



VASCULITIS UK

NEWSLETTER JOURNAL



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Chairman's Report

This year has probably been the strangest ever. We started with hope that things would improve nationally and internationally, no one in January or February could have anticipated the arrival of a pandemic.

As people with suppressed immune systems and a variety of different forms of vasculitis, we were immediately put into the high risk and shielding group.

This meant not just the cancellation of our AGM but all of our support group meetings, and of course nearly all of our fundraising activities. Although some people have been very creative, with the virtual Great North Run and Burpees (I had to look that up!). All those runners entered for the 2020 GNR have been rolled over for 2021. The pandemic has obviously, affected our finances, but we are lucky in not having any paid staff or offices.

We have unfortunately, lost a few people to covid-19 but considering our health we have all been very careful in following the guidance. Here, I would like to thank the efforts of Gareth Garner (our own expert), Susan Mills and John Geddes, in keeping the advice on our website up to date, accurate and easy to read. They were at one point changing the guidance every few days.

The trustees have been meeting virtually throughout the lockdown. We already used "GoToMeeting" before the lockdown because of our various health problems, but had still tried to meet face to face. Its now all online. We had considered an online AGM, and still might if this pandemic continues into 2021.

The trustees are: Dorothy Ireland, coming into my second year as Chair, and fundraising coordinator. I have also been working on various policies and with Vasculitis International on World Vasculitis Day.

John Mills, vice chair and Director of Operations, even though he's been very ill this year still managing to keep us on our toes.

Kelly Jefferies, our secretary, runs the shop and designer.

Gareth Garner working with the Scientific Advisory Board and has been using his knowledge of immunology to keep our website accurate.

Zoi Anastasa has been working with John on the Research panel. Is our representative on Eurodis, and an ePag for RITA ERN, and on Vasculitis International.

Martin Makin is part of the fundraising team. He is a very active Runner.

David Newman now represents Vasculitis on London based conferences.

Susan Mills' first job is as John's carer but she does so much more. She works on the website, sends out the parcels, holds the stock, helps with the helpline and is our presence on various social media platforms.

The trustees co-opted Ian Kayes onto the board and he is now established as our honorary treasurer. Ian was an optometrist. He's been very successful in claiming our gift aid and in identifying new investment for money held for research. He's worked closely with me and our auditor on a new finance policy and in setting up online banking.

We made the call for research in 2019. We had 11 applications. They were ready to go out for peer review when we went into lockdown. Nearly all our medical advisors went to work on Covid-19. We, therefore, had to postpone the research. We are hopeful that they will start the peer review process, soon. During the lockdown we received two requests for Covid-19 related research. The trustees agreed to fund these. One was from Nottingham looking into the effect of Covid-19 on people with vasculitis. The second was from Addenbrookes looking into the Antibody responses in immune suppressed patients. We also, attend some medical conferences and take our information stall. This year we had planned to attend the British Society of Rheumatologists and the Royal College of Nurses. With duties shared among the Trustees. The intention was to raise our profiles and awareness with the medical profession. But of course, all conferences were cancelled.

This year was the first Vasculitis International day on the 15th May. We had planned many things to coincide with it, including our AGM. Kelly had worked on designs to go out on social media and raise awareness. Although we made mention of it, all the activities were cancelled. Let's hope, we can celebrate 2021!

There are many ways to fundraise for Vasculitis UK. The obvious is to have an event like a raffle or cake sale, or run in a race. Even if it is virtual. Raising awareness is also part of what we do. We have information leaflets and t shirts. I always have a few leaflets with me, just in case it's a new doctor. There's also making use of online shopping like Amazon. We are signed up for Amazon smile. This means we get a small percentage of the money you spend. We're also registered with Easy giving which a lot of other online shopping companies use, and PayPal giving.

There's no doubt that this has been the strangest of years! We will hopefully come through it stronger and more able to use the new technologies, and maybe with the research a better understanding of vasculitis. Please everyone, take care.

Dorothy Ireland
Chair Vasculitis UK 1180473

Vitamin D3: A Strategy for Fighting off Covid-19

When I was a young lad, just after the war, in the days of gas lamps, steam trains & horses & carts, the NHS was newly born. One of the worst features of the NHS for me was a daily dose of a teaspoon of cod liver oil. In my mind, I can still recall the awful taste. Even the promise of a sweet or a rare piece of chocolate afterwards was not enough to compensate. But my mum told me it would give strong bones and ward off colds.

As we all know, Vitamin D is essential for healthy bones, by regulating calcium uptake and metabolism. But it does even more. It acts like a hormone. It is not so widely known that vitamin D – mainly Vitamin D3 – plays an important role in regulating the immune system.

When I was a child, in those early days of the NHS, Ricketts was a serious & common disease. Caused by short-age of Calcium and/ or vitamin D in growing children, it caused bow-legs, which persisted into adulthood. In WW1 and WW2, it was a regular reason for rejecting British recruits to the forces. So, to ensure healthy kids, under the new NHS, children were given – or offered – cod liver oil, along with welfare orange juice and dried milk for babies. We make our own Vitamin D naturally, when the skin is exposed to ultraviolet light. Our distant ancestors evolved in sub Saharan Africa, where the sun is intense, with too much UV light, so they developed darker skin to block out excess UV rays. But they still received enough to ensure adequate Vitamin D. However, at the end of the last ice age, as the ice retreated, people migrated north and south towards the poles where sun is much less intense and summers are shorter.

In these temperate zones, a very dark skin became an evolutionary disadvantage as it filtered out the UV light, resulting in Vitamin D deficiency. Cooler temperatures and cold winters necessitated wearing clothes, thus reducing skin exposure to UV rays even more. Thus, over many generations, evolution resulted in the loss of protective melanin pigmentation from the skin. The further from the Equator, the paler the skin. Thus people from Mediterranean countries tend to have a light brown or olive skin, whilst those from Scottish or Scandinavian countries tend to have pale or white skin, usually with red or blonde hair. People of Celtic or Pictish origin paradoxically often have very white skin but have still retained their black hair.

Now, in 2020 pale-skinned people fear skin cancer caused by over-exposure to UV light, so they tend to cover their skin more and use high factor sun lotion. Atmospheric pollution reduces the amount of UV light reaching ground level. Doctors are now seeing a resurgence of ricketts in children, considered to be largely due to insufficient Vitamin D.

There are 4 types of Vitamin D. They all function in the body like hormones. Vitamin D2 is more associated with absorption of calcium from the gut and bone formation & replacement. Vitamin D3 has a powerful effect in regulating cell metabolism and regulating or moderating the function of the immune system. Thus Vitamin D3 has an effect in making the immune system not stronger, but more effective. As Covid has demonstrated, our bodies can suffer from an "over-enthusiastic" response to infection from our immune system. The "cytokine storm" is a feature of this and not unlike the catastrophic immune system response sometimes seen in some types of vasculitis, leading to multiple organ failure and sudden death.



Serious studies are now taking place to investigate if there really is a benefit from improving Vitamin D3 levels in terms of reducing infections such as common cold & flu and improving the course of the disease in those affected by the Covid virus.

There are limited dietary sources of vitamin D3, mainly oily fish (salmon, tuna & mackerel), beef liver, with lesser amounts found in cheese and egg yolks. A varied healthy diet containing oily fish combined with normal sun exposure will provide adequate Vitamin D3 for most of us. Those with a poor diet or low exposure to UV light such as elderly or housebound people (eg. those who are shielding for a long time) or those with a pigmented skin may have inadequate levels of Vitamin D3, making them more vulnerable to everyday infections and Covid.

