



# VASCULITIS UK

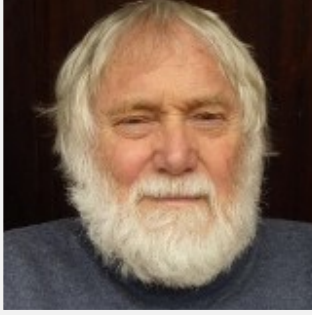
## NEWSLETTER JOURNAL



Spring 2015

Issue 49

## Chairman's Report



Since Vasculitis UK rose from the ashes of the Stuart Strange Vasculitis Trust in 2010, the organisation has grown dramatically in size, influence and effectiveness. Vasculitis UK is now recognised as one of the foremost voices for the vasculitis "community" around the world.

This has certainly not happened by accident; it is the result of a lot of careful planning and hard work, mostly by a very small group of volunteers, but with substantial help and support from a growing number of doctors and other healthcare professionals.

However, success comes at a price. New initiatives, such as having a stand at medical conferences, being involved in medical professional and patient bodies, forging links with other charities and greater involvement in NHS planning all take time. They are in addition to the everyday running of Vasculitis UK - supporting existing and new members, supporting fundraisers, publishing the newsletter and patient information booklets, liaising with doctors, hospitals and local support groups, running the online shop and of course, monitoring the online discussion groups and maintaining the website.

Vasculitis UK has now outgrown its strength! Most of this work is carried out by that same small group of volunteers. Having so few people running the organisation, (most have vasculitis and are past the "first flush of youth") makes Vasculitis UK very vulnerable. If we are to keep Vasculitis UK going and ensure it continues as long as it is needed we need more people involved, with a new governance and management structure. There will be a consultation exercise about this over the next few weeks, which will offer members a chance to influence and vote on the proposals.

We have recently advertised, through the social media, for extra volunteers to help in these activities. The response has been excellent. However we might still need to think the unthinkable and consider having paid staff to take on some core administrative activities.

The Vasculitis UK website has played a very large part in Vasculitis UK's success. It is now viewed by people worldwide. In the UK we take the right to reliable patient information rather for granted, but this is certainly not universal. In order to make our valuable information accessible to a wider range of people, at minimal cost to V-UK, we are planning to add a "translate" facility to the website.

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This will be as part of a proposed major overhaul of the website, which will make it easier and clearer to navigate, easier to maintain, add to and edit and will allow us to offer better services, such as giving local groups the facility to have their own "mini-website" within the Vasculitis UK website.

Last autumn, Vasculitis UK launched a "call" inviting applications by 31<sup>st</sup> January for research grants up to maximum £50,000 each. The trustees agreed to allocate up to £150,000 in total. Without breaching confidentiality, I can disclose that we received ten excellent applications. The selection process, overseen by Mike Patnick and the Scientific Advisory Board, is very rigorous, formal, independent and impartial. The successful bids will be announced in time for the AGM in May.

*John Mills*

Cover photograph: The Valley Girls of Cherwell Valley during their five day cycle ride across Rajasthan in February 2015

# A Day to Remember - Vasculitis Patient Symposium

## Saturday 18th April 2015



The first International Vasculitis Medical Conference took place in Copenhagen in 1988. Since then, every two years there has been a conference in a different city in Europe or the US. In 1993 it took place in Cambridge, in 1998 in Birmingham.

This year the conference is in London on 19-22 April. To coincide with the medical conference and take advantage of the presence of so many top vasculitis experts in London, Vasculitis UK are hosting a one-day Patient Symposium in the same venue as the Conference. We believe that this is the first time such an event has taken place, to tie in with the medical conference.

The event is co-hosted with PMRGCA UK, Lauren Currie Twilight Foundation and the US Vasculitis Foundation.

This will be a very busy, lively, interesting and interactive day for everyone with vasculitis, family and carers or anyone with an interest in vasculitis! A unique opportunity to hear and talk to some of the most knowledgeable vasculitis experts in the world. Truly a day to remember!

**Date: Saturday 18<sup>th</sup> April 2015.**

**Venue: London Business Design Centre, Islington, London. N1 0QH**

**Time: Registration opens 9.15. Meeting opens 10.00. Meeting closes 17.30**

**Cost: £55 per delegate; including registration fees, all day tea and coffee, and full hot buffet lunch.**

**Children: Age 12 or under – free**

**Booking: register and pay online at: [www.eventbrite.co.uk/e/vasculitis-patient-symposium-2015-tickets-14082415885](http://www.eventbrite.co.uk/e/vasculitis-patient-symposium-2015-tickets-14082415885)**

or contact [john.mills@vasculitis.org.uk](mailto:john.mills@vasculitis.org.uk)

### Speakers:

**Dr Neil Basu** (Aberdeen)

**Dr Nina Brown**  
(Manchester)

**Dr Maria Cinta Cid**  
(Barcelona)

**RNS Julie Ingall**  
(Portsmouth)

**Dr Rachel Jones**  
(Cambridge)

**Dr Peter Lanyon**  
(Nottingham)

**Professor David Scott**  
(Norwich)

**Dr Peter Merkel**  
(Philadelphia)

**Dr Nataliya Milman**  
(Ontario)

**Dr Janice Mooney** (UEA)

**Dr Jo Robson** (Oxford)

**Prof Caroline Savage**  
(GSK)

**Professor Ann Morgan**  
(Leeds)

**Dr Louise Watson**  
(GOSH)

**Dr Richard Watts**  
(Ipswich)

*Continued on page 4*

## Vasculitis Patient Symposium - continued

### Topics:

ANCA vasculitis  
[Wegener's (GPA), MPA,  
Churg Strauss (EGPA)]

Giant Cell Arteritis

Fatigue

Drugs and Side Effects

Who gets vasculitis?

Takayasu's Arteritis, HSP,  
Behçet's, CNS Vasculitis  
and Neuropathy

Holistic and Long Term  
Care,

Patient Experiences

New developments in  
diagnosis and treatment

### Programme:

A mixture of short presentations, plus parallel "workshops" on specific groups of topics (Small Vessel Vasculitis; Large Vessel Vasculitis; Less common types of Vasculitis; Ongoing care in Vasculitis) plus "Meet the Doctors" – panel discussions.

For more details of the programme, transport and accommodation, see the website:  
[www.vasculitis.org.uk](http://www.vasculitis.org.uk)



◀ The London Business Design Centre has facilities for the disabled, including a ramped entrance, lifts to all floors and disabled toilets on all floors.



The Patient Symposium has been organised by Vasculitis UK in conjunction with, and supported by, James and Emma Caldwell of innov8 Conference Services, Staly Industrial Estate, Knowl Street, Stalybridge, SK15 3AJ. [www.innov8-conferences.co.uk](http://www.innov8-conferences.co.uk)

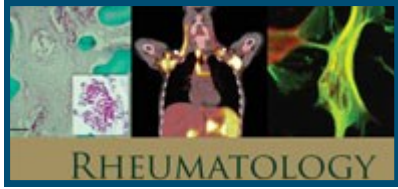


### Vasculitis UK Annual General Meeting Sunday 10th May 2015

The 2015 AGM will be held on Sunday 10th May. Please see the attached flier for full details about the AGM. On this occasion the AGM will be held at a new venue.

**The Village Urban Resort Hotel, Brailsford Way,  
Chilwell, Nottingham, NG9 6DL**

## British Society for Rheumatology Autumn Conference - Case-based discussions



The British Society for Rheumatology's Autumn Conference was held on 27 and 28 November 2014 at the Hilton Brighton Metropole hotel. The theme of the Conference was "Case-based discussions with world experts". John and Susan Mills attended the meeting and Vasculitis UK had an exhibition stand and literature table.

It was an interesting two days, especially the vasculitis section which was introduced by Professor Raashid Luqmani. There were doctors presenting and sharing difficult complex case studies of vasculitis from all over the UK. A Q&A session followed each case presentation, which included lively audience participation.

It was obvious, from the presentations, that no two cases of vasculitis are exactly the same, even if the patients are diagnosed with the same vasculitis disease. It often remains difficult for doctors to diagnose vasculitis, but when you see the treatments which were available 20 years ago and compare these with those which are available today, it is obvious that great strides in drug therapy and treatment have occurred.

It was emphasised that the key is, early recognition, prompt diagnosis, prompt and appropriate treatment and that these actions do improve patient outcomes and save lives.

It was also emphasised that close monitoring of the patient is essential, and this is where a specialist rheumatologist nurse becomes invaluable.

It was suggested that using the BVAS (Birmingham Vasculitis Score) and Chapel Hill Guidelines, would help in diagnosing vasculitis. It was further suggested that blood tests alone should not be the only indicator to show the presence of vasculitis or to indicate disease activity. Other considerations should be taken into account such as the patient's general health, the history given, physical examination and the results of other test.

There were about 200 doctors at the vasculitis meeting, many of them young doctors. It is hoped that the meeting would ensure that those attending would be better able to recognise, diagnose and treat vasculitis in the future.

As a result of the vasculitis session John and Susan did a brisk trade in handing out Vasculitis UK information (booklets and leaflets), and a number of useful contacts were made.

*Report by John & Susan Mills*



My computer went down for about five minutes the other day, so I went downstairs and spoke to my family.

*They seem like nice people.*

# Postgraduate Educational Afternoon Hammersmith Hospital, Imperial College, London

Wednesday the 3<sup>rd</sup> September 2014

Richard Eastoe, together with John and Susan Mills attended the third Vasculitis education session organised by Professor Justin Mason at the Imperial Vasculitis Centre at Hammersmith Hospital in London.

