



VASCULITIS UK

NEWSLETTER JOURNAL



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AUTUMN 2016 ISSUE 52

Should these people have died?

The news of the recent deaths of several relatively young people, directly due to vasculitis, was very upsetting and it set me reminiscing.

Three days before Christmas 2009, I received an email from the fiancée of a 27year old woman, Virginia, living in Scotland. She had been ill for two years but was rapidly getting worse. She had nose bleeds, shortness of breath, fatigue, joint pains and night sweats. Two months previously the doctors had suggested the possibility of Wegener's Granulomatosis, but nothing had been done other than to make an appointment for her to see a consultant rheumatologist in February.

At that time the charity was still the Stuart Strange Vasculitis Trust. Vasculitis UK was in the future. Unlike now, we had little direct contact with doctors. Christmas and New Year is not the best time to get rapid answers. I sought advice from our only medical contact who replied when back after the break, urging that she should see a rheumatologist immediately and offered to see her as an urgent referral. I passed the message on.

I heard nothing further until 29th January when the fiancée emailed saying that Virginia had died that morning in intensive care, 16 days after her 28th birthday. She had still not been seen by a consultant rheumatologist. Had her disease been properly investigated and treated, she would most probably be alive today.

That was the epiphanic moment when Susan and I first cried, then started on a mission to do our best to prevent future such unnecessary deaths from vasculitis. Sadly, since then the list of those who have died prematurely due to late recognition and diagnosis of vasculitis or misdiagnosis or inappropriate treatment still continues to grow.

We all understand that vasculitis is often not easy to recognise, diagnose and treat.



Chairman's Report

For most of us now living with vasculitis, the process of getting a diagnosis and effective treatment was reasonably rapid, but there are exceptions. Manning the Vasculitis UK email and telephone helpline and monitoring the online discussion groups gives one an insight into the experiences of those who are not so well served by their doctors, hospitals and the NHS.

Fortunately, the majority of doctors who treat vasculitis patients are extremely dedicated, very knowledgeable about vasculitis, understanding and empathetic. But there are a few who choose to work beyond their knowledge and experience and refuse to accept when they should seek advice from colleagues. Perhaps some of these don't want to admit their lack of knowledge to their peers or maybe they feel their knowledge and experience is beyond question. For these I have identified a new disease – ASIDS – Arrogant Self-Important Doctor Syndrome. They are a rare breed, but dangerous for patients and difficult to handle!

We are very fortunate in the UK in having the NHS. But wonderful though it is, it too has its warts. There are some parts of the UK where you would be well advised not to have vasculitis – especially a rare type. Access to the latest, most effective drugs can be a problem. Patients with unusual or particularly difficult to treat conditions, needing exceptional procedures or drugs are supposed to be covered by the IPFR process – Individual Patient Funding Request. It was always a rather slow

process – not good for seriously ill patients in urgent need of treatment. However this flexibility in the system is now being steadily eroded by the NHS administration, such that most IPFRs are now automatically dismissed without further consideration. This causes anger and frustration among the medical professionals, but ultimately it's the individual patients who are the losers.

Another, rather strange phenomenon we come across through the helpline and discussion groups is the patient who asks for help, support and advice, but when they are given sound advice – perhaps to question the diagnosis or the treatment or to seek a referral for a second opinion, they disregard it. Maybe because they are afraid of their GP or consultant, or don't want to offend them. Maybe because they only want to hear what they want to hear, not wanting to take "toxic drugs", wanting to cure themselves by diet or alternative medicines. Some just believe that "doctor always knows best" and should be followed blindly.

There have been just a few cases over the years where people have been given excellent advice via helpline or others in the discussion groups, but they chose to ignore it, and died as a consequence. We can only "lead the horse to water, but can't make it drink!".

There is plenty of evidence to show that patients who are well informed and educated about their illness and become actively involved and engaged with their medical team in managing the disease will fare much better than those who adopt a passive role.

AGM 2016

This meeting, held on 15th May in the impressive University of Derby Enterprise Centre, was attended by about 60 members family and friends. Chairman John Mills reported on the activities of the year and said that two trustees, Danni Brunwin and Jacqui Moran, had stepped down from the Board. He went on to describe the international success and popularity

of the Vasculitis UK website and the activities of the charity over the previous year in terms of education and awareness. He reported that £100,000 had been allocated for research by the trustees in this financial year and applications were being considered.

He then introduced the plans for the current year, including changing the status of the charity to that of a "Charitable Incorporated Organisation" or CIO, which has several advantages. In the absence of the treasurer, the chair presented a brief summary of the charity's finances over the previous financial year.

The meeting then considered election and re-election of trustees. Three new nominees were introduced, Gareth Garner, David Newman and Prof Caroline Savage. All were elected. As the constitution requires that a new chair should be elected, it was proposed that Caroline Savage should be chair elect, taking over as chair in 2017, with John Mills continuing as acting chair in the interim.

Full minutes of the formal AGM are available from secretary Jann Landles on request. See back cover for contact details.

Following the formal proceedings, Dr Dimitrios Chanouzas of Birmingham University gave an account of his research (the CANVAS study) into the role of cytomegalovirus in ANCA vasculitis, describing how the CMV alters the immune system, making those patients at greater risk of infection and possibly increasing the risk of heart disease and stroke. CMV is found in most healthy people, causing no illness. The research study is ongoing.

RAIRDA

A meeting organised by the British Society for Rheumatology last autumn, between senior medical professionals, NHS administrators and patient support charities for rare rheumatological disorders looked at the many problems facing doctors and patients in diagnosing

and managing these diseases. This highlighted, among other things, the common problems facing those with rare auto-immune diseases.

Over the summer, a new partnership had been developed between the British Society for Rheumatology and 3 charities, Lupus UK, Scleroderma/Raynauds UK and Vasculitis UK. The Rare Auto-Immune Rheumatic Disease Alliance is the first stage in bringing together all the rare auto-immune disease patient groups, to give a stronger combined voice and increase influence on health policy. This involves the four member charities sharing the cost of a dedicated part-time staff member at BSR and will allow access to the powerful resources, staff and experience of the BSR team, offering the opportunity to interface with the Department of Health and Government in a way that they could not do as individual charities.

A more extensive report on this will be published in the autumn newsletter, when the activities of the group become more clearly defined.

Vasculitis Patient Conference and Charity Gala Ball

Full details of this exciting and very patient focused event, with something for everyone (children are welcome too!) are to be found in a separate leaflet included with this newsletter. Don't miss it. Delegate places are limited, so do book early.

Informational Needs of Carers Questionnaire.

This too is included with the newsletter. Please don't ignore it. This research is being supported financially by Vasculitis UK, so we want it to be a great success.

Brexit Fallout.

Whatever your personal views about the merits or otherwise of Brexit, it will be bad news for people with rare diseases, especially those needing access to new drugs. The European Medicines Agency (EMA),

currently based in London but largely paid for by the EU, is the EU's licensing body for new drugs. It has a similar role to the Food and Drugs Administration (FDA) in the US. This involves pharmaceutical companies going through a long, complex and expensive approval process for each new drug. Once approved they are then accepted for use throughout the EU – a large potential market. Following the referendum, the EMA is already preparing to move from London, probably to Paris.

Once the UK has left the EU, the pharma companies will have to make a separate application to the UK's Medicines & Healthcare products Regulatory Agency (MHRA). However, this will only gain access to the relatively small UK market where there is almost a monopoly purchaser – the NHS. They may think it is not worthwhile going through the separate process for access to such a small, tightly controlled market.

To understand more about the role of the EMA, enter this link into your internet browser: - https://en.wikipedia.org/wiki/European_Medicines_Agency

There is more bad news. The new system of European Reference Networks for Rare Diseases (ERNs) was set up by the EU to improve communication and knowledge sharing about rare diseases between doctors throughout Europe. The Auto-Immune and Auto-Inflammatory ERN (which includes vasculitis) has just been set up, with Leeds as the UK Specialised Centre. At present, Vasculitis UK has representation in the European Patient Advisory Group (EPAG) for this ERN but this may no longer apply once the UK leaves the EU. The future of the UK's role in this exciting and important new initiative is now very uncertain as it is funded entirely by the EU.

To understand more about ERNs, enter this link into your internet browser: - <http://www.eurordis.org/news/what-european-reference-network>

John Mills

YOUR DUTCH VASCULITIS FAMILY



'Let me take you to the dentist'. With these words Joyce Kullman, executive director of the US Vasculitis Foundation, introduced me in 2013 to your chairman John Mills. There was an immediate click and we stayed in touch. We exchange information easily and together we try to set up a European network of vasculitis patient groups. So when John asked me to write a little article on our Dutch vasculitis organisation I of course responded: 'of course'.

ABOUT US

The name of our organisation is 'Vasculitis Stichting', a name you should not even try to pronounce. The ch-sound in the middle of the word Stichting makes most British people think there is something seriously wrong with our throat. The meaning of the word is simply 'foundation'. The organisation was founded in April 1989. Its initial name was Friedrich Wegener Stichting since it was completely focused on GPA or 'Wegener's disease'. To better reflect our current activities we renamed the organisation 'Vasculitis Stichting' as per January 2013.

MEMBERS

At the beginning of 2016 we had just over 1.300 members with 1.200 of them being a patient. GPA with its 840 patients is still counting for the vast majority of them.

ORGANISATION AND FUNDING
The organisation has no paid staff and no office. It is run by 45 volunteers with a small board, working from home and renting space when needed. Members pay an annual fee of €25. On top of that we get an annual grant from the Ministry of Health of €35.000. The latter is a fixed amount available to all Dutch patient organisations with over 100 members each paying a contribution of at least €25 per annum. We have a medical advisory board of leading vasculitis experts and a good relationship with most hospitals and doctors treating vasculitis patients.

