VASCULITIS UK

NEWSLETTER JOURNAL

Member of EURORDIS Rare Diseases Europe

SPRING 2020 ISSUE 59

Chairman's Report

This is not the report I originally wrote for the spring newsletter, but as you can understand, I felt the need to write a new one.

We are now all in "Lockdown" a word probably none of us would imagine would apply to a great economy. Something more from an authoritarian state, but here we are! Self-isolation has happened before and been successfully applied in the village of Eyam, Derbyshire. They chose to quarantine themselves to protect the rest of the county for a year in 1666 at great cost to themselves but saved their neighbours. A lesson for those not following the new restrictions.

The trustees have been meeting through video conferencing, and took the decision to cancel the AGM set for the 17th May. The thought of so many immune suppressed people with multiple comorbidities gathering in one place, made the decision easy. We may look at this again over the summer to see if it's feasible to try in the Autumn. At present no one can predict where we will all be.

Time to mention a few of our heroes, working in the background. Gareth Garner and Susan Mills have been diligently working with our IT team to keep the information about Covid-19 as accurate and up to date as possible. This is Gareth's area of expertise. Sometimes with daily changes. They have also been answering questions raised in the online support groups.

The admins on the Facebook group (Zoi Anastasa, Kath McIntosh, Susan Mills, Louise Spencer, Kieron Clougherty and myself) who have been screening posts before allowing them to be posted. We are checking for scam reports or instant cures, all of which get deleted. We are also trying to make sure that things don't get too heated and will turn off comments, if they do. If you are not on Facebook then this might be something to consider at this time of isolating or shielding. People are very supportive.

We also have the helpline 03003650075, which has understandably been very busy. People are scared and need reassurance. We will listen and help if we can but we can't make this go away. It's not helped by normal appointments being cancelled when we know we need regular monitoring and treatments.

A hero not corona virus related is Ian Kayes who took on the task of processing our gift aid. Then successfully applying to HMRC to recover over £5000.

The one person I could never leave out is John Mills, who despite being very ill earlier this year, is taking all the applications for research grants through the long process of being approved. I understand that there are 11 in the process. The process has now been put on hold as the professionals who would do the peer reviews are now battling Covid-19.

Many of our support groups have cancelled meetings. Please though find other ways to support the members in your groups. This might be through phone calls. A chat can make such a difference when we can't go out. Many fundraising events have also been cancelled from the London Marathon to cake sales. I have quite a list. Please don't worry or take any chances. The charity will be fine, we don't have offices or salaries to pay. Please also, consider when ordering from the shop. We do have some items in stock but we can't order anything new as our suppliers are currently closed. We would struggle to get packages to the post office.

Finally, I just want to say stay safe, wash hands, follow the isolation instructions by keeping your distance. Use other means of communication Skype, Facetime, messenger or through the window to a neighbour and family.

Take care
Dorothy Ireland
Chairman Vasculitis UK
1180473

Things that didn't happen

Spring 2020 looked like being a busy time for Vasculitis UK.
In April the British Society for Rheumatology annual Spring Conference was to take place in Glasgow. This is usually the best time in the vasculitis calendar for talking to doctors and building relationships, as well as an opportunity for us to learn by taking part in some of the lectures and poster exhibitions; so Vasculitis UK was booked to attend and have a stand in the main exhibition hall. This was cancelled, but the BSR promptly published all the abstracts and posters online – offering a "virtual" presence.

On 1st May there was to be a full meeting at the Royal College of Medicine HQ, in London, of the UK & Ireland Vasculitis Study Group, (UKIVAS) which represents most of the senior vasculitis doctors in the UK & Ireland. UKIVAS has just started to expand into vasculitis education for professionals. Naturally this meeting was cancelled.

In June, Vasculitis UK was to have a stand at the Royal College of Nursing Congress in Liverpool. This too has been cancelled, but might be "rescheduled". Various fund-raising events, such as the London Marathon, due to take place over the summer, have been cancelled between now and September. This is of serious concern for most charities as these events represent a major source of charity income.

Things that might still happen

UKIVAS The aborted UKIVAS meeting in May is being re-scheduled as a virtual, online meeting. As a typical UKIVAS meeting comprises 50-100 participants, this is technologically challenging. Vasculitis UK Funded Research last autumn, as in previous years, Vasculitis UK set a budget of £150k to support vasculitis research. In November, a "call" was put out among the community of vasculitis professionals for grant applications. (Individual grants are limited to £50k. A full research study may cost in excess of £1million, but £50k is usually sufficient for a pilot/feasibility study). The closing date for applications was 31st January. Once all applications are in, there follows a rigorous process of "peer review" whereby each application is checked by at least two acknowledged experts in the subject of the application, according to set criteria.

After this, the VUK Scientific Advisory Board members review the results of the peer review process and make their recommendations on which applications should be approved to the Vasculitis UK Board of Trustees. In a typical year, we receive 5-6 applications. On this occasion we received a record 11 applications, most of which seemed to be of high quality and worthwhile. Many applications named one or more "co-applicants". Applicants and co-applicants are not allowed to be also peer-reviewers for that round of applications. Thus, with 11 applications we needed 22 independent reviewers. The medical vasculitis world is small. Most of our usual reviewers were also applicants this time round. Thus we struggled to find suitable reviewers for all 11 applicants.

Then, in late March, having looked beyond the UK for additional reviewers, we found that most of those who had already agreed were being drafted away from their normal clinics to the "front line" in the battle against Covid-19 and were no longer available to carry out a review. In the light of this, the Scientific Advisory Board members were unanimous in agreeing to postpone the whole awards process until the autumn or such time as everything returns to "normal".

BSR Conference. There is usually a Main conference in the Spring and a less well attended "Case Based" conference in the autumn. This year, the BSR may decide to make the Autumn Conference the main one.

Things that Did Happen

Scottish National Systemic Vasculitis Network.
In early December, Susan & I were invited to the formal launch by NHS Scotland of the "Scottish National Systemic Vasculitis Network". This took place at Stirling University. Scotland (like Wales) has a problem with equable distribution of healthcare due to the fact that the geographic area is large but the population is small; most of the population is based in a few large centres (Glasgow, Edinburgh, Aberdeen, Inverness, Dundee) with the remainder thinly spread over a large, often rugged terrain, including fairly remote island communities. This is a challenge, especially when dealing with rare diseases such as vasculitis. A routine hospital clinic visit might entail a 2 day round-trip with an overnight stay. Or worse. Thus the idea developed that "virtual" clinics could be developed so that a patient with vasculitis, living, say, in the Outer Hebrides might have access to a leading consultant in Glasgow, Edinburgh or Aberdeen for their diagnosis and case management.

NEWS in Brief

"The Letter"
In mid-March it was announced that those most vulnerable to coronavirus due to their medical condition or medication would receive a letter from their hospital or consultant advising them of their risk status and how

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to proceed. Unfortunately there is no existing database which lists these high risk patients, so at a time when hospital departments were already in chaos and short-staffed due to the pandemic, staff had to go through

thousands of individual records manually, assessing the risk level of each patient, unsurprisingly, this process took many days. As vasculitis is a multi-organ disease, some vasculitis patients are seen in more than one department or even different hospitals. Some whose risk was actually quite low were told that they should be "shielding" for 3 months, whilst others, whose actual risk was high did not receive a letter and some carried on working.

Plasma Exchange Study

We were asked by Dr David Collister of Hamilton University near Toronto, Canada, if we could help him find ANCA vasculitis patients with experience of Plasma Exchange. Thanks to the Vuk Online Groups we were able to introduce him to 14 possible interviewees.

Adrenal Insufficiency Information

Leeds Rheumatologist, Sarah Mackie, asked for help in compiling a patient friendly information leaflet warning patients about the hidden risk of cortisol insufficiency in people taking steroids. Vasculitis UK trustee Zoi Anastasia was able to help as an "expert" patient in the process of drafting the leaflet and members Kath McIntosh & Anne Southren helped in reviewing & editing. We hope to demonstrate the finished leaflet in a later edition.

VOICES project

Dr Rosemary Hollick, supported by Avril Nicoll in Aberdeen are working on a research study called "VOICES" – Vasculitis Outcomes In Terms of Care Experiences Study. Vasculitis UK are assisting with this project.

Vasculitis International

Vasculitis International started life at the International Vasculitis Conference in London in 2015, as Vasculitis Europe, the joint brainchild of John Mills of Vasculitis UK and Peter Verhoeven of the Dutch patient organisation, Vasculitis Stichtig. The intention was to offer a united "voice" for the vasculitis patient organisations in Europe, to share knowledge & information and encourage research. Not wishing to discourage emerging groups in countries outside Europe. It was decided to re-form as Vasculitis International. The organisation now has legal status and a website – see www.vasculitis.eu . Vasculitis International now included Vasculitis Ireland, as well as organisations in France, Finland, Greece, & Italy and is part of the FAIRVASC research project (see elsewhere in this edition).

EUVAS is the European Vasculitis Society - an open collaboration of physicians interested in research and education in vasculitis. EUVAS has representatives from many medical specialties based both inside and outside the European Union. EUVAS conducts a range of activities including clinical trials and studies into the assessment of vasculitis. EUVAS is a partner for interested researchers in the development of collaborative studies. EUVAS has links with other vasculitis research groups: Groupe Français D'étude des Vascularites and Vasculitis Clinical Research.

UKIVAS MEETING

UKIVAS is the title used for the UK's Vasculitis Study Group which is for medical professionals with a serious interest in vasculitis. The main focus of UKIVAS is currently the UK & Ireland vasculitis database. UVIVAS is now taking on more of a professional educational role. Maybe, with financial support from Vasculitis UK, UKIVAS might in the future adopt more of a leading role in the UK vasculitis community.

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COVIDENCE UK
YOUR DATA, FIGHTING CORONAVIRUS

Sign up to the COVIDENCE UK Study and contribute to the fight against coronavirus. A team of doctors, scientists, public health specialists and health economists from six universities -Queen Mary University & Kings College, London, The London School of Hygiene & Tropical Medicine, Edinburgh & Swansea Universities and Queen's University, Belfast have joined together in a national study investigating how long standing medical conditions like vasculitis and other factors like diet & lifestyle may interact to influence susceptibility to coronavirus disease and its complications. The national study goes under the title "Covidence UK". This might lead to simple modifications to these factors which could reduce the risk of coronavirus disease while we wait for a vaccine. As some vasculitis patients are at increased risk of coronavirus, this study may be of special relevance.
The researchers are looking to recruit a broad mix of people from all over the UK, including those who have NOT had coronavirus infection, and those who HAVE already had proven or suspected coronavirus infection. The study will involve filling in an on-line questionnaire to collect information about your lifestyle, diet, long-standing conditions and prescribed treatment. Completion takes 30-60 minutes. After that, you will be contacted monthly via email to report possible symptoms of coronavirus disease. The data you provide will be linked to your medical records, to allow the study team to investigate whether coronavirus infection may affect long-term health. For further information, please visit the study website: https://www.qmul.ac.uk/covidence/

FROM THE EDITOR

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

Dear readers, firstly I hope you are all safe and well and welcome you to the spring edition. For obvious reasons it is slightly behind the proposed publishing date, this is also due to my Mac deciding it was not going to be out done by a global virus, so it self-isolated on me completely, which proved to be difficult at first because this happened just after everywhere closed down!.....Panic first ensued, but nowhere near like the panic over toilet rolls!
A new Mac was sourced and I was able to then start to put together the vast amounts of articles, photos that were streaming in prior to this.

I've been fortunate in some ways being a key worker within the food industry, and a Union Rep/Branch Secretary because I've not stopped working, in fact I've been a lot busier than normal, so for me I've not been climbing the walls like many of you may have been or still are whilst in isolation. So I admire you all for what you are doing to protect yourselves. It has been great to see how the nation has responded to all our NHS and care workers, I just hope that when we come out the otherside of this, as my grandaughter Alexa says in the picture below "THIS WON'T BE FOREVER" that they are remembered and rewarded properly for everything they continue to do for us and not forgotten or left behind, otherwise all the clapping we've done will have been pointless!!

I'm hoping that society changes and especially it changes those that are meant to be leading us, by becoming more caring, for example it has amazed me how within weeks those living on the streets were able to be housed, It goes to show that there is a chance we can live in a society when it cares for all.
Since the new Mac was up and running, I made use of it producing a short video for Vasculitis UK Awareness Month, I cheekily added a donate page against it and managed to raise £230 for VUK after sharing on facebook!
Inside this packed edition, there are also some great fundraising stories along with some personal ones, eleven pages of life during Covid-19 and so much more so please enjoy and i'll look forward to creating the Autumn edition for you. (*The front cover picture was created by Shanali Perera, her poem also features on p27.)*

(Alexa Ferreira Aged 4)

A Black Tie Affair!

On Saturday 23rd November 2019, Mike and Sue Smith hosted a black tie dinner for the Beresford Pierce Freemason's Ladies Evening at the Allerton Court Hotel in Northallerton with the proceeds of the money raised being donated to Vasculitis UK. My husband, Ian, and I were invited to attend as representatives of Vasculitis UK. We had a wonderful night, meeting lovely new people who all made us feel very welcome, tucked into a delicious three course meal and thoroughly enjoyed watching others enjoying themselves on the dance floor afterwards (I will admit that I had a good "bop" on my chair though). Mike and Sue were gracious hosts and sat us with them and their family at the head table. They sold raffle tickets on the evening with some fantastic prizes - the bottles of alcohol in particular seemed rather popular - which raised over £400! Mike very kindly thanked the charity in his speech for the help and advice they received when Sue was diagnosed with Vasculitis and added they were very grateful as they didn't think Sue would be where she is today with regards to her treatment without the support they received.

