



VASCULITIS UK

NEWSLETTER JOURNAL



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Rare Diseases Europe

The Doctors' Dilemma

With most types of vasculitis, it can be a great relief for both patient and doctor to reach a firm diagnosis leading to clear treatment plan which, hopefully, will lead to remission and perhaps eventually even "full" remission, when no medication is required. However, for the doctor and especially in the case of ANCA vasculitis, it is very difficult to decide when is the right time to discontinue maintenance treatment with immune-suppressing drugs. For some patients there are minor lingering symptoms or persistently high ANCA levels. Discontinuing those maintenance drugs too soon may result in a damaging relapse, but continuing unnecessarily may result in increased risk of infection or even cancer. So what is needed is a "biomarker" – probably something that shows up in a blood test – to indicate when it is safe to discontinue maintenance treatment. Professor Lorraine Harper (Birmingham University Hospital) and Professor Alan Salama (University College Hospital) are working together on research to find out if such a biomarker exists. They are currently assessing if there are sufficient patients with ANCA vasculitis willing to take part in their proposed study.

Avoiding a "Pig in a Poke".

This ancient phrase has fallen out of common parlance. It means "a pig in a sack" and was used in the context of "buying a pig in a poke" or in other words to buy something unseen or on trust. When it comes to vasculitis, this might apply to rheumatologists or maybe nephrologists too. There is no specialist qualification in vasculitis. Qualified doctors who choose to go down the "Rheumatology Specialist" training route will receive training in managing the relatively common osteo & rheumatoid arthritis diseases as well as many other more rare rheumatic disease such as Juvenile Idiopathic Arthritis, Psoriatic Arthritis and Ankylosing Spondylitis.

In addition they will receive some training in recognising, diagnosing and treating vasculitis – alongside many other rare auto-immune rheumatological diseases, such as systemic lupus (SLE), systemic sclerosis (scleroderma) Raynaud's disease, Sjögren's disease, myositis – a long list. There are 20 distinct types of vasculitis and these vary greatly from case to case both in how they affect individuals and how they respond to treatment. As in many diseases, especially rare ones, practical hands-on experience can count for at least as much as theoretical knowledge from lectures and textbooks.

As a patient, the best you can hope for is that your new rheumatologist or nephrologist consultant has a "Special Interest in Vasculitis". But even this might indicate a deep knowledge, understanding and experience of vasculitis or that the consultant has a wish to learn more about vasculitis and has maybe diagnosed and treated 2-3 cases of vasculitis in the past year – remember there are 20 types of vasculitis.

Vasculitis is rare so it is probably not reasonable or practicable for rheumatologists to have an additional specialist qualification in diagnosing and treating vasculitis. But

many of the rare autoimmune diseases overlap and have similar symptoms and treatment regimes involving suppressing the immune system. Some patients actually have 2 or more of these diseases at the same time.

So maybe it **would** be feasible for rheumatologists, nephrologists, immunologists and other specialists who diagnose and treat these diseases to have a formally recognised qualification to demonstrate that they do have an in depth understanding of this type of disease, how to diagnose them and how to treat them.

There are around 3000 patients in England who suffer from Behçets Disease – a particularly unpleasant type of vasculitis which is notoriously difficult to diagnose and to treat. There are 3 dedicated centres in England where Behçets is diagnosed & treated. They do a great job, but each centre is only responsible for 1000 patients.

There are over 2000 **new** cases of vasculitis **each year**, rather more new cases of lupus and many new cases of scleroderma, myositis, Sjögrens and other rare autoimmune diseases. So in total an awful lot of patients around the UK suffer from one or more of these rare autoimmune diseases. Like vasculitis, patients around the country with these diseases suffer delayed recognition & diagnosis and confusion over appropriate & effective treatment.

Surely a strong case could be made for creating a number of highly specialised centres (perhaps one for each teaching hospital) where patients suspected of having one or more rare auto-immune diseases could be referred to get a proper diagnosis and treatment plan before being referred back to their local hospital for ongoing treatment on a "shared care" basis. This is how the Behçets centres operate. Complex cases or those unresponsive to normal treatment may continue under the direct care of the specialist centre.

The Behçets centres were given substantial additional funding to set them up and run them. There's no spare money in the NHS these days, but with just a little extra cash and imagination, existing resources could be redeployed to develop a much improved NHS for those many thousands newly diagnosed or living with with rare autoimmune diseases.

New Trustees & Volunteers

2018 saw major upheaval and disruption in Vasculitis UK. A number of trustees resigned for a number of reasons. However, several fresh and more enthusiastic trustees stepped up to replace those who left and were duly appointed at the AGM. These include Jayne Hardman, Kelly Jefferies & Richard Remorino. Wendy Bryant volunteered to take over Research Awards Administration, working with Gareth Garner. Martin Makin, of green hair and marathon running fame is being co-opted to strengthen the team. Martin has raised many thousands for Vasculitis UK. In this years Great North Run, Martin ran for Vasculitis UK and came 77th out of a field of 58,000runners.



Chairman's Report

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TSB Bank

The charity has banked with Trustee Savings Bank since its early days as the Stuart Strange Trust (when it was probably known as Lloyds Bank). However, the TSB management decided to reorganise their IT systems, which resulted in us being unable to access our accounts or pay our creditors for several weeks. We are now in the process of transferring the charity's business to the Coop Bank. This will not have any impact on members or existing arrangements such as standing orders.

Talking politics

The bad news about Brexit, especially for those suffering from a rare disease, keeps coming in. The European Medicines Agency is no longer based in the UK, which may mean delays in introducing new drugs. There are questions about continuity of supply for drugs imported from Europe. Both the BMA and Royal College of Nurses have expressed great concern about staffing levels when EU born medical professionals are required to return to Europe. The exciting new European Reference Network was set up with EU funding. It is intended to address the problems of equality of access to expert medical opinion for those living far from centres of expertise. The UK was set to play a key role, but now the UK is being progressively excluded as we are no longer going to be involved in financing it – which seems only fair!

The government are in the process of making things just a bit worse for people with rare diseases by reducing the funding for NICE from £66.4m to £51.2m, such that NICE is proposing to address the shortfall by introducing charges for assessing/approving new drugs. NICE controls access to new drugs under the NHS. The pharma industry is global and the UK is already considered an unattractive market, due to the NHS's haggling over prices.

Drugs for treating vasculitis are usually "re-purposed" drugs, already approved by NICE for treating more common diseases, such as rheumatoid arthritis (RA) or diabetes, which represent a large potential market. But if a drug like rituximab, already approved by NICE for treating RA is found also to be effective for treating vasculitis, it has to go through the same process for treating relatively few people – ie a very small market compared to the RA market. The charges are not just nominal. Under the new system, a pharma company seeking approval for use of rituximab for treating vasculitis could face an up-front charge of £150,000 for the application, non-refundable if the application is unsuccessful. This is hardly going to encourage pharma companies to introduce new drugs or look for new uses of existing drugs for treating the relatively small numbers of people suffering from any of the 7000 known rare diseases.

Vasculitis Education for Professionals.

Encouraging professionals who see, treat and work with people suffering from all types of vasculitis to improve their understanding and experience of these complex diseases, just has to be a good thing and it is something that yields immediate benefits for patients, whereas funding research

may not produce any useful result and any benefits for patients may not become apparent for many years. Although, for a variety of purely operational reasons, Vasculitis UK did not invite applications for research grants in 2017-18 we will be putting out a "call" this autumn & will continue to do so each year when funds permit. However, this year Vasculitis UK is working with the British Society for Rheumatology, "co-badging" Vasculitis Fellowships. This scheme offers 5 places for consultants and other BSR members on a short but intensive course involving theoretical and practical sessions dedicated to vasculitis. Unfortunately, the BSR can only support 5 applicants at a time, but we hope to be able to repeat the course in future years. The closing date for applications was 31st August and the response was overwhelming, with applications far exceeding the available places. Also this year we awarded funding to help Renal Nurse Specialist Sarah Hardy from Liverpool to take part in a professional education course (see *centre pages*) and in the Spring we supported medical student Sam Myers in attending the EULAR conference in Amsterdam where he presented a paper about his undergraduate vasculitis research project. (see *centre pages*).

Joining the Dots- AI Guided Diagnosis for

Rare Diseases

Driverless cars are not quite with us yet, but the AI (artificial intelligence) and "machine learning" behind such cars is very much with us. As well as playing chess to Grand Master standard, trained artificial neural networks can do many sophisticated jobs faster and more effectively and reliably than we humans. One example is interpreting medical images – CT scans and MRI scans – where they can be "trained" to identify patterns in complex data. This is already being trialled at Imperial College. Skilled and experienced radiologists are in very short supply, so it's not so much a case of AI putting people out of work, more a case of remedying a skill shortage.

When it comes to diagnosis in vasculitis (and other rare diseases) it often needs medical experts with comprehensive knowledge and experience to make an accurate diagnosis, taking into account a myriad of non-specific symptoms and diverse investigations – blood & biopsy results and imaging. We at vasculitis UK often refer to it as "joining the dots" or "putting together the pieces of a jigsaw & seeing the picture emerge". A-I machines with trained neural networks are really good at spotting emerging patterns. Add to that some sophisticated algorithms of the sort used by Google, Amazon & Facebook and a vast database of signs & symptoms, which already exists in the UKIVAS vasculitis database and anonymised NHS patient data and you have the ingredients of a formidable diagnostic machine.

Doctors with the necessary knowledge and comprehensive experience and understanding which gives them the ability to consistently and reliably recognise and diagnose rare diseases do exist but they are few & far between, so they are in great demand. For we humans, it is very difficult, probably impossible, to transfer a lifetime's accumulated

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knowledge and experience to another human being. But for an “educated” machine this is no problem. Machine learned knowledge and experience can be readily shared between machines, and unlike humans, machines don’t forget, so the learning is both cumulative and it can be shared. So someone with a smartphone or a laptop in the remotest corner could have access to the most sophisticated and up to date diagnostic “mind” on the planet.

But all this would cost quite a bit of money to develop & set up. Not the sort of money that Vasculitis UK has in its coffers. Cancer Research UK recently dedicated £100m to a project. The UK government could dedicate £1bn to such a world changing project – far more rewarding (and much cheaper) than Crossrail or HS2. Or maybe the Bill & Melinda Gates Foundation could develop it as an “open” free to use gift to humanity. Google Corp do have a philanthropic division and access to the “Deep Mind” computing system. If there was a will somewhere there would certainly be a way to be found. But what about all those redundant doctors, who would probably be quite hostile to having their traditional role and power usurped? They could concentrate on what they should be doing best; talking to and understanding patients. Humans prefer talking to humans

rather than machines, so doctors could take on the role of “interfacing” between man and machine, much as in ancient times priests and mystics interfaced between man and the gods. After all, most of modern medicine still has its foundations in the teaching of Ancient Greece, Rome and Islam, most notably Hippocrates, Socrates and Asclepius.