Overdosing of Vitamin D is very rare and unlikely due to sunlight exposure or dietary sources. The maximum daily dose is considered to be 1000-4000 International Units or 25-100 microgrammes. A daily cod-liver oil capsule will not take you beyond these limits and you can buy a year's supply from Amazon for only £12. Avoid proprietary brands which can give a much higher dose and consult your doctor before taking supplements if you have kidney disease.

The full benefits of Vitamin D3 are still not clearly established but the above information might partly explain why Covid tends to have a worse effect on the elderly and people of colour and why it seems to be more virulent in the dark days of winter. Susan & I have each routinely taken a fish oil capsule since March. So far no discernible ill effects and remarkably free of colds & sniffles. Of course, that's not evidence. But we're doing what Nanny NHS & Mum advised 70 years ago.

"The Scottish Health Department are providing extra advice for individuals in high risk groups who are "shielding". They are also providing these people with a free supply of Vitamin D supplements over the winter for added protection."

John & Susan Mills

Lay Summary

How many people with vasculitis died during the 1st wave of the COVID-19 pandemic compared to the general population?

We looked at whether people with vasculitis, and other similar rare diseases, were affected more seriously during the COVID-19 pandemic than the general population, and whether people with vasculitis had an increased risk of dying during this time.

People with rare diseases often have poorer health outcomes than people with more common diseases. A recent large UK study by OPENSAFELY found that people with common autoimmune diseases, such as rheumatoid arthritis or psoriasis, had a little increased risk of death due to COVID-19. However, not much is known about the risks to people with vasculitis during COVID-19.

Our findings:

We looked at the electronic health records of over 55,000 people with vasculitis in England. During March and April 2020, the first two months of the COVID-19 pandemic in England, we found that 892 (1.6%) people with vasculitis died.

Our main findings were:

- When compared to before COVID-19, the risk of dying during March and April 2020 for people with vasculitis was surprisingly not higher than the average during March and April of the previous 5 years.
- The highest rate of death among people with vasculitis during the previous 5 years was during the 2015/16 influenza season, and the second highest was during the 2014/15 influenza season; both of these were higher than during March and April 2020 during the COVID-19 pandemic.
- The rate of death during March and April 2020 was higher than the rate during March and April of previous years that did not coincide with that year's influenza season.

Implications

- We recommend that you have the flu jab (influenza vaccine) each year. People with illnesses requiring immunosuppressive treatment are eligible for the annual influenza vaccine regardless of age. You can access this via your GP.

Future work:

- This work does not show the effect of shielding during COVID-19, and whether things may have been worse without shielding. To answer this question we will look at rates of COVID-19 infection and the reasons why people died in people with vasculitis compared to the general population.
- The work will help to inform plans for shielding, how to deliver healthcare and prioritise services to keep open during a second wave of COVID-19. It will also inform future priorities for COVID-19 vaccination if and when a vaccine becomes available.

This summary relates to work contained in: ***Risk of death during the 2020 UK COVID-19 epidemic among people with rare autoimmune diseases compared to the general population. A whole-population study in England, using data from the National Disease Registration Service and the Registration of Complex Rare Diseases - Exemplars in Rheumatology (RECORDER) project.*** Emily J Peach, Megan Rutter, Peter C Lanyon, Matthew J Grainge, Richard Hubbard, Jeanette Aston, Mary Bythell, Sarah Stevens, Fiona A Pearce. doi: <https://doi.org/10.1101/2020.10.09.20210237>



FROM THE EDITOR

This editorial feature is done in loving memory of my dear Sister, Clare Grossman, who was taken from us at the age of 38 due to Wegener's granulomatosis (GPA) back in 2010.

Dear Reader, welcome to our slightly later edition firstly I must mention a correction from our last publication on page 11 DOCTOR Janice Harper - we made a typo by calling her Professor Janice Harper and not to be confused with Professor Lorraine Harper.

This Edition was quite a struggle to get out and at one point we weren't even sure we would have one at all, but we thought it was in everyone's best interest to get something out so hopefully it is still delivering as the intention in normal times, what ever they might be!

We have some wonderful stories and valuable information inside this edition and its so good to see that many are still fundraising and raising awareness for this fantastic charity, which is truly needed during these unprecedented times, let's hope that by the time our next edition hits the door mats we are all in a better place, somehow, as we now enter another lock-down in England in two days at the time of writing this that time seems so far away, please stay safe and I would like to wish you all the merriest Christmas as you can from the editorial team and lets hope 2021 is a much better one for us all.

Kevin



The VUK Christmas card designed by Kelly Jefferies will be available from the VUK online shop from the middle of November.

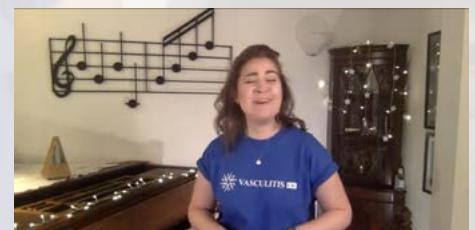
<https://www.vasculitis.org.uk/shop>

Cecily Redman In Concert



Cecily Redman streamed a concert fundraiser for Vasculitis UK has so far raised over £1,000 to date.

Cecily has an extremely rare type of Vasculitis called Takayasu Arteritis <https://www.vasculitis.org.uk/about-vasculitis/takayasu-arteritis>, you can still view the streamed concert at the following link: <https://youtube/KZrilz6fr04>



Me and My Shadow – the inner dialogue

Whispering I hear

As my 'consciousness' walks hand in hand with my 'shadow'

"Is it my shadow? Or Is it yours?" Asks consciousness from shadow

"I stand with you", says consciousness "Do you stand with me, shadow"?

"Look who's talking" says shadow, "You or me?"

You keep saying, I only cast your gloom

And, now you ask whether I stand with you?"



Arguing with shadow
Laughing with shadow

Running away from shadow
Catching up with shadow

Avoiding shadow
Seeking shadow

Stepping out with shadow
In-tune with shadow

Engaging with shadow
Embracing shadow

Trying to feel superior to shadow
Feeling inferior to shadow

Touching shadow
Shrugging off shadow

Supporting shadow
Rejecting shadow

Liberating from shadow
Returning to shadow

Being kind to shadow
Being angry at shadow

Forgiving shadow
Reflecting with shadow

Respecting shadow
Empowering shadow

A step closer to being synchronous with shadow?
A step closer for inner life 'consciousness' and outer life 'shadow',
to be in vibrational harmony?
Resonating as one?

Whispering stops
All is still
Well, well
Is this indeed a step closer to be in sync with my 'whole' self?

Shanali Perera



The British Paediatric Neurology Association and James Lind Alliance have just launched a Priority Setting Partnership survey to help define the Top 10 unanswered questions about the treatment of Childhood Neurological Conditions. For more information about the Priority Setting Partnership please visit our website which sets out our objectives and who is involved in our Steering Group.

We would like to invite you to help us ensure that the surveys and workshop we carry out involve those whose lives are affected by these conditions and the clinicians who treat them.

The first stage of the PSP is to ask patients, carers, and clinicians, via an online survey, for questions about childhood neurological conditions where there is uncertainty about the effectiveness of treatments.

Following the end of the survey, an interim prioritisation exercise then takes place, before a priority-setting workshop is convened where participants, representing patients and clinicians, debate and finally arrive at a Top 10 list of research priorities.

The eventual aim is to turn these priorities into funded research questions that have the potential to go on to improve the lives of children with these conditions.

