



# VASCULITIS UK

## NEWSLETTER JOURNAL



Page	Contents
	<b>FUNDRAISING</b>
6 - 7	Our Fantastic Fundraisers
	<b>PATIENTS STORIES AND LOCAL SUPPORT GROUPS</b>
4 - 5	Cambridge Rare Disease Summit
12	Support Groups
13	Trustee and Volunteer News
16-17	Neeyan's Kawasaki Journey
19	Online Peer to Peer Support Group
26	Local Vasculitis Support Groups
	<b>NATIONAL CONFERENCES, MEDICAL AND RESEARCH</b>
8	UKIVAS
9	A Behçet's Day in Aintree / Research Update
14-15	Kawasaki Disease
18	Kellgren / Consultant News
21	RAIRDA / Vasculitis in Europe
	<b>ABOUT VUK</b>
2 - 3	Chairman's Report / From the Editors
10	Defining me by Shanali Perera / Winster Village
11	Congratulations
20	Rare Disease Day
22-23	Vasculitis Remembers / In Memoriam
24-25	In Memoriam and Donations
27	Events calendar
28	Officials - Contact Details



# Changes at the top

Professor Caroline Savage is an eminent figure in the vasculitis world. For many years she led the nephrology department at Birmingham QE Hospital, treating many cases of vasculitis. She was very supportive of the old "Stuart Strange Vasculitis Trust" which later became Vasculitis UK. In more recent years she joined the pharmaceutical multinational GSK as Head of Innovation.

At the AGM two years ago, Caroline was elected as chair of vasculitis UK on the understanding that she was about to relinquish her post with GSK – it's not generally considered a good thing for a patient support charity, run by vasculitis patients solely for the benefit of patients to be too closely intertwined with "Big Pharma". So she adopted the role of chair elect for the interim period.

Now, two years on, Caroline announced to trustees that she is definitely about to retire from her "day job" but has changed her mind and for personal reasons no longer wishes to be the chair of Vasculitis UK.

Unfortunately Vice-chair Mike Patnick also announced to the Board of Trustees that he too is stepping down. This came as no surprise as Mike and his wife have long been planning to emigrate to Israel, where their son lives. Mike made a great contribution to Vasculitis UK by setting up a robust Research Governance structure and overseeing the complex & tedious "Charitable Incorporated Organisation" application for the Charity Commission. Fortunately this is now almost completed and we hope to submit it in few weeks. We are greatly indebted to Mike and his legacy will certainly live on.

Lynn Laidlaw has also stepped down as research grant administrator, having moved on to bigger and better things with Arthritis Research UK. The loss of both Lynn and Mike means we have nobody with the knowledge and skills to process grant applications, so we might have to adopt a different strategy for making best use of the money which is set aside each year for research funding.

## Your Personal Data, Vasculitis UK & Facebook

In the wake of the Cambridge Analytics and Facebook scandal, I would like to reassure you that at Vasculitis UK we are very conscious of our responsibility to keep your personal details safe and protect your privacy. We only collect essential details for the Vasculitis UK database and mailing list – full name, full postal address inc postcode; plus type of vasculitis, year of birth and email address. We never allow third party access to the database. Occasionally we are approached by academic researchers wanting to send a questionnaire to a particular type/category of patient. If we are happy with the bona-fides of both researcher, the project and the questionnaire, we mail out

the questionnaires to the selected group of patients ourselves, so the researchers do not have access to any personal data.

Do remember that if you request it you can have a printout of such personal details as we have on file and you can request that your details should be deleted – but of course that means no newsletter or any other communication by post or email.

Remember also that we have absolutely no control over Facebook, so if you use one of the online discussion groups you should always only share personal information which you are happy to share with the whole world!! Dorothy Ireland is our new General Data Protection adviser. She will be happy to receive any comments or complaints – [Dorothy@vasculitis.org.uk](mailto:Dorothy@vasculitis.org.uk)

Tocilizumab approved by NICE for treating complex GCA. After 2 lengthy meetings, in January and February, the NICE Single Technology Appraisal Committee approved the use of the new biologic drug tocilizumab for treating selected cases of Giant Cell Arteritis. These are cases which have stopped responding to the usual high dose glucocorticoids (Steroids) or the side-effects of the steroids are becoming a major problem. The usual regime for tocilizumab is for it to be administered for up to a year. After this there is a presumption against re-treating with tocilizumab – which seems odd. However most people seem well pleased with the outcome of the appraisal. A "Patient Expert Witness" from Vasculitis UK represented the Patient Voice at both sessions of the appraisal.

Powerful Stuff! Members of the Vasculitis Facebook group have been so impressed with the benefits of rituximab that they've rechristened it "Unicorn Juice".

Charitable Incorporate Organisation. We started the process of changing the charity's status to that of a CIO about 3 years ago and had just about completed the process when the Charity Commission changed the rules and that put us back to square 1. Mike Patnick has been working busily over recent months to come up with a revised application and this is now ready to go on show and members will be invited at the AGM to vote on whether or not to accept this version and submit it to the Charity Commission. You can find the full text of the CIO application on the Vasculitis UK website.



## Chairman's Report

*John Mills*

## From The Editors



Kevin Soper

Hi Readers and welcome to another packed edition of the Vasculitis UK Newsletter.

Inside this edition there are many informative articles along with some very inspirational personal stories, as ever there are our fantastic fundraisers, of whom without them and all the kind donations received the work done by Vasculitis UK could never be achieved.

Many of you also helped raise Vasculitis UK profile during Rare Disease Day, hopefully you will all get involved in our Vasculitis Awareness Month in May as well.



Graham Baker

*Kevin & Graham*

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

## 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/>**



VASCULITIS UK

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



VASCULITIS UK

## 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](mailto:john.mills@vasculitis.org.uk)  
[lynn@vasculitis.org.uk](mailto:lynn@vasculitis.org.uk)  
Post: John Mills  
West Bank House, Winster, Matlock  
DE4 2DQ

# Cambridge Rare Disease Summit 2017 By Suzanne Morris

Last year Cambridge Rare Disease Network (camraredisease.org) put a call out for Patient Journey posters to be part of the 3rd Rare Disease Summit (#CRDN2017) in October.

They said **“Journey maps go beyond the static medical view of a condition by illustrating the patient experience, promoting emotional responses and empathy and providing a visually compelling story of the patients’ journey.”**

The theme for the summit is “Re-imagining the Patient Journey”. Poster competition entries could be from patient groups, charities or individual patient’s - including those who didn’t have a formal diagnosis.

As a professional Graphic Designer I was drawn to the challenge of how to visually communicate Vasculitis from a patient’s perspective to an audience of medical professionals that would including pharma representation, clinicians, students and researchers, patient groups and other Rare Disease stakeholders.

Lynn Laidlaw, who I am sure you all know is the Vasculitis UK Helpline Support and Research Grant Administrator was keen to help me. When we started talking about the competition Lynn said to me that the “patients’ journey” is becoming a buzzword in the NHS and it would be great to get the message out there about Vasculitis in this way.

**VASCULITIS Cluedo?**  
A RARE & UNPREDICTABLE DETECTIVE GAME  
Presented by Vasculitis UK  
*Do you have enough clinical curiosity?*

**VASCULITIS Cluedo?**  
**INTRODUCTION TO THE PATIENT JOURNEY**  
The board represents the Diagnostic Odyssey for patients with 6 rare forms of Vasculitis.  
The object of VASCULITIS Cluedo? is to diagnose which, of the over 18 different variants of Vasculitis, each of the 6 patients has as they move around the board which represents various hospital departments. Which speciality will have the necessary clinical curiosity and experience to diagnose them?  
Around 80% of rare diseases are monogenic, Vasculitis isn't. Patients present with a wide variety of clinical symptoms to different specialities. When playing detective it's important to remember that no 2 patients are the same!  
The patient's journey is determined by the "multi-factorial life dice". Each roll of the dice will highlight a differing combination of factors which impacts on:  
i) The patient's physical and mental health and overall well being  
ii) The differing manifestation and presentation of their Vasculitis symptoms  
iii) Where in the hospital their diagnostic odyssey takes them next  
Each factor has an associated number which determines how quickly the patient can move between specialities and departments. Some of the factors implicated in developing Vasculitis are:  
1. .... Genetic  
2. .... Environment (e.g. diet, pollution)  
3. .... Infection  
4. .... Drug reactions  
5. .... Life events (e.g. bereavement, pregnancy, stress)  
6. .... Unknown!

**Are you able to tell which Vasculitis variant each of the 6 patients have?**  
**Where should their diagnostic odyssey take them next?**  
**Will they ever receive definitive treatment or find a cure?**

**MEDIC DETECTIVE CLUES**  
to be used alongside clinical curiosity...

**DIAGNOSTIC CLUES:**  
• Seropositive • Blood tests  
• Ruling out mimics • Autoantibodies  
• Imaging • Inflammatory markers  
• Input from experienced medical specialities • Genetics

**SUSPECTED DISEASE:**

**PROBABLE DRUG PATHWAY:**

**CLUES FOR THE 6 PATIENTS:**

- ESONOPHIC GRANULOMATOSIS WITH POLYANGIITIS (GPA):** What is affected? What is the aetiology? What is the prognosis?
- BEHÇET'S DISEASE (BD):** What is affected? What is the aetiology? What is the prognosis?
- HYPEROCULOPHARYNGEAL VASCULITIS SYNDROME (HVS):** What is affected? What is the aetiology? What is the prognosis?
- TAKAYASU'S ARTERITIS (TA):** What is affected? What is the aetiology? What is the prognosis?
- POLYARTERITIS NODOSA (PAN):** What is affected? What is the aetiology? What is the prognosis?
- CENTRAL NERVOUS SYSTEM VASCULITIS (CNSV):** What is affected? What is the aetiology? What is the prognosis?

**TREATMENT & DRUGS:**

- GPA:** High-dose corticosteroids, cyclophosphamide, azathioprine, rituximab, plasma exchange, intravenous immunoglobulin, supportive care.
- BD:** High-dose corticosteroids, azathioprine, cyclophosphamide, rituximab, plasma exchange, intravenous immunoglobulin, supportive care.
- HVS:** High-dose corticosteroids, cyclophosphamide, azathioprine, rituximab, plasma exchange, intravenous immunoglobulin, supportive care.
- TA:** High-dose corticosteroids, cyclophosphamide, azathioprine, rituximab, plasma exchange, intravenous immunoglobulin, supportive care.
- PAN:** High-dose corticosteroids, cyclophosphamide, azathioprine, rituximab, plasma exchange, intravenous immunoglobulin, supportive care.
- CNSV:** High-dose corticosteroids, cyclophosphamide, azathioprine, rituximab, plasma exchange, intravenous immunoglobulin, supportive care.

