VASCULITIS UK

NEWSLETTER JOURNAL

SPRING 2022 ISSUE 63

Chairman's Report

I'm writing this a we approach the second anniversary of lockdown. It's been a real struggle for those of us who are immunosuppressed. Firstly, getting recognition that we needed help. I remember getting the letters from "Matt" telling me, I was Clinically Extremely Vulnerable and all the details of shielding. Then just one from Sajid Javid telling me shielding had finished but you must try to continue to shield.

Thankfully some wonderful scientists, especially Prof Sarah Gilbert and her team, at Oxford and others across the globe worked at incredible speed and cooperation to develop the vaccines. Unfortunately, viruses also mutate quickly to fool the vaccines. We're now familiar with Alpha, Delta and omicron, with deltacrom and B2a of waiting in the wings. The government have now announced a spring booster. Hopefully, we will get the invite without having to fight for it.

Over the last two years, Vasculitis UK has had to change the way we funded research grants. We normally make a call which goes through a lengthy process of peer review and may take 2 or 3 years for completion. We were approached by The University of Nottingham to fund research into those on rituximab and whether they make antibodies. The board of trustees acted as the per reviewers in order to enable this research. The results are imminent, but confirm what we probably already knew that we struggle to make antibodies.

Since then, we have become co-funders of the much larger MELODY study. This again is looking at the presence of antibodies in those who are immunosuppressed. I received a pack, and was pleased to find I had IgG antibody, this is the one that decreases more slowly therefore giving longer protection.

Please don't worry if you've not shown a line for either there are other parts of the immune system working for you.
All of our long-term research was put on hold for the two years but will hopefully start again as covid "eases". Ongoing research that was being funded by Vasculitis UK have asked and been granted extensions to their research, as the clinicians were moved from laboratories to more frontline Covid rolls. We have put out the "Call" for this year.
Those who are members of the Facebook support group will have noticed what seems an increase in our members catching covid this time round. There's been a great exchange of help and advice about the testing and antivirals now available, and how to get hold of them.
Thankfully only a few have been hospitalised, but unfortunately, we have lost some members, our thoughts are with their families.

Our new trustees have been settling into their new roles. **Charlie Harper** has set up the "Young Adults group" on Facebook. I think I'm definitely above the age limit! He has also been working on how we store and access member details. We will be hearing more about this in the future.

Jennifer Harper has set up the new "basket" for the shop which went live a few weeks ago. This makes viewing and purchasing from the shop "a one click", rather than having to email for the item and pay via another. She now runs the shop.

Charlotte Smith has been supporting me with the fundraising. She has developed a fundraisers pack and is dealing directly with fundraisers. She has more ideas she wants to develop.

Heidi Pollard has taken over the role of treasurer. We thank Ian Kayes for getting us through a difficult time.

John Mills has been very ill but still manages to send emails. **Susan Mills** is his carer but does so much more for the charity. She represents us on RAIRDA and still sends out the shop orders.

Zoi Anastasa has been taking over more of John's roles in representing vasculitis among the

medical professionals. Most of this is by webinar but can be all day. She has also been representing us on Vasculitis International and working on the International Vasculitis and ANCA workshop for patients in Dublin during April.

Peter Rutherford does a lot behind the scenes and has giving us great advice in recent times.

Dorothy Ireland, as well as Chairman I still am the Fundraising Coordinator.
This year, Covid permitting, we have 26 runners for the Great North Run in September and 10 for the Great South Run. It's the first time in a while that we've had both. If you live near these events I'm sure they would appreciate a cheer. Other types of fundraising are still below our normal level but that is understandable.

We've taken the decision early this year to hold the **AGM** by zoom. It will be Sunday the 15th May 2022 at 1pm (this is also world vasculitis day). Details of how to log on will be on the website and social media. I am sorry for those that don't have access to computers or smart phones, but with so much uncertainty about covid we couldn't have a Face-to-Face event. As ever, if anyone would like to join the trustees, please submit a letter to myself (dorothy@vasculitis.org.uk) with your reasons and how you can benefit Vasculitis UK.
Thank You for continuing to support Vasculitis UK and take care.

Dorothy Ireland

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

Spring has finally sprung, although the recent weather forcasts suggest otherwise.
Time to grab your favourite beverage and settle into a chair and immerse yourself into this latest edition.
As life transitions into the new normal, and many of those around us go back to how life was pre covid, many with conditions like vasculitis are still in an anxious place as learning to live with covid will take much longer, especially where face masks are concerned, or to go back to a socially active life.

There are a couple of new features in this edition, including some great personnal stories, and a feature from one of our online support groups.

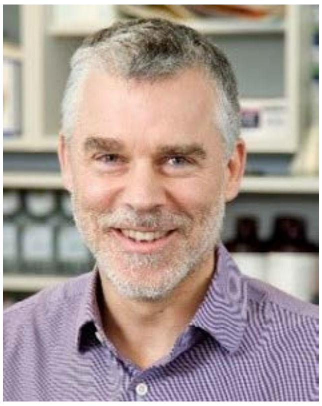
Chris Soper's story on page 20 came about after an email from her requesting a copy of this newsletter. After a couple of correspondences, it turns out we may well be related. I then asked Chris if she would kindly submit a personal story for this edition with a hope for others to follow and submit a story going forward of which she kindly obliged. So if any of you reading this would like to feature in future editions please contact me.
Shanali's story is once again an inspiration one, and if you follow the link on her article you can read her full story.

We are a bit light on our fundraiser section, but that is expected as we come out of various lockdowns and hopefully over the coming months this will pick up to the normal level we are use to.

Thanks for taking the time to read and indeed get involved.

Kevin Soper (Editor)

INTERVIEW WITH PROF. MARK LITTLE (TRINITY COLLEGE DUBLIN) - FAIRVASC



Mark Little (TCD) leads the Registries team in EUVAS, is co-chair of the UK-Ireland Vasculitis Registry (UKIVAS) and is the strand leader for autoimmune diseases in ERN RITA. He has been working on the creation and integration of AAV registries for over a decade. He established the Vasculitis Ireland Network registry and biobank, leading to support of genome-wide association studies, development of novel AAV biomarkers and the impact of environmental triggers on autoimmune disease. Mark is the Technical Coordinator of FAIRVASC project.

1. What was your motivation to create Fairvasc? (https://fairvasc.eu/about-us/)

The challenge that we face is that vasculitis is a rare disease, so it is really not possible to accumulate sufficient numbers of patients to study from regional or national data sources such as registries. On the other hand, creation of a central registry across Europe is extremely complex and often financially unattainable. There are also very significant data protection challenges in the creation of such a central hub so we decided to take a different view on this, one which is aligned with the direction of travel of the European Joint Program: creation of a semantic web interface that would allow a researcher or policy-maker to query across multiple european registries at once.

2. What tools does the Fairvasc project provide members of the consortium with?

The beauty of this semantic web approach is that the seven registries underpinning the FAIRVASC project are all uplifted into a common data source, into a common ontology which makes sure that they are all interoperable. That means that we use the same terms for describing features associated with the disease- ANCA vasculitis in each of the registries, no matter which country they come from. This uses a data modeling technology called RDF and effectively renders the registries that are connected to this interface machine-readable and queryable through this single point.

The other important aspect is that the data queried on each registry is aggregated at source. Therefore, the only data leaving the registry site is aggregated and therefore does not come under the jurisdiction of the GDPR. This makes data protection issues very much simpler. more complex analysis, such as regression or time series analyses, we are exploring with Professor Louis Aslett from Durham University the possibilities of advanced privacy preserving techniques such as homomorphic encryption. By adopting this approach, we aim to have access using a single interface to around 7000 patients with ANCA vasculitis in the first FAIRVASC release. This allows us to really start to answer important questions relating to this disease, such as the factors that lead to a poor outcome and the effect of various treatments, such as new treatments like the C5a receptor blocker, avacopan.

3. Are you planning to expand the project and what are the main future goals for Fairvasc?

The other great advantage of this approach is that this is effectively a plug-and-play technology. If a new registry is interested in joining the FAIRVASC project there is a series of tasks at the beginning to map their dataset onto this common ontology and expose this through an RDF Triplestore to the Fairvasc interface. Once that is achieved this registry gets added to the overall pool. To assist this process we have introduced a “model registry” based on the open-source software REDCap through the Euvas Registries Group. This effectively creates a ready-made database for implementation locally and, importantly, uses the same dataset across the all registries. This will make the mapping and interoperability very much more straightforward.

There are currently about 10 registries engaging in this process that we hope to plug into the FAIRVASC interface in due course. The project runs until around the middle of 2023 so it is very important that we consider the sustainability of the infrastructure beyond this date. Therefore, we are very much aligned with the EUVAS registries group which is key to establishing processes and safe mechanisms for interaction with industry. Finally, and probably most importantly, we are ensuring that we develop the FAIRVASC software in alignment with the European Joint Program for Rare Diseases so that, when we complete this project, we become one of the stable of EJP projects and therefore mainstream into the long-term objectives of the European Commission for handling data from patients with rare diseases.

New Online Shop

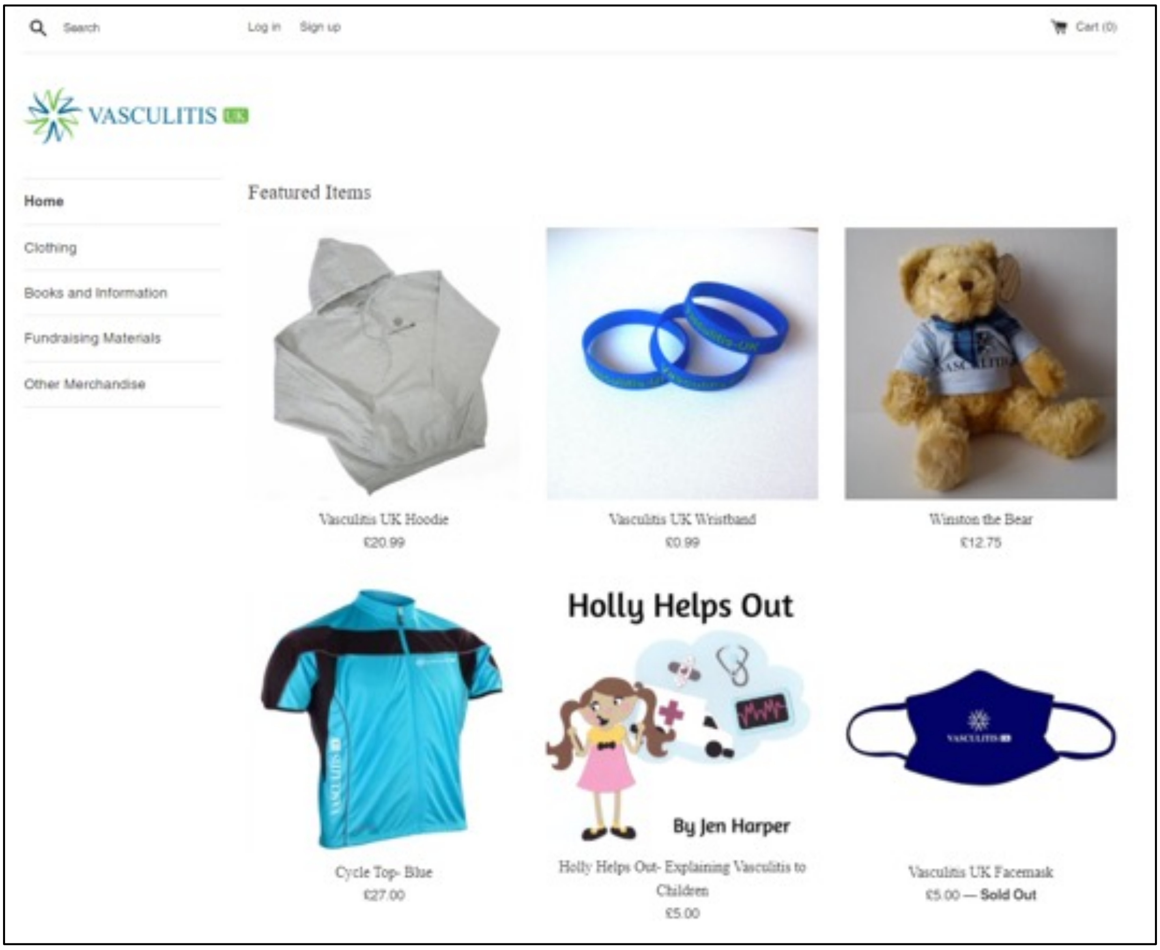
The board of trustees is pleased to announce that we are firmly in the 21st Century!

