



# VASCULITIS **UK**

NEWSLETTER JOURNAL



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Well, what a year 2020 was!

I don't think any of us will forget it, even though we might want to. I hope you've all come through safely and had your covid-19 vaccination. We have sadly lost a few members but not as many as we at first feared. Our thoughts go out to their families. We know from the online support group that a few have had the virus and come through it.

Unfortunately, we still learn through the helpline, of people being diagnosed too late. Its not a call we want to receive. We also get a lot of newly diagnosed contacting us. I think we can all remember when the consultant says you've got vasculitis, before the days of Dr google. Followed by "you will need to take a chemo drug and high dose steroids". I know I was terrified. I was given a leaflet on the ward from Stuart Strange (the predecessor of Vasculitis UK). The contact name on the back was Paul Pegg who I happened to know. After 3 weeks in hospital, I called him and joined, that was 13 years ago. Since then, I've always got our leaflets in my bag. I give them to the opticians, chemist, dentist and anyone else who asks. I think it is one way we can all spread the word and raise awareness.

This year's AGM will be online. Many of our support groups have been leading the way, with virtual coffee mornings. We've set the date for Sunday 16<sup>th</sup> May 2021 starting at 1pm, via Zoom. That is the day after World Vasculitis Day. You'll need to provide your own refreshments!

When we became a Charitable Incorporated Organisation (CIO), we decided to make our membership free (donations always welcome). Our members are all those on our mailing list for this newsletter. If you would like to be included in that mailing list and to request the log in details for the AGM, please contact [susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk) The details will then be sent out to you.

One third of the Trustees are required to stand down and seek re-election, at the AGM. This year, those seeking re-election are **John Mills**, **Martin Makin** and **Zoi Anastasa**. Their formal applications will be available at the AGM. I would urge you to support all three. The work John has done over the years is second to none, he has taken a small insignificant charity to the top in terms of respect from many leading consultants. He is also the Vice chairman and Director of Operations. Zoi is starting to take over many of John's attendance at conferences and on the Scientific Advisory Board. Martin is working with me on the Fundraising, in particular the Great North Run.

The other trustees, are myself **Dorothy Ireland**, current chairman and Fundraising coordinator. **Kelly Jefferies**, secretary and runs the shop, also does our graphic designs. **Ian Kayes**, our treasurer, keeping a very close eye on the finances. His report will be available at the AGM. **Gareth Garner**, member of the scientific advisory board, has been updating our covid-19 information and giving very clear explanations of vaccines, on the web and support group. **Susan Mills**, doing most of the behind-the-scenes work, web updates and posting packages out. **David Newman** who runs the London support group and attends the London conferences. We do have places for more trustees, if you would like to join us, please email me [dorothy@vasculitis.org.uk](mailto:dorothy@vasculitis.org.uk) giving your reasons for wanting to be a trustee, and what you think you could offer the board.

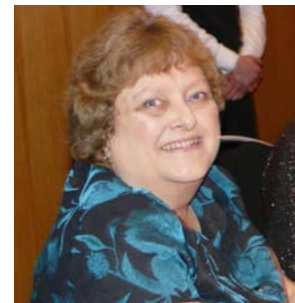
Our Treasurer has prepared a detailed balance sheet for the AGM. It shows that our income from fundraising has been declining in recent years but by 20% over the last 12 months. This is a lot less than some of the bigger charities. So, thank you to all who have fundraised or donated to us.

Our Fundraisers have been very creative this year, with many of the big events like the London Marathon and the Great North Run cancelled, as well as local runs and smaller events too. Instead, we've had a virtual concert, people running a marathon and even more incredible distances at home or locally. Plus, a head shave from Australia!

At the start of the pandemic, the normal research programme was brought to a standstill. We had 11 requests for grant funding ready to go for peer review. Many of the reviewers and the researchers were called to the frontline to treat covid patients. The process for these delayed grants will hopefully, start again soon. Even the 2019 research has been delayed and extended. We will be making another "call" for research grants in the autumn.

Instead, we funded some short-term research from the Universities of Cambridge and Nottingham. Findings reported in the last Newsletter. In February, we were approached by Nottingham to fund another piece of research, very relevant to vasculitis "Do people with Vasculitis mount an effective response to covid-19 vaccine, and for how long?". This research has started. The lead researcher Prof Lucy Fairclough has agreed to be a speaker at the AGM.

I hope you're all having your vaccinations when called for them. Take care and stay safe. I hope to see many of you at the AGM.



## Chairman's Report

**Dorothy Ireland**  
**Chairman of Vasculitis UK**

# Dear Reader



Welcome to this our 61st edition, I have made some adjustments to the look of our Newsletter / Journal and I hope you like it.

Your views are always welcomed as well as your input, if you wish to have contributions considered please let me know, and I will try to accommodate them.

Yet again it has been a very tough year, my heart felt thoughts go out to any of our readers who have lost loved ones for whatever reason.

As we now hopefully start to ease out of this pandemic, with vaccinations now being rolled out and testing available we should all start to feel there is now some light at the end of the tunnel, being able to see those we love more often, and to get out and socialise, and hopefully get back to some sort of normality.

There is no doubt like many other charities, fundraising has been hit hard and although many of you have still been able to fund raise in some way shape or form of which is much appreciated we still need our fantastic fund-raisers out there working their magic as this is the lifeline for our charity. We look forward, to many of you getting involved as we move forward, which you can start with getting involved in World Vasculitis Day 2021 in May - details on page 11.

So grab your favourite beverage and enjoy!

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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.

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### 10 Top Tips for Surviving Vasculitis

I'm a Vasculitis Veteran! As Susan has pointed out elsewhere in this newsletter and to the whole wide world, it's 20 years this month since I made the acquaintance of Dr Friedrich Wegener & his nasty disease. That was also my first close encounter with the Man in the Black Hoodie, carrying a Scythe. Fortunately for me the respiratory consultant, working with the rheumatologist at my small local hospital, armed with prednisolone & cyclophosphamide, proved to be more than a match for Dr W's deadly disease, so on that occasion the Grim Reaper was denied his prey and I'm still here to tell the tale.

So I reckon my long experience of living with GPA gives me some sort of entitlement to lecture others on how to cope with this rotten illness.

Here they are - not necessarily in any particular order:-

- 1) Try to keep a positive outlook at all times. I know, not easy! Stand up for yourself – be assertive – but never rude. Remember that the meek rarely inherit the earth, they usually get trampled underfoot by the assertive. Educate yourself about your disease. Understand it - & the treatment.
- 2) Eat a healthy balanced diet ensuring a full range of nutrients.
- 3) Have fun & look for fun, but make sure it's harmless fun & nobody gets hurt in the process. Try to smile all the time and laugh a lot. Whiners & whingers are usually tolerated by others, but tend to be avoided & not much loved.  
  
Don't wallow in self-pity.
- 4) Keep a good sense of humour but don't laugh too much at your own jokes. Jokes & funny stories at your own expense, usually go down well but beware making jokes at the expense of others.
- 5) Remember that there's always someone worse off than you – unless you happen to be that person who's worse off than everyone else – in which case, disregard this point
- 6) Covid rules permitting, keep those you love closely around you. If rules & propriety permit, hug & squeeze them often & tell them you love them often.
- 7) Remember love is like nature's prednisolone. When you experience it, it almost always makes you feel better, but then if it's suddenly taken away, you can get serious withdrawal symptoms.
- 8) Try not to be lonely - unless you really enjoy just your own company. As Covid has taught us over the past year, there are various ways of keeping in touch with family & friends. If you live on your own, with no friends of family nearby, Vasculitis UK has 2 fabulous online communities (on Facebook & HealthUnlocked). You can talk to others online at pretty much any time of day. When things are bad & you're feeling low, you can have a good whinge to others who will understand. When things go well & you're feeling good about yourself, you can share your triumphs with others & they will cheer you on.

There's the Timeline – for information & support,

The Young Vasculitis Group –for 16-30 yr olds,

The Carers group and

The Green fingers, Hobby Craft & Cookery group.

- 9) Keep active – physically & mentally. More about this later. Stay positive.
- 10) Fall in love just a little bit from time to time. A strictly virtual flirtation to make your heart beat a bit faster. We're not talking here about having an affair! If you have a long term partner, remind yourself how much you love them and how important they are to you:- then tell them how much you love them. I know it's unfashionably sexist to say so, but even at close on 80, my attention is still captured by a pretty face. Nothing serious or physical, I assure you; nothing horrid or sordid. Nothing to do with sex (that can be important too, but not in this context). It's like a virtual flirtation with someone who doesn't even know you exist & you will never meet - just a Mills & Boon style romantic fantasy. Never someone you meet in real life, that could be dangerous. It might be a character in a film or TV drama, or a musician or a character in a book, someone like that. It's all in my head & makes me feel a bit young again and good inside, Of course Susan immediately recognises the signs & rolls her eyes at me but she knows full well that she's the one and only true love of my life.

### On Keeping Mobile

If, like me, you have a natural aversion to gratuitous exercise, and then you get an illness or two which makes exercise or physical activity difficult or cause pain or shortness of breath, it's all too easy to become slothful & indolent. Sport is out. My natural reaction if a ball is heading my way is to duck. Golf & cricket are so slow and mind-numbingly boring.

But a lack of regular exercise, especially cardiovascular exercise (the sort that makes your heart beat faster) is definitely not good for your health & well-being. So if you have a staircase, don't get a stairlift or move to a bungalow, unless your doctor strongly advises it. Going upstairs gives a short burst of cardiovascular exercise and it's exercise with a purpose! But do take your time & take care you don't trip coming down.

Quite a few people experience very tender or burning feet due to vasculitis induced neuropathy. This can seriously restrict your mobility Do discuss this with your doctor.

Do take care of your feet & if you struggle reaching down that far and don't have anyone to trim your nails, do visit a chiropodist/ podiatrist.

Seriously overgrown toenails can render people totally immobile.