ANCA

AI - as discussed above, is now being used by some labs to interpret the results of ANCA assay. However, doubt has been cast on the reliability and value of straight ANCA results as it produces too many false positives. Conversely a negative ANCA reading does not rule out vasculitis. This confuses doctors, especially the less experienced. The anti-proteinase and/or anti-MPO reading is possibly more reliable, but in the absence of positive PR3 or MPO ANCA, it is the clinical diagnosis which should guide treatment. Biopsy and other indicators can be more reliable. If patients are not confident that they are getting appropriate advice from their medical professionals they should seek a second opinion.

John Mills

From The Editors



Graham Baker

Hi Readers, well here we are again with another autumn edition. It only seems like spring was just here, maybe a reasonably good summer helped that happen!

Graham, our joint editor is having to take a step back at present due to family commitments, his involvement over the last few years since we both took on this role, has been very beneficial, both to me and the charity as a whole but I’m sure you our readers will all wish him well during his time away and look forward to him coming back when he can.

Looking at all the fundraising pages and reading through the articles as they came in, it once again showed how busy you have all been by raising funds and awareness, which gives me a challenge each edition to capture it all as it happens. That same commitment and passion that drives you to get involved drives me, to help deliver these newsletters through the memory of my dear sister Clare who was suddenly taken away through Vasculitis back in 2010.

So keep up the great work that you all do because without you there is no content.

If you would like to contribute in anyway with this newsletter for future editions please contact me at: kevin@vasculitis.org.uk



Kevin Soper

Kevin

For information and advice about vasculitis you can Telephone - Email or if you prefer Write



john.mills@vasculitis.org.uk
susan@vasculitis.org.uk

Helpline

Post: John Mills
West Bank House, Winster, Matlock DE4 2DQ

0300 365 0075

Tim and Jamie Aim High to Assign Vasculitis to Room 101



Tim Moxley, Jamie Turley, family and friends walking from Caemarfon to Portmeiron on a 101 mile trek around the Llyn Peninsula from 23rd to 30th July to raise awareness for Vasculitis UK and try to assign Vasculitis to Room 101, in Memory of Lydia, Tim's wife who very sadly lost her life to vasculitis.

Here are some photos of their trip - they also took with them, a special guest, Winston the #Vasculitis Awareness Bear who also is featured on the front cover.

So far they have raised over £1500.



Des Winks Memorial Football Match



What an amazing game of football in memory of Des Winks. The final score was 9-5 to Des Winks FC, raising over £750 for Vasculitis UK

An entertaining game saw World XI take the lead within the 1st 10 minutes through Ian Laing, but Des Winks hit back with a close range header from Robin Dixon. World XI then edged in front once more to make the score line 2-1 through Lewis Coultas. Each team quickly exchanged goals to make the score line 3-2, Ben Slater's neat finish for Des Winks, then the World XI scored through Nicko Dunn.

Des Winks XI pushed on and found an equaliser in the form of Robin Dixon, who added a his second of the game after good work from Martin Wray on the right wing. Shortly before halftime came the goal of the game, with a lovely team move from Des Winks after several passes Martin Hadrick found Ben Slater on the left wing who picked out Robin Dixon in the centre who unselfishly dummed his shot to allow Alex Wray to fire in the at the back post. The halftime whistle was imminent when World XI struck back by a quality finish from Mikey Barker. Halftime all square at 4-4.

Both teams came out fighting in the second half and it was Des Winks who struck first through Tom Hicks who found space in the box to fire home. World XI then pushed on to try and find an equaliser but found it tough to get past the impressive Josh Neal and Carl Stephenson at the back. The continued attack left themselves exposed at the back. A through ball heading towards the prolific striker Robin Dixon was intercepted by a World XI defender but unfortunately for them, trickled into their own net making the game 6-4 and a 2 goal cushion for Des Winks. This had taken its toll on the opposition who quickly found themselves 3 goals behind when Ben Slater volleyed in his second of the game in the top corner making it 7-4.

Des Winks couldn't celebrate just yet as Mikey Barker grabbed his 2nd of the game with a neat finish at the near post, beating the impressive Michael Harland in goal, reducing the deficit to 2 goals. With 15 minutes to go, Des Winks looked impressive on the counter attack and when Ben Slater picked up the ball on the edge of the box, he turned his man and coolly slotted the ball in the back of the net to claim his hat trick and all but confirm victory. Traditionally, the game would be finished off with a goal from managing director Martin Wray who pounced on a spilled catch by ex Elgin City goalkeeper Johnny Smith, allowing Wray to tap home and complete the 9-5 victory over the World XI.

The Des Winks goals came from Skoda Salesman Ben Slater (3), VW Salesman Robin Dixon (2), Our accounts manager Alex Wray (1), Managing Director Martin Wray (1), occasional painter and decorator Tom Hicks (1), plus 1 own goal. The rest of the world goals came from Mikey Barker (2), Ian Laing (1), Lewis Coultas (1) and Nicko Dunn (1).

Some of Our Fantastic Fundraisers



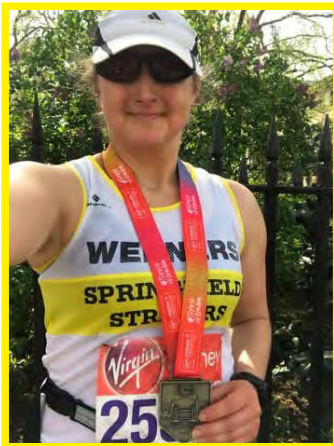
Tom Connors took part in a wing walk 9 days before his 79th birthday, in memory of his wife, Elizabeth who so very sadly lost her life to Vasculitis in August 2017.



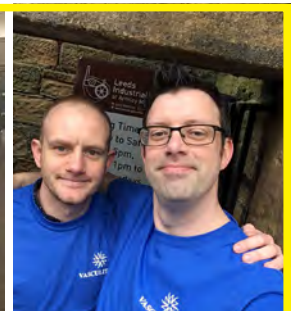
Flitwick Dolphins Channel Swim, raising over £12,000 for different charities, Vasculitis UK being one of the charities, raising over £2,000. To read more of their story please follow this link <http://www.flitwickdolphins.org.uk/index.php/squads/dolphins-swim-the-english-channel>



Congratulations to Janine Osbourne who ran the London Marathon, which is an amazing achievement as Janine has Vasculitis, Granulomatosis with Polyangiitis



Sarah Hammon ran the London Marathon on behalf of her friend Suzanne Morris who has Vasculitis in 4hrs 42minutes & 6 seconds



Elizabeth Draper and Charlotte Calderbank family, friends and work colleagues have raised over £2500 for Vasculitis UK. Including a match funding donation of £500 from Charlottes's employers, Provident Financial. The fundraising events included coffee mornings, cake and bake sale, office curling competition, works darts match plus Elizabeth and Charlotte ran the Leeds 10k back in March 2018, which for Elizabeth, who has Vasculitis was an amazing achievement.



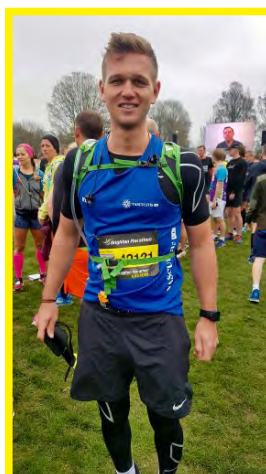
Chris Holmes (left) 200 mile cycle challenge for VUK



Ryan Cotton's 40th birthday celebrations - Ryan (left) raised £430 for VUK on behalf of his mum Lynne Colton who has had Vasculitis for many years.



Charity Soul Night for two charities organised by Jacqui Kelly Avril Starr on behalf of Susie Bower who has vasculitis.



Ryan Garnham - ran the Brighton Marathon for VUK on behalf of his mum Julie who has vasculitis



Colin Cole cycled from St David's in Wales to Ness point in Lowestoft on behalf of his wife Vanessa who has vasculitis and to fundraise and raise awareness for Vasculitis UK. Colin amazingly, cycled around 100 miles a day. (inset) Colin after completing his 400 mile cycle ride



Diane and Louise (left) completed The Three lochs Way for VUK in memory of Louise's mum they have raised over £1400

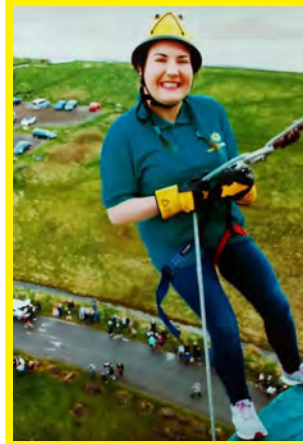
Some of Our Fantastic Fundraisers



Congratulations to Gill Partridge who ran the Brighton Marathon for VUK



Lynda Connors Cake and Bake Sale in memory of her Mum Elizabeth, who very sadly lost her short battle with Vasculitis, earlier this year



Danielle Potter completed the Leasowe Lighthouse Abseil in memory of her mum and for VUK. Sadly Danielle's mum lost her life to vasculitis in 2015.



Platinum Solutions Fundraising Day for VUK for Vasculitis Awareness Month



Karen Sherlock held a Fundraising and Vasculitis Awareness Evening in Matlock. She presented a short video clip explaining what vasculitis is before everyone was provided with a small buffet. She was supported by local Shop Keepers for food and raffle prizes.



David Newman from Vasculitis UK accepting a Cheque from Theresa on behalf of Little Waitrose Holborn.



Platinum Care Solutions Fundraising for Vasculitis UK



Martin Makin, ran the London Marathon, also an amazing achievement as Martin has vasculitis Granulomatosis with Polyangiitis



Bistro Ann Community Cafe, named after Ann Southern who has Vasculitis, have been fundraising for Vasculitis earlier this year



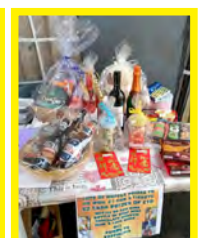
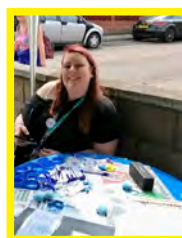
Georgia Upjohn ran the Edinburgh Festival Marathon on behalf of her brother Ben and for VUK.



Charity afternoon tea hosted by Mia & Darren Weston, Hannah Wheeldon and Adele Rafton, fundraising for Vasculitis UK, as part of their Great North Run Sponsorship



Jo King and family ran the Folkestone coastal 10k for Vasculitis UK



Kayla Jayne, who has vasculitis her mum and daughter held a Vasculitis Awareness stall in their home town in Alfreton. Kayla also raised just under £200 for Vasculitis UK.