**CLINICAL DEPARTMENTS:** ACCIDENT & EMERGENCY, RHEUMATOLOGY, HAEMATOLOGY, NEUROLOGY, EARS, NOSE & THROAT, GP SURGERY, NEPHROLOGY, OPHTHALMOLOGY.

**KEY FEATURES:** ACCIDENT & EMERGENCY, RHEUMATOLOGY, HAEMATOLOGY, NEUROLOGY, EARS, NOSE & THROAT, GP SURGERY, NEPHROLOGY, OPHTHALMOLOGY, PATIENT FORUMS, SUPPORT GROUPS, SYMPOSIA, AGMs, & CONFERENCES, TOP SECRET FORMULA TO A CURE BROUGHT TO YOU BY RESEARCH, TRIALS & POTIONS X RELEASE DATE To Be Announced!

The brief was to design an A0 poster that reflected the Patient Journey, using the 4 headings:

- Causes of the condition**
- Symptoms and treatments**
- Impact of the condition**
- Hopes and aspirations for the future**

Lynn and I are both Behçet's Syndrome patients and we were very keen to have Behçet's and other rarer forms of Vasculitis featured on the Vasculitis UK poster, and a rare disease summit was the perfect place to get all of them some much-needed attention.

(continued on page 5)

Over the summer we set about working out how to explain 6 rare disease patient journeys with the added complication that no two Vasculitis patients have the same journey!

This soon became known as the “diagnostic odyssey” and was explained with the help of a very well known board game and its set of characters... but, with a medical twist. I did the design and Lynn worked out the best way to succinctly explain the complex medical information/details.

We were selected as 1 of the 5 poster entries given the opportunity to have the poster projected onto the main screen in the auditorium and were offered the opportunity to give a 5 minute to pitch to the audience.

This pitch was presented from the patient journey perspective “...if you had 3 wishes what would they be?”.

As you can imagine, we were delighted to be told that the Vasculitis UK Poster was selected as the overall winner.

The Trustees of Cambridge Rare Disease Network said **“Your poster was nominated as the best overall design for its incredible creativity and impact. The novel way in which the complex journey was portrayed really cleverly draws you in and is extremely memorable. Congratulations to all of you for your contribution to this - you should be very proud!!”.**

During the Summit we had an overwhelmingly positive response to the poster and some very supportive comments about our 3 wishes in the 5-minute pitch.

The poster will be going along to several conferences this year (having already been to the UKIVAS meeting in London in January) and it will be on display at the Vasculitis UK AGM in April. It would seem that that the poster is rapidly becoming famous in its own right!



CRD SUMMIT BOOKLET

## Some of Our Fantastic Fundraisers



Andrea Makin



Lisa Hetherington



Mary MacIvor



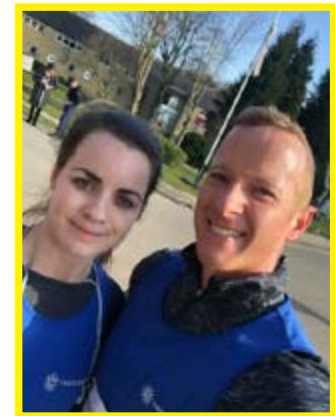
Photo shoot for the Great North Run



Gill Partridge 40 things to do at 40 for VUK



Tracey Pollard & Claudia Spencer (left) Byfleet Running Festival



Sophie Done & Martin Richardson who ran the Huddersfield 10k in 59 & 48 mins respectively. They ran to support Holly Hampshire who has GPA.



Malcolm Bruce and daughters Clare & Laura raising funds at a Craft Fair



### Little T's Holiday Cottage

Tracy Martin has been a supporter and fundraiser for Vasculitis UK since her partner, Gordon Mott, sadly died in 2006 after fighting vasculitis for several years.. She has a holiday cottage in the picturesque town of Holt in Norfolk. Visitors to the cottage make contributions to Vasculitis UK in return for borrowing books from the cottage's library.

If you would like to take a holiday in Tracy's charming character cottage, visit the website [www.littletscottage.co.uk](http://www.littletscottage.co.uk). Or 'phone Tracy 01359-233343



Holly's Easter Fundraiser

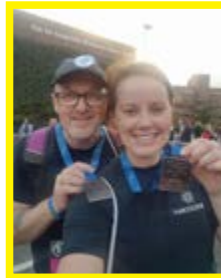
## Some of Our Fantastic Fundraisers



Andrew Lund 100K for VUK for 2017



Malcolm Bruce and daughter Clare Birmingham half marathon



Zoi and Elaine's Christmas Bazaar raising over £378



Andy Lund



Jo and Natalie who made it back in one piece after their Snowden trek on behalf of their friend Kelly Bowles who has vasculitis and supported by Platinum Care Solutions

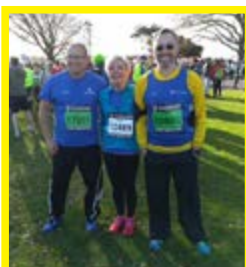


Madeleine Raven, Charlotte & Aimee's School Cake Sale



Congratulations and thank you to Harrison, Nicola and Lucy running the Surrey Kids Half on Mother's Day on behalf of their Mum who has vasculitis and for Vasculitis UK

Pam & Mark Nagle, Wayne Catt Great South Run



### Stratosphere Tower Jump – Las Vegas

Jill Holmes was dared to jump 855ft from the Stratosphere Tower in Las Vegas by her friend Nick. So Jill jumped in memory of her mum Joyce Holmes and for Vasculitis UK, raising £327.





Written by  
Prof Mark Little *Trinity College, Dublin*  
Prof Neil Basu *University of Aberdeen*  
Prof Alan Salama *University College London*

The UKIVAS (UK and Ireland Vasculitis Rare Disease Group) Registry is a collaboration between patients, clinicians and scientists to create the first comprehensive database of vasculitis patients in the UK and Ireland. The Registry contains information on patients with systemic vasculitis attending numerous centres across the UK and Ireland, and is spread across two databases: the primary UKIVAS registry run from Oxford and the linked RareRenal registry run in conjunction with the UK Renal Registry. The long-term vision is that, through long-term data collection, a detailed picture of the clinical course of vasculitis in the modern era will be built, thereby improving diagnosis and treatment of patients with vasculitis.

The past year has seen several important milestones:

- Across both databases, we have enrolled our 5000<sup>th</sup> patient with vasculitis. This is a tremendous achievement and probably makes UKIVAS the largest such registry in the world.
- Version 2 of the UKIVAS registry has been rolled out, with massive input from the Oxford team, and Anthea Craven, Joe Barret and David Gray. This is built on a revised ethical framework, which allows linkage with other data sources, such as UK cancer registries and primary care databases, substantially expanding the amount of data available for analysis.
- Vasculitis UK has funded an external review of the registry governance, in light of upcoming changes in data protection legislation. This was performed by the European Institute for Innovation through Health Data and places the registry on a sound governance footing going into the future.

VUK representatives have attended UKIVAS steering committee meetings, which take place every six months. This ensures the patient voice is central in strategic development of both the registry and the wider UKIVAS society, as well as helping to develop a sustainable model to safeguard future expansion.

## UKIVAS Meeting January 2018

Susan & I, with Lynn Laidlaw, were privileged to take part in the Spring 2018 meeting of the UK & Ireland Vasculitis Study Group (UKIVAS). This took place at the Royal Free Hospital in NW London and is normally restricted to practising clinicians with a serious interest in treating patients with vasculitis. As usual, the morning session, led by Dr Neil Basu & Prof. Mark Little, was taken up with the business of the UKIVAS registry (or vasculitis database). Prof Little reported that 4595 patients have now been recruited from 67 sites, making it the largest dedicated vasculitis database in the world. UKIVAS has always struggled to find the money to fund the registry. Attempts are now being made to find a pharma industry partner or partners to ensure the continuing survival and growth of this valuable resource.

The meeting discussed how UKIVAS might extend its vasculitis educational role more widely – such as by holding vasculitis education days.

The afternoon session, led by Prof Alan Salama and Dr Ruth Pepper, was themed “Defining unmet clinical need in systemic vasculitis”. Lynn Laidlaw gave a presentation on the patient’s perspective of unmet need, which was well received. Drs Fiona Pearce & Peter Lanyon gave a presentation on the unmet need in ANCA vasculitis care, based on an audit of real-life practice & outcomes. Dr Reem Al-Jayoussi prompted a very active & interesting discussion on Persistent ANCA positivity – when to discontinue immunosuppressive treatment in patients who have been clinically in remission for a long time but still have a persistently high ANCA level. Joanna Tieu spoke about the use of Intravenous Immunoglobulin replacement therapy in patients whose immunoglobulin levels had fallen too low following treatment with rituximab.

Scott Henderson spoke about the use of macrolides – a group of anti-

biotics which includes erythromycin – as adjunctive therapy in treating Anca Associated vasculitis (AAV). Steve McAdoo spoke about the combined use of rituximab, cyclophosphamide and plasma exchange in treating severe ANCA vasculitis and the merits of low dose cyclophosphamide in combination with rituximab for treating renally involved AAV. Ebun Omoyinmi spoke about the role of Complement in vasculitic disorders. David Jayne gave a roundup of the clinical trials currently in progress.

The session closed with a presentation by Prof. Lionel Ginsberg on the diagnosis & management of peripheral neuropathy in vasculitis. The incidence of this varies from 15% in GPA, 40% in MPA and Rheumatoid Vasculitis with up to 60% in EGPA & Polyarteritis Nodosa. Peripheral neuropathy is not usually associated with Takayasu Arteritis or Anti-GBM disease.

**John Mills**



# A Behçet's Day at Aintree

**A**intree, near Liverpool, is widely famed for its race course, the home of the Grand National. There were no horses in sight when Susan & I visited Aintree Hospital for the annual meeting of the three Behçets centres.