Sue has previously raised funds for Vasculitis UK by selling cards of her artwork in a local gallery and also designed the Christmas card for VUK in 2019!

By Kelly Jefferies,
Vasculitis UK Secretary


From left to right: Sue, Mike, Kelly and Ian


A couple of attendees - note the VUK bug on his jacket!

Climbing Kilimanjaro

When asked to write a short piece about the fundraising recently undertaken about my little brother Mike, I thought, where do I begin and how do I keep it succinct.

In short he has a relentless passion for a challenge. As 16 he took his mini apart and put it back together again. He'd joined the TA whilst working full time in IT. He raced motorbikes to relax!, which was hard to watch!

As an older adult he told us one day he was going to enter the London marathon. He bought a book about marathons and did a bit of training and completed the London marathon but that wasn't enough, he had to run the Edinburgh marathon too the following year.

Not to let any dust gather under his feet for charity he abseiled down the 452 ft Radio city tower in Liverpool dressed as a superhero, on a windy day. In amongst these (crazy) activities he joins the homeless each year for a sleep out to raise awareness. The most recent sleep out was last Friday, just as the temperature dropped.

Last year he talked about the possibility of climbing Kilimanjaro. Pie in the sky I thought. 12 months later there he was, flaunting his Vasculitis T-shirt at -28 degrees, 19341m high on the summit. His quest raised £740.91 for Vasculitis UK. He is also a fantastic brother, son and dad and is our superhero.

Catherine Cotter

As a retired optometrist, having worked in hospitals and private practice, I have some insight into health matters. I have experience in finance both from self-employment and as a treasurer for local groups. I am married with two children and three grand-children and live in Derbyshire.

I first encountered vasculitis in my final professional exams many years ago. In an oral exam I was interrogated about temporal arteritis (GCA). As an indolent student, I knew nothing about it. After a few very uncomfortable minutes (it felt like hours), I had it explained to me with the comment "You won't forget this ever again" – how true. Despite this, I passed the exam. Vasculitis got its revenge in 2013 when I was diagnosed with Wegeners (GPA).

Ian Kayes
Hon Treasurer

Symposium in Honour of Professor Charles Pusey Imperial College London

On Wednesday 5th February 2020 I attended, as a trustee representing VUK, Prof Pusey's retirement symposium. The symposium was well attended by many senior clinicians and post graduate students in the field of Nephrology, including Vasculitis.
The symposium consisted of a series of lectures on Globular Disease and Nephritis given by leading academics in that field, who paid tribute to Professor Pusey for his valued input over the years plus many comments of his humorous nature too. Excerpts from letters sent in by patients, mentioning his caring side of his treatment to them, were also read out.

He was very fond of using his red pen when commenting on student's papers, writing the date at the top of the page. One student seeing the date 3/10 thought that he had marked down the work she had done. This brought laughter from the audience.
Professor Charles Pusey now has a role as one of Scientific Advisors to Vasculitis UK, working along side Prof Scott, Prof Jayne and Prof Watts.

Below is an resume of Prof Charles Pusey's career to date.

Charles qualified from Cambridge University and Guy's Hospital London and, after early appointments at Guy's, joined the Royal Air Force, where he gained experience in General Medicine and Renal Medicine. On leaving the RAF, he moved to Hammersmith Hospital as Senior Registrar in Renal and General Medicine to Professor Keith Peters. He started his research on a MRC Clinical Research Training Fellowship and was subsequently awarded a Wellcome Trust Senior Research Fellowship. This led to his appointment as Senior Lecturer at the Royal Postgraduate Medical School, later merged with Imperial College London. He was appointed Professor of Medicine at Imperial in 2003.

Charles was active in clinical practice in all aspects of renal medicine, led a large multidisciplinary vasculitis service, and contributed to the general medicine service for many years. He has continued both clinical and laboratory-based research in parallel, and his work has focused on autoimmunity and inflammation in renal disease, including the mechanisms underlying primary and secondary glomerulonephritis. He has helped to develop and taken part in many of the multicentre trials in AN CA-associated vasculitis. He has published over 500 articles on renal disease, mainly on glomerulonephritis, vasculitis and anti-GBM disease, and contributed chapters to the major textbooks on renal and general medicine.

Charles was an enthusiastic teacher at undergraduate and postgraduate levels, and has supervised over 40 PhD/MD students. He has a particular interest in clinical academic training, and was previously Director of Clinical Academic Training and Head of Postgraduate Medicine at Imperial. For the Trust, he has been Director of Research and Development, the first Director of the Imperial NIHR Biomedical Research Centre, and Director of Education. He has served as Academic Registrar at the Royal College of Physicians of London and Chairman of Kidney Research UK, and is a Fellow of the Academy of Medical Sciences.

David Newman (Trustee)

One of Vasculitis UK's biggest fundraising events is the great north run

At this years event we have over 20 runners registered runners. Here are a few from the 2019 event telling us about their experience.

Angela MacAusland
My finish times was 02:09:37
2019 was the first time I had run the Great North Run (even though I had completed nearly 30 half marathons before) and I can honestly say it was the best half marathon race I have ever taken part in. The atmosphere from the moment we arrived in Newcastle city centre until we eventually (reluctantly) left South Shields at the end of the day – was incredible. The spectator support all the way along the route was so inspiring, I have never taken part in a race before where there was anything other than jelly babies handed out – during GNR – we were offered ice-lollies, fruit, sweets, crisps and beer. It was more like a party than a race. Running a race like this, for charity, makes the occasion all the more special and memorable as I know it wasn't just about me, but how many others will benefit from this. GNR is a bucket list race for any runner.

I ran a time of 2 hour 6 mins. I was registered as Kathryn Morris.

Running the great north run for Vasculitis UK was an amazing experience. During training, I kept hitting a wall after an hour and a half so I was worried I wouldn't finish the race. But the incredible support of the crowd and the encouragement of all the other runners kept me going to the end. Running for a charities that touched the lives of the people I love made the sense of achievement when I stumbled over the finish line even more special. To anyone thinking about doing it, I would say don't hesitate. You will feel elated and proud, knowing you've made a contribution towards supporting such a great charity.

Jenniger McMahon
My time was 2:26:48

The GNR was an event I had wanted to take part in for many years. I wasn't disappointed - the atmosphere of happiness, support and solidarity created by the crowds lining the route was incredible and made every step a small victory. The biggest motivation of course was the money our team was raising for Vasculitis UK who support those, like my dear friend Lisa, living with the condition daily. I am proud to have completed the run and proud to have been part of something that will hopefully make a difference to others.

Caroline/Heather
We felt a great sense of achievement finishing the GNR last year. The crowd were fabulous and there was a unique atmosphere there, it made it a fabulous experience.

Martin Makin 1.21.19
I found that exercising has helped me in my combat of GPA, and believe any daily aerobic exercise can aid both your physical and mental health whilst dealing with a disease like Vasculitis. However, it's important to talk to your doctor before starting an exercise routine. He or she might have advice on what exercises are safe and any precautions you might need to take while exercising.

If you would like to run in an event for Vasculitis UK then please contact me martin@vasculitis.org.uk we are currently full for this years event, if we have interest for more runners then we can try for more charity places in the forthcoming years.

Official Times

Odette Bowes	3.57.35
Martin Makin	1.21.19
Angela MacAusland	2.09.37
Heidi Pollard	2.16.21
Caroline Eyles	2.50.23
Kathryn Morris	2.06.32
Jessica Randle	2.57.32
Racheal Graham	2.06.08
Gemma Mercer	1.59.26
Phil Mercer	1.59.26

Gemma, Phil and Glen

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

Chris Newsom walked Coast to Coast for VUK and raised an amazing £827.
The walk is a 194 mile trek across Northern England, devised by the walking legend Alfred Wainwright. It starts at St Bees in Cumbria and finishes at Robin Hoods Bay in Yorkshire.

FundraIsing night for Vasculitis UK at The Moles Rest - Thank you to Mark and Maz Sayer, Cheryl Cook, Lynne Ward, Carol Leech, Roy, Hayley and Marie.

Charlotte Edwards, who is in year 5 of St Gilbert's school, Stamford, with friends Sofia, Lottie, Lauren, Arthur, Lois, Bella, Fergus and Harry held an 8 hour silence and raised an amazing £662 for VUK. Charlotte's mum has Vasculitis.

Craft and Art Fair
Matlock Derbyshire raising £145

Lisa Farrow -
Christmas Vasculitis Charity night.... raising almost £1600 pounds

Helen Taylor fundraising for Vasculitis at her local church hall coffee morning.
Delighted to report that they raised £481.80

Sarah Hall - Heritage Christmas Tree Festival

Lynn Rogers Christmas Lights - Fundraising for VUK

Lucy Grant and school friends at Ton yr ywen Primary School in Cardiff fundraising for Vasculitis UK

Vasculitis UK Christmas Tree - Bakewell Christmas Tree Festival

Cyclophosphamide: Friend or Foe?

Georgina Ducker & Chetan Mukhtyar
Rheumatology Department, Norfolk and Norwich University Hospital, Norwich, UK

Introduction

The ANCA associated vasculitides (AAV) are a collection of rare auto-immune diseases comprising of three separate syndromes - granulomatosis with polyangiitis (GPA), microscopic polyangiitis (MPA) and eosinophilic granulomatosis with polyangiitis (EGPA). Current management involves immunosuppression with three recognised phases of treatment, remission induction, remission maintenance and treatment of relapse and this has been adequately covered in recommendations that Vasculitis UK has been involved with in developing – British Society for Rheumatology recommendations and European League Against Rheumatism recommendations.

It is worth pausing for a moment presently to just think about the phrases we use for describing the stages of vasculitis and its treatment – remission induction, remission maintenance and relapse. They are similar to the lexicon of a cancer specialist. This has a bearing on our discussion today.

Cyclophosphamide

Cyclophosphamide belongs to the same family of chemicals as 'mustard gas' – the Nitrogen Mustards. Although this drug has its origins in chemical warfare, it was repurposed for use as chemotherapy in cancers with great success. Cyclophosphamide can cause infertility, bone marrow suppression, bladder toxicity, increased risk of bladder carcinoma, nausea and vomiting amongst other things. It is easy to see this as a deadly drug that is to be regarded as a 'foe'. However, the enemy of my enemy can be my friend! Untreated Wegener's granulomatosis (GPA) had a mortality of more than 80% at 12 months. A seminal study published by Anthony Fauci and colleagues (the same person who has been seen next to Donald Trump, leading the American response to the coronavirus pandemic) in the 1980's showed how the use of this 'foe' helped improve survival to more than 80% at 12 months. But what was good for induction of remission was not so good for maintaining remission. There was a high risk of cancer – especially related to the kidney and bladder. This led to further searches for a way to provide safe maintenance of remission – ultimately best provided by Azathioprine.

Rituximab

Rituximab is an immunological agent. It is a 'smart bomb', that wipes off mature B-cells – precursors of the cells that make antibodies including ANCA. It doesn't upset the tummy, it doesn't make you lose hair, and it doesn't predispose you to getting more cancers. Since we can use it in all stages of the disease, we can technically give up using the terms 'remission induction' and 'remission maintenance'. It can be repeated every 6 months for several infusions and the vasculitis will respond well. So, it is a friendly drug that doesn't have a sting in the tail. Or does it?

The choice of drug for remission induction

When choosing a drug for inducing remission in AAV, we look for three things to help us choose the right agent.

1. Does the drug work – efficacy
2. How quickly does it work – after all in AAV, time is organ!!
3. Is the drug safe?

Clinical trials have demonstrated that cyclophosphamide and rituximab are effective for use in remission induction. In patients with new GPA and MPA, there was no difference in the efficacy of the two drugs. There are national and international guidelines advocating the use of these drugs in managing AAV. There is no doubt both of these drugs are effective in treating AAV. Both of them appear to induce complete remission at about 90 days. So, they both act slower than we would like. The side effect profile does differ, but the number of adverse events between the two drugs in clinical trials was exactly the same. So, the two drugs are effective, work as quickly as each other and have the same risk of adverse events.

In order to choose the correct drug for patients with

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new disease, it is worth looking at the side effect profile a bit closely. The historical risk of cancer after cyclophosphamide was related to the cumulative dose used when it was administered orally as a daily dose. It is estimated that once the total dose gets to about 25-30 grams, the cancer risk might start rising. However, the cancer risk of cyclophosphamide has been mitigated by switching to an intravenous pulsed regimen which delivers a maximum of 7.2 grams over 13 weeks, lowering the cumulative dose and thus the cancer risk. The risk of urinary bladder inflammation and bleeding was also mitigated by concurrent use of MESNA. This is a drug that converts the cyclophosphamide into harmless products while it is collected in the bladder waiting to be evacuated. Since the harmless products don't irritate the urinary bladder, the risk of bladder inflammation, bleeding and future cancer is minimised.