If your mobility is seriously impaired a pair of sticks or elbow crutches can help. There are several variations on the Zimmer frame. Being safe from falls is essential but feeling safe is also important. Modern powered wheelchairs can offer the ultimate in mobility combined with protection.

Electric mobility scooters can give you a significant range of mobility when feet and legs are failing. There's a huge range of models. Some are pavement-only models restricted to 4mph. Others are more powerful travelling on the road up to 8mph with a range of 20 miles or more and larger wheels capable of rougher terrain.

Susan had been badgering me for a long time to try a mobility scooter so we could get out & about more together or with grandchildren or for dog walks. Having lost my sense of balance, due to a stroke in the pons area of the brain, I thought they looked very



unstable and to be honest it did not fit my self-image. The body may be nearly 80 but my brain thinks I'm nearer 40.

However I consulted my friend Steve in our village who is a retired paediatrician & is seriously immobilised due to MS but does his best to live life to the full. He showed me his "mobility scooter" and I was sold! Far from being bad for my self image, this model enhances it. So now I can imagine I'm one of "The Lads", a bit of a rebel, when riding my Harley Davidson style 3 wheeler bike. A geriatric Hells Angel, tearing around the countryside at 8mph.

Sometimes you can make a virtue out of necessity. It's opened up a whole world of possibilities. And it's certainly upped my street-cred with the grandchildren!!

### **A Star is Born**

Nephrologist Professor Alan Salama, of UCL/Royal Free hospital in N.London is deservedly well known in the vasculitis world for his clinical and research activity. However, this spring Alan added to his CV by breaking into the music world as a singer/songwriter. He set out to raise money for Kidney Research UK & Vasculitis UK by launching a video recording, where he performs his own composition, with the catchy title "Vasculitis Messed Me Up" – sung to the tune of the well-known sea shanty, the "Wellerman Song". You can see & hear Alan's debut recording by visiting the Vasculitis UK website [www.vasculitis.uk.org](http://www.vasculitis.uk.org) & scroll down the homepage. Then click on Sea Shanty – in blue.



Although not yet in the charts, Alan's agent is in discussion about a guest appearance at Glastonbury later in the summer. Plans for a UK tour with Ed Sheeran & Beyoncé are on hold due to covid restrictions and Alan's clinical commitments. Trade Journal "The New Musical Express" has tipped Alan as the "Most Rising Star" of 2021.

### **Florence and the Seven Nightingales**

Florence Nightingale was born on 12<sup>th</sup> May 1820 at Holloway near Matlock (about 8 miles from our village) into a well-off middle class family. She is revered as the founder of modern nursing – the "Lady with the lamp". Disturbed & shocked by reports of the horrific conditions in the military hospitals during the Crimean war she went with a group of volunteers to do what she could to improve a situation where ten times as many soldiers in hospitals died due to disease when compared to those who died from their wounds.

Florence set an example of compassion, commitment to patient care and diligent and thoughtful hospital administration. She introduced novel practices such as hand washing and general hygiene, with an organised military approach.

Thus, when it finally became apparent to the government that a pandemic was inevitably coming our way and they decided to create seven new temporary emergency hospitals, it was entirely appropriate that they should be called Nightingale Hospitals.

No expense was spared in creating these hospitals which were ready for use in days rather than years. Using existing buildings such as exhibition and conference centres like the NEC, wards & patient bays with oxygen and electricity were created;

presumably with most of the other facilities of a modern hospital – laboratories and xray facilities etc.

If Florence had been around to advise she would immediately have seen the flaw. Hospitals are primarily about people, not buildings & fancy equipment. Of course, Covid-19 was going to supply the patients, but what about the doctors, consultants, nurses, physiotherapists, radiographers, radiologists, phlebotomists, the myriad of specialists and special technicians.

The NHS has for several years been experiencing a staffing crisis on all fronts. From consultants to nurses and ancillary staff, recruitment is a problem. Vacancies go unfilled, adverts for consultants, trainee specialists, nurses and ancillary staff result in few applicants.

These people are all highly trained, the best ones are highly experienced. There was never going to be any possibility of staffing these hospitals, intended to cater for patients with complex medical problems, needing various levels of intensive care, without poaching staff from other hospitals.

The NHS, unlike the armed forces, does not have a body of highly trained personnel in reserve, waiting to be called into service. The NHS is kept running at 110% of capacity.

Despite this, the huge surge in Covid cases and the scandalous shortage of PPE, staff throughout the NHS rose to the occasion. Whole wards and departments changed round and relocated. Extra beds squeezed in. Most important of all, staff who were scared for their own safety as well as that of their families, in the face of this as yet little-understood and frequently fatal disease, They saw what covid could do to their patients and knew it could happen to them.

They often changed job roles to face the immediate emergency. They missed meals and worked excessively long hours, knowing all the time that they were putting their own lives at risk – over and above the call of duty. Innovative new treatments were trialled and tested – some with unexpected success.

Like a stately version of HMS Victory, HMS NHS in full sail ploughed through the Covid battle field with all guns blazing.

Thus it was that the Nightingale Hospitals, which were created at an initial cost of £350m (which grew to £500m) with a total potential bed-capacity of 12,000 patients were created and dismantled having never treated a single covid patient.

The ½ billion pounds spent leaves no legacy – other than for those awarded the necessary contracts. The money's gone. Like the money spent on Track & Trace. Gone forever!

Those many heroes of the Covid campaign – the doctors, nurses, cleaners and so many others who risked sacrificing their survival might reasonably have expected more of a reward for risking their life & their future than clapping on a Thursday evening and an enamel NHS pin badge.

A 2.1% rise for nurses, as recommended, by the NHS pay plan would have been nice but now there's only money left for a 1% rise. I suspect that, despite her conservative middle class upbringing, Florence would not have been very impressed!

**John Mills. April 2021**



Euvas is the **European Vasculitis Society**, which is aimed principally at experts in vasculitis and those with a special interest in vasculitis and who plan to become experts.

UKIVAS is the **UK & Ireland Vasculitis Study Group**, which has two points of origin:

- 1) The "Lockwood Club" – a UK vasculitis study group set up in memory of the pioneer in the study of ANCA vasculitis, Martin Lockwood, who sadly died in an accident.
- 2) The UK & Ireland Vasculitis Registry – set up by Drs Mark Little & Alan Salama (both now Professors) to provide a national database of vasculitis cases.

### **EUVAS** - International collaboration on vasculitis.

The European Vasculitis Society or EUVAS came together over 20 years ago to conduct clinical trials in vasculitis funded by the European Union. The EU wanted hospitals with vasculitis expertise to come together and agree common ways of managing patients - to harmonise, in their words - and then to improve the lot of vasculitis patients by comparing treatments and come out with recommendations for everyone to be able to follow.

This all worked well and around 10 years ago EUVAS linked together with groups in North America, Japan and Australia/New Zealand to form a global consortium which has conducted the PEXIVAS and RITAZAREM trials, both of which have now been completed and this has served to extend the 'model' of harmonisation around the world. The pharmaceutical industry has now become more interested in vasculitis and is building on these foundations, for example with the recent successful trial of a new drug for vasculitis, avacopan.

EUVAS is involved in several other projects but I would like to mention education of younger specialists interested in learning more about vasculitis. Annual residential courses have been run in Cambridge and in Florence with plans to continue next year. Meanwhile we are developing remote learning tools such as webinars and podcasts.'

(Professor David Jayne; Cambridge. April 2021)



**UKiVAS** is a national collaborative group of experts interested in improving outcomes for patients living with vasculitis. The UKiVAS initiative recruits patients to allow collection of anonymous clinical information on all types of vasculitis to improve our understanding of these rare diseases.

UKiVAS currently recruits patients from >90 UK and Ireland centres including >7000 patients. The group are very grateful to everyone who has agreed to participate in this data collection study as it will help improve outcomes for other people living with vasculitis. Over the past year, the UKiVAS have extended their purpose and demonstrated their true strength by rapidly gathering information on how covid affects individuals with vasculitis and it has pooled expertise when clinicians have been faced with challenging patient cases.

In addition to gathering information and sharing best practice, the group participate in the education of colleagues through regular events such as the recent Royal Society of Medicine webinar.

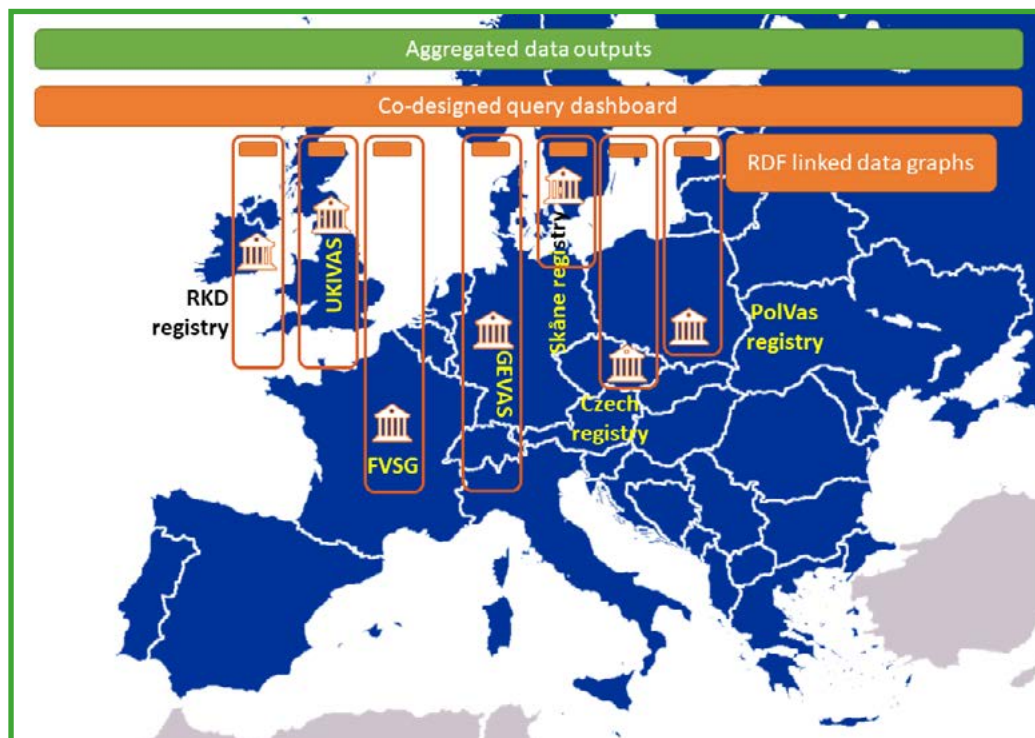
(Dr. Louise Oni, UKiVAS Communications lead. April 2021)