ACTIVITIES

We publish a 36-40 pages' magazine called Vasculine every 4 months. It has a balanced content in the categories scientific, medical, medicine, personal, foundation and general. Even in this digital era the magazine still meets a serious need and it is highly appreciated by our members. Of course we have some brochures and other printed material as well and since no organisation can do without a website, you can find us on www.vasculitis.nl

Every odd year we organise a big event in the centre of the Netherlands (we are an extremely large country you know...) where 15-20 specialists run workshops on vasculitis related topics. They cover

organs like heart, lungs, kidneys and skin but also topics like medication, research and things like fatigue, mindfulness etc. Last year we had 18 speakers and just over 500 people attending. In the even years we organise 8-10 local meetings, each of them usually attended by 40-60 people. We then have one or two speakers who zoom in on a particular form of vasculitis.

FINALLY

A lot of what we do and a lot of the problems we face in The Netherlands are of course similar to what you experience in the UK. And there is not 'a-bunch-of-gnomes' doing the work for us. My wife was diagnosed in 2002 when we lived in the West Midlands (Kenilworth to be precise). We went through the usual shock and at that time information on vasculitis was really, really scarce in the UK. With the help of a lot of volunteers John Mills and his wife Susan have changed that UK landscape completely. For no other reason than to serve vasculitis patients. My plea to you: 'Please, don't you ever take that for granted'.

Warm regards on behalf of your entire Dutch 'vasculitis family',
Peter Verhoeven.

From The Editors

Welcome to all our readers to this our third edition as editors and we hope you are finding it both engaging and informative.

There are many exciting things inside this edition including all the information you will need for the 2017 Patient Symposium and Gala Ball being held in Manchester.



We also say hello to many new faces of both trustees and volunteers and sadly goodbye to others.

Vasculitits UK are still in need of volunteers so if you or someone you know would like to help by getting involved as a volunteer please contact susan@vasculitis.org.uk

We also have our annual Christmas card designs which have been created by Kelly Jefferies Details for these are below.



This edition like all the others have many of you our Fantastic Fundraisers

we are sorry if not all of you have made this edition but all fundraising photos can be found on the website <http://www.vasculitis.org.uk/about/fundraisers-photo-gallery>.

We hope you enjoy this edition and please contact either of us if you would like something to be considered for future editions.

*Happy Reading
Kevin & Graham*

VASCULITIS AWARENESS CHRISTMAS CARDS 2016

These cards have been designed exclusively for Vasculitis UK by Kelly Jefferies.

We have a few packs of assorted designs of previous year's Christmas cards for sale pack of 10 cards & envelopes £1 plus p&p £1.50.

Pack of 5 cards & envelopes £2 plus p&p £1.20
 Pack of 10 cards & envelopes £3.50 plus p&p £1.75
 Message inside - Merry Christmas and Happy New Year
 Reverse of card - information about Vasculitits UK



Available from the VUK shop
<http://www.vasculitis.org.uk/shop> or telephone 03003650075

Diary of training and taking part in the London Marathon 2016



Usually marathon training is a strictly structured 16 week plan of long runs, tempo and speed work. With a young family I have never been able to stick to any of that, so with having GPA (Wegener's Granulomatosis) on top, this was going to be no different. As predicted my training did not follow any plan whatsoever, with only 4 long runs of 15, 2 x 16, and a 17 mile completed in March, just before my 3rd infusion of Rhituximab. This was at the time of the Ashby 20, a race many runners locally use as a prep for London, and a race I had intended to do. So just a few days after Rhituximab, I decided it was wise to pull out.

With only 17 miles done as my longest run, on the 24th April I lined up on the GFA (Good For Age) start at Greenwich Park, London with thousands of other runners.

The only plan I had was just to get round, and if possible under 3 hours 15 minutes, the time I needed to guarantee entry next time.

The gun goes off, and you jog off, you can't go much quicker as the crowds are huge. It takes a mile or 2 to thin out and strangely it feels easy, and you find it hard to hold back, the first 4 miles I completed at 6min 45sec pace, over 20 seconds quicker than I'd planned.



If I didn't slow down, I would hit the wall for sure. It was at this point I noticed a fellow Charnwood AC runner, who like me had set off to fast but wanted to run around 7.10 pace. So for the next 11-12 miles we stuck to our desired pace.

Going through halfway at 1hr 32 I felt strong, and this also gave me time for the inevitable slowing down of the second half. With 10 miles to go I was back on my own, so I slipped in a few quick miles, and then 20 miles came, and so did the hurt. This was unknown territory for me, I had not run this far since my last London in 2013, and not with this disease.

This is where I have to thank Andrea, my wife, the previous day she had my name printed on my Vasculitis vest. Hearing people shouting and cheering me, spurred me on. Thinking about the last two and half years of my GPA life, spurred me on. Thinking about each and everyone who had sponsored me, spurred me on, but most of all YOU. This was about me, but also about everyone. Putting our troubles to one side, being able to do what we want, telling all Vasculitis diseases to do one. We are stronger together, and I was thinking about all of us over the last 6 miles. Yes I got slower, I wanted to stop, but no way was I going to. I was running to beat Vasculitis, and I did.

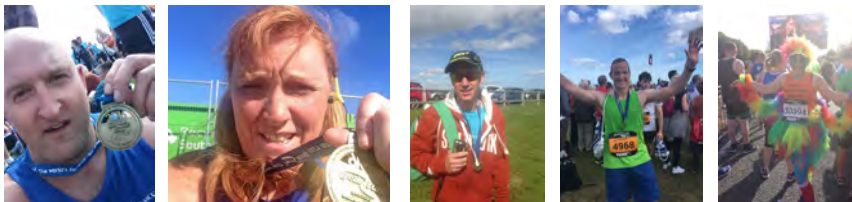
3 hours 7 minutes 37 seconds after setting off from Greenwich Park, I turned onto the Mall and aeroplaned into the finish.

Never before has a race meant so much, yes I run 10ks, and half marathons often, but a marathon, quicker than my first one. I was happy, I was over the moon.



KEEP FIGHTING, WE CAN.

Martin Makin



Pictured above are our fantastic fundraisers who recently competed in this years Great North Run, from left to right: Roger Clarke, Tracey Denham, Martin Watson, Martin Makin, Martin Richardson and Rebecca Wass.

Super Girl Emily Marsden

Emily has Vasculitis and has been busy fundraising with her friends she has raised over £1000 for Vasculitis UK, Emily pictured



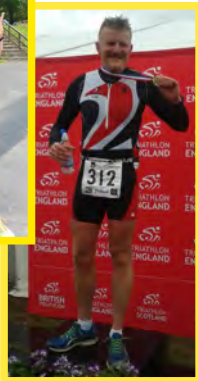
above presented our Chairman John with a cheque at the recent Scarborough Vasculitis support group meeting.

She is also pictured on the front cover with her school friends where they had a sleepover to raise awareness and funds in support of Vasculitis UK.

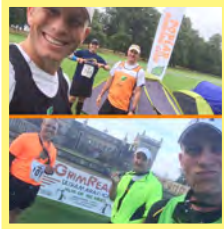
Some of Our Fantastic Fundraisers



Andrew Robertson



Craig Sharp
Grim Reaper Ultra running on behalf of two friends who have Vasculitis



Hannah and Katy Gung Ho West Midlands for Katy's mum



Jann & Sue accepting a cheque for VUK at the Trafford Business Expo



some of our runners in this year's British 10k



Fun in the Garden Fundraising
Iris Bradley held 2 fun days in her own garden on behalf of her daughter Karen who has vasculitis and for Vasculitis UK. One event was Pie and Mash with family and friends and one tea, Sandwiches and bingo. A total of £702 was raised.



UK Ghostbusters raised over £500 at the London Film & Comic Convention 2016



Ruth Newton Rheumatology Specialist Nurse running the ASDA York 10k pictured with daughter Carol



Jenny Dunlop Sky Dived in memory of her Nan



Lisa Mitchell raised an amazing £528 for Vasculitis UK in a sponsored Chocolate Fast.



Vasculitis UK member Derek Wheatland is a dead ringer for the famous Star Trek character Jean Luc Picard. Derek appears in character at various events across the country and as Jean Luc Picard he has donated £200 to Vasculitis UK.



Mark Jones swam 64 lengths in one hour for VUK raising £1300



Skegness Beach to Chesterfield Spire Nick, Neil & Derek



Claire Smith Birmingham 10k



Lisa Mitchell Cake and Bake Sale £430



Andrew Robertson pictured above with the Mayor of Hartlepool after his final triathlon



Jenny Hyett & Katie Bucksby in competed in the London SW Tough Mudder



Bev Massey and work colleagues from Lancaster Insurance Tough Mudder UK raised £825

Wegener's Granulomatosis (GPA) and the Nose (Part2)

Nose Deformity And Reconstruction In The Individual With Systemic Vasculitis

Dr Callum Faris MBBS (Hons) MRCS FRCS ORL-HNS.
 Consultant/Specialist ENT, Facial Plastic Reconstructive Surgeon
 The Nose Reconstruction Clinic, Poole Hospital NHS Trust

Dr Hade Vuyk MD PhD Consultant/Specialist ENT, Facial Plastic Reconstructive Surgeon.
 Department of ENT Head and Neck Surgery Free University VUMC, Amsterdam
 www.dr.vuyk.nl

The Vasculitic Nose

Wegener's Disease - Granulomatosis with Polyangiitis (GPA)

GPA is the most common vasculitis to affects the nose, Wegener's disease (GPA) causes an inflammation of the medium and small sized blood vessels. If this process continues untreated and the disease remains active a stepwise progressive injury to the nose can occur.



Although most affected individuals have nasal symptoms, only some individuals have progression to the more severe forms of nose deformity. According to one large study the frequency of a nasal septal perforation was 33% and 28% for saddle nose deformity.