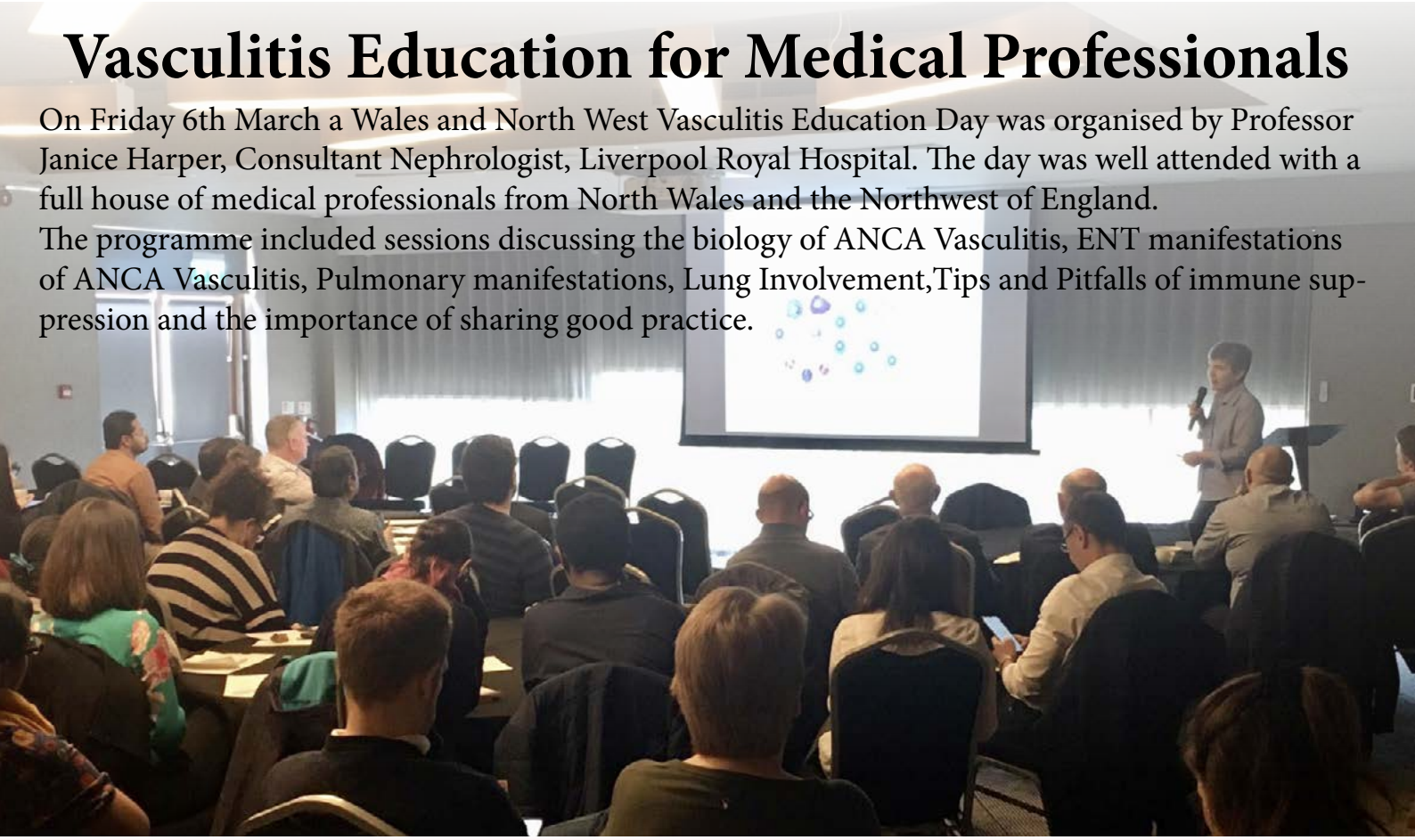
When treating relapsing disease, clinical trials show that rituximab is superior to cyclophosphamide. In that instance, it is not advisable to use further cyclophosphamide unless there are extenuating circumstances. Cyclophosphamide may also jeopardise the fertility of women who are nearing menopause. As a general rule, we would try not to use it in women who are still planning their family.

So, cyclophosphamide might not be such a foe after all. Looking closely at Rituximab, we know that individuals receiving multiple rituximab infusions are at increased risk of infections. When we take away the nasty ANCA producing cells, it comes at a cost by depleting the good antibodies protecting individuals from infections on a daily basis. This depletion of antibodies is called hypogammaglobulinemia. It is thought to occur in up to 50% of AAV patients receiving regular rituximab, putting them at risk of Serious, Persistent, Unexpected or Resistant (SPUR) infections which may require hospitalisation, further immunomodulatory treatments and antibiotics. Rituximab might not be the loyal 'friend' after all.

Cyclophosphamide has been used for nearly 50 years in treating patients with AAV therefore clinicians have the benefit of experience and confidence in using cyclophosphamide. We have learnt to adapt the way we use this potentially toxic drug. With the changes made to the cyclophosphamide regimen, from an oral to pulsed intravenous regime and the use of MESNA, many of the ill effects have been negated. We are just finding out the problems of long-term rituximab use and we haven't quite understood how to get our patients out of the problem of recurrent infections satisfactorily, should that happen. Cyclophosphamide is the evil we know and therefore it is the first choice for inducing remission in AAV for most of our patients.

Vasculitis Education for Medical Professionals

On Friday 6th March a Wales and North West Vasculitis Education Day was organised by Professor Janice Harper, Consultant Nephrologist, Liverpool Royal Hospital. The day was well attended with a full house of medical professionals from North Wales and the Northwest of England.
The programme included sessions discussing the biology of ANCA Vasculitis, ENT manifestations of ANCA Vasculitis, Pulmonary manifestations, Lung Involvement,Tips and Pitfalls of immune suppression and the importance of sharing good practice.



How can patient data help us understand complex rare diseases?

Dr Fiona Pearce, Clinical Lecturer at the University of Nottingham, explains how the Registration of Complex Rare Diseases - Exemplars in Rheumatology (RECORDER) Project is using national electronic health records to improve the health of people with rare diseases.

Rare Disease Day takes place on the last day of February each year to raise awareness of rare diseases and their impact on patients' lives. To honour the day, Fiona's answered some questions about her research. She explains how the project is using data about rare autoimmune rheumatic diseases to help make a difference to people's care.

What is the RECORDER project? RECORDER is a collaboration between the University of Nottingham, Nottingham University Hospitals NHS Trust and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

The project finds different ways to register people with rare autoimmune rheumatic diseases, and uses the data to improve our understanding of these diseases and the care patients receive. Rare autoimmune rheumatic diseases are non-genetic or "complex" rare diseases that usually start in adult life and can be difficult to diagnose.

Why is this project needed?

Data of rare disease patients is often fragmented. There are several reasons for this including that not all rare disease patients are seen in specialist centres and most rare diseases do not have standard codes that allow them to be identified in health data. This makes finding out information about rare diseases and rare disease patients challenging. For some conditions, basic information like the number of people with a rare disease, and how and where they are treated, are unknown.

It takes longer for people with rare diseases to get the right diagnosis and treatment than people with more common diseases. Often there is no evidence-based treatment at all for a rare disease because of the difficulties of finding enough people to test out treatments in a clinical trial.

How can patient data help?

Information on how many people have a rare disease can be used to help the NHS plan healthcare services. Information on who has a rare disease can be used to help target healthcare towards the right people, and plan and run clinical trials to find new treatments.

Often this information exists already in the NHS or in research studies, but it is collected on computer systems that don't talk to each other. We need a focused, collaborative effort to join-up this crucial information.

What happened and what are the benefits?

We worked with hospital doctors around the country to find out how reliably the number of cases of some rare autoimmune rheumatic diseases are recorded in hospital administrative data. For the diseases that could be reliably identified, we used data from every hospital in England to answer questions aiming to improve the way the NHS delivers healthcare.

Examples include:

1. We identified all the people in England who are living with ANCA-associated vasculitis, which planners of NHS services can use to support the introduction of new treatments.
2. We discovered how many children develop Kawasaki disease each year, so that this can be used to plan the likely demand for a potentially life-saving treatment called intravenous immunoglobulin.
3. We found out which hospitals treat large numbers of people with rare types of vasculitis, so that researchers know where to undertake clinical trials of treatments.

Who collects the data and how is it kept safe?

This work uses data that has been provided by patients and collected by the NHS as part of their care and support. This work combined hospital administrative data (Hospital Episode Statistics) and data collected by hospital clinicians to deliver patient care. All patient data is held by Public Health England under strict security standards.

NCARDRS has legal permission to collect patient-level data and use it to protect the health of the population. This permission is granted under Section 251 of the NHS Act 2006. Everyone working with patient data involved in RECORDER has had extensive training in information governance and follows strict rules regarding patient confidentiality.

What's happening next?

The RECORDER team is expanding, and we will soon be publishing national data on some rare autoimmune rheumatic diseases in peer-review articles. We'll also have all our reports available online because we're really committed to keeping people informed about this work.

Help create a national register for people with rare rheumatic diseases

A key commitment of the UK's Strategy for Rare Diseases is to create national registries. Better data will help us to find out how many people have each rare disease, how they are diagnosed, and how and where they are treated. This will give better information to people living with rare diseases, their doctors, and the commissioners of health services. It will mean that more people with rare diseases can be involved in research, and this will result in the development of new and better treatments. The aim of this research is to improve health for people with rare diseases.

I am working with the National Congenital Anomaly and Rare Disease Registration Service, which is part of Public Health England. They are starting to collect data on rare diseases. The work I am doing means that they can prioritise rare rheumatic diseases (such as Lupus, Vasculitis, Myositis, Sjögren's syndrome, Scleroderma and Behçet's disease). We need to do research on the best ways to find and register people with rare diseases. Can you help us find a way to do this effectively and efficiently?
If you would like to give your views, and help shape or champion research on the best ways to do this please contact: fiona.pearce@nottingham.ac.uk, Dr Fiona Pearce, Clinical Lecturer, University of Nottingham.

The nose is an organ too

This is a lay summary of a paper written by Consultant Rheumatologist,Chetan Mukhtyar, of Norfolk & Norwich University Hospital. It was originally published in the "Rheumatology"Journal.

Heinz Klinger in 1931 and Friedrich Wegener in 1937provided the first descriptions of a new disease characterized by vasculitis and granulomatosis. This diseasehas been called Wegener's granulomatosis (WG) and later, granulomatosis with polyangiitis (GPA). Classic GPA was typified by a 'triad' of upper airway, lower air-way and kidney involvement.

The concept of 'limited' disease was introduced in a case series of 16 patientswith 'massive pulmonary lesions', including 7 with'extrapulmonary lesions,' in the absence of active renal involvement.

In 1974, the adjective **'localized'** was used to describe this **'partial expression' of disease**. It is worth noting that the adjectives *were **not** used to describe better outcomes* with treatment, *just the lack of renal disease.* In 1995, the European CommunityStudy Group on Clinical Trials in Systemic Vasculitisagreed that the subgroup of WG that had only upper and/or lower respiratory tract disease would be defined as 'localised GPA'.

After 1971 cyclophosphamide became the mainstay of treatment for induction of remission in GPA. Increasing concerns about bladder toxicity ed to the use of pulsed intravenous cyclophosphamide and a search for alternative immunosuppression. The 1990s saw the first studyof methotrexate in GPA.

A single clinical trial in 2004 established that methotrexate was as effective as cyclophos for initial induction of remission in "non organ-threatening (ie normal renal function) GPA. This became embodied in the first European guidelines for managing GPA. The original concept of "local" disease referred to those were not in immediate danger of death or renal failure, but in fact most GPA patients have evidence of renal disease on biopsy.

The term localized/limited disease has also been used to describe non-organ-threatening disease, particularlyinvolving the nose and upper airways. **The problem is that the nose is an organ too**. Nasal inflammatory disease often causes irreversible loss of smell. Not uncommonly, this is associated with significant structuraldamage of bone and cartilage (e.g. saddle nose deformity).

In a cohort of individuals who were classified as having localized GPA, 28% developed a saddle nose deformity, 24% had a septal perforation and 10% had orbital wall destruction. These changes equate to significant organ damage and are also associated with major quality-of-life issues.

Methotrexate was introduced to treat GPA as a 'safer' alternativeto CYC because of bladder toxicity and long-term cancer risk. However, in the long-term follow-up of the randomized controlled trial comparingMTX to CYC in patients with non-organ-threateningGPA, there was no difference between the risk of cancer, infection or organ failure between the two groups although when MTX was used to induce remission, there was small increase in relapses, leading to a significant increase in the use of corticosteroids and otherimmunosuppressive drugs, including including cyclophosphamide. Considering that each relapse of GPA is potentially capable of end-organ damage, the use of MTX as a safer agent is false economy.

The bladder toxicity risk of cyclophosphamide was reported at a timewhen CYC was used orally and without the co-prescription of MESNA. (The use of MESNA co-prescribed with intravenous CYC neutralizes CYC products in the bladder, reducing the harmful effects in the bladder to an extent where this is a rare problem.) (The risk of cancer related to cyclophos is historical and related to cumulative exposure totalling more than 36 g). With the current approach of using intravenous cyclophos, as setout in the updated recommendations, a maximumof 7.2 g would be used to induce remission, followed bythe use of remission maintenance agents.

Clinical trials have sometimes excluded patients with "localized/limited" disease. For example, a large

randomized controlled trial of rituximab versus cyclophos excluded this group of patients.. This creates a self-perpetuating situation where these cases are not included in meaningful clinical trials because they have been historically thought to be suffering with benign disease.