# EUVAS registries: linking research, clinical care and the patient across Europe

Mark A Little<sup>1,2</sup>,

1. Trinity Health Kidney Centre, Tallaght University Hospital, Dublin
2. European Reference Network for rare immune disorders (ERN-RITA)

European vasculitis registries have seen recent consolidated development not observed in the previous three decades. This has arisen on the back of the establishment of the European Reference Networks, enhanced funding for rare diseases and a pharmaceutical industry imperative to obtain real world phase 4 data on novel medication use. The vision of an integrated and sustainable framework to capture and use longitudinal clinical data from patients with vasculitis from across Europe is now achievable. A key plank in this endeavour is the European Joint Programme funded FAIRVASC programme<sup>1</sup> which aims to link seven vasculitis registries (Figure), with a total of 15,500 recruits, using a bespoke semantic web platform. These registries include the VUK supported UKIVAS registry, which is already supporting substantial research initiatives in the UK and Ireland. This is designed to allow further registries to “plug in”, thus maximising interoperability and accessibility of the registry data to researchers and policy makers. This is aligned with the establishment of the EUVAS model registry which incorporates an agreed data dictionary and a ready-made REDCap<sup>2</sup> database co-developed with industry support that can be deployed easily at sites seeking to develop new registry initiatives. We envisage that these two programmes will be linked in a new EUVAS registry office and integrated with the ERN-RITA registries group, to create a sustainable platform for European vasculitis registries to grow from in the future.



1 <https://fairvasc.eu/>

2 <https://www.project-redcap.org/>



In March 2015 aged 42, I was diagnosed with vasculitis, likely IgA (HSP). I had always been fit and well but had suffered some nagging bugs and sudden lethargy during sports activities in the months leading up to my one and only flare. On that day I felt unwell, when we were on our way to visit my wife's family and she did initially think I was trying to dodge the visit! However within a very short space of time I experienced severe pins and needles followed by stomach pains, vomiting, passing blood and a rash appeared across my body. I was admitted to Northampton General Hospital and received a prompt diagnosis and outstanding care from Dr Nandi in particular to whom I will be forever grateful.

Fortunately my kidneys made a full recovery and I have remained in clinical remission but I now have an irregular heart beat and have seemingly had TIAs (a mini-stroke) and am due a pacemaker longer term.

I have been grateful for advice received from Vasculitis UK so I would like to fund raise once again. Dorothy kindly arranged a place for me in the Great North Run

last year which was of course deferred to this September. Typically I also managed to secure a first London Marathon ballot place after years of trying.

The marathon follows three weeks later so GNR fits nicely into my training plan and solves the problem of getting back to my city centre hotel - I'll have to run most of the way to hit the target mileage!

**Graham Mully**

## Virtual Bake Sale



Harefield Cricket Club family raise £1,361 for Macmillan Cancer Support & Vasculitis UK



Me and my mum did a virtual bake sale for our friends in November. We had people either coming round to the house (socially distanced of course) to collect cake or we even sent some in the post to some of my friends in London! After 2 days of baking and 8 batches of cake, we raised £105!"

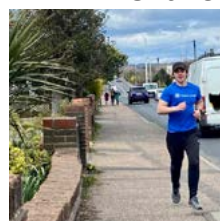
**Sarah Taylor**

Grace Round (right) has raised over £350, doing 100 squats, on behalf of her mum, Marie who has Vasculitis.



Anthony Waton is walking 100 miles (or more!) in his local Sussex countryside, to improve his fitness during lockdown and after a serious health scare last Year. Vasculitis is a hidden rare disease, Anthony was diagnosed in 2011. He wanted to get fitter and help Vasculitis UK at the same time. Anthony has raised over £1000.

Max Brotherhood has raised £888 by taking part in the David Coggins Challenge, for VUK, on behalf of his grandad who has Vasculitis.



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





Sadly two of Scissett Football club's long standing members lost close family members to Vasculitis.

Each year they hold a series of fund raising activities and, around 18 months ago, they decided their annual fund raising activities for that year would be shared with Vasculitis UK.

One of their main fund raisers that year was a Variety Night with live stage acts (magician, singer, comedian) as well as an auction of donated prizes. The evening was a great success and raised over £2,000 with 25% going to VUK. ( £532 )

It had been their intention to continue fundraising for a full year and then hopefully hand over a substantially bigger cheque. However Covid came along and ground everything to a halt. So they decided to wait a while to see if the country got back on track but unfortunately, as we are all aware, that wasn't to be the case so at their committee meeting it was decided it would be wrong to hold on to the monies raised; especially with no return to normality in sight and therefore handed the monies raised over to VUK.

## Fundraising during Corona Virus

Well, what an unusual and tough year it has been for those who are fundraising and charities that rely on donations alone. I think it's safe to say we have all seen a reduction in fundraising income. Vasculitis UK has been no different and when events had to be cancelled back in March 2020, nobody could have foreseen what the next 12 months would bring. One of our biggest fundraising activities comes from running, from local 10k races to the big National events. The majority of these were cancelled including the two big events 'The London Marathon' and 'The Great North Run', where money is normally made through sponsorship. With the cancellation of these events, a lot of virtual runs went ahead. This is where you run the distance anywhere on your own, record your time/mileage and send it in. Sally Rawlins completed the virtual GNR this year and hopes to join the other 20 runners at this year's event on the 12th September. Keep an eye on our website for updates from your team. Fingers crossed it goes ahead this year. Well done to Sally. We also have Bex Morgan running in the London marathon in support of her sister Megan who was diagnosed with GPA. We wish you lots of luck. See Bex's Charity Page Link

<https://uk.virginmoneygiving.com/fundraiser-display/showROFundraiserPage?userUrl=BexMorgan1&pageUrl=1>

Many of our fundraisers have had to think outside the box to raise funds this year, due to all group events being cancelled. Jennie Jones did the 4 x 40 challenge, this being, 40 days of not drinking alcohol, 40 walks, 40 bike rides and 40 spin classes. I bet you needed a drink after that!

Cecily Redman performed from her own front room streaming live on you tube on the 28th October. Cecily has the rare form of vasculitis Takaysu Arteritis, which she was diagnosed with whilst touring with the Musical Avenue Q. The stream was fabulous and a huge success.

We even had fundraisers over in Australia, running the 'South coast century'. A 100km ultra marathon, which is just over 62 miles, which is truly remarkable.

These are just a few of our great fundraisers, and there are many more of you that have helped during this unusually hard year for us all. This has meant that overall Vasculitis UK only saw a 20% reduction in funds raised compared to previous years.

So what's happening this year? We have Ultra walkers, cylosportive, charity fairs and we have someone completing 100 squats a day for a month!

Visit Vasculitis UK fundraising page for details of all our fantastic fund raisers.

So, from Vasculitis UK and the trustee's, I would like to thank all our exceptional fundraisers, without you we would be unable to support the many projects funded to help those suffering with all types of Vasculitis.

**Martin Makin (Fundraising Coordinator)**

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



# RARE DISEASE DAY 2021 - 28th February

There are over 6,000 rare diseases and around 300 million people live with a rare disease across the world. The last day of February is dedicated to these people, it is Rare Disease Day, and it is a global celebration.

**Genetic Alliance UK** runs the events for Rare Disease Day in the UK.

In England, a parliamentary event is organised annually as part of the celebrations. This year the event was online because of the pandemic and it was very well attended by people living with rare conditions in all four (4) nations. I was able to attend from the comfort of my sofa, wearing my slippers.

Without doubt the patient voices were these which captured our emotions. Their stories, their experiences, their hopes were the most important part of the event.

Every nation was represented by local MPs / Parliamentary champions and all of them committed to work hard for the implementation of the new Rare Disease Framework. I really hope that they will. The plan is good, but it needs to be implemented.

Rare diseases matter. Rare disease patients matter.



Supporting



RAREDISEASEDAY.ORG

2021



Zoi Anastasa



Claudia was diagnosed with ANCA Vasculitis early in 2019 after being wrongly diagnosed with Sarcoidosis in 2018. Claudia submitted her personal Vasculitis story to Rare Disease U.K. as part of their Rare Disease Awareness Campaign.

You can read Claudia's story by following this link to the Rare Disease U.K. website

<https://www.rarediseaseday.org/stories/7059?fbclid=IwAR3zhU4C2HR3SWZsY1S3vPMbKsmqbaS4Mur-lCfFALbHLZpf88ep7rMgwAk>



## World Vasculitis Day

15th May 2020

Do you have anything planned to raise awareness? All outside of course! Coffee Morning, BBQ, Afternoon Tea, to hold for family and friends? Create a Video or Blog to share with friends on line or via social media? Last Year was the first International Vasculitis Awareness Day, even during lockdown many patients and their families, doctors and associates came together to raise awareness. The theme for last year was V for vasculitis, here are a few photos as a reminder.





**Shanali Perera is raising awareness of Vasculitis and fundraising for Vasculitis U.K. on International Vasculitis Awareness Day on May 15th 2021.**

Shanali says

"I am a contemporary artist, educator, retired Rheumatologist, and a person living with vasculitis, based in Manchester, UK. I am doing a walking challenge to fundraise for Vasculitis UK, to support my Vasculitis community. As well as raise awareness on Vasculitis, globally together with our extended family of Vasculitis communities around the world".