The first survey is now live! We would be hugely grateful if you could send the survey link to your friends and contacts https://www.surveymonkey.co.uk/r/BPNA_JLA_RESEARCH_PSP

If you would like to promote the survey via social media the three accounts that will be used during this time to tag or reference us are Facebook - BPNA.org / Twitter @BPNA_org / Instagram @child-neuroconditionsurvey

If you have any questions about the PSP please do let us know by contacting the PSP Administrator philip.levine@bpna.org.uk

Rare Autoimmune Rheumatic Disease Alliance Latest Report



RAIRDA have just published a report based on our survey of 1,300 people with rare autoimmune rheumatic conditions. These people are facing a Chronic Crisis as the impact of COVID-19 exacerbates issues they faced before the pandemic.

From April 27th to May 15th 2020 RAIRDA conducted an online survey of people with RAIRDs. They received over 1,300 responses from across the UK. This report is based on these survey responses and covers a range of issues which have affected people with RAIRDs during the COVID-19 pandemic from healthcare to employment and financial issues.

Key findings

54% of respondents to the survey were currently shielding.

80% of people with these conditions had experienced a change in their care.

37% of these people said that their ability to manage their condition had been affected as a result. Virtual or telephone appointments can be helpful, but on their own they are insufficient to give all these patients the care they need.

33% of people with RAIRDs say the pandemic has adversely impacted their household finances compared to 23% of the general public.

34% of people with RAIRDs said that advice from the health service or the government was "unclear and contradictory".

Some people raised concerns about accessing healthcare due to not wanting to add to the burden on the NHS or fears of infection with COVID-19. However, many more commented that they felt 'abandoned' due to a lack of clear information about their level of risk or the way their treatment plan had been changed.

To read the full report please follow this link <https://rairda.org/our-reports/>

ACHIEVEMENT THROUGH HOPE AND INSPIRATION

By Anna Reavell



I was diagnosed with ANCA positive MPO vasculitis in March 2018. Along with the general symptoms it mainly affects my lungs and kidneys. I responded well to rituximab and apart from an emergency admission with possible sepsis later in the year I did well. Sadly 2019 I relapsed and after several months struggling to walk and getting extremely breathless I had another induction course of rituximab and was moved onto 6 monthly maintenance treatment.

In February 2020 I decided that I would do Couch to 5K. Luckily, I live in the countryside and can avoid people so when I had to shield, running became a focus and really helped. I soon found that I was running 3 times a week and I was feeling better than I had done in over 3 years. Always liking a goal, and in a moment of what some might call madness, I wondered if I would be able to run a marathon! Half hoping my consultant would say no, I got the 'all clear'. My training plan included needing a rituximab infusion in August but I had not taken into account how much my walking, let alone running, would deteriorate and how breathless I would become so training was paused. Then due to Covid restrictions I heard that the New Forest Marathon would probably be cancelled. Good news followed, a new venue had been found, it would be a week later meaning it would be 6 weeks after my infusion, however the new course was twice as hilly!

On the day, we were all given a separate start time so we could socially distance. This meant quite a few runners had already started. I set off at a good pace and really enjoyed the first 10 miles even overtaking a few people. I think I then hit 'the wall'. I thought this might be at mile 20 not 11 and I did not know if I would finish. The hills had taken quite a lot out of me, so I decided that I would walk up the steeper ones if needed. Psychologically this really helped. Counting down the miles in single figures from mile 16 also gave me another boost and by 20 miles I knew I would make it. I even ended up running a little more than the full marathon as my running watch had not recorded 26.2 miles!

It is definitely the hardest thing I've physically done. My official time was 5 hours 21 minutes and 17 seconds.

I remember reading in the newsletter about people having completed a race or climbing various peaks. Those stories gave me hope and inspiration when I was struggling with my new diagnosis. Vasculitis UK has supported me on several occasions, and I am pleased to have raised over £600 for them.

I also really hope that I too, will give others with vasculitis, hope that with a bit of luck and a lot of determination you can achieve your own crazy goals.



Mr & Mrs Reavell

Jemma Jones - 4x40 Challenge at 40 for VUK



Michael McCabe (Peter Pan) ran the Virtual Edinburgh Marathon 2020 Raising over £700 for Vasculitis UK



Jemma has raised over £1000 during the COVID19 lockdown, for VUK. Jemma's mum has Vasculitis.

With the cancellation of many fund raising events this year, its great to see so many of you still finding ways to raise funds for Vasculitis UK.

One of those events was the Great North Run, where there should have been 20 of us pounding the roads of Newcastle to South Shields. With the event cancelled there was the opportunity for a Virtual Great North Run.

One of our fundraisers Sally Rawlins decided to complete the challenge, and in her own words.....

I was diagnosed was MPA Christmas 2018 with kidney involvement. When I was first diagnosed I could hardly walk never mind run and thought I would never get back to it as I was a keen runner pre diagnosis.

I was really pleased to get a place in the Great North Run for Vasculitis UK but sadly this was not to be. This would have been the 40th year of the GNR and to celebrate this a challenge was launched to run 40 runs over 78 days. Due to shielding I had not been out running very much but decided I would take this up and set the alarm very early to be up and back before anyone else was about. I managed to run 217 miles during July and August. This helped towards training for the Virtual Great North Run that I completed on 13th September. It was a hot day and I was pleased to finish in 2.18 hours.

Sadly due to Covid 19 I couldn't have a big fundraising event but did manage a socially distanced afternoon tea in my garden to boost my fundraising efforts for our charity. As of 30th September Sally had raised £828.00 for VUK.



Next year Sally is hoping to line up with 20 VUK fund raisers and 50,000 other runners in Newcastle to complete the Great North Run 2021.



Kyri Roebuck and Tillypops have raised over £143, Selling masks for Vasculitis UK. Find out more by following Tillypops face book page.

<https://www.facebook.com/groups/tillypopscharitypettoys/?ref=share>



Kat Smart pictured below completed her 100 Centurion run the week 25th May, running 115 miles, raising £490 for Vasculitus UK. Which is an amazing achievement as Kat suffers from Fibromyalgia & PTSD.



Vasculitis UK member, Margaret Duckett lives near Preston & is a member of Stonyhurst Golf Club. This year's Lady President agreed to dedicate her Lady President's day tournament in support of Vasculitis UK. The first planned event was rained off, but the second was more successful and resulted in the presentation of a cheque for £200. The photograph shows members, socially distanced, making the formal presentation.

Vasculitis in India- A PGIMER, Chandigarh experience

By Professor Aman Sharma, Clinical Immunology and Rheumatology Wing, Department of Internal Medicine, Postgraduate Institute of Medical Education and Research, Sector-12, Chandigarh-160012, India.

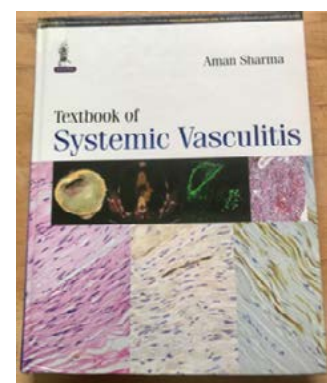


The epidemiological description of vasculitis from India is largely based upon the studies done at tertiary care teaching hospitals. Post graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India, which has been declared as '*Institute of National Importance*' by an Act of Indian parliament, is one such Institute at the fore front of vasculitis care and research in India. ANCA associated vasculitis and Takayasu's arteritis are the two most common types of vasculitis seen by us. Behcet's, Polyarteritis Nodosa and systemic disease associated vasculitis are also seen frequently. Giant cell arteritis is rare. Recently a relatively large cohort of newly diagnosed monogenic disease, DADA2 has been reported.