Localized disease is not benign. It is often associated with unrecognized systemic disease. It is certainly organ-threatening, has a high risk of relapses and causes a lot of damage No individual suffering with "localized" GPA considers themselves fortunate and using this adjective trivializes their experience, producing a false sense of complacency in the treating clinician,without successfully achieving any clinical goals.

Summary by John Mills: May 2020 Original reference:-

Chetan Mukhtyar, John Mills, David G I.Scott, The nose is an organ too, *Rheumatology*, keaa073, https://doi.org/10.1093/rheumatology/keaa073"

Jayne's New Nose

Jayne Hardman suffered from "Limited Wegeners" which was treated using only methotrexate & prednisolone. She suffered from progressive collapse of her nose until one day the remains of her nose fell off, leaving her with just a hole where her nose should be. This turned her from a confident, outgoing person to a reclusive wreck. Eventually, a well-known nephrology consultant came to Jayne's rescue. After bringing her GPA properly under control using rituximab, several osseo-integrated implants bearing magnets were inserted into remaining bone tissue. These were used as retainers for a silicone prosthetic nose. Jayne now has a "removable" nose made to her own specification – "much nicer than my real nose". In fact she also has a "summer" (tanned) nose and a pale one for winter use.

Jane before GPA

With implants fitted

The final result:Jayne with prosthetic nose

The Norwich & Norfolk University Hospital (NNUH)

Giant Cell Arteritis service has been shortlisted for a quality improvement award by the Royal College of Physicians.

The Giant Cell Arteritis (GCA) service treats the most common form of adult vasculitis, which is an auto-immune disease where the body's immune system attacks blood vessels, and commonly causes headaches, joint pain, facial pain, fever, and difficulties with vision.

Patients need urgent treatment to prevent complications, the most severe of which is irreversible blindness.

Consultant Rheumatologist Chetan Mukhtyar, who leads the service, which is a partnership between the rheumatology and ophthalmology departments at NNUH, says:

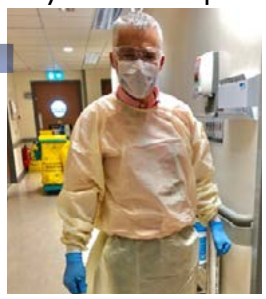
"I am really proud that 10 years of work in setting up an exemplary service has been recognised. Improving the quality of care for patients with vasculitis has been my life and mission for a long time."

The FAIRVASC Project

FAIRVASC is a Vasculitis Research project promotes by EUVAS, the European Vasculitis Society and RITA – The European Reference Network for rare immune disorders. It is bringing together leading scientists, clinicians, and patient organisations from across Europe to approach vasculitis with a Big Data toolkit.

The project has been awarded €2.3 of EU funding and is led by the ADAPT consortium (the world leading Scientific Foundation of Ireland Research Centre for Digital Technology) based at **Trinity College Dublin, Trinity Translational Medicine Institute and Tallaght University Hospital, Dublin.** Science Foundation Ireland funds oriented basic and applied research in the areas of science, technology, engineering and mathematics.

A rare condition such as vasculitis requires very large quantities of data in order for researchers to draw conclusions about possible treatments or cures. Since there are so few patients in any one European country, it is essential to combine the databases of patient registries of several countries. This will ensure a sufficient dataset is available for meaningful research.



Professor Mark Little in anti-coronavirus battle gear!

Key Principal Investigators involved in FAIRVASC are Declan O'Sullivan, Professor in Computer Science and Principal Investigator at ADAPT and Mark Little, Professor of Nephrology in Trinity College Dublin, Consultant Nephrologist at Tallaght University Hospital and Principal Investigator at SFI ADAPT Research Centre.

Professor Mark Little, Trinity College, Dublin.

In FAIRVASC, this large new European resource will be analysed to identify features (clinical and physical characteristics, etc.) that predict how a patient's illness will develop, and what their major health risks are. These markers can, in the future, be developed into new predictive tools that help doctors to choose the best treatment options for the individual patient.

In addition to Trinity College, Dublin, the full consortium involves institutions in Italy, France, Sweden, Germany, Poland, Prague as well as the "Vasculitis Stichtig" (Dutch equivalent of Vasculitis UK) and Glasgow University (Thanks to funding by Vifor Pharma).

There is also strong patient involvement in the form of Vasculitis International, which includes Vasculitis UK, Vasculitis Stichtig, Vasculitis Ireland and other European patient organisations. The Vasculitis International participation is funded by INSERM the French national public health research organisation.

Filming on the Front Line

The 2-part "Hospital" series on BBC 2 broadcast on Monday & Tuesday 11/12th May was a special edition "Fighting Covid-19". This is a harrowing account of the earlier days of fighting the virus, on the front line. Filmed at the Royal Free Hospital Hospital, N.London, it features Professor Alan Salama, well known to many vasculitis patients. It is real life very human drama, with sad death, unexpected survival, the hospital running out of beds, oxygen and mortuary space and the trialling a new anti-viral drug.
Currently available on i-player.

Professor Alan Salama

Prof Alan Salama with camera crew during filming

Life under lockdown

Coping with coronavirus

Surviving Corona virus with GPA

Hi I'm Kevin I'm a 53 years old, I was diagnosed with Wegeners Granulomatosis GPA in November 2013, after a long hard grueling 6 months of chronic fatigue, sinus problems unable to move with joints pains.

After torturing the hospital they found a nodule in my right lung, few lesions on the brain and months after, a collapse of the septum. I was given the usual steroids for a few years and infusions of Rituximab which got everything settled down, but as fellow sufferers know only too well, the pain and fatigue never goes away unfortunately.

It was in the 2nd week of March this year when I started to get a bit of a temperature, back of the head headaches, occasionally feeling very dizzy, and a dry cough. Then on the 17th of March I started struggling with the breathing, and of course started panicking thinking of the covid19, and praying it wasnt.

I had my last infusion of Rituximab in November last year and knew that my immune system was compromised and feared the worse. So by midday I started feeling a lot of pain in my right lung restricting the lifting of my arm, so the alarm bells started ringing because I had suffered pleurisy years ago, and immediately recognized the pain. I contacted my GP which was closed to it being a public holiday and the recorded message prompted me to call out of hours doctor, he then told me to call the Covid 19 emergency number 111.

After being passed from pillar to post and calling different numbers I kept trying to tell them I was immunosuppressed, until finally a doctor called me back and I told them that I could feel breathing and pain getting worse by the minute. Then finally the doctor informed me that an ambulance was on the way and would be taking me to The Mater hospital in Belfast. As you cam imagine the fear and panic overwhelmed me with thoughts of "will I come back" "is this the end". So the ambulance arrived and as I was dreading, the paramedic was wearing a mask and apron.

I arrived at hospital and entered in by a back door with all the nurses and clinicians stepping back and clearing the way for me, I think they were more scared than me. One nurse was assigned to me taking me into a room, with a lock on it, to take all my vitals. My oxygen levels were fine, a little bit of a temperature. So she gave me some fluids and painkillers intravenously.

She also arranged for an x-ray and radiographer to come to the room. I knew by this stage that it was likely to be Covid 19. The X-ray had showed up pleurisy at bottom of right lung and blood showed up an infection which the doctor said most likely confirms Covid 19. I was adamant with getting a swab test just to make sure, but the doctor explained that there's not much testing being done and that they mainly stopped testing the week before and that it wouldnt make much difference.

After 4 hours they decided to discharge me, but on the understanding if my breathing deteriorated or if I started to cough up blood, I was to call ambulance immediately. Thankfully it didnt come to that, and after about 5 days the pain in lung lessened and breathing got better.

I class myself as very fortunate to have minor symptoms considering my compromised immune system. To be honest I hardly took any pain relief in the following days, I guess you become accustom to pain over the years with vasculitis and build up a tolerance. But I do recommend fellow sufferers to heed the advice and keep well isolated just to be on the safe side, because it is not worth the risk, its hard enough struggling with vasculitis daily for most of us, so please please stay safe everyone.

Kevin Byrne

Links to newspaper articles of other Vasculitis patients surviving COVID19
https://www.yorkshirepost.co.uk/health/coronavirus/they-saved-my-life-80-year-old-leeds-man-thanks-nhs-staff-after-beating-coronavirus-2538524

https://www.shropshirestar.com/news/health/coronavirus-covid19/2020/04/11/dont-risk-it-say-coronavirus-survivors/

Links to other newspaper articles of other Vasculitis patients surviving COVID19
https://www.bbc.co.uk/news/uk-england-london-52527736

LIFE UNDER LOCKDOWN

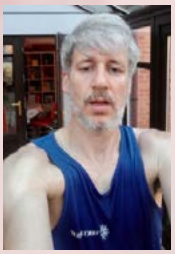
Hello my fellow vascies!
I have now been shielding for more than 3 weeks at the time of writing this.
What an opportunity to not do everything I had planned. As many of us, I avoid planning ahead. Vasculitis tends to mess up my plans anyway. This year I made the exception. I planned a trip to Greece to surprise my mum on her birthday. Meaningless to tell you that it didn't happen. Instead I have received texts, emails and letters advising me not to leave my house. I feel very privileged. The system didn't fail me - I am aware it failed many others.
Who would know that I would make my happy dance because after 2 long weeks I managed to get a supermarket delivery slot?

I admit that I had a proper melt down just 10 days in lockdown. My anxiety hit the roof, I became paranoid with disinfecting and checking on my family members' cleaning procedures. I am now much calmer, accepting the situation and adapting to being a prisoner in my lovely home.
I worry daily about my elderly parents and my brother that live 2,500 miles away. Will I be able to do my routinely summer trip? Are they safe? I hope we will all celebrate our survival over a proper Greek feast!

What I miss mostly is a hug; my gorgeous puppy Rosa tries her best, hugging and giving me wet kisses. My partner and son still go out (dog walks, essential shopping) so I stay 2 meters away from them. I miss taking my dog out on walks and strolling around taking pictures. I sit in our back yard enjoying the lovely weather. The social event of the week is clapping for NHS and other key workers every Thursday evening.
I stand in front of the window and clap from the safety of my front room.
My life has changed once again, so what? I put my brave smile on and I do my happy Friday crazy dance as usual. My partner, my son, our cat and dog, my family and friends and you my vascie family are with me on this journey. Thank you!

Zoi Trustee Vasculitis UK

Hello
So when lockdown began i was thinking 'as long as i'm careful i should be ok to carry on working, training etc'. Then when the schools shut, and my three children were at home, and my wife Andrea became furloughed, i was the only one going out, possibly putting myself and my family in danger of contracting Covid-19. It was this and finally recieving the NHS high risk letter that made the decision easier for me, I am now off work till the end of June. So how am i coping, a lot better than i thought. One of the concerns i had, apart from staying safe, was keeping up with my training, this is important to me, and helps with my mental well being. So with myself and Andrea both training for the Great North Run, we purchased a treadmill. This has possibly been the one thing that has kept me going during isolation, and of course Andreas baking.



Martin - Trustee for Vasculitis UK

Hi
John was told by his consultant on the 16th March that because of COVID19 he should stay at home and not go out. John had not long been home from a stay in hospital after yet another bout of sepsis and a chest infection.
John was also contacted by his Rheumatologist and GP a week later and told to stay at home. We registered with the government online "Protect and Shield" link on their website.
John does not go out but we do enjoy our garden. I walk our dog, Buster twice a day, keeping well away from other walkers.

We relied on our children and our village shop for food for 3 weeks, until we were allocated a high priority online shop with Sainsburys. We still continue to support our village shop but now we don't have to rely on our family for shopping.
John received al letter from his Oncologist on the 18th April telling him to stay at home until at least July 12th.
We are very grateful we live where we do, have our garden and I can walk Buster. We have also been very well occupied and very busy working for Vasculitis UK and manning the helpline.

Susan and John - Trustees Vasculitis UK

Hi
"Being on lockdown on your own in a flat with no balcony or garden can be difficult. Luckily I'm kept extremely busy with the pandemic as I am a virologist which is a good distraction. Keeping in close contact with your friends and family while being isolated is a brilliant way to feel less distanced from the world. It's helped me. We do pub quizzes or group chats on FaceTime. You'll be amazed what seeing another persons face does for loneliness.
Can anyone recommend a good series to watch?

