



VASCULITIS **UK**

NEWSLETTER JOURNAL



SPRING 2023 ISSUE 65

Here we are into our third year of covid. Personally, I've had 6 doses of vaccine. Waiting for the spring booster to be rolled out in April. I still have the cough from last April. I know its still very difficult to get a GP appointment, getting through on the phone is an accomplishment. Our consultants do seem to be working through their lists.

Our research grants are being completed, if two years behind schedule. The reports are available on our website. The current call for grants is working its way through the stages, hopefully for the trustees to approve and then announce at the AGM. We have been very involved with the MELODY study, looking at the immune response to the vaccine of patients taking Rituximab and other immunosuppressant drugs. Thank you all who volunteered.

Just before New Year we were delighted to hear that John Mills had been honoured with an MBE from His Majesty King Charles. John is in very poor health so would be unable to travel to London. Instead, the ceremony was conducted by the Lord Lieutenant at his local pub. I was very lucky to be invited, along with Zoi from Vasculitis UK. Those who live in the East Midlands were able to see the highlights, which included John saying "the pub probably has better food than the palace!" I was also interviewed. The citation told of many years of service to the community and to Vasculitis UK.

The Trustees have been working within their roles to increase the charities profile. Jen Harper assisted by Zoi Anastasa have brought in new stock to the shop and shopify seems to be working well. Please let them know if you would like us to

stock something, within reason, if course.

Charlotte Smith has attended and given a presentation at the BSR conference. It was well received. Charlie Harper has also been

attending conferences and talking to people at our stall. We have been using some new graphics especially for these events. Susan Mills, as ever, works incredibly hard, not just in caring for John but ensuring we meet targets and take enough of the right stock to events. Heidi Pollard, our treasurer, keeps a close watch on the finances. Then a few weeks ago surprised us by saying she was going to Everest Base Camp, once again fundraising for us. Peter Rutherford is always ready with advice when we need him. We hold trustee meetings by zoom.

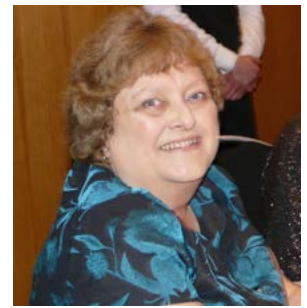
I share the fundraising with Charlotte. We do have places for this year's Great North and South Runs. I would also ask if you are holding an event please let us have more than a week's notice, so we can get items out to you. Zoi has settled into her new role as Director of Operations and attends seminars and conferences, keeping the name of Vasculitis UK in the forefront. Which for a small charity is an achievement we must thank John for.

After two years of cancelled conferences, they returned last year.

In April

we will have a stall at the BSR (British Society of Rheumatologists) conference in Manchester, along with Susan and Charlotte attending will be Shanali, herself a rheumatologist.

In May, Charlie and Zoi will be attending the RCN (Royal College of Nurses) congress with volunteers Anthony and Giles Hart. If you would like to be a volunteer at future conferences or events and feel confident to talk about vasculitis to health professionals then please email zoi@vasculitis.org.uk or susan@vasculitis.org.uk



Chairman's Report

The Annual General Meeting (AGM) will be by Zoom again this year. There's still too much Covid to chance us all being together. Date 21st May 2023 start 1pm. Speakers to be announced, provide your own refreshments. Login details will be on our website and social media. If you don't have access to these then please email zoi@vasculitis.org.uk or call the helpline 03003650075. We are always happy to welcome new trustees. Please read the duties on the Charity commission website charity commission trustee duties - Search (bing.com) . If you want to join us, please send a letter outlining your experience and how these may be of use to the charity, to dorothy@vasculitis.org.uk

Dorothy Ireland



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This editorial feature is done in loving memory of my dear sister, Clare Grossman, who was sadly taken from us at the age of 38 due to Wegener's granulomatosis (GPA) back in 2010. As a family we had no idea about vasculitis, or how we could support her, or get support for ourselves. By the time we did through VUK, it was too late for Clare but we as a family, and especially for myself in getting involved via this Newsletter have found great comfort, and I am truly thankful for being given the opportunity from VUK, via John and Susan Mills to give something back.

Dear Reader



Well here we are at the beginning of spring, and this our 65 edition of your newsletter/journal.

Our front cover is obviously that of our previous chairman John Mills MBE, who received his honour in his local village pub more on this inside.