Septal Perforation

This is a defect in the mucosa and cartilage causing a hole in the partition (septum) of the nose



Severe Saddle

In severe cases the septum can be progressively damaged. The saddle nose deformity worsens and the nose becomes shortened and the tip of the nose rotates upwards.

This saddle deformity can be reconstructed in a single surgical procedure. Surgical intervention requires reasonably good general health and that the affected individual also be in long term remission.

Other Types of Systemic Vasculitis

Relapsing Polychondritis – Has a variable affect on the nose. Various sub-sites can be affected so the nose can be spared. If the nose is affected it can mirror Wegener's disease with pain and nasal stiffness progressing to perforation and saddle nose deformity.

Systemic Lupus – rarely causes septal perforation < 5%, or nasal collapse/saddle.

Microscopic Polyangiitis – Often limited to crusting and epistaxis and sinusitis, progression to progressive nasal collapse is rare

Nose Reconstruction

Timing of Nose Reconstruction

Generally two years of remission is required before undertaking reconstructive surgery.

Septal Perforation (hole in the septum)

Perforations can cause little or significant functional symptoms for affected individuals. The mainstay of treatment is treating the underlying active disease, and any co-existing sinus disease in the acute phase. This is achievable with nasal saline sinus rinse and oral antibiotics if required (directed by your ENT Surgeon) and treatment of the underlying vasculitic disorder (directed by your Rheumatologist). In the presence of vasculitis most septal perforations are not repaired. Lubrication with Vaseline and saline douches can help treat perforation related symptoms.

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Saddle Nose Deformity And Its Correction

Saddle nose deformity is not a disease, it is the clinical description/appearance of the nose that occurs following loss of support of the nose from destruction of the nasal septum. This lack of support produces a typical concavity to the bridge of the nose in side (profile) view – like the shape of a horse's saddle, hence the term 'saddle nose deformity'.



Correcting the saddle requires rebuilding of the septum to re-support the mid portion of the nose. this is done by taking cartilage grafts from ears or from your rib cartilage.

There are various grading systems to saddle nose deformity. The majority can be corrected in a one-stage procedure as a day case patient. Extreme cases may require more than one stage to successfully reconstruct the nose.



This case example (left) demonstrates nasal collapse, which has produced a severe septal saddle. The nose deformity is reconstructed with the patients own cartilage from their ear or rib in one operation.

Nasal Full Thickness Reconstruction

When conditions affect the full thickness of the nose there can be deficiencies in all 3 layers of the nose. This is rare in vasculitis but more common in cancer reconstruction. Using case studies from nose reconstruction shown below we demonstrate how the nose can be rebuilt even if the majority of the nose is missing.

Majority of Nose Missing From Cancer



Three layers of the nose are reconstructed. Using techniques from nose reconstruction a normal nose can be achieved over 4 operations, each 3 weeks apart. Only the individuals own tissue is used with no implants to reduce the risk of infection. The patient now has a functioning nose that appears normal at conversational distance (however faint scars are still noticeable).

Prosthetic Rehabilitation

Nasal prosthesis can be fashioned to correct complex deformities. This can either be as a temporary measure till surgery can be scheduled or as a permanent management for the patients wish to avoid surgery or patients medically unfit to undergo several surgeries..

Is Nose Reconstruction Funded On The NHS?

Nose reconstruction for vasculitis disease is funded on the NHS.

Key points for the individual with vasculitis and nasal deformity:

Vasculitic disease can affect the sinuses and external nose.

Wegener's is the most common entity to cause external nose deformity and the degree to which it does this is variable

Septal Perforations are not classically repaired in the setting of vasculitis

Saddle nose deformities can be repaired in remission

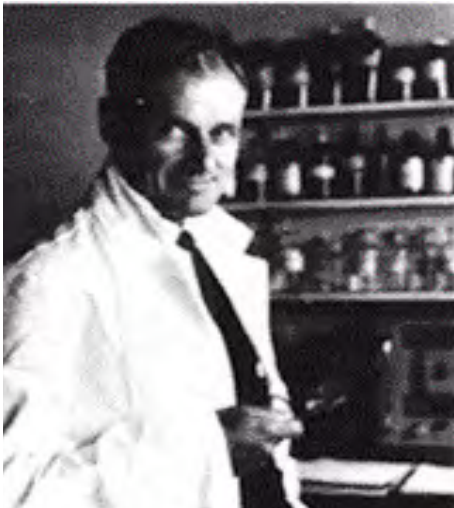
The Kellgren Centre – Manchester University Hospital

Dr Ben Parker Consultant Rheumatologist

The Vasculitis service at the Manchester Royal Infirmary (MRI), part of Central Manchester University Hospitals NHS Foundation Trust, is led from the Kellgren Centre for Rheumatology. We are a self-contained department that offers our own dedicated reception and waiting room, clinic rooms, an ultrasound room, and phlebotomy services alongside the offices of the rheumatology team. The Kellgren Centre is commissioned by NHS England to provide a specialist service for patients with complex vasculitis and systemic lupus erythematosus (SLE) to patients across the North West of England.

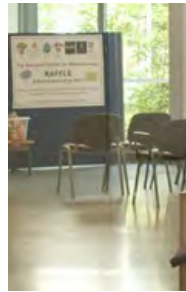
The Centre is named after Professor Jonas Kellgren, who became the first Professor of Rheumatology in the UK (and possibly Europe) in 1948. The Centre was officially opened in the new development of Central Manchester Hospitals in 2007 by his widow. Currently the service looks after several hundred patients with systemic vasculitis and is a renowned Centre of Excellence for managing patients with SLE.

The Clinical Lead for the



lupus and vasculitis service is Professor Ian Bruce, Professor of Rheumatology, Honorary Consultant Rheumatologist and Director of the Manchester Musculoskeletal Biomedical Research Unit (BRU). Supporting

Professor Bruce is Dr Ben Parker, Consultant Rheumatologist and Clinical Senior Lecturer in Rheumatology at the University of Manchester, who also provides a secondary and tertiary service for patients with vasculitis from across the North West.



Professor Bruce and Dr. Parker each provide two clinics every week for patients with vasculitis and related connective tissue diseases, with a focus on patients with refractory or severe disease who may require biological therapies, also providing inpatient care when patients are admitted to the inpatient service.

Dr. Parker also provides a transition service for young adult patients managed by Pediatric Rheumatologists in the Royal Manchester Children's Hospital,



(L-R) JoAnne Nicholson (CTD research practitioner);
Dr Ben Parker (Rheumatologist)
Dr Rachel Gorodkin (Rheumatologist)
Professor Ian Bruce (Rheumatologist)
Sr. Emma Powell (Clinical Nurse Specialist)
Karen Winterburn (PA)
Jamie Niblett (Biologics co-ordinator)
Dr Sarah Skeoch (specialist registrar)
Dr Eoghan McCarthy (Rheumatologist)
Sr Lillian Tames (senior CTD research nurse)

helping move younger patients more smoothly into the adult rheumatology service. Professor Bruce also provides a specialist Pregnancy service with Feto-Maternal Health colleagues in St Mary's Hospital.



Consultant colleagues within the Kellgren Centre, Dr. Rachel Gorodkin and Dr. Pauline Ho, also provide weekly connective-tissue disease clinics and inpatient management for patients with vasculitis and related diseases. The department is also very well supported by experienced Clinical Nurse Specialists and senior specialist rheumatology trainees who rotate through the Department to gain experience in complex rheumatology, including vasculitis and the connective-tissue diseases.

We are very fortunate to have a very close working relationship with our colleagues in renal medicine. The renal vasculitis service is led by Dr. Mumtaz Patel, who runs a weekly renal vasculitis clinic and reviews patients who require inpatient nephrology care.

The renal team, one of only three renal centres in the North West, offers a full biopsy service and all acute treatments that may be required by patients with acute, severe systemic vasculitis.

To facilitate coordinated multidisciplinary care across specialties the Kellgren Centre operates several multidisciplinary team meetings each month, with a particular focus on nephrology.

For example complex cases are discussed with colleagues from rheumatology, nephrology

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and immunology in a monthly meeting. Catch-up sessions are also run fortnightly between the rheumatology and renal teams to ensure communication is as effective as possible for those patients who are currently inpatients or under shared care.

We are also very fortunate to have regular team meetings with our colleagues in chest medicine and have long established relationships with several key ENT surgeons and ophthalmologists. This close collaboration between the rheumatology and renal teams, and the wider hospital, ensure patients receive high quality care that addresses all manifestations of a complex and multi-system disease, providing access to the full acute hospital service for those patients that require it.

The Kellgren Centre is an active research department with an emphasis on research in connective tissue diseases and is fortunate to have a large research team embedded in the department.

Professor Bruce and Dr. Parker are Principal Investigators on several clinical trials and contribute to several national vasculitis studies. The Centre has also recently been awarded an Outstanding Best Practice Award from the British Society for Rheumatology for its innovative biologics service.

“Dr Ben Parker will be a speaker at the Vasculitis Symposium in March 2017”.

Links

<http://www.cmft.nhs.uk/royal-infirmary/our-services/rheumatology>

<http://www.cmft.nhs.uk/royal-infirmary/our-services/renal-care>

[http://www.cmft.nhs.uk/saint-marys/our-services/maternity-services/our-services-and-clinics/antenatal-care/specialist-maternity-services/lupus-in-pregnancy-\(lips\)-clinic](http://www.cmft.nhs.uk/saint-marys/our-services/maternity-services/our-services-and-clinics/antenatal-care/specialist-maternity-services/lupus-in-pregnancy-(lips)-clinic)

<https://research.cmft.nhs.uk/facilities-services/musculoskeletal-biomedical-research-unit>

Twitter @kellgrentre

NEW EULAR AAV GUIDELINES

The new European League Against Rheumatism (EULAR) guidelines for treating adult ANCA vasculitis were published this summer. Dr Max Yates of University of East Anglia played a leading role in developing these guidelines. He has very kindly provided a patient-friendly summary which explains the basic points contained in the guidelines. You can find the summary on the Vasculitis UK website under “About Vasculitis/Guidelines: Treatment, Management and Advice” or at the link shown here: -

<http://www.vasculitis.org.uk/about-vasculitis/guidelines-EUCLAR>

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/>

Vasculitis UK AGM May 15th 2016 (Derby University)

The AGM was held at the new venue, at Derby University and was well attended by 65 members.