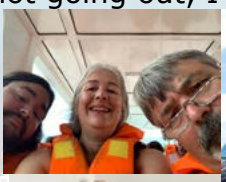
Gareth Trustee Vasculitis UK (also working from home)

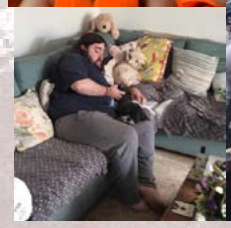
Hello
My husband, son & I have been shielding/ self-isolating since March 16th as we were very worried about the pandemic that had already hit China & parts of Europe. We decided this as a family & I have to confess that not everyone agreed with us at first but, as the daily death tolls have risen frighteningly, we are glad we made this decision. My son's college and our GP wholeheartedly supported us along with my parents, who have been helping us with our shopping. Our daughter, who is expecting her second baby in September, is also shielding and her partner has had to temporarily move back to his mother's - on the advice of the hospital - as he is a key worker. It has been a difficult time but we have kept in contact via telephone/texting/video chat so we can still speak to each other & see each other. We've also discovered my daughter is having a second son so we're very excited!
I trialled the first ever video consultation with my GP surgery & have been given an email address to contact my GP so that I don't have to spend ages trying to get through on the telephone. I did have to break my isolation temporarily to visit the hospital for my Infliximab infusion on April 2nd. I don't mind admitting I was extremely nervous about it & wore gloves & a face mask to protect myself. It wasn't as busy as usual and the staff were lovely with me, understanding I was nervous & laughed with me about the face mask making me look like an actual ginger ninja (I am affectionately known as the ginger ninja by my family & friends - my grandson even calls me Nanna Ginge!). My consultant, Professor Ann Morgan, is following the guidelines from the BSR (British Society for Rheumatology) & believes it is vital I continue to receive my infusions along with my daily maintenance medication. I'm happy to report that I don't have any symptoms of the Coronavirus over 10 days later so it was worth it to have my treatment, although I took every precaution I could.
I registered with the government vulnerable scheme at the earliest opportunity & have received two food boxes so far.
We have also now been given a weekly delivery slot with Asda but it took quite some time to set this up so I'm incredibly grateful my parents have been able to help us in the meantime! The most positive thing I have experienced so far is seeing my family willing to make sacrifices to keep me safe - especially my son who was 18 on April 9th but hasn't left the house in almost a month to protect me! I hope you enjoy my ginger ninja photo & are staying as safe as possible!

Kelly - Trustee Vasculitis UK

Giles's Story - Living with parents who are Key Workers

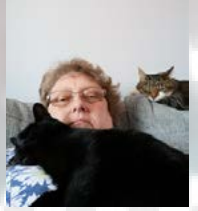
I feel like I'm in a more unique situation during this pandemic because as well as being labelled most vulnerable to the disease which means minimal contact and not going out, I also happen to be living with parents who are both key workers in occupations where contact with infected is more likely. That being nursing and funerals. So during most of the week when I'm at home on my own during the day, I'm quite happy as I have many activities to keep myself occupied and try to focus on doing two of those every week (from playing video games, to writing a Crime Drama, to learning Japanese etc.).





I'm always more paranoid when my parents are back in the evening as I'm always thinking they may have come into contact with someone who has the virus and that's probably not going to end well for me, especially when two key workers means the chances of getting it are doubled.
Though the longer my isolation has gone on, the more positive I've started to feel as it's one more week towards the end of the tunnel and one more week where I haven't been infected.

Hello
I went into lock down just after moving house. The first few weeks were spent emptying boxes. I still haven't got the bookcases for all the books! My garden needs a lot of work and a landscape gardener but that will have to wait.



I have taken to bird watching and knitting. I finally received my shielding letter and my Asda supermarket delivery slots. My eldest daughter has been collecting my prescriptions and anything else I need. Both my daughters are key workers. My youngest daughter has had covid-19.
My companions are enjoying my being in lock down, as you can see from the photo.

Dorothy - Chair for Vasculitis UK

VUK Helpline - Coronavirus Confusion

The PM and NHS England made an announcement on March 23rd to all those who have underlying health conditions stating they would all be receiving a "letter" to advise them to stay at home, shield or practise strict social distancing. In addition to this they were told they would be notified by Supermarkets for online and high priority shopping. By Friday 25th March the government also provided an online link for those who thought they maybe high risk but had not received a letter.
From Monday 28th March the VUK helpline both by telephone and email was absolutely inundated with calls and emails by those who had Vasculitis, lived with someone who has Vasculitis and parents who have children with Vasculitis. It was a full time job, 7 days a week for 2 weeks just trying to keep up with the calls and emails.

The calls were from those who had immediately chosen to lockdown in panic with no letter but also had no family to help out so no access to shopping or food.
One lady, who lived alone and had no family, telephoned me to tell me she only had 3 days of food left.
Some calls and emails were from those who could not work from home, had not received a letter but were expected to carry on working because without that "letter" there was no proof they were high risk.
Some calls were from parents so very concerned about whether to send their children to school or not.
Some calls were from those who had received a letter but had been in full remission for years and couldn't understand why they had received a letter.

Some calls and emails were from those who had no idea if they were high risk or not. Some calls were from those who thought they may lose their job because they had not received the letter.
After the first 2 weeks we then started receiving calls and emails from those who were so very worried about signing "Do Not Resuscitate" documents sent to them by their GP practice.

This was then followed by another 2 weeks of calls and emails from those who had still not received a letter while others had received 2 or even 3 letters telling them to lockdown for a further 12 weeks. Also from those who had not received any notification from any Supermarkets regarding online shopping.

The government gave little or no notice to hospitals and GP practices regarding sending out these letters to high risk patients but still expecting all medical professionals to completely change the way they work, changing to telephone consultations wherever possible, some consultants having to close down their departments and move to the front line leaving a skeleton staff to deal with sending out letters and changing appointments.
Even 7 weeks on, some patients have still not received their letter. Some patients suffering from some of the rarest types of conditions probably never will. Up to today, those suffering from Motorneurone Disease have not received a letter at all.

It would seem those who are considered high risk and vulnerable will be asked to lockdown until there is a vaccine. But do talk to your consultant if you have any concerns.

If you have not received a letter and think you are high risk please do register with the government link https://www.gov.uk/coronavirus-extremely-vulnerable it can take up to 7 days to receive an acknowledgement.

Citizens Advice Bureau give very useful information and advice via their website https://www.citizensadvice.org.uk/health/coronavirus-what-it-means-for-you/

If you are running low on food or are without food please contact your Local Authority as many are sending out food parcels.

Please do contact the VUK helpline and we will also help with advice and sign-posting for support.
https://www.vasculitis.org.uk/helpline

Susan Mills

Vasculitis Clinic at Birmingham Queen Elizabeth Hospital. The Vasculitis team and COVID19

By Sarah Logan. Advance Nurse Practitioner. Birmingham Queen Elizabeth Hospital.

We are all united in experiencing the unique and fast changing challenges that the COVID19 pandemic has and continues to present. Throughout the pandemic we have endeavoured to work as a team, albeit often communicating remotely to continue to provide the best possible care for our patients with ANCA Vasculitis. COVID19 has not stopped people developing, being diagnosed with disease, or experiencing relapsing ANCA Vasculitis.

Urgent new patient referrals continue to be seen promptly as needed. Established patients with upcoming appointment and treatments have been reviewed remotely by the multi-disciplinary team. Routine face to face clinic appointments have been suspended temporarily. Telephone clinics have been put in place. We have discussed with some patients pausing maintenance treatments and deferring clinic appointments. Arrangements have been made for local blood test monitoring for people living long distances from the hospital. Locally we now have off-site blood test monitoring arrangements and a special clinic has been set up for those people who are 'shielding' at Birmingham Dental Hospital. We have managed huge amounts of repeat prescribing of immunosuppression sending medications out in the post.

Our intravenous treatments have continued to be administered in our renal infusion suite which is in a separate part of the Queen Elizabeth Hospital Birmingham. The nursing team reassure and support the patients during this worrying time. The chairs used in the infusion suite have been 'socially distanced'. Patients are screened for signs or symptoms of COVID19 before entering the unit. Patients and staff wear masks and no accompanying relatives or friends are allowed to attend.
We are using these treatment times as an opportunity to clinically review our patients. This has reduced the number of times newly diagnosed and people with relapsing disease have to leave their homes for medical appointments. At home medication supplies are delivered to the unit rather than peo-

ple going to the pharmacy to collect them.
Everyone is looking out for each other, we still have laughs and jokes, friendships are made and experiences are shared whilst people attend for their treatment.
Parking for all is easier!

Suits and stiletto heels have been exchanged for scrubs, trainers and goggles. Consultants and Registrars initially moved to working twelve hour shifts, four days on and four days off. A once a week multi-disciplinary team meeting is held - where we discuss and agree treatment plans for people with ANCA Vasculitis. Social distancing, coffee and cake are the order of the day!
As time moves on we are now looking at the next phase of managing COVID19 and how we will find safe practical ways of seeing patients.
We are looking to implement video consultations. Staff and patients alike are learning how we make telephone consultations work well for individual people. Many people are ready with a list of their medications, blood pressure and any questions to hand when we call.

COVID19 has inevitably caused huge amounts of sadness and distress to many people, there are undoubtedly some positives. We are, as ever learning and this time is allowing us to push forward with some positive changes in how we care for people.
We are doing what we have all trained for – to care for people, in order to do that we need to care for ourselves and those we work with.
Spring is blossoming and vibrant in Birmingham, pollution levels are low and birds are singing loudly. Take care and stay safe….

Professor Lorraine Harper: Birmingham QE Hospital.
In scrubs preparing for the Covid front line.

A Patient's experience of the coronavirus pandemic

I realised fairly early on that the implications of the coronavirus pandemic would be serious for GPA patients like me at high risk from infection. I started working from home and isolating from the beginning of March. I stocked up the cupboards and freezer anticipating I might be ill or unable to get out. This turned out to be a good move, what with others panic buying and the unavailability of my usual online shopping slots. This was a major worry at first and took some while to resolve after registering with gov.uk as "Extremely Vulnerable". How was I going to collect my prescriptions? My partner couldn't go and queue up for fear of exposure. Thankfully, neighbours helped out and now deliveries are available.

I recall the severity of the risk of catching Covid 19 really hit home with me when the Shielding guidance came out, I thought "if I get this, it's game over for me". It was a low point but I set about complying within the household and only going into the garden. Surprisingly, I haven't found this too difficult and have been working as normal from home, with a supportive team doing the same. Thank goodness for good IT and Microsoft Teams! I'm sure to a large degree being able to carry on working has been my saving grace. It helps, having a schedule to keep to, which keeps one occupied; even though I don't think colleagues fully understand what Shielding entails.

My first trip outside the house came on 1st May, as my 6 monthly Rituximab was due at the Queen Elizabeth in Birmingham. I was extremely apprehensive at the thought of leaving the house and going into a hospital environment. I was half hoping it would be postponed. However, I spoke to Sarah, our wonderful Specialist nurse, and she reassured me that all measures had been put in place to minimise the risk. Plenty of hand sanitising stations on the way up to the Renal Hub, hand washing on arrival, issued with a mask, temperature taken and increased distancing between patients. The atmosphere was calm, friendly and relaxed as always. It was good to get all the blood tests done, to be seen by Sarah and hopefully I will be ok for another 6 months.

So what does the future hold? No treatment or vaccine yet so it is still high risk out there for Vasculitis patients. I'm taking it one day at a time and am in no rush to get out there again, but I do understand that for some this is very hard to do for financial or mental health reasons. What are the implications for our family relationships from the strict shielding regime? Only time will tell.

Stick with it and stay safe!

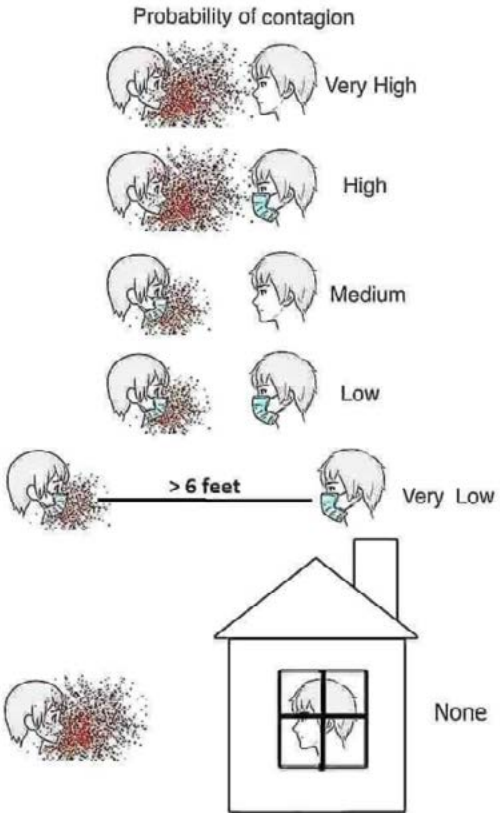
Pam Comelio

To Mask or Not to Mask? Is that the Question?

The UK is becoming decidedly out of step with most of the rest of the world when it comes to the wearing of masks in public spaces. Granted, the WHO does NOT recommend facemasks for everyday use by the public, nor do the SAGE group who advise the UK government. The official line is that there is no evidence to support the general wearing of masks, but then nobody has seriously looked for such evidence and there's no evidence that they do not help.

Nobody denies that those healthcare workers who are in contact with patients who are or might be infected with covid-19 should have full PPE (Personal Protective Equipment) including a well-fitting face mask conforming to set standards. This PPE is (quite properly) for the personal protection of the healthcare worker. The authorities worry that if wearing masks becomes commonplace, the public will exhaust the stocks needed for healthcare workers. But nobody is suggesting that facemasks for the general population in public places need to be regulation compliant.

Let's look at what we know about the coronavirus:- it's a respiratory virus, a type of viral pneumonia, spread mainly by droplets expelled when talking, coughing or sneezing. As the droplets fall and dry out they land on surfaces where the virus can survive for days on hard impervious surfaces, where they can be picked up on the skin and spread by fingers – hence the importance of regular hand-washing; the virus is rendered inert by soap. The virus usually enters the body via mouth, nose or eyes or broken skin. It is killed by UV light in sunlight or bright daylight.The virus is not usually present in fresh open air.