We have a new and improved online shop which replaces our older system. Now you can browse our range of Vasculitis UK merchandise and place an order with just a few clicks.

We sell a range of clothing and accessories and have a range of books available to purchase. Some of our resources, including e-books and printable downloads for fundraising, are available for free.

All proceeds raised from sales go directly back into the charity, enabling us to help more people in the vasculitis community.

To visit the shop, please visit https://vasculitisuk.myshopify.com/ or head to our website, www.vasculitis.org.uk and click 'shop' on the bar at the top.



Rituximab and Covid-19

The MedicineMatters website (a resource for healthcare professionals) is offering a 13-minute video of a discussion between Prof David Jayne of Cambridge University and Prof Sebastian E. Sattui of the University of Pittsburgh, looking at how to address the challenges that Covid 19 poses for rituximab-treated patients.

https://rheumatology.medicinematters.com/covid-19/rituximab/sebastian-sattui-david-jayne/20074700

"Being in lockdown and shielding for months, I had nowhere to go but inwards. "

Shanali

#MyMSKStory #GetVocal

The week beginning October 12th 2021, Let's Get Vocal shared the stories of people living with musculoskeletal (MSK) conditions alongside researchers from Manchester Biomedical Research Centre & across the UK.

#MyMSKStory
12-15 October
@letsgetvocal

The stories told via social media included Juvenile Idiopathic Arthritis, Myositis, Scleroderma, Raynaud's, Lupus, Rheumatoid Arthritis and Vasculitis.
This was to raise awareness of all musculoskeletal conditions.
Shanali Perera shared her own extraordinary story, a Rheumatologist living with vasculitis.

You can an read Shanali's story on line:
https://wearevocal.org/wlrs/listen-up/am-i-imagining-this/?fbclid=IwAR1-IUytw3AabOrrATb1EgOqEst-vrlma-Up0r-qEP22sCkEsb3apiZVY6mA

#MyMSKStory #GetVocal

Vasculitis comprises a group of 18 rare auto-immune diseases, which involve inflammation and swelling of the lining of the blood vessels, which partially obstructs or blocks blood flow to tissues or organs, causing damage to or death of the affected tissues or organs.

VASCULITIS UK

"It was through Vasculitis UK that I realized that I wasn't the only person going through this condition."

Shanali

#MyMSKStory #GetVocal

"One moment, I was seeing the everyday struggles patients go through and the next, I was living it."

Shanali

#MyMSKStory #GetVocal

New Trustee

I first became aware of Vasculitis when my sister was diagnosed with GPA in 2018. I have spent time since researching the condition to learn more.

I was delighted to be accepted as a Trustee in 2021 and I'm looking forwards to being part of the charity's next phase of development.

I live in West Yorkshire with my husband and our lurcher and I'm an Accountant by profession. I love running and walking and am lucky to live in a part of the country where beautiful countryside is on my doorstep. I also love reading and spending time with with friends and family.

Heidi Pollard
Director of Finance

WHAT DOES RAIRDA DO?

BUILD AN EVIDENCE BASE AND POLICY POSITIONS FOR FUTURE WORK

SHAPE PATIENT PATHWAYS

CONTRIBUTE TO CONSULTATIONS

RAISE THE PROFILE OF RARE AUTOIMMUNE CONDITIONS

WORK IN PARTNERSHIP TO AMPLIFY OUR VOICES

RAIRDA

On the 28th February 2022, RAIRDA joined LUPUS UK, Scleroderma and Raynaud's UK, Vasculitis UK, MS Society, Blood Cancer UK and Kidney Care UK as well as other charities in voicing concerns to the UK Government in considering the needs of all higher-risk patients (like people with RAIRDs) and assessing their risk of catching COVID-19. No person should have to face being at risk because they simply can't afford a COVID-19 test.

We and other charities called on the Government to:

- continue to make adequate numbers of lateral flow tests available for free for those 1.3 million people that are eligible for Covid-19 treatments, their households and personal contacts, regardless of whether they have symptoms or not; and
- to provide new money to the NHS and Local Authorities to continue to fund regular testing of frontline health and social care

To date of writing this article we had received no reply or plan.
For more up to date information https://rairda.org/updates-and-news/

How many people in England have Takayasu Arteritis?

Mr David J Groves Research Fellow - National Disease Registration Service.
Dr Fiona Pierce - Nottingham University Hospitals Trust

Takayasu Arteritis is one of the rarer forms of vasculitis. There has previously been little known about how many people in England are affected. We are very pleased to report the results of this research we have conducted at the University of Nottingham and in collaboration with the National Disease Registration Service at NHS Digital, and Professor Justin Mason at Imperial College London. This work was funded by a Vasculitis UK research grant.

We used electronic health records in England to see how many people have Takayasu arteritis. We found that in 2020 there were 1094 people living with TAK in England, which is a prevalence of 19.3 people with Takayasu arteritis per million people in England. About 80% of people living with Takayasu arteritis were female, and about 77% of White ethnicity.

The annual rate of new diagnoses (incidence) of Takayasu arteritis, has been fairly stable over the past 15 years until the COVID-19 pandemic. Overall, about 1.2 people are diagnosed each year per million people in England, and about 75% are female.

Our Fantastic Fundraisers

Chloe and friends managed to raise over £800 for VUK taking part in the Hertfordshire Half. Chloe managed to beat her target time of 2hr 22minutes.
Chloe had never heard of vasculitis when Mum was diagnosed with 16 years ago. But even with seeing the impact vasculitis has had on Mum's life, it hadn't prepared them for when Dad was also diagnosed 2 years ago.

Annie Barton (pictured left) held a Christmas carvery with a few friends at Saxon hall and held a raffle for Vasculitis UK Raising £160

Telford and Wrekin 10k 17th April 2022
Katie Proctor is running this 10K to raise awareness of vasculitis and in memory of Paul.
To read her story and donate please follow the link below;

Katie Proctor is fundraising for Vasculitis UK (justgiving.com)

MASSIVE well done to Lucas Fox, inspired by their pack forum discussions at start of term, Lucas set off on his own personal challenge to do some fundraising.
He walked 1 million steps during October & raised £2000 for his chosen charity - Vasculitis UK.
Strangford District Scouting
County Down Scouts
Scouts NI

Joe Harper ran the Brighton half marathon for VUK on behalf of his brother Charlie who was diagnosed with GPA and is also a trustee. He has seen Charlie struggle with numerous operations and wanted to raise awareness of vasculitis. Joe has raised over £700.

Aaron raised £205 by having his headshaved his head for VUK. Here are his Before and after photos.

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

Our Fantastic Fundraisers

Great North Run 11th September 2022
We have our full allocation of 20 runners for this year's event. We also have some who deferred from last year. Plenty to cheer on if you live nearby. I'm certain they would all appreciate your support either on the day or by donating through their JustGiving pages, when they are set up. We do hold a reserve list and usually need at least 2 or 3 before July.

The runner are:

Anna Mayhew, Ty Buckley, Sally Payne, Katie Pugh, Katie Manford, Jack Biggs, Julie Brown, Jeremy Moore, Glynn Wallace, Rachel Thornton, Nicola Corbett, Andrew Thomson, Julie Black, Mike Elliott, Julie Sams, David Raggett, Emma Brady, Leanne Armstrong, Heidi Pollard, Elaine Grice, Graham Mully, Rachael Graham, Mahmood Nassar, Sameh El-ghazzawy, Julie Longdon, Jessica Randle.

GLYNN'S JOURNEY

My Vasculitis Journey …so far!!!
Background info first. I decided to run the London Marathon aged 66 years in 2016 It took me 6 hours and 10 minutes and I vowed never to do it again…however I ran my second London Marathon in 2017 in 6 hours and 5 minutes. No luck in entering 2018 & 2019 but got into the Vitality Big Half in 2020. Happily completed the course in 2 hours 45 minutes!

Obviously raising money for charities throughout - I certainly wasn't going to win! After the 2020 race felt a little tired, more so than usual. Within weeks both of my ears had bad infections, my hearing was terrible I had tinnitus and a lot of pain. Then every single joint in my body began to ache. I am used to arthritis but this was on a different level. My legs doubled in size with a build up of fluid in both. Life was a living hell; the pain was exceptional. This is happening in the middle of a pandemic so seeing a doctor face to face was impossible. The receptionist said to sort one thing at a time.

My youngest daughter was getting married in September and I really wanted to walk her down the aisle, so I opted for discussing the ears. With the intention of getting the joint pain sorted next. Syringing was done but it made no difference and by now I could barely walk, or even get up in the morning without help from my wife. Being a total believer in the NHS it was with much trepidation, even reluctance, that I went private for an assessment. By now we are in July and I am in a wheelchair – the pain was too much for walking.

Then I was a very lucky man in that the consultant I saw knew pretty well straight away what was causing me so much pain and anguish. Dr Merry drew off the fluid from my legs he then gave me a steroid injection in my backside, and I had a blood test, chest X ray and gave a urine sample. He told me to go back in a week for a follow up. Within 24 hours life became bearable again and I was able to walk again.

I went back the following week and Dr Merry was delighted that I was out of the wheelchair. He told me that there was a long trek ahead but it could be sorted out given time and effort and luck! He was very reluctant to give me the name of what was causing me such pain, he eventually wrote down Wegeners on a scrap of paper and told me under no circumstances to "Google" it as I would scare myself to death!!!

You can guess what the first thing I did when I got home, I "Googled" it and scared my self (almost) to death. Since then, I have had the blood in the wee, heavy steroid dosage (gradually decreasing). 6 infusions, methotrexate tablets then injections. Two hospital emergencies with possible heart attacks, one for extreme breathlessness, Adcal, folic acid, Lansoprazole etc – I have felt sick for days on end felt exhausted for weeks at a time and, of course, the pleasure of Brain Fog.

BUT BUT BUT I discovered VASCULITIS UK and became part of a wonderful group to whom I owe so much. I spoke to John early days and he was so lay back and considered in his help that I immediately had full confidence in him. I also heard Sue giving advice in the background, which has all proved to be invaluable. There are so many people helping who I can only applaud for their kindness.