John Mill's presenting the "Chairman's Annual Report" Plus vote of thanks to retiring trustees and voting in of new Trustees
<http://www.vasculitis.org.uk/about/meet-the-trustees>



Dr Dimitrios Chanouzas discussing the CANVAS clinical trial at Birmingham Queen Elizabeth Hospital



Mark Jones - cheque presentation for £1300, raised by Mark for swimming 64 lengths in one hour for Vasculitis UK. Mark also has Vasculitis which makes this quite a personal achievement.



Registration, lunch and a chat in the Conservatory.



Drawing of the raffle prizes, by John and Dimitrios, prizes kindly donated by members of VUK



Presentation and vote of thanks to Dr Dimitrios Chanouzas by Chairman John Mills



RESEARCH GRANT

We are pleased to announce that after a very robust selection process Vasculitis UK is funding more Vasculitis research.

The Scientific Advisory Board has awarded a Project Grant of £47,519, over 12 months, to Professor Paul Brogan and Dr Despina Eleftheriou of Great Ormond Street Hospital in London.

The Project is entitled "Discovering novel genetic causes of cerebral vasculitides of the young" and should commence in October.

Research Grant Application & Travel Bursaries

Vasculitis UK will shortly be advertising this year's "Call" for research grant applications and there will be a limited number of travel bursaries available for doctors and AHP's taking part in the 2017 International Vasculitis Conference in Tokyo.

Check the "News" and "Research" pages on the VUK website

<http://www.vasculitis.org.uk>

An App to Support Vasculitis Patients and Research

Get Involved: help in designing a research app.



In conjunction with patientMpower (<https://www.patientmpower.com/>) we are designing a smartphone/tablet/web app designed to support patients with vasculitis. This will include personalised tips on staying well, help with medication adherence, a place for storing health data (such as blood pressure, blood results) and a means of enhancing patient-physician interactions. We would like your input into the design of this app.

We also envisage it as supporting vasculitis research, by allowing direct recording of patient reported outcomes and linkage of relapse events to environmental factors. Ultimately, we aim to provide a personalised tool to assist you and your doctor in getting the dose of immunosuppression right and in predicting relapses before they occur"

If you have ANCA vasculitis which has involved your lungs, nose or sinuses, are now in remission, and you would like to be involved in developing this software, please contact Eamonn Costelloe (eamonn@medicaleguides.com)



Professor Mark Little (Trinity College, Dublin) & Professor Alan Salama. (University College, London)

MEET KELLY JEFFERIES

Hi, I am Kelly Jefferies, I'm 39 years old & I live in Leeds, West Yorkshire with my husband, Ian, who is also my full-time carer, and our 14 year old son.

I'm very lucky to have a fantastic support network as my parents, daughter, son-in-law & 7 month old grandson live just around the corner. My GP, who has been a massive support, is very nearby too.

I have three auto-immune disorders; [Behcet's Syndrome](#), Systemic Lupus (SLE) and Antiphospholipid Syndrome (APS).

I have been poorly since I was a small girl, but, despite numerous tests, scans & specialists over the years, my parents were always told they couldn't find anything wrong with me so, naturally, they believed the medical professionals & thought I was a "drama queen"!

In December 2000, at 33 weeks into my second pregnancy, I had a massive placental abruption resulting in my second daughter being stillborn & almost losing my own life. It was at this time that the APS was diagnosed.

I went on to have my son in April 2002 and then in the summer of 2004, I started with stroke type symptoms and, after some tests & brain scans, I was diagnosed with Cerebral Lupus & started on infusions of cyclophosphamide, a form of chemotherapy.

Rather than being shocked, like my family were, I was just relieved to finally know I had something wrong with me & it wasn't "all in my head"!

In early 2011, my then Rheumatologist suddenly mentioned Vasculitis to one of his students in front of me at my appointment so I went away & researched it as he'd never mentioned Vasculitis before, especially to me and I didn't know what it was. This is when I found Vasculitis UK and I contacted John & Susan Mills, I told them how badly managed my symptoms were & it took them about a year of gently prodding me to go for a second opinion.

I travelled to Addenbrooke's Hospital in Cambridge with Ian, to see Dr David Jayne who diagnosed me with Behcet's Syndrome & SLE and he referred me on to a fantastic Rheumatologist in Leeds, Prof Morgan who specialises in Behcet's Syndrome and Large Vessel Vasculitis.

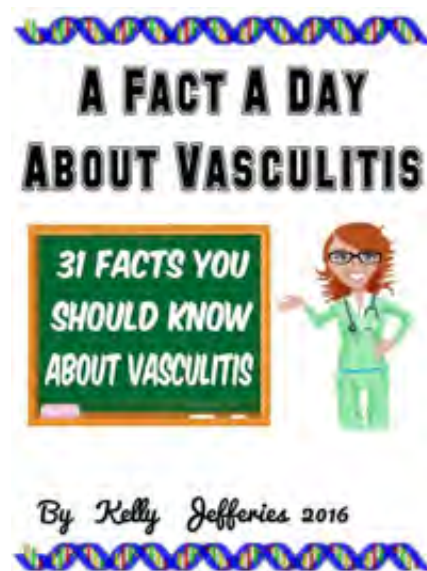
I have been a staunch supporter of VUK ever since and I'm extremely grateful to have been given a correct diagnosis.



I started making graphics to raise awareness of, not only Vasculitis & the different Vasculitic diseases, but also the brilliant work VUK do. I have no formal training in graphic design but found it helped to pass my time & keep my brain ticking over when I am well enough. In 2015, I decided to do a "Fact A Day Throughout Vasculitis Awareness Month" series of graphics to put some facts out about Vasculitis, for use on social media that every day people would understand.

When John & Susan told me they were making "A Fact a Day About Vasculitis" into a booklet for Vasculitis Awareness Month 2016, because Dr Reem Aljayyousi, Consultant Nephrologist at Leicester Royal Infirmary used the graphics for a support group presentation & suggested it, I was speechless & deeply honoured. I was also happy they were to be sold for a small amount with all proceeds going to VUK as this meant that I wasn't just helping to raise awareness but funds too!

Prior to falling ill, I worked in administration & secretarial roles so I will also be helping with the [VUK shop](#) orders assisting the on-line shop co-ordinator when needed so we can get the VUK awareness products out in the public eye as well as colourful graphics I make which are mainly for social media.



Helpline

for information and advice about vasculitis by telephone or email. If you prefer you can write to us.

**Helpline Telephone:
0300 365 0075**

E-mail

john.mills@vasculitis.org.uk

lynn@vasculitis.org.uk

Post: John Mills

West Bank House, Winster, Matlock
DE4 2DQ

New Patient Representatives on ePAG

The newly elected ePAG (European Patient Advocacy Group) patient representatives were announced in May 2016 and John Mills chairman of Vasculitis UK has been elected as one of the 5 patient representatives (ePAG) for rare immunological and autoimmune diseases in Europe.



Member of **EURORDIS**
Rare Diseases Europe

EURORDIS created the ePAGs to engage patient organisations and ensure a democratic process of patient representation in the decision-making processes around European Reference Network

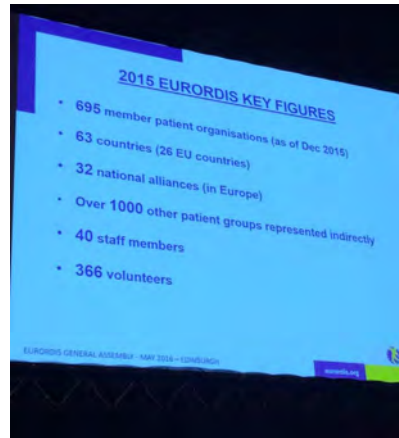
Please follow these links for further details

<http://www.eurordis.org/content/newly-elected-epag-patient-representatives?platform=hootsuite>

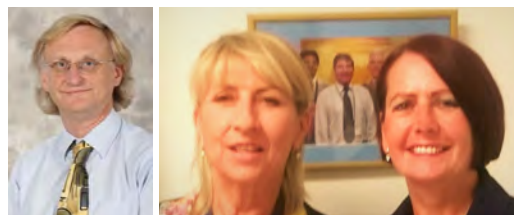
<http://www.eurordis.org/sites/default/files/epag-table-for-website.pdf>



Eurordis Conference 2016



Alastir Kent Genetic Alliance and Dr Larissa Kerecuk with delegates from the conference



Dr Richard Watts & Dr Janice Mooney with Research Assistant Karly Graham



Dear Vasculitis UK members


We are vasculitis specialists Dr Richard Watts, Ipswich Hospital and Dr Janice Mooney and research assistant Karly Graham, from the University of East Anglia.

Vasculitis UK are sponsoring our study, exploring the informational needs of people with vasculitis **and** the people who care for them. You'll find in this newsletter two questionnaires, one information sheet and a reply-paid envelope. We would be very grateful if you would fill in the relevant questionnaire (either as someone with vasculitis or carer) and return to us in the reply-paid envelope, within the next month if possible. If you prefer, the questionnaires can be done online using this link below:

<https://www.surveymonkey.co.uk/r/9SR76X7> but please don't do both.

Best wishes and many thanks

Richard Watts, Janice Mooney and Karly Graham



Vasculitis UK 2017 Patient Symposium & Gala Ball



These two exciting events are both hosted and generously supported by James and Emma of Innov8 Conference Services



Vasculitis Patient Symposium

Don't miss the 2017 Vasculitis Event of the Year.