Professor Charles Pusey opened the session giving an update on the progress of the centre. He explained that both their referrals and waiting times were increasing but with changes in hand to address this he was very pleased with their progress.

The first presentation was entitled "Vasculitis - the Paediatric Experience" by Dr Paul Brogan from Great Ormond Street Hospital.



Dr Brogan talked about Henoch Schönlein Purpura (HSP) which is the most common form in children. He said that there was a lot of debate around treatment of the disease and concluded that more clinical trials

were needed.

He spoke about Kawasaki disease and mentioned that in 2013 a group of genes (including FCGR2A, ITPKC and others) had been identified in relation to the disease.

Dr Brogan also talked about Polyarteritis Nodosa (PAN) saying that a genetic link had been made via genetic mutations in the growth factor ADA2. He felt that with this discovery and more research and trials there was a good chance of finding a cure for PAN.

Dr Brogan also mentioned CANDLE syndrome (Chronic Atypical Neutrophilic Dermatositis with Lipodystrophy and Elevated temperature) in relation to PAN. CANDLE is an auto-inflammatory disease as opposed to an autoimmune one like Vasculitis but has similar characteristics and treatment options.

Dr Brogan also talked about current trials and research into ANCA vasculitis in children and finally spoke about Takayasu's. He wondered whether there would be benefit from working

with Prof Justin Mason at Hammersmith.

Following Dr Brogan's presentation there was some interesting discussion during which he mentioned a new type of vasculitis - STING (STimulator of INTERferon Genes) Associated Vasculitis of Infancy.



We then heard from Professor Simon Bowman, the new president of the British Society for Rheumatology (BSR). Prof Bowman outlined his challenges for the

BSR and said that they welcomed the opportunity to build relationships with patient organisations like Vasculitis UK.

Next up was Dr Suchita Nadkarni from the Queen Mary University of London. She spoke about the role of neutrophils in the progression of Giant Cell Arteritis (GCA). Her conclusion was that neutrophils are important and may contribute to the re-emergence of GCA.

Dr Steve McAdoo from Imperial College was next to speak about crescentic glomerulonephritis (CGN) in multi system autoimmune disease. He said that CGN can be seen in Lupus and HSP but is most common in anti-GBM disease. Standard induction and maintenance treatment leads to good outcomes but he felt that a kidney biopsy is useful in understanding the disease progression and can influence the treatment options.

Dr Enrico Tombetti, an honorary specialist registrar at Imperial College, spoke about the treatment of refractory Takayasu's with Tocilizumab. He said the drug was an option but that MRI and PET scans were essential to assess inflammation in blood vessel walls. Prof Justin Mason noted that some of the Italian scanning techniques were unfortunately not available on the NHS due to time and cost constraints.

After the break came two case studies.

*Continued on page 7*

## Postgraduate Educational Afternoon - continued

The first case from Charing Cross hospital was not vasculitis. However the patient had been treated with abnormally high levels of Rituximab and developed Enteroviral Encephalitis. The conclusion was that when using Rituximab it is essential to monitor IgG levels to reduce the risk of viral reactivation such as this, Hepatitis B and Progressive Multifocal Leukoencephalopathy (PML). Interestingly a comment was made that Dr David Jayne warns that the most common cause of infection is high steroid use.

The second case from Hammersmith was of a patient with Idiopathic Retroperitoneal Fibrosis (IRF). This is a rare and frequently relapsing disease of the aorta. Treatment with steroids is

effective and whilst there have been no clinical trials, immunosuppression may also be appropriate and Rituximab has been shown to be very effective. The conclusion was that IRF is a systemic autoimmune disease and that CT and MRI imaging are essential for diagnosis and management.

This was another full afternoon at Imperial. We continue to be very privileged to be invited to these events and to gain some fascinating insights into new research and treatment options for some of the rarer autoimmune diseases.

*Report prepared by Richard Eastoe*

## 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, 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](http://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 person to manage it.

### What can you do to help control your pain?

**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 to manage it well. Self-management programmes can help you to do this and you should consider them alongside other treatments]. 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.

The above is a guide to self-management of your pain. 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.

## Vasculitis Education Day - Manchester 4th December 2014

In December, Richard Eastoe, John and Susan Mills attended an education day for clinicians organised by Dr Sahena Haque, Dr Nina Brown and the NW Vasculitis Steering Group.

This was a packed day of talks by eminent clinicians. Vasculitis UK had arranged to film the presentations and which will hopefully be available to view online.

First to speak was **Dr Phil Riley**, a paediatric rheumatologist at the Royal Manchester Children's Hospital.

He spoke about a number of types of paediatric vasculitis although he said that 70% of cases were Henoch Schönlein Purpura (HSP) or Kawasaki's Disease. He concluded that HSP was predominantly benign and self-limiting. But he believed that more research was needed regarding HSP with kidney involvement. He also thought that adult and childhood HSP are the same condition.

Next to speak was **Dr Hedley Emsley**, a neurologist from the Royal Preston Hospital.

He spoke about neurological involvement in vasculitides such as PAN, Churg Straus (EGPA), Wegener's (GPA) and Giant Cell Arteritis (GCA). He told us how infection was a common cause of neurological problems such as stroke and warned to be aware of similar mimics of vasculitis.



After a break came **Professor Ian Bruce** a rheumatologist from the University of Manchester.

Prof Bruce spoke about his experiences using Rituximab to treat vasculitis. He said that there was good clinical

evidence for using Rituximab in both induction and maintenance of remission in ANCA vasculitis although he felt that it was important to be involved with a specialised treatment centre.

**Professor Raashid Luqmani**, a rheumatologist from the University of Oxford was the next speaker; his topic was about the assessment of small vessel vasculitis.

He discussed the limitations of the ANCA test and the advantages of using the Birmingham Vasculitis Activity Score (BVAS) and the Vasculitis Damage Index (VDI) both prior to treatment and then during maintenance assessment.

Prof Luqmani reported that the clinician driven UKIVAS registry now covers all types of vasculitis. The new RUDY patient driven registry focuses on patient outcomes but will be linked with UKIVAS.

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*“The RUDY patient driven registry focuses on patient outcomes but will be linked with UKIVAS”*

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After lunch we heard from **Professor Rob Moots**, a rheumatologist at the Behçet's centre in Liverpool.

Prof Moots described Behçet's syndrome and the multi-disciplinary approach they take. He said that they have referrals from all over the UK and use a Behçet's database which will be linked to the UKIVAS registry.

Vasculitis UK's Chairman, **John Mills** then spoke about the patient experience. John spoke of his background and experience with vasculitis. This was a great opportunity to speak directly to clinicians about the relationship between patient and professional.

**Professor Lorraine Harper**, a nephrologist from the University of Birmingham, spoke about (AAV) ANCA Associated Vasculitis.



Prof Harper said that immunosuppression saves lives but infection and cardiovascular disease can still kill patients. She said that the most common problem was respiratory infections.

She said that non-live flu and pneumonia vaccination is safe and recommended. The vaccine response should last for at least two years.

In conclusion Prof Harper said that there was a need to improve the assessment of risk factors in the treatment of AAV.

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## Roving Reporter - Interview with Professor David GI Scott

Prof David GI Scott has recently "retired" as consultant Rheumatologist at the Norfolk and Norwich University Hospital. He is still honorary Professor of Rheumatology Norwich Medical School. He is a past President of the British Society for Rheumatology.



Prof Scott recently agreed to be the chair of the new Vasculitis UK Scientific Advisory Board. In his long and distinguished career he has been author and co-author of numerous publications on rheumatology and on vasculitis. Here Prof Scott talks about his professional life and gives us a little insight into what makes him tick.

**Hello, and thanks for agreeing to this interview. Perhaps you could start by telling us why you are known as David GI Scott.**

There is another professor of rheumatology called David Scott. He is David L. Scott who is Professor of Rheumatology at Kings Hospital London. We were both lecturers at Birmingham and we are also good friends. We were appointed as professors at about the same time, and we have both been the Presidents of the BSR. As I'm sure you will appreciate the similarity in names has caused quite a bit of confusion over the years. So he is Prof David L Scott and I'm Prof David GI Scott.

**So, what made you decide on a medical career?**

My father was a surgeon, my mother a GP and many of my family were also doctors. From a young age I vowed I would not become a doctor. I first did engineering at university, but I found that a bit boring. I also noted that the medical students worked hard and played hard and were more fun!. Away from family pressures I decided that maybe a medical career was what I really wanted. Needless to say my parents were speechless.

*My father was a surgeon , my mother a GP and many of my family were also doctors. From a young age I vowed I would not become a doctor*

**You have always had a special interest in treatment and research into vasculitis - can you tell us why'?**

When I started as a registrar in Bath in the late 1970's I met Dr Paul Bacon and he got me interested. Like many vasculitis doctors I have to

thank Paul for my early introduction to vasculitis. From those beginnings I then did an MD in Vasculitis from 1979-81. My interest in treating patients with vasculitis and undertaking vasculitis research has continued since.

**Even though you are retired I believe you have several honorary appointments.**

I am "retired" from my NHS post but I still have an honorary contract at the Norfolk and Norwich University Hospital where I do a vasculitis clinic once a month. I have an honorary appointment as Chair of the Medical School, and I also work for one of the local Clinical Commissioning Groups where I act as their secondary care representative.