Takayasu Arteritis: research update and new horizons

Dr Kavina Shah & Professor Justin Mason

Hammersmith Hospital, Department of Rheumatology

Takayasu arteritis (TA) is an inflammatory disease of the large arteries (large vessel vasculitis) that can lead to narrowing and blockage of arteries, or less frequently dilatation of the arterial wall and aneurysm formation (<http://www.vasculitis.org.uk/about-vasculitis/takayasu-arteritis>). TA particularly affects the aorta (the main artery taking blood from the heart to the rest of the body) and its branches, which supply the brain, heart, limbs, kidneys and intestines. The pulmonary arteries which send blood to the lungs may also be affected. TA is a rare disease affecting young people, with preponderance for females. There are 0.7-1.5 new cases per million people in Europe per year, with an average age of onset of 23 years. Presenting symptoms include fatigue, weight loss, night sweats, fevers, joint and muscle pains, light headedness, neck pain, cramping of the limbs, chest pain and general malaise. The diagnosis is made by combining symptoms with clinical examination, blood results (typically elevated inflammatory markers ESR and CRP), and a variety of scanning techniques including ultrasound, CT angiography, MRI angiography and PET-CT. Why a specific individual develops TA is unknown. However, it is likely to be the consequence of environmental factors and a susceptible genetic background. Although it is postulated that infection precipitates the disease process, this remains unproven.

Treatment aims to improve symptoms and prevent any further damage and/or scarring to the blood vessels. To reduce active inflammation in arteries, steroid therapy (prednisolone) is initiated in combination with steroid-sparing immunosuppressant tablets such as methotrexate, azathioprine or mycophenolate mofetil. In very severe disease, when urgent treatment is required, intravenous cyclophosphamide may be recommended. In 2016, NHS England published a commissioning policy for the use of tocilizumab for Takayasu arteritis. Tocilizumab is a biologic therapy. It is an antibody which blocks the action of an inflammatory protein called interleukin-6 (IL-6). This action of tocilizumab decreases inflammation and helps prevent damage to the arteries. NHS England permit the use of tocilizumab in patients who have not achieved control of disease despite the use of first and second-line treatment including steroids and disease-modifying therapies such as cyclophosphamide, methotrexate, azathioprine and mycophenolate for a minimum of 6 months. Tocilizumab is first given via an intravenous infusion, and subsequently via injections under the skin every week, starting 28 days after the initial infusion. After 6 months of treatment, a CT or MRI scan of the aorta is carried out to determine the response to tocilizumab. In our experience at Hammersmith, 14 TA patients have been treated with tocilizumab. They have shown an excellent response, with the majority of patients demonstrating an improvement in the level of inflammation in the blood as well as reduction in arterial wall thickness on imaging. These responses then allow a reduction in their

steroid dose. Two patients had to switch from tocilizumab to other biologic treatment, one because she had concomitant inflammatory bowel disease and another as the TA was deemed not to be controlled on tocilizumab. These patients were switched to infliximab (another type of biologic treatment). The average prednisolone (steroid) dose before the prescription of tocilizumab was 12 mg daily and fell to 4 mg per day (12 months after starting treatment). This represents a significant improvement and substantially reduces the risk of unwanted steroid side-effects. Four out of 14 patients managed to stop steroid therapy within 12 months of starting tocilizumab.

At Hammersmith Hospital, Justin Mason, Professor of Vascular Rheumatology runs a tertiary large vessel vasculitis service. He has built a cohort of over 150 TA patients. Referrals are received from national and international institutions for reasons including requests for a second opinion, for confirmation of diagnosis due to lack of optimal imaging techniques elsewhere, for diagnostic uncertainty, treatment challenges and patient preference. The patients are typically followed up twice a year in the clinic and are monitored by clinical assessment, blood tests and imaging to ensure response to treatment.

As TA is such a rare disease, and so many questions about it remain unanswered, it is imperative to conduct high-quality medical research in order to improve outcomes for patients. The research effort requires the considerable help and forbearance of the patients. The research programme at Hammersmith Hospital receives funding from the Imperial College NIHR Biomedical Resource Centre. The principle aims are to identify underlying causes of the condition, to understand its natural progression, to develop new blood tests/imaging approaches to aid both disease monitoring and to measure responses to treatment. The ultimate goal is to develop new treatments that avoid steroid therapy and its associated side-effects.

Research-led changes in the management of Takayasu arteritis

- Use of non-invasive imaging in a large cohort of patients has allowed us to establish that a combination of positron emission tomography (PET) imaging and either magnetic resonance (MRI) or computerised tomography (CT) imaging is the most effective way to diagnose TA.
- Serial studies of MR imaging of patients attending the clinic has demonstrated that MRI is a safe and effective way to monitor disease and the response to treatment. We have also developed a novel scoring system for MRI scans for use in future clinical trials.

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- Collaboration with our vascular surgery colleagues has helped us to define protocols to improve the outcomes of surgical intervention and angioplasty in TA.
- In collaboration with TA specialists in Italy, we have conducted studies that have: (i) helped with interpretation of PET images in TA patients with artificial arterial grafts, and (ii) shown how studying matched PET and MR imaging of individual arterial lesions might identify those patients most at risk of worsening disease.
- Analysis of blood samples from >100 TA patients has identified microscopic particles that might help to identify those patients with otherwise undetectable disease activity.

Current research projects

- In collaboration with colleagues in the USA we are contributing to a multi-national effort to identify genetic contributions to the development and outcome of TA.
- We are seeking funding for a detailed analysis of plasma samples from patients with TA, to address the urgent need for new biomarkers to help in diagnosis and in the assessment of response to treatment and prognosis. This work will be done with col-

leagues from centres including Cambridge, Southend, Italy, Turkey and the USA.

- With cardiology colleagues we are exploring new methods for analysing coronary artery disease in TA, aiming to identify those patients most at risk of complications.
- Funding has recently been obtained to study new approaches for PET scanning in TA. We hope these will be more sensitive and help identify persistent disease activity.

Acknowledgements

We would like to thank all of our patients who attend the large vessel vasculitis service at Hammersmith Hospital, for their dedication and participation in the various research studies. You have made a major contribution to the field of Takayasu arteritis from developing the scientific knowledge base to understanding optimal treatment strategies and monitoring techniques. This has enabled us to enhance our expertise and to advise national guidelines and recommendations with the ultimate aim of optimising patient care and outcomes.

I have just read Vasculitis: Sick and Tired of Being Sick and Tired by *Sheri Schwar*

It is the personal story of Sheri Schwar who was diagnosed with Takayasu's Arteritis just after giving birth to her daughter. The writing style is very much a stream of consciousness rather than a more structured piece of writing. The book was recommended to me by a fellow vasculitis patient at the local meeting because my story echoes the authors.

I found the book thought provoking and informative, as well as there being parallels with the author's journey and attitude to life and mine. Schwar doesn't sugar coat her experience, nor does she add drama, she re-tells her experiences, medical, family life and the impact the TAK has had on her life and how she came to readjust to her diagnosis. She shares the trials and difficult times with TAK as well as the things she feels she has gained for her journey as a TAK patient with her very doctor a.k.a. "coach". I recommend this to anyone with TAK, or to give to others to help them understand one of the rarer forms of Vasculitis.

Suzanne Morris



VASCULITIS UK AGM and General Meeting April 2018

Trustees John Mills, Dorothy Ireland and Susan Mills and approximately 60 members including family and friends attended the 2018 AGM.



Dr Pani Gopaluni: is a PhD student working with Prof David Jayne in Cambridge. He discussed the different types of Vasculitis and causes of inflammation. He talked about the different treatments and maintenance for ANCA Vasculitis, also “how” to adapt these successful treatments for non ANCA types of Vasculitis. These treatments are currently on trial and researchers are especially looking at treatment for those who have failed conventional treatment. The ethos has changed now, so they are not just looking at the efficacy of the drug but the well-being of the patient and their quality of life.

Professor Peter Rutherford is part of the team at VIFOR Pharma developing Avacopan. He talked us through the way the immune system reacts and starts to go wrong. He also discussed testing drugs to suppress the complementary cells so preventing the Vasculitis becoming active.



He talked about the ongoing European study; so far only 20 patients, replacing steroids with Avocapan.

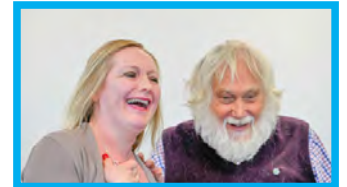
They still need to increase the test sample and see if there are any side effects. The new clinical trial is 300 patients and will report in 2019. Medical trials are important but so is the patients’ experience. He talked about a new Patient Reported Outcome tool which has been developed in Bristol; which may help for a better outcome and understanding for patients.



Dr Pani, Prof Rutherford and John Mills

New VUK trustee - Jayne Hardman: began her presentation with her party trick of

removing her nose. She says it’s been quite a journey. Jayne has raised the profile of Vasculitis with the general public and has very recently



appeared on TV programmes in magazines and newspapers. She says “I think I have had Vasculitis for 2000 days”. She had her nose problem from March 2012 to January 2018. She was diagnosed with Limited GPA but says there’s nothing limited about it as it affected other areas. Jayne would like to see that definition go



Acting Vice Chair Dorothy Ireland presented VUK’s possible plans for the future

Martin, Jayne, Zoi, Leanne and Angharad, Facebook Vasculitis friends finally got to meet face to face (see below)



FAMILY AND FRIENDS RELEASE CHARITY CHRISTMAS SINGLE

In our Spring newsletter tribute was paid to Christine Bean, who passed away in December 2017. Now her husband Clarry, along with family and friends, has recorded a song in her honour which will be released on Friday 7th December, in time for Christmas. 25% of all proceeds from the sale of the record will be divided equally between Prospect Hospice (where Christine spent her final weeks) and Vasculitis UK.

The single, entitled “Christmas (The Way It’s Meant To Be)” is an original song written by Clarry with a family friend, Andy Merryweather, which commemorates her in a positive and loving way. The recording features Clarry on lead vocals, with additional vocals from his son Danny and daughter Abby, as well as a backing chorus featuring many of Christine’s relatives and friends. Backed by talented musicians including co-writer Andy on piano and Wurlitzer, the song also features a string quartet.

Clarry says: “It’s a song that on first listen will resonate and connect with anyone who has lost a loved one. A song about love and bravery, a song of inspiration. Through her incredible attitude my beautiful wife inspired so many people: family, friends and medical professionals alike. It is our hope that this song will also have a positive impact on the lives of people who hear it and engage with the words, and that Christine’s spirit will be carried far and wide by its message. And of course we hope to raise a significant amount of money for the hospice and VUK.”