The studies done at PGI have shown that PR3 positive Granulomatosis with polyangiitis (GPA, previously known as Wegener's granulomatosis) is the most common ANCA associated vasculitis, followed by MPA and EGPA. Our patients had relatively less severe renal involvement. Various studies on histopathological correlation, ANCA status, Renal, Neurological, ENT and pulmonary involvement, cytokine profile, HLA associations and proteomics on MALDI-TOF have been carried out in these patients. One challenge that our patients face is the cost of therapy, and our experience showed that cost effective biosimilar rituximab is safe and efficacious. Takayasu's arteritis is also common here. A diagnostic criterion, and various clinical, imaging and laboratory studies in Takayasu's arteritis have also been published from here. Our colleagues from the pediatrics clinical immunology and rheumatology services are actively working in the area of Kawasaki disease. Both classical polyarteritis nodosa and DADA2 have been seen and reported. The role of CT angiography in PAN was highlighted by the work done here. Recently, we published a collaborative study which showed that DADA2 is common in adults, with patients having both disease onset and establishment of diagnosis well into the adulthood. Novel presentations like pancreatic infarcts, posterior reversible encephalopathy syndrome and diffuse alveolar hemorrhage were reported in these patients. It was also shown that biosimilar TNFis are also effective for most of the clinical manifestations. Unlike the western world, giant cell arteritis is rare in Indian population, and these patients are a decade younger with severe eye involvement. Behcet's disease presenting with severe eye involvement and arterial aneurysms is also seen.

The other area of our great interest has been relapsing polychondritis. This disease is rare, but some of the manifestations like airway involvement may be fatal. PET-CT studies done in our patients showed asymptomatic airway involvement and large vessel vasculitis in these patients.

Realizing the need to increase awareness about systemic vasculitis, two plenary sessions were devoted to systemic vasculitis during the national conference of Indian Rheumatology association (IRACON) hosted at PGIMER in 2014. Prof David Jayne and Prof Justin Mason from UK, and Prof Loic Guillevin (France) and Prof Wolfgang Gross (Germany) delivered key note addresses during these sessions. First International vasculitis symposium



was organized at PGIMER in 2018 in which Prof Richard Watts, Prof Justin Mason, Dr Chetan Mukhtyar from UK and Prof Loic Guillevin and Prof Alfred Mahr from French vasculitis group participated. This meeting was attended by more than 600 delegates from all over India. PGIMER had to be a co-host for the second edition of this meeting to be held at Bengaluru this year but that had to be postponed due to the COVID 19 pandemic.

We have started the Indian vasculitis registry and Indian Relapsing polychondritis registry. We also participated in the ACR EULAR led DCVAS study for developing criteria of various vasculitides, and I also got an opportunity to be an expert reviewer in that study. We were also involved in the development of relapsing polychondritis disease activity index (RPDAI) and relapsing polychondritis damage index (RPDAM). We are now collaborating with the NIH investigators led by Peter Grayson and Marcella Ferrada for development of classification criteria of relapsing polychondritis.



(Left to right) - Prof Alfred Mahr, Dr Chetan Mukhtyar, Prof Aman Sharma, Prof Loic Guillevin, Prof Richard Watts, Prof Justin Mason,

Special supplements on systemic vasculitis in Indian Journal of Rheumatology (Guest edited by myself and Prof Richard Watts, (<https://www.sciencedirect.com/journal/indian-journal-of-rheumatology/vol/10/suppl/S1>) and International journal of Rheumatic diseases (Guest edited by myself, <https://onlinelibrary.wiley.com/toc/1756185x/2019/22/S1>) provide our perspective about these diseases and would make interesting reading for the people interested in the field. Textbook of systemic vasculitis edited by myself (<https://www.jaypeedigital.com/book/9789351526520>) has become very popular amongst rheumatology fellows and practitioners, physicians, pulmonologists and pathologists. I must thank John Mills for presenting this book as an award at the vasculitis UK stalls during many BSR meetings.

The various challenges facing our patients in our large country are limited availability of vasculitis experts at big tertiary care centers, costs of travel and therapy, treatment side effects, infections and co morbidities. We need patients to form self-help groups like vasculitis UK. Some baby steps have been taken by creation of FB pages by some patients. I have been constantly encouraging my patients and I hope that the dream of having group run by our patients soon becomes a reality. These groups will surely help our patients.

I hope that you would take good care of yourself and stay safe during these testing COVID 19 times. Stay safe. God bless you all.

Aman Sharma

Pandemic and the virtual conference experience

By Dr Shanali Perera



The year 2020 offered and continues to offer unprecedented, uncertain and unsettling times. As a result of this, we have had to adapt in creative ways to work around travel and come with new ways to substitute face-to-face meetings. Attending zoom meetings and virtual conferences have been a first-time experience for me. Doing a presentation or workshop via zoom has taken a bit of getting used to. Although it can never replace the true spirit of face to face meetings, it certainly is a good alternate option to stay connected and continue being active during these challenging times. Present day Digital media has transformed the landscape of online social networking allowing wider interaction with others through a variety of platforms and forums. The pandemic has revolutionized how we utilise online platforms to maintain interpersonal connections, share and contribute thoughts, reflections with others. This not only breaks the isolation; it also contributes to social learning and increases self-worth.

Vasculitis Ireland Awareness (VIA) 2020 Conference, offered such an opportunity for me. I was invited to speak on my encounter with art and illness and I am sharing with you my reflections and take on the conference experience. But firstly, how did this come about? I met Patricia Ryan, Co-chairperson of VIA last year, at a photoshoot event which was part of 'See Me Hear Me' patient creative campaign for ANCA vasculitis, held in Manchester. It was this connection that led me to the event. VIA celebrates 10yrs this year. Due to COVID-19 restrictions, the Annual Conference was held online over two days via a zoom call presentation. I found this virtual conference an amazing experience. The split of two days also helped with my attention span, which I must confess is limited at times. I get fatigued out and overwhelmed if I concentrate for a few hours at a time. Some of you might be able to relate to this.

Day 1 was Friday the 9th of October, where an evening session was held. Kicking off with Dr Michael Clarkson, Consultant Nephrologist from Cork University Hospital covering '*Vasculitis care during the COVID19 Pandemic*'. We then moved on to Silvia Fleming, a teacher attached to The League of Health Ireland doing a session on '*Vasculitis friendly exercises*'. Then, we had '*Metabolic Syndrome: relevance to Vasculitis Covid and beyond*', a talk by Dr Eamonn Molloy, Consultant Rheumatologist at St Vincent's Hospital, Dublin just before the tea break.

After the break, came a session that most of you are familiar with – the '*See Me, Hear Me, Patient Engagement*' co-creative initiative for patients with ANCA vasculitis delivered by Dijana Krafcsik from Vifor Pharmaceuticals. I have to slightly digress at this point, just to mention that Vasculitis UK played a significant role in this initiative. For those of you who are not familiar with it is worth checking the website out. www.myancavasculitis.com