Behçet's Disease is a very rare and particularly unpleasant form of vasculitis. It is notoriously difficult to diagnose and treat. Several years ago, thanks to some shrewd and effective lobbying by the Behçet's Syndrome Society, NHS England agreed to fund three specialist centres dedicated to diagnosing and treating Behçet's disease. These are situated in London, Birmingham and Aintree. Each year, the three centres hold a joint meeting to share clinical audit results, experiences and research findings. Susan and I were privileged to be invited by Professor Robert Moots to attend this year's meeting, which was held at Aintree Hospital. Prof Moots leads the Aintree Centre.

**S**urveys have shown that the time from onset of symptoms to time of diagnosis can be as long as 20 years. Thus first signs may be in childhood but the disease is not recognised & diagnosed until well into adulthood.

Data presented at the meeting compared Patient Activity and Outcomes between centres for both adults and children as well as Clinical Outcomes such as flares, oral and genital ulcers, skin lesions and active eye disease. Around 100 new patients are seen in the 3 centres annually. (There is a separate Paediatric Behçet's clinic for

under 16s at nearby Alder Hey Hospital). Time from date of referral to being seen varies from 2-8 weeks. More than 50% of those referred are found **not** to have Behçets Disease (BD). Most of those referred have a diagnosis of either coeliac or irritable bowel disease. Outcomes are general assessed by the frequency and severity of relapses & flares. There was a comparison shown of how many patients received different biologic drugs.

**M**any patients are referred from other vasculitis treatment centres. Once diagnosed and with a treatment plan, most are referred back to the local centre on a "shared care" basis, which can save the patient a lot of travelling. However particularly problematic cases may be retained within the Behçet's centre for ongoing treatment. When prescribed expensive biologics, these patients usually get the prescription approved within 24hours.

**O**ne of the unique features of the Behçet's centres is that **all** patients are offered the support of a clinical psychologist. They also have access to one-one support from a trained fellow BD sufferer, thanks to the partnership arrangement between the Behçet's Syndrome Society, NHS England and the centres.

The whole system seems very well run and effective and those of us with non-Behçet's vasculitis can only look on with a mixture of awe and envy.

*John Mills – March 2018*

## Research Update

As reported in the last Newsletter VUK ran another very successful Research Grant funding round in 2017. The contracts have now been signed and work on the Grants is underway. The funded research is as follows

- 1) Dr Rachel Jones University of Cambridge. Study entitled " Tissue Biopsy study in ANCA associated Vasculitis ", £40,750 over 12 months
- 2) Prof Alan Salama University College London, Centre for Nephrology ,Royal Free Hospital, Study entitled " Investigating the aetiology of Subglottic stenosis in GPA using novel in vitro models ", £42,578 over 24 months
- 3) Dr Louise Oni, University of Liverpool. Study entitled " Working towards a diagnostic test to enable stratification of children with IgA Vasculitis ( HSP ), £21,222.95 over 12 months
- 4) Dr Despina Eleftheriou, Institute of Child Health, University College London. Additional funding of £8560 for the Grant we funded last year entitled " Discovering novel genetic causes of cerebral vasculitides of the young "
- 5) Dr Theresa Page, Imperial College London. Study entitled " Does the calprotectin: RAGE axis contribute to pathogenesis in ANCA associated Vasculitis?" £12,000 over 12 months

**Lynn Laidlaw**

## Defining Me

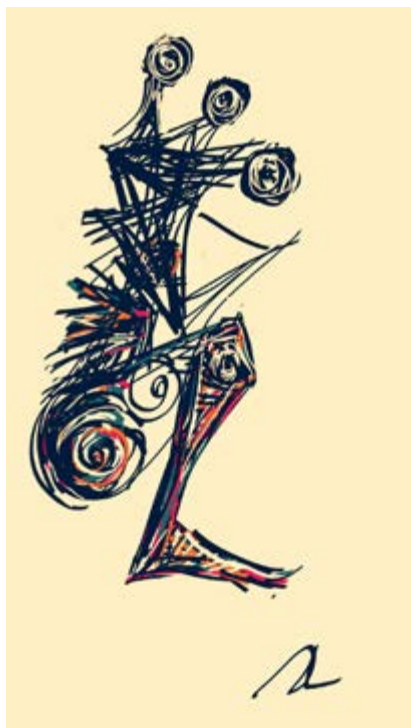
I stumble  
I fall  
I break  
I mend  
I get back up

I keep stumbling  
I keep falling  
I keep breaking  
I struggle to get back up  
I listen...

I feel pain  
I burn  
I weep  
I scream  
I listen....

I lose sight  
I lose control  
I lose me

I ask myself  
Who I,  
Want me to be?  
Need me to be?  
Make me to be?



I struggle  
I adapt  
I alter  
I shift  
I cope  
I listen

I define me  
I defy being defined by illness

I the author  
I the architect  
I the enforcer of my life journey  
Define Me

I find me again

I see me now  
Do you see me?

*Shanali Perera*

## A Big Thank You to Winster Village

**W**e would like to say a big thank you to Carolyn Ludlham, Postmistress of Winster village shop. Carolyn has been celebrating her 25<sup>th</sup> Anniversary as Postmistress of Winster shop earlier this year, so as part of her celebration John and I would also like to thank Carolyn for all her support to us and for Vasculitis UK this last 8 years.

Carolyn has always been very helpful giving advice for the best value of money for packing and posting fundraising parcels, fundraising packs, newsletters and other general VUK mail.



John delivering a large consignment of VUK post to Carolyn at Winster Post Office.

We would also like to thank Winster

Guisers for donating £100 to Vasculitis UK. Winster Guisers perform every Christmas each year, fundraising for local charities. This is the second year running the Guisers have donated to Vasculitis UK.



***Susan and John Mills***

# Congratulations!!!

Below is an article from the Nursing Times about Specialist Rheumatologist Nurse Alice Muir.

Alice won a Nursing Times Award. Alice is great supporter of Vasculitis UK and was a big part of the Vasculitis Young Weekend back in November 2016.

Vasculitis UK would like to thank The Nursing Times for allowing us to publish this article.



## Tai chi classes to help people cope with long-term health issues



This initiative won the HRH The Prince of Wales Integrated Approaches to Care Nursing Times Awards

### Key points

**Tai chi is a holistic form of exercise involving gentle, slow and flowing movements**

**Tai chi can be used as a therapeutic intervention for people with long-term health issues**

**The programmes of the Tai Chi for Health Institute are suitable for people who struggle with conventional exercise**

**Setting up tai chi classes requires thinking about funding, training, safety, sustainability and inclusivity**

**Tai chi classes can be set up at low cost using existing resources and involving participants**



**Author** Alice Muir is a specialist nurse in rheumatology at Circle Nottingham NHS Treatment Centre.

**Abstract** After regaining health following serious illness with the help of tai chi, a rheumatology nurse decided to set up tai chi classes for people with chronic inflammatory and autoimmune conditions in the Nottingham area. Having trained as an instructor, she generated interest, secured free venues, launched the first classes, then convinced participants to become instructors themselves. People with a range of long-term health issues can now access low-cost tai chi classes with physical, psychological and social benefits.

**Citation** Muir A (2018) Tai chi classes to help people cope with long-term health issues. *Nursing Times* [online]; 114: 2, 32-33.

Patients with long-term rheumatology disorders find it difficult to manage conventional exercise, yet exercise has significant health benefits for them. Tai chi is a holistic form of exercise that most people can manage – although some of its more martial forms will not be suitable for those with health problems.

### Benefits of tai chi

There are five traditional styles of tai chi and many different forms. Some are more martial than others and require greater stamina and dexterity, but most involve mindful, gentle, slow and flowing movements and diaphragmatic breathing.

Tai chi can be used to help people maintain and improve their health, regain health after acute illness, injury or surgery, and manage issues arising from long-term health problems. The gentle exercise helps maintain musculoskeletal health and function while the meditative aspect is relaxing and stress-reducing. Learning tai chi can help people regain a sense of control and autonomy, while attending a class brings psychological and social benefits.

Research has highlighted health benefits of tai chi, particularly for rheumatoid arthritis (Han et al, 2004), chronic obstructive pulmonary disease (Ngai et al, 2016), cardiovascular disease (Hartley et al, 2014) and falls prevention (Gillespie et al, 2012). It can also help older people reduce stress, improve posture, balance and mobility, and increase muscle strength in the legs ([Bit.ly/NHSChoicesTaiChi](http://Bit.ly/NHSChoicesTaiChi)).

### Discovering tai chi

The patients I care for have a range of chronic autoimmune and rheumatic diseases that cause debilitating symptoms such as pain, stiffness, extreme fatigue, depression and anxiety, and can result in isolation and loneliness. I have spent many years looking for solutions to help them cope with long-term health issues such as various forms of arthritis.

In 2009, I was myself unwell and needed something to help me regain health. I attended tai chi classes, and found them helpful. On my return to work, I decided to create tai chi classes for people living with long-term rheumatology disorders. It seemed a positive thing to do.



## Support Group Meetings

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

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

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



Beds, Bucks and Herts support group held a lunch at The George Buckden Saturday 2nd December they also had a mini fashion show during lunch.



Plymouth Vasculitis Support Coffee morning



Leicester Support Group Christmas lunch



West Country support group held a Christmas Lunch



health unlocked



facebook



East Midlands Christmas Party

## Report from the Cambridgeshire Support Group

### THE MEETING

41 of us came to the meeting on the 11th November, at the Holiday Inn Cambridge, including 10 who were new patients and their relatives and friends. The feedback from the meeting has been excellent - both our speakers were much appreciated and I think that, as ever, everyone enjoyed the chance to chat and exchange experiences - "it was great to see people and the sense of friendships developing". The Holiday Inn did a good lunch of sandwiches and chips - a guilty pleasure for some - before we started the meeting.

### SPEAKERS

Suzanne Morris's energy, creativity and passion were clear in her description of the Vasculitis UK "Patient Journey Poster" that she and Lynn Laidlaw had just presented to the Rare Disease Summit in Cambridge. We were not surprised that their poster about the experience of Behcet's patients had been voted the winning poster at the Summit. Suzanne's design, based on Cluedo figures, was so clever and really epitomised the feeling of bewilderment that so many rare disease patients experience, especially in the early stages of their "patient journey". "Suzanne was so inspiring and is achieving so much" was a subsequent comment. (Suzanne's Vasculitis UK Christmas cards also went well - another example of her skill as a graphic designer.)