The CD version of the single features an exclusive second track, which is a remixed version of Christine’s 2007 recording of Sting’s “Fields of Gold”. It is particularly poignant that her singing was captured for all to hear, as for the last few months of her life she lost her voice completely, and was only able to communicate by whispering.

For further information, including a preview of the song and details of how to order or download a copy of “Christmas (The Way It’s Meant To Be)”, visit www.illuminatemylife.co.uk

#illuminatemylife

Hidden Disability Lanyard



Here I am on my flight from London Gatwick Airport last week with the ‘Hidden Disability Lanyard’ which helps airport staff to identify anyone who may need assistance but where it is not obvious. I collected mine from the airport before departure and it proved to be very helpful. On the way out there was a fairly long bus transfer from the gate to the plane and I was permitted to get on the bus with the speedy boarding passengers so that I could get a seat and then on the return journey - I was struggling big time to walk from the plane to passport control and

I was directed to the special assistance passport desk thus avoiding all the standing and queuing.
<http://www.vasculitis.org.uk/living-with-vasculitis/travel>

Lorraine Morton

Support Group Meetings

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



There are Vasculitis Support Groups in a number of regions in the UK. Please see the Support Group list on page 26. If there isn't a group in your area you might like to consider starting one. You don't have to start big with a venue and speaker, it could be a small gathering at home or in a local pub. This is an excellent way to meet and support other vasculitis patients, and starting small is much less stressful for the organisers.

All the Support Groups mentioned in the Support Group list are autonomous in that they are not "administered" by the Trust. However, it is one of the aims of the Trust to help and support the Support Groups.

East Midlands Vasculitis Support Meeting September 2018

Dr Reem Aljanyousi, Consultant Nephrologist, Leicester Hospital gave an excellent presentation discussing steroid regimens and withdrawal of steroids, on going clinical trials and ANCA vasculitis.

Nurse Specialist Alice Muir, Circle Nottingham NHS Treatment Centre, also gave an excellent presentation discussing living well with vasculitis, including fatigue and management of fatigue



Dr Reem, Alice and Kate



Bucks, Herts, Beds, Cambs and Essex Get Together

7 'Weggies' and partners from 5 Counties at Support Group meeting in the 'Feathers Inn at Wadesmill.



facebook



health unlocked



Spring West Country Support Group lunch in Dawlish

Thanks to Ian and Linda for arranging.

Fundraising in 2018

We've had another marvellous year of fundraising. The things people put themselves through never fails to surprise me. I am also very thankful to them as it helps with money towards research and raises awareness. The last 12 months raised over £85,000 through online donations. This year we started with dry January, abseiled a lighthouse, walked round 3 lochs, had a pensioner wing walk, climbed Snowdon, skydived, climbed the Atlas Mountains, a boxing match and a football match. We've had events too, an art exhibition, various fairs and coffee mornings and cake sales. Most of all, though, we have had runners and riders. So many bike rides over incredible distances. Marathons, the London and many others, half marathons and 10k races. Not just

here but in Greece and Istanbul. Our biggest event has been the Great North Run on 9th September. We paid for 20 places and they filled very quickly. In the end we had 22 runners. The stand out was Martin Makin who came 77th out of 58,000 and did much to organise the runners of Leicestershire to fundraise for us. He has now joined my team and will be advising me on how many places to try for next year. These will be posted on our website and Facebook group for people to apply for. I must also thank other members of the fundraising team: Susan Mills for organising the fundraising packs and posting them out, Emma Caldwell and Julie Scott who contact the fundraisers with me.

Kelly Jefferies who does incredible designs for posters for events, and Janice who sends the thank you cards. A Big Thank you to all our fundraisers, no matter what you raised you've increased awareness of our rare disease.

Dorothy Ireland



Janice Mather (The Newsletter proof reader) had a VUK Fundraising Table at the end of her garden for the bank holiday weekend in June. She makes and sells jewellery and donates the money to VUK

art@gravellybarn

We are a group of artists who have worked together for 11 years. Following a very successful final show at Ware College, Hertfordshire where we all studied art as mature students. In 2005 we decided to take on the challenge of organising exhibitions at Gravelly Barn in Braughing to promote our work together with other local artists.

We combine this passion with fundraising for numerous charities including the well-known national charities, the lesser known national charities and small local charities. Our website (www.gravellybarn.com) gives details of the exhibitions we have staged and the charities we have supported.

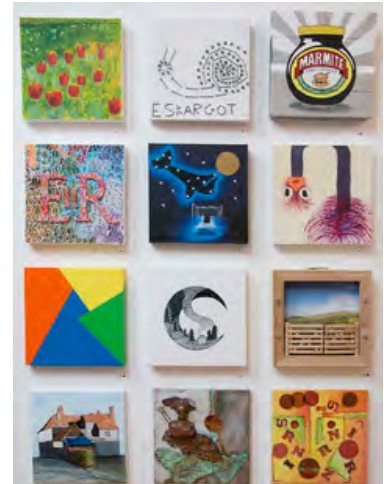
To date we have raised well over £100,000. This is the second time we have raised money for Vasculitis UK. This year at our 'Choice Matters' exhibition. This exhibition is based on the same concept as the Royal College of Art postcard exhibition. The exhibition encourages artists of all standards to enter.

Each artist purchases a 12" canvas for £10 this can be completed in any medium and they are all hung and sold anonymously for £45. Several artists with vasculitis exhibited. We raised £12,000 for our chosen charities including Vasculitis UK. We were able to donate £1,500 to Vasculitis UK.

The reason we chose Vasculitis UK is that my daughter was diagnosed nearly 3 years ago with EGPA (Churg Strauss), she is a young mum with 4 daughters. To everyone's surprise number 4 was born last November just six weeks after she became aware that she was pregnant. We are very pleased to say that both mother and daughter are doing well. She had amazing support from the Addenbrooks team to see her through what was the most traumatic birth she has had.

We have found a lot of support both from the Vasculitis UK website and the Facebook page so useful. When one has a rare disease it is comforting to know that one is not alone in this difficult situation

Our next exhibition is our Christmas exhibition which is being held at Gravelly Barn between November 15th and 18th.



Incontinence and Cerebral/CNS Vasculitis By Vivienne Dunstan

I'm a volunteer for Vasculitis UK, helping with queries on the Facebook and Health Unlocked groups for eight years. I have been living with cerebral vasculitis since 1994, starting when I was aged just 22. Anyway I was struck that in a recent query about cerebral vasculitis and its presentation four people initially responded with their experiences, and of those three people (i.e. 75% at that point), including me, mentioned having significant bladder and/or bowel incontinence. This isn't unique: I've known many patients over the years with brain forms of vasculitis report struggling with bladder and/or bowel incontinence, even if the exact percentage affected would be hard to quantify, and I don't think has ever been properly estimated.

I'm really conscious that this is an aspect of this one in a million form of vasculitis that is grossly under appreciated by medics, so they don't always realise it can be caused by the disease, or understand treatments that can help, or refer people on to urologists for more investigation and help. Nor do they usually think in terms of arranging for free pads to be supplied to people (I've had to wear incontinence pads permanently since my early 20s because of this). Nor is incontinence usually mentioned as a symptom in lists of symptoms (often rather vague to be honest, certainly from the patient viewpoint) written by medics writing about this particularly rare form of vasculitis. And it makes me angry! I've helped so many other patients over the years with cerebral/CNS vasculitis who're distressed and struggling with incontinence, but not getting the help from medics that they should. And I want that to change. I'd like medics supporting cerebral/CNS vasculitis patients to have a better awareness of this potential aspect of the disease, so the patients affected are better supported.

Of course incontinence problems aren't an issue for every single patient with this form of vasculitis. Similarly there can be other causes for incontinence, such as urinary tract infections (though these would normally be temporary) or interstitial cystitis. But sometimes vasculitis affecting the brain can cause continence problems. And medics need to be aware of this, and investigate it and treat it accordingly. It can sometimes be a sign of increased vasculitis disease activity, needing more immunosuppression. And there are treatments that can often help with the incontinence, for example anti-spasmodic drugs.

So that's my plea. This is very much a personal opinion piece. I'm not a medic, though I do have a PhD. I'm just trying to raise awareness of one of the most poorly recognised symptoms of vasculitis, which can be extremely distressing for patients, and isn't always addressed properly by medics. Please change this! Thank you.

VASCULITIS FUNDING

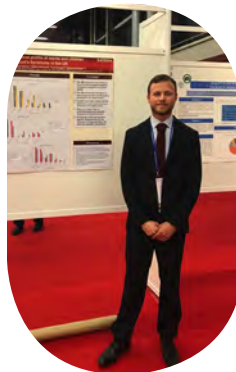


Sam Myers is a junior doctor at the North Middlesex University Hospital, London. He is very passionate about rheumatology and research into systemic, inflammatory diseases. He has been researching a rare inflammatory disorder called Behçet's Syndrome. He went to present this research at the Annual European Congress of Rheumatology (EULAR) conference in Amsterdam this year. This conference is one of the largest and most prestigious rheumatology conferences in Europe.

EULAR 2018:

My fascination for rheumatology stems from the holistic way one must treat these patients. Nearly every organ system can be affected in these complex diseases. Therefore, it is vital that rheumatologists regularly update their knowledge about these diseases and their treatments. This is why it is so important to attend conferences to discuss new developments and techniques with leading clinicians in the field: allowing our patients to overall benefit.

The research presentations that I went to were fascinating. I met clinicians who had dedicated their lives into trying to solve a small piece of the disease puzzle. As only a small, but crucial finding of a disease process, can unlock an array of different treatment options for patients. With advances in the field developing rapidly and biological therapies revolutionising the treatment of inflammatory disease, now is a very exciting time to join the specialty.



(pharma companies told us about the new drugs available through Virtual Reality !)
After reading countless research papers from these clinicians, it was so inspiring to finally meet these people in the flesh and discuss their work. My favourite was Dr John Stone from Harvard University, who presented his cutting-edge trial of a new biological medication given to patients with Giant Cell Arteritis with promising results.



Behçets Syndrome:

My research looked at Behçet's Syndrome in the UK, comparing the clinical features in both adults and children. There are very few studies that have looked at the differences between these two cohorts as it is a rare syndrome in the UK. Our study is the largest to date. We discovered a very different clinical profile of the disease that presents within the UK child cohort. This could completely change the way Behçet's Syndrome is diagnosed in the UK and perhaps elsewhere.

Our research was very well received and generated a lot of interest at the conference.