I did get to walk my daughter down the aisle – such a proud moment. When I saw that there was an opportunity for me to raise funds for VasculitisUK by taking part in the Great North Run, I jumped at the opportunity. I am still far from well but I WILL make it around the course. I may not be the fastest or the fittest but I sure as hell will be one of the HAPPIEST to make it around the course.

Glynn Wallace

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

VASCULITIS GREEN FINGERS FOOD AND FUN HOBBIES OF ALL FORMS

OUR KRAFTY CROCHET

Warriors

Whilst looking through some of the support groups I could see there were many of our vasculitis warriors who are very much into craft, which helps them in a very positive way both either as a distraction away from their condition or just in having a passion with a certain hobby or craft.

This month in particular the focus is from our green fingers, food and fun - hobbies of all forms group members is around crochet. Feedback on how craft helps was beautifully put by Kit Donaldson who said "I do use crafting to help cope with mental health that has been shattered with the vasculitis diagnosis". Having any condition like those our warriors have, shows just how much having craft to occupy their minds helps with one's mental health and well-being.

Below is Saira's story, this may well lead to a regular feature so if you have a passion for any craft and would like to showcase or talk about it to our readers please let me know.

Seasoned crocheters handle their hook with finesse, their hands hardly moving as the exquisite garment expands with speed as they work. My crochet hook and wool handling lacks technique and is certainly cumbersome but that certainly doesn't stop me.

As someone who has always enjoyed craft, knitted my first jumper at 11 and used to sew clothes and the occasional wedding dress for friends, I was late to crocheting.

I first started crocheting about 11 years ago when I was pregnant with my last child. My mother-in-law came to visit from Algeria and was crocheting a blanket for a relative. She used to carry her crochet hook and ball of wool around in her handbag and sit crocheting away whilst watching television, hardly ever glancing at the quickly growing pattern emerging from her swift fingers.

I asked her to show me how to do it and she didn't hesitate. She said I was a natural and thus gave me the confidence to not worry about reading patterns or naming any stitches. Her philosophy was that there is no such thing as a mistake in crocheting as long as you like the look of the stitch you're doing. She showed me some very intricate lace-work she was doing and it really was exquisite with a tiny hook and very thin thread.

She bought me a second hand carpet bag that contained assorted rolls of wool and a bundle of knitting needles and crochet hooks from a market in East London and that became my practice supply. I remade the carpet bag using some material left over from curtains I'd made and a fancy roll cloth to hold my needles and hooks and then started scouring the internet and watching you-tube videos to get ideas.

The first thing I made was some fingerless gloves and hats for my children. Crocheting is very satisfying. It works up quickly, if you make a mistake it's very easy to unpick and I realised that once I had an idea of some basic stitches and how to shape I could basically make it up as I went along.

The majority of items I have made are hats, fingerless gloves, cowls, scarf's and sweet animal cowls for young children. I have made them for all my family and a lot of friends.

I love choosing the wool and I particularly like wool with flecks or a rustic Aran-look about them. I tend to stick to polyester which these days feels like wool but can be washed frequently and still feel and look like new. If I use thinner yarn I tend to double it up with another complementary thread to add texture. For the cowls I use fat needles and bulky yarn.

I was diagnosed with GPA Vasculitis coming up to four years ago. My disease is controlled through the biological drug Rituximab but at times I have been really poorly and not been able to do very much at all.

When my hands are painful and swollen I can't crochet but I do wear my fingerless gloves all the time! I have found in times of ill health my hobbies of crocheting along with very occasional sewing, jewellery making and piano playing have really helped me to feel productive again and have helped build up self worth again.

When I'm very ill it can really help with the passing of time and feeling hopeful if I plan some ideas and then produce them at some later stage when I'm more able. Seeing my young family members looking so cute with their crocheted hats and cowls that I've made for them really makes me feel joyful! My next plan is to think about making some crochet baskets, and rediscover the art of macramé!

Saira Ibrahim

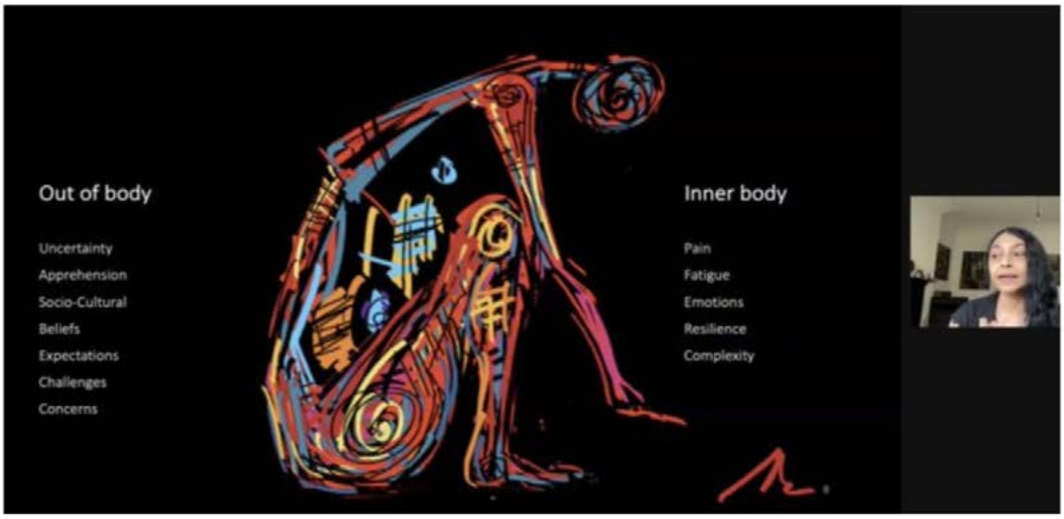
THE SECOND UKIVAS ONLINE EDUCATIONAL VASCULITIS WEBINAR FOR MEDICAL PROFESSIONALS

Over two days, November 17th and 18th 2021, UKIVAS, the UK & Ireland Vasculitis Study Group, teamed up in partnership with the Royal Society of Medicine (RSM) to lay on their second educational webinar. Over 600 medical delegates signed up for this webinar.

The programme ran from 8.45am to 6pm on each day. The list of speakers included doctors from the UK, Europe, Australia & USA. Most types of vasculitis were covered. Although the webinar was courtesy of the nephrology department of the RSM, throughout, the theme was very multidisciplinary. https://www.rsm.ac.uk/events/nephrology/2021-22/neq51/

Day 1 – As we expected from a UKIVAS event, there was much emphasis on registries and databases. Treating and managing Vasculitis in the era of COVID19. ANCA negative Vasculitis & Auto-inflammation. Discussing other, rarer types of Vasculitis eg: Behcets Disease, Cryoglobulinemia , Get It Right First Time (GIRFT).

Day 2 – included a session discussing Patient Perspectives, which included presentations from John Mills – Vasculitis UK, Julie Power – All Ireland Vasculitis Support, Shanali Perera – Healing & Art. Other sessions covered: ANCA Vasculitis, IgG4 Related disease, Glucocorticoid Impact, Renal Manifestations in Children, Anti GBM, Large Vessel Vasculitis.


Out of body

Uncertainty
Apprehension
Socio-Cultural
Beliefs
Expectations
Challenges
Concerns

Inner body

Pain
Fatigue
Emotions
Resilience
Complexity


Dr Maria Casal Moura, Division of Renal Pulmonary and Critical Care, Department of Medicine, Mayo Clinic College of Medicine and Science, Rochester

Dr Emre Bilgin, Rheumatology Research Fellow, Department of Internal Medicine, Division of Rheumatology, Hacettepe University Faculty of Medicine, Vasculitis Research Centre, Hacettepe University

5:30pm Concluding remarks
5:35pm Close of meeting

Agenda - Day 2

8:45am **Welcome and introduction**
Dr Allyson Egan, Chair, Care Pathways, UKIVAS and Past President, Nephrology Section, Royal Society of Medicine and Dr Stephen McAdoo, Treasurer, UKIVAS, President, Nephrology Section, Royal Society of Medicine

Session one: Vasculitis: Cellular pathways, molecules and therapeutics

Chairs: Dr Paul Lyons, Cambridge Institute of Therapeutic Immunology and Infectious Disease, University of Cambridge and Dr Tina Chrysochou, Past President, Nephrology Section, Royal Society of Medicine and Consultant Nephrologist, Salford Royal Hospital NHS Foundation Trust

8:55am **Cells, ANCA and small vessels – the fundamental biology of AAV**
Professor Richard Kitching, Nephrologist and Paediatric Nephrologist, Monash Health, Monash University Centre for Inflammatory Diseases

9:20am **Platelets more than markers of inflammation in AAV**
Dr David Mathew, Renal Registrar, Barts Health NHS Trust

9:35am **B cell depletion in tissue after rituximab for AAV**
Dr Mark McClure, Renal Registrar and Vasculitis Research Fellow, Cambridge University Hospital

9:50am **Single cell transcriptomics of postnasal space lymphoid tissue to investigate tissue-based immunity in eosinophilic granulomatosis with polyangiitis**
Mr Matthew Coates, Wellcome Trust ENT-Vasculitis Clinical Research Fellow, University of Cambridge

10:05am **Longitudinal impact of anti-IL 5 therapy in eosinophilic granulomatosis with polyangiitis. Update on UKIVAS Care Pathways working group**
Dr Allyson Egan

10:20am **IgG4-related disease**
Professor Augusto Vaglio, Nephrology and Dialysis Unit, Meyer Children's Hospital and Department of Biomedical, Experimental and Clinical Sciences, University of Firenze

10:40am **Comfort break**

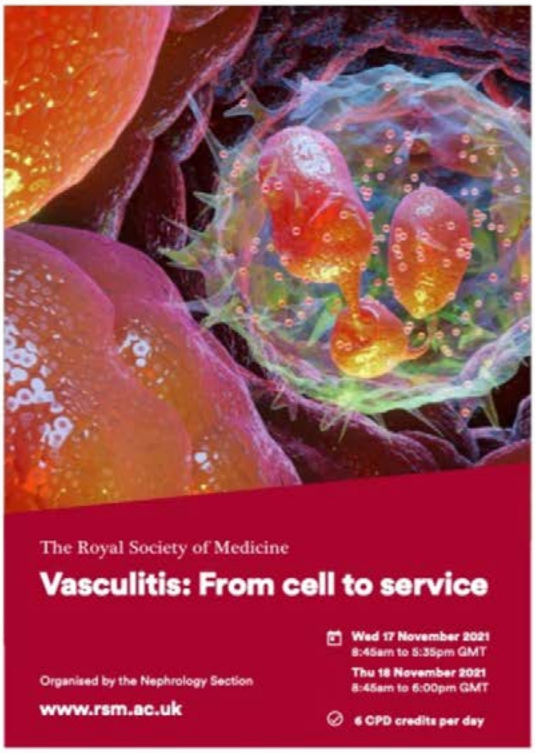
Session two: Patient perspectives

Chairs: Professor Justin Mason, Professor of Vascular Rheumatology, National Heart and Lung Institute, Imperial College London and Professor Charles Pusey, Emeritus Professor of Medicine, Imperial College London

10:50am **Living with vasculitis – what matters most?**
John Mills, Julie Power, Shanali Perera

Vasculitis:From Cell to Service

- John Mills Vasculitis U.K.
- Lived with GPA since 2000
- Co Founder of VUK along with my wife Susan
- Retired Dentist – 40 years Clinical Practice



This webinar was another triumph for the UKIVAS working group. Vasculitis patients certainly owe a great debt to Dr Allysson Egan and Dr Steve MacAdoo, working for UKIVAS with RSM ,who put this "virtual" vasculitis conference together, so professionally and with amazing support for each speaker.