**Along with Dr Richard Watts you were the co-editor of the book "Vasculitis in Clinical Practice". I understand this is currently being revised.**

Yes, the revision has recently been finalised. Dr Chetan Mukhtyar has collaborated with Richard and me on this revision. There's a new chapter on IgG4 disease (see note on page 9). Mainly the changes are to do with the change of nomenclature for the various diseases following the decisions made at the International Chapel Hill Consensus in 2012. There's also a chapter updating the treatment of vasculitis in view of published research and the recommendations on the use of Rituximab in the treatment of vasculitis.

**As chair of the new V-UK Scientific Advisory Board how do you see your role?**

I see my role as ensuring that whatever money we have to spend on research is spent advisedly. Also ensuring that we try to move forward in a sensible way, reflecting the requirements of the membership, and with research applications being appropriately peer reviewed. In a nutshell, to give a professional and scientific assessment of the research funding requests, whilst being sensitive to the needs of the charity.

**Thank you for taking part in this interview. Finally, perhaps I could ask, you lead a very busy life, but does Prof David Scott get time to relax, and if so, how?**

I love to relax with my wife and family. I have three sons and one granddaughter who is 2 and a half. I play a little golf - but not very well. I have recently taken up running again, which I do rather slowly at the moment. However I join lots of other runners on Saturday mornings as we attempt the Park 5K. I've managed 12 park runs this year.

*Continued on page 10*

## Interview with Prof David GI Scott continued

My mother was a great fisherwoman and she loved to fish on the Spey, and she passed on her love of fishing to me. Every year I go up to the Spey and I find fishing there extremely relaxing.

Here is a photograph of me with a salmon I caught a year or so ago.

RR



### Note on IgG4

IgG4 is a newly recognized entity, but in fact it is an old one. The disease can involve multiple organ systems, frequently in a metachronous fashion (i.e., first one organ, then another, and then another). The disease tends to cause mass-forming lesions that can mimic cancer, infections, and conditions such as granulomatosis with polyangiitis (Wegener's) and eosinophilic granulomatosis with polyangiitis (Churg Strauss).

## Vasculitis Education Day - Manchester - continued from page 8



**Prof Justin Mason**, a rheumatologist from Imperial College London. Was the last speaker of the day. Prof Mason spoke about assessment and management of Takayasu's and large vessel vasculitis.

He said that delay in diagnosis is the main issue and that there is a definite role for aggressive immunosuppression prior to surgery as long as critical intervention is not required. He felt that MRA, CTA and FDGPET imaging has transformed the diagnosis and management of Takayasu's.

He reported his success in treating patients with Tocilizumab and said that Rituximab might be another effective treatment.

Prof Mason also said he believes that there is a large vessel form of GCA that is confined to the aorta.

*“MRA, CTA and FDGPET imaging has transformed the diagnosis and management of Takayasu's”*

It was a privilege to attend this event and to hear leading clinicians talking passionately about their work in research and the treatment of people with vasculitis.

*Report by Richard Eastoe*

### **Editor's note:**

*This was a very full programme and this summary doesn't really do it justice. However a more comprehensive report will be added to the Vasculitis UK website in due course.*



Vasculitis UK has 3 entries available for the British 10K London Run on Sunday 12th July 2015.

If you would like to enter the event to raise money for Vasculitis UK please contact Dorothy Ireland - 07721082113 or e-mail: [dorothy@vasculitis.org.uk](mailto:dorothy@vasculitis.org.uk)

## Thames Riverside Walk



very windy, cloudy but dry day. We were really pleased about the number of people taking part, and a massive amount of money was raised. We decided to make it an annual event and changed the name from Jacqui's Thames River Path Walk to Vasculitis Annual River Path Walk.

The 2014 walk was less well attended but we had a really good day. At the finish of the walk, we found a small café called The Kitchen@Tower. The café has a small outside seating area which, although it is in the centre of London, was quite quiet. The waiter serving was really kind when we told him we had just walked 10 kilometres and gave us a 10% discount on our drinks. Then Sally, the manager, came out and gave me £20.00 to give to V-UK.

I met Karen St.Ledger when I started the SE London/NW Kent Support Group and we have become firm friends ever since. We arrange to meet every so often for coffee/tea to support each other and have a general chat. We both suffer from GPA/WG so it is great to have a good friend with the same disease to share our thoughts on medications, symptoms and how we are generally feeling. It was during one of meet-ups that I had an idea to have a walk along the Thames to maybe raise some money for V-UK.

We thought this would be a great place to meet up at the end of the 2015 walk. I emailed Sally asking what the cost would be to hire The Kitchen@Tower and amazingly Sally told us that it would be free, as long as it is after her lunch trade.

I hope you will join us and support VUK and raise awareness of vasculitis as well as getting sponsorship for your walk. John Mills will be giving a talk when we have finished the walk we all meet up at the Kitchen@Tower.

For the 2013 walk we had V-UK yellow balloons, many of which burst as it was a

We are looking forward to meeting you all.

## Join us for The Annual Vasculitis Thames Walk: 16th May 15

**New for 2015: two routes available 6 or 3 miles  
plus finish celebrations at The Kitchen@Tower**



Walk price includes entrance to The Kitchen@Tower and a Thames Walk Goodie Bag including T-shirt, fundraising information, and more !

## A Day in the life of Sarah Logan, Clinical Nurse Specialist, University Hospitals Birmingham NHS Foundation Trust

My day starts travelling to work through scenic Bournville, home of Cadbury's, the chocolate manufacturers.



The traffic around the hospital is ever increasing and so I park my car in Selly Oak and walk through the University of Birmingham campus which is home to 'Old Joe', the 100 year old University clock tower. This is the tallest free-standing clock tower in the world and dominates the skyline and is also home to peregrine falcons, although I have yet to spot them!

The new Queen Elizabeth Hospital is adjacent to the old Queen Elizabeth Hospital and both are close to the University of Birmingham and the Medical School.



The walk takes about fifteen minutes and gives me the chance to prepare myself for the day ahead. My day starts with checking emails, phone messages and outstanding investigation results, hopefully with a cup of tea! Then I aim to sign off clinic letters which can then be sent out to patients and their family Doctors.

I offer a telephone helpline service for patients and healthcare professionals also call in with queries. This is an interesting and challenging

part of my role – I never know what the next phone call will involve. One phone call can change the rest of my day and involve liaising with the medical team and arranging for someone to come to the Kidney Assessment Team for review and possibly admission for investigations and treatment.

I visit any new patients that are in-patients; I spend time with them explaining their condition and the treatment plan and give them an information pack about Vasculitis including details of Vasculitis UK. I also see patients when they are in for day case treatments. I work closely with our team who administer treatments such as Cyclophosphamide and Rituximab, particularly ensuring that patients have the information they need about their treatments and that the necessary monitoring is completed.

Thursday is Vasculitis clinic day and so we have a team meeting at midday to prepare for the clinic. This is followed by a Joint Ear Nose and Throat (ENT) clinic which is held in the ENT department of the new Queen Elizabeth Hospital.

The clinic provides the opportunity for people with troublesome ear, nose or throat symptoms such as nasal crusting and bleeding to be assessed jointly by a Consultant from the Vasculitis team and an Ear, Nose and Throat Consultant. Assessment often includes naso-endoscopy (passing a small camera into the nose) which allows us to look closely at the lining of the nose and throat and identify whether there is evidence of active Vasculitis which may need extra treatment.

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*Working together as a team means we  
can make informed decisions with  
patients at the clinic*

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This is a very interesting clinic and working together means that we can make informed decisions with patients at the clinic and make a treatment plan without the need for them to return to the Vasculitis clinic for results.

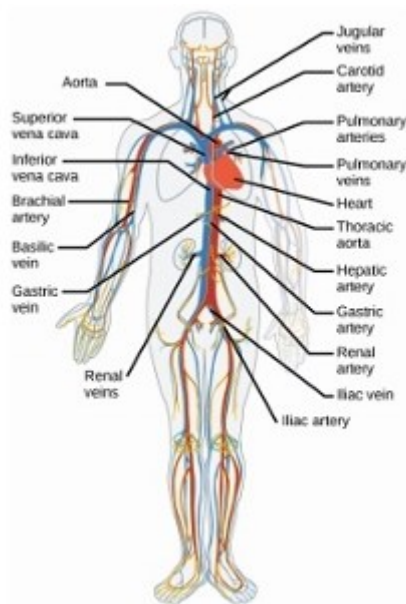
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# Takayasu Arteritis

## What is Takayasu Arteritis?

Takayasu Arteritis (TA) is an inflammatory disease of the large arteries. TA particularly affects the aorta (the main artery taking blood from the heart to the rest of the body), and the pulmonary artery (which sends blood to the lungs). The major arteries that arise from the aorta may also be affected. These include the subclavian arteries that supply the arms, renal arteries to the kidneys, coronary arteries in the heart and carotid arteries in the head and brain.

In some patients, widening of the aorta results in failure of the aortic valve in the heart, necessitating replacement. In 90% of patients one or more of these arteries become narrowed or blocked, hence TA is also known as "Pulseless disease". In 25 per cent of patients part of an artery may swell, forming an aneurysm.



*Illustrations above: Circulation diagram sourced from the "Arteries, Veins, and Capillaries" section of Robert Bear and David Rintoul's article, "The Circulatory System," Connexions, August 19, 2013.*

## Who are affected?

TA is a very rare disease of young people with the initial symptoms arising in those between 5 and 40 years of age. Although both sexes may be affected, 80-90 per cent of patients are female. TA has worldwide prevalence and may affect all races. However, the disease is thought to be more common in patients originating from the Far East, Japan and the Asian sub-continent.