Watch Shanali's video "I am not the illness - I am a person first" <https://www.youtube.com/watch?v=D7wYoHaLQow>

Read Shanali's story - [https://www.justgiving.com/fundraising/shanali-perera?utm\\_source=facebook&fbclid=IwAR3j-0BUgslVJkuf53jocLjUeuFTfquniN-U43lvCM-kyt3LH4tl9ivJ-Clw](https://www.justgiving.com/fundraising/shanali-perera?utm_source=facebook&fbclid=IwAR3j-0BUgslVJkuf53jocLjUeuFTfquniN-U43lvCM-kyt3LH4tl9ivJ-Clw)



kyt3LH4tl9ivJ-Clw

Shanali has also designed a special T-shirt for her own fundraising event and for International Awareness Day - May 15th.

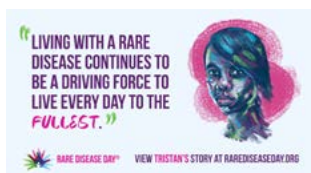
T-shirt , running vest and cap will be available from May 1st from the Vasculitis UK online shop <https://www.vasculitis.org.uk/shop> but also on the day at Shanali's walking fundraising walk.

**Message from Vasculitis Chile re World Vasculitis Day**

We would like to join in this year for the awareness campaign, as patients with vasculitis, the level of pain we feel. All of the people with vasculitis in our group say "when I'm in the emergency room or at the doctor's office and he or she or the nurse asks us "according to the pain scale from 1 to 10 what number describes the level of pain you feel now" we answer "I feel like I'm burning!! I feel like I'm in the middle of flames!!"

You know here in Chile there are just a few doctors that know how to treat vasculitis. The authorities think this is something "on our heads," that's why we would like to do something to make an impact on society to call attention to our disease or at least try.

Editors note: Despite being 7,500 miles from the UK, the problems for vasculitis patients seem remarkably familiar! We will try to post the Vasculitis Chile video on the Vuk website.



# JOHNS'S STORY

## Wegeners Granulomatosis – diagnosed 2001



John and Susan Mills in Paris for the International Vasculitis Conference 2013

Exactly 20 years ago this month, my husband John was taken seriously ill. He had not quite been his normal robust self for a few months. Niggling health problems, a lingering blocked up nose, sinusitis, aching hips and aching legs. He had meant to make an appointment with the GP but never quite got round to it. John worked very hard as an NHS dentist in a large rural practice and was always so very busy. In the February we had been skiing, John certainly was not himself and his legs really ached. I remember him telling me that he felt as though he was skiing through treacle.

Anyway, one evening in April, he was insulating the loft with a fibre glass material when he suddenly starting coughing up copious amounts of blood. This certainly started the alarm bells ringing both with John and his GP. John was referred to the hospital as an emergency. Radiographs revealed shadows on both lungs, sputum tests were taken and he was given a raft of blood tests and sent home. John was signed off work. A few days later he was admitted as a day patient for a lung biopsy.

We had to wait 3 weeks for all the sputum tests, biopsy result and blood tests to return from the laboratory. Both Sarcoidosis and TB had been discussed as a possible diagnosis. During those three weeks John's health deteriorated rapidly, he was still coughing up blood, having nose bleeds, suffering with a very large mouth ulcer, the size of a 50 pence piece on his soft palate, he became very weak, leg and arm strength became weak and he was struggling to breathe. Within 2 weeks he was confined to bed and was given oxygen by the bed. He needed assistance to go to the loo and he had lost 13kg. He refused to be admitted into hospital.

During the third week of April, we really thought we were going to lose John. But one doctor, a Dr Hadfield, just thought he might have a disease called Wegeners Granulomatosis but TB had to be ruled out first before he began treating John and he needed the result of the biopsy. I looked WG up on the internet and frightened myself to death but I did find Paul and Jill Pegg from the Stuart Strange Vasculitis Trust (SSVT). They were both a great help and a support to me. I shall never forget them.



John - Prednisolone chubby cheeks - 1 year after diagnosis

At the end of the third week it was confirmed John indeed did have Wegeners Granulomatosis (WG). Only just in the nick of time. John was at this time drifting in and out of consciousness. As soon as WG had been confirmed he was rushed into hospital, given high dose steroids and he started his Cyclophosphamide infusions. He was given 6 infusions over a period of 12 weeks. After the very first infusion he began to feel so much better, by the third infusion he was ready to return to work.

He did return to work, but with hindsight he probably returned too soon and should have waited just another few weeks: his stamina was still low and he would tire very easily especially as he was moved onto oral cyclophosphamide then maintenance immune suppressant therapy and the steroids were reduced. (Rituximab was certainly not available back then and MMF only became available in 2005).

We always have said life with vasculitis is certainly different from the one we had planned: not worse, but very different. We still managed four exotic holidays, bought a house in SW France in the September of 2001 when house prices there were very low, and continued to renovate our own house here in the U.K.

We sadly had to stop the skiing – his legs never regained the strength to ski again and John no longer could walk up hills due to the scarring on his lungs. But we managed walking on the flat, the odd cycle trail outing, grandchild care and holidays here in the U.K.



Cephalonia, 4 months after diagnosis



First Vasculitis U.K. Patient Symposium 2015

In 2007 John was diagnosed with a DVT due to the Vasculitis and in 2008 was diagnosed with bladder cancer due to the accumulative effect of years of taking oral cyclophosphamide. In the last five years, John has also suffered other health problems mostly due to the advancing years but probably also due to being immune suppressed for over 15 years.



Zooming with Prof Chris Whitty April 2021

Thankfully treatments and drugs to manage vasculitis are much better today than back in 2001. In 2009, John was asked to become chair of the Stuart Strange Vasculitis Trust (SSVT), which he did, and in 2010 the SSVT became Vasculitis UK.

I just cannot believe where the last 20 years have gone!

**SUSAN MILLS  
APRIL 2021**



## The People's Friend Magazine interview with Kelly Jefferies Trustee for VUK, discussing Giant Cell Arteritis, published March 6th 2021.



We had a real journey to get to our grant call this year. We began the process back in late 2019 when we launched a call for research grant applications. As part of a selection process which involves rigorous peer review, in early 2020 (in the days before Covid-19) we tried to find 2 appropriate peer reviewers for each of the 11 grant applications we had received in our 2019/20 call. No easy feat! Finding 22 suitable reviewers was certainly a challenge. We had just set up the process when the pandemic struck. Consequently, most of our reviewers were seconded to the "Covid frontline" and (very understandably) forced to withdraw their offer to peer review. Thus, we decided to postpone the whole review process and wait for Covid to go away!! We also decided that we would not invite any more applications until we had cleared the 2019 backlog of applications.

After much consideration we restarted the peer review process in November 2020. In February we finally convened the Scientific Advisory Board to decide on which studies to fund. We would like to offer our sincere thanks to all of our peer reviewers, without whom we would not have been able to even consider proceeding with the grant call. We are delighted to announce that the following applicants received funding for their exciting and varied projects whose aims mirror Vasculitis UK's priorities.

**1. Preclinical studies to develop an RNA targeting novel genetic therapy for STING-associated vasculitis with onset in infancy**

UCL Great Ormond Street Hospital - £49,712 Asst. Prof. Despina Eleftheriou (Co-applicants; Prof. Paul Brogan, Dr Haiyan Zhou & Prof. Philip Hawkins)

This 12-month project aims to identify an effective and targeted treatment for SAVI. SAVI (STING-associated vasculitis with onset in infancy) is a rare, devastating and life-threatening genetic form of vasculitis causing severe and persistent inflammation throughout the body, especially in the skin, blood vessels, and lungs.

Asst. Prof. Despina Eleftheriou has shown that there is now a very realistic opportunity to develop a new treatment for SAVI, using RNA-targeting therapies that can specifically inhibit the faulty, disease causing gene. This will target the root cause of the inflammation driving this genetic form of vasculitis; this approach has never been attempted for vasculitis, but is an innovative way to tackle this severe, life-threatening disease.

If successful, the results of this preclinical study will then inform the development of an international programme of work for novel genetic therapies in humans with SAVI, and related genetic diseases with similar disease mechanisms.

**2. Peptide Immunotherapy in experimental MPO-ANCA vasculitis**

Imperial College London - £50,000  
Dr Maria Prendecki (Co-applicant: Dr Steve McAdoo)

This 18-month project will investigate how to create tolerance in AAV by studying laboratory rats which develop vasculitis closely resembling disease seen in patients with AAV. In both these rats and many humans with AAV, the component of white blood cells that is recognised as foreign by the immune system is a protein called myeloperoxidase (or MPO). In order to create tolerance to this protein, it is important to know which part of the MPO protein is important in causing disease.

By studying ways of creating tolerance to prevent or cure disease in rodents, Dr Prendecki will lay the foundation for testing these treatments in patients with AAV. Similar treatments have already

# RESEARCH FUNDING

been tested in patients with other autoimmune diseases, such as multiple sclerosis, and they have been shown to be safe in humans, suggesting that this approach may be effective in patients with AAV.

**3. Evaluation of CD27+ memory B cell reconstitution following rituximab maintenance therapy in ANCA associated vasculitis as a guide to future dosing**

University of Cambridge - £51,562

Dr Rona Smith (Co-applicants; Dr Mark McClure & Prof. David Jayne)

This study will look at 36 patients, with AAV (ANCA associated vasculitis) who have received rituximab. Through a detailed analysis of the returning B cells in the blood stream, they hope to identify a biomarker that reliably predicts an impending flare and may be used in combination with other factors in a relapse prediction model and in future studies to guide the optimal timing of subsequent rituximab doses.

Studies like this are needed to help identify patients who may benefit from a more personalised and tailored treatment plan, to achieve maximal effectiveness of the drug with minimal side effects.