Susan Mills
November 2021

INTERNATIONAL RESEARCH STUDY

In April 2020 I saw a post on the Vasculitis Support (UK) facebook group asking for people with ANCA vasculitis, who had experience of dialysis and plasmapheresis, to be involved in an international research study. I passed on the details of my husband Mark (he has Microscopic Polyangiitis which destroyed his kidneys in 2016, and received immediate plasmapheresis on diagnosis and ongoing haemodialysis until his transplant in 2019). During an initial Zoom call with the doctor who was acting as patient liaison it became clear that I could make a useful contribution (as Mark's care partner during his years of home haemodialysis, and as his living kidney donor in 2019), so I was also invited to be formally involved. Three other vasculitis patients from the UK, US and Canada were also invited to join the panel, which also included 17 clinicians and methodologists.

The intention of the work was to develop some new "Rapid Recommendations" (1) for the treatment of ANCA Associated Vasculitis (AAV). The trigger for the development of this new guideline was the recent PEXIVAS study which appeared to show that plasmapheresis brought no benefits but brought increased risks, and which was felt to be influencing clinical practice amongst doctors treating patients with vasculitis. Rapid Recommendations are designed to systematically collate and examine *all* the evidence which can inform frontline clinical practice, and produce treatment guidelines; and development of them involves clinicians, methodologists and patients working together.

As a panel the questions we were looking to answer were:

1. Which patients with AAV and kidney involvement, if any, should receive plasmapheresis?
2. Should patients with AAV and pulmonary haemorrhage without kidney involvement receive plasmapheresis?
3. Should patients with AAV receive a reduced dose regimen of glucocorticoid (steroids) during the first 6 months of therapy?

Over the next few months we had many long Zoom meetings with the doctors and researchers from around the world, with the aim of answering these three questions. The evidence for Question 3 was pretty unambiguous: a reduced dose regimen of steroids resulted in a decrease in serious infections, and no increase in death or ESKD. The reduced dose steroid regimen was strongly recommended. The evidence for Question 2 was more uncertain, with fewer AAV patients having pulmonary haemorrhage with no kidney involvement, and risks and benefits being harder to assess. The outcome of discussions was a weak recommendation against plasmapheresis.

Much of the discussion centred round Question 1. We examined the evidence from all the previous relevant studies, which actually showed that while the PEXIVAS headline had been that plasmapheresis measurably increases the likelihood of developing a serious infection, with no reduction in the combined outcome of death or End Stage Kidney Disease (ESKD) i.e. kidney survival, an analysis of all the data available showed that plasmapheresis *did* bring a measureable reduction in the likelihood of proceeding to ESKD and thus dialysis within 2 years. Mark and I were extremely pleased to see a separation of death and ESKD as outcomes in our discussions, as while we would argue strongly that dialysis is highly unpleasant as an outcome, it is (usually) better than being dead!

During the discussions as to how the potential risks and benefits of plasmapheresis should be assessed, it became apparent that the input of Mark and I as people with experience of life on dialysis was important. We made it very clear to the doctors that dialysis and transplant have such an impact on quality of life that we strongly believed many people would be prepared to take a bigger risk of infection in order to reduce their chances of ending up on dialysis, or even just delay it for a few years. We were also able to make the point that dialysis is considered such a medically undesirable state of affairs with its own risks and consequences, that doctors are prepared to take significant risks to get people off dialysis and transplanted (e.g. giving plasmapheresis to facilitate tissue or blood incompatible transplants or to fight rejection in trans-

Continued on page 13

Continued From page 12

plants, and operating on healthy living donors to get people transplanted). Our input prompted the doctors to develop a questionnaire, which would assess the infection risk people would be prepared to accept vs the potential to avoid dialysis. We felt that even though it would delay the publication of the RapidRec, it was important to seek the opinion of more people who had experienced dialysis, regardless of the underlying cause of their kidney failure, as it would help us to understand what risks would be acceptable to patients, in particular those with lived experience of dialysis. Mark and I helped to design, develop and circulate this international questionnaire, and the results were presented (2) as a poster at the American Society of Nephrologists meeting in November 2021, and will also be presented at the International Vasculitis and ANCA Workshop (3) in Dublin in April 2022.

The discussions resulted in a consensus that AAV is a complicated scenario, and that for patients with a lower risk of progressing to ESKD (based on creatinine, speed of kidney decline, biopsy results etc.) there should be a recommendation against the use of plasmapheresis, but that for patients with a higher risk of progressing to ESKD, there should be, a recommendation for plasmapheresis as the potential benefits outweighed the potential risks. Both of these recommendations were “weak”, meaning that it was recognised there would be variations in the levels of risk patients were prepared to take, depending on their individual circumstances, and that discussions between patient and doctor were key.

I have talked about how Mark and I were able to contribute to the development of these treatment guidelines with our experience of plasmapheresis, haemodialysis and transplant, but the other patient partners involved were also able to give valuable contributions in their areas of experience e.g. pulmonary involvement and serious infections. I would urge anyone with lived experience of vasculitis to take part in this type of exercise if you get the opportunity. It was interesting and thought provoking, and I believe that our experience brought life to the various statistics from the studies analysed, and prompted the doctors to think about the long term consequences of treatment decisions which they often don’t see in their brief clinics, consultations or ward rounds. All the doctors involved were keen to hear our thoughts even where they contradicted or challenged their own, and we certainly saw it as a privilege to be representing patients as equal partners in the discussions. Our patient liaison (Dr David Collister from the University of Alberta, Canada) was exceptional in providing us with the information we needed, and encouraging the contributions of all patients as well as responding to my many additional questions and opinions.

The Clinical Chair of the panel (Professor Alfred Mahr from Kantonsspital St Gallen, Switzerland) perfectly summarised the experience thus: “I will always remember this journey as a lesson that people can come together and make things happen even in the middle of a pandemic paralyzing the world, and as a great plea for shared decision making as the key component of medical practice”

The full Rapid Recommendations have now been published in the British Medical Journal (https://www.bmj.com/content/376/bmj-2021-064597) with all the patient partners/caregivers listed as co-authors.

(1) The *BMJ* Rapid Recommendations (see https://www.bmj.com/content/354/bmj.i5191) were initiated by the MAGIC Evidence Ecosystem Foundation (MAGIC, https://magicevidence.org/) together with *The BMJ* in 2016 to circumvent organisational barriers and to provide clinicians with guidance based on the most current practice-changing evidence.
(2) American Society of Nephrology | Kidney Week - Abstract Details (asn-online.org)
(3) https://vasculitis2022.org/

Lesha Farrar

Dr Andreas Kronbichler was until recently a consultant nephrologist in Innsbruck, in the beautiful Austrian Tirol. Andreas has a deep interest in research and he has now joined the team in Cambridge, working with Professor David Jayne. Here he shares his initial impressions of working in the NHS, compared with other European countries.

Comparative analysis of healthcare systems in central Europe and the United Kingdom

Dr Andreas Kronbichler PhD *(Consultant Nephrologist, Addenbrooke's Hospital, Cambridge)*

Most healthcare systems in the industrialised world are based on principles proposed by John Maynard Keynes, a Cambridge-based economist, and others who aimed to refine his theory. Following this principle, the countries should save during times of thriving economy and invest money once economics are downside trending. Healthcare systems in such a scenario never come with a benefit, but it will allow access to healthcare for the vast majority of people living in a country. These principles are relevant for most countries in the European Union and the United Kingdom.

Alongside a national "big" insurance such as the National Health Service (NHS), countries such as Germany and Austria also have other smaller insurance companies which offer similar benefits. In addition, also private insurances exist, which offer additional benefits outlined below.

Most physicians in private practice are accepting the general insurance, but a proportion (for example some dermatologists) are completely "private", that means that a private insurance covers the full costs. A general insurance would reimburse approximately 20% of the costs. There is no referral from a GP needed to see a specialist in this scenario. For outpatient services, these options become more popular in recent years. Prices for such a service vary and a doctor of medicine charges around £200 including basic laboratory, ultrasound, carotid ultrasound and echocardiography as part of an annual check-up.

The outpatient services provided by hospitals were not subject to a backlog before Covid-19 and not so during the pandemic. That means that a general nephrology patient (for example) with priority will be seen within a couple of days, while elective appointments will take up to a month. There are basically no waiting times for investigations ordered even in an outpatient setting and with "low" priority, eg.CT Scan within a week or high-resolution CT scan of the lung within 24 hours. The majority of dialysis patients in an area with a good nephrology coverage will see a consultant every day; a consultant will lead the ward round every day.

The amenities are different to other countries, and patient rooms are up to date with a maximum of 4 beds in one room, which is then usually separated in two-and-two bays. In nephrology, most rooms fit 2 beds, and this allows a better control of spread of infections, which became relevant in Covid-19 and before during influenza times. If a patient is privately insured, they can usually choose their treating physician and will face some further priorities (i.e.also seen by professors during referrals to other specialties, investigations within a day). Waiting times for patients with a general insurance are highest for glaucoma surgery (approximately 6 months), and for knee/hip replacement (approximately 3 months).

Another important point is that the access to "high-tariff" medications is easier, as there is a possibility to prescribe tocilizumab for giant cell arteritis, mepolizumab for eosinophilic granulomatosis with polyangiitis and rituximab (off-label) for (i.e.) minimal change disease without any restrictions (no MDT discussion, no discussion with insurance companies, etc.). In terms of avacopan, discussions are ongoing about its prescription for GPA or MPA. But it is likely that access will be possible for a majority of patients. As the treatment costs are around 70,000 £ a year, a more restrictive approach will be necessary to satisfy the insurance.