Back to the conference. The last session for the evening was by Dr Padraic Dunne, Lecturer of Positive Psychology and Health at the Royal College of Surgeons in Ireland on '*Managing Anxious Thinking and Symptoms. Acceptance*'. Now, this is a talk that was very close to my personal experience, views and my very own art concept. He is an Immunologist, a patient with a Rheumatological condition, practising psychotherapist and meditation teacher. He was speaking about things we cannot control vs. things we can when we go through our illness journey. What I took from that is, making a list of the things we can control perhaps can help us to focus on them better, than spending time to dwell on what we can't control. I can certainly relate to that. In the beginning, I had lost total control of the direction my life was heading. I could not control my day, my symptoms or how the illness was evolving. But, I found I could control what I draw and create. This certainly helped me to focus on what I can do vs. what I can't, giving me a sense of purpose and achievement. That in turn helped me to regain some control over being dominated by the illness and was my turning point. It was a form of emotional self-regulation that helped me to learn to walk past old expectations and standards set by my 'pre-illness' self and re-define aspects of a 'new version of me'. Reflecting on that may prove useful to those of you, who can relate to this, going through similar situations. He also pointed out 'how acceptance of the situation' is the key to move forward. There again, that struck a personal note with me. For example, by drawing what my pain looked like, art helped me to understand what's going on with me, how it affects me, how do I perceive my pain and how it's impacting my lifestyle. Part of coping with the illness was about learning to accept my new circumstances and understanding the limitations I would face in my new reality. Another point to ponder on. Dr Dunne further went on to explain

about neuroplasticity. I will come to why this subject fascinates me. From my understanding, Neuroplasticity – or brain plasticity – is the ability of the brain to modify its connections or re-wire itself. Without this ability, any brain, not just our human brain, would be unable to fully develop from infancy to adulthood or recover from brain injury. Our brain's structure changes as a consequence to stimuli, such as accidents, strokes, illness, other activities and so on. Imaging studies with MRI scans and other imaging show that with proper rehabilitation, the injured brain rewires and recovers its function. Rehabilitation treatment is achieved by focused "stimuli", this time it is a therapeutic type of stimuli. Wait for it... and ... Art and Creativity activities are such stimuli! You will soon see why his session connected with me at a very personal level. It tied in very nicely with the content of my talk, planned for the next day.

Moving onto, Day 2 Saturday the 10th of October. The morning session included '*Recent Advances in Vasculitis Care in Ireland*' by Prof. Mark Little, Consultant Nephrologist based at Tallaght Hospital, Dublin. Then the '*AVERT study*' was covered by Trinity Health Kidney Centre: Rare Kidney Disease Registry Nurse and Dr Michelle O Shaughnessy Consultant Nephrologist at Cork University Hospital. Gears were switched a little with the next session, '*Vasculitis Friendly Exercises*' by Silvia Fleming, Teacher - The League of Health Ireland.

After the tea break, talk on '*Decompress: defining the disease course and immune profile of COVID-19 in the immunosuppressed patient*' by Dr Emma Leacy followed by the opportunity to meet Dr Dunne again, after the previous evening talk for a session on '*Body Scan Meditation*'.

Then there was Lunch....

Next up was me, after lunch with my talk '*Illness, Self-Expression and Human Resilience*', shifting gears again. I shared a snapshot of my journey using art to transform my illness experience into a more meaningful way of living, moving from a clinician to a patient. Highlighting how Art helped to see and tell my story from a place of deeper understanding. Illness makes you a different person, 'who you were' has now transformed into 'who you have become', a new person with an added personality: the illness. My talk aimed to cover 'how Art can be a tool to explore further as an approach to the self-management of illnesses to help modify lifestyles and deal with challenging situations'. The potential benefits I felt by facilitating self-expression through creativity. As well as expand on 'how art creates a common language to highlight poorly addressed issues that revolve around people living with chronic ill-health'. Adding to our understanding of emotions and examine socio-political, religious, cultural issues influencing patients; their beliefs and perceptions. I now draw your attention back to our brain. My talk also touched on 'how drawing relies on 'vision and visualizing, creation, intuition, and seeing the big picture'. These states are accessed within the right side of our brain. Pain perception also happens on the right side of the brain. Coming back to the subject of 'neuroplasticity', Art has been found to effectively deliver intense stimuli to various areas of the brain to expand brain plasticity, and it can take over neural connections formerly inhibited by pain centres or similar negative brain areas. This can help "pinch" back neuron pathways from the pain affected areas. Now, that is food for thought, along with the questions, 'Would visually capturing the invisible subjective world of feeling, by giving a structure or form to make it visible and tangible, make a meaningful difference to the person going through it?' A difference in connecting with it all? understanding it? accepting it? communicating it to others?'

Back to the next session, '*a patient journey*' by Cecil Armstrong (patient) and Dr Chris Hill, Consultant Nephrologist at Belfast City Hospital. This was a fantastic session highlighting challenges that are shared by the patient and the clinician. Parting video on '*Introduction to Music Therapy*' by Margarete Collins, Music Therapist and professional member of IACAT was a great note to end the conference.

As a speaker, attending the conference I took away valuable insights drawn from the fabulous blend of sessions. Quite the variety of topics, I thought and a great mix of academic, pandemic and holistic themes covered. People had the opportunity to unmute and asked questions from the speakers as well as use the chat option to type in queries. This proved very effective, allowing the participants to share comments and questions as well as contribute their ideas. The moderators on both days did a terrific job and it was a brilliant effort by the organizing committee. I hope my version of a somewhat modified running commentary gave you a hint of what this virtual conference experience looked like and given you lots to think about. Perhaps even a glimpse of more to come in future events. Even when we do get the opportunity to hold face to face meetings in the future, having screens for participants to access meetings and conferences remotely can be utilised much more than the pre-pandemic era. Something else, to think about as we look ahead, moving forward armed with pandemic 2020 learning experiences.

'No man ever steps in the same river twice, for it's not the same river and he's not the same man'.
~Heraclitus (535BC – 475BC)

SEE ME HEAR ME

See Me Hear Me forms part of a mission to help patients around the world diagnosed with ANCA Vasculitis to lead better, healthier lives.

ANCA Association patient group representatives from all over Europe were involved at every step of the development of this creative initiative and even helped to choose its name SEE ME. HEAR ME.

The accompanying artwork is from a series of designs created by Shanali Perera – an artist, rheumatologist, and vasculitis patient. <https://www.changinglanes.me/>

To read more please follow this link <https://www.myancavasculitis.com/> via the Vifor Pharma website.

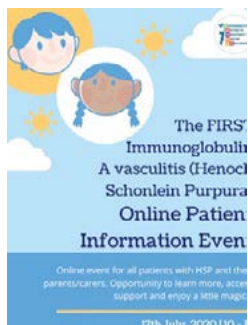
Susan Mills



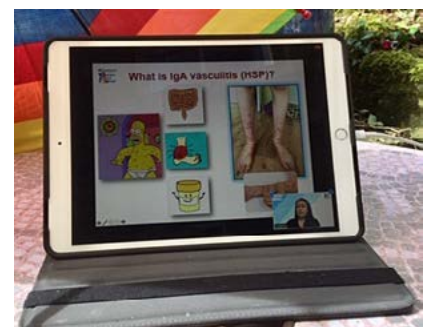
The First Immunoglobulin A Vasculitis (HenochSchloein Purpura) Online Patient Event

“Seek to learn constantly while you live”, quoted Solon the Athenian more than 2500 years ago.

When I was given the opportunity to participate in the first IgA Vasculitis online Event, I gladly accepted it. I am used to be a silent observer in these events so having to present something was a challenge for me.



What is IgA (HSP) Vasculitis; what can trigger it; when to worry; how is it diagnosed and how is it treated; is this type only affecting the skin; does it affect all ages; can it be serious; why is kidney monitoring essential? These and more were discussed in this online event. Dr Louise Oni, Prof. Christian Hedrich and Prof. Alan Salama gave an insight of this type of vasculitis to the participants – patients and carers. I gave a small presentation from Vasculitis UK about the support we provide to vasculitis patients and their families. Participants also had the opportunity to ask the panelists questions and raise their worries.



Did you know that poor dental hygiene can trigger IgA vasculitis? I certainly didn't. Follow the link and you will not only learn about IgA vasculitis, but you will enjoy some magic too.