**4. Incidence of cardiovascular events and common cancers in ANCA-associated vasculitis and Takayasu's arteritis in the English population**

University of Nottingham - £49,766

Dr Megan Rutter (Co-applicants; Dr Fiona Pearce, Dr Peter Lanyon & Prof. Richard Hubbard)

This research group has identified the number of people in England living with AAV and TAK using routinely collected healthcare data. They will be added to a national rare disease register called NCARDRS. This register will have many benefits, such as allowing better health service planning. Another benefit is that once the people with AAV and TAK are known, the team can use other healthcare data to determine how many of them develop cardiovascular problems such as heart disease, strokes and blood clots. They will also be looking at how often people with AAV or TAK develop 5 common types of cancer: breast, prostate, lung, bowel and bladder. They will then compare the rates of these diseases with people of the same age and sex who do not have AAV or TAK to see whether the rate in AAV and TAK is the same, decreased or increased.

Determining the risk of cancer and cardiovascular disease associated with vasculitis has been identified by Vasculitis UK and its members as a priority and the team are ideally placed to answer these questions with the data they have. Once this method is developed it can then be applied to other types of vasculitis.

## Emerging Research Questions - COVID-19 Studies

As a result of the emerging situation around COVID-19 and the number of research questions that needed to be answered urgently for Vasculitis patients, we have funded three studies this year aiming to address these issues.

### 3. Do people with vasculitis mount an effective response to COVID-19 vaccination, and how long does it last for?

University of Nottingham - £53,364.00  
Asst. Prof. Lucy Fairclough

People with vasculitis may not develop as effective a response to COVID-19 vaccination as healthy people of a similar age. It is also possible that response following vaccination among people with vasculitis may not last as long as that in healthy people of a similar age. This means people with vasculitis may be less well protected following vaccination, and perhaps require more frequent booster doses of vaccination than healthy people.

The team plan to test the response to vaccination in 50 people with vasculitis and compare this to the response to vaccination in 50 people of a similar age from the general population. All patients will receive their vaccine as they usually would (when they are invited in their priority group).

Research has shown that there are two key components to the immune system response that protect against COVID-19 infection – these are levels of protective antibodies, and numbers of protective memory T-cells produced. The protective T-cell response may be particularly important in people who have been treated with Rituximab, because Rituximab directly affects the cells which make antibodies. They will measure both types of responses using tests already developed and working in the immunology labs in Nottingham. This will allow them to measure how effective the response to vaccination is among people with vasculitis, and how long it lasts, as well whether particular treatments (e.g., steroids, or rituximab) affect the response to vaccination.

They aim to use the results to inform discussions with the makers of health policy around vaccination.



### 1. The effect of COVID-19 on people with vasculitis: a whole population study in England Nottingham University Hospitals £32,856.71

Dr Megan Rutter

People living with rare autoimmune rheumatic diseases (vasculitis and connective tissue diseases) are prescribed medications which weaken their immune system. Many also have other medical conditions because of their disease and treatment. They may be at increased risk of severe illness or death from COVID-19 infection, so the NHS sent letters to many asking them to practice enhanced social distancing (aka “shielding”). What we don’t know is how big their risk is from COVID-19, nor whether changing or stopping treatment would make their risk higher or lower.

The team will use the existing health records of all people in England and combine this with information about who has rare autoimmune rheumatic conditions and their medicines, and who has had COVID-19. Their preliminary work has found 63,155 people with vasculitis to study, of whom 1.7% have died since the beginning of the COVID-19 pandemic, making this the largest cohort of people with vasculitis we are aware of worldwide. The study aims to answer these questions:

1. Does having vasculitis affect a person’s risk of severe COVID-19 infection (defined as hospital admission or death) during this pandemic?
2. Amongst people with vasculitis, does current immunosuppressive treatment influence (increase or decrease) their risk of severe COVID-19 infection?

The results will be used to inform patients, clinicians and healthcare policy decision-makers.

### 2. SARS CoV-2 antibody responses in immunocompromised patients

University of Cambridge - £7,500  
Dr Rona Smith & Dr Rachel Jones

In the Covid-19 pandemic, immunosuppressed patients are currently advised to shield. However, immunosuppressed patients with kidney disease either receiving dialysis, or monitoring for renal transplants or immune disease, require frequent hospital attendances thus increasing their risk of exposure to COVID-19. A test to measure antibodies to the virus which causes COVID-19 infection (SARS CoV-2) has been developed in the immunology laboratory at Addenbrooke’s Hospital, Cambridge.

In this study approximately 900 patients (300 on dialysis, 300 with a kidney transplant and 300 patients with immune disease) will be tested 3-monthly for antibodies to SARS CoV-2. Differences in antibody responses will be compared between these three groups and with healthcare workers (from a separate study) who are not immunosuppressed. Different immune drugs and poor kidney function may affect antibody responses and the ability of antibodies to prevent further COVID-19 infections. It is very important that doctors learn about antibody responses in immunosuppressed patients to provide patients with correct medical advice and to adapt hospital services to protect high risk patients.

## Covid Vaccine Research Study.

A project funded by Vasculitis UK.

The Immunology and Rheumatology teams at The University of Nottingham and Nottingham NHS Trust have joined forces to answer the all important question about both the quality and duration of the immune response to new SARS-CoV2 vaccines.

SARS-CoV2 is the virus that causes COVID19, and the vaccines developed aim to generate an immune response to this virus. Importantly, this means if an individual is then exposed to the virus they can mount a very rapid immune response to clear the virus before it causes disease.

What we do not know at this stage is how good this immune response to vaccination is in individuals with Vasculitis and how long it lasts. To answer these questions we will examine the immune responses in both Vasculitis patients and compare this to age matched healthy controls. Importantly we will examine both the level of antibodies produced against the vaccine as well as the cell mediated response. Both these parts of the immune system are key to provide protection for future infection with the virus.

The Immunology team have developed techniques to examine the quality of the immune response. Specifically we will take blood samples to enable us to isolate plasma for antibody measurement and isolate cells for examining cell mediated responses. The Immunology team have already started to collect healthy control samples (see photo). The photo shows Dr Fairclough and two PhD students employed on this grant to answer these all important research questions.

*This research is a collaboration involving immunologist Dr Lucy Fairclough & rheumatologist Dr Fiona Pearce, both of Nottingham University.*

### COVID-19 antibody responses in immunocompromised patients

Patients with vasculitis are immunosuppressed because of the treatments they receive. This means their immune system does not work normally, making them more vulnerable to infection. Immunosuppressed patients have been shielding within their homes during the COVID-19 pandemic, awaiting vaccination. Since the roll out of COVID-19 vaccinations in the UK, government advice states that shielding can now end.

However, immunosuppressant medications may reduce vaccine responses as well as infection responses and it is important for doctors to be able to advise immunosuppressed patients on how well their patients are protected against COVID 19 infection following vaccination, so may provide the correct medical advice. COVID 19 antibody tests measure whether a patient has had COVID-19 infection or a vaccination at some point in the past.

Different immune drugs and poor kidney function may affect antibody responses as well as the ability of antibodies to protect against future COVID-19 infections.

Drs Rachel Jones and Rona Smith, are two consultants in Cambridge who specialise in vasculitis and other kidney conditions. They are running a research study including up to 1800 patients with more than 600 patients recruited so far. Three groups of shielding patients are being enrolled into this study:

1. patients with vasculitis receiving immune-suppressants,
2. patients with a kidney transplant receiving immune-suppressants,
3. patients with kidney failure on dialysis.

Patients in this study are having blood tests to measure COVID-19 antibodies every 3 months for an 18month period. Differences in COVID-19 infection and COVID-19 vaccine antibody responses will be compared between the three patient groups, as well as with a group of healthy individuals.

This study will also compare antibody responses between different COVID-19 vaccines and the effect of the various different immunosuppressive medications that patients receive. The aim of this study is to be able to advise patients better on their future risks of COVID-19 and whether additional vaccines or other protective strategies against COVID-19 are needed.

*Vasculitis UK*



# PROTECT trial

The PROTECT-V (PROphylaxis for paTiEnts at risk of COVID-19 infecTion) has started recruitment in Cambridge. The PROTECT-V trial is designed to test drugs that may prevent Covid-19 infection in vulnerable patients with kidney disease or who are receiving immunosuppression. Covid-19 has had a huge impact these individuals. The rapid roll out of vaccination has been very welcome news, but it is unclear if these patients will mount as strong responses to the vaccine as healthy individuals.

The first agent to be tested in the PROTECT-V trial is nasal niclosamide, an agent usually used to treat intestinal worms in tablet form. Niclosamide has shown real promise in the lab, with early tests revealing niclosamide could stop SARS-CoV-2 multiplying and entering cells of the upper airways.

The trial has now been awarded Urgent Public Health Prioritisation and will roll out across the UK in the coming weeks. It will recruit at least 1,500 patients, who will initially be randomised to receive either a placebo (or dummy) drug, or niclosamide nasal spray, in addition to all their usual treatments and Covid-19 vaccination. The trial has been designed so that other promising preventative agents can easily be added to the trial platform.

In addition to government funding, the PROTECT-V trial is also funded by LifeArc, Kidney Research UK, the Addenbrooke's Charitable Trust and UNION therapeutics and is supported by the NIHR Cambridge Biomedical Research Centre. UNION therapeutics is supplying the drug.

More information can be found on the website <https://www.camcovidtrials.net/trials/PROTECT>

(Dr Rona Smith; Addenbrookes, Cambridge.)

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## NEW BSR ACCREDITATION SCHEME

The British Society for Rheumatology (BSR) has launched a new UK-wide "Quality Review Service". (QRS) This is a quality improvement process open to all NHS rheumatology services across the UK. It aims to raise standards, improving patient service and experience by promoting excellence in all aspects of rheumatology and targets improvement in patient care and experience.

It does so by offering a professionally-led accreditation service giving independent external validation and a continuous quality improvement development through a three-year quality review cycle, by using the first UK-wide rheumatology-specific best practice standards, which set out the best approach for services to follow to achieve the best service and experience for patients.