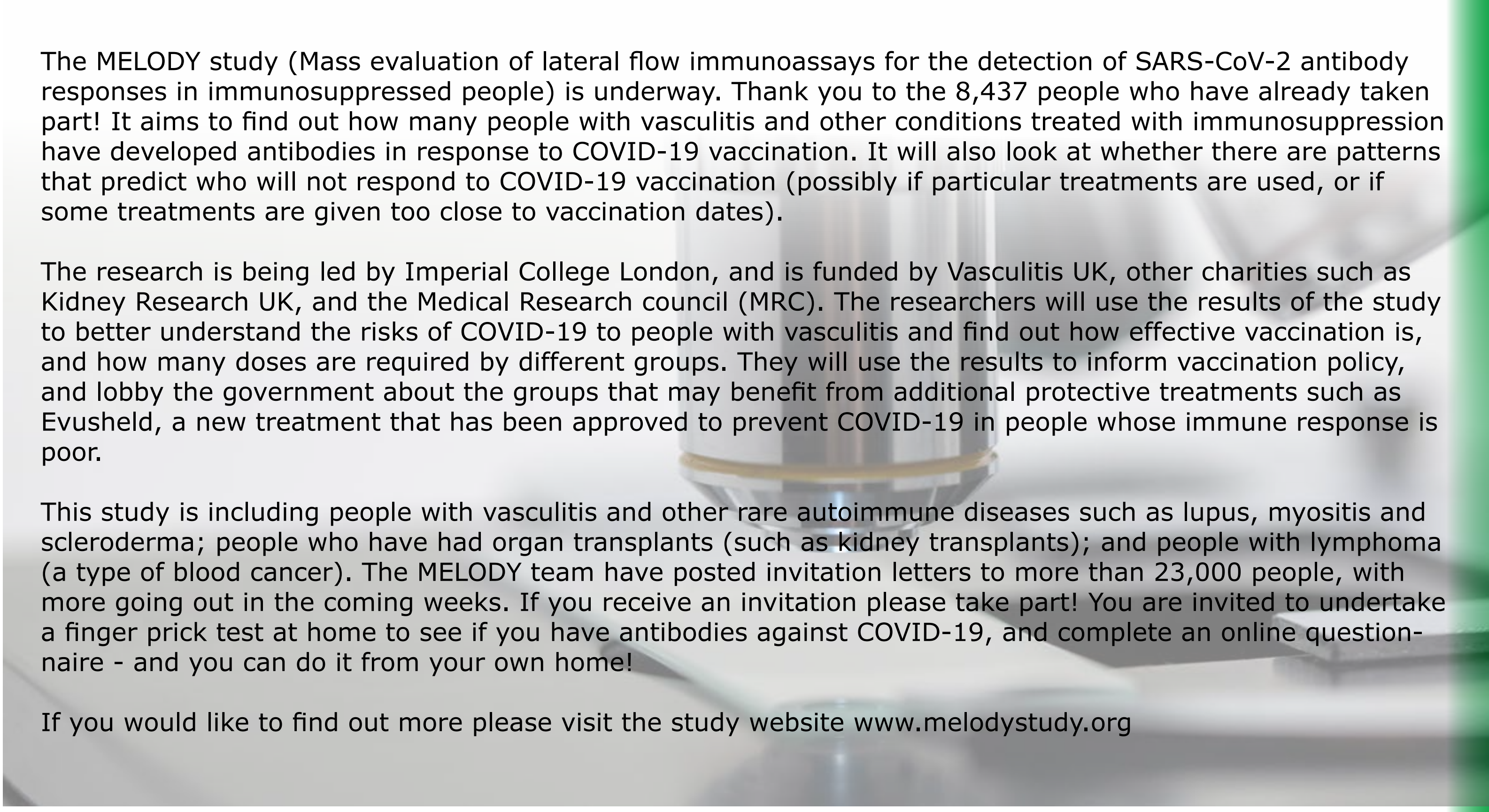
This "liberal" prescription pattern needs to be questioned in times of high healthcare expenditure. There is the possibility that inexperenced physicians might prescribe high-tariff drugs without appropriate knowledge of the scientific literature.

Thus, a UK approach seems to be appropriate in my eyes, wherein discussions about duration of therapy, indication and potential side effects are discussed in a multidisciplinary team setting.

In my first months working as a consultant in the NHS, I was somewhat shocked by the reluctance of general physicians (GPs) to execute actions I have asked for (i.e. referral to dermatology, initiation of specific medication, etc.). In order to have a "shared care" for a patient, it seems important that patients have a GP as a primary physician who takes care but also liaises with specialists to improve patient's outcome.

A definite advantage in the UK is the strong focus on research and the possibility to participate in international trials. Austria, as a small country, is unattractive for pharmaceutical companies and most trials are not opened as regulatory costs are high. The UK is particularly attractive and thus most important trials are initiated at several sites. This also creates a "better knowledge" and expertise in fields of medicine, which in turn improves services provided to patients. Dedicated vasculitis services do not exist in most countries of the world and this has also negative impact on funding options and awarenessof these rare diseases.

MELODY STUDY UPDATE - Dr Fiona Pierce - Nottingham University Hospitals Trust



The MELODY study (Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people) is underway. Thank you to the 8,437 people who have already taken part! It aims to find out how many people with vasculitis and other conditions treated with immunosuppression have developed antibodies in response to COVID-19 vaccination. It will also look at whether there are patterns that predict who will not respond to COVID-19 vaccination (possibly if particular treatments are used, or if some treatments are given too close to vaccination dates).

The research is being led by Imperial College London, and is funded by Vasculitis UK, other charities such as Kidney Research UK, and the Medical Research council (MRC). The researchers will use the results of the study to better understand the risks of COVID-19 to people with vasculitis and find out how effective vaccination is, and how many doses are required by different groups. They will use the results to inform vaccination policy, and lobby the government about the groups that may benefit from additional protective treatments such as Evusheld, a new treatment that has been approved to prevent COVID-19 in people whose immune response is poor.

This study is including people with vasculitis and other rare autoimmune diseases such as lupus, myositis and scleroderma; people who have had organ transplants (such as kidney transplants); and people with lymphoma (a type of blood cancer). The MELODY team have posted invitation letters to more than 23,000 people, with more going out in the coming weeks. If you receive an invitation please take part! You are invited to undertake a finger prick test at home to see if you have antibodies against COVID-19, and complete an online questionnaire - and you can do it from your own home!

If you would like to find out more please visit the study website www.melodystudy.org

VASCULITIS UK

AGM 2022
15th May-1pm

Online
(Joining details announced soon)

Please join us at our annual general meeting in May to hear from medical experts and to find out out Vasculitis UK's plans for the coming year.

VASCULITIS UK

Helpline

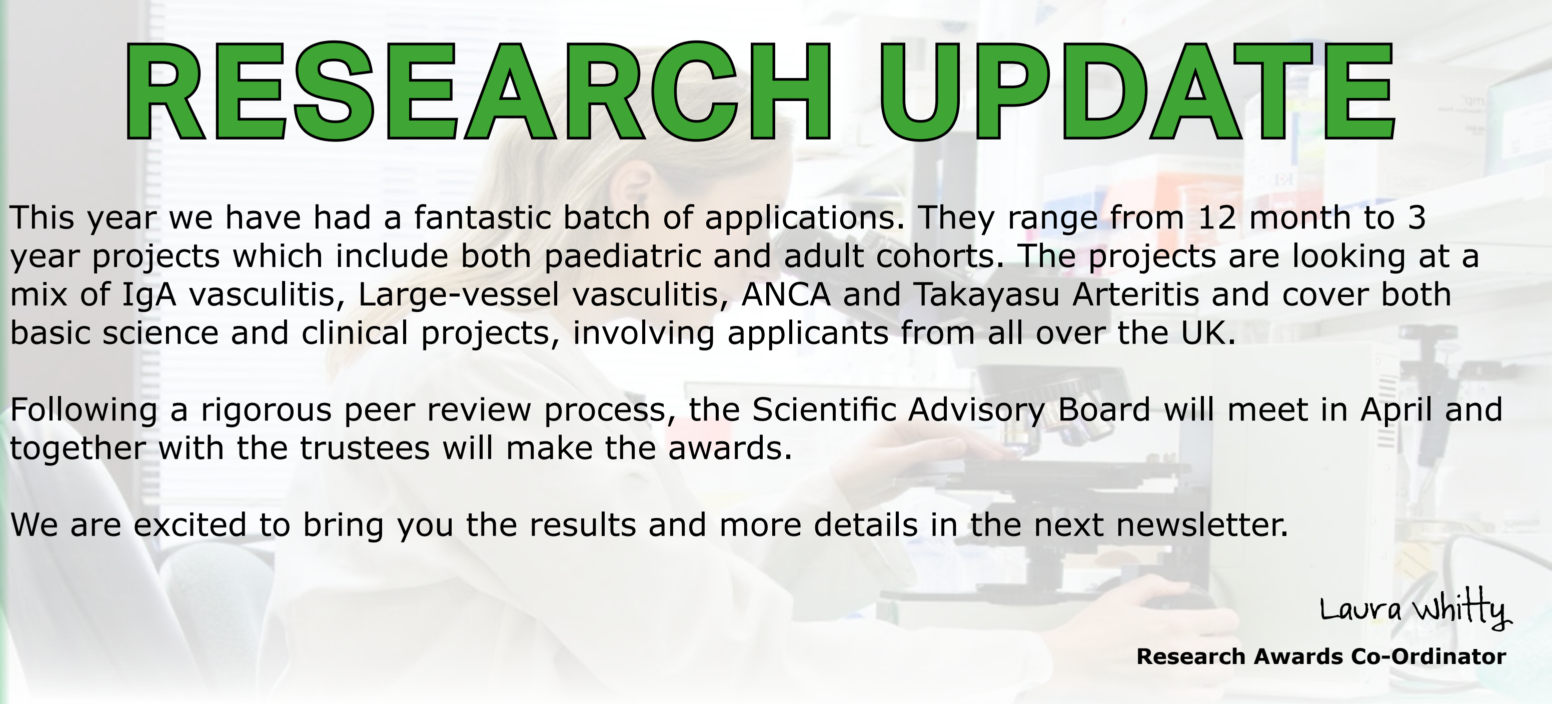
for information and advice about vasculitis by telephone or email.

If you prefer you can write to us

E-mail
john.mills@vasculitis.org.uk
zoi@vasculitis.org.uk
Post: John Mills
West Bank House,Winster, Matlock
DE4 2DQ

Helpline Telephone:
0300 365 0075

RESEARCH UPDATE



This year we have had a fantastic batch of applications. They range from 12 month to 3 year projects which include both paediatric and adult cohorts. The projects are looking at a mix of IgA vasculitis, Large-vessel vasculitis, ANCA and Takayasu Arteritis and cover both basic science and clinical projects, involving applicants from all over the UK.

Following a rigorous peer review process, the Scientific Advisory Board will meet in April and together with the trustees will make the awards.

We are excited to bring you the results and more details in the next newsletter.

Laura Whitty

Research Awards Co-Ordinator

Help Advice & Support

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

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

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

For all the latest information and news,

visit the Vasculitis UK website http://www.vasculitis.org.uk/

Tell your story

Do you have a personal story to tell?

Many of our readers have a story, and although some may not wish to talk openly about their vasculitis journey some find it a release mechanism and it helps them to move forward with their battles through life whilst living with vasculitis.

If you would like to share your story please contact me and your story can be told.

kevin@vasculitis.org.uk

Diagnosed with **VASCULITIS?**

Living in the **UK?**

Aged **18 to 39?**

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

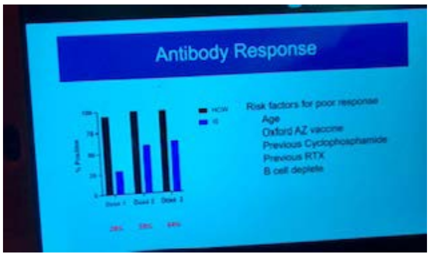
Join the community:
https://www.facebook.com/groups/vasculitisukyoungadult
Email: Charlie@vasculitis.org.uk

VASCULITIS UK

John and I joined this excellent International Vasculitis Patient Conference on line via my iPad. John's health has deteriorated very much recently and he is unable to venture far. We were so very disappointed we could not attend in person but were so very grateful we could attend on line via the Webinar and Zoom. The conference was live steaming from Dublin & registration was free of charge. Twitter - #Vasculitis22

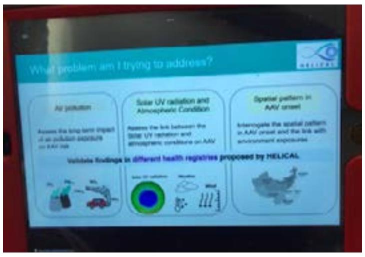
On the Saturday afternoon, presentations included - The Patient Experience Living with Vasculitis, Managing Fatigue & Vasculitis, Effectiveness of Vaccines & Boosters - COVID19, Cardiovascular Risk in ANCA Vasculitis, Environmental Triggers in Vasculitis, Giant Cell Arteritis, Vasculitis in Children, Microbiomes & Vasculitis, Molecular Influences in Vasculitis & Data Protection in Vasculitis Research.
Speakers included- Dr Stephen Mcadoo, Dr Emma Lacy, Dr Matthias Busch, Prof Lorraine Harper, Dr Louise Oni, Dr Andreas Kronbichler, Maria Christofidou, Gisela Pattarone, Farah Kamberovic, Michal Zutcinski, Enoch Havyarimama, Dr Elaine Houben.