Dr Joanna Tieu, Rheumatologist and visiting Clinical Research Fellow with the Addenbrookes Vasculitis Team, based her talk on patient questions and issues around Rituximab. A number of members of our group sent in their questions in advance and Joanna did an excellent job of answering them and giving us an overview of the use of Rituximab - and indeed the generic forms of it that are now available. One new patient was "delighted to be getting so much more of the information he needs" and another felt that her question had been answered simply and clearly, after months of angst.

### Lesley Noblett

below is a selection of slides from the presentation

**Purpose of this talk**

- Provide general information about vasculitis that relates to the questions posed from the group
- Provide information about rituximab and its use in treating vasculitis
- Individualised advice is best through your treating team who have your history, blood results and scans to make decisions

**Vasculitis - sources of confusion**

**Rituximab - what is it?**

- B cells are white blood cells
- B cells have lots of functions including making antibodies, that help to fight infections, but can also be harmful when they recognise the wrong thing (e.g. vasculitis, rheumatoid arthritis)
- Rituximab is a type of "biologic" drug that targets a component of the immune system - B cells
- Rituximab temporarily removes B cells from the body, which therefore reduces the harm that they may be causing

**Rituximab - does it work?**

- We have lots of studies, including 2 trials to tell us that rituximab can be used to treat ANCA associated vasculitis (induce remission)
- We know that a lot of people with ANCA associated vasculitis will have features of their disease come back (relapse)
- Lots of different treatments are used to prevent a relapse (maintenance therapy), including azathioprine, mycophenolate, methotrexate, rituximab
- We have multiple studies, including 2 trials to tell us that rituximab can be used to keep people in remission in ANCA associated vasculitis.



VASCULITIS UK

# Trustee and Volunteer News



**C**ongratulations to VUK trustee Gareth Garner on gaining a 1st degree in Biomedicine at Chester. Gareth is currently undertaking a PhD in Infectious Diseases.



**T**his is a remarkable achievement for Gareth as he was diagnosed at the age of 16 with Anti GBM Goodpastures Disease (an extremely rare type of vasculitis), and lost one year of schooling.



The charity is sorry to announce that Anita Parekh has decided to stand down as a volunteer for VUK. Anita worked with treasurer Pat Fearnside for many years before taking on the role of the VUK Finance Officer after the untimely death of the Pat in 2015. Anita is now concentrating on further education for herself and spending more time with her young daughter. Anita will be missed by all the trustees and other volunteers at VUK, but we wish Anita all the best for the future. Anita will still be associated with the North West Vasculitis Support Group.



We would like to welcome Emma to our team of volunteers who will be supporting Dorothy and Julie with fundraising.

Hi, my name is Emma and I first came across Vasculitis UK when my daughter Kira was diagnosed with HSP at the age of 3. At this stage we hadn't heard of Vasculitis and wanted to find out as much information as possible and John and Susan were fantastic and offered so much help and support to us at a very scary time. Since then I have wanted to help raise awareness of Vasculitis

as much as possible to help others diagnosed have a better understanding of what Vasculitis is. This has been done in several ways such as Kira and other family members running the Manchester run a number of times and also organising the first Vasculitis Charity Ball in 2017 in Manchester, which was a huge success and raised lots of money and awareness for Vasculitis UK.

As well as raising 4 children, having 3 cats and 2 dogs I also run my own company, innov8 Conference Services, which organises large events and AGM's around the world as well as also running a number of our own in house events.

## Raising Awareness



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](mailto:susan@vasculitis.org.uk)



Zoi and Elaine



Christmas Tree Festival - Vasculitis Awareness

# Have you heard of KAWASAKI DISEASE?

Maybe not! And you'd be in the majority!

Although – we know we are talking to a highly informed audience here at Vasculitis UK, so many of you may well have heard of Kawasaki Disease. But if you have, the likelihood is you'll have an impression of the disease which is held by many. After all, if we know Kawasaki Disease we know –

***It's really rare – right? – No! It is increasingly common, hospital admissions increased fourfold in the last decade in England.***

***It only occurs in very young children – right? – No! 25% of patients are over 5 years of age.***

***Heart damage happens but only in a very small proportion of patients when treated – right? – Oh, no! In 28% of treated patients their hearts are affected – 19% have persisting coronary artery aneurysms.***

There are many, many “myths” around Kawasaki Disease and in this article we want to navigate through these – and more.

## About Societi Foundation, the UK

### Foundation for Kawasaki Disease

Societi Foundation is a registered charity. We're a small Notts based organisation, volunteer run.

Our organisational purposes include:

- raising awareness of Kawasaki Disease so that it can be recognised early and quickly treated – this includes sharing knowledge across the medical profession
- working with clinicians to improve clinical supervision for Kawasaki Disease patients
- enabling relevant research projects – and
- working closely with the UK parent support group KSSG, to support them to achieve their aims

We don't provide family support – because KSSG do that brilliantly already. They are our close partner and we share a website. You'll find KSSG pages and contact details on our site at [www.societi.org.uk](http://www.societi.org.uk) if you're part of a family affected by Kawasaki Disease, looking for support or a listening ear.

## What is Kawasaki Disease?

Identified in 1967 in Japan by Tomisaku Kawasaki, Kawasaki Disease is an enigmatic and serious illness. It is the second most common form of vasculitis in children, mainly affecting young children, although 25% of those diagnosed are over five years old. Kawasaki Disease affects the heart in 28% of treated children and it is the leading cause of acquired heart disease in UK children. The cause of the disease remains unknown.

Kawasaki Disease affects hundreds of children in the UK each year and is increasingly common. In the last decade, Societi Foundation research shows a fourfold increase in hospital admissions for Kawasaki Disease in England alone – and globally a doubling of cases in the last decade has been reported. It is not clear why this is.

Kawasaki Disease has a range of symptoms including a characteristic and distinctively persistent high fever for five days or more, rash, bloodshot eyes, “strawberry” tongue, cracked, dry lips, redness of the fingers and toes and swollen glands in the neck. Kawasaki Disease can be present with some (a typical Kawasaki Disease) or all of these symptoms. Kawasaki Disease presents atypically in significantly more infants, and in any infant with a persistent fever, Kawasaki Disease should be considered. If any child has a persistent high fever for five or more days, a Kawasaki Disease diagnosis must be considered.

## What is the problem? Awareness!

As Kawasaki Disease presents with several symptoms common to a variety of other childhood diseases and infections it is often misdiagnosed or diagnosed late.

If left untreated or if treatment is delayed Kawasaki Disease can cause coronary artery damage. Children affected by Kawasaki Disease have much improved chances of a good recovery with timely diagnosis and the correct treatment.

The perception in the UK of Kawasaki Disease as a rare illness has contributed to dangerously poor awareness levels in the medical profession and hampers both clinical resource allocation, research funding availability and long term clinical support. There is almost no public knowledge of Kawasaki Disease currently, except where families have been directly affected of course. The ability for parents to advocate for their children when affected by Kawasaki Disease, for the correct and timely treatment, is therefore absent.

A recent UK and Ireland study showed that on average, children waited over 7 days for initial treatment between 2013 and 2015. The study showed a link between later treatment and poorer outcomes, with those children treated at 10 days of illness having a significantly greater risk of serious, lifelong heart damage. (BPSU Kawasaki Disease incidence study, UK and Ireland, 2013-15)

Slow treatment and low levels of awareness of Kawasaki Disease are putting hundreds of children's hearts at risk every year in the UK. A lack of awareness of Kawasaki Disease amongst 'front line' clinicians needs to be addressed, in order for Kawasaki Disease to be considered as a possible diagnosis at a much earlier stage.

Kawasaki Disease Symptoms



**In the UK, children affected by Kawasaki Disease today face the same poor prospects in terms of outcomes as they did 30 years ago.**

To address this – whilst we recognise that there are many, many causes of fever, we need clinicians to be aware of the need to CONSIDER Kawasaki Disease early for any child with a persistent high fever, especially one showing two or more of the above symptoms. They could have Kawasaki Disease and prompt treatment could be the difference between recovery and lifelong heart disease.

### How can I get involved?

It's our ambition that every clinician and every parent knows Kawasaki Disease!

Raising awareness of Kawasaki Disease is simply our top priority. We know that Kawasaki Disease is SERIOUS. Awareness is URGENT. And so we are determined to tell "just" 65 million people about it! That's everyone in the UK. If you'd like to help us raise awareness there are lots of ways you can help.

If you're a GP, doctor or work in a clinical setting, we can provide RCPCH endorsed information leaflets which help raise awareness with both medical professionals and the public alike. Our website includes downloadable resources such as educational posters, learning links and links to research – all of which help build knowledge and increase levels of awareness based on up-to-date information. You'll find a 'For Clinicians' tab in the main menu bar at [www.societi.org.uk](http://www.societi.org.uk) with lots more information.

If you're a family member affected by Kawasaki Disease – or someone interested in helping to combat the leading cause of acquired heart disease in our children, there are fundraising and awareness raising resources – including an information pack, on how to start your awareness raising journey called "Your Kawasaki Conversation" on our website.

You'll find that at [www.societi.org.uk](http://www.societi.org.uk) in our Fundraising tab, under 'Getting Started'. Everything can be downloaded but if you want hard copies of anything just fill in the contact form on the website and let us know!

**If you download, share or display anything we'd love to know – so do get in touch.**

**You can stay in touch easily too - follow us on Twitter @Societi\_UK\_KD or Instagram @societi\_uk\_kd**

## Kawasaki Disease? Remember **TEMPERS**

Children with **Kawasaki Disease** are characteristically irritable!

**T** Temperature - Persistent high fever

**E** Erythema - reddened hands and feet with swelling

**M** Mouth - dry, sore mouth, cracked lips, 'strawberry tongue'

**P** Pace - Treat early to reduce potential heart damage

**E** Eyes - bloodshot, non-sticky conjunctivitis

**R** Rash

**S** Swollen glands in neck, often just one side

**If a child has a PERSISTENT FEVER and two or more of these symptoms THINK KAWASAKI DISEASE!**

**5 days of fever? THINK Kawasaki Disease**

**RCPCH**  
Royal College of Paediatrics and Child Health

[www.justgiving.com/societi](http://www.justgiving.com/societi)

[societi.org.uk](http://societi.org.uk)

*.....Please THINK Kawasaki Disease*

## Neeyan's Kawasaki Disease Journey

June the 26th 2016 was the day my healthy old son first got a virus and didn't of at the time; I Calpol and Nurofen. rash appeared and would, I thought of meningitis and did the glass test. However the rash faded. I breathed a sigh of relief, but also started to get the gut feeling that something was seriously wrong and it didn't feel right.



and active 8 year high fever, which start of a normal really think much managed it with After day three, a like many parents

Neeyan's fever was not dropping and his symptoms were getting worse. He stopped eating, was really irritable and was struggling to walk. Then he started to really freak me out by hallucinating and being delusional. Symptoms came and went away again and after 5 medical assessments, either at the GP or at our local hospital, we kept being told my son had a viral infection. He was prescribed antibiotics but I just knew it was something so much more.