Rheumatology teams have patients' needs at the centre of their care and a service that applies for accreditation will strive to meet the QRS standards to ensure that they do and will continue to meet best practice. Services achieving accreditation commit to a three-year quality review cycle and to instil best practice into their daily processes. Patients will see improvement in their care and experience and can have their say on the service they receive.

QRS is for services covering all rheumatology conditions, including lupus, scleroderma, and Sjögren's syndrome.

Former BSR president and lead clinician for the Quality

Review Service working group, Dr Liz Price said "For the standards to be effective, a multi-disciplinary approach was needed. We brought together rheumatologists, specialist nurses, allied health professionals and patients from across the UK; this working group has spent more than two years developing and testing standards to bring you and your rheumatology services a set of achievable 'best practice' standards".

Dr Price reflected on the origin of the QRS: "I first started thinking about this when, in the early days of my BSR presidency, I was invited to undertake a number of visits to departments. I realised that although there are obvious similarities, there were also significant differences in the ways that departments organised their services.

Through QRS, the same standards are applied across all four home nations, England, Wales, Scotland, and Northern Ireland. The aim of QRS is to highlight and celebrate individual rheumatology service's strengths and to help identify areas for development.

Dr Liz Price notes: "Patients will have reassurance that their service is accountable and works to UK-recognised standards. It will have been inspected by patients themselves and patients' views taken into account during the process.

# SUPPORT GROUP NEWS

## East Midlands Vasculitis Support Group



East Midlands Vasculitis Support Group held their very first zoom coffee morning on Easter Monday, April 5th 2021.

Around 16 members joined in the coffee morning, most by video one or two without video.

The coffee morning lasted for 60 minutes.

Topics discussed were activities done while shielding, best takeaway meal providers to use, vaccines, vaccine experiences and research studies, best family holiday destinations in the U.K. and recommended disability holiday desti-

nations in the U.K.

Everyone certainly enjoyed chatting and catching up, the hour soon flew by.

The next coffee morning is planned for May.

Susan Mills ( EMVSG )

## How we have got on – West Country Support Group by *Philippa Fortescue*

The Covid situation in the South West has been far easier than in much of the country as rates have been relatively low even when we had the influx of visitors last summer. Many of us Vasculitis sufferers are not confined in the centres of big cities and we have been able to get out even when in 'shielding' as most of us have been. The walkers have been walking, particularly those with dogs, and even the less mobile have managed to get out and about a bit when permitted. I do feel for those in shielding who felt not just 'locked down', but 'locked in' – under 'house arrest'!

Our wonderful West Country Support Group co-ordinator Charlotte Stoner has come up with various activities to keep us all in touch. First there was a collection for a group donation for VUK as so many fund raising activities ground to a halt. We normally meet up for several social lunch gatherings and since we were saving on them, it seemed a sensible idea to donate those savings to Vasculitis UK - over £400 was raised. All those missed carvery lunches with dessert, coffee and drinks. We look forward to when they can start up again!

Next scheme was a Zoom meeting with about 20 of us there to hear the speaker Dr Richard Haigh, a Consultant Rheumatologist from the RD&E hospital. He understandably spoke on what was then known about Covid and Vasculitis and answered questions. It was early days then and he stressed that we should be as careful as we could be and take no chances. How things have moved on since then. It was the first of our Zoom meetings and Charlotte got it up and running with the help of her family. Unfortunately a rather too friendly character 'Heidi' joined us and hijacked the meeting so poor Charlotte had to hurriedly shut the whole meeting down and then re-start it with our speaker waiting in the wings and ready to go. All part of the learning experience in these odd times. Zoom/webex seem to be a great way of holding meetings and far easier than going out at night to some unknown venue. They also enable one to 'virtually' attend Vasculitis meetings all over the country.

We have had several Zoom coffee mornings since then and they have been wonderful for keeping in touch. A great variety of topics come up for discussion, not necessarily related

to vasculitis. Recently we have compared notes about reactions to our 'Jabs'. Most have had few or no side effects, but a couple of us had 2 days feeling quite fluey. If I felt that bad after a vaccination, I do wonder how I would have been if infected by Covid19. I don't normally react to flu jabs so I was not expecting side-effects. The vaccination programme has gone very well in the South West, but at this stage most of us are hoping that all will go equally well for our 2<sup>nd</sup> jabs in April.

Another useful topic that has come up at the coffee mornings is checking that we are all being given the same information about time between vaccinations and hospital treatment. It is very reassuring to find that it is the same for us all. We chat about lots of other things, such as what is worth watching on Netflix, so the group activities have really helped us to get through these very difficult times and have really been something to look forward to. Now we are all hoping for more freedom in the coming months and some good weather to get out and about after our second jabs, and maybe even meet up in person for a much missed carvery lunch!

If you would like to join the West Country Vasculitis Support Group – which has members stretching from Cornwall and Devon to Dorset and Somerset, please contact Charlotte Stoner by emailing : [westcountryvasculitisgroup@outlook.com](mailto:westcountryvasculitisgroup@outlook.com)

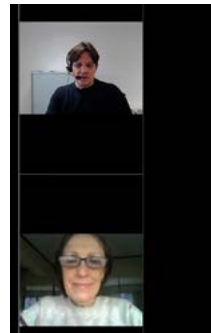
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## European Reference Network Rare Autoimmune Auto Inflammatory & Primary Immune Deficiency Webinar

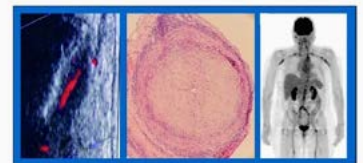
ERN-RITA Webinar: Advances in the treatment of giant-cell arteritis

Giant Cell Arteritis (GCA) is the most common vasculitis in adults. References to GCA have been found as early as the 10th century. In the early 1930's the disease was known as "Horton's disease"; in the next decade, the term "temporal arteritis" became quite popular. In a 1941 article in The Journal of Pathology, J.R. Gilmour named the condition "giant cell arteritis" based on microscopic examination of inflamed arteries.

Corticosteroids remain the cornerstone of the pharmacological treatment, but the therapy of Giant-Cell Arteritis is evolving, and new treatments are getting introduced.



### ADVANCES IN THE TREATMENT OF GIANT-CELL ARTERITIS



MARIA C CID  
VASCULITIS RESEARCH UNIT  
DEPARTMENT OF AUTOIMMUNE DISEASES  
HOSPITAL CLINIC, UNIVERSITY OF BARCELONA, IDIBAPS  
BARCELONA

ERN RITA organised a webinar about the current and developing treatment strategies in GCA. The speaker Dr Maria C Cid, MD, Senior Consultant at the Department of Autoimmune Diseases, Associate Professor at the University of Barcelona, gave an update of treatments and research of treatments for GCA. You can find the webinar in ERN RITA's website, but here are some main points.

Glycocorticoids (prednisolone) are given to get the patient in remission, but one of the biggest challenges in GCA are the relapses which are linked to glucocorticoid tapering. Relapses require re-treatment, and a vicious circle begins. There is an unmet need for more effective and safer treatment in GCA.

Synthetic DMARDs like azathioprine, mycophenolate, even cyclophosphamide have been used to help decrease the use of steroids. Only methotrexate has been tested in controlled trials and is widely used in treating GCA. There is a consensus that higher doses of methotrexate should be trialed.

Targeted therapies like infliximab, adalimumab, tocilizumab, anakinra and others have been tested or are currently tested for use in GCA treatment. Abatacept has been found to be slightly more effective than placebo to sustain remission at 12 months and the trial is ongoing. TFN- blockers have unfortunately not shown signs of efficacy in the first trials. ANTI-IL-6 / IL-6R (tocilizumab, sarilumab, sirukumab) have been trialed, but only tocilizumab has been completed.

According to the GiACTA trial findings tocilizumab has been a major advance in the treatment of GCA. It has a good safety profile, it reduces flares, it helps decrease glucocorticoids intake and 42% of patients can expect sustained remission. Current data do not support monotherapy.

Therapeutic options continue to be investigated in order to help sustain remission and improve the quality of life in patients with Giant-Cell Arteritis.

Zoi Anastasa (ePag ERN RITA)

# Hannah's Story - 10 Years On

## 10 Years - Since Intensive Care



Hannah today - aged 35 with her dog Hetti

10 years ago I was in an induced coma. I couldn't breathe because my lungs were bleeding, in fact many of the blood vessels in my body were becoming inflamed and rupturing. The whites of my eyes were solidly red, my kidneys weren't good, I was bruising wherever more than the lightest touch was needed

and blood wasn't getting to my extremities consistently. My plasma had been replaced and I was on all sorts of medicines in huge syringe drivers stacked all around the head of my bed with lines in my neck, my wrist and hand.

I had already been in hospital for several weeks hearing doctors tell me they didn't know what was wrong with me but that they were testing me for the likes of TB, HIV and rare kinds of cancer. I had allergic reactions to medicines, and all kinds of uncomfortable tests and biopsies.

When I presented at A&E I just thought that I wasn't recovering quickly enough from a winter chest infection. I had already been to my GP several times in the few weeks prior and had been on anti-biotics and steroids that were just not helping. I had been coughing up small amounts of blood regularly which I had convinced myself was from my very sore throat. By the time I got to intensive care I knew that what I had was called "Wegener's Granulomatosis" (now called Granulomatosis with Polyangiitis), a type of A.N.C.A Associated Vasculitis and my immune system was to blame. My own body was at war with itself-inflamed, angry and attacking healthy cells. The doctors were working to put out the inferno in my body by dampening my immune system with Cyclophosphamide, very high doses of steroids, plasma exchange and everything and anything they thought might help even slightly.