<https://www.liverpool.ac.uk/eatc-for-children/engagement/events/>

Zoi (Vasculitis Trustee)

Participating In A Covid-19 Trial

When I attended a drive through Coronavirus test, there was a leaflet inside asking for volunteers for a trial to train medical detection dogs to detect Covid-19. The leaflet, explained they needed volunteers who were due to have a Coronavirus swab test or had had one in the previous 24 hours and have suspected mild Covid-19 symptoms to wear a face mask for at least 3 hours, nylon socks & a shirt for at least 12 hours.

As a patient advocate for Vasculitis UK and having taken part in other trials, I am a firm believer in volunteering for trials that can help other people in the future so when I arrived home I registered my interest. They got back to me quickly, I explained that I have pre-existing conditions and I am immunosuppressed but they were happy for me to enrol.

I received my pack on the Tuesday morning, I read through the paperwork (which was basically ensuring I knew what I was signing up for and to fill in my details to consent) and filled in the consent forms.

I put the mask on (which are similar to the ones handed out in hospitals) and did not have any discomfort at all as I could breathe easily. I had the mask on for over 4 hours in total before I followed the instructions on how to package it back up in foil and place in a bag. I put the shirt and socks on around 10pm and was in bed around midnight. It was a warm night so the nylon socks did make my feet a little hot but I had my tower fan on overnight to cool the room down so I managed to wear them all night – along with the shirt – with no problems.

In the morning, I then followed the instructions again on wrapping them in foil and then the bag, wiping the bags with alcohol wipes before putting into another bag and, finally, into a mailing bag along with my paperwork with a prepaid address label to attach. All the foil, bags, alcohol wipes etc are provided. My husband then popped the bag in the post box and that was all I had to do!

I received an email 3 days later to let me know they had received my samples, asking me a few questions (such as, did I have any adverse reactions while wearing the mask/socks/shirt) and asking for a copy of my Coronavirus test results, which were negative, (which is something they need and a specification of being a volunteer which I was aware of and happy to do).

I can highly recommend anyone who is suffering from suspected mild Covid-19 symptoms and needs a swab test to enrol in this trial as it made me feel good about myself for being able to help in the fight against Covid-19 as I haven't been able to do much due to being clinically vulnerable and having to shield.

PLEASE check out their website which has lots more details including what they hope to

Dogs are being trained to detect people with coronavirus to prevent the spread of infection and reduce unnecessary quarantine.



**YOU CAN HELP
MAKE A REAL DIFFERENCE**

If you have had a recent coronavirus diagnosis or you are booked in for a test, you can be part of this exciting research by collecting your body odour on clothing samples we will provide!

It is quick, simple and you can do it yourself at home. Please contact us as soon as possible.

Call: 0207 927 2777

Email: coviddogs@lshtm.ac.uk

Visit www.virusdogs.com for more information.



achieve, information and photos of the 6 dogs taking part in the trial, what happens to the data etc. The one thing that most impressed me the most was that 1 Covid-19 medical detection dog, once fully trained, could screen up to 250 people per hour. Imagine how useful that would be in scenarios such as airports, sports arenas etc – it is amazing, just like the dogs and staff who have trained them!

Kelly Jefferies

Research Roundup

Delays in Processing Grant Applications

As part of its research governance policy, when assessing research grant applications, each application is subjected to a rigorous peer review process by at least two experts appropriate to each application. Research projects may be mainly clinical or scientific (more laboratory based) or a combination of both. With 18 types of vasculitis, it is important to match applications with reviewers .

In the early spring of 2020 we had a record number of 20 varied applications to assess. This necessitated finding 20 suitable reviewers. With a rare disease like vasculitis, the pool of suitable experts is small. We had just managed to find & recruit 20 suitable peer reviewers when the pandemic was taking off. Most of our potential reviewers had to withdraw their offer to help Vasculitis UK as they were being drafted from their departments to serve on the Covid front line. So we had no option other than putting the whole grant assessment process on hold.

Thus, with a backlog of 20 unprocessed applications, we are unable to launch a call for new applications this autumn, which is very sad.

Only now are we able to restart the process, as the doctors have returned to their departments and caught up with the backlog of their own cases. Unfortunately, Covid now seems to be resurging again, so we are keeping fingers crossed that we can process the logjam and once more launch a call for new applications in 2021.

New Neuropathy Study

Many people with vasculitis have experienced neuropathy as part of their illness, although they might not know it. It may manifest as motor nerve neuropathy causing conditions such as foot drop or as loss of sensation/numbness.

Neuropathy also can affect the autonomic nerves. These nerves are involved in the unconscious or "automatic" control of many bodily functions, such as blood pressure, bladder control, digestion, sweating, pupils adjusting between dark & light – affecting night driving, exercise intolerance – where the heart rate fails to adjust to activity level, erectile dysfunction in men, vaginal dryness & loss of libido in women.

This new study, for which an MRC grant is being sought, will be undertaken by Dr Robert Hadden of Kings College, London and Professor of Oxford University. As far as I know, it is the first comprehensive study of neuropathy in vasculitis. Whilst neuropathy is not life-threatening, it can have a serious impact on quality of life in many ways. The project will require much patient input and Vasculitis UK patients will have the opportunity to submit a questionnaire about their experience of neuropathy.

NICE & Avacopan

Avacopan is a newly developed drug which has been undergoing clinical trials as an alternative to prednisolone in treating ANCA associated vasculitis. As part of its responsibility for identifying and assessing potentially beneficial new drugs or procedures, the National Institute for Clinical Health & Excellence carries

out "scoping" exercises to see if the drug or process should be assessed for use in the NHS. This is not the same as the process for licensing drugs. Many drugs are licensed but not approved by NICE for use in the NHS.

NICE is currently "Scoping" Avacopan. If Avacopan meets the criteria for being safe and potentially beneficial, NICE will carry out a "Single Technology Appraisal" of Avacopan to decide if it is both clinically effective and cost effective – ie if it does what is claimed to do and represents value for money.

New Guidelines For treating EGPA (Eosinophilic Granulomatosis with Polyangiitis/Churg Strauss Syndrome)

EGPA is a rare type of ANCA vasculitis which is associated with late-onset asthma and raised levels of eosinophils in the blood and tissues. (Eosinophils are a type of white blood cell, normally seen in a routine White Blood Cell count, but in relatively small numbers).

EGPA is a multi-systemic vasculitis characterised by asthma, sinusitis, peripheral eosinophilia, pulmonary infiltrates, neuropathy, and the involvement of other organs such as the heart, the kidney and the skin.

Due to its complex nature, multiple disciplines are involved in the care of EGPA patients, dictating an integrated and collaborative approach. EGPA is generally more difficult to diagnose, treat and control than other types of ANCA vasculitis. Commonly used immunosuppressant drugs such as methotrexate, azathioprine and mycophenolate do not seem to be effective in EGPA. Rituximab seems to produce less satisfactory results in EGPA than other types of ANCA vasculitis. EGPA is more likely to have associated cardio-vascular disease.

However, recently introduced "Biologic" drugs, such as Mepolizumab are changing the outlook for those with EGPA. Currently there are no specific guidelines for the management of EGPA. Thus a panel of internationally recognised vasculitis experts has been convened under the joint chairmanship of Professors Lorraine Harper of Birmingham and Raashid Luqmani of Oxford.

It is hoped that new cross discipline guidelines will be agreed this will result in the harmonisation of patient care and improved outcomes.



Before I had my daughter, people were quick to give their two pennies' worth and tell me exactly how parenthood would be. They warned me about the lack of sleep, the perpetual mess, and the horrors of childbirth which awaited me. I decided early on in pregnancy that if I managed to keep the family alive and well, my maternity leave would be a success, even if I never left the house. I didn't realise it at the time, but I may just have been on to something. I never expected staying home and keeping everyone safe would be the explicit focus of my first months as a new mother; I have definitely been living up to the title of 'stay at home mum'.