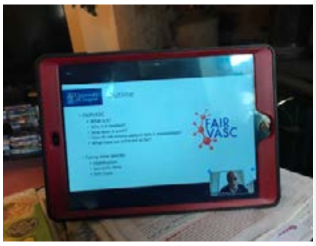
Round the table discussion - "Vasculitis Today & World Wide".
Dr David Jayne UK, Prof Richard Kitching Australia, Prof Peter Merkel USA, Prof Kevin Cassar Malta,


Antibody Response

Risk factors for poor response
Age
Oxford AZ vaccine
Previous Cyclophosphamide
Previous RTX
B cell deplete


How does it compare to adults?


What problem am I trying to address?

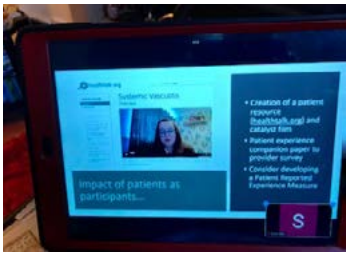


On the Sunday morning presentations included - Patient Reported Outcomes (PROs) , PROs Registries, Patient Reported Outcome Measures (PROMs), The Fairvasc Project, The Voices Project, ERN RITA patient journeys and Art, Vasculitis & the Lived Experience.
Speakers included Prof Peter Merkel, Dr Matthew Rutherford, Nathan Lea, Dr Allyson Egan, Dr Rosemary Hollick, Dr Shanali Perera, Peter Verhoeven & Julie Power.


What is all this telling us?

KEEP
CALM
AND
LISTEN TO
PATIENTS


Today is about...


- Creation of a patient resource (healthtalk.org) and catalyst film
- Patient experience companion paper to provider survey
- Consider developing a Patient Reported Experience Measure

Impact of patients as participants...

We just wanted to thank Julie Power - (Vasculitis All Ireland Awareness) and Peter Verhoeven - (Vasculitis International) for all their hard work organising and presenting this very informative and excellent vasculitis patient conference.
If you did register you should be able to catch up on the conference via the Vasculitis International website. https://www.vasculitisint.com/

Susan Mills

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 John Mills to discuss setting up a group.

BIG CONVERSATIONS FOR LITTLE PEOPLE

ALL ABOUT SNOT

It's green, sticky, and undeniably icky, but did you know that snot plays an important role in our immune system?
Nobody can avoid snot; we've all had dreadful colds which make our noses stream and many people with conditions such as vasculitis find that snot is a permanent unwelcome guest in their day to day lives. But why is it there? And is there anything we can do about it?
Read on for 10 fun facts about snot.

1. Snot has an important job- to keep germs such as bacteria and viruses out of the body. Rather than letting them invade important body parts such as your lungs, snot traps nasty germs.

2. You make around one litre of snot each day. It lines your nose and throat and most of it will get swallowed!

3. Picking your nose isn't a good idea. It can lead to breaking the delicate skin in your nose and introducing germs. Blow your nose into a tissue, bin it, and then wash your hands for the most effective snot removal.

4. Sneezes can travel fast! It is estimated that droplets from sneezes can travel up to 60mph—about as fast as a car driving on the motorway—which is why it's always a good idea to cover your sneezes.

5. A chemical called myeloperoxidase, which is an enzyme in some of your white blood cells, causes snot to turn green.

6. The main ingredients in your snot are water, salt and protein.

7. Animals make snot too!

8. Young children catch on average 6-8 colds a year, whereas adults catch on average 2-4 colds. Most colds may be snotty but are easy to recover from. You should pay special attention to good hand hygiene if you have a cold and live with someone who is immunosuppressed, as colds can take them longer to fight off.

9. It is thought that the germs in snot can survive for around 24 hours on surfaces, another reason why using tissues and washing your hands is a good idea!

10. Eating your bogies probably won't make you ill, but it is definitely icky!

Activity: Make your own Snot Slime
Have you ever noticed that when you have a cold, your snot seems to take on a life of its own? It may start out clear and watery but as time goes on, it becomes thicker, greener, and far more sticky.
You can make your own snot at home with just a few ingredients.

You will need:
Between ¼ and 1 tsp borax crystals dissolved in 250 ml water
1 part PVA glue and 1 part water mixed together
Green food colouring (just a few drops)
Bowls
Spoons/ popsicle sticks for stirring

How to make it:
Mix together your borax mixture and your glue mixture, adding a couple of drops of green food colouring. Use different quantities of each to make different consistencies of snot slime. Have fun experimenting! Please note that neither real snot nor snot slime should be eaten!

On line Support Groups

Vasculitis Hobbies - Green Fingers, Food and Crafts
https://www.facebook.com/groups/136279183906122/

Chill Out, Relax & Unwind

Our Vasculitis hobbies page was developed as a place we could enjoy either our own hobbies or other peoples. It's a page where we celebrate achievements despite having our condition; a place we can relax and perhaps forget for a moment, the debilitating affects of Vasculitis.

Many of us have taken up new hobbies, developed ones we'd forgotten we had (or didn't have time to pursue), adapted ways to continue what we did, or just visit the page to enjoy other's achievements.

There are albums to browse through and it can be as simple as enjoying a great view or a beautiful sky, through to running a marathon. Others post photos of plants they've grown, music they've played, their pets, a good book they've read; the variety is astonishing.

It's a page of positivity. A break from the condition. A relax on a not so good day.

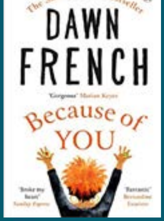
Maria Williams

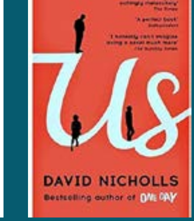
Vasculitis Book Club

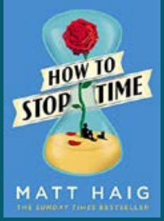
The Vasculitis and Rare Disease FB Book Club was created in the summer of 2020, when we were all in lockdown during the pandemic.

The group has been very successful & extremely popular, membership is growing.

A few examples of books read to date







https://www.facebook.com/groups/264318624787878/?ref=share

Tell your story

Send your story to kevin@vasculitis.org.uk

I'm not even sure when it all began. Hi, I'm Chris Soper, 73 years old and live in Bromley, Greater London, bordering Kent. I have Vasculitis GPA with kidney impairment and my renal function is currently between 32 – 38 %. I'm treated at Kings College Hospital, SE London.

Until recent years I had been pretty healthy all my life, no ops, no broken bones, no hospital admissions (okay, my last one was in 1953 to have my tonsils out). I've had sinus problems most of my life but most people have some weak spot I reasoned! GP visits were quite infrequent and when friends told me about the trials of their various ailments my standard response after sympathising was, "Well I don't do hospitals." Well I do now. Big time!
I still don't know what, or how, it all happened.

Perhaps you remember Swine Flu in 2009? I dutifully took the Tamiflu anti virals the NHS was dishing out then to ward off a potential pandemic. Within 2 weeks I became quite unwell, extreme fatigue, weight loss, stiff knees, breathless. For a year I was passed between different consultants, Rheumatology, Gastroenterology, Respiratory and my liver results were consistent with heavy drinking. I got used to being questioned about my alcohol intake, "No really doctor, a few glasses of wine a week or a G &T" A difficult year passed and I gradually returned to normal, liver included! "Yes, perhaps it was a virus', the Consultant agreed with what I had been suggesting all along.

Next year ear problems surfaced and I suddenly went deaf in one ear, felt unwell, unbalanced and could hear my own heartbeat all the time. A dismissive GP told me that it would clear up within 9 months! Exasperated a private consultation resulted in grommets being inserted in both ears for 'glue ear' and the ENT surgeon said there was no possibility whatsoever of it clearing by itself.

2018 what a year! Against a backdrop of an elderly relation's repeated admissions and discharges to hospital and a younger relation being suddenly diagnosed with an inoperable brain tumour, I again started feeling fatigued; the breathlessness, weight and hair loss resurfaced. I attended my local hospital as an ambulatory patient for batteries of tests and the diagnosis was 'probably Epstein Barr' or Glandular Fever as it's better known.
Life was very difficult indeed in a busy household. Again slowly I regained my health and energy and we had planned a big trip to Singapore and Australia for April 2018. The day before we were due to fly, I felt so weak; I couldn't even lift my handbag, let alone get to Heathrow for a 13 hour flight to Singapore. The trip had to be cancelled at the last moment.

Fast forward to October 2019 and I had recovered enough to do the trip so off we went. It was great to see relatives and we had an amazing time. I did get a bad sinus infection just before we left Australia but strong antibiotics from a GP in Melbourne soon put that right – except it didn't! On the return flight to London via Singapore I had chronic stomach pains and the whole flight was a nightmare. Once I got home they continued until my GP sent me to urgent care. Colostrum Difficile this time from too strong antibiotics prescribed by the Australian doctor. Carry on Christine. Grit your teeth!

Christmas 2019 came and went and yet again I was breathless and fatigued. On 6th January I was admitted to my local hospital with a suspected blood clot on the lung but it was then diagnosed as serious pneumonia. "The state of your lungs" the Consultant said to me disapprovingly as I stared at a chest x-ray that looked like a white snowstorm. Pumped full of intravenous antibiotics for 8 days and sent home utterly sleep deprived and poorly!

Then Covid happened and you know the rest. Face to face hospital appointments gave way to phone calls and a long wait began for the results of a bronchoscopy and lung wash. I was passed from one consultant to another as the hospital became overwhelmed. Then, Halleluiah, in May I was passed via phone to my 3rd Respiratory Consultant who had come out of retirement to help with the deluge of Covid patients. Dr Sawicka listened, questioned, and wanted details (I always keep records). She sent me for tests and x-rays as she felt 'something wasn't right'. She wrote that I had one of two illnesses- post organising pneumonia or the rare Wegener's Granulomatosis.

She then requested I go for yet one more X-ray and blood test. I did and the same evening I received a call from a 111 doctor who had just got my results. I thought he had got the wrong person when he told me to go straight to my local hospital A & E immediately. Hours later I was admitted and given a blood transfusion though had no idea what was going on. After all, I felt ok-ish, just very, very tired! The next day I was transferred by ambulance to Kings College Hospital, Renal Department.

More drips, transfusions and a kidney biopsy. A kind consultant crouched by my bed and congratulated me on becoming a member of the "Rare Disease Club." I had GPA (Wegener's) and I later found my kidneys had gone from being in "pristine condition" to 13% function in about 17 days. Scarring was so severe that my function would eventually climb with treatment and a renal diet back to the dizzy height of 37% at very best.
So followed a regime of high Pred and Rituximab but with the excellent care from King's I made good headway. I joked that I was under every department there beginning with an "R", Renal, Respiratory, and Rheumatology. No stone unturned, no "twinge" ignored in spite of Covid and exhausted staff! A renal diet has helped as well as listening and co-operating with the doctors and renal dieticians. I now go prepared for appointments with urine samples and lists of questions. I joined Vasculitis UK in August 2020 and it has been so helpful from the actual helpline phone to publications and FB support forum (though I don't do "social media").