Neeyan was not getting better, in fact he was getting worse and I decided enough is enough and took him back to the hospital. I remember waiting an hour in the hospital with Neeyan lying in my arms. He was deteriorating so badly that I almost got up and was about to be that frantic parent who shouts at the receptionist; but then we were called in. This doctor was on the brink of discharging us with a change in antibiotics and a diagnosis of Scarlet Fever; but then she moved her stethoscope to his heart and that is when my world turned upside down. He was immediately rushed into emergency with a heart rate of 230 and an open diagnosis.

That began the worst night of my life, just sitting and watching. The doctors were not telling me anything except that the diagnosis was open, as they started him on IV antibiotics and IV fluids as he had not eaten in 5 days. I never slept the whole night as I watched Neeyan heart rate soar so high and then drop. It was crazy listening to all the beeping. Hospitals are not good places in the night for sure!!! He was just so sick and I couldn't do anything except watch. I couldn't cry as I was in shock and couldn't take in what was happening. I kept looking at the notes which I had been keeping and trying to work out if I had missed something. For some reason I didn't even go to Dr Google which is a surprise as I am such a googler!

I answered questions after questions from many doctors who were all interested in Neeyan but no one was giving me any answers. They kept us isolated but we were stuck in A&E as there were no beds on the ward. Neeyan had to have his own room because they did not know what was wrong with him. Precautions I guess.

It was the next day when our consultant came in with six other people, who I now know were Trainee Students. It was then he first spoke the words "Kawasaki Disease." I had never heard of this before and I was certainly never prepared for what was about to unfold over the next 9

days. With Kawasaki disease there are no blood tests and a clinical diagnosis is made based on the symptoms that Neeyan presented with. These were high fever, rash, lethargy, arthritis (Neeyan couldn't even walk), swollen glands, swollen feet and hands, extreme irritability plus so many more.....

I could not believe what I was hearing when the consultant said he was 10% sure that it was Kawasaki and I recall challenging him on treating my seriously ill child based on a certainty of only 10%. That consultant trusted his gut that day in making a clinical diagnosis and looking back now, it was he who saved Neeyan's life. I will forever be in his debt as I now know that sadly this is not the case for many parents of children with Kawasaki.



The consultant said they would start treatment straight away with high dose aspirin 4 times a day and stomach protectors. The main medicine was a blood product called Intravenous Gammaglobulin. The main priority was to reduce his fevers and save his heart from damage. I was reassured that a treatment plan was in place. Once again I trusted my gut and we had a diagnosis on day six of the ten day window which had been allowed

I thought all was now on track - but No!!!! Neeyan became resistant after two doses of IVIG and needed more aggressive treatment. This is rare in itself as IVIG is meant to be the best. They couldn't control the inflammation as the disease managed to find its way through Neeyan body and the Kawasaki disease was not content until it had damaged Neeyan's heart. To be told there was no choice but to change the treatment plan was pretty tough to deal with. How could I not have a choice when I live every single day by my choices in work and at home; but now I had no choice except to trust the medical team in their efforts to save Neeyan's heart from any further damage.

It seemed to me like playing roulette with Neeyan's life as they continued to treat Neeyan for Kawasaki disease, but as he was not responding they still kept his diagnosis as "open". They continued to take bloods every day to rule out any other possible life-threatening illnesses. Neeyan needed high dose methylprednisolone and then Infiximab to finally halt the inflammation. However despite my best efforts even I couldn't save Neeyan heart from being damaged. When Neeyan's heart broke my heart broke too!! Neeyan's coronary arteries had dilated to 4mm at the time and he currently has to take Asprin every day to prevent his blood from clotting, along with regular follow-up Echoes on his heart.



Neeyan had his first ECHO Stress test done a year ago too. Neeyan will be under long term surveillance for life now to keep an eye on his heart. To me it seems not fair that Neeyan has to go through all of this at such a young age however he is so brave and strong and is my HERO.

Neeyan is doing well now and back in school. However as a result of the KD the school recognised a change in Neeyan's behaviour and support us through "Place to Be" (a counselling service).

The long term follow up care within the UK seems to be inconsistent and that is a worry for many parents. You are already battling against something you have never heard of but then you then have another battle on your hands with follow up care. Thankfully I did my research and we are now followed up at the Evelyn Hospital. I am so grateful for their follow up care and I now trust that my son will have the very best of care; but sadly this is not the case for many parents

Now I am on a mission to raise as much awareness as I can to save other children's hearts from being damaged. Kawasaki disease is known statistically as a rare disease however since our diagnosis I am finding it is not so rare and more common than we think. The numbers are increasing year on year here in the UK. However hardly anyone knows what this disease is despite it being the [Number 1 cause of ACQUIRED heart disease in the UK in children.](#)

My awareness campaign will never stop as until we know what causes Kawasaki disease as I am convinced that once they find the cause they will also find the cure and I want to know why Kawasaki disease chose my son in my life time.

Kawasaki disease is more common than some types of meningitis. However whereas meningitis is now widely recognised, few know of Kawasaki disease. It's time we changed that and got parents and the medical professionals all recognising the symptoms and thinking of Kawasaki disease #Think Kawasaki

Societi and KSSG are both volunteer-funded organisations which are fighting for more awareness of Kawasaki disease. However they are also fighting for UK diagnostic protocols, so there are no more misdiagnosed cases, along with clear UK guidelines for treatment and long term follow up care.

Neeyan's journey is all part of this and will now appear in eLearning modules for medical clinicians as well as short videos to support new families of children who have been diagnosed with Kawasaki disease

<http://www.kssg.org.uk>/<http://www.societi.org.uk/>

I support both these charities as when Neeyan was diagnosed I decided that no parent should be in the position of ignorance that we were in. If I had just known about and thought of Kawasaki Disease, Neeyan's outcome may have been better. I have raised awareness in many ways and will continue to do so, as awareness, knowledge and understanding of Kawasaki Disease needs to be raised in the same way that awareness of both Meningitis and Sepsis was raised by recent campaigns.

***Thank you for taking the time to read  
Neeyan's Kawasaki Journey***

### ***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](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 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.*





# Kellgren- 10 Years of Service in Manchester

Many of you will have heard of The Kellgren Centre for Rheumatology. But for those who have not it is based in Manchester Royal Infirmary.

From here it manages a broad range of musculoskeletal and autoimmune disorders. However, did you know that the Kellgren Centre celebrated its 10-year anniversary in December 2017?



Kellgren Centre  
Vasculitis and Lupus Team, Lead by Prof Ian Bruce

The centre is named after Dr Jonas Henrik Kellgren, who in 1947 was appointed clinical director to the University of Manchester Centre for Research in Chronic Rheumatism.

While in 1953, Dr Kellgren was appointed Professor of Rheumatology at Manchester, the first such appointment in England.

As well as providing a clinic for patients with a wide range of conditions including Vasculitis and Lupus, the centre is a leading translational research centre with strong links to The University of Manchester Centre for Musculoskeletal Research, NIHR Manchester Biomedical Research Centre and Manchester Academic Health Science Centre.



The staff and supporters used the celebration to demonstrate the wide range of services such as their popular nurses' clinic where patients can spend more time than in a normal consultation discussing their concerns, as well as highlight their clinical studies.

Vasculitis UK would like to wish Professor Ian Bruce, Dr Ben Parker and the other members of the multidisciplinary team at the Kellgren Centre every success in the next 10 years.

**Jann Landles**



Congratulations to Consultant Nephrologist Dr David Jayne who has been promoted to the chair of Clinical Autoimmunity, Department of Medicine, University of Cambridge

Prof David Jayne is Reader in Vasculitis at the University of Cambridge, and Honorary

Consultant Physician and Director of the Vasculitis and Lupus clinic at Addenbrooke's Hospital.

He is a Fellow of the Royal Colleges of Physicians of London and Edinburgh and Fellow of the Academy of Medical Science. He has undertaken numerous studies into vasculitis and is the current President of the European Vasculitis Society (EUVAS). His research group in Cambridge conducts international clinical trials in vasculitis and earlier phase clinical trials and biomarker studies in vasculitis and lupus.



Also Congratulations to Consultant Rheumatologist Dr Richard Watts who was given the accolade of Professor by the University of East Anglia (UEA) for his medical and academic achievements.

With a clinical career spanning three decades, Prof Watts remains as committed as ever to the continuous development of treatment for rheumatic conditions.

photo courtesy of the Ipswich Star

Prof Watts started at Ipswich Hospital in 1994 and was appointed a clinical senior lecturer at Norwich Medical School - based at UEA - in 2005.

He has held several other notable positions, including chairman of the Norfolk and Suffolk Clinical Research network and medical advisor to the National Rheumatoid Arthritis Society.

Prof Watts also served as editor-in-chief of the "Rheumatology" Journal between 2002 and 2008.

# ONLINE



## An enlightening environment of experiences

By Kelly Jefferies

Being diagnosed with a rare disease is extremely tough but finding other people who understand the myriad of emotions that overwhelm you is like finding a pot of gold at the end of a rainbow!

From a personal point of view, finding Vasculitis UK and the Vasculitis Facebook support group nine years ago was a bit like finding the final piece of a jigsaw I had been trying to find for eons.

Sharing experiences with each other, swapping tips (such as which foods help with certain symptoms - like nibbling ginger biscuits if you're feeling nauseous) and having somewhere where you can share your thoughts, feelings and symptoms without fear of being judged or worrying you will upset your friends and/or family members is so uplifting and a wonderful sense of relief.

This journey is difficult enough without the feeling of loneliness added into the mix and the peer to peer support group is a lifeline for many people; patients, family members and friends alike. I am partially deaf in both ears so I find telephone conversations difficult at times but being online I can share my experiences and help others without having to worry that I haven't quite heard or understood someone. I have also become increasingly less mobile over time and find it difficult to travel anywhere on my own without the help of my husband, who is my full time carer.