There are many of you out there fundraising and I'll be expecting plenty of images and write ups for the autumn edition. We also look forward to your stories to feature in future editions like Robert's in this one.

Zoi, our Director of Operations has been busy

along with many of our trustees and volunteers of whom without them the cogs of this fantastic charity just do not turn and move it forward which then benefits all of us.

We are always needing volunteers so please get in touch with Susan or Zoi, there details can be found on the back page.

Any reader wishing to submit content for any future edition please contact myself and will try to include them.

So grab your favourite tippie and enjoy!

Kevin Soper (Editor)

Vasculitis News - Chile



Vasculitis Chile

Jeannette Núñez Gonzalez a dentist from Chile, contacted John Mills a few years ago to request guidance and information for Granulomatosis with Polyangiitis.

orate clinical guides for Dentistry.

A few weeks ago, on February 28th, Rare Disease Day, Vasculitis Chile organised an important meeting with patients from different groups of rare diseases, doctors also participated.



Jeanette has written to thank John for the information he sent her, it was of great help for Jeanette's work, she was able to guide many patients and work colleagues with whom she shared the information.

Jeannette has now joined a study group in Chile with rheumatology specialists as she wants to have more knowledge to be able to elab-

Jeannette gave a presentation at the Conference relating to her work as a dentist but also explained how John's help had been invaluable and she also shared the news of John's important recognition of being awarded the MBE, he received in England, in the New Year Honours this year.



Jeannette said "Congratulations!! It is a pride! Well deserved for his valuable work for so many years in his country. You are our archetype to follow..."

Trustee News

Climbing New Heights

In April of this year Heidi Pollard (VUK Treasurer) will be on her way to Everest Base Camp.

Heidi will be trekking to the base camp of the highest mountain on Earth in memory of her beautiful sister, Sarah who very sadly lost her life to vasculitis 4 and an half years ago.

The highest point will be 5,500m (18,000ft) above sea level where oxygen is around 50% less than at sea level and with some long 8/10 hour trekking days, Heidi will need all our support. Thank you.

Susan Mills

SCAN HERE TO SUPPORT



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 training course by UKIVAS

The United Kingdom and Ireland Vasculitis Society (UKIVAS) held their first residential educational course in Cambridge last December.



For those who are not familiar with UKIVAS, let me introduce you to it. It started as a collaboration between patients, clinicians, and scientists to create the first comprehensive database of vasculitis patients in the UK and Ireland. As everything else it has evolved over the years and is now a society supporting every aspect of vasculitis.

As a patient I see it as a community of doctors who have interest in vasculitis and are willing to share their knowledge and experience with the clinicians that want to learn more about vasculitis.

UKIVAS kindly asked Vasculitis UK to have a stand there and that's how my journey to Cambridge started.

What an honour to represent Vasculitis UK in an event only for clinicians. And what a task to hold a stand for 2 days on my own! To make it even more challenging I had to drive from Plymouth to Cambridge in the snowstorm that hit UK. It was late afternoon when I arrived, Cambridge was magical all dressed in white! I got the stand ready – I am still surprised that I managed – and went for a stroll in the campus.

It was like walking in a postcard. Met some lovely students, we made a snow-family, had a snow fight and talked about their experience of studying there.

Vasculitis UK had offered bursaries to 5 junior doctors to attend, the applications were so many that UKIVAS decided to sponsor another 5 applicants. They even had to pause the registration at some point as they reached the capacity they could accommodate. Seeing so many doctors attending events to educate themselves about vasculitis warms my heart as a patient.



The 2 days course was intense, and it was hard to choose which of the parallel sessions to attend. The rooms were full of doctors, junior doctors, and consultants. The speakers were clinicians with very good vasculitis knowledge from many different hospitals in the UK. Some of them had to present online as the weather didn't allow them to attend in person. Paediatric vasculitis, large and small vessel vasculitis, ANCA associated vasculitis, diagnosis and classification of vasculitis, eye, brain and ENT involvement and much more were on the agenda. I hope this is the

start of vasculitis education days in the UK!

The stand was busy during the breaks. Some clinicians came to say hello, others were interested in what we do and how we support patients. Most left with a bag full of booklets and leaflets and a handful of chocolates!



I would like to thank Prof David Jayne for giving me the opportunity to raise the patients voice during dinner and of course thank all the doctors that had to stop eating their dessert to listen to me! A big thank you to UKIVAS and the organising committee, and a special shout to Karen Ellis who