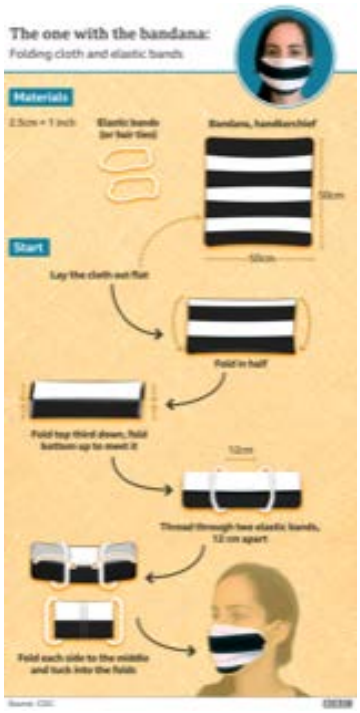


People who are infected & infectious to others may be asymptomatic – with no signs or symptoms of the disease. So there is no way of knowing if the person next to you is infectious or not. Similarly, you do not necessarily know if you are infectious to others.

As the number of new cases of coronavirus declines we can see that social distancing and shielding and handwashing are effective in controlling spread of the virus. But we can't live forever in lockdown. As we mingle more the risk of spreading the disease increases.

As the nice graphic shows here, if **you** wear a simple mask, it will give you moderate protection from droplets expelled by others near you who might be infected. But if ***everybody*** wears a simple mask we will help to protect each other. If you should contract the virus, the less exposure you have to the virus, the less likely it is that it will affect you badly.

A simple face mask is easily made using a man's cotton handkerchief folded inwards from each side, to make a wide 3 ply strip. Then fold the two open ends in. Use 2 large rubber bands for ear straps. After use the handkerchief should be unfolded, washed in hot soapy water or machine washed. Then (ideally) press with a hot iron & refold for reuse.



Covid-19 & Kawasaki Disease

Recent reports in the press have suggested that there is a new type of coronavirus disease, affecting children, which resembles Kawasaki Disease (KD). The Kawasaki Disease Societies around the world (including Italy, Canada, UK, Spain & Australia) issued a joint statement, summarised here:-

All our communities have been affected by the recent, worrying press reports. In the past few days, following media reporting, we have received a lot of questions on any possible link between COVID-19 and Kawasaki Disease. We understand the concerns and anxiety of families with a history of Kawasaki Disease.

Regarding children previously diagnosed with Kawasaki Disease, to date, the available information does not seem to indicate that these children are at greater risk of contracting COVID-19 or have a different response to COVID-19 (if any) than other children. Fewer cases of Kawasaki Disease than would be normally expected at this time of year are currently being seen – not more. It is vital however that both during this pandemic and in the future, that the medical community and parents are actively aware of the symptoms of Kawasaki Disease. The single defining characteristic is a distinctively persistent high fever. Other symptoms can include a rash, cracked lips and sore mouth, bloodshot eyes, and swollen glands in the neck.

“All the information we have so far shows that, overall, COVID-19 affects a very small number of children. The expert doctors advising our organisations have been **consistent** in their guidance to us and this is what they say:

“At the moment there is no proven link and no increase in new Kawasaki Disease cases.

“Some of the symptoms associated with Kawasaki Disease may also be the same as those associated with COVID-19 infection. However, symptomatic and complicated COVID-19 infection remains rare in children compared to adults according to the European experience. The trend so far is similar in Canada.”

“Kawasaki Disease is an increasingly common inflammatory disorder, and whilst no infection has ever been proven to be the sole trigger, the scientific community believes that any one of many infections may trigger Kawasaki Disease in susceptible children. For the majority of cases, Kawasaki Disease occurs without ever identifying any infectious cause.”

“There is no current indication that overall rates of newly diagnosed Kawasaki Disease (without shock) are increasing with the pandemic, nor that children who have previously had Kawasaki Disease are at increased risk of more severe COVID-19 infection.”

Together, we urge parents/caregivers to seek medical advice if you are worried about your child for whatever reason. Contact your usual doctor or online / telephone medical advice line. If you need urgent advice, call your country’s emergency number and if a professional tells you to go to the hospital, please do so.

For more information visit https://www.societi.org.uk/kawasaki-disease-covid-19/

VASCULITIS UK

A Grand Day Out

By way of setting the scene: my initial encounter with Dr Wegener's interesting disease was in 2001 (when I was non'but a lad of 57). My brush with GPA fortunately left my kidneys fairly intact but my lungs pretty well trashed. 20 years and lots of immune suppression later, vasculitis is little more than a distant memory, but prostate cancer and a few other co-morbidities have now taken centre stage.

The cancer initially made me incontinent but perversely it later stopped me weeing altogether. If untreated, this leads to kidney failure. However modern medicine came to the rescue in the form of a suprapubic catheter – a hole punched through below the belly button directly into the bladder, through which a catheter tube is inserted directly. Not a jolly solution but it's surprising what you can get used to. The tubes & bags are my "external plumbing". Now read on:-

The combination of "underlying health issues" resulted in my receiving "The Letter" from my oncologist and "The Email" from my rheumatologist, both advising me to hunker down & "shield" for a while – until mid summer.

We could also book a delivery slot with the local supermarket. So apart from emerging to clap for the brave people in the NHS on a Thursday evening, we laid low, doing essential work for Vasculitis UK and watching rubbish on TV.

Fast forward to two nights ago when my amazing suprapubic catheter became irrevocably blocked – despite all my best unblocking efforts. The threat of spending the rest of my life on dialysis loomed again. But a phone call to urology revealed that despite coronavirus, as Matt Hancock, the NHS was indeed open for business and I would be fitted in at lunchtime. Remember, after 6 weeks of lockdown & shielding, we're no longer sure where the door to the Big Outside is. Will the car still start or has all the fuel evaporated? Will Susan have forgotten how to drive. We were nervous.

We set out, blinking in the Spring sunshine, on our big adventure, the 12 mile trip to our local District General Hospital. More cars on the road than we expected.

We arrived at the hospital and it was like a miracle. Instead of driving round and round looking for a parking space – as usual, we had a choice, the car park of our choosing. On entering the hospital, everything was working but it was eerily quiet.

We went through almost deserted corridors, nervously expecting corona viruses to leap out & get us.

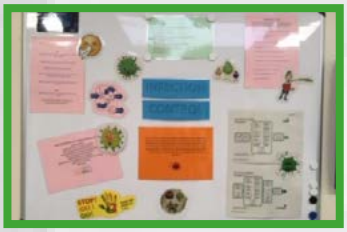
All the staff seemed quite happy and confident and not scared at all.

Arriving in the department we were both given masks and gloves – was this for our protection or to protect the staff from us?

The seats in the waiting room had notices taped on to ensure we maintained social distancing whilst waiting. Everyone was very friendly, as usual, and not at all nervous. I went into the treatment room; everything was as normal. My "procedure" was completed as usual and I left with fully functioning new suprapubic catheter.

So I'm extremely grateful to the dedicated staff of the NHS who go to work every day, probably scared for themselves and their families, but they put that aside to provide my routine care.

John Mills: May2020



Travelling as the Pandemic Hit Home

Dr Reem Al Jayoussi was until recently a very popular consultant nephrologist at Leicester University Hosptal. Much to her patients' dismay, Reem and her husband decided to take up short-term posts in Dubai. However Covid-19 tends to disrupt people's plans. This account also illustrates how the United Arab Emirates have handled the epidemic.

My husband, children and I were looking forward to our spring break in the UK and were due to travel mid-late March. We had moved to the Middle East in August 2020 to be closer to my family and take on new challenges while our children are not tied to major exams. This would have been our first trip back to the UK as a family since moving continents and the children were very excited, looking forward to seeing their friends and grandparents.

By the second week of March it was becoming clear that the pandemic would soon affect travel, thus we brought forward our travel to the UK to focus on my elderly (in their 80s) parents in-law, Peter and Phyllis, with plans for them to stay with us. We arrived in the UK just as the social distancing advice was announced and it became immediately clear that it would not be safe for my parents-in-law to travel.

We did not meet any friends (which our young children found hard, but understood). We ensured Peter and Phyllis were well set for a prolonged lockdown and decided to return to Dubai on the 19th March, only 3 days after arrival in the UK and just before we expected travel restrictions to start.

A few hours before our flight was due to depart, Dubai restricted border entry and we were not permitted to board. After 5 days of waiting and negotiating with the UAE authorities, we were allowed to return on a near empty flight. There have been no further passenger-carrying flights from Birmingham to Dubai since.

The UAE have taken the approach to isolate and test in its response to COVID-19. It has one of the highest per-capita test numbers and admits all COVID-19 patients into hospital, irrespective of symptoms. 'Field' hospitals to accommodate the numbers of patients have been opened.

On arrival in Dubai, we were quarantined without passing immigration. We were all tested for COVID-19 by nose swab (the 7-year-old requiring some encouragement) and remained inside the airport hotel for 4 days until the results were available. There were 200-300 people in similar circumstances and a further 100 or so individuals in transit, trying to get home. It was an uncertain time for many. With negative swab results, we were permitted to enter Dubai and transferred, under Police escort through deserted streets, to another hotel in Dubai.

We were well looked after, but not permitted to leave the hotel room. Home working and home schooling were welcome distractions. We stayed a further 8 days until the results of a second swab were negative. We concluded our 14-day quarantine period at home.

Subsequently, the lockdown measures were more stringent than the UK. For most, leaving the home was only permissible, by issue of a permit requested on each occasion online, for essential reasons (groceries / healthcare) once every 3 days. Since late April, these have been relaxed and there are no limits to leaving the home between 7 am and 10pm. It is possible to visit family in small numbers and the shopping malls, the latter only if aged 12-60 years old. Home working is encouraged, and the schools will remain closed until September, at least. Mindful of the discussions in the UK, it is a requirement to wear a mask outside the home.

There are similar approaches in other middle east countries. My parents (in their 70s) are currently in Jordan and we have been unable to visit them for similar reasons. But the grandparents, whether in Jordan or the UK, remain safe.

The demographics of the UAE are such that the fatality rate is fortuitously low, and our hospitals, both public and private, have been focused on caring for symptomatic patients with COVID-19. This like many other countries has impacted on routine care and the medical students' placements have been suspended and replaced by daily online distance learning.

Our thoughts continue to be with our former NHS colleagues on the front line and our patients.

Letter from Italy Dottore Augusto Vaglio; Director of Nephrology Department University of Parma Italy.

(Augusto is one of the leading vasculitis experts in Europe)

It has been (and still is) a shock. In Italy it was a shock as it was anywhere else. Everything frozen, fear on people's faces, dramatic changes in our behaviour. Warm relationships crystallised into a computer screen. Everything turned into a virtual experience, which you don't imagine how sterile it is until it becomes the rule. We have lived and are living all this. As doctors we actually have quite an easy task: we need to reassure our patients, be close to them, and take care of them. We have tried to do all this, and I hope our vasculitis patients did not feel lost.

A scientific note, just to reassure our patients further: we have completed a study on Italian patients with systemic autoimmune diseases (including different forms of vasculitis), where we observed that patients with systemic autoimmune diseases receiving maintenance immunosuppression do not seem to be at higher risk of getting COVID-19 infection or developing severe complications. This also emerges from another study performed in the US. This can be good news, but, of course, (much) caution must be taken.

What have we learnt, what are we learning? Well, a lot. Maybe the most important lesson is that we need to stay close, close to our families, close to our friends, close to our patients and colleagues. Nothing will help more than feeling someone is close to you.

Augusto

News from the Front – Liverpool

RAF helps NHS Vasculitis Nurses

Treatments for Vasculitis have continued here throughout the Covid –19 pandemic and to help with the comfort of our nurses delivering these treatments whilst wearing face masks for long periods the RAF have come to their aid.
My nephew Chief Technician Peter Wakefield who is in the RAF made 3D printed clips for face masks to alleviate ear pain from the elastic ear loops.
Intravenous treatments for all vasculitides are given on the infusion unit at Broadgreen Hospital and all staff were supplied their own personal mask clip. These are light weight and easily cleaned and wearing them has completely eliminated ear discomfort from the tight facemask elastic.
Public support over the past few weeks has been amazing and these gestures of kindness are truly humbling.

Thank you so much RAF .
Advanced Nurse Practioner - Sarah Hardy
Liverpool University Hospitals FT

LIFE ON THE FRONT LINE

Addenbrookes Vasculitis Clinic 12 under coronavirus

Managing the evolving COVID 19 pandemic has meant rapid changes across the NHS, with re-deployment of staff and reshaping NHS services to prioritise emergency work and reducing risk of spreading COVID 19 infection to patients and staff. This has been a particularly worrying time for patients with vasculitis, who because of their immunosuppressive treatments are higher risk of severe COVID 19 infection.

In Cambridge we rapidly changed the majority of vasculitis outpatient appointments to telephone consultations. We now perform approximately 90 phone appointments per week with only 10 patients attending in person across our 3 weekly clinics.

This has meant the waiting room is quiet, and social distancing is easy to employ, making patients feel safer in the clinic. A new off-site blood testing facility has enabled safe blood testing for local patients and GPs have been supportive, performing blood tests for patients further afield. Immunosuppressive infusions have been a big concern for patients who are trying to avoid attending hospital. We usually recommended that patients continue to receive their infusions on the day unit, which are important vasculitis treatments. Although, in some cases delaying the long acting drug rituximab has been possible, provided patients are well and blood monitoring is possible. Patients attending the day unit must be free from symptoms of infection, are encouraged to wear masks and unfortunately relatives or friends can no longer attend with them.