Through the peer to peer support group I have been able to make friends with people from around the UK and even from other countries and I don't have to worry about meeting them in person as I can chat to them privately if I wish to or several of us can chat together on a post which is such a solace!

We recently posted a poll in the group asking what the upside and downside of being part of the group are and why. We had some fabulous and very personal responses (see below a small selection of the responses) but the main downside that seems to crop up time and again is the sadness that is felt when people post about how badly they are struggling. This downside is, in my opinion, only a downside because of the friendships that are formed, the feeling of members being part of a "Vasculitis Family" and genuinely being concerned for each other. Therefore, anyone seen to be struggling will be met by feelings of sadness by the other members but it's also at times like this that you see the greatest strength of the group as you witness members rallying together to form a cushioned barrier of support, whether it's advice, understanding or just to let that member know you are thinking of them.

I have been extremely privileged to be a moderator in the peer to peer support group for a number of years now, having been asked originally because I have one of the more rare versions of vasculitis; Behcet's Syndrome. During this time I have seen many members join, become active and form friendships they never would have thought possible before they joined the group.

All of the moderators including Susan Mills, Dorothy Ireland, Zoi Anastasa, Kath McIntosh and myself, Kelly Jefferies, do this voluntarily and because we all enjoy being able to help others. I am especially proud to say that it is wonderful to see so many

people from all walks of life, regardless of age, gender, where they live or work, brought together for the same reason for themselves, a friend or family member being diagnosed with a rare disorder that can be massively debilitating and lonely, just sharing thoughts, feelings, good news, bad news or just wanting a chat.

## I was diagnosed with Vasculitis, Please, switch on a Light!

By Zoi Anastasa

An increasing number of online support groups have embraced the features of social networking. The most obvious advantage to online support groups is accessibility. For many years people had to travel to a predetermined location in order to attend a support meeting. The meetings for chronic illnesses like vasculitis were a few per year. People often couldn't travel because of health or financial issues.

Online groups may not be for everyone, but they can be an incredible resource for people who cannot access support otherwise. Members in online groups have access 24h/day, 7 days a week. Geographic and transportation barriers are absent. People with mobility problems, speech and hearing difficulties can participate.

Online support groups like Vasculitis Support (UK) have emerged as a result of the need of support and the need of people to know more about the health condition they are confronting. Being diagnosed and living with vasculitis can be a challenge. Being a carer of someone diagnosed with vasculitis comes with its own challenges too.

What do the members of the online support group think about it?

Nicky

*Until I found this group I felt lonely and frightened. Just those few words I had at the beginning of joining this group helped me so much...welcome to the group and if there is any way we can help then let us know. Now I can give support to others and I don't feel so isolated.*

Karen

*It has also shown me how amazing and tenacious people can be. I have gained valuable insight and that helps me to hopefully be more supportive and understanding.*

*Thank you all so much. As the partner of someone who has vasculitis, this site has been invaluable. When he was first diagnosed it felt like I was walking around in a pitch black room, disoriented and not having any knowledge of anything. This page was and still is my light switch. We all know Google is not your friend when it comes to researching chronic conditions, especially complicated ones. You are amazing x*

Melanie

*Negative - sometimes when you see other people's symptoms and issues you can start looking for these problems yourself, making you a little hyper-aware. Sometimes when you hear bad stories about consultations or Drs, it can make you doubt whether or not you are getting the best care. In general a well monitored support group is beneficial. The key is having people that care and can be part of a team working behind the scenes and members that respect each other! We are privileged to be part of the Vasculitis Support (UK) group and we hope it will be there to support the vasculitis community.*

**We do our best and with the support of our members, we will keep that light on!**

# Rare Disease Day 2018



As part of the Rare Disease Day Awareness campaign Vasculitis UK have launched a new video channel, Vasculitis UK TV. <http://www.vasculitis.org.uk/about-vasculitis/vasculitis-uk-tv>



This is the initial selection of videos which were recorded at the Vasculitis UK Patient Symposium in March, in Manchester 2017. We hope to add more videos and visual information to the Vasculitis UK Channel TV in the future.

Getting this TV channel off the ground as taken a lot of hard work and we are grateful to Dave Richardson from RichTVUK for recording and editing videos from the 2017 patient symposium and for creating the Vasculitis UK TV channel and also to John Geddes for providing website technical support.

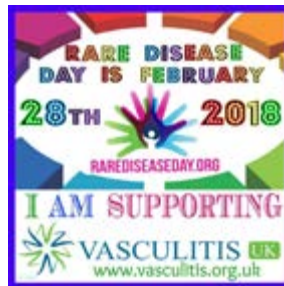
Many of you got involved on Rare Disease Day 2018 via social media, posting sharing and tweeting images either of your own or the ones pictured right. These designs were created by our very own and very talented Kelly Jefferies. Thank you Kelly for all of your creative work and thank you all our readers who got involved on the day as well.

The new Swindon Vasculitis support group spent the morning of Rare Disease Day in the library at Wootton Bassett with an amaz-



ing stand, they spoke to quite a few people and

handed out some information to raise awareness of vasculitis and their own new vasculitis support group.



Amanda Mond, aged 16 gave a presentation to her school on Rare Disease Day about her own type of vasculitis called Polyarteritis Nodosa. She also raised £182.50 for VUK by sharing information leaflets and collection tin.

**VASCULITIS AWARENESS MONTH IS MAY 2018**



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



Since October 2016 Vasculitis UK has been working in partnership with the British Society for Rheumatology and our sister autoimmune charities, Lupus UK and Raynauds/Scleroderma UK to create the Rare Auto-Immune Rheumatic Disease Alliance (RAIRDA) Some readers may recall having taken part in a major online patient experience survey last year, which was conducted by RAIRDA. The results of this survey have been used to compile a report which has recently been published.

### **About RAIRDA**

RAIRDA is a partnership established to bring together clinical and patient organisations and other key stakeholders in order to improve care for people living with rare autoimmune rheumatic diseases. It was formed following a stakeholder workshop and subsequent report which sought to raise awareness of the challenges facing people living with these conditions and develop joint solutions to help overcome these. Our members include LUPUS UK, Scleroderma & Raynaud's UK, Vasculitis UK and more recently, British Sjögren's Syndrome Association as an affiliate member.

RAIRDA aims to provide a single, strong voice that will raise the profile of this group of conditions, influence policy and guide future research. We plan to extend an invitation to Myositis UK, extending our membership to 6 charities.

### **Rare Disease Report**

Following a patient survey for people who have Vasculitis, Lupus and Scleroderma and Raynaud's, RAIRDA is in the development of a policy report setting out key data on patient journeys (diagnosis delay, access to treatment etc), with a view to develop recommendations and to call on policy makers and parliamentarians to improve care for patients and families affected by rare conditions. The recommendations and issues will be highlighted to the Department of Health, Parliament and other key organisations. The report was released on the 28<sup>th</sup> of February, on Rare Disease Day 2018.

### **Membership of the UK Rare Disease Forum.**

RAIRDA is a current member of the UK Rare Disease Forum set up to steer development of the UK Strategy for Rare Diseases (the Strategy) and was tasked with the Strategy's governance after its publication in 2013 by the Department of Health. The Forum's membership included representation from the rare diseases community, industry, academics and researchers. The Forum has an extended stakeholder membership to ensure that the stakeholder voice covers the full breadth of rare diseases, including those diseases or conditions with a non-genetic basis. The Forum and its membership should complement existing mechanisms by which individual members of the Policy Board already engages with Rare Diseases stakeholders.

As part of our work for the Membership of the UK Rare Disease Forum, we are members of a "task and finish" group to take forward specific projects pertinent to the UK Strategy for Rare Diseases. The Group is currently engaging with relevant DH policy officials and stakeholders on mapping the diagnostic pathway for patients with rare diseases, with Vasculitis being selected as a case study disease area.

To read the full RAIRDA report go to the VUK website <http://www.vasculitis.org.uk/news/rairda-news-2018-02>

## Vasculitis in Europe



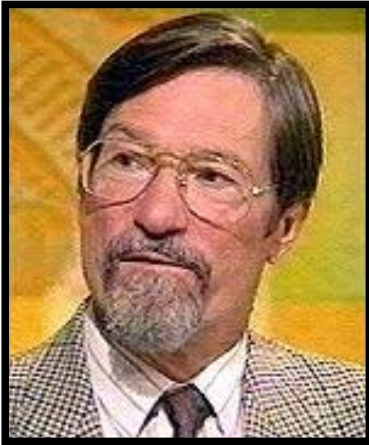
Most countries in Europe do not have a national vasculitis patient organisation. The notable exceptions are France and Holland, which both have flourishing national patient organisations – "Vasculitis Stichtig" in Holland, led by Peter Verhoeven and "France Vasculites" led by Raphael Darbon. I was fortunate to receive copies of the winter editions of their magazines – both high quality, in full colour, full of meaningful content, with 36 pages for one and 40 pages for the other.

Like our own Vasculitis UK Newsletter, both feature a sizeable educational academic/scientific item – such as an article on the Advocate trial – the use of Avacopan as an alternative to glucocorticoids (such as prednisolone). Ironically the Dutch magazine has quite a long article about the European Medicines Agency relocating from London to Holland in the wake of Brexit!! The French magazine contains a focus on Polyarteritis Nodosa and Kawasaki Disease and a long article about the link between the gut microbiome and the immune system.

A novel feature of the French Mag has been "The Adventures of Phil le Neutrophile".

Phil is a cartoon character and his adventures are used to illustrate the effects of different types of vasculitis.

# Vasculitis UK remembers Paul Bacon



Paul Bacon, a giant of British Rheumatology, died peacefully on 12<sup>th</sup> January 2018 after a short illness. Paul was Emeritus Professor of Rheumatology and the first Professor of Rheumatology in Birmingham after endowment of a chair by the Arthritis Research Council, the forerunner of Arthritis Research UK, in 1981.

Through his seminal work on developing instruments to record and measure disease activity, Paul transformed many areas of rheumatic disease, including rheumatoid arthritis and systemic lupus erythematosus, but he had a special affinity for vasculitis. As a young consultant at the Royal National Hospital for Rheumatic Diseases in Bath and Southmead Hospital in Bristol, he set up a specialist vasculitis clinic to explore the differences driving the different forms of vasculitis.