Following the great success of last year's 2015 Vasculitis UK Patient Symposium in London we are pleased to announce that the 2017 Vasculitis UK Patient Symposium will be held in Manchester, followed in the evening by a Gala Dinner and Charity Ball.

When? Saturday 4th March 2017 9.45 – 4.00pm

Where? Manchester Piccadilly Mercure Hotel

Who's if for? People with vasculitis, carers and families of people with vasculitis and anyone with an interest in vasculitis.

Children are especially welcome, with their own special space and entertainment.

What's it about? The theme of the day is:-
"Improving Vasculitis Care: Patients and Professionals Together in Partnership for better Vasculitis Care"

Will we be fed? Tea & Coffee on arrival and throughout the day.
A two course hot/cold buffet lunch.

How much? Adult delegate £45.00 each
Child delegate £22.50 each
Combined Symposium & Ball £85.00 each

How to book? For more information & to book online, visit
www.vasculitis-symposium.co.uk

For further information visit: www.vasculitis.org.uk/news
If you cannot book online, or for other enquiries: call 0300-365-0075

The prestigious Manchester Piccadilly Mercure Hotel is in the centre of the city, but it has its own car park and is only a short distance from the Manchester Piccadilly mainline station.

For those who wish to arrive the day before or stay over for the Gala Dinner & Ball, or just to make a weekend of it enjoying the attractions of the historic capital of the cotton industry, there are hotel rooms - from budget to luxury - at special rates - see the special event website
www.vasculitis-symposium.co.uk



Symposium Programme



This will NOT be a day for just being talked at!

Delegates will be encouraged to join in discussion and contribute their suggestions and questions.

There will be morning & afternoon panel Q&A sessions.
These will inform both future strategy and future meetings.
You can help to shape the future of vasculitis care.

The day will be chaired jointly by Dr Peter Lanyon & Professor Caroline Savage.

Keynote Address

Dr Peter Lanyon, President of the British Society for Rheumatology & former chair of the Rheumatology Specialised Services Clinical Reference Group. Peter will deliver the keynote address:-

“Working together to improve standards of care and outcomes.”

See the provisional programme of speakers below:-

Professor Jackie Andrews : Vasculitis care in Leeds.
European Reference Networks

Dr Fiona Pearce : Recognition & Diagnosis of ANCA vasculitis

Professor Robert Moot : Centres of Excellence; The Behcets
Experience.

Dr Louise Oni: Henoch Schonlein Purpura.

Dr Ben Parker: Manchester’s new Kellgren Centre for Rheumatology
The transition from paediatric to adult services

Dr Shanali Perera: Art, Inflammation & the Illness Experience

Clare Jacklin: Emotions, Relationships & Sexuality

Lynn Laidlaw: A typical day on the VasculitisUK helpline.

Kira Conroy: A childhood of coping with HSP

Gareth Garner: Vasculitis & the teen years; coping with Goodpastures disease

Peter Verhoeven: Vasculitis support in Holland; European Patient Advisory Groups;
the new Vasculitis Europe Group.





Where and When? Mercure Manchester Piccadilly Hotel.
Saturday 4th March at 6.30pm till late!

Tell me more:

- Drinks reception in the International Terrace
- Welcome Drink on arrival
- 3 Course Gala Dinner
- Half a bottle of wine per person on the table
- The chance to take part in the Charity raffle and Auction with great prizes to be won
- A full packed evening of entertainment
- Dress: Smart Casual

How much? £60 per person. Reduced rate £85 pp for combined tickets for both Symposium & Gala Ball.

Booking online: www.vasculitisball.co.uk

For further information: www.vasculitis.org.uk/news

Or to enquire about booking other than online: call 0300-365-0075

VASCULITIS UK

*Special discount rates at city centre hotels are available for those staying overnight.
For details see the special event website: www.vasculitisball.co.uk*

*Why not make it a weekend break and enjoy the many attractions in Manchester
or spend a day in the nearby beautiful Peak District.*



British Society of Rheumatology Spring Conference Glasgow 2016 (A Retrospective Review)

The conference was attended by 2000 medical professionals from the UK and Europe.



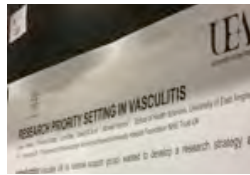
The Vasculitis UK stand attracted a great deal of interest from doctors, nurses and physiotherapists.



Dr Janice Mooney (Norwich & Norfolk) & John Mills – (Chairman of Vasculitis UK)



Research Abstract/Poster "Setting Research Priorities for Vasculitis" – which is part of the Vasculitis



UK Research Strategy.
<http://www.vasculitis.org.uk/research/research-strategy>

Dr Peter Lanyon – Consultant Rheumatologist Nottingham Queen Elizabeth Hospital - Newly elected President of the BSR for 2016/2017



Dr Neil Basu (Aberdeen) & Dr David D'Cruz (Thomas & Guys) led the Vasculitis Research Poster/Abstract Tour, which attracted a great deal of interest.



BVAS Activity Score Abstract BSR Conference

New Alliance for Rare Autoimmune Rheumatic Diseases

This Alliance is made up of four founding partner organisations, the British Society for Rheumatology (BSR), Lupus UK, Vasculitis UK and SRUK, all of whom have worked tirelessly over many years to help improve the lives of patients with these rare autoimmune diseases. The Alliance emerged from a national workshop hosted by the BSR at the Spring Conference 2016, which sought to raise awareness of our group of diseases and to start

making connections across the wider community and into Government, in order to bring about better outcomes for all our patients.

The workshop report "[A collaborative approach to improving outcomes in Rare Rheumatic and Musculoskeletal diseases](#)" sets out a number of recommendations, including building a rare rheumatic disease partnership and helping to improve knowledge about this disease group by establishing a national audit.

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

Vasculitis Awareness Ireland Future Health Summit – Dublin May 2016

As a result of my completion of the EUPATI (European Patient Academy in Therapeutic Intervention) course, and being a member of the Irish Patient Platform IPPOSI, I was asked to assist in presenting at a patient workshop at the recent Future Health Summit in Dublin.



Julie Power VAI (Ireland)
Future Health Summit June 2016

This is a major annual event about empowering the patient, information and accountability with 5 summits, 2000 delegates, 160+ speakers, 7 patient workshops and 100+ exhibitors. Our workshop (IPPOSI) covered the importance of patient education and empowerment as well as the availability of reliable, objective information to patients on medicines research and development.

We discussed the capacity of patients and the lay public to be effective advocates and advisors in all aspects of research with the scientists, clinicians, regulatory authorities and ethics committees. We were able to present from differing perspectives, from a large organisation

with employed staff, a small voluntary group to individual input. I was able to discuss how our small support group grew and became involved with various aspects of research, and how we have been able to facilitate change in our care. We are very fortunate to have a good working relationship with the clinicians involved in Vasculitis research here in Ireland. This has proved to be mutually beneficial allowing research to be approved in a timely fashion and compliance in participating in the individual projects. Several examples of success have been our input into the consent form, to allow it to be more comprehensive and fully inform the individual of the preservation of confidentiality, what happens their samples, their right to withdraw from study and access to results.

We also endorsed the use of the cd163 protein (identified in the Biobank research project), which helped get ethical approval for its use in hospitals. This involves identification of flare of vasculitis disease involving the kidneys using a urine dipstick, ensuring relevant treatment starts at an early stage and avoiding organ damage, inappropriate use of antibiotics and biopsy and the design of a new 5 year piece of research called the AVERT project, which

involves the use of an app to record information.

We have had input into consultation documents in both Northern Ireland and Southern Ireland Health services. In Northern Ireland, we are looking forward to the start of a new two year pilot Vasculitis service as a result of working with the Public Health Agency, Health and Social Care services and the clinicians.

These examples show the power of the patient voice, even as a small organisation. There is a tendency to think that the doctors must know everything, but we live in a world where new diseases are being identified everyday - 1 in 17 people have a rare disease, we are surviving longer, and we are likely to develop more than one condition in our lifetimes. The medical profession cannot know everything about every condition, it is up to us to inform them about our particular condition, and help them, help us. We have important knowledge that can help in the idea stage (what is important to us, what will or will not work), the development stage and the end stage.

Our involvement could potentially cut down on the waste and hopefully speed up development of necessary drugs and interventions.

Julie Power

Support Group Meetings

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



Leicester Support Group April 2016



Oxford meeting March 2016



West Country Vasculitis meeting



West Country Summer barbeque



Lincoln Support Group



East Midlands Vasculitis Support Lunch



Dr Omar Nawaytou speaking at the Merseyside, Cheshire, N Wales Support Group



New Plymouth Support Group - June 2016



North Yorkshire Vasculitis Meeting April 2016



40 People attended the Scarborough Vasculitis Support Meeting



facebook



health unlocked

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/>**

**CHAIRMAN ELECT
CAROLINE SAVAGE**



Professor Caroline Savage was formerly a consultant of Nephrology at Birmingham Queen Elizabeth Hospital and Chair of Nephrology at the University of Birmingham.

In 2009 she joined GSK becoming Head of the Experimental Medicine Unit.

Caroline was closely involved in the formation and development of the Stuart Strange Vasculitis Trust and maintains a very strong interest in Vasculitis. Caroline is married to Adrian, they have two daughters and live near Cambridge.



The charity is sorry to announce that Dannie Brunwin has decided to stand down as a trustee of VUK. Dannie has been a trustee for three years and was the



My name is Gareth; I am currently studying Biomedical science at the University of Chester but I'm originally from Cambridge. I was diagnosed with Anti-GBM disease when I was 16 after a lengthy stay at Addenbrookes Hospital, around the same time as my mother was diagnosed with Bechets disease.