National guidelines were quickly produced in March to guide doctors and patients on the need for shielding or enhanced social distancing. At the end of March, we sent letters to our 1800 patients attending vasculitis clinic to provide guidance on whether they should be shielding or undertaking enhanced social distancing. And since the end of April the shielding team in Cambridge has been able to register patients on the national shielding database to facilitate home deliveries of medication and food. Our team of four specialist nurses and five research nurses have adapted their working patterns to prioritise support for the clinical service as well as COVID 19 research. Priorities are following up on community blood results, responding to patient's phone calls and messages. New research studies include a national trial to see if hydroxychloroquine prevents COVID infection in vasculitis patients, as well as work investigating the severity of COVID 19 infections in vasculitis patients and immunity after infection.

The COVID-19 pandemic has clearly had a huge impact on the way we work. However, the encouragement, support and donations from patients, colleagues and the public is inspirational for our team!

Stella

Isolation #2

Isolation,
how do you see me?

You see me mostly as a 'sinking ship'
You see me as cheerless 'kinship'

I am submerged, during life's hustle, bustle and rustle
The moment life stills and quiet sets in
The moment you are forced to pause and slow down
The moment you are stripped from routine, I emerge

I know 'on the whole' you see,
Inspiration
Imagination
Insight
Ideas, as positive drives
Why can you not see me, as one?

You mostly see me as the drive
to make you mope, downbeat
Sometimes even to make you cry

Help me to make you upbeat
Help me to make you smile

See me beyond the gloom
See me beyond the moment
See me in the light

Shanali Perera

JANES STORY HOW DID IT ALL START?

I had been ill for a few years, just low-lying disease which caused many small but un-concerning symptoms. Both the GP and I thought I was just doing too much, with a full-on job and two young children. However, I didn't improve, I was exhausted, had frequent nose bleeds, vision changes, tingling fingers and toes. Then, about eight years ago, my wisdom teeth became infected, and after removing all four teeth and having three lots of antibiotics and still not getting on top of the infection, the Dentist suggested that something was seriously wrong, and I should push for blood tests from the GP. He probably saved serious damage to my kidneys in persuading me to get help.

It wasn't quick to get diagnosed from here, my blood tests showed inflammation, but it was months before I got to a point where I couldn't walk up a few steps without having to stop as my legs felt like I had run a marathon. A GP finally admitted me to hospital and endured two weeks of tests, including blood cultures, blood tests, ECG's, echocardiograms, CT scans. A kidney biopsy eventually diagnosed vasculitis. I needed to have fluid removed from around my heart; I had 400mldrained. I left the hospital with a bag of drugs and a referral to the clinic two weeks later.

Vasculitis has affected and left damage in my kidneys, ears, nose, aortic arch and root, and I still build up fluid around the heart.

I now have the following confirmed diagnosis:
• Granulomatosis with polyangiitis (GPA), which affects my small blood vessels. This has left lasting damage on her kidneys, eyes, nose and ears.
• Large vessel vasculitis, Takayasu arteritis, which has caused inflammation in the main aortic arch and root straight out of her heart. There is also inflammation in one of my coronary arteries carrying blood to my heart.
• Hypothyroidism, and
• Adrenal insufficiency.

In November 2019, I secured an article in the You Don't Look Sick, a weekly series published by the Metro newspaper, discussing invisible illness and living with a condition that other people can't see. We cannot share the full details but if you click the link you can read the full story (Or search the internet for 'Metro Vasculitis don't look sick').

"Jane, who is author of Chronic Illness: "Learning to Live Behind My Smile", tells Metro.co.uk: 'There is no cure for vasculitis, we live in the hope of a drug-free remission, but this is often difficult to achieve, I haven't reached this nirvana in eight years. 'I describe the illness to my children as a volcano, sometimes quiet, sometimes erupting, explaining that the eruption could be a small gurgle or a life-changing blast. All explosions leave damage in their wake.' She was diagnosed eight years ago but had been experiencing symptoms for around three years before she finally got answers."

https://metro.co.uk/tag/you-dont-look-sick/

A typical day in the life with Vasculitis
Some days I feel nearly normal and can live a full life, but other days I am beyond tired from just getting ready in the morning; these days are very frustrating. I am immune suppressed so I also catch any cough, cold or chest infection going around, this can be dangerous as I cannot fight illness very well and have ended up in the hospital a few times on IV antibiotics.

I have fatigue issues because my aortic arch is inflamed, so I walk very slowly and struggle with even a small incline. I am prevented from doing anything that could add pressure to the aorta, for example, lifting heavy items or exercise which puts pressure on the heart. So, I walk the dog slowly, I go to yoga and when I am not flaring, I try and swim.

It is hard to live with the constant knowledge that anything can cause a flare to happen. And that each time a flare comes I need to increase my medication and risk additional lasting damage being done to the parts of the body affected. Often a simple cold can take weeks to recover from and will leave me with blood in the nose for an even longer time.
It is extremely frustrating as my brain is still ambitious, but my body is not capable of keeping up with my dreams.

My job involves writing, and so when I was first diagnosed and had months of treatment stuck at home, I started to write down what was happening and how I felt. Over time, this journal of my new life became my coping strategy, it helped me to process all the ups and downs. Then as the illness went on, and on, I looked back over my writing and thought that maybe it could help others in a similar situation, somehow I managed to turn it into a book.

continued on Page 29

The book is focused on how to live with a chronic illness, but not on the specifics of my illness. The symptoms almost do not matter, it is the mental aspects of getting through the uncertainty, finding the right doctors and managing the hospital visits and medication. And most importantly getting out of bed every day and facing the world in the best way you can manage with how you feel, which is tough.
https://www.amazon.co.uk/Chronic-illness-learning-behind-smile-ebook/dp/B07TTDTN78

Where am I now?
I take between 15-20 tablets a day. And I must praise my GP and Addenbrookes hospital consultants for managing my care between them. It is complicated, but I use the online ordering system through my GP and try to hold a months' stock. Then every few weeks I measure out about 20 days' worth of tablets into little boxes so that each morning I can just throw them down my throat without thinking about the number of tablets or the side-effects. Also, this helps me to make sure I never run out of any supplies.
I have Rituximab infusions every four months and have just started on Hydroxychloroquine as the disease is not really under control. My adrenal glands are not very good after 8 years of prednisolone, so I carry a warning bracelet and card that I am steroid dependant.

Vasculitis UK
When I was first diagnosed my local hospital gave me very little information, just a bag of medication. However, since then I have referred myself to the specialists at Addenbrookes, who have been amazing. Also, the information from the Vasculitis UK patient association is exceptional: https://www.vasculitis.org.uk/ and I could not have got through the last eight years without their information and support. Over the years, we have fundraised for the charity as it is run completely by volunteers and the amount of time and effort, they input is unbelievable. My 9 year old daughter recently raised over £660 by completing a sponsored silence at school with some friends.
The problem with a rare disease is that the money to fund patient support is not there. I have been lucky because the people who run Vasculitis UK have put their whole life into making people like me understand the impacts of this disease. I am eternally grateful.

The Facebook group has helped lots over the years. Vasculitis is rare, so it is often not possible to have a face to face meeting so to have an active social media group really helps. https://www.facebook.com/groups/VasculitisUK/

With a rare disease, people do not understand anything about it! When a friend says they have diabetes, then you have some understanding of the challenges and treatment they may face, you don't know the specifics, but you have an idea. For me, friends do not understand at all, and I don't blame them, I am not sure I fully understand myself.

The other, probably my serious difficulty, is the lack of funding pushed into research and development for rare disease treatment; the commercial payback will be less than for more 'common' illnesses. The funding for supporting patients is also lacking, we don't get Macmillan nurses, or cancer drugs fund or Diabetic nurses to support us. In reality, we are lucky if we can find a hospital and GP which actually understands our disease.

Clinical trials are another issue, as even if funding can be found, it is difficult to recruit the number of patients needed to show effectiveness when the population you are recruiting from is so small. We are often provided with drugs originally designed for 'similar' diseases, for me, this is medication original intended for lupus or rheumatoid arthritis.

My coping strategies
Try and stay positive, and don't blame anybody for the future you have. It is easy to be consumed by the illness and want to try and find out 'why me?' but often this will not help. You have to learn to live with the illness in a way that works for you, fighting against it every day will just leave you even more exhausted and very frustrated. If you cannot cure it then you need to manage it the best you can, so find the best doctors and be honest with them. If you don't have trust in your doctor, then go and find one that you will and ask for a referral. NHS choices allow you to request to be seen elsewhere: https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs/

Jane Edwards

My story begins on an airplane.....
I was in the second year of uni and flying back from Palma, where I'd visited my then long-distance boyfriend Charlie. I was 19 years old, adventurous, in shape and healthy – apart from the depression and anxiety.
Sat in the luxury of an Easyjet seat, I felt a digging in my shoulder blade. Weird. It went away, so I didn't think much of it.
Fast forward two weeks, when I get off the plane from Iceland. I know – what uni student can afford two holidays in one month!? I worked part-time, and this trip was a gift from Charlie, who wanted me to have my dream holiday. I'd spoken about Iceland for years, longing to bathe in the Blue Lagoon and straddle the tectonic plates. I just didn't know it would be the last time I felt like me.

On the journey home, I felt digging in my ribs, which only got worse by the time we'd reached our hometown coach station. The walk home was 10 minutes – I could easily smash that. But that night, I couldn't. My sailing strength and youthful assumption of immortality dissipated into nothing. First, my boyfriend insisted on carrying all the bags – I told him he was being silly. But then the pain increased, I couldn't breathe, I was dizzy, it hurt a lot. Our ten-minute journey turned into a forty-minute battle which ended in me staggering through the front door. A paramedic comes, but all of my obs and stats were fine. Weird. I took some painkillers and forgot it ever happened, until exactly a week later when I was bawling my eyes out from the pain. It felt like knives had been stabbed into my ribs, and the crying wasn't helping my already laboured breathing. My mum was terrified, and one ambulance journey and a dose of morphine later, I was in the hospital with suspected pulmonary embolism. Even though they thought I had a blood clot, they wanted me to go away and come back in the morning. Safe to say I stayed there, and after many blood tests, a CT scan, urine tests and a 14 hour wait, they found a light show of nodules in my lungs and gave me the three probabilities of what was wrong:

1. From all my traveling, I'd got an infection. It could be that a bug (yes, a bug) had made its way into my heart, which was pumping lots of little bugs through my blood system. I still don't understand that, nearly 4 years on, but okay.

2. I had an autoimmune condition.

3. I had cancer.

Everyone was very much hoping for option number one, as grisly as it sounded, and my mum naturally leapt to option number three and began tearing her hair out. But I wouldn't get the answer easily. Throughout the year I deteriorated, and I'm still recovering from the trauma of it today. The stabbing chest pains continued, and my lung capacity nosedived. I could barely breathe, and a lot of the time couldn't walk. Blood came out everywhere apart from my ears (small victories), I lost weight, I vomited constantly, and my bowels completely gave up. My boyfriend, who has Ulcerative Colitis, couldn't believe the pain I was in. Because I had to be near a toilet so often, any plans I made were flaky at best. Charlie had to wash me, bring me sick bowls, help me vomit (and good god does that boy hate vomit!), and help me walk. I couldn't go out into the cold, and sometimes I even had to crawl up the stairs. The anxiety of going anywhere was overwhelming – I'd gone from flying solo to not wanting to leave my home city. My flakiness made people angry – someone even wrote a whole load of abusive scribblings about me on Facebook the day I was diagnosed, which still traumatises me to this day.
The girl who sailed, adventured, and flew all over the world died the day she walked off that plane. After many hospitalisations and endless tests and scans – I'm talking x-rays, CT scans, ultrasounds, echocardiograms, and to quote 2017 Seren, "enough of my blood to fuel a small island of vampires and enough pee to fill a canal"– my consultant had run out of ideas. I was given a choice that would change my life – to go on medication and hope everything gets better without knowing what it is – or to continue without medication and have a lung biopsy to assess once and for all what was happening to my body. I chose the lung biopsy.

They could've done one when this all started, but they didn't want to perform such an invasive surgery on someone so young, which I understand. I wrote in my first ever blog on vasculitis: *"they performed a bronchoscopy (which, by the way, was effing terrible), which then gave me the all clear for a lung biopsy (which, also by the way, wasn't the most fun thing either). Twelve days later, I walked into my consultant's office and got my diagnosis: Churg Strauss Vasculitis."*
Ever since that diagnoses day, my own D-Day, on 14th November 2017, I have been adapting to a new normal. I have experienced severe depression and anxiety in direct relation to my condition, as well as stigma, discrimination, and online abuse. I've had plenty of infections due to my immunosuppression (I'm talking thumb infections and Scarlet Fever – what's that all about!?), and gained a substantial amount of weight due to the steroid medication, which admittedly did save my life. I have lost friends and endured many identity crises and breakdowns.
My life has never been the same, but over time I have adapted to the new normal and figured out how to live life to the best of my new ability. Things may have changed, but that's okay – I'm happy now.
And hey, at least I got to fully enjoy my dream holiday in Iceland.