## What is the aetiology (cause)?

The cause of Takayasu's arteritis, and why an individual develops the disease at any one time remains unknown. The disease is most likely to be the consequence of environmental factors and a susceptible genetic background. One common but unproven hypothesis is that it is precipitated by an infection. The rarity of the disease worldwide means that it is very difficult to identify an underlying cause. The inflammation involves white blood cells invading the wall of the artery predisposing to damage and scarring.

## What are the symptoms?

The initial symptoms of TA are typically non-specific and may include one or more of: malaise (a general feeling of being unwell), profound fatigue, fever, night sweats, weight loss, myalgia (muscle pain), arthralgia (painful joints), rash. Additional symptoms can include dizziness/light headedness, shortness of breath, cramping pain in the arms, legs or chest on exertion.

Carotidynia, (pain and tenderness over the carotid arteries in the front of the neck) is also found in approximately 25 per cent of patients.

## Making a diagnosis

For diagnosis the patient should fulfill three or more of the criteria: 1. Onset of disease  $\leq$  40 years. 2. Claudication (severe muscle pain due to cramp caused by narrowed blood vessels) of an extremity. 3. Reduced brachial artery pulsation. 4. Difference in systolic blood pressure  $>10$  mmHg between the arms. 5. Aortic or subclavian artery bruit. 5. Angiographic abnormality

In practice clinical examination most commonly detects decreased or absent pulses in the arms and less frequently in the legs. Using a stethoscope, bruits\*, (a loud 'whooshing noise') may be detected, over the neck, chest or kidneys indicating narrowed arteries. High blood pressure is commonly found. In recent years specialist scans have been introduced to aid diagnosis and identify inflammation, narrowing and dilatation of arteries and the extent of the disease. These include positron emission tomography (PET scanning), magnetic resonance angiography (MRA), high-resolution ultrasound and CT angiography

## Treatment

Treatment is aimed at improving symptoms and preventing further damage and/or scarring to the blood vessels.

*Continued on page 13*

## Takayasu Arteritis continued

When there is active inflammation in the arteries, treatment is started with steroids, usually prednisolone, and often in combination with an immunosuppressant drugs. Those commonly used include methotrexate, azathioprine or mycophenolate. These drugs increase the effectiveness of steroid therapy and help to reduce the dose of steroids required. In patients with persistent or very severe disease, cyclophosphamide may be recommended. In recent years, for refractory disease, biologic therapies, including tumour necrosis factor inhibitors such as etanercept and infliximab have been used successfully, as has tocilizumab which targets interleukin-6.

### Pregnancy and Takayasu arteritis

Many women with Takayasu's arteritis achieve one or more successful pregnancies. It is very important for a woman planning to have a baby to talk to her specialist before trying to conceive.

### Prognosis

The long term prognosis of TA is good. Approximately 20 per cent of patients will have a monophasic self-limiting disease (just one inflammatory episode). More typically, the disease follows a relapsing and remitting

course.. In the majority of patients the TA appears to 'burn out' after a period of 2-5 years, and treatment can be gradually withdrawn. With early intervention and careful monitoring in a specialist centre TA can be effectively treated.

### Key Points

- TA is very rare in the UK and mainly affects young women
- Presenting symptoms are often non-specific and missed
- Treatment with steroids and immunosuppressants is effective in many cases
- Surgical repair or angioplasty to narrowed blood vessels should only be performed in severe cases and after the inflammation is controlled.

The full text of this article can be read and downloaded at:

[www.vasculitis.org.uk/about-vasculitis/takayasu-arteritis](http://www.vasculitis.org.uk/about-vasculitis/takayasu-arteritis)

## A Day in the Life of ..... Continued from page 11

A brisk walk follows to the Old Queen Elizabeth Hospital where the Vasculitis Clinic is held in the Wellcome Trust Clinical Research Facility. The research facility provides the additional support needed for the wide range of research projects that many of our patients are involved in.

*I help people to come to terms with coping with troublesome symptoms such as fatigue.*

We continue to look for better ways of managing Vasculitis and reducing the risk of long-term complications from both Vasculitis and its treatment.

Vasculitis clinic is a busy time. As well as being part of the team seeing patients I support people, helping them to come to terms with

their condition, understanding their treatment and coping with troublesome symptoms such as fatigue. I organise treatments and monitoring and have sources of information about Vasculitis and the treatments we use. I also refer patients to other health care professionals such as the Clinical Psychology team for help with issues such as adjusting to a long-term condition and fatigue management.

At the end of clinic we have a brief review meeting and I usually leave with a big 'to-do' list! After clinic it's time for home. 'Old Joe' marks my leaving time and next stop is home to cook dinner, take my daughter to her dance lesson and walk our Border collie dog.

*Sarah Logan*

## Personal Story: When feeling ill was simple



*Caroline Meyrick has Takayasu Arteritis and here she tells us her story about the early days and her journey to a diagnosis and proper treatment.*

In the old days, before vasculitis, feeling ill was a simple business, and quickly cured! A couple of paracetamol and a long walk with the dogs sorted most things. If that failed, a session with the physio or a short course of antibiotics fixed me up and sent me back into the usual fray. After all, I didn't have time to be ill - teaching, three children, two dogs and a husband who was often away kept me from such foolish ideas.

Then I started having unexplained pains in my arms; flickers of pain that centred in a some places and then moved on to others. I would get home from work and take the dogs out. It felt as though I was 'walking through treacle' and I was slightly sick and dizzy. Stress, I told myself, or low blood sugar. Calm down, dear, and don't take them out until you've had a cup of tea and a biscuit. Nothing to worry about.

Then more: I would suddenly lose about half a stone in weight and my skirts and trousers would need belts at work. But hey, that was great and wasn't I clever to be able to do that without trying? Meanwhile nights were getting difficult with night sweats and constant attacks of cramp that woke me two or three times, so I was tired whenever I woke up. "It's your age" said my GP, "try some HRT and see if that helps". It made no difference, but I was reluctant to stop once I'd started, and my GP had begun to pigeon hole me into his slot for the tricky and unexplained.

I tried keeping a list of some of the symptoms, and some of the things that were becoming more and more difficult. But it looked so bizarre that I tore it up and told myself that no one would believe it, and that I must be imagining things. I was an assessor for the Duke of Edinburgh Award scheme for fifteen years, so I thought I was fit, but colleagues started teasing me about my blotched and shattered state when I got to the top of a hill, and I worried about the numbness and coldness of my fingers. On the other hand most of them were younger than me, and I still got up the hills with them! So snap out of it, get fitter before you set out, I told myself.

But still, things were getting hard - lifting heavy pans, changing pillowcases, doing up my bra, holding a heavy textbook, going for a swim, buying cat food from the top shelf of the

supermarket. I'd stepped down from full time teaching and was writing a textbook, and had to shorten the time spent at my computer as I felt so sick and dizzy. And I was so tired all the time.

*"It's your age" said my GP "Try some HRT and see if that helps." It made no difference, but I was reluctant to stop once I'd started.*

I went back to school part time to cover a maternity leave; I thought a change of scene would do me good. One day I turned round from the board and looked at my students - it was like looking at a jigsaw of the class, with the pieces moving about and the colours slightly funny. It was a small class, and near the end, so I took some paracetamol, went home and rang the optician. He checked my eyes and could find nothing wrong. Perhaps it was a form of migraine? Stupidly I didn't tell my GP about it, even though it happened again.

Then I collapsed on New Years Day. I had been feeling like rubbish over Christmas, but we had my husband's ninety-one year old aunt staying with us, and she was full of beans and putting me to shame. Don't collapse on New Years Day; it just isn't a good idea and you get sent home with 'unexplained collapse' on your notes and fitted into another pigeon hole. Three more collapses and blue light dashes to A&E, three more referrals and back home because the big monitors there said that there was nothing wrong with me.

My GP was getting exasperated, particularly as I now had no pulse anywhere in either arm, and no one in the hospital seemed concerned about it. Then another referral to a different team - the vascular surgery one - and everything changed. They took the lack of pulse seriously, told me that they thought I was suffering from 'pulseless disease' or Takayasu's arteritis, and that the problem was treatable. This was enormously important psychologically. After all a disease that is 'as rare as hens teeth' is something that you (and your doctors) google and the internet is gloomy, especially if you look at American websites.

Continued on page 16

## Personal story continued

The hospital diagnosis was confirmed by an ultrasound of my arms, a CT scan and a biopsy of my temporal artery that was clear and pointed to Takayasu's rather than Giant Cell arteritis. Further confirmation came from a PET scan.

My diagnosis came about three years after I first noticed the claudication in my arms, and my arteries must have started blocking up years before the pain started.

Why did it take so long? I don't blame my GPs who were dealing with something that our local surgery had never met before, and doctors are trained to start with the simple diagnosis and work down. They just never got as far as me.

I probably blame myself a bit for not telling enough of my weird and wonderful symptoms and giving them a chance to think a bit more. Or for connecting the optician and the GP.

I do think that there is a problem with modern medicine, which relies so much on machines and not enough on touch. The most useful person in this whole journey was the masseuse who sent me back to my doctor as she had

never had someone respond to massage in the way that I was doing.

Three years later, I have a diagnosis of large vessel vasculitis, and treatment with rituximab has restored me to a quality of life that once seemed impossible. I even hit two fours in a family cricket match last summer!