This illness has led me down some unexpected avenues. My first call to Vasculitis UK was answered by Dorothy Ireland in Derbyshire. By way of conversation we found we had both been at the same primary school in Clapham and brought up within a few roads of one another. Not receiving a copy of the newsletter led me to call Kevin Soper, the Editor and after a chat and some emails we believe there might be a distant family connection.

As far as I'm concerned I'm most definitely not a warrior or on a journey. In fact I don't like the terminology of illness. I'm a person who happens to have an unusual auto immune condition. There have been some highs and real lows, even some funny moments. I'm having treatment, trying to get on with a much more limited life and hoping later this year I will be in remission (of either kind). I hope for better times ahead and am thrilled at the prospect of a first grandchild in May.

What I have learnt is that:-
1) Illness can suddenly happen even if you lead a healthy lifestyle.

2) That it's humbling to go from very good health to serious illness.

3) I will always be grateful to Dr Sawicka, the retired consultant who pursued my case, went the extra mile, thought outside the box and possibly saved my life without ever actually seeing me.

4) Be thankful to the wonderful staff at Kings College who pulled out all the stops during the pandemic.

5) Be grateful to the team at Vasculitis UK and those who give so much time and knowledge which really makes a difference even on the bad days.

Chris Soper
February 2022

RARE DISEASE DAY FEB 28TH 2022

DID YOU KNOW THAT

VASCULITIS AFFECTS ABOUT

2 - 3000 NEW PEOPLE

EACH YEAR IN THE UK

RAREDISEASE.ORG.UK/RDD2022/RARE-REPOSITORY

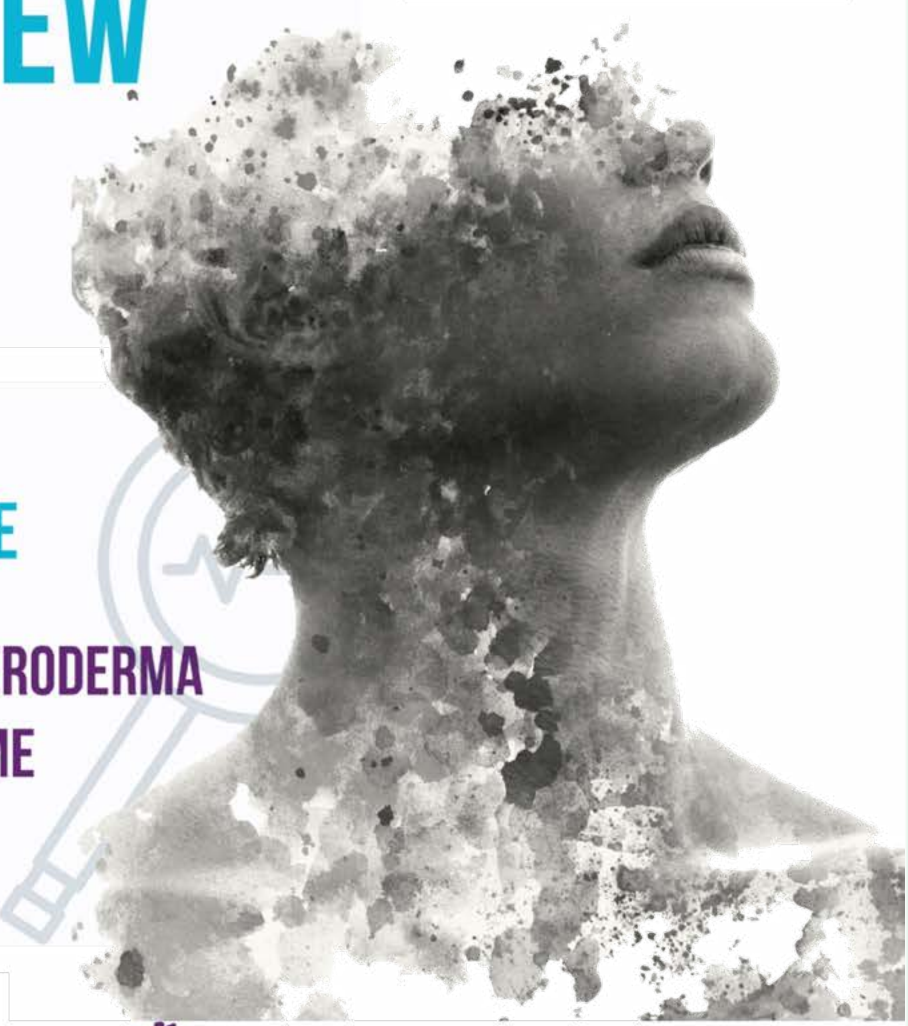
RARE DISEASE DAY®

KEITH

" I WAS DIAGNOSED IN 2015 AND AT 65 YEARS OLD WONDERED WHATEVER THIS DISEASE WAS ABOUT. IT HAD AFFECTED MY KIDNEYS VERY BADLY AND THE DOCTORS WERE UNDECIDED WHAT COURSE TO TAKE..."

RARE DISEASE UK

RARE IS MANY RARE IS STRONG RARE IS PROUD



DID YOU KNOW THAT

AROUND 9,000 PEOPLE

WILL BE DIAGNOSED WITH

VASCULITIS, LUPUS, SCLERODERMA AND SJÖRGEN'S SYNDROME

EVERY YEAR

#RAREDISEASEDAY 28 FEBRUARY 2022

SHARE YOUR STORY

RAREDISEASE.ORG.UK/RDD2022/RARE-REPOSITORY

DID YOU KNOW THAT APPROXIMATELY

170,000 PEOPLE

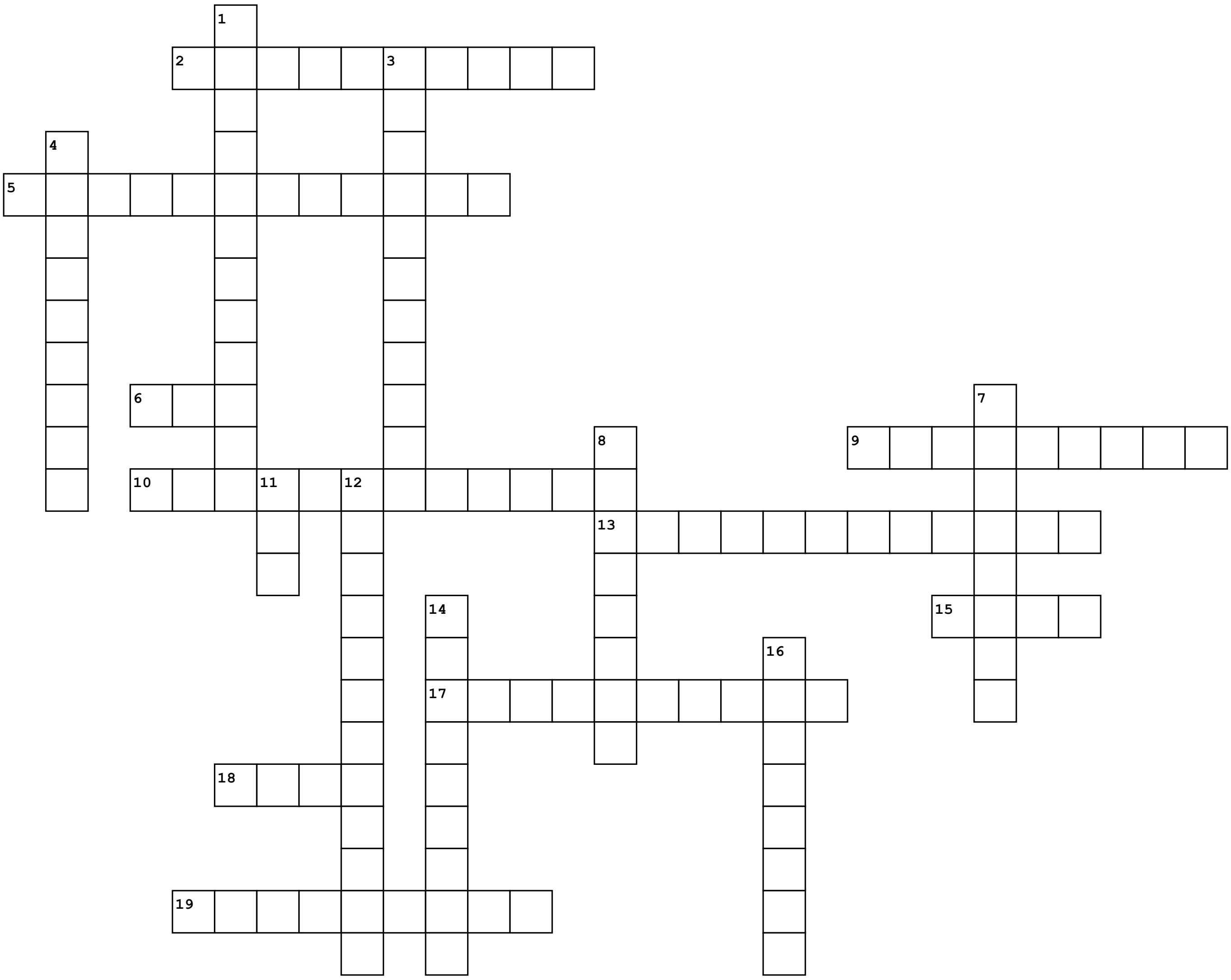
WITH

RARE AUTOIMMUNE RHEUMATIC DISEASES

LIVE IN THE UK

#RAREDISEASEDAY 28 FEBRUARY 2022

Vasculitis UK crossword



Across

2. general name for the drugs you take
5. a type of consultant specialising in kidneys
6. type of vasculitis usually affecting kidneys, lungs, ears and nose
9. relating to the skin
10. a steroid commonly prescribed for autoimmune conditions
13. treatment that uses powerful chemicals to suppress the immune system
15. common general skin symptom
17. a condition where your body targets itself accidentally
18. autoantibodies that attack your neutrophils
19. types of anti-inflammatory drugs e.g. rituximab

Down

1. a strong chemotherapy treatment
3. prescribed for bacterial infection
4. the goal where your condition is controlled
7. second most common type of vasculitis in children
8. tissue death
11. a type of blood clot usually in the leg
12. your bodies natural response to injury or infection
14. confirmed nature of the illness or problem
16. the delivery system for many stronger drugs

VASCULITIS UK

YOUNG ADULT GROUP

A community for young adults (aged 18-39 years) living with vasculitis

WE NEED YOUR HELP

We want to create a page on the VUK website telling others about the Young Adult Group. I realise that it can feel too personal to put your story out there online. So we thought that instead, we can create word clouds for different topics, where all quotes used are anonymous. We want to hear from everybody, from the big to the small things you have done to make you feel YOU again!

Contact : Charlie@vasculitis.org.uk

Donating To VASCULITIS UK

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

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

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

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

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

Virgin money giving Donate here

Donate with JustGiving

PayPal MasterCard VISA

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

THE BIG SPRING CLEAN FOR VASCULITIS UK

Spring has officially sprung! At this time of year, we look forward to the beautiful bulbs flowering and greenery returning around us. However, it also means it's time for the annual Spring Clean.