Our daughter, Heidi, was born in February and a couple of weeks later, my husband, Charlie, started his second set of cyclophosphamide infusions. Just a couple of weeks after that, we began shielding due to coronavirus. The drama was nothing new to us. Since Charlie was diagnosed with GPA in February of 2019, I became pregnant, we got married, we bought our first home and had our baby. All of this happened whilst Charlie was undergoing treatment with rituximab and cyclophosphamide and receiving multiple surgeries on his throat. In some strange way, being advised to stay home for months on end felt like a bit of a break, and although we were navigating our way through early parenthood whilst *still* trying to bring Charlie's disease under control, we were determined to make the most of spending our time exclusively at home.



To help pass the time, I began writing stories for children. First, I wrote a book about a baby in lockdown, based on photographs I'd taken of the things we had been doing at home. Then, I wrote a book about the science of COVID-19, both books written as a means of capturing these crazy times for Heidi, who will have no conscious memory of any of this. My latest book was written out of necessity: I knew that one day we'd need to explain vasculitis to Heidi but there were limited resources out there to help us do so. I wrote 'Holly Helps Out' for all of those who have been affected by vasculitis and would like to help their families to understand it. The book covers the onset of a parent's vasculitis and life following diagnosis and treatment; it focuses on explaining the illness, introducing some of the medical professionals who will support the family, and what life with a chronic illness means for the family. I'm really pleased to be able to share this story with others who would find it useful. Other than Charlie, we don't know anyone else in real life who is living with vasculitis; my hope is that now I've written this book, Heidi won't grow up feeling that she is the only one whose dad has a chronic illness.

We've been taking small steps to normality since shielding was paused at the start of August. Most of our time is spent at home, with trips to the park and socially-distanced meet ups with friends and family. 18 months ago we never expected our lives to look like this, but as Holly learns in the story, life with vasculitis doesn't have to look bad, only different!

Jen Harper, wife of Charlie who has GPA, and mum of Heidi (8 months)

The book will be available in hard copy from the VUK online shop from the middle of November. <https://www.vasculitis.org.uk/shop>

New Rheumatology Nurse Specialist at Norfolk & Norwich Hospital



Vasculitis Specialist Nurse

I began my new role as a specialist nurse in February 2020 to support patients with vasculitis and connective tissue disease (CTD). I am based in the Rheumatology Department at the Norfolk and Norwich University NHS Hospital and work alongside 2 consultants, Dr Chetan Mukhtyar (Vasculitis) and Dr Cee Yong (Connective Tissue Disease)

I had only been in post for 5 weeks before the lockdown was announced due to the covid-19 pandemic, but even in that short space of time; I learned an incredible amount with the support of the consultants and of course the patients themselves. The patients I have encountered in the last few months have been inspiring. I now have vasculitis books downloaded onto my Kindle for bedtime reading in my quest to expand my knowledge on these conditions.

The introduction of lockdown was a worrying time for our patient group as many were labelled as clinically vulnerable due to the nature of their conditions and treatment. During these unprecedented times, with staff redeployed and relocated to other premises, we managed to run a limited telephone service for patients that had developed new or worsening symptoms allowing prompt assessment and the provision of advice. Following a pause in routine services, our clinics are being re-established but this work is now largely carried out via telephone. In an ever-changing health service, the Rheumatology Department is functioning differently to pre-pandemic with far fewer face-to-face appointments and more virtual appointments. It hasn't stopped us from wanting to deliver great care. We continue to look at ways to develop and improve our service for the benefit of our patients.

As a Specialist Nurse, I run several clinics a week, providing education and counselling on new medications as well as providing patients with an opportunity to discuss their diagnosis and its impact on their lives. I also have monitoring clinics to assess disease activity after patients with vasculitis/CTD have started their treatment. I am also providing an annual review clinic giving patients the opportunity to discuss other aspects of their health such as family planning, lifestyle, cardiovascular and osteoporosis risk factors. In between these clinics the patients also have open access via the advice line. We encourage our patients to phone promptly if they are experiencing any problems relating to their vasculitis/CTD diagnosis and treatment.

These are very exciting times for vasculitis and connective tissue disease management in Norwich and I feel very privileged to be part of this process.

Georgina Ducker

ROYAL COLLEGE OF NURSING ACCREDITATION GRANTED TO VASCULITIS TRAINING COURSE



Two years ago Vasculitis UK supported my MSc dissertation to research and design a training programme for the delivery of intravenous Cyclophosphamide and Rituximab for the treatment of ANCA-Associated Vasculitis. The Royal College of Nursing (RCN) have now accredited this programme of study and the first training day was held last month.

Nine Vasculitis nurses from four Merseyside hospitals attended what proved



continued from page 18

to be a very successful workshop. RCN accredited certification will be awarded once delegates have accurately completed a detailed workbook which tests and challenges their knowledge to safely deliver these medications for autoimmune disease. Administration of these medications in the clinical environment is also assessed to ensure practical competence.

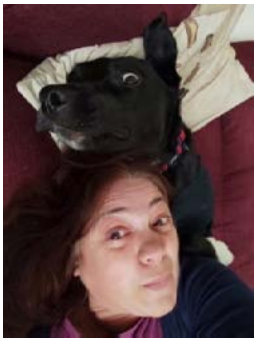


I would like to thank Vasculitis UK for supporting this work which will not only facilitate the favoured route of administration of these vital treatments for our vasculitis patients but it also addresses Health & Safety Executive recommendations and legislative requirements, Care Quality Commission standards and meets the 'Getting Right Frist Time' NHS improvement programme training standards.

For further information contact Sarah Hardy, Vasculitis Advanced Nurse Practitioner Sarah.hardy@liverpoolft.nhs.uk

Sarah Hardy

Having a rare illness during a pandemic



A year ago I was starting visiting shops to get my first Christmas presents; I booked tickets for a surprise visit to my parents the coming spring and couldn't imagine what 2020 will bring.

As all of the people in the high risk or extremely vulnerable group last March I was asked to shield for several months. Monthly monitoring was cancelled, as even going to the surgery was classed as an unnecessary risk. What a wakeup call! This was real and I had to adjust to a new way of living for some time. Not easy, as most of you know.

Having a rare illness like vasculitis is like being on a roller coaster all the time. During a pandemic this became even more evident. Fellow vascies complained about cancelled appointments, about how difficult it was to get through to their GPs and here am I having maybe even better care than before. All my face to face appointments changed to phone call appointments, all of them were on time and my doctor really listened to my concerns. My GP surgery did welfare checks by phone and made sure I was handling the situation.

In the uncertainty the pandemic caused it was a comfort to feel looked after. I understand that our area was not hit badly from Covid-19 and that has possibly played a positive role on my healthcare during the pandemic. What is certain though is that the wellbeing of a patient should be important and considered in the health plan made.

I am so grateful to Dr King and his team in Derifford hospital, Plymouth and St Levan surgery – especially to Dr Gastone and my nurses – for looking after me the last 6 years. I really wish this could be the average care for all vasculitis sufferers. We truly deserve a holistic care!

By Zoi Anastasa



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

We received many other donations from members and supporters, for which we are most grateful.

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.

Donations totalling £70 were received in memory of Rita Ackroyd of Northallerton, who passed away on 27th March 2020.

A memorial donation of £50 was received from the family of Francis Barber, who passed away on March 20th 2020, due to cancer.

The family & friends of John Richard Hill of Portsmouth donated £100 in his memory. He died in January this year due to ANCA vasculitis.

Funeral donations totalling £175 were received in memory of Mrs Suzanne Seddon of Suffolk.

Donations totalling were received in memory of Maureen "Jane" Davis who was born in Enfield on Christmas Day 1940. She lived latterly in Norfolk in retirement. and leaves a bereaved husband, Allen, two sons and six grandchildren.

Graham Frost of Caerphilly contracted EGPA(Churg-Strauss Vasculitis) in September 2000. He sadly passed away in February of this year. His widow, Jenny, has made a donation of £200 to Vasculitis UK in his memory.

Donations totalling £465 were received in memory of John Price of Congleton who sadly passed away in August this year, age 50, after suffering kidney failure due to MicroscopicPolyangiitis. A keen footballer and coach, John was partner to Sonia for 27 years and father to Chloe and Jack.

Donations totalling £150 were received in memory of Robert (Bob) Cowley, brother to Jane Knowles of Coventry. He was a much loved brother and uncle.

John Knox of Pembrokeshire sadly passed away recently. At his funeral, his family requested donations to Vasculitis UK in lieu of flowers, resulting in donations of £288.

Donations to Vasculitis UK in lieu of flowers resulted in a total of £50 donated in memory of Mrs Julie Guest of Newquay.

Donations of £920 were received in memory of the recently deceased John Holmes. He passed away in August age 73. A resident of the Minster in Isle of Sheppey, his late wife Joyce passed away in 2016. They were married for 46 years.



Joyce & John Holmes





Donations & Fundraising



Margaret Robertson recently gave a talk to the Durham U3A group. This prompted Mike & Nina Parker to donate £20 to Vasculitis UK.

Robert Scroby of Leicester kindly donated £50 to Vasculitis UK

The Beresford Peirse Masonic Lodge at Bedale in North Yorkshire held a Christmas Ladies' Evening which generated proceeds totalling £1000 which the donated to their nominated charity, Vasculitis UK.

Peter Pan (aka Michael McCabe) raised over £720 (+Gift Aid) by running a virtual Edinburgh Marathon, (accompanied by friends including Tinkerbell & Tick Tock Croc) round his garden. Michael has Polyarteritis Nodosa or PAN.

A donor living in Birmingham, who has vasculitis and wishes to remain anonymous, has made a second generous donation to Vasculitis UK, of £15,000 to support vasculitis research.

Gwen Kay of Stockport made good use of self isolation and joined the fight against Covid by making face masks, which she offered to friends in exchange for a £5 donation. Thus she was able to donate £150 to Vasculitis UK.

A Lady President's Day at Stonyhurst Park Golf Club raised £200 for Vasculitis UK.

Many others have made donations in addition to those listed here. We are extremely grateful for all donations received, especially in these difficult days of the Covid pandemic.

Donating To VASCULITIS UK

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

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

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

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

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



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

Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group

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

Cambridge Group

Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

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

Leicestershire Group

Leicestershire Group Website <https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home>
Tricia Cornforth - lvsg@btinternet.com

Lincolnshire Group

Sandra Lee - 0754 514 4777 - sandylee777@hotmail.co.uk
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London

North London Group
Dave Newman - 07429137670 - david.newman@londonvsg.org.uk

Merseyside, Cheshire and North Wales Group

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Dave Birch - 0151 7229049 or 07968226230 - davebirch@talktalk.net

North East Group

Margaret Robertson - 07443016665 - mgtrub@talktalk.net
susan@vasculitis.org.uk

Norfolk Vasculitis Support Group

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The North West Group

Jann Landles - Anita Parekh nwvasculitis@outlook.com

Northamptonshire Group

Maurice - northantsvsg@gmail.com

Northumberland and Cumbria (Contact person)

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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 - mgvsgwm@blueyonder.co.uk

West Country Group

Website <https://vasculitiswest.wordpress.com/>
Charlotte Stoner - 01626 872420 - the.stoners@talktalk.net

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 - 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 - james-walker@outlook.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

Given the continuing COVID-19 situation we have made the difficult decision to postpone the Vasculitis and ANCA Workshop in 2021.

As a community we understand the need for a conference where we can meet together in person to discuss and share knowledge, so we have decided against hosting a virtual conference.

Therefore we confirm that the 20th International Vasculitis and ANCA Workshop will take place on newly scheduled dates, 3-6 April 2022 in Dublin.

We would be most grateful if you can update your event listings/calendars and update your members about the new re-scheduled dates.

Conference Title: 20TH International Vasculitis and ANCA Workshop

Date: 3-6 April 2022

Location: Dublin, Ireland

Website: www.vasculitis2022.org

Email: Vasculitis2022@conferencepartners.com



Thank you very much for your support.

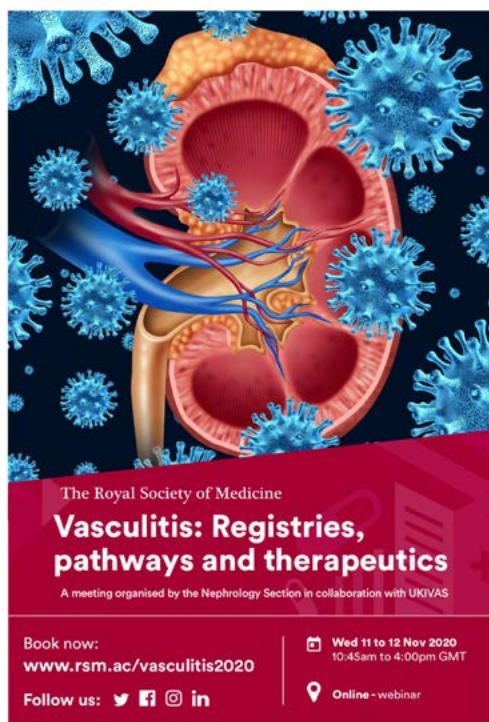
PROF MARK LITTLE
Conference Co-Chair Vasculitis2022

DR MICHAEL CLARKSON
Conference Co-Chair Vasculitis2022



British Society for Rheumatology

Date: 26-28 April 2021
British Society for Rheumatology Annual
Conference 2021 is going online.



EHIC – European Health Insurance Card
From 1st January 2021, UK residents
will no longer be covered by EHIC.
Travel Insurance

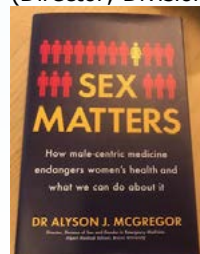
Travel insurance is essential for travel outside the UK, and for some people with a complicated medical history, the cost can sometimes be a shock. It is worth checking the cost of insurance before you go too far in developing your travel plans.

This link via the VUK website gives information regarding Travel Insurance recommended by our members <https://www.vasculitis.org.uk/living-with-vasculitis/insurance>

Please note: Vasculitis UK are not recommending any of the above and do not have any links with these insurance providers. These details are given in good faith and for information only.

Book Review:

“Sex Matters” by Dr Alyson McGregor
(Director; Division of Sex & Gender in Emergency Medicine. Brown University, Rhode Island, USA)



The title of this publication may sell books, but it is misleading: it should really read “Gender Matters”.as it’s sub-title indicates – “How male-centric medicine endangers women’s health and what we can do about it.” She puts forward the argument that men and women are fundamentally more different in their makeup than the traditional “boobs & tubes” difference.

Her arguments are convincing – such as a woman having a heart-attack does not show the standard “male pattern” presentation of a coronary, so her serious life-threatening condition goes unrecognised when she arrives at A&E.

Dr McGregor is an unapologetically committed feminist, but her case is very much evidence based. You can get a good preview of the book in her Ted Talk.- “Why Medicine Often has Dangerous Side Effects for Women”. – just Google Alyson McGregor & Ted Talk.

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. 1019983**

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