*Caroline*



*The photo shows Caroline with the junior part of the cricket team.*



## 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 your 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.

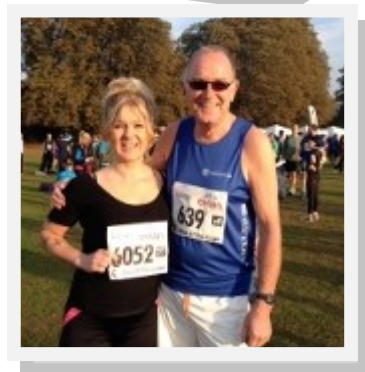
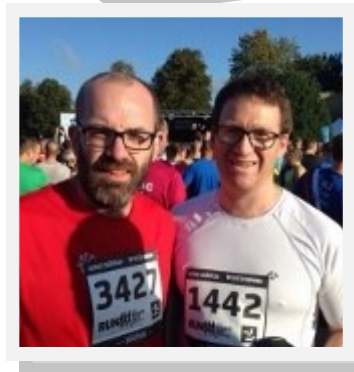
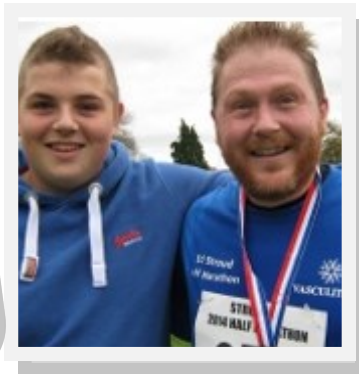
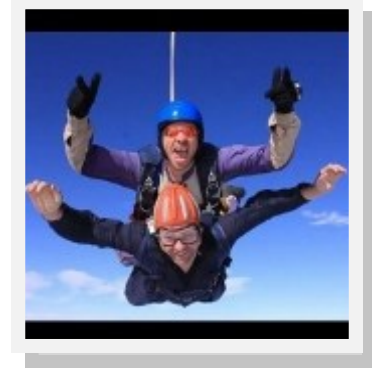
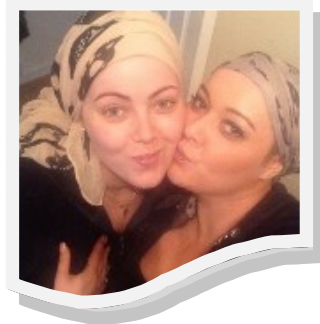
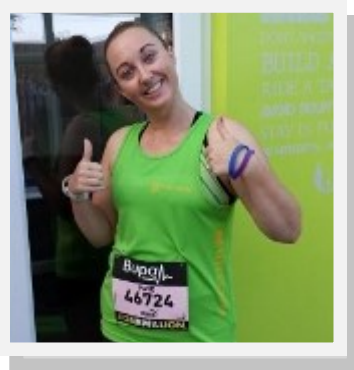
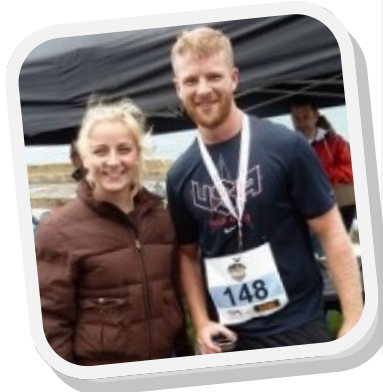
Please remember that **Gift Aid** can increase your donation by 25 per cent at no extra cost to you.

For further information about donating to Vasculitis UK, please contact the Treasurer: contact details on page 28.





## A few fundraising photographs



**Row 1:** Elliott Smith, Marios Kakos, Annie Jennings. **Row 2** Faye Bell, Grace & Paula Timmins, Paul Hunter  
**Row 3:** Team Harry, Ed Butcher & Dan, Richard Holland. **Row 4:** Neville Horner, Peter Micallef, Richard Jones & Diane

These are just a few of our Fabulous Fundraisers. See more at: [www.vasculitis.org.uk/about/fundraisers-photo-gallery](http://www.vasculitis.org.uk/about/fundraisers-photo-gallery)



## Our fantastic fundraisers

*Vasculitis UK is very grateful to everyone who fundraises for the charity. Without your help and dedication we would not be able to help vasculitis patients, raise awareness and fund research here in the UK. Thank you to you all.*

In August 2014 **Elaine Alesbrook** and **Sarah Skinner** together with Ruby and William held a Cake and Bake Stall at Claycross, Derbyshire. They raised £165.

**Rita Allen** of St Osyth, Essex held a garden party in the summer of 2014 and raised £335. Rita's garden parties have been an annual event but unfortunately she is now unable to carry on with this tradition. Many thanks Rita for all you've done.

In December **Ruth Allen** of Buxton sold costume jewellery at a local bazaar. The jewellery had been kindly donated by a friend, **Tony Paine**, and had been made by his Auntie. The sale raised £109.

**The Beaverbooks Charitable Trust** of St Annes on Sea have kindly donated £617.50 from the money they allocate from the Trust annually. V-UK member, Julie Brady is employed by Beaverbooks and we are grateful that Julie recommended our charity this year.

**Faye Bell** has completed several of the 8 half marathons she is attempting in 2015 to raise money for V-UK. So far this year she has raised £50.

**Sue Bodill** of Standish donated her £50 Christmas card money to the charity.

**Paul Brightwell's** wife was diagnosed with vasculitis in 2014. They work together and because she was ill he didn't get time to shave. So he grew a beard and then had it shaved off to raise £250 for V-UK.

**Buckingham Charity Cup Competition** - once again the members donated £70 to V-UK in October 2014.

**Ed Butcher's** wife Sarah was diagnosed with WG (GPA) in 2012. To show his appreciation of the help and support given to them both Ed entered the Stroud Half Marathon in October. Ed has raised £822.50

Thanks to Ali Marston and the customers of **Caythorpe Post Office**, near Grantham for the £79 raised through the charity box on the counter.

**Christmas cards** - Thank you to everyone who donated money to V-UK in lieu of sending Christmas cards in 2014. Over £150 was raised.

**Mary Coulson memorial walk.** The annual walk in Benfleet organised by Mary's husband Barry and their daughter has raised £300.

**Amanda Creed** held a bake sale in November at her place of work (Nike). Amanda has WG (GPA) and was helped by a colleague, and a local shop kindly donated some baked goods to add to Amanda's work.

In October **Claire Douglas** entered the Cardiff Half Marathon for a family member, Col, who has vasculitis. Claire raised £110

The Partners of **ES Group Ltd** of London, decided not to send corporate Christmas cards in 2014 and instead to donate to a charity chosen by the staff. Vasculitis UK was chosen and ES Group have kindly donated £400.

**Judith Fullwood** of Bridgnorth, and her husband who was recently diagnosed with vasculitis, kindly donated £100 in lieu of sending Christmas cards and the cost of postage.

**Generation Gap** are the singing duo of father and daughter - Clarry Bean and Abby Mansi. At their Christmas concert in 2014 they raised £125 for V-UK

**Ghostbusters UK** continue to raise funds for Vasculitis UK - their chosen charity in 2015. £146 was raised at a tombola and £155 at DigiCon Doncaster.

Tony Hart, his family, and the customers at **The Gryphon Harvester**, Grange Park, London [www.harvester.co.uk/thegryphonfield/](http://www.harvester.co.uk/thegryphonfield/) have kindly donated £150 from "bits and bobs" and from the collection tin at the hotel.

In the summer of 2014 the clients of **Hairforce hairdressers of Corton**, Suffolk, held a raffle for V-UK and raised £105.

**Team Harry** (Craig, Sam, Alan and Claire) had a great day in the Great South Run, finishing in respectable times, and raising £840. They did this for their Dad who watched at home and was so proud.

**Jenny Harwood** of Rainton near Thirsk makes beautiful decorations and aprons which she sells to raise funds for V-UK. In October she donated £125. In December she held a Christmas stall and raised a further £321.60.

*Continued on page 19*

## Fantastic fundraisers continued

**Chloe Hoggood** and friends raised a further £788 towards the Lands End to John O'Groats cycle ride in 2014.

**Hunstanton Methodist Church** presented a cheque to Lesley Noblett (who represented the charity) for £1000 raised by the congregation. Their minister had to retire early after developing Wegener's (GPA)

**Paul Hunter** braved the skies in September and skydived for young Jessica Watson who has CNS vasculitis. Paul raised almost £900 which included a £200 donation from **Seaton Delaval Community Matters**.

**Mrs M Jackson** celebrated her 65th birthday in 2014, and kindly donated £25 to V-UK

**Annie Jennings** held a coffee morning and finished this off by subjecting herself to the ice bucket experience. Annie raised £650.

**Richard Jones** was diagnosed with vasculitis just over a year ago, but in September he entered the Ealing Half Marathon. Richard has raised £1065.

The Athens Authentic Marathon beckoned to **Marios Kakos** in November. He did this event for his mother-in-law, Linda who has vasculitis. Marios raised £490.

A Christmas food and craft fair was held at the **Lathkil Hotel**, Over Haddon, Derbyshire ([www.lathkil.co.uk](http://www.lathkil.co.uk)) in November 2014. Over 14 local businesses were present as was Santa **John Mills** Claus in his grotto. **Elaine Alesbrook**, **Sarah Skinner**, and **Susan Mills** ran a stall selling homemade cakes, V-UK Christmas cards, tree decorations and jewellery. The event was held in aid of V-UK and raised £417.