I remember the night when I was put to sleep. My Mum and Dad were by my side and I, thankfully (and, I believe, in answer to prayer), was not aware of the gravity of what was happening. All I knew was that I was exhausted and I wanted to sleep and not be in pain anymore. It didn't cross my mind that I might not wake up again. I had been minimally communicative for days as I'd been wearing a constant positive air pressure mask to force air into my lungs. Even if I'd felt the need, I wouldn't have been able to say anything to my parents, but I remember the comfort of their faces above me and touch on my left hand. I was intubated and placed on a ventilator. My parents were taken into a side room and told that it was extremely unlikely that I would make it through the

weekend. My four siblings came to Derriford hospital, to my bedside, to say goodbye. My friends gathered together to pray that I would make it.

But 10 days later my eyes flickered open to a tugging in my throat. I didn't know where I was, I didn't know what was going on. I couldn't move, my muscles had wasted to the point that I couldn't even scratch my nose. I had a tube in my nose to my stomach giving me food. My feet were in bad shape having been the last on my body's list for oxygen. My toes and parts of my feet were necrotic, dead. But I was alive and I was breathing on my own.

For the first few days I was still heavily medicated and for most of the time was in a delirious state of happiness, but in my head I kept thinking "why are you so happy, you should be terrified". Eventually the reality hit me and I became overwhelmed by what had happened. The consequences became clearer and Doctors came to my bedside with news that was difficult to hear- I would need surgery to remove the necrotic parts of my feet.

This surgery would mean that I would possibly never walk again and that I would be permanently disabled. My lungs had taken a beating and would never fully recover and I had become so dangerously poorly so quickly that plans to preserve my fertility had been shelved in favour of plans to keep me breathing.



My Feet - My most recent surgery was November 2020

I flipped between several different attitudes to all this information "at least I'm alive" was the one that more often than not came out of my mouth, but more complex feelings swam around in me too as I experienced the trauma in waves.

A new sort of life began, one of chronic illness and disability. I began a different relationship with my body and a different relationship with the world.

With my niece at a family wedding about a year after ITU, My hair had grown back, but I was still on a lot of medication hence the "moonface".



In the last ten years I have been treated in more than six different hospitals and had a lot of surgeries on my feet. I've had numerous procedures, infusions, medicine regimes and developed other chronic conditions such as T1 diabetes as a result of my wonky immune system. My right lung is scarred and has contracted so that my diaphragm has naturally moved further up into my chest to compensate and I have a condition called Bronchiectasis. There have been numerous needles, blood tests and drugs and if I could buy every Nurse, Doctor, Radiographer, and Health Care Assistant that I've met along the way a drink I would be very poor indeed!

The mental toll has been huge and I struggle with ICU related PTSD to the point that even the smell of cling film can reduce me to tears (it often smells like oxygen masks). Intensive Care aftercare has really improved in the last ten years, but I struggled to get the help I needed. This can still make hospital visits difficult for me and often completely catches me off guard, the noise of a medical machine or even sometimes the very specific taste of hospital tea can bring memories flooding back. These memories are not always traumatic, some make me laugh, like the time I asked the nurse with the drinks trolley where my flight was going and why I was in bed instead of a plane seat and some make me smile, like remembering my friend's faces by my bedside.

When Vasculitis reared its ugly head in my life its presentation was quick and very aggressive. I was young, only 25 years old and probably the fittest and healthiest I'd ever been.

For a long time I felt like my life was never going to be what I had planned it to be and that made me sad, under confident and depressed, but then I realised that I could make new plans. I didn't feel up to returning to my demanding role in the Youth Offending Service and I had left school with just 4 GCSE's as my education had been blighted by illness too when I struggled with post viral chronic fatigue due to Glandular Fever. So I decided to pursue the education I had missed and returned to college to take an Access to Higher Education Course. I then proceeded to take an English degree and then an MA in Victorian History and Literature and in September I hope to start a PhD.

These undertakings have not been easy as I have been having various treatments along the way, have had Osteomyelitis in my amputation site on my left foot twice and I was diagnosed with Type One Diabetes in my second year at university. My life is the one I planned, the plans might not be the original ones, but they are mine and I'm proud of what I've achieved.



Mum and Dad - who look after me so well

To mark 10 years since my diagnosis I told part of my story on social media and my family and friends donated £450 to vasculitis UK. I am so grateful for the support I have received through this charity.

*Hannah Burden, Age 35, Leicestershire*

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### **French Health Authorities Advise 3<sup>rd</sup> Vaccine dose for heavily immune suppressed patients.**

In a recently released note the French Directorate General of Health recommends administering a third dose of Pfizer / BioNTech and Moderna vaccine to immunocompromised patients.

In a note shared with French health professionals on Sunday, the Directorate General of Health recommends administering a third dose of Pfizer / BioNTech and Moderna vaccine against Covid-19 to all immunocompromised people.

“The injection of a third dose of mRNA vaccine is necessary for severely immunocompromised people,” insists the DGS, relying on an April 6 opinion from the French Vaccine Strategy Orientation Council. The DGS lists the people targeted by this recommendation: “solid organ transplants, recent bone marrow transplants, dialysis patients, patients with autoimmune diseases under strong immunosuppressive treatment such as anti-CD20 or anti-metabolites.

This additional dose must be injected at least four weeks after the second injection, “or as soon as possible for people who have already exceeded this time”, specifies the DGS. On the other hand, this recommendation **does not** concern cases of “chronic renal insufficiency who are not on dialysis, patients with cancer and patients with autoimmune diseases under other immunosuppressive treatments”, for which another recommendation on vaccination will be shared “later “.



## RSM Covid Webinar – Interview with Prof Chris Whitty

During Lockdown, the Royal Society of Medicine has been holding a series of regular online webinars for members and guests, under the banner of “RSM Live”. We were fortunate to be invited to attend the event on 31<sup>st</sup> March, in the “Covid-19” series, with the Chief Medical Officer, Professor Chris Whitty as Guest Speaker and the topic, unsurprisingly, was Covid 19.

The presentation took the format of an interview with Prof Whitty, with Professor Sir Simon Wessley posing the questions. We are all now familiar with seeing Chris Whitty on our screens; as Sir Simon pointed out, he is now a TV celeb and we might expect to see him soon on Strictly or Celebrity Bake Off.

But the Chris Whitty we saw here was much more relaxed and at ease, confidently and coherently answering questions from his medical colleagues and peers rather than when in the tense Downing Street briefings, fielding questions from journalists.

Various messages came across in the hour long interview. In summary:-

- There is no evidence to suggest a significant decline in immunity as time passes following vaccination. The second dose reinforces and enhances immunity.
- Early evidence seems to show that vaccination does result in a reduction in transmission.
- There’s no discernible difference in effectiveness between the vaccines:” the best vaccine is the one you are getting!”
- Antibody levels are not the only factor in disease resistance so they are not a reliable indicator of acquired resistance to covid.
- So far, some of the variant viruses are better at transmitting (ie more infectious), which gives them an advantage, but so far they are not found to cause worse disease & are still vulnerable to the effect of the vaccines.
- There is no evidence of increased anaphylaxis risk with the Astra Zeneca (Oxford) jab.
- Medicine is always a matter of balancing risks with benefits; for young children the risk of catching or suffering significant damage due to Covid is very small, so the advantage for them of having the vaccine is small, but any risks from the vaccine are the same for all ages. Vaccinating young children solely to protect adults would be unethical.
- All pandemics produce exponential growth ie they have a very high rate of spread, so prompt effective measures are always needed.



## Medicinal Cannabis: Reviewing the evidence

An international review has found a lack of scientific evidence to support the use of cannabis in treating pain.

The appraisal of evidence, carried out by the [International Association for the Study of Pain \(IASP\)](#), is believed to be the largest to date. It looked at all relevant published laboratory and clinical research on the topic of active compounds in cannabis, called cannabinoids, and reducing pain.

Researchers found that although preclinical studies and anecdotal reports from patients support the hypothesis of using medicinal cannabis products to reduce pain, the currently available clinical data does not support this in practice.

Their work is outlined in a series of papers published this month in the journal *Pain*.

This is not a door closing on the topic, but rather a call for more rigorous and robust research to better understand any potential benefits and harms related to the possible use of medical cannabis, cannabis-based medicines and synthetic cannabinoids for pain relief Professor Andrew Rice Department of Surgery & Cancer

According to the reports, the data on efficacy and safety fail to reach the threshold for the IASP to endorse the general use of cannabinoids for pain control. The authors clarify that the review is limited to using cannabinoids to reduce pain and did not consider the use of cannabinoids for other therapeutic areas – such as reducing spasms in multiple sclerosis.

[Professor Andrew Rice](#), from Imperial's Department of Surgery & Cancer, and chair of the IASP's Presidential Task Force on Cannabis and Cannabinoid Analgesia, said: "While the IASP cannot endorse the general use of cannabinoids for treatment of pain at this time, we do not wish to dismiss the lived experiences of people with pain who have found benefit from their use."

In a position statement, [available online](#), the IASP says that it recognises that some national and regional jurisdictions already permit the use of cannabis and cannabinoids for pain relief, for other medical indications, or for recreational use. But it adds that more research is needed "to elucidate the benefits and harms of therapeutic use of cannabis and cannabinoids for the treatment of pain."

Vasculitis UK is a member of, and contributes to support the work of, [RAIRDA](#) (the Rare Autoimmune Rheumatic Disease Alliance) a coalition of charities and clinicians working to improve care for people with these conditions. Since the start of 2020, Noah from Principle Consulting, a social enterprise which works with a number of charities, has acted as the secretary for RAIRDA under the direction of the 4 member charities (Vasculitis UK; Lupus UK; Scleroderma Raynauds UK & Sjögrens UK).

Here are some of the highlights from RAIRDA's activity since March 2020:

In June 2020, RAIRDA published a report based on 1,300 survey responses on how people with RAIRDs have been impacted by COVID-19. The survey data was subsequently used to give evidence to the House of Commons Health and Social Care Committee and the Welsh Senedd's Health, Social, Care and Sport Committee.

The report has also been cited in further research. Following up from this, in October 2020, RAIRDA hosted a video roundtable with clinicians, patients, and representatives from NHS England. Due to the disruption of the second and third waves of the pandemic, we are still following-up on this event but understand it has helped NHS England understand the issues facing patients and clinicians.



Over the course of the year parliamentarians in the Welsh, Scottish, and UK parliaments have tabled questions on issues raised by RAIRDA and we secured 3 pieces of coverage in national media. RAIRDA also recently gave evidence at the session of the All-Party Parliamentary Group on Vulnerable Groups to Pandemics. RAIRDA has also worked with a coalition of large charities to raise issues around shielding and vaccinations, including through meetings with the Vaccine Minister and NHS England.

\*

Whilst RAIRDA's 2020 activity mainly focused on responding to the issues caused by COVID-19, in 2021 we are now looking at how we can encourage health services to 'build back better' and deal with the backlog of care that needs to be delivered. We believe the evidence of the impact of COVID-19 on people with rare autoimmune rheumatic diseases, gathered by RAIRDA and others, will help us build a strong case for this. Additionally, the new UK 'Rare Disease Framework' has a specific mention of the need to diagnose 'non-genetic' rare diseases (such as RAIRDs) earlier. As all four nations of the UK will need to explain how they're enacting this framework, to hope to encourage actions which will support people with RAIRDs.

Noah Froud. Principle Consulting. April 2020





## 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](http://www.justgiving.com/VasculitisUK/Remember)

A donation of £435 was received in memory of John Price. John was a volunteer for a children's football team for four years.

Donations totalling £70 were received in memory of the late John Richard Hutton.

£50 in donations in lieu of flowers was received in memory of Mrs Julie Guest.

Donations totalling £370 were received in memory of John William Holmes of Minster on Sea, Sheerness, Kent.

A cheque for £15 was received in loving memory of Cary Rendell.

Donations totalling £130 were received in memory of Edward Hoseph Rose of Mansfield, Notts.

Jane Everitt donated £30 in memory of her partner Adrian Tomblin, who sadly passed away on 13<sup>th</sup> October 2017.

Keith Adlam of Melton Mowbray sadly passed away just before Christmas 2020. Bereaved are his wife, Jane and their daughter Caroline. Neighbours Caroline & Glyn donated £25 in his memory.

Tina Heath once again made her annual donation to Vasculitis UK in memory of her much-loved sister, Lorna, who sadly died on 6<sup>th</sup> January, 7 years ago, age only 49, due to GPA. On this occasion Tina donated £100 instead of the usual £50.

Margaret Galloway of Port Erin, Isle of Man, donated £50 in memory of a good friend Brian Louth, who sadly died in late 2020, leaving a widow, Pat.

Funeral donations of £217 were received in memory of Violet Tweddle of Middlesbrough.

Ann Wall suffered from EGPA (Churg Strauss Syndrome). Sadly she died in April 2020 due to late diagnosed myeloid leukaemia. Her sister, Mrs Helena Warnock, set up a standing order for Vuk as an annually recurring memorial to Ann.

Funeral Donations totalling £835 were received in memory of the late Brian James Louth of Hayling Island, Hants, who passed away last December, aged 83, leaving a widow.

Donations totalling £105 were received in memory of Pauline Boardman of Bolton who sadly passed away last December after a 2 year battle with vasculitis. She left a bereaved husband and was a much loved mum to Kevan and Megan.

A donation of £209 was received in memory of Sandra Clarke of Hucknall, near Nottingham, who sadly passed away in the early part of this year.

Donations totalling £380 were received in memory of Mr Alan David Boland of Neath, near Port Talbot, South Wales, who sadly passed away earlier this year.







## Donations & Fundraising



**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.*

A donation of £30 was received, from someone in Scotland, in lieu of a 40<sup>th</sup> birthday gift.

Swithland Spring Water very generously donated £1100 to Vasculitis UK to mark Christmas 2020.

Judith Ramczyk of Buxton kindly donated £100 to Vasculitis UK.

Kyrie Roebucks donated £30 to Vasculitis UK, the proceeds of her annual "Tillypops" online Easter egg hunt.

Janet Worman kindly donated £40 to Vasculitis UK.

Wendy Smith founded the charity Nwas Henoeh Schonlein Support which was recently wound up. She kindly donated the residual funds of £764 to Vasculitis UK.

The Bank of New York Mellon Corporation kindly donated £2000 to Vasculitis UK.

Claire Gilmour kindly donated £30 to Vasculitis UK and her aunt donated a further £20. Claire, her husband & son were all hospitalised due to the covid virus, but are recovering.

## 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](mailto:family.davies@btinternet.com)  
Christine Lee - 01480 869162 - [chrislee0307@btinternet.com](mailto:chrislee0307@btinternet.com)

### Cambridge Group

Lesley Noblett - 0776 5897780 - [cambsvsg@gmail.com](mailto:cambsvsg@gmail.com)

### Canterbury area (Contact Person)

Margaret McGrath - 01227 638469 - [margaretmcgrathfmsj@yahoo.com](mailto: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](mailto:Dorothy@vasculitis.org.uk)  
Susan Mills - 01629 650549 - [susan@vasculitis.org.uk](mailto: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](mailto:lvsg@btinternet.com)

### Lincolnshire Group

Sandra Lee - 0754 514 4777 - [sandylee777@hotmail.co.uk](mailto:sandylee777@hotmail.co.uk)  
Caroline Meyrick - 01780 460354 - [cmmeyrick@gmail.com](mailto:cmmeyrick@gmail.com)

### London

North London Group  
Dave Newman - 07429137670 - [david.newman@londonvsg.org.uk](mailto:david.newman@londonvsg.org.uk)

### Merseyside, Cheshire and North Wales Group

Susan Chance - 01244 381680 - [susan chance53@icloud.com](mailto:susan chance53@icloud.com)  
Dave Birch - 0151 7229049 or 07968226230 - [davebirch@talktalk.net](mailto:davebirch@talktalk.net)

### North East Group

Margaret Robertson - 07443016665 - [mgtrub@talktalk.net](mailto:mgtrub@talktalk.net)  
[susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)

### Norfolk Vasculitis Support Group

Mark Sayer - [m-sayer@hotmail.co.uk](mailto:m-sayer@hotmail.co.uk)

### The North West Group

Jann Landles - Anita Parekh [nwvasculitis@outlook.com](mailto:nwvasculitis@outlook.com)

### Northamptonshire Group

Maurice - [northantsvsg@gmail.com](mailto:northantsvsg@gmail.com)

### Northumberland and Cumbria (Contact person)

Martin Thomas - 07765 888987 - [nwukvsg@gmail.com](mailto:nwukvsg@gmail.com)

### Oxfordshire Group

Sue Ashdown - 01295 816841 - [vsgoxford@gmail.com](mailto:vsgoxford@gmail.com)

### Plymouth Group

[elaine203@live.com](mailto:elaine203@live.com)

### Scarborough Group

[ruth.newton@york.nhs.uk](mailto:ruth.newton@york.nhs.uk)

### Solent/Portsmouth Group

Julie Ingall - [Julie.ingall@porthosp.nhs.uk](mailto:Julie.ingall@porthosp.nhs.uk)

### Surrey Group

Peter surreyvsg@gmail.com

### Sussex by the Sea Vasculitis Support Group

Antony Hart - [Antonyghart@outlook.com](mailto:Antonyghart@outlook.com)

### Swindon Support

Wendy and Lisa [swindonvsg@mail.com](mailto:swindonvsg@mail.com)

### West Midlands Group

David Sambrook - [davsamuk@yahoo.co.uk](mailto:davsamuk@yahoo.co.uk)  
Margaret Gentle - 0121-243-5621 - [mgentle128@gmail.com](mailto:mgentle128@gmail.com)

### West Country Group

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

### West Sussex Group

John Bailey - 07752 122926 - [johnbee4@googlemail.com](mailto:johnbee4@googlemail.com)

### North and West Yorkshire Groups :

Richard Eastoe - 01423 520 599 email [richard@yorkshirevasculitis.org.uk](mailto:richard@yorkshirevasculitis.org.uk)

### East Yorkshire Group :

Rachel Weeks - 07968 959 850 email [rachel@yorkshirevasculitis.org.uk](mailto:rachel@yorkshirevasculitis.org.uk)

### North East Yorkshire Support Contact :

Richard Eastoe - 01423 520 599 email [richard@yorkshirevasculitis.org.uk](mailto:richard@yorkshirevasculitis.org.uk)

### South Yorkshire Social Group Contact :

Jenny Gosling - email [jenny@yorkshirevasculitis.org.uk](mailto:jenny@yorkshirevasculitis.org.uk)

## WALES

### North Wales - (Contact Person)

Pat Vernalls - 01766 770546 - [patvernalls@btinternet.com](mailto:patvernalls@btinternet.com)

### North Wales Group (group also covers Merseyside and Cheshire)

Susan Chance - 01244 381680 - [susan chance@53@icloud.com](mailto:susan chance@53@icloud.com)

### South Wales Group

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

## SCOTLAND

### Edinburgh and Lothian (Contact Person)

Jimmy Walker - 07725 770103 - [jamzywalker@gmail.com](mailto:jamzywalker@gmail.com)

## Republic of IRELAND

### (Contact Person)

Joe O'Dowd - 00353 (086) 2345705 - [dwodo@iol.ie](mailto:dwodo@iol.ie)

### Ireland - Vasculitis Awareness Ireland

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

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





**British Society for Rheumatology (BSR) Annual Conference April 26th - April 28th 2021  
( Medical Professionals Only )**



**University Hospitals Birmingham**  
NHS Foundation Trust

**West Midlands Vasculitis Network ( medical professionals only ) 10th May 2021**



**United Kingdom All Ireland Vasculitis Group Meeting (UKIVAS) ( Medical Professionals only )  
May 28th 2021**



**U.K. Kidney Week 5th October - 15th October 2021**



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## 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

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### Vice Chair & Director of Operations

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