I am incredibly grateful for Vasculitis UK in supporting me to present my research at EULAR. Thank you so much for this amazing opportunity.

Sam Myers EULAR 2018



FOR PROFESSIONALS



Treatment for vasculitis often involves chemotherapy immunosuppression such as cyclophosphamide or monoclonal antibody therapy such as Rituximab. For nurses to administer these treatments safely specific

advanced knowledge, training and competence must be achieved and maintained. Formal training programs can be difficult to access, take many weeks to complete the theory component and even longer to achieve practical competence. Courses are expensive and are specifically intended for cancer care and are not targeted to vasculitis specific management.

I am very grateful that Vasculitis UK has supported me to devise a specific training program including competency assessment for registered nurses to administer treatments specific to the treatment and management of vasculitis. I aim to complete this by autumn 2019 to be submitted as my dissertation to complete an MSc at Chester University.

This will be a work based project commencing in September 2018 that will facilitate strategic developments in the care of vasculitis patients, utilising knowledge and skills gained through

theoretical study to develop, support and enhance clinical care. It will also provide a mechanism that enables higher education to work in partnership with external organisations to design and deliver a service which will meet specific needs efficiently and economically.

This seminal programme will facilitate the delivery of high quality, safe vasculitis care and may provide an opportunity for patients to receive treatment and therapies not currently available in some centres, for example intravenous administration of cyclophosphamide when currently only the oral preparation can be given.

It is intended that as a result of this dissertation a comprehensive training package will be produced in a format that can be utilised by any vasculitis service.

With luck, a good wind and a lot of hard work over the next academic year I will complete my MSc and be able to share with you all the details of this vasculitis treatments training program next autumn.

Sarah Hardy

Vasculitis Advanced Nurse Practitioner
Royal Liverpool & Broadgreen Hospitals University NHS Trust

CULITIS UK

Vasculitis U.K. and the British Society for Rheumatology are working together to offer 5 "Vasculitis Fellowships".



Successful applicants will experience 3 days of intensive education about all types of vasculitis and will get first hand practical experience working in clinical sessions with a leading expert in vasculitis.

My experience as a WG patient



At just 13 years old, my doctor kept telling me that all I had was a cold and that I should go back to school and carry on taking my inhalers, for what they thought was asthma. But one night I could barely catch my breath and the strong inhalers were making me dizzy, my Mum thought enough was enough.

Luckily at the time my Dad had a job, which meant we were all entitled to private health care. My Mum insisted that we go private, just to get some answers. I was seen quickly and had a blood test: it came back to reveal that I had Wegener's Granulomatosis. I don't remember much about that appointment, other than running out of the doctor's room crying. The nurse found me and tried to calm me down and explain more clearly. All I took away from the appointment was that I would have to take tablets for the rest of my life and I thought this was the worst thing in the world. I was wrong.

I immediately began treatment on high courses of steroids, antibiotics and immunosuppressants, which included Azathioprine, Methotrexate. At 15 years old, my bones were deteriorating and so the doctors put me on medication to prevent me from getting Osteoporosis. This was very worrying as a young teenager, but my bones could later improve because I was young.

My health was up and down, but no real signs of improvement. At 16 years-old, one day I found that I was struggling to breathe, I had started to turn blue and I nearly collapsed. Luckily, my consultant was there and rushed me straight to hospital where I was admitted overnight with oxygen and on observation.

Although this was my first hospital admission since my diagnosis, it definitely wasn't my last.

My family and I had to take the risk at 16 years-old that I should immediately undergo a more vigorous course of chemotherapy (Cyclophosphamide) to hit WG hard and to relieve my symptoms, but it wasn't a cure. The drugs came with high risks; such as not being able to have children and having my eggs frozen wasn't an option because I was too young.

At 19 years-old my Mum had done some research and found out about a weekend seminar on Vasculitis in Cambridge. We met expert consultants from Addenbrookes Hospital in Cambridge and I asked for a referral to the hospital as quickly as possible to be cared for by Dr Jayne and Dr Sivasothy, At my appointment with Dr Sivasothy, respiratory consultant, he told me that I will need to have surgery on my trachea immediately, which may result in me having a tracheotomy, otherwise I will die. At the time I thought he was just being melodramatic and I didn't want the embarrassment of having a hole in my throat!

Once it had hit home, just how severe my health was, I agreed to the surgery and woke up and was relieved to find that I didn't have a hole in my throat, nor was I in ICU! I cried

with relief! I couldn't talk at the time, but I scribbled down on a board to the nurse and surgeons, 'Thank you'.

After having my life-saving surgery, I went on to have further laser surgeries on my trachea with steroid injections, and I was finally able to breathe normally and to enjoy life as a young adult. Life was good, I was building up my confidence from ballooning out after years of steroids and I was going on holidays with friends. Doing what normal 20 year-olds do.

The only symptom I had that bothered me was a watery right eye, and it did knock my confidence a little as it looked like I was crying most of the time, but compared to how things were, I just got on with it.

I met a guy called Nathan from an online dating website and it was going well, we had been seeing each other for nearly a year, but my eye was getting worse and of course, as it was constantly watery, it got infected.



Literally overnight, my eye had swollen to the size of a golf ball and I couldn't open it properly and I was in excruciating pain. My Mum rushed me to Addenbrookes hospital where I was admitted straight away.

I hadn't wanted to see anyone as the swelling was not just in my eye at this point, but it was all around my face and I felt hideous. After 48 hours of worrying if my eye would explode and I would be blinded, I had the surgery and it was successful. When I came around afterwards, I was able to properly see not just my new boyfriend Nathan, but also my Dad and two brothers. At least the swelling had gone down.

I am now 31 years old and I have been in remission for over eight years and my consultants believe that if you are in remission for over five years, then you are cured! I finally have a new lease of life; my then boyfriend Nathan, has become my husband and we have a one-year-old baby girl called Rebecca. Last year I was able to run the Great South Run and I'm off the medication.

I wanted to encourage other WG patients that there is light at the end of the tunnel and it will get better.

Fiona Stanton



Ain't No Mountain High Enough

On 26th June, Christina (who has Vasculitis) and one of her friends climbed and descended Snowdon to raise money for Vasculitis UK. A couple of hundred was raised by friends and family, to support the pair who climbed 975 metres in 29°C heat to reach the top.

What makes this adventure more impressive is that Christina was only 7 days post surgery

and relies solely on a feeding tube for hydration and nutrition purposes.

Whilst ticking off two challenges on Christina's bucket list, they recorded through photos their journey up and down Snowden for everyone else to enjoy.'



Gordon Brown and Craig took part in the Great North Run, supporting Vasculitis UK.

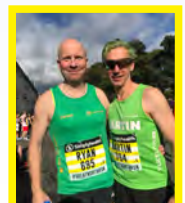
They chose Vasculitis UK as it's a charity

that is close to them and in particular for one of their good friends - Joel. Joel's mum, Lynne, sadly lost her battle, due to complications related to the illness, earlier this year; a condition she worked so hard to raise awareness of and supported other sufferers whilst working tirelessly to support and grow the Vasculitis UK charity. So far they have raised £900, you can read their full story and still donate at:



<https://www.justgiving.com/fundraising/geordie-cal-smash-the-gnr>

Martin Makin sent us the Images below from the recent Great North Run. Martin along with 21 other runners for VUK competed in this fantastic event. Martin came 77th out of around 58,000 runners...76 places behind Sir Mo, well done to all those involved.





ANCA Associated Vasculitis and the Kidney

Mark E. McClure (left), Vasculitis Research Fellow, Addenbrooke's Hospital, Cambridge
 Rachel B. Jones (right), Consultant in Nephrology and Vasculitis, Addenbrooke's Hospital, Cambridge



Key Points

- Each kidney has approximately one million highly specialised filtering units called glomeruli. Each glomerulus contains a bundle of tiny blood vessels which are very vulnerable to attack in ANCA associated vasculitis.
- Kidney involvement is very common in ANCA associated vasculitis
- Diagnosis of kidney involvement is made from blood tests, urine tests and often a kidney biopsy
- Treatment usually involves high dose steroids combined with immunosuppressive medications such as cyclophosphamide or rituximab. In severe cases, a treatment called 'plasma exchange' may also be used to help remove ANCA from blood.
- Patients with vasculitis in the kidney may have normal kidney function, or mild-moderately reduced kidney function, or sometimes complete kidney failure (known as end stage kidney disease (ESKD)).
- Some patients may need dialysis treatment if their kidney function is too low. This is often temporary as kidney function can improve with prompt treatment for the vasculitis. Unfortunately, the kidney function does not return in some cases and these patients will require either long-term dialysis treatment or a kidney transplant.

Introduction

Vasculitis is inflammation and damage to the walls of various blood vessels. The word vasculitis is derived from the Latin "vasculum" = vessel + "- itis", inflammation. Another term for vasculitis is angiitis. Each of the vasculitis diseases is defined by certain patterns of distribution of blood vessel involvement, particular organ involvement, and laboratory test abnormalities. ANCA associated vasculitis includes three diseases, each with a rather long name: 1) granulomatosis with polyangiitis (GPA, previously called Wegener's), 2) microscopic polyangiitis (MPA), and 3) eosinophilic granulomatosis with polyangiitis (EGPA, previously called Churg-Strauss). All three diseases cause inflammation of small blood vessels and are associated with a key protein factor in the blood called 'ANCA'. Because small blood vessels are found all over the human body, any part of the body can be affected. The kidneys are full of small blood vessels and are the most commonly affected major organ(1).

Where are the kidneys and what do they do?

There are two kidneys in a human body, each about the size of a large potato, located on either side of the spine, just below the rib cage.

The major functions of the kidneys are as follows:

- Remove waste products from the body in urine
- Regulate the body's fluid balance to prevent dehydration or excess water retention
- Release hormones that regulate blood pressure
- Produce an active form of vitamin D that promotes strong, healthy bones
- Control the production of red blood cells

Each kidney contains about a million functioning units called nephrons. A nephron consists of a filtering unit of tiny blood vessels called a glomerulus attached to a tubule. When blood enters the glomerulus, it is filtered (or sieved) allowing small waste products to be released with fluid from the blood, which then passes along the tubule. In the tubule, chemicals and water are either added to or removed from this filtered fluid according to the body's

needs, the final product being urine which flows from the kidney through a pipe called a ureter into the bladder.

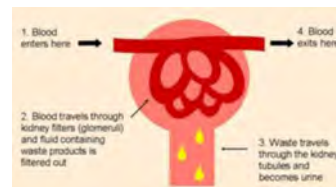


Figure 1: A glomerulus

How does vasculitis affect the kidneys?