Seren

Poem written by Victoria Ellis

Just Beneath the Surface

Yet another yes, so eager to please
Piled it up so high, I'd done it with ease
But just beneath the surface, it had to started slither
The serpent swelled as my eyes grew dimmer

As the load became heavy, my chest felt tight
Hands shuddered, body ached, I was in fight or flight
And just beneath the surface, sat biding his time
He observed it all, nose below the waterline

My body started to tighten, creaking and stiff
It'd wondered too close, and fallen from the cliff
And just beneath the surface, he had started to grow
Feeding and gorging, he finally pulled me below

My legs gave way, skin set to explode
A delirium of swelling that simply wouldn't slow
And he burst to surface and hissed his forked tongue
Grinning he spat, "this has only just begun"

And he lurched himself forward, he attacked from behind
A grunt and slap, he probed deep in my mind
He located the place, the one marked with "shock"
He fashioned a key, and opened the lock

And exploded out, a river of fear
Gathering speed, it moved up the gears
He fed and he grew, engorged with my pain
Now at full height, he knew no restrain

He wrapped himself around me, and tightened his squeeze
My body contorted, I had started to seize
And he smiled and laughed as he bored into my eyes
"You are mine forever", and I believed his lies

But all of a sudden, he loosened his grip
The river of fright had now run to a drip
His body all shrivelled, starved of his food
This terrible beast could no long delude

I lifted one brow, I could finally see!
I opened both eyes and ripped myself free
He slunk beneath the surface, back to his lair
And awaits the time when I stumble back there

Victoria Ellis - Vowles (IgA Vasculitis)

In Memory of Hannah Taylor

Family and friends have donated £1505 to Vasculitis UK in memory of Hannah.

In November 2019, Hannah was admitted to hospital with suspected pneumonia, which turned out to be vasculitis C-ANCA. Sadly, her symptoms were not spotted early enough and the vasculitis had already taken over. She was rushed to Wythenshawe Hospital and placed on an ECMO machine. The team there did an amazing job looking after Hannah for 7 weeks but unfortunately all of her organs eventually failed. Hannah tragically passed away on 12th January at the age of 27, having never suffered from any previous health problems. We hope that by raising awareness of vasculitis and fundraising for research, that more can be done to help others get earlier diagnosis and treatment.

Hannah was a truly beautiful person, inside and out. She will be loved and missed by many people.

Emily Taylor (Hannah's sister)

In Memory of Tracie Jayne Jacob

Zoi Anastasa – Saying goodbye to one of the Vascie princesses

When I got diagnosed with vasculitis, and joined the Vasculitis UK Facebook Support Group, Tracie Jayne Jacob was the first online vascie friend I made. We started our vasculitis journey almost at the same time we had children at the same age and we soon found out that we could chat for hours.

A common online friend created the Vascie Princesses chat group and over the years a strong friendship bond was created between all of us.
Tracie was diagnosed with COVID-19 on the 23rd of March. Her health over the years had declined and although she fought very hard, she very sadly lost the battle on the 4th of April.
Tracie was a kind; thoughtful; fun; supportive and caring person. She was a wonderful mum; she adored her daughter Jazz. Tracie was very closed to her family and loved her bunny. A true pet lover, she was often fundraising for a pet shelter. She was truly loved by her partner Mark, a man that came to her life and filled it with joy, passion and respect.

If your path has crossed with Tracie's I am sure you will agree with me, she was a sunbeam bringing warmth and light to other people's lives. She will always be in our hearts.
Rest in peace my beautiful vascie soulmate.

Bequests - In Memoriam

The charity has a simple and sensitive JustGiving page for those who may wish to raise funds for Vasculitis UK by celebrating the life of a loved one. If you would like to remember a loved one in this way to help raise funds for the charity please visit: **www.justgiving.com/VasculitisUK/Remember**

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

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

Funeral donations totalling over £500 were received in memory of David Charles Huxter of Bridport, Dorset, who sadly passed away in the autumn of 2019.

Donations totalling £500 were received in memory of Mr Jeffrey Paul Wells,of Weymouth, Dorset, who sadly passed away on 30th July 2019.

The family of Mary Coulson of Benfleet, Essex, who died over 10 years ago due to vasculitis, made a donation of £500 to Vasculitis UK in her loving memory. Over the past 10 years, the Coulson family have been srtong supporters of and regular donors to this charity.

Numerous individual donations totalling £280 were received in memory of Vasculitis UK member Gill Harvey of Glen Vine, Isle of Man, who recently passed away leaving a bereaved widower, Geoff. Gill suffered from GPA. A mother & grandmother, Gill was very popular in her community. She played both piano & organ and sang in her church choir. £50 was also donated by the IoM Organ & Keyboard Society.

A further £310 was donated in memory of Gill Harvey by those present at her funeral at Marown Parish Church, Isle of Man.

Donations totalling £90 were received in memory of Esme Hyndman of Swansea.

Donations totalling £170 were received in memory of Mrs Evelyn Best, of Portstewart, Northern Ireland, who passed away in October 2019.

A donation of £200 was received in memory of Mr Allen Farnworth of Carlisle, who died age 92 following a stroke He led a full, happy & active life. His daughter, Valerie, suffers from vasculitis.

Donations totalling £524 were received in memory of Ruth Hodson of Southwell, Nottinghamshire.

£202 (inc Gift Aid) was donated in memory of Edward (Eddie) Norris of Cambridge.

A collection at the funeral of Mr John Arthur Smedley of Littleover, who died last October, age 70, resulted in donations totalling £458.

David Moir of Inverurie, Aberdeenshire sadly passed away in April last year. Donations in his memory amounted to £1405.

Swales £70

Donations totalling £90 were received in memory of David Nicholas (Dai) Somerfield of South Wales.

Robert Young donated £50 in memory of his wife Anna who sadly passed away in March 2016.

A further donation of £35 was received in memory of Mark Anthony Flegg, who passed away in 2017 due to secondary liver cancer, having fought a 15 year battle with GPA.

Donations totalling £1239.80 were received in memory of Mrs Maureen Stevenson Haynes who sadly died in November last year, age 79. She was a very experienced in Scottish Dancing, which she taught nationally and internationally: she only gave up dancing last year.

A donation of £75 was received in memory of Lorna Wright, who passed away in January 2014 due to complications arising from GPA.

Donations totalling £349 were received in memory of of Rob Howard,who sadly passed away in December last year.

A donation of £20 was received in memory of Mrs Eunice Rowe of Hitchin, Herts.

Funeral donations totalling £394 were received in memory of Mrs Jennifer Dodd of Yeovil.

Donations totalling £385 were received in memory of Gary Anthony Rendell of Worthing, West Sussex.

Funeral donations totalling £875 were received in memory of Christopher Frank Swainson.

A JustGiving page was opened in memory of Hannah Taylor,of Manchester, who died in January, due to late-diagnosed GPA vasculitis, at the tragically young age of 27, having never previously been ill. The Justgiving page for Hannah had raised almost £1800 by early March.

£340 was donated in memory of the late Brenda Pedley of Baslow, Derbyshire, who died on 17th December 2019, aged 83.

Funeral donations totalling £360 were received in memory of Mrs Guinevere Elizabeth Davies of Wiltshire who sadly passed away in January 2020

Donations totalling £244 were received in memory of the late Hannah Taylor of The Wirral, Cheshire.

A donation of £1000 was received from Mr John Holmes of Sheerness, Kent, in loving memory of his beloved wife Joyce, who passed away in April 2016 aged 67.

Donations totalling £373 were received in memory of the late Jean Haigh.

Donations totalling £145 were received in memory of the late Janet Botham of Hope Valley, Derbyshire, who died in December 2019 age 72 years.

A total of £825 was donated in memory of Christopher Frank Swainson who passed away in December 2019.

£178 was received in memory of the late Veronica Louise Heitzman who passed away,age 63, on 1st January 2020.

Funeral donations totalling £415 were received from family & friends of the late James Thompson of the Wirral.

£1040 & $530 were received in memory of James Riddell of Herne Bay, who sadly passed away on 29th February this year, aged 68, due to GPA.

Funeral donations totalling £300 were received in memory of Mr Lewis Crossan of Newcastle on Tyne, who passed away age 72 in February this year having suffered from GPA since 2016.

Donations & Fundraising

Vasculitis UK received £200 from the Benevity Giving Scheme.

St Gregory's Union of Catholic Mothers, Merseyside, kindly donated £75 to Vasculitis UK

Vasculitis UK received £800.50 from the PayPal Giving Fund.

Lorraine very kindly donated £1000 to Vasculitis UK.

Swithland Spring Water of Leicestershire have once again made Vasculitis UK their chosen Charity of the Year, resulting in a Christmas Donation of £1100 to Vasculitis UK in lieu of sending out Christmas cards to their customers.

Margaret Robertson of Chester-le-Street donated £549 to Vasclitis UK – the proceeds from her poetry book sales, speaking engagements and sale of donated items on Ebay.

Following Tim Moxley's "Vasculamble" a further £50 was donated in memory of Tim's wife, Lydia.

Sarah Taylor of Meltham, with Mum & Dad Helen & Simon, held a coffee morning which raised £486.50 for Vasculitis UK.

The staff of Keebles Solicitors of Sheffield once again donated to Vasculitis UK, their chosen charity for 2019. This resulted in a final cheque for £169.

Renal Nurse Specialist Sarah Hardy passed on donations of £130 raised over Christmas by a patient in the Broadgreen infusion unit, Liverpool.

Janice Mather and Susan Mills had a stall at Matlock Arts & Crafts Fair in December, selling creative items contributed by members of the Vasculitis Facebook Hobbies Group. This raised £145 for Vasculitis UK.

Vasculitis UK were awarded £230 as a share of Buckingham Charity Cup Competition. This is a competition between local football clubs in Buckingham & Aylesbury Vale.

Rachel Marsh of Hopton, Norfolk was nominated for a Community award by the Rotary Club of Great Yarmouth. She kindly donated the £100 award to Vasculitis UK.

Rachel is a teacher at Hopton C of E Primary Academy. Her colleagues at the school donated £35 to Vasculitis UK in lieu of sending Christmas cards.

The "Woirked All Britian" Group is an association of amature radio enthusiasts. They have a charitiable arm of the society which makes awards. This year the committee kindly agreed to donate £500 to Vasculitis UK

VASCULITIS UK

Donating To VASCULITIS UK

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

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

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

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

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

Virgin money giving Donate here

Donate with JustGiving

PayPal MasterCard VISA

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

Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group
Janine Davies - 01525 372733 - family.davies@btinternet.com
Christine Lee - 01480 869162 - chrislee0307@btinternet.com

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

East Midlands Group
East Midlands Website Group https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home
Dorothy Ireland - 01332 601303 – Dorothy@vasculitis.org.uk
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

Leicestershire Group
Leicestershire Group Website https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home
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Lincolnshire Group
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The North West Group
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Swindon Support
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Margaret Gentle - 0121-243-5621 - mgvsgwm@blueyonder.co.uk

West Country Group
Website https://vasculitiswest.wordpress.com/
Charlotte Stoner - 01626 872420 - the.stoners@talktalk.net

West Sussex Group
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North and West Yorkshire Groups :
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East Yorkshire Group :
Rachel Weeks - 07968 959 850 email rachel@yorkshirevasculitis.org.uk

North East Yorkshire Support Contact :
Jennifer Wormald - 01937 586 734 email jennifer@yorkshirevasculitis.org.uk

South Yorkshire Social Group Contact :
Jenny Gosling - email jenny@yorkshirevasculitis.org.uk

WALES

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South Wales Group
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Ryan Davies – ryan@wegeners-uk.co.uk
Angharad Jones - Angharadjones.vas@gmail.com

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Republic of IRELAND

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

Ireland - Vasculitis Awareness Ireland
Vasculitis Awareness Ireland Website http://vasculitis-ia.org/
Julie Power - 028 44 842889 - vasculitisireland10@gmail.org.uk

International Vasculitis Awareness Day May 15th 2020

May 15th 2020 is the first ever International Vasculitis Awareness Day. To celebrate the occasion, Rare Revolution Magazine is launching a Vasculitis Special Edition. This features the work that has been done jointly between Vasculitis UK and other European members of Vasculitis International; the project was funded by Vifor Pharma & facilitated by Havas Life Science as part of the "My ANCA Vasculitis" and "See me, Hear Me" project to raise awareness & understanding of ANCA vasculitis. The online magazine can be found by using this link: http://edition.pagesuite.com/html5/reader/production/default.aspx?pubname=Rare%20Revolution&edid=f511f3d7-ee38-41d7-b6d9-243e4de20f28 or visiting the Rare Revolution website.

Rare Disease Day 29th February 2020

Rare Disease Day is officially held on the last day of February every year and this year, in 2020, it fell on a very special day – 29 February. To mark Rare Disease Day 2020, Rare Disease UK hosted three receptions in Wakes, England and Scotland with an aim to raise awareness of rare diseases and improve access to care, treatment, information and support.

https://www.raredisease.org.uk/news-event/rare-disease-day-2020-2/

Support Group Meetiings in The Olden Days - Before Lockdown

East Midlands Support Group Christmas Lunch

North East Vasculitis Support Group Meeting March 2020

HONORARY LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

Established in 1992 by the family and friends of Stuart Strange, in his memory.
Formerly known as the Stuart Strange Vasculitis Trust
Registered Charity No. 1019983

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