Although it might be something you dread, a good clear out can provide an opportunity to support patients with Vasculitis across the UK.

There are many websites out there that will turn your clutter into cash and I've included some of my favourites below to help inspire you to take on a spring clear out:

Music Magpie www.musicmagpie.co.uk

Music Magpie will buy your unwanted CDs, DVDs, Books and even tech. All you have to do is enter the items you'd like to sell on their site and they'll tell you how much they'll pay. Print out your free postage and drop off your items and Music Magpie will send you the cash in a matter of days.

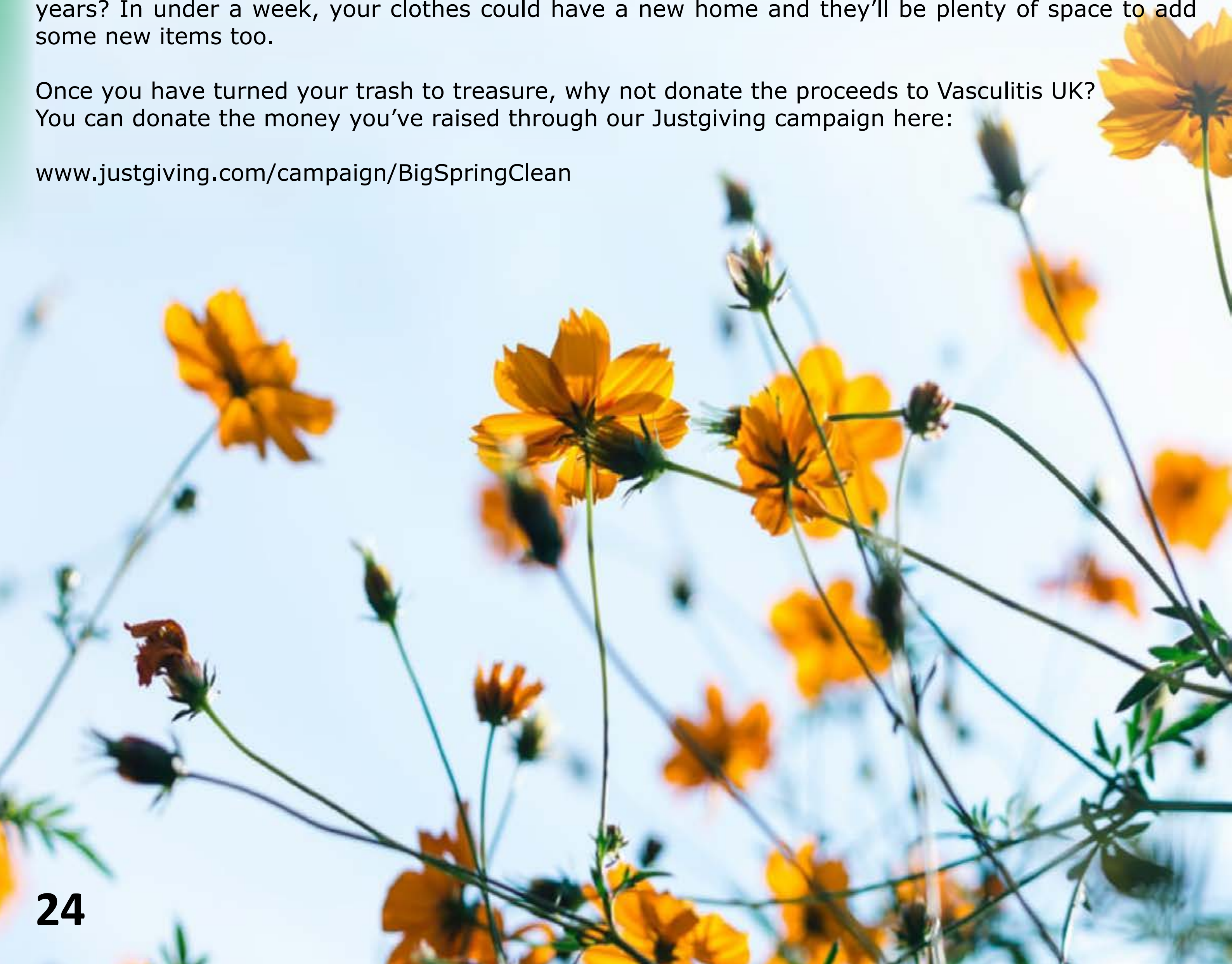
Facebook Marketplace en-gb.facebook.com/marketplace

Facebook Marketplace is a great tool to sell most unwanted items but it is particularly great for selling larger items such as furniture. Just take a few photos on your mobile, follow the steps and your advert will be live in seconds!

Ebay www.ebay.co.uk
Ebay is fantastic for selling clothes. Got an old dress or coat that has been sitting in the wardrobe for years? In under a week, your clothes could have a new home and they'll be plenty of space to add some new items too.

Once you have turned your trash to treasure, why not donate the proceeds to Vasculitis UK?
You can donate the money you've raised through our Justgiving campaign here:

www.justgiving.com/campaign/BigSpringClean



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**

Flegg
In loving memory of Mark Anthony Our hearts are full of memories
With pride we speak your name Though life goes on without you
It will never be the same

Mum and Dad Mrs Tina Heath of Cookham, Berks donated £50 in memory of her beautiful sister Lorna Wright who died 8 years ago from GPA

Denise Welch of Mold Flints. Sent donations of £1015 in memory of her mother Elaine Williams who passed away in October 2021 a few days after a belated diagnosis of vasculitis

£731.90 collected in memory of Erica Evans who passed away in August 2021 after suffering for many years with vasculitis

Funeral donations in memory of Mr Martin Green of St. Austell, Cornwall totalling £240

£100 in memory of Keith Gibson from his cousin Maria Errington
Gordon Robson- £440 raised so far after Gordon passed away after a short period of illness from Vascultiis. He loved his family, friends, golf and holidays.

Kevin Neville- £2973.89 via JustGiving in memory of Kevin Neville.
Richard Whitaker- £210 donation in memory of loving Dad and Grandad, Richard

Steph Kelly- £759 raised in memory after suffering with Vasculitis for a short period of time.

Max Jean Louis Butt- £525 recieved in lieu of flowers. Max suffered from vasculitis since just before he retired but will be remembered with a big grin on his face and a twinkle in his eye.

The wife of John Sim, of Hinckley, Leicestershire, sadly passed away due to Covid infection, having suffered from kidney failure due to vasculitis, from which she suffered for 3 years

Donations totalling £35 were received in memory of the late Richard Whitaker of Hetfordshire.

Donations totalling £122 were received in memory of the late Ken Treadwell of Royal Wooton Bassett, Wilts.

Donations totalling £255 were received in memory of Maureen Ann Woodward of Cheltenham, who passed away age 82.

Cheques to the value £65 were received in memory of Mrs Eileen Dennison of Surrey. Bereaved are her two daughters.

donation of £255.04 in memory of Maureen Ann Woodward aged 82.”

“donation of £122.02 in memory of Ken Treadwell

In memory of Bernadette (Bernie) Pearson of £455, from Belfast.

Donations & Fundraising

Mrs Lesley Wysom of Hartley, Kent set up a Standing Order for £10 monthly in thanks for help from VUK following their daughter’s diagnosis of vasculitis.

Mr Colin Toms of Tunbridge Wells donated £50

Mrs Sue Sherrard of London NW7 donated £100

Mr Neil McKay of Chapel-en-le-Frith, Derbys. gave £100

Mrs Margaret May of St. Albans £50

Mr Mike Kurjakovski of Northants set up a standing order for £20 a month
Mr Robert Bradley of Poole a standing order of £30 a month

Mr David Mackey of Hillingdon, Middx who has MPA donated £1000

Mrs Margaret Robertson (and husband) £223.50 raised through talks, and selling poetry books and other donated items
Rajendra Minstry- £195 raised so far in lieu of flowers
Mo Woodward- £867 received in lieu of flowers

Maureen Ellis- £60 donated. Maureen suffered for many years with the condition.

Theresa Kim Evans- £600 raised

Anne McCulloch- Mum, Anne McCulloch, lived with Vasculitis for over 10 years. She was diagnosed shortly after she retired. Her son Stuart is completing the Stirling Half Marathon to also raise funds for the charity.

Kerry McGuigan- £471 in donations received as this was a cause close to her and her husband Shamus hearts.

A very generous donation of £8000 from the Proctor Family Charity has recently been given.

The Landlord & Landlady, David & Marilyn Bentley, of the Old Bowling Green Inn at Winster in Derbyshire, very kindly donated £250 to Vasculitis UK.

A donation of £60 was recieved from Stephen Mark Buckley with permission for selling some scrap metal from his employer.

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

Canterbury area (Contact Person)
Margaret McGrath - 01227 638469 - margaretmcgrathfmsj@yahoo.com

East Midlands Group
East Midlands Website Group https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home
Dorothy Ireland - 01332 601303 – 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
Susan Chance - 01244 381680 - susanchance53@icloud.com
Dave Birch - 0151 7229049 or 07968226230 - davebirch@talktalk.net

North East Group
Margaret Robertson - 07443016665 - mgtrob@talktalk.net
susan@vasculitis.org.uk

Norfolk Vasculitis Support Group
Mark Sayer - m-sayer@hotmail.co.uk

The North West Group
Jann Landles - Anita Parekh nwvasculitis@outlook.com

Oxfordshire Group
Sue Ashdown - 01295 816841 – vsgoxford@gmail.com

Plymouth Group
elaine203@live.com

Scarborough Group
ruth.newton@york.nhs.uk

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 :
Richard Eastoe - 01423 520 599 email richard@yorkshirevasculitis.org.uk

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

North East Yorkshire Support Contact :
Richard Eastoe - 01423 520 599 email richard@yorkshirevasculitis.org.uk

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 - susanchance@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/
Julie Power - 028 44 842889 - vasculitisireland10@gmail.org.uk

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

EVENTS

British Society for Rheumatology Annual Conference (medical professionals only)

25-27 April 2022
Venue SEC Glasgow & Online

West Midlands Vasculitis Network Group (medical professionals only) June 14th 2022

United Kingdom & All Ireland Vasculitis Study Group Meeting (medical professionals only) 14th June 2022

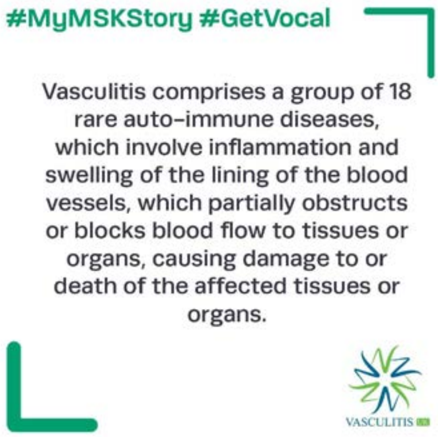
TRAVEL INSURANCE

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 John or Susan Mills details on page 28



#MyMSKStory #GetVocal

Vasculitis comprises a group of 18 rare auto-immune diseases, which involve inflammation and swelling of the lining of the blood vessels, which partially obstructs or blocks blood flow to tissues or organs, causing damage to or death of the affected tissues or organs.

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

Published by:
VASCULITIS UK

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