The kidneys are packed with millions of highly specialised tiny blood vessels called glomeruli (plural for glomerulus). These are very vulnerable to attack in ANCA vasculitis and can become inflamed, swollen and can even burst. This is called glomerulonephritis. When this happens, blood and proteins frequently spill into the urine. Luckily, we have so many glomeruli that we can afford to lose a few without any problems. But if enough glomeruli are damaged, then the overall function of the kidneys is reduced.

How quickly can it progress?

Kidney vasculitis can vary in severity. Some patients have a very aggressive kidney vasculitis known as rapidly progressive glomerulonephritis (RPGN) that can lead to a rapid decline in kidney function and the need for dialysis within days and weeks if left untreated. Conversely, some patients have normal or only very mild reduction in kidney function.

How common is kidney involvement in ANCA vasculitis?

Kidney involvement is very common. It occurs more frequently in MPA (90%) and in GPA (70%) and less frequently in eGPA (25%) (2).

How do I know if the kidneys are involved?

Symptoms

Symptoms of kidney failure are non-specific and often mixed up with other symptoms of vasculitis, including tiredness, lethargy and loss of appetite. There is very little nerve supply to the kidneys so pain is rarely a feature. Some patients may have no symptoms at all.

Signs

Brown, tea-coloured urine from blood leaking into the urine may be seen. However usually the blood in the urine is invisible to the eye and is only identified when urine is tested in the clinic.

Blood tests

Creatinine is a waste product in your blood that comes from muscle activity. It is normally removed from your blood by your kidneys, but when kidney function is reduced, the blood creatinine level rises. Your doctor may talk to you about creatinine level. Another more accurate measure of your kidney function is Glomerular Filtration Rate (GFR), which is a calculation that takes into account your age, sex, ethnicity and creatinine and provides an estimated percentage of normal kidney function. More than 60% GFR is considered to be satisfactory. When GFR is less than 10%, dialysis is usually necessary.

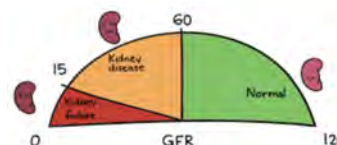


Figure 2: Levels of Glomerular Filtration Rate (GFR)

Urine tests

Urine can be easily tested in the clinic for several factors including markers of urine infection, sugar (glucose) and for blood and protein. The presence of blood and protein in

Continued on Page 19

the urine is abnormal, and should alert doctors to the possibility of active vasculitis or other inflammatory diseases affecting the glomeruli in the kidneys. Urine can be sent to the laboratory for further analysis. Under the microscope the urine red blood cells look 'dysmorphic' or misshapen. The actual amount of protein in the urine can be calculated as either protein creatinine ratio (PCR) or albumin creatinine ration (ACR). The amount of blood and protein in the urine usually reduces as the vasculitis is treated, but in some patients, does not go away completely and persists at a low level. Patients with vasculitis normally have their urine tested at each clinic visit to check for changes in the amount of blood and protein in their urine.

Kidney biopsy

If there is any suspicion that vasculitis is affecting the kidneys, a kidney ultrasound scan will usually be performed to check that the kidneys are normal size and shape, followed by a kidney biopsy under local anaesthetic. ANCA vasculitis causes a distinctive pattern of inflammation when examined under the microscope, so not only do biopsies help with the diagnosis of vasculitis, the extent and pattern of inflammation and scarring can be a useful tool in predicting how much improvement in kidney function is likely to occur with treatment, and the likelihood and extent of long-term kidney damage (3).

Treatment of renal vasculitis

The treatment of kidney vasculitis comprises an 'induction phase' of 3–6 months to rapidly reduce inflammation and prevent permanent organ damage, followed by a longer 'maintenance phase, or relapse prevention phase' once remission has been achieved. Initial induction treatment involves the use of high dose steroids in combination with immunosuppressive drugs; cyclophosphamide and/or rituximab. If the level of kidney function is very low (creatinine >500µmol/l), an additional treatment called plasma exchange is often used. Once remission is achieved, less intensive treatment is used with low dose steroids, and either azathioprine or intermittent rituximab infusions for two years, or longer if a patient is at high risk of relapse.

What about renal relapses?

Relapses in the kidney are identified by the recurrence or increase in level of blood in the urine (usually non-visible – identified on urine dipstick testing) and worsening renal function on blood tests. Fluctuations in the amount of protein in the urine are not good indicators of active disease, and are usually related to chronic damage and scarring. Relapses are treated with the same approach as for a newly diagnosed patient, although rituximab is increasingly being used, to avoid repeated courses of cyclophosphamide.

End Stage Renal Disease (ESRD) and Dialysis

Approximately 20% of patients with renal vasculitis develop end stage renal disease (ESRD) within the few years after diagnosis, which means that they need dialysis and maybe considered for kidney transplantation. A smaller proportion of patients require dialysis immediately when their vasculitis is first diagnosed, of whom approximately 60% will be able to stop dialysis as their kidney function improves with treatment(4). Dialysis is a treatment that removes wastes and excess fluid from the body, either directly from the blood, using a haemodialysis machine (usually in hospital) three times a week or from the fluid in the abdomen every day using peritoneal dialysis at home. The majority of patients with renal vasculitis do not need dialysis because treatments are effective at stopping the vasculitis process, and kidney function shows some improvement in many patients. However, the majority of patients are left with some degree of impaired kidney function known as chronic kidney disease, CKD. Because CKD is associated with high blood pressure and risk of cardiovascular disease, patients with CKD often receive blood pressure and cholesterol lowering tablets.

Predictors of ESRD in ANCA vasculitis

The risk of ESRD is largely determined by the degree of renal impairment at the time of diagnosis. Generally, the higher the initial creatinine level, the greater the chance of reaching ESRD. The worst prognosis is usually seen in patients who required dialysis near diagnosis (6)disease relapse, and death in patients with ANCA small-vessel vasculitis before and after end-stage renal disease (ESRD). The kidney biopsy pattern is also a reliable predictor of ESRD. The worst outcomes are associated with a heavy scarring (sclerotic) appearance that is usually accompanied by irreversible kidney impairment. Other risk factors for the development of ESRD include older age, resistance to treatment and renal relapses (7).

Kidney transplantation in ANCA vasculitis

For patients who are fit enough to undergo kidney transplantation, this is a good option for patients with ESRD secondary to renal ANCA vasculitis. However, there are no consensus

guidelines on renal transplantation in patients with ANCA vasculitis and practices vary between centres. A survey of transplant centres across Europe identified 107 renal transplant recipients with ANCA vasculitis. All consultants felt that vasculitis should be in remission at transplantation, 16% believed that ANCA should be negative pre-transplant and 40% felt that one should wait >12 months after remission before transplanting. Overall, 70% of the transplants were still working after 10 years (8)16% believed that ANCA should be negative pre-transplant and 40% felt that one should wait >12 months after remission before transplanting. Remission was defined by all as an absence of clinical symptoms of vasculitis, but three respondents (13%.

Recurrence of vasculitis in kidney transplants

About 10-15% of patients will have symptoms of vasculitis after a kidney transplant. Not all returning symptoms affect the kidney. Recurrence of vasculitis can occur but rarely cause loss of a transplanted kidney. If you look at all patients with ANCA vasculitis 10 years after their transplant, about 8% of them will have lost their kidney due to recurrence.

Summary

The kidneys are highly specialised organs containing millions of tiny blood vessels that are constantly filtering and regulating the contents of your blood. Unfortunately, these blood vessels are very vulnerable to attack in ANCA vasculitis. Prompt diagnosis and early treatment are the most important factors to improve outcomes. While most patients do not reach end-stage kidney disease, for those that do, kidney function can be supported by dialysis and for patients who are fit enough, renal transplantation is a good treatment option. Overall outcomes continue to improve and the development of more effective, less toxic treatments, undoubtedly will lead to even better outcomes in the future.

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Mark McClure, Rachel Jones

Well-being

Some great tips for being well

Foods that fight inflammation

Harvard Health Publication Updated: August 13, 2017 Published: June, 2014

Doctors are learning that one of the best ways to quell inflammation lies not in the medicine cabinet, but in the refrigerator.

Your immune system becomes activated when your body recognizes anything that is foreign—such as an invading microbe, plant pollen, or chemical. This often triggers a process called inflammation. Intermittent bouts of inflammation directed at truly threatening invaders protect your health.

However, sometimes inflammation persists, day in and day out, even when you are not threatened by a foreign invader. That's when inflammation can become your enemy. Many major diseases that plague us—including cancer, heart disease, diabetes, arthritis, depression, and Alzheimer's—have been linked to chronic inflammation.



One of the most powerful tools to combat inflammation comes not from the pharmacy, but from the grocery store. "Many experimental studies have shown that components of foods or beverages may have anti-inflammatory effects," says Dr. Frank Hu, professor of nutrition and epidemiology in the Department of Nutrition at the Harvard School of Public Health.

Choose the right foods, and you may be able to reduce your risk of illness. Consistently pick the wrong ones, and you could accelerate the inflammatory disease process.

You can Read the full article at: <https://www.health.harvard.edu/staying-healthy/foods-that-fight-inflammation>



I am a sixth form student currently studying Biology, Chemistry and Physics at A level. I was lucky enough to be selected to take part in a Nuffield research placement, where I researched Giant Cell Arteritis at Norfolk and Norwich University Hospital, with the help of Dr Mukhtyar. Dr Mukhtyar is a Rheumatology consultant who has a long standing interest in Giant Cell Arteritis.

Giant Cell Arteritis (GCA) is the most common vasculitis in people over 50. This disease causes inflammation of medium and large blood vessels, in particular the extra cranial branches of the carotid artery, but it may also involve the aorta and its major branches. This condition is often recognised by a new headache and raised inflammatory markers. Often patients may have difficulty in chewing their food (jaw claudication), symmetrical shoulder pain and stiffness (polymyalgia rheumatica).

It is known that this condition is kick started by the leaking of activated white blood cells from the very fine blood vessels in the walls of the arteries. We also know that patients with long-standing diabetes may get problems with micro-circulation (which is why they get problems with the circulation in their eyes, for example). We therefore hypothesized that patients with diabetes may actually have some protection against development of giant cell arteritis.

We looked the sugar levels (HbA1c) of 81 individuals with GCA and 162 age (matched by decade of life) and gender matched controls (individuals who were referred for consideration of GCA, but the final diagnosis was not GCA). We found that the HbA1c was higher in individuals who did not have GCA. When we did a test that compared observed vs. expected numbers (Chi-squared test) we found that we observed 47% less patients with diabetes than expected amongst those with GCA.

We concluded that there is a link between diabetes and GCA that needs further exploration and that this relationship may actually help clinicians when making a diagnosis of GCA.