I've already worked in a few areas of health care such as a dispenser in a pharmacy, and I'm currently on bank at a local hospital.

Gareth

Further to this, I help run the Young Vasculitis UK Facebook page allowing the younger 'vasculitis population' to ask questions and get advice from similar people. I also volunteered for the patient symposium in London (2015), which I'm hoping to do again in the near future. In my spare time I enjoy listening to music, attempting to kick a ball around and reading. However, the reading usually involved some kind of Anti-GBM based research paper!



David Newman

I lived my formative years in Scotland before moving to London in 1969 where I worked with London Transport for 40 years. I enjoy working with people and helping them.

In 2012 I was diagnosed with Rheumatoid Vasculitis so in March 2013 I founded the London Vasculitis Support Group based in Swiss Cottage, Hampstead for people with vasculitis, their families and carers. The group's venue has excellent transport links from most of London. Today we have members coming from all parts of London and the surrounding Home Counties.



I have had experience in fundraising

for other charities and hope to be able to do the same for VUK in the future.

I am also a Trustee for Camden Carers Centre being involved with the HR committee there. This is a charitable organisation related to the Carers Trust and is highly respected for the work that they do in promoting the cause of unpaid carers in the London Borough of Camden through the provision of support, information and advice.

My other interests include gardening, ecology and conservation and occasionally I go sailing on an old Scillonian pilot cutter belonging to my friend.

instigator for the successful Young Vasculitis UK online FB support group. Dannie will be missed especially for her contribution and graphics for Vasculitis awareness month and for her support and participation at the British Society of Rheumatology Conferences. We wish Dannie all the best for

the future and hopefully we will be seeing Danni and her lovely family again, on the famous VUK Thames Riverside Walk.



Volunteer News

Vasculitis UK welcomes Lynn Laidlaw as our Helpline and Online Support / Research Administrator



Hi, I am Lynn, have just turned 50 and live in Central Scotland with my husband and 2 sons. I have been a nurse for 20 odd years, mainly in Intensive Care. I became involved with

Vasculitis UK a few years ago when I first became unwell and was struggling to get a diagnosis, John, Susan and everyone else provided me with invaluable help and support.

I started volunteering with VUK on the helpline over a year ago as I was desperate to give something back to VUK. I am unable to work at the moment due to ill health and appreciate the opportunity to use my medical knowledge and keep my brain ticking over. I had to travel all over the UK and saw lots of different Consultants before my diagnosis became clear so I understand how difficult it can be. Sometimes it's a case of knowing who to see and what questions to ask to help the process. I also support the Vice Chairman Mike Patnick as Research Administrator, help monitor the Vasculitis UK online support groups and attend medical conferences and meetings on behalf of VUK.

KELLY-JEFFRIES

Online Shop and Awareness Graphics

Hi, I am Kelly, I'm 39 years old & I live in Leeds, West Yorkshire with my husband, Ian, who is also my full-time carer, and our 14 year old son. I have three auto-immune disorders; Behcet's Syndrome, Systemic Lupus (SLE) & Antiphospholipid Syndrome (APS).

I'm very lucky to have a fantastic support network as my parents, daughter, son-in-law & 7 month old grandson live near to me. My GP, who has been a massive support, is very nearby too.



I have been poorly since I was a small girl, but, despite numerous tests, scans & specialists over the years, my parents were always told they couldn't find anything wrong with me so, naturally, they believed the medical professionals & thought I was a "drama queen"!

Prior to falling ill, I worked in administration & secretarial roles so I am very happy to be volunteering to help run the VUK online shop and to continue my role in raising Vasculitis awareness.

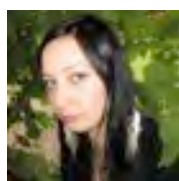
Vicky Taylor

Sadly, Vicky Taylor has had to stand down as a volunteer as benefits advisor for Vasculitis UK due to personal reasons and family commitments. Vicky has helped and supported so many seeking benefit advice and information. Vicky has very kindly written a new benefits and work page for the VUK website, giving as much available information and advice as possible. You can view the new page by following this link <http://www.vasculitis.org.uk/living-with-vasculitis/government-benefits>

Vasculitis UK needs more volunteers if you are interested or know someone who would like to become a volunteer please email: susan@vasculitis.org.uk



Lucy Riveiros



The charity is sorry to announce that Lucy Riveiros has decided to stand down as a volunteer of VUK. Lucy has very successfully

managed the VUK shop for the past few years.

Lucy will be missed especially for her contribution and graphics for the Vasculitis UK Christmas cards, VUK jewellery, wedding favours and for her support and contribution for Vasculitis Awareness month.

We wish Lucy all the best for her the future and for her new business venture.



Some of Lucy's designs for VUK

Well-being

Some great tips for being well

A healthy diet is important for the vasculitis patient, especially for those who are struggling with food intake.

Healthy eating will, by definition, help anyone who has diabetes or who has gained weight and wants to do all they can nutritionally to stave off infection and disease long term.

Some vasculitis patients will require a special diet and this will be arranged via the hospital dietician.

It is important to adhere to this regime. For those with kidney involvement you may find the kidney care cookbook *Rediscovering Food and Flavours* from Kidney Research UK helpful.

This cookbook was created by TV Chef Lawrence Keogh, Head Chef at Roast and BBC's Saturday Kitchen along with Renal Dietician, Diane Green.

The book contains 16 recipes. It is now available free of charge from local Dieticians for patients who need to control their diet due to chronic kidney disease.

It can be downloaded at: <https://www.kidneyresearchuk.org/health-information/resources/free-recipe-book>

If you do not need a special diet, you should aim to cut down on starchy foods - bread, potatoes, rice and pasta, replacing these with fresh fruit and vegetables. You should also avoid processed food and grain fed meat. The omega 3 fats in oily fish such as salmon, mackerel, trout



and sardines are beneficial in autoimmune disease. Also omega 3 can be found in flaxseed, walnuts and green leafy vegetables.

Omega 3 fish oil supplements containing EPA and DHA can be helpful. However, it should be noted that these do react with some medication. These, and other supplements, should not be taken without discussion with your doctor or nutritionist.

A sensible eating regime should be adopted especially for those patients taking steroids. This will help control weight gain. Excessive dieting is not recommended for the vasculitis patient. Also, when taking steroids there is an increased risk of developing osteoporosis. Increased calcium in the diet can help prevent osteoporosis developing. Eating broccoli, yogurt, skimmed milk and tinned sardines are recommended.

Where the drug regime allows the drinking of alcohol this should only be in moderation. There are some immune-suppressant drugs where drinking alcohol is contra-indicated. Your doctor will discuss this with you if it is relevant in your case.

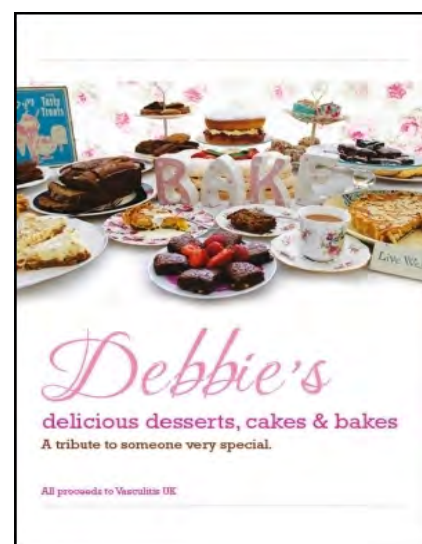
For further information about nutrition, diet and lifestyle - Ani Richardson is a lupus patient with a first class honours BSc and an MSc in Nutritional Medicine. She recommends a useful recipe book: "The everything anti-inflammation diet book" by Karlyn Grimes ISBN 978-1-4405-1029-8

An ideal Christmas present for family or friends and to raise awareness of vasculitis "Debbie's delicious desserts, cakes & bakes recipe book"

In 2013 the sales of this wonderful book raised £6,700 for Vasculitis UK. The book was a fitting tribute to someone very special, Debbie Gregson, who died due to complications of Wegener's Granulomatosis (GPA). Debbie's great passions were her family and baking. The book was put together by some of her close friends using all of Debbie's own recipes.

If you would like to buy a copy for family, friends or just for yourself. (The cost is £5 plus p&p)

Please contact Susan on susan@vasculitis.org.uk or visit the VUK online shop at <http://www.vasculitis.org.uk/shop>



Young Vasculitis Autumn Weekend in the Peak District

A Friday and Saturday night away with the option of coming for one night or both, it will be very relaxed and will give everybody the opportunity to talk about their own type of Vasculitis, but more importantly it gives everyone the chance to make new friends.



November 25th, 26th and 27th 2016 – staying over the Friday and Saturday nights

Age Group 18 – 40 years old

Hathersage YHA House – in the beautiful [Peak District](#)

Sleeps a maximum of 42 people (the whole house is ours for the weekend)

5 minute walk from the train station – trains from Sheffield and Manchester

30 minute drive from the M1, Junction 29

<http://www.visitpeakdistrict.com/Hathersage-Hathersage/details/?dms=3&venue=6070823>

In the village – 4 pubs, 4 cafes, 2 restaurants, take away, a bank and lots of shops

Maybe an early visit from Father Christmas too.

Spouse / partner / close friend welcome, within same 18-40 age group

Cost – 20 people - £18 per night
25 people - £15 per night
30 people - £12.50 per night

so the more take part the less expensive it will be.

Coming along for the weekend will be a young doctor who is a research and clinical doctor for Vasculitis. She cannot wait to be part of it!! Also a young specialist nurse.

Anybody who is interested in coming along or would like any further information please email Emma emma@vasculitis.org.uk or Susan susan@vasculitis.org.uk

Emotions, Relationships and Sexuality

Adapting to life with vasculitis can be a challenge which will become easier the more you know about it.

Most people can cope more effectively with the changes in their lives if they understand what is happening and why. In most cases life will be different but not necessarily worse.