**Legal & General** have kindly matched the fundraising of Andrew Delnevo and David Cartwright (in 2014) in the sum of £500

**Owen Long** of Ferryside, Camarthenshire has CNS diagnosed 2 years ago. Owen makes steady progress and he kindly donated his Christmas money - £100 - to V-UK.

**Annie Jennings** of North Shields held a coffee morning and also endured the ice bucket challenge and raised a total of £650.

**Richard Jones** of London entered the Ealing Half Marathon on 29 September and raised £1065.

**Marios Kakos** entered the Athens Authentic Marathon in November. Marios' mother-in-law Linda has vasculitis. Marios raised £490.

**J**

**Jake Lawler** entered the Tough Mudder Challenge in 2014. He did this because his dad, Steve, was diagnosed with vasculitis in February 2014. Jake has raised £285.

**Reginald Lowe** of Loughborough donated £100 as "a late thank you for a Christmas get-together."

Proud mum **Dawn Lye** cheered on her children **Jake and Gemma** when they entered the 10K Santa Fun Run in Victoria Park in December. The children raised a wonderful £598.

**Jeannie Lymath's** mum was diagnosed with MPA in Aug 2014. January saw Jeannie undertake a "dry month" and has raised £193.

**Tracy Martin** has a holiday cottage in Holt, Norfolk ([www.littletscottage.co.uk](http://www.littletscottage.co.uk)) where she has an "honesty box" with proceeds to V-UK. In 2014 the Tracy's box raised £80.

**Samuel McMahon** entered the Huddersfield 10K in February in memory of his dear father Keith who died due to vasculitis aged 61. Samuel has raised £581.50.

**Paula Morris** enjoys the occasional tippie, but she had a "sober October" and raised £235. Paula's mum was recently diagnosed with vasculitis.

**Hayley Proctor** put her skills to the test in a Pink Collar Boxing match in November. She boxes to keep fit and raised £280 for V-UK in memory of her mum.

**Carol Rodriguez** together with her daughter Isabel walked the Camino Ingles to Santiago de Compostela during the summer of 2014. The walk was in memory of Carol's husband Gonzalo. Carol has now raised a further £252 of which £126 was matched funding by her employers - Boots - from their "Make a Difference" fund.

**Margaret Robinson** of Chester-Le-Street held a fundraising event at her home in the Autumn and raised £175 for her favourite charity.

With thanks to **Rolls Royce, Bristol** for the donation of £525

**Sarah** and **Malcolm** of The Post Office, Great Lumley near Chester-Le-Street raised £105 through a sale of books in the village post office.

**Scholes Methodist Choir** of West Yorkshire held two Christmas "Singing and Sunday lunch" gatherings at **Totties Garden Centre & Olive Tree Bistro** ([www.tottiesgardencentre.co.uk](http://www.tottiesgardencentre.co.uk)) in December, and kindly donated £222 to Vasculitis UK.

*Continued on page 20*

## Fantastic fundraisers continued

The boys at **Sherborne School** in Dorset spent most of the 2013-14 Academic Year raising money for V-UK through various collections within the school. They kindly raised £209.

**Elliot Smith** thought it was a good idea at the time to enter the St Oswalds Ultra Marathon in September. However, he did it for his younger sister Alex, and we believe he actually enjoyed the experience and raised £2685.20.

**Paul Smith** of Studley has donated £300 instead of buying Christmas presents for friends and family.

**The Spire Club of Newark** meet monthly for lunch and to enjoy each other's company. They fundraise during the year. One of their members has vasculitis and they have kindly donated £200 to the charity.

**Swithland Spring Water Ltd** of Swithland, Leicestershire, kindly donated £850 at Christmas. This was instead of sending out Christmas cards. One of their team has vasculitis.

**Emma Taylor** organised a Halloween Party at The Beehive at Heathfield, and raised funds for the charity.

**Ron and Michelle Thomas** sadly lost their niece to vasculitis in the summer of 2014. In her memory they held a disco at The Crooked Billet in Stanford-le-Hope in October and raised £256. Thanks to the local Morrison supermarket who donated goods to the value of £30.

To show solidarity with her sister Paula, who has vasculitis, **Grace (Gronya) Timmins** bravely had her beautiful locks shaved to raise money for V-UK. Grace has raised £1820.70.

**Tulliallan & Kincardine Parish Church** held a Christmas concert to raise money for Vasculitis UK on behalf of Mrs Rebecca Dryburg's daughter Sharon Clyne who has vasculitis. The concert, together with other donations from friends and family raised £340.

**The Valley Girls** are a group of friends from Oxfordshire and in February they cycled across Rajasthan. (See cover photograph). They have also held an Indian summer party, a posh jumble sale and a Burns night supper. The total amount raised will be noted in the Autumn Newsletter. One of the ladies, Sharon Simmonds' husband, has CNS vasculitis. Sharon has raised £1100 together with a separate donation from the Faccenda Group for £1000.

**Derek Wheatland** in January Derek took to the piste for the first time since being diagnosed with vasculitis. His friend kept tally of the number of times he managed to ski down the slopes and raised £208.

**Williams, Grove** kindly donated £650 towards Georgia Upjohn's team who cycled the length of Britain in the summer of 2014.

**Donations made via JustGiving, VirginMoneyGiving and PayPal.** Vasculitis UK would like to thank everyone, many who wished to remain anonymous, for donations made to the charity via JG, VMG and PayPal.

## PatientView

Providing up-to-date medical information for patients and healthcare professionals.

PatientView (previously known as Renal PatientView) is an online facility for patients, where you can upload your own information, or information is transferred by your hospital or unit, and includes test results plus information on your diagnosis and treatment. You can view this from anywhere you want and share with anyone you want.

PatientView is available to patients if their hospital or 'unit' has signed up to it. At present that is most renal units in the UK, plus it is now becoming available in some places for patients with Inflammatory Bowel Disease and Diabetes.

It is anticipated that other disease categories will be added in due course.

With PatientView you can:



Want to see if you can join? Visit: [www.patientview.org/#/](http://www.patientview.org/#/).

The key partners are the Department of Health, the Scottish Government and The Renal Association.

## Vasculitis Support Groups



**SOUTH WALES** - Llantrisant Leisure Centre was the venue for the January meeting of the South Wales VSG, which is led by Jenny Fulford-Brown (left in the photo). There were

26 at the meeting.

Emma Hughes (right in the photo) from Rare Disease UK/Genetic Alliance UK gave an excellent presentation about the implementation of the new Rare Disease Strategy in Wales and how this might affect the NHS in Wales by improving access to specialist care and new drugs for those with rare diseases, such as vasculitis.

If you are struggling to access services for diagnosing and treating Vasculitis in Wales please contact Emma: [emma@geneticalliance.org.uk](mailto:emma@geneticalliance.org.uk)



**EAST MIDLANDS** - The group met for Christmas Lunch at the Dog and Duck at Shardlow. There was a very jolly group of 16 and even Father Christmas paid a visit.

**WEST COUNTRY** - 27 members of the group met at the Smugglers Inn, Dawlish to enjoy an excellent Sunday lunch and to socialise with other vasculitis patients and carers.



*Reports of the October VAI Conference, the October East Midlands meeting, and the November Cambridge meeting can be read on pages 22, 23 and 24.*

### VASCULITIS UK SHOP

The on-line shops has a full range of quality goods from clothing to jewellery. All the profits go towards boosting the funds of the charity. A small selection of the items on offer can be seen below:



To see the full range please visit the Vasculitis UK Shop at: [www.vasculitis.org.uk/shop](http://www.vasculitis.org.uk/shop)



Vasculitis UK can provide you with information to help when claiming government benefits.

If you are claiming or appealing about benefits then contact: Jann Landles - details on page 28.

**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 V-UK website: [www.vasculitis.org.uk/living-with-vasculitis/insurance](http://www.vasculitis.org.uk/living-with-vasculitis/insurance) or contact John or Susan Mills - details on page 28

## Vasculitis Awareness Ireland - 3rd Annual Conference October 2014 - Living Well with Vasculitis

Saturday kicked off with a short talk by Julie Power about the work of the VAI, and Valerie Logan, Trinity Research Coordinator, came along on both days to answer any queries about taking part in the Vasculitis Research and how to participate.

Dr Eamonn Molloy, Consultant Rheumatologist, St Vincent's, Dublin, gave an informative talk about Vasculitis, the causes, the clinical features, symptoms, treatments, relapses, other issues, management, role of diet and exercise and the importance of research.

He was followed by an interactive talk by Patricia McCrystal, Chartered Psychologist, Specialist in Pain Management, Southern Health and Social Care Trust. Patricia explained the psychology and biology of pain, explored our beliefs about pain and the options we have to deal with pain, either dwell on how we used to be, how we will cope in the future or to live the present as much as we can. Basically for those of us who suffer chronic pain, pain is our reality, we should seek to understand it, learn how to pace our activities, nudge the edges of pain, get SMART goals- **S**pecific, **M**easurable, **A**chievable, **R**ealistic, **T**imely, think self compassionately, rationalise our thinking, move mindfully, and proactively manage ourselves.