Mia Dale

Practical guide to Infection

when taking immune suppressing medication.

There has been a lot of flu and other infections around in this last year. Vivienne Dunstan thought it would be a good idea to write an article on what that means for patients with Vasculitis whose immune system has been dampened down with immunosuppressant drugs.

The majority of patients with vasculitis are on immunosuppressive drugs, such as prednisolone, Cyclophosphamide, Rituximab and Azathioprine. Whilst these medications are necessary to treat the vasculitis they also carry risks, one of which is the increased risk of having an infection. One of the immune system's jobs is to fight off infection. Different types of infection can be caused by bacteria, viruses and fungal organisms. Immune suppressing drugs can increase the risk associated with all of these.

We don't want to scare anyone. The purpose of this article is to highlight these risks and give patients practical information. Knowledge is power. We will often have to explain to NHS staff about our increased risk, especially if they aren't knowledgeable about vasculitis and the drugs we take.



Influenza (Flu)

'Flu can be potentially life threatening and serious, particularly for people with underlying health problems - it's not the same as before we developed Vasculitis. The best way to protect yourself is to get an annual 'flu

vaccination, but you must discuss this with your consultant first. It will be safe for the majority of people with vasculitis to have the 'flu vaccine each year. These are for the " best guess " as to what strains of 'flu will be active, but they don't always get it right!

It is important to be aware that we can still get the 'flu. Symptoms to look out for include fevers and chills, aching all over, possible diarrhoea, breathing difficulties and a sore throat or cough. It is very important to seek medical advice from your GP. Telephoning is often better than going out and potentially spreading the infection to others. Sometimes anti viral medication can help and it is important to realise that 'flu can turn into pneumonia or other infections and you must seek help if you aren't getting better or are feeling worse. Two things that can help are paracetamol for fever and making sure that you keep well hydrated. Influenza is a virus; it is not treated with antibiotics.

Flu Vaccinations 2018/19

The fact that this year there are two different flu jabs on offer has caused some confusion so we decided to ask Prof Lorraine Harper for a definitive answer , she says those with vasculitis should have the "trivalent" version as this is likely to work better for people who are either older or have been immunosuppressed.

The other version is known as the "quadrivalent" type and offers protection against a wider range of virus's but is not likely to work as well for the above described groups.

As always please discuss with your vasculitis consultant but probably your GP as he/she is unlikely to fully understand the situation for vasculitis patients.

There is also a vaccine that protects against pneumococcal infections, which cause pneumonia. It is meant to last a lifetime but for some immunosuppressed patients, or those with chronic kidney disease may need it repeated. Again, you should check with your Consultant.

Bacterial Infections

These are caused by " bugs "and are usually treated with antibiotics. They can affect almost any organ but the main types of bacterial infections affect the lungs, urinary tract , sinuses, ears, throat and skin. If your vasculitis has affected your lungs, kidneys or sinuses then you may be at a higher risk of infection. Most infections are usually easy to treat but the medications used for vasculitis mean that we are at greater risk of "atypical " or "opportunistic " infections. These bugs may be rarer or resistant to normal antibiotics and may need special antibiotics, antivirals, or antifungals .

It is a good idea to hand in samples of sputum, urine or swabs of any skin breaks etc to be sent to the lab for testing before starting antibiotics to make sure that your doctor has prescribed the appropriate one to treat the infection. Check with your specialist nurse or consultant if you should stop taking your normal immunosuppressant medication when on antibiotics for an infection as the advice can be different for each patient. Be aware of the signs and symptoms of severe infection which is known as sepsis, these include confusion, shivering with a fever, passing a reduced amount of urine, cold hands and feet with a high temperature, fast heartbeat and breathing. These symptoms need to be taken very seriously and may require very prompt treatment, always stress to NHS staff that you are immunosuppressed and at greater risk of severe infection. If you feel your symptoms are not being taken seriously then ask the direct question " could this be sepsis " and ask the reasons why they think it isn't , especially if you ask them to write your questions in your notes and their response.

We hope this short overview of infection has been useful and welcome any feedback.

Vivienne Dunstan

(Dr Nina Brown Consultant Nephrologist, Salford Hospital Manchester)





VASCULITIS UK *2nd Charity Ball 2019*

I am so pleased to announce the date for the second Vasculitis Charity Ball 2019 which will be held on Saturday 2nd March, at the iconic Hilton Manchester Deansgate Hotel. The evening will commence with a drinks reception at 6.30pm in the Deansgate Suite Foyer, followed by fun and games in the Deansgate Suite where the event will take place. Whilst guests enjoy a delicious 3 course meal there will be a live singer to serenade the guests during their meal by one of Manchester's best live entertainers Rick Moorhouse. There will also be a raffle during the night with the chance to win some great prizes as well as a live auction taking place to bid for lots of fantastic items such as signed memorabilia, experience days or maybe an item from your favourite football team or idol.

Tickets for the event are now on sale at <https://innov8-conferences.co.uk/event/vasculitis-charity-ball/> and they are £50.00 per ticket or you can get a table for 10 at a reduced price of £450.00, which includes:

- Drinks Reception
- ½ Bottle of wine per person
- 3 Course Gala Dinner
- Live Entertainment
- The chance to be in the Raffle with some great prizes
- The chance to bid in the Live Auction on the evening

After the huge success of our first ever Vasculitis Charity Ball which took place in 2017 I am really excited to be organising this next Ball and looking forward to seeing everyone there on the night and raising money and awareness for the fantastic charity Vasculitis UK, who have helped so many families over the years.

Emma Caldwell
Director



Help Advice & Support

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

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

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

For all the latest information and news,

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

Interesting Meeting



As a change from Vasculitis UK, in August this year John and myself met in Sheffield for lunch with old friends, Professors Peter Rutherford and Ray Norton. Peter is the medical lead in rare renal disease for the Swiss pharma company Vifor. Vifor contributes towards the funding for the UKIVAS database and are the company behind Avacopan, which is currently being trialled as an alternative to prednisolone in treating ANCA vasculitis. Ray is a biochemist, now working in pharmacology at Monash University, near Melbourne, Australia. Ray's special field is exotic peptides derived from organic sources, initially from intestinal parasites, more recently from sea anemone toxins and currently from scorpion venom. Perhaps surprisingly, constituent organic chemicals derived from these complex toxins can turn out to have pharmacological applications in modern medicine. One of these peptides has been developed for use in auto-immune disease – multiple sclerosis. A possible use in treating vasculitis has not yet been explored. Other applications such as in pain control and rare renal disease are still under investigation.

The photo shows L-R, Myself and John Mills , Prof.Peter Rutherford & Prof Ray Norton.

Susan Mills

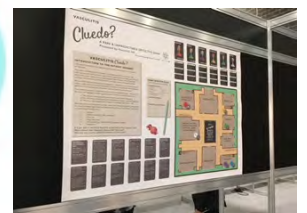
BSR CONFERENCE May 2018



This last spring, the British Society for Rheumatology held their 3 day Annual Conference in the beautiful Royal Albert Dock in Liverpool. This conference is attended by around 2,000 medical professionals.

Vasculitis UK were invited to have a stand at the conference, so for the 4th year running John and I set off for Liverpool and this time were accompanied by Suzanne Morris. Many of you will remember Suzanne as she created and designed the award winning Cambridge Rare Disease, Patient Journey poster competition and the VUK 2017 Christmas card.

The 3 days were extremely busy for the VUK stand and the interest in Suzanne's Cluedo Patient Journey Poster was amazing.



It was also the first year the Rare Autoimmune Rheumatic Alliance (RAIRDA) were invited to have a stand. This Alliance includes Vasculitis UK, Lupus UK, Scleroderma Raynaud's UK, BSR and the British Sjogrens Society. You can read more about RAIRDA if you follow this link. <https://www.rheumatology.org.uk/rairda>



Susan Mills



In Memoriam



Liverpool Charity & Voluntary Services made a donation of £1000 on behalf of the J.A. Shone Memorial Trust.

A donation of £154 was received in memory of the late Robert Edward Stanton of Flintshire

Donations totalling £576 were received in memory of the late Alan Roy Falkner of Northam, Devon

John Holmes of Sheerness, Kent donated £600 to vasculitis UK in memory of his dearly loved wife, Joyce, who sadly passed away in April 2016.

Donations totalling £193 were received in memory of Neil Emmett and a further £647 was raised Via JustGiving

Louise Jackson & her partner Diane walked the 34 miles of the 3 Lochs way in memory of Louise's mum, June Irving, who sadly died age 68 after a short battle with vasculitis. They raised £1522 to go towards vasculitis research.

We received a donation of £140 in memory of David George Ellis of Grantham who sadly passed away in January 2018, having won a battle with vasculitis but then falling victim to cancer.

A total of £925 was donated in memory of Jon Wingfield, whom many members of the online discussion groups will remember.

He was very keen on researching his type of vasculitis. Jon sadly passed away after fighting EGPA since 2013. He used to claim that he should be in the Guinness Book of Records for having 6 auto-immune disorders 1) alopecia, 2) Type 1 diabetes 3) asthma, 4) sarcoidosis 5) Addison's Disease and 6) vasculitis; Churg-Strauss Disease.

£494 was donated to Vasculitis UK in memory of the late Thomas Pilkington.

£50 was donated in memory of Stanley Sprague of Ilfracombe who had suffered from GPA (Wegeners) since 1992. He passed away in December 2017 age 85, having been married to Doreen for 62 years.

Funeral donations totalling £238 were received in memory of Mr John Dennis Richards of Swindon, Wiltshire

Donations totalling £200 were received in memory of David George Ellis of Grantham who passed away in January this year.

Funeral donations totalling £113 were received in memory of Ian Rylands of Llandudno.

A donation of £100 was received in memory of Bill Henshaw who sadly passed away in December 2012

Funeral donations totalling £316 were received in memory of Clifford Fitch of Ipswich, who passed away on January 5th this year.

Tim Moxley once again donated the proceeds of his book, "LCR" in memory of his much loved wife, Lydia, thereby donating a total of £200 this year .

Charles Henderson of Paisley in Scotland kindly donated £50 in memory of his wife Patricia, who passed away in April this year. Patricia suffered from Takayasu Arteritis for many years and more recently contracted Motor Neurone Disease. For several years Patricia was the Vasculitis UK contact person for the West of Scotland.

Donations totalling £285 were received in memory of the late Robert Simons of Alresford in Essex.

Donations totalling £515 were received in memory of Carol Roderick of Crawley, Surrey, who passed away on Sunday 18th April this year.

Funeral donations totalling £225 were made in favour of Vasculitis UK in memory of Gwenda Jean Cooper of Portsmouth, who passed away on 29th March this year.