Emotions, relationships and sexuality are subjects which often crop up in conversations either via the VUK helpline or in VUK online discussion groups.



The National Rheumatoid Arthritis Society (NRAS) has published a booklet discussing the impact that RA can have on personal relationships.

This applies much the same to people with vasculitis as it does to those with RA.

NRAS have very kindly given permission to promote this high quality, very readable 100 page booklet via our website for the benefit of those who have vasculitis.

"Clare Jacklin, co-author of this book will be speaking on this topic at the Vasculitis Symposium & Gala Dinner in March 2017".

The hard copy booklet is available free of charge via the NRAS website – page 2 under available publications <http://www.nras.org.uk/publications/2>
If you do order a copy, please make a small donation to NRAS to cover their costs.

More of Our Fantastic Fundraisers



10 year old Simon Coates took part in the Henley Triathlon, for the third year running, on behalf of his mum, Alison who has Takayasu Arethritis

Liz Rogers and dad David at the Birmingham 10k



Nurse, Anna Mayhew, Addenbrookes Hospital ran the Birmingham 10k and London 10k for Vasculitis Awareness Month for Vasculitis UK raising over £560.

Anna says "I have worked in a unit at Addenbrookes Hospital giving treatment to patients with vasculitis for 13 years. My lovely Grandfather, 'Pobs', also had vasculitis (Wegener's). This was only diagnosed when he died in 1992. Things have come a long way in diagnosis and treatments of Vasculitis since then, but there is much more to be done.



Holly Hampshire's sister Tarn & friends tackling the Three Peaks Yorkshire



Jennifer Winnard completed in the London to Brighton Walk on behalf of her Grandad who has Vasculitis



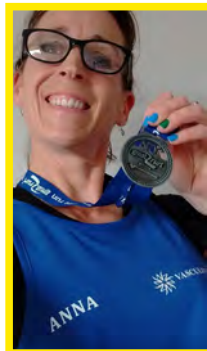
Donations were made on Guests' behalf to Vasculitis UK to celebrate the marriage of Jonathan & Leanne on Saturday 2nd April 2016



I know the importance of trying to raise awareness of vasculitis and all the on-going work and research into the treatment of vasculitis. This is a great opportunity for me to be able to support Vasculitis UK and raise awareness of their fantastic work and support of those affected by Vasculitis.



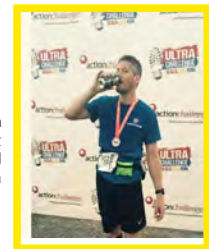
Ann Cully & Pam Greer (Ladies Captain Grange Park Golf Club, St Annes) presenting a cheque for £3870 to John Mills for Vasculitis UK, at the East Midlands Summer meeting June



Anna Mayhew completed in the Birmingham 10k

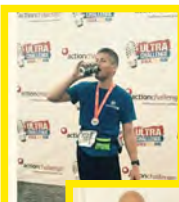


Mark Griffin ran the Bristol 10k on behalf of his wife Sarah



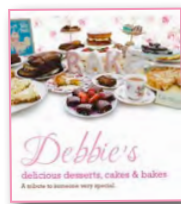
Sami Burgess, skydived on behalf of one of her dearest friends Amie and raised over £1000, Sami wrote a beautiful poem for Amie too.

Do you know about the illness vasculitis...neither did I. Until a dear friend was diagnosed and explained how she felt so poorly and I asked why. Since beginning chemotherapy she continues to walk around with a smile on her face, Not complaining about how the world can be such a cruel place. Instead she is fighting every single second of every single day, Telling the world she is a fighter and is here to stay. I realised how all the problems I had now seemed so small, That when something in the world attempts to knock you down... you refuse to fall. You are an inspiration, a fighter this much is true, The bravest lady I know so I thought well what can I do... After a lot of thinking a light bulb moment finally came... I'm going to go 12000ft up in to the sky and jump from a plane. So now I need all of your help to raise awareness and funds for Vasculitis UK. And to let this lady know you are a hero, you will beat this keep fighting and smiling every second of the way. Do you know about the illness vasculitis...neither did I.



Andy Makin ran in the South Coast Challenge Ultra on behalf of his brother Martin who has vasculitis. Colin Kennedy ran in the South Coast Challenge Ultra on behalf of his wife Carol. Between them both they have raised over £1700.

Sonia Logan completed in the 105k Isle of White Challenge on behalf of mum in law Maxine



Sam Cunningham and friends have raised £850 with the sale of Debbie's Cake and Bakes Book, in memory of Debbie. To buy Debbie's cake and cakes recipe book please follow this link to the VUK shop. <http://www.vasculitis.org.uk/shop>

Charlotte Stoner from the West Country Vasculitis Support Group, based in Teignmouth, is delighted to have received £379 from Jemma, Carol and Liz through the Waitrose' Community Matters scheme.



Hannah Jarvis and friend Kate in The Leicester Twilight Run



Simon Coates fundraising for his mum who has Takayasu

Andrew takes part in the Spanish City Triathlon, "8 down 2 to go" plus Andrew hits the local headlines. An inspirational athlete has battled through a rare illness and chemotherapy sessions to keep up his fundraising.



Read more at: Sunderland Echo <http://www.sunderlandecho.com/news/an-award-winning-wearside-triathlete-keeps-on-competing-despite-illness-flare-up-and-chemotherapy-1-8078482>

Vasculitic Leg Ulcers - Val Reynolds (Leg Ulcer Nurse Specialist Dorset NHS) (With Additional Comments by Lynn Laidlaw)

Assessment



- 1) Always refer to a specialist service if Vasculitis is suspected or diagnosed.
- 2) Insist on a multi disciplinary team approach especially if systemic features are present and make sure your team talk to each other (Dermatologists, Rheumatologists etc)
- 3) Be aware that immunosuppressants make us more at risk of rare, atypical infections, if antibiotics are given insist on a swab test of the ulcer before taking the antibiotics. This should be sent to bacteriology to culture the responsible bacteria and make sure that you have been prescribed the appropriate treatment.

Management

Ask for a specialist nurse to be involved in your leg ulcer care (Tissue viability or leg ulcer specialist.) Many District Nurses or practice nurses won't have experience of managing Vasculitic leg ulcers. A good question to ask any of your care providers is "how much experience/how many patients have you see with this". If the answer is not many don't be afraid to seek a second opinion from a more experienced clinician.

Psychological support is very important to all patients with Vasculitis, especially if you have an ulcer that is taking a long time to heal and impacting significantly on your day to day life, there is also the burden of altered body image.

Counselling or a referral to a clinical psychologist can be very beneficial and help cope with chronic pain as well.

Ask for a referral to a Physiotherapist, Occupational Therapist and Dietician if you are experiencing mobility problems related to the ulcer. Occupational Therapists can provide aids to help at home including perching stools if standing is a problem and also bath aids.

To aid wound healing a balanced diet with sufficient protein is important.

Chronic pain- What can I do to help myself?

The following is an extract from the booklet "Managing Chronic Pain" produced by the Scottish Intercollegiate Guidance Network (SIGN).

The booklet covers many topics to help you understand your pain, covering issues such as how it is assessed and how to manage your pain, including complementary medicines.



You can view the booklet at: www.vasculitis.org.uk/living-with-vasculitis/dealing-with-pain

Nobody else can understand your experience of pain or what it feels like to live with it every day. You are the best person to understand your pain and the best to manage it.

You can try to "self-manage" your pain. This could include:

- Formal self-management programmes (group-based, individual or online); or
- Informal self-management (for example, learning about pain management by reading about it).

Learning about your pain and understanding it can help you manage it well. Healthcare professionals can help you find a self-management programme that suits you.

Take medication regularly: To achieve good pain control, it is usually important that you take your medication every day, as guided by your healthcare professional, even if your pain doesn't feel as bad. You should not change the dose of the medication or when you take it until you have discussed this with your healthcare professional.

Exercise: Staying active can help to improve your pain in the long term. If you are not sure what exercise is best to do with your pain, discuss this with a doctor or physiotherapist.

It is important that if you are experiencing pain you should discuss this with your GP or consultant and follow the regime suggested by your healthcare professional.

IN MEMORIAM



Vasculitis UK receives donations from bequests and funeral collections in memory of particular individuals who have suffered from vasculitis, or where vasculitis affects a family member. Our sympathies are extended to the families and friends of those mentioned below.



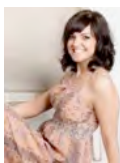
The Trust is extremely grateful for families remembering us in this kind and generous manner.

All donations received will be used to fund activities of the Trust, especially our research projects.



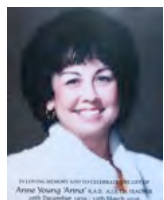
Author Tim Moxley has donated £700, proceeds from his latest book, LCR, to Vasculitis UK

in memory of his wife Lydia, who sadly lost her life in 2015 to complications of vasculitis. The book looks at the life of Lawrence of Arabia, examining who he really was, and what legacy has been left behind by this amazing character. <http://www.vasculitis.org.uk/shop>



Michelle Dring, family and friends have now raised over £5250 for Vasculitis UK in memory of Michelle's sister, Rachel Dring, Rachel sadly lost her life to Vasculitis

October 2014, aged 24 years old. <https://www.justgiving.com/RachelJMDring>



Steve Young, family and Friends have raised over £580 in memory of Steves mum (Anne) Anna. Anna very sadly lost her life to complications of vasculitis March 2016. <https://www.justgiving.com/AnnaYoung39>

[AnnaYoung39](https://www.justgiving.com/AnnaYoung39)

Donations totalling £45 were made in memory of Anne Young, former dance teacher of Folkestone, Kent, who sadly passed away in March 2016 as a consequence of vasculitis. A Justgiving page in her memory also resulted in donations.

A donation of £1000 was received from the J.A.Shone Memorial Trust.