---

*We should seek to understand pain,  
learn how to pace our activities, and  
nudge the edges of pain*

---

Prof Mark Little, Consultant Nephrologist, Tallaght, Beaumont, St James's and Trinity Kidney Research. spoke about latest developments in Vasculitis research. A biomarker (CD 163, (protein for indicating inflammation) in the urine has been identified as being raised when disease is active. Being able to use this will determine if disease is active (and it is not an infection) and treatment needs to be started. The research team awaits the authorisation of a test stick for this protein (Glomstix). Also awaited

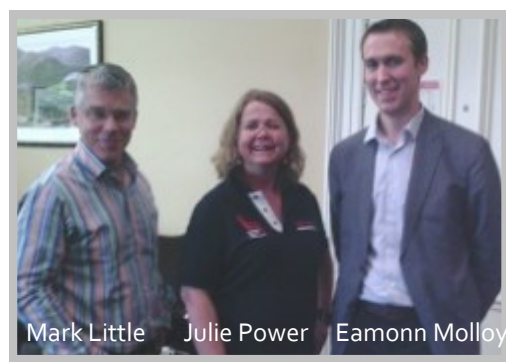
authorization of a new research method called Leukopheresis stem cell donation, which will allow synthesis of the vasculitis disease.

David Edgar, Consultant Immunologist, Royal Victoria Hospital, Belfast, spoke about a new proposal for a Vasculitis Network in NI. This would mean a more co-ordinated approach to treating people with Vasculitis and allow sharing of information amongst the healthcare professionals. This would lead to the development of protocols of care and sharing of current information, which will benefit us all. The first meeting should happen in November, with Eamonn and Mark giving presentations. This could roll out to all Ireland in the future.

On the Sunday representatives from Dun Laoghaire Citizen's Advice Bureau came along to answer questions on benefits, support services available and medical card entitlement on a one to one basis.

Aoife Synott, Senior Occupational Therapist, Harold's Cross Hospital, Dublin gave us a very informative talk on Fatigue Management. This was followed by a comprehensive talk from Dr Radzi Rodzlan, Tallaght Hospital, Dublin about our blood tests, explaining what they are, why they are important and normal levels. This was followed by a brief video showing the role all our blood cells have in our disease.

Report by Julie Power



Definition of Prescription: A physician's guess at what will best prolong the situation with least harm to the patient. - Ambrose Bierce

Definition of Consult: To seek approval for a course of action already decided upon. - Ambrose Bierce

Life is ten percent what happens to you and ninety percent how you respond to it. - Lou Holtz

## East Midlands VSG Meeting - October 2014



This was the third meeting of EMVSG; it was attended by over 30 people. The Guest Speakers were Dr Peter Lanyon and Dr Fiona Pearce from Nottingham University Hospital.

Dr Lanyon started the afternoon by talking about his role as Chairman of NHS England Rheumatology Specialised Services Clinical Reference Group (CRG). He described how NHS England is nationally accountable for NHS Outcomes and leads the new commissioning system for Primary Care Health Services, Armed Forces and Offender Health. NHS England also has the task of developing clinical and patient led national strategies for commissioning through 75 CRGs in England. Each CRG is responsible for a different type of specialised care.

The patient advisory groups involved with Rheumatology Specialised Services are Lupus UK, Scleroderma, Ehlers Danlos and Vasculitis UK. Dr Lanyon also talked about the new Rare Disease Strategy, firstly by stating how important it was to listen to patients and encourage networking between doctors and nurses nationally to improve early detection and diagnosis and coordinated care.

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### *The Patient Advisory Groups involved with Rheumatology Specialised Services are Lupus UK, Ehlers Danlos and Vasculitis UK*

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Dr Lanyon then went on to talk about how evolution has influenced development of the immune system. He discussed the individual types of vasculitis, giving examples and showing photos of inflammation of the lungs, necrosis of digits and how GCA is recognised and diagnosed.

He also gave the example of how the combined Vasculitis clinic at Nottingham QMC operates, involving consultants and nurses in Rheumatology, Renal, ENT and Respiratory departments, working together as a team. He also added a slide and talked about the NICE Guidelines for induction treatment using Rituximab to treat ANCA Vasculitis.

Dr Pearce spoke about how currently there is no coordinated process in the East Midlands to ensure consistency in the management of rare rheumatic diseases such as Vasculitis. As a result of this there is likely to be a significant variation in standards of care and outcomes depending on where patients are being treated.

She also said that this is likely to be influenced by both the process of care and the degree of availability, support and interaction with specialised centres, where larger volume of care, usually combined with research, is delivered. Eliminating this variation aligns directly with NHS England's strategic direction to ensure equity and excellence in provision of care, regardless of location.

Dr Pearce also talked about her investigations into the distribution of recorded vasculitis cases in the East Midlands area. This shows that there are less recorded cases within the city of Nottingham than in rural areas. The reason for this is yet unknown and deserves further investigation.

Dr Pearce also stated there were a growing number of clinicians in the East Midlands who have an interest in Vasculitis. Dr Lanyon and Dr Pearce also spoke together about how there is a plan to improve the care of those in the East Midlands living with rare autoimmune rheumatic diseases by utilising a positive community of clinicians within a structured framework of networking service delivery.

After a well deserved tea break, both Dr Lanyon and Dr Pearce stayed on to answer questions and to chat to everyone. This was an excellent meeting and the EMVSG would like to thank Dr Pearce and Dr Lanyon for giving up their own spare time to come along and talk to us.

### **Susan Mills** (Secretary EMVSG)



Susan Mills, Dorothy Ireland, Dr Lanyon, Dr Pearce and Lisa Ranyell

## Cambridge VSG Meeting - November 2014



Our November meeting was a very special one, and possibly the first time that the results of a clinical trial were presented to patients and in particular to some of the patients who had taken part in the trial. Invitations were sent out to patients who participated in the MYCYC trial – mostly to those in the East of England and Midlands. We also advertised the session to the support group and via the Vasculitis UK website. The result was our biggest meeting ever! Nearly 100 people attended.

A quarter of those present were patients (and their family, friends and carers) from the MYCYC trial. With so many people, we had to hire the whole of the conference suite at the Holiday Inn, and the logistics of using a number of rooms were more challenging than usual!

The session started with a sandwich lunch and the chance to meet up with old and new friends. We then convened in the main hall to hear Dr David Jayne who heads the Vasculitis Team at Addenbrookes Hospital in Cambridge, talking about the importance of clinical trials. A very big thank-you is due to David and his team for suggesting this meeting, providing the speakers and for the sponsorship, which helped make it possible.

He gave us a real insight into the history of clinical trials and their importance. We all gained an understanding of how the trials lead to better treatment for patients and how they drive standards up. It was also good to hear that the UK is a good environment for these trials and just how much the patients are valued for their essential input. "Vasculitis patients are wonderful!" We squeezed a lot of questions in here, as David was unable to stay for the final session.

We then broke into groups, which amongst other things, came up with questions for the Q and A session at the end of the afternoon. A big thank-you is due to the people who helped with the groups – Vasculitis specialist nurse Karen Dahlsveen, Mal O'Neil, Richard Eastoe and Li Gu.

The final session welcomed Dr Rachel Jones, Vasculitis Consultant at Addenbrookes, who has led the MYCYC Trial, and who talked to us about how and why it was put together and something of the, as yet unpublished, results.

Rachel stressed just how complex it is to co-ordinate such a trial, which was spread over 25 centres and over a long timescale. She paid special tribute to specialist nurse Karen Dahlsveen who had co-ordinated the whole worldwide trial.

The talk was much appreciated by everyone, and especially by the 12 "MYCYC" patients who attended. This may not have been a large number, but, in the spirit of all the other statistics we absorbed, it still represents 8.5% of the 140 strong world-wide sample. .

The meeting concluded with a Q&A session. The panel were Rachel, Karen Dahlsveen and John Mills, Chairman V-UK, who stood in for Dr Jayne.

*Report by Lesley Noblett*

## Forthcoming Vasculitis Support Group Meetings

**NORTH WEST/LANCASHIRE - 29th March**

**OXFORDSHIRE - 29TH March** - Annual seminar

**YORK, NORTH & EAST RIDING - 26th April** - Social lunch

**EAST MIDLANDS - 4h May**

**SOLENT (PORTSMOUTH) - 16th May, September (Conference tba) 7th November, and December** (Christmas event tba)

**LIVERPOOL, CHESHIRE & NORTH WALES - 8th May**

**CAMBRIDGE - 4th July**

**VSG WEST MIDLANDS - 11th October** - Annual Meeting



## In Memoriam

Vasculitis UK often 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 the activities of the Trust, especially our research projects



**Mrs Margaret Elizabeth Anderton** of Ellesmere Port was diagnosed with WG (GPA) in 2012. Margaret fought very hard, she was very brave and never complained. Sadly Margaret passed away in October 2014 at the age of 61. Her dear husband Ron and family and friends donated £1082 in Margaret's memory.

**Mr Fredrick Bates** of Upminster was 86 years old when he passed away. Mr Bates was diagnosed with vasculitis in 2010. He had responded well to medication but sadly passed away in November 2014. Frederick was the main carer for his wife Lorna. He loved sequence dancing and had won a number of awards. Mr Bates leaves three children, Graham, Lesley and Stephanie. Family and friends have donated £185 in his memory.

**Mrs Shirley Bird** of Thornton Cleveleys was a long time member of V-UK having been diagnosed with WG 20 years ago. She died suddenly on 27th December. She leaves her husband Garry (of 42 years) two sons and grandchildren. Shirley's greatest love was her family and she adored children and ran the village playgroup. She spent her working life as a primary school teacher. One of Shirley's passions was gardening and her garden was testimony to this love. £605 donations in Shirley's memory were kindly made by family and friends.

**Mrs Mary Coulson.** Mr Barry Coulson of Benfleet has donated £100 in memory of his late wife Mary. The donation came to Barry via his late aunt who was very fond of Mary, and Barry feels that she would have wished for the money to be donated to Vasculitis UK.

**Mr Gordon Childs** of Wroughton, Wiltshire, died suddenly on 9th November. The members of the Brookmeadow Park Residents Association kindly donated £201 to V-UK in Gordon's memory. Also family and friends donated £232 at Gordon's funeral service. It had been Gordon's request that donations be made to V-UK. Gordon leaves his wife Mavis after nearly 60 years of marriage, and their daughter Carla. Mavis is a long-standing member of the charity and Carla has WG.

**Mrs Joy Evone Edges** of Alvaston was a vasculitis patient and member of V-UK. Sadly Joy passed away in November. Her son Peter, family and friends have kindly donated £55 in Joy's memory.

The world of football and bowls lost one of its most popular personalities with the death of **Mr Christopher Field** of Eastbourne in the summer of 2014. Chris was diagnosed with vasculitis in 2013. He made reasonable progress and was determined that he would bowl again by the end of the summer. Sadly this was not to be. Over 200 people attended his "wonderful send off" which celebrated his life, raising £1010 in his memory. He is greatly missed by his wife Jan, his sister and brothers and his special nieces.

**Mr Paul Stephen French of Rivenhall, Essex** passed away unexpectedly, aged 69, in September 2014, 10 days after being diagnosed with vasculitis. Paul was a wonderful husband to Pat for 45 years, a loving Dad to Tina and Maria, "super hero" Granddad to Leah, Holly and Taya. In his younger days Paul played football. He supported Colchester and Man U., and also enjoyed a flutter on the horses. His family and friends have donated £2171 in memory of a wonderful husband, father and friend.

**Mr William (Bill) Henshaw** of Codsall, Wolverhampton was a vasculitis patient and passed away in December 2012. On the anniversary of his death Mrs Henshaw kindly donated £100 in Bill's memory.

**Mrs Maureen Lakin** of Wath-on-Dearne was a vasculitis patient and a long standing member of the charity. Maureen sadly passed away in February. Even with failing health she always had time for others and their problems. One of Maureen's passions was playing the piano, which she did really well. Maureen leaves her dear husband Reg who she first met at a local dance over 50 years ago, falling instantly for his good looks, charm and possibly his naval uniform! She also leaves her children Keith, Mark and Amanda together with grandchildren and great grandchildren. Family and friends have donated £255 in Maureen's memory to Vasculitis UK

Continued on page 26

## In memoriam - continued

**Mr John May** of Birkdale, Southport was diagnosed with WG in 2002 and in the intervening years he suffered from throat cancer and then lung cancer, and sadly passed away in the Autumn of 2014. John was very brave and upbeat and never complained. He loved football, preferring to play rather than watch. He also took time to befriend a neighbour whose wife had dementia, even though he was ill himself. John's wife Lorraine, his family and friends have donated £439 in memory of Lorraine's "handsome and caring husband of 44 years".

**Dr Peter McNiven** of Swansea was diagnosed with WG (GPA) nine years ago. Unfortunately Peter died in June 2014, aged 69, from pneumonia. Peter was a wonderful husband to Betty and father of Neil and the late John. He was also grandfather to six children. Peter had been a librarian at Manchester University and he was a published historian. Peter's lifelong passion was ornithology and he loved 60's music. Being born in Doncaster Peter always supported Doncaster Rovers. Betty, has kindly donated £100 to V-UK in Peter's memory.

Peter Noble has made a further small donation to the charity of £23 from his late father's estate - **Mr Ronald Andrew Noble**.

**Mr Derek J Penny** of Aberdeenshire was diagnosed with vasculitis 10 years ago. Sadly he passed away in December 2014. His daughter, Mrs Linda Rodgers, family and friends have kindly donated £90 in Mr Penny's memory.

Mrs Margaret Neech has kindly donated her Premium Bond winnings of £50 in memory of her dear son-in-law **Mr Fred Sterling** of East Sussex who passed away in March 2013.

**Mr Thomas Raphael** of Borgue, Kirkcudbright sadly passed away only three months after being diagnosed with vasculitis. His wife Kathleen together with family and friends donated £800 in lieu of flowers at Thomas's funeral in August 2014.

**Mrs Catherine Cristina Rounph** of Cheltenham was a long standing member of Vasculitis UK, having been diagnosed with WG (GPA) over 20 years ago. Unfortunately in December 2012 she was diagnosed with Progressive multifocal leukoencephalopathy

(PML) and in December 2013 with squamous cell carcinoma. Even with all her problems Catherine remained positive and lived as full a life as was possible. Catherine leaves her husband Harry. Daughter Claire, her mother and three brothers. Family and friends have donated £1070 in Catherine's memory.

Mrs Margaret Neech has donated the £50 she won on the Premium Bonds in memory of her dear son-in-law **Fred Stirling** of East Sussex .

**Mr Geoffrey Taylor** sadly passed away in February 2014. His daughter and son have kindly donated a further £30 in Mr Taylor's memory.

**Mrs Angela Waller** of Buckingham was diagnosed with rheumatoid arthritis at Christmas 2012. Unfortunately she was then diagnosed with vasculitis in August 2014. Sadly Angela passed away in October 2014 at the age of 58. Angela leaves behind a loving husband, Gordon. Angela's family and friends have kindly donated £868 in her memory.

**Mr Maurice White** of Lydney, Gloucestershire passed away in 2014 aged 77. Mr White was diagnosed with vasculitis in 2005 but he also had a number of other illnesses including rheumatoid arthritis and diabetes. During healthier times Maurice loved walking his dog, fishing, game-keeping and gardening. These became increasingly difficult but he remained strong and contented throughout. He leaves Sue, his wife of 51 years, daughter Linda, son John and grandchildren Harrison, Karleigh and Jazmin. Maurice is greatly missed. The family and friends donated £205 in his memory.

**Professor Rupert Hugh Wilkinson** of London had a long and distinguished career and was emeritus Professor of American Studies and History at Sussex University and a writer of ten books including *Surviving a Japanese Internment Camp* (2013). He was born in Surrey in 1938. As a child he moved with his family to the Philippines where, with his mother and sister, he was interned as an enemy alien in a prison camp for three years. He died of vasculitis plus pneumonia on 21st December. Professor Wilkinson leaves a wife, Mary, children Matthew, Camilla and Clara and six grandchildren. Family and friends have so far donated £317 in his memory.

## JustGiving/Remember

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

## Bequests

If you would like to consider leaving a bequest to Vasculitis UK, please contact John Mills (details page 28).

## Vasculitis Support Groups



Below you will find the contact details for Vasculitis Support Groups in England, Wales and Ireland. In addition there are details for contact persons in the UK and the Republic of Ireland who do not run actual Group meetings.

The supporters who do not run an actual group are marked \*\*

### **Beds, Bucks & Herts**

**Janine Davies** 01525 372733  
family.davies@btinternet.com  
**Christine Lee** 01480 869162  
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### **Cambridge**

**Lesley Noblett** 0776 5897780  
cambsvsg@gmail.com

### **Canterbury area \*\***

**Margaret McGrath**  
01227 638 469  
margaretmcgrathfmsj@yahoo.com

### **East Kent \*\***

**Brian Hart** 01227 369774

### **East Midlands**

**Dorothy Ireland** 01332 601303  
irelanddot@hotmail.com  
**Lisa Ranyell** 01664 857532  
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**Susan Mills** 01629 650549  
sandjmills@btinternet.com

### **Edinburgh, Lothian & Central \*\***

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

### **Essex**

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

### **Glasgow \*\***

**Patricia Henderson** 0141 581 1711

### **Ireland — Vasculitis Awareness Ireland**

**Julie Power** 028 44 482889  
vasculitisireland10@gmail.com

### **Lancashire/North West**

**Jann Landles** 07979 180145  
**Anita Parekh** 07921 682232  
nvwascutitis@hotmail.co.uk

### **Lincolnshire**

**Pam Todd** 01526 268106  
ayla.todd@gmail.com

### **London — North London**

**Dave Newman** 0742 913 7670  
david.newman@londonvsg.org.uk

### **London - SE London/NW Kent**

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

### **Merseyside, Cheshire and N. Wales**

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01244 381680 susanchance53@icloud.com  
**Dave Birch**  
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davebirch@talktalk.net

### **North Wales \*\***

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patvernalls@btinternet.com

### **North West (Cumbria) \*\***

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### **Oxfordshire**

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### **Solent (Portsmouth)**

**Julie Ingall** julie.ingall@porthosp.nhs.uk

### **South Wales**

**Jenny Fulford Brown**  
02920 218795 jenny.swvas@gmail.com

### **Surrey**

**Contact position Vacant**

### **West Country**

**Charlotte Stoner**  
01626 872420 the.stoners@talktalk.net

### **West Midlands (VSGWM)**

**David Sambrook** davsamuk@yahoo.co.uk

### **West Sussex \*\***

**John Bailey** 07752 122926  
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### **York, North & East Riding**

**Richard Eastoe** 01423 520 599  
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### **Yorkshire - West**

**Lynne Jacques** 01274 412378  
lynne@vasculitis.org.uk

### **Yorkshire - South \*\***

**Pat Fearnside** 01709 583722  
pat@vasculitis.org.uk

**The Ring** A support group in Norfolk for RA patients.

**Judith Virgo** jvirgo@fsmail.net

# 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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