Donations totalling £240 were received in memory of Mrs Catherine Anderson Potter of Hertfordshire who sadly passed away in May of this year.

Funeral donations totalling £105 were received in memory of Mrs Alexina Allinson of Hockley, Essex, who passed away in June.

Donations totalling £407 were received in memory of Adrian William Ball, of Mansfield Woodouse, husband of Valerie. He sadly passed away in April this year. Additional donations of £250 were made. These were the proceeds of a charity football match in his memory, held by the bus drivers of Mansfield Stagecoach.

Funeral donations to the value of £290 were made to Vasculitis UK in memory of Mrs J M Wheeldon of Cotgrave, Nottingham, who passed away in April 2018.

Following the funeral of the late Robert McCafferty of Lancaster, donations to the value £175 were offered to Vasculitis UK.

A total of £229 was donated to Vasculitis UK at the funeral of Mr Douglas Bower of Norfolk, who passed away in June this year.

Donations of £517 were received in memory of Mr Graham Jones, of Lichfield, husband of Sheila, who passed away on 16th July this year.

A funeral donation of £25 was received in memory of the late Roger Keys.

A funeral collection in memory of Robert Bruce Craig of Stockton, Worcestershire raised £149 for Vasculitis UK.

A collection at the funeral of Alexa McCluskey, wife of Bob McCluskey, of Aberdeenshire, who sadly passed away in July of this year due to vasculitis, raised £600 which was donated to Vasculitis UK in her memory.

Paul George Best passed away in July this year. A donation to Vasculitis UK of £50 was received in his memory.



Sarah Pierce of Halifax, tragically and suddenly passed away on the 23rd August 2018, aged only 49 years old, from Vasculitis, that developed without warning. Sarah's family and friends have, up to date, donated over £2400 to Vasculitis UK in Sarah's memory.

A funeral collection in memory of Antony Mark Royle of Cheadle resulted in a donation of £245 to Vasculitis UK

Donations & Fundraising

Margaret Robertson raised £224.50 by holding a Beetle Drive and giving a talk to a Ladies Club.

Dawn French of Ravenscar kindly donated £184.45 to Vasculitis UK

A donation of £50 was received from the Monday Club in Roundswell, Barnstaple, North Devon.

The students of Champion School & Lan-

guage College in Northamptonshire raised £195.21 for the benefit of Vasculitis UK.

Joan Knox of Perth kindly donated £100 to Vasculitis UK.

The Channel Swim Team of 2017 (see report elsewhere in this edition) raised an amazing total of £2194 for Vasculitis UK.

The students of Durham Trinity School & Sports College raised £75 which they

kindly donated to Vasculitis UK.

Noel Hickson of Bournemouth kindly donated £100 to Vasculitis UK.

A donation of £100 was received from Valerie Liesnham of Chandlers Hill in Hampshire.

Alastair Weatherston of Edinburgh kindly donated £100 to Vasculitis UK.



Donations & Fundraising



At a presentation ceremony with the Mayor of Bournemouth, the Rotary Club of Bournemouth donated £1,600 to Vasculitis UK. This represented the proceeds of the Annual Easter Saturday Quarter marathon which is held on Bournemouth Sea Front, organised by Bournemouth Eastcliff Rotary.

The Masonic Charitable Foundation "Relief Chest Scheme" kindly donated £500 to Vasculitis UK.

The boys of Sherborne School in Dorset held various collections within school over the past academic year. This resulted in a donation of £310 to Vasculitis UK.

Elizabeth Draper and Charlotte Calderbank took part in the Leeds 10k Canal Canter with a Just Giving target of raising £500. In fact, they raised £1704 for Vasculitis UK through JustGiving. Once Gift Aid is reclaimed this makes a total in excess of £2000 Charlotte's employers, Provident Financial run a Good Neighbour scheme whereby they match funds raised for charity by employees. They donated a

further £500 in recognition of Charlotte's fundraising, making the total over £2500.

The Holborn branch of Waitrose organised an in store collection for Vasculitis UK, thereby raising £167 which was presented to Vasculitis UK trustee Dave Newman at a presentation at the store.

Guarantee Laundries of Dorset kindly made a donation of £652 to Vasculitis UK.

Anna Mayhew, a senior sister in the Infusion Service at Addenbrookes Hospital, raised £100 in sponsorship money for Vasculitis UK by taking part in the Greek Marathon, last November.

Ruth & Tony Northen of Banbury kindly donated £1000 to Vasculitis UK.

Karen Sherlock of Matlock held a vasculitis open evening for her friends and neighbours. This resulted in donations totalling £210.00, although the main purpose of the evening was to raise awareness of vasculitis.

Jacqueline Kelly of Bedford, whose sister suffers from vasculitis, held a fund-raising event which raised over £525 in support of Vasculitis UK.

Angela Clarke held a party to celebrate her 50th birthday & requested donations to Vasculitis UK in lieu of gifts, raising £150 for the charity.

Ryan Cotton's 40th birthday – raised £430 for VUK via Justgiving on behalf of his mum Lynne Cotton who has had vasculitis for many years.

Kirstie Downes works at the Coral betting shop in Cleaton Moor, Cumbria. She and the team there raised money for Vasculitis UK in support of a customer who sadly passed away due to vasculitis. Her employers supported the venture which resulted in a donation of £750 via the Ladbrokes Coral Trust.

A donation from Toftwood Spiritualist Group of £25 was received resulting from a charity cycle ride involving Colin Coles

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.

Donating To VASCULITIS UK

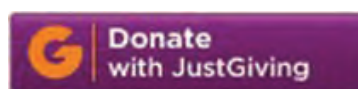
*The charity is **entirely** dependent on voluntary donations
Just £8 a year will pay for the printing and posting of both your
Spring and Autumn Newsletters*

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

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

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

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



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

Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group

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

Cambridge Group

Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

Canterbury area (Contact Person)

Margaret McGrath - 01227 638469 - margaretmcgrathfmsj@yahoo.com

East Midlands Group

East Midlands Website Group <https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home>
Dorothy Ireland - 01332 601303 - Dorothy@vasculitis.org.uk
Lisa Ranyell - 01664 857532 - lisa.ranyell@ntlworld.com
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

Essex Group

Jules Darlow - 07789 113144 - jules.essexvsg@googlemail.com

Leicestershire Group

Leicestershire Group Website <https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home>
Tricia Cornforth and Lynn Smolinski - lynnlvsg@outlook.com

Lincolnshire Group

Sandra Lee - 0754 514 4777 - sandylee777@hotmail.co.uk
Caroline Meyrick - 01780 460354 - cmmeyrick@gmail.com

London

North London Group

Dave Newman - 07429137670 - david.newman@londonvsg.org.uk

South East London & North West Kent Group/

Bi-Ennial Thames Riverside Walk

Jacqui Moran - 07792 412768 - jacqui.moran1@ntlworld.com

Merseyside, Cheshire and North Wales Group

Susan Chance - 01244 381680 - susan-chance53@icloud.com
Dave Birch - 0151 7229049 or 07968226230 - davebirch@talktalk.net

North East Group

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

Norfolk Vasculitis Support Group

Mark Sayer - m-sayer@hotmail.co.uk

The North West Group

Jann Landles - jann@vasculitis.org.uk
Anita Parekh - anita@vasculitis.org.uk

Northumberland and Cumbria (Contact person)

Martin Thomas - 07765 888987 - nwukvsg@gmail.com

Oxfordshire Group

Sue Ashdown - 01295 816841 - vsgoxford@gmail.com

Plymouth Group

elaine203@live.com

Scarborough Group

ruth.newton@york.nhs.uk

Solent/Portsmouth Group

Julie Ingall - Julie.ingall@porthosp.nhs.uk

Surrey Group

Group under discussion

Sussex by the Sea Vasculitis Support Group

Antony Hart - Antonyghart@outlook.com

Swindon Support

Wendy and Lisa swindonvsg@mail.com

West Midlands Group

David Sambrook - davsamuk@yahoo.co.uk
Margaret Gentle - 0121-243-5621 - mgvsgwm@blueyonder.co.uk

West Country Group

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

West Sussex Group

John Bailey - 07752 122926 - johnbee4@googlemail.com

North and West Yorkshire Groups :

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

East Yorkshire Group :

Rachel Weeks - 07968 959 850 email rachel@yorkshirevasculitis.org.uk

North East Yorkshire Support Contact :

Jennifer Wormald - 01937 586 734 email jennifer@yorkshirevasculitis.org.uk

South Yorkshire Social Group Contact :

Jenny Gosling - email jenny@yorkshirevasculitis.org.uk

WALES

North Wales - (Contact Person)

Pat Vernalls - 01766 770546 - patvernalls@btinternet.com

North Wales Group (group also covers Merseyside and Cheshire)

Susan Chance - 01244 381680 - susan-chance@53@icloud.com

South Wales Group

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

SCOTLAND

Edinburgh and Lothian (Contact Person)

Jimmy Walker - 07725 770103 - james-walker@outlook.com

Republic of IRELAND

(Contact Person)

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

Ireland - Vasculitis Awareness Ireland

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

Paul Bingham

Paul Bingham of Tadworth in Surrey sadly passed away in February this year. Paul was one of the founding trustees of the newly constituted charity, Vasculitis UK, which emerged following the demise of the Stuart Strange Vasculitis Trust. Paul was very energetic in his support of Vasculitis UK. He single-handedly organised a major fund-raising raffle which raised a large sum for the newly created charity. Paul suffered from other health problems besides vasculitis over the past two years.

EVENTS CALENDAR



BRITISH SOCIETY FOR
RHEUMATOLOGY

Paediatric and Adolescent Rheumatology Conference 17th - 18th October 2019 - Southampton
BSR Annual Conference 30th April - 2nd May 2019 - Birmingham

NORTH EAST VASCULITIS SUPPORT GROUP MEETING

FREEMAN HOSPITAL NEWCASTLE

SATURDAY, 17TH NOVEMBER, 2018 09:30- 12:00



UKIVAS (United Kingdom & All Ireland Vasculitis Study Group) Meeting 10th December 2018 - London

Vasculitis Charity Ball 2019 will be held on Saturday 2nd March, at the iconic Hilton Manchester Deansgate Hotel. The evening will commence with a drinks reception at 6.30pm in the Deansgate Suite Foyer.

TRAVEL INSURANCE

Vasculitis UK have a comprehensive list of Companies who provide travel insurance for Patients with pre-existing conditions.

Details are available on the VUK website:

www.vasculitis.org.uk/living-with-vasculitis/insurance

or contact John or Susan Mills details on page 28



If you would like something to be considered for future newsletters please contact either:
kevin@vasculitis.org.uk or
graham@vasculitis.org.uk

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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