Donations totalling £135 were made in memory of Mr Peter De Basio of Ilkley, West Yorkshire.

Donations totalling £185 were made to Vasculitis UK in memory of Mr Brian Hunt of Maidstone, Kent.

A total of over £915 was donated in memory of Ian Griffin, of Stevenage, who lost his battle with GPA in December last year.

William Barlow of Wigan died due to vasculitis in October 2005. His widow, Eva, passed away in February this year. The family kindly donated a total of £400 to Vasculitis UK in memory of Eva.

Donations to Vasculitis UK totalling £226 were made in memory of Mrs Wendy Maria Hall of Huddersfield.

Vasculitis UK was chosen as the beneficiary of donations to the value of £650 in memory of Mrs Sheila Margaret Gardner, of Banstead in Surrey.

A donation of £75 was made in memory of Mrs Joan Cook of Runcorn, Cheshire.

Donations to the value of £40 were received in memory of Mr Ivor Aston of Nuneaton.

£300 was donated in memory of Mr Leslie Harper of Doncaster, who died aged 76 in February

A cheque for £30 was received in memory of Daniel Carpenter of Warrington.

More than £2,600 was donated by family and friends in memory of Robin Day of Falkirk, who very sadly lost his battle with vasculitis earlier this year.

A fundraising event organised by Diane Dunn, in memory of her lovely mam, Margaret Georgeson of Gateshead, raised £672 for Vasculitis UK.

Donations totalling £140 were made in memory of Joyce Small, of Hampton Hill, Middlesex, who died in May this year.

£348 was received in funeral donations in memory of Ricky Henderson of Skegness, Lincolnshire.

Donations totalling £1,130 were received in memory of Mrs Joyce Margaret Holmes of Minster on Sea, Kent

Vasculitis UK benefited from donations totalling £468 in memory of Mr William Charles Eydman who died in March, aged 87 years.

£150 was received in memory of Mr Fred Sterling, farmer and footballer of Sussex.

Vasculitis UK received a donation of £156 in memory of Mrs Josephine Cole of Notttingham.

A total of £548 was donated in memory of Mr Roger Glynn Morris of Harrogate

A further £110 was donated in memory of Paul French. This was in addition to donations through Just Giving.

A collection at the funeral of Ian Shellard of Heath, Cardiff, raised £284 for Vasculitis UK

A donation of £50 was received in memory of Jo Cole of Eastwood, Nottingham, who died suddenly in March.

Donations totalling £250 were received in memory of Roy Hartley of Huddersfield, who died in May. A further £400 was donated via Just Giving.

The two daughters of David Lynes set up a Justgiving page in his memory. A total of £2580 was raised for Vasculitis UK. David sadly died due to Churg Strauss Syndrome in July this year.

Donations totalling £878 were received in memory of Elizabeth Margaret Lowndes of Ahbourne, Derbyshire, who died in June aged 78.

A donation of £100 was received in memory of Andy Willows of Annesley Woodhouse, near Mansfield, who died 3 years ago due to vasculitis.

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.



IN MEMORIAM



A total of £582 was donated in memory of Michael Kenneth Ward of

Northamptonshire, who died in June.

Donations totalling £182 were received in memory of Mr E.D. Tew of Llandudno.

A total of £272 was donated in memory of Mrs Mary Brenda Regan, who died in June this year.

Donations totalling £490 were made in memory of Michael James Daniels of Shefford, Bedfordshire. Wendy Hardwick fought a 20 year long battle with Wegener's and more recently with cancer. She sadly died in May this year. Funeral donations of £240 were given for the benefit of Vasculitis UK.

Jeanie (Sheena) Taylor was born in 1934. A nurse who specialised in cardio-thoracic intensive care, she was a passionate advocate of the NHS, campaigning politically in its support. In 2011 she was diagnosed with Rheumatoid Vasculitis and MPA after which she set about raising

awareness of vasculitis and rare diseases. Sadly, she succumbed to a massive stroke last October, aged 81. Her family have donated £3350 to Vasculitis UK in her memory.



Donations & Fundraising

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

Stephen & Susan Ellis donated £50 to Vasculitis UK to commemorate the marriage of Mohammed and Lesley Yusuf, in lieu of a wedding present.

Lisa Hetherington raised £122 in sponsorship for Vasculitis UK by taking part in a 10k trail run. This was matched by a further £120

Mark Jones of Chelmsford, Essex, has ANCA vasculitis. He raised £1050 in sponsorship for Vasculitis UK by swimming one mile (64 lengths) in one hour at South Woodham Ferris Leisure Centre. His employers, JW Froehlich, added an extra £250 in matched funding, bringing the total to £1300. Mark presented the cheque at the Vasculitis UK AGM in May.

Pam Greer was elected Lady Captain of Grange Park Golf Club, St. Helens. Her good friend, Ann Cully, has vasculitis and Pam chose Vasculitis UK as Lady Captain's chosen charity for her year.

This resulted in a donation of £3870 which was formally presented at the East Midlands Support Group Summer Lunch.

Cheryl Hobson raised £83 for Vasculitis UK by selling craft items at her workplace, NGA Human Resources.

Victoria Gorton took part in the Manchester 10k run on 22nd May, raising £550 in sponsorship.

The Warden Lodge (No.794) in Lichfield donated £340 to Vasculitis UK. These were the proceeds of a raffle and Garden Party in aid of Vasculitis UK.

The employees of IPM Global Mobility Ltd of Peterborough, nominated Vasculitis UK to receive a donation of £250 from the company's management.

Judith Newell, of St Austell, Cornwall, held an exhibition of her art in the village hall. She raised £400 from the sale of her pictures, which she donated to Vasculitis UK in memory of her niece, Debbie Gregson, who died due to vasculitis 3 years ago.

Nick and Caroline Meyrick held a lunch in their village hall to celebrate their 50th wedding anniversary. Instead of gifts, their friends donated to Vasculitis UK, raising an amazing £711.

Sonia Logan embarked on a long walk around the Isle of Wight. She covered 106km and in the process raised £950 for Vasculitis UK. Sonia's mother in law, Maxine has Takayasu Arteritis.

The pupils of Sherbourne School in Dorset have once again supported Vasculitis UK by collecting and donating a total of £570.

Hannah Jarvis's mum has vasculitis, so Hannah took part in the Gung Ho 5k fun run, raising £242 for Vasculitis UK

On 23rd June, Mona Powell of Kidderminster celebrated her 90th birthday. Both she and her grand-daughter have vasculitis, so she asked friends to make donations to Vasculitis UK in lieu of gifts, raising £660 for the charity.

Bev Massey and colleagues completed the Tough Mudder course at Belvoir Castle in May, raising an amazing £775 for Vasculitis UK. Their employer, Markerstudy Ltd contributed an additional £50, bringing the total to £825.

Ruth Newton took part in the ASDA York 10k run in August, raising £185 in sponsorship.

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



Collection Box Donations – Thank you to :-

Darling Buds Of May Flower Shop Baslow
<http://www.darling-buds.com/>

Charlotte's Book Launch
<http://www.writingtimes.co.uk/charlotte-baker>

Poppy Patch
<http://www.poppypatchwork.co.uk/>

Elaine Aylesbrook, Family Sproats and Ali Marston



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 Kent (Contact Person)

Brian Hart - 01227 369774

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

Lancashire/North West Group

Jann Landles - 07979 180145 - nwvasculitis@hotmail.com

Anita Parekh - 07921 682232 - nwvasculitis@hotmail.com

Leicestershire Group

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

Tricia Cornforth - lvsg@btinternet.com

Lincolnshire Group

Sandra Lee - 0754 514 4777 - sandralee_506@faimail.net

Caroline Meyrick - 01780 460354 - cmmyerick@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 - susan53@icloud.com

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

North East Group

susan@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

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

Yorkshire Group

Website www.yorkshirevasculitis.org.uk

North Yorkshire Group

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

Lynne Jacques - 01274 412378 - lynne@yorkshirevasculitis.org.uk

York, North & East Ridings Group

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

Jennifer Wormald - 01937 586734 - Jennifer@yorkshirevasculitis.org.uk

Yorkshire (North/West) Group

Lynne Jacques - 01274 412378 - lynne@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 - susan53@icloud.com

South Wales Group

Jenny Fulford-Brown - 029-2021-8795 - jenny.swvas@gmail.com

Ryan Davies - ryan@wegeners-uk.co.uk

SCOTLAND

(Contact Person)

Lynn Laidlaw VUK Helpline 0300 365 0075 - lynn@vasculitis.org.uk

Edinburgh and Lothian - Contact Person

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

Glasgow - Contact Person

Patricia Henderson - 0141 581 1711

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

EVENTS CALENDAR

John Mills and Lynn Laidlaw will be representing Vasculitis UK at the Autumn Conference both as delegates and with the Vasculitis Awareness Stand.



The two-day conference brings together consultants and next generation rheumatologists to share and exchange clinical best practice through case-based discussions on four main topics including Vasculitis. <http://rheumatology.org.uk/events/conferences/overview/default.aspx>



UKIVAS Vasculitis Workshop Cambridge for Medical professionals

11th – 13th January 2017

Both John and Lynn will be attending

Vasculitis Symposium Education Day and Gala Charity Ball



4th March 2017 (See pages 15-18 for details)



British Society Rheumatology Spring Conference 2017

Lynn Laidlaw and John Mills will be representing Vasculitis UK at the Conference

Vasculitis Support Group Leaders Annual Meeting 29th October 2016

<http://www.vasculitis.org.uk/about/local-support-groups>



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

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**

Officers, Trustees and Volunteers

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john.mills@vasculitis.org.uk

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Caroline Savage

VICE-CHAIRMAN:

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Prof David G.I. Scott
Dr Richard Watts

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Jennifer Fulford-Brown
Gareth Garner
Dorothy Ireland
Susan Mills
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