These principles carried through to his work in Birmingham where, in the early 1990's, he initiated development of the Birmingham Vasculitis Activity Score. Often referred to as "BVAS", this score has been used world-wide and has been instrumental in driving forward clinical trials to refine use of established therapies, as well as to support development of new, innovative ones. Paul's far-sighted development of BVAS and the accompanying

Vasculitis Damage Index score, illustrate his commitment to undertaking research that ultimately benefited patients and their treatment.

In April 1998, the 8<sup>th</sup> International Vasculitis and ANCA Workshop was held in Birmingham, recognising the important centre that Birmingham had come to occupy for pioneering research and treatment of vasculitis. Paul was very much in the centre of things and the success of the meeting reflected, in part, his energy and enthusiasm for vasculitis. That the Workshop took place in Birmingham was fitting given that Paul was to step down from the ARC Chair a few years later, in 2002.

Beyond Paul's formidable talents as a physician, he was also an inspirational teacher, a supportive colleagues and friend to many, not only within the UK. After he retired, he continued to collaborate and support colleagues in India with development of the Indian Takayasu Activity Score. His legacy includes over 380 published papers that have been cited over 20,000 times.

An obituary for this remarkable man has been published in Rheumatology and can also be found on the Vasculitis UK web site.

*Caroline Savage, February 2018*



## In memory of Christine Bean who died December 2017

Clarry, Christine's husband, children Abi and Daniel have been raising money for two charities which provided Christine and her family with a huge amount of care and support, Vasculitis UK and Prospect Hospice.

Christine was diagnosed with Granulomatosis with Polyangiitis (WG) in 2009. Abi, Christine's daughter said "Vasculitis UK were instrumental in helping the family understand, and come to terms with, this complicated disease. They provided Mum and Dad with a crucial network of support and information over a grueling 8 years. In addition to her WG (GPA) Mum was diagnosed with cancer - and although she outlived every medical prediction, we knew it wouldn't go on forever, and after a brief recuperation stay at Prospect Hospice this summer, she was taken there in November for what would be her final few weeks with us. The level of care at Prospect was fantastic - for Mum and for the whole family."



Lynne (on the right) - At the launch of the West Yorkshire Vasculitis Support Group 2013

## In memory of Lynne Jaques who died January 2018

Lynne was diagnosed with MPA some years ago but in December of last year Lynne started suffering with further health problems. Unfortunately her condition deteriorated in the New Year and very sadly she died. She will be sadly missed by so many people.

Lynne set up and organised the West Yorkshire Vasculitis Support Meetings in 2013 and was also a trustee of Vasculitis UK for a time. Lynne was instrumental in designing and organising the circle of V's, Vasculitis UK lapel awareness enamel pin badge.

Photo courtesy of Bradford Telegraph & Argus

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.*

## Bequests

Elsie Willows of Kirby in Ashfield recently passed away age 80. She left a bequest of £1000 to Vasculitis UK. A collection at her funeral, in lieu of flowers, resulted in a further donation of £405 to Vasculitis UK. Elsie's son, Andy Willows, sadly died at a tragically young age as a direct result of vasculitis.

## In Memoriam

Carol Day, and her children Kim & Jeremy, from Crewkerne in Somerset, held a memorial day for Carol's husband, raising a total of £1700 for the benefit of Vasculitis UK.

A collection at the funeral of Mrs Catherine Wallace of Aberlady, East Lothian, raised £450 for Vasculitis UK. Cath valiantly fought WG for 5 years, but was finally overcome. She is sorely missed.

Mrs S Hilton of Newcastle, Staffs, kindly donated £220 to Vasculitis UK.

Jennifer Ann Follett of East Grinstead sadly passed away last August, age 69

Funeral donations in her memory, totalling £255, were made in favour of Vasculitis UK. Jenny was an SRN, qualifying after training at Lambeth Hospital. She died, sadly, after a 20 year battle with vasculitis. She is survived by her husband, John and daughters Jo and Nicola.

A donation of £100 was also received in memory of Jenny Follett from her dear friends Mike & Barbara Cooke, living in South Carolina, USA.

Funeral donations totalling £402.75 were received in memory of the late Merle Nelson of Dussindale, Norwich.

Donations totalling £100 were raised at a celebration of the life of Mick Webster of Morley, Leeds. Mick sadly died due to vasculitis and other complications aged 74. He was predeceased in 2002 by the love of his life, Christine Appleyard. They left a son and daughter & 3 grandchildren.

A funeral collection in memory of Mr Stephen Harris from Petersfield, Hampshire, raised £135. Stephen sadly passed away in July, aged 56.

Donations from family and friends at the funeral of Gladys Douras, in September, raised £274.40 for Vasculitis UK.

Jayne Coulson did a sky-dive last July to raise money for Vasculitis UK in memory of her Mum, Mary Coulson who sadly died in June 2009 due to vasculitis. Jayne and Barry (her dad) along with family and friends donated £900 in sponsorship and Jayne's Justgiving page raised a further £300, bringing the total raised in memory of Mary Coulson on this occasion to over £1200.

Sadly, Mike Field of Bromsgrove recently passed away. Funeral donations in his memory raised £300-70 for Vasculitis UK.

A collection at the funeral of David Greenaway, BEM, JP, of Didcot, Oxfordshire, in August, resulted in donations in favour of Vasculitis UK totalling £568.

In response to a dare, Jill Holmes of Sheppey, Kent did a 855ft bungee jump from the Stratosphere Tower in Los Angeles. The £100 bet and £227 in other donations were donated to Vasculitis UK in memory of Jill's mum in law, Joyce Holmes.

Author Tim Moxley's dearly loved wife, Lydia, sadly died due to vasculitis in 2015. So Tim wrote a book in her memory and donated the royalties to Vasculitis UK.

Funeral donations totalling £595 were offered in memory of Derek Gee of Rainford, near St Helens, who sadly passed away in October, leaving a widow, a daughter and two much loved granddaughters. Derek enjoyed travelling and photography and was a keen student of German.

The members of the "Spire Club" of Newark have been regular supporters of Vasculitis UK. Club member Ron Bruce, of Newark, sadly passed away last autumn and Spire Club members made a donation of £100 in his memory.

Funeral donations of £50 were made to Vasculitis UK in memory of Mrs Joan Cosali of Malvern.

A collection at the funeral of Mrs Audrey Mary Emery of Malvern raised donations for Vasculitis UK, totalling £490 in her memory.

Donations totalling £650 were made in memory of John Adrian Tomblin of Lound, Near Retford, Notts who passed away last autumn.

Janet Barcello was a nurse at the Royal Glamorgan Hospital in Llantrisant. She first fell victim to Wegeners (GPA) in 1997, but made a good recovery and for the following 8 years she had a fit life, running and walking with her husband Jeff and she continued to work as a nurse. In 2007 she suffered a severe relapse which left her disabled and forced to retire on health grounds. In November 2017 Jan had a further relapse with severe complications, which sadly resulted in her sudden death, age only 60. She was a fun loving lady who touched the lives of all those she met. A collection at her funeral resulted in a donation of £204 to Vasculitis UK.

Donations totalling £550 were made in memory of Mrs Glayne Biles of St Fagans, near Cardiff who sadly passed away died in January. "She was a wonderful lady who will be missed by so many".

Funeral donations totalling £250 were made in memory of Brian James Thornton of Sidcup, who sadly passed away in October, age 78. Brian sadly died only a few days before celebrating his 56<sup>th</sup> wedding anniversary. He leaves a widow, Jean, four children and 8 grandchildren.

Mrs Lynda Margaret Woodhouse of Minster-on-Sea sadly passed away in November. Donations in her memory totalled £480.

A donation of £49 was received from St Nicholas Church, Guisborough PCC (Teesside) in memory of George Hesk of Guisborough.



## In Memoriam



A funeral collection in memory of Ronald McLellan Taylor Bruce of Newark resulted in a donation of £220 to Vasculitis UK.

Jane Everitt of Lound, near Retford made a donation of £30 to Vasculitis UK in lieu of sending Christmas cards, in memory of her partner, John Adrian Tomblin who passed away in October last year.

Donations in memory of Cheryl Hensman of Aylesbury were received totalling £2,974. Cheryl died tragically, age only 38, very shortly after being diagnosed with vasculitis.

Lorraine May of Southport donated £500 to Vasculitis UK in memory of her late husband, John May, who died in 2014.

A funeral collection in memory of Christopher Turner of Corsham, Wiltshire raised donations totalling £354 for Vasculitis UK

Former nurse Jackie McGuire of Lockerbie joined Vasculitis UK in 2009 after contracting GPA. Sadly she lost her fight last December and died due to complicating factors. Jackie's partner of 40 years, Bill Patterson, kindly donated £1000 to Vasculitis UK in her memory, to support research.

A donation of £25 was received from Sherryl Plumb in memory of her cousin, John Barnett of Goring on Sea, West Sussex.

Funeral donations totalling £348 were received in memory of Mrs Doreen Dorothy Boone of Bridgwater, Somerset.

Donations totalling £586 were received in memory of Lynne Jacques of Bradford. (see elsewhere in this edition for Lynne's obituary)

Donations to the value of £125 were received in memory of Mr John William Osborne of Brentwood, Essex.

Sadly, Eric Gray of Ware, Hertfordshire, passed away in January, leaving a bereaved partner. A donation of £15 was made in his memory.

Donations totalling £125 were received in memory of Mr John William Osborne of Mountnessing, Brentwood, Essex.

At the request of his wife, funeral donations totalling £839 were received in memory of the late Clive Richards of Helston, Cornwall.

Funeral and other donations totalling £549 were received in memory of the late Christine Bean, who very sadly died in January following long fights with both vasculitis and cancer.

Donations totalling £4086 were received in memory of John Michael Barnett of Goring-by-Sea, West Sussex

## Donations & Fundraising

Malcom Bruce of Bromsgrove fell victim to vasculitis, but as he recovered he decided to do some fundraising for Vasculitis UK. With the aid of his daughters, Laura and Claire, he raised £238 running a craft fair stall and raised sponsorship totalling over £850 through JustGiving by taking part in the Birmingham half-marathon. His employers donated £200 in matched sponsorship, resulting in total donations of £1500 for Vasculitis UK.

S.E.O'Reilly, address unknown kindly donated £1200 to Vasculitis UK for research.

