.org.uk

Director of Operations

Zoi Anastasa
zoi@vasculitis.org.uk

Secretary:

Vacant

Treasurer:

Heidi Pollard - Director of Finance

Fundraising Co-Ordinators:

Dorothy Ireland
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