On the occasion of their 25<sup>th</sup> wedding anniversary party last autumn, Maria & Tony Hill, of Bristol, requested donations to Vasculitis UK in lieu of gifts, thereby raising £180 for the charity.

Mrs S Parekh recently celebrated her 70<sup>th</sup> Birthday. She asked friends to donate to Vasculitis UK in lieu of gifts, resulting in donations totalling £150.

A fundraising event among the employees of SSP Ltd, of Halifax, resulted in a cheque for £126.13 being donated to Vasculitis UK.

A Quiz night at the George & Dragon Pub in Stoke Golding near Hinckley, Leicestershire' raised £206 for Vasculitis UK.

The staff of the London Branch of Mizuho

Bank Ltd hold a monthly "dress down" and Cake Sale. In September, Vasculitis UK was nominated as the beneficiary charity by friends and colleagues of fellow member of staff, Linda Flegg, whose husband, Mark, recently died due to vasculitis.

Linda Griffiths invited 16 friends around for a "Pampering Evening", with drinks & nibbles & facials given by her friend Pam. Linda gave a short talk on vasculitis. Everybody had a lot of fun and a raffle and donations raised £152 for Vasculitis UK.

Waye Catt took part in the Great South Run in October, raising £410 in sponsorship for Vasculitis UK.

Sompting Village Morris Side (near Worthing) very kindly donated £200 to Vasculitis UK. A close relative of one of their members has vasculitis.

The Fordham Vehicle Show kindly donated £750 to VasculitisUK. This represented money raised during their local event.

The Year 5 Pupils in Dolphins & Panda classes of Ospringe CE Primary School, in Faversham, Kent, held a "Life Skills Day" where pupils created items to sell to family and friends. They chose to donate the money raised, £125.46, to Vasculitis UK

Evie Higgs recently held a cake sale in

support of Vasculitis UK and raised £52.50 for the charity.

One of the members of staff of Swithland Spring Water is affected by vasculitis, so the company kindly made a donation to Vasculitis UK in lieu of sending Christmas cards, resulting in a donation of £950.

Gareth Jones of Ceredigion gave a talk to a local heritage group and accepted a donation of £25 to Vasculitis UK in lieu of his travel expenses.

Teresa Davies of Llandeilo, Carmarthenshire, donated £100 to Vasculitis UK in lieu of sending Christmas cards.

Naomi Sheeter held a cake sale for Vasculitis UK which raised £168.

Investment management company InvescoPerpetual has a charitable foundation, Invesco Cares Foundation, which donated £3000 to Vasculitis UK.

Mel Alexander has GPA. Mel and his family decided that instead of doing "Secret Santa" they would donate to Vasculitis UK. This resulted in a donation of £300 to the charity.

Anna Mayhew raised £240 for Vasculitis UK by taking part in the Greek Marathon in November.





## Donations & Fundraising



Joyce Blackwell of Sidmouth kindly donated £100 to Vasculitis UK.

Ridgacre Methodist Church at Quinton, Birmingham raised £110 for Vasculitis UK from their Christmas card and Annual Charity Carol Service. One of their congregations is affected by vasculitis.

Rob Kelly and Becky Davis were married at Frenchay Parish Church, Bristol, in December. A collection at the wedding raised £87 which they donated to Vasculitis UK.

The staff of the Alderman Swindell Primary School in Great Yarmouth, Norfolk, made donations to Vasculitis UK in lieu of exchanging Christmas cards, thereby raising £38.50 for the charity.

A donation of £227 was received from Royal Bank of Scotland as part of the RBS charity fundraising activity.

Donations totalling £135 were received from Buckingham Charity Football Cup. Of this, £70 came from Buckingham Athletic Football Team and £65 from the Committee.

As part of their annual Corporate Giving, the BGL insurance and financial services Group in Peterborough kindly donate £10 to Vasculitis UK.

Yvonne Orchard of Towcester, Northants, one of the "quilted team" kindly donated £50 to Vuk.

Margaret Robertson of Chester-le Street gave a talk to a Ladies Club and held a Beetle Drive thereby raising £184.50 for Vasculitis UK.

Joyce Stone, the wife David Stone of Ross-on-Wye, has GPA. Their son has a charity box in his works canteen which raised £50 for Vasculitis UK.

Dawn French of Ravenscarr raised £185.45 for Vasculitis UK from the sale of handmade cards.

Robyn Mond of London's daughter, Amanda, has polyarteritis nodosa. She raised £182.50 for [Vasculitis](http://www.vasculitis.org.uk) UK by giving a talk about her illness at her school.



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)

**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](http://JustGiving.com), [VirginMoneyGiving](http://VirginMoneyGiving) or by PayPal.*

## Donating To VASCULITIS UK

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

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

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

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

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



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

# Get in touch with your local Vasculitis Support Groups

## ENGLAND

### Beds, Bucks & Herts Group

Janine Davies - 01525 372733 - [family.davies@btinternet.com](mailto:family.davies@btinternet.com)  
Christine Lee - 01480 869162 - [chrislee0307@btinternet.com](mailto:chrislee0307@btinternet.com)

### Cambridge Group

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

### Canterbury area (Contact Person)

Margaret McGrath - 01227 638469 - [margaretmcgrathfmsj@yahoo.com](mailto:margaretmcgrathfmsj@yahoo.com)

### East 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](mailto:Dorothy@vasculitis.org.uk)  
Lisa Ranyell - 01664 857532 - [lisa.ranyell@ntlworld.com](mailto:lisa.ranyell@ntlworld.com)  
Susan Mills - 01629 650549 - [susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)

### Essex Group

Jules Darlow - 07789 113144 - [jules.essexvsg@googlemail.com](mailto:jules.essexvsg@googlemail.com)

### Leicestershire Group

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

### Lincolnshire Group

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

## London

### North London Group

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

### South East London & North West Kent Group/

#### Bi-Ennial Thames Riverside Walk

Jacqui Moran - 07792 412768 - [jacqui.moran1@ntlworld.com](mailto:jacqui.moran1@ntlworld.com)

### Merseyside, Cheshire and North Wales Group

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

### North East Group

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

### The North West Group

Jann Landles - [jann@vasculitis.org.uk](mailto:jann@vasculitis.org.uk)  
Anita Parekh - [anita@vasculitis.org.uk](mailto:anita@vasculitis.org.uk)

### Northumberland and Cumbria (Contact person)

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

### Oxfordshire Group

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

### Plymouth Group

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

### Scarborough Group

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

### Solent/Portsmouth Group

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

### Surrey Group

Group under discussion

### Sussex by the Sea Vasculitis Support Group

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

### Swindon Support

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

### West Midlands Group

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

### West Country Group

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

### West Sussex Group

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

### Yorkshire Group

Richard Eastoe - 01423 520 599 - [richard@yorkshirevasculitis.org.uk](mailto:richard@yorkshirevasculitis.org.uk)  
Website [www.yorkshirevasculitis.org.uk](http://www.yorkshirevasculitis.org.uk)

### York, North & East Ridings Group

Richard Eastoe - 01423 520 599 - [richard@yorkshirevasculitis.org.uk](mailto:richard@yorkshirevasculitis.org.uk)  
Jennifer Wormald - 01937 586734 - [Jennifer@yorkshirevasculitis.org.uk](mailto:Jennifer@yorkshirevasculitis.org.uk)

## WALES

### North Wales - (Contact Person)

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

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

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

### South Wales Group

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

## SCOTLAND

### Edinburgh and Lothian (Contact Person)

Jimmy Walker - 07725 770103 - [james-walker@outlook.com](mailto:james-walker@outlook.com)

## Republic of IRELAND

### (Contact Person)

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

### Ireland - Vasculitis Awareness Ireland

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

# EVENTS CALENDAR

## Cambs Vasculitis Support Group Meeting

21st April Holiday Inn Cambridge 12.30 - 4.30 pm

£11 per person to cover lunch and room hire

An opportunity to meet over lunch, find others in the same boat and to listen to expert speakers. Friends and relatives are always welcome and form an important part of our group. Always a friendly and informative occasion.

A Speaker from Addenbrookes Hospital, Cambridge is to be announced.

Contact Lesley Noblett [cambsvsg@gmail.com](mailto:cambsvsg@gmail.com)

## EUVAS EUROPEAN

### Vasculitis Course

19<sup>th</sup> - 21<sup>st</sup> April 2018

Florence, Italy

Invited speaker John Mills, VUK Chair, on behalf of the Patient Organisation, Vasculitis Europe



## VASCULITIS AGM

Derby University Enterprise Centre

29<sup>th</sup> April 2018, Derby



## BRITISH SOCIETY FOR RHEUMATOLOGY ANNUAL CONFERENCE

1st May - 3<sup>rd</sup> May, Liverpool



## British Society of Dermatology Annual Conference

3<sup>rd</sup> - 5<sup>th</sup> July 2018 Edinburgh



## UK & Ireland Vasculitis Study Group

7<sup>th</sup> June, Edinburgh



## BRITISH SOCIETY FOR PAEDIATRIC AND ADOLESCENT RHEUMATOLOGY ANNUAL CONFERENCE

17<sup>th</sup> - 19<sup>th</sup> October 2018, Southampton



## Vasculitis UK Newsletter

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

# HONORARY LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

**Established in 1992 by the family and friends of Stuart Strange,  
in his memory.**

**Formerly known as the Stuart Strange Vasculitis Trust  
Registered Charity No. 1019983**

## Officers, Trustees and Volunteers

### Chairman:

John Mills  
john.mills@vasculitis.org.uk

### Hon Secretary:

Jann Landles  
secretary@vasculitis.org.uk

### Treasurer:

Duncan Cochrane-Dyet

### Finance Office:

Richard Remorino

### Medical Advisors:

Dr David Jayne  
Prof David G.I. Scott  
Dr Richard Watts

### Trustees:

Jane Elsom  
Jennifer Fulford-Brown  
Gareth Garner  
Dorothy Ireland  
Susan Mills  
David Newman

### Volunteers:

Graham Baker  
Emma Caldwell  
Kelly Jefferies  
Janice Mather  
Julie Scott  
Kevin Soper

### CONTACT US

#### Helpline:

0300 365 0075

#### Website:

[www.vasculitis.org.uk](http://www.vasculitis.org.uk)

#### Address:

West Bank House  
Winster  
Matlock  
DE4 2DQ

#### Phone:

01629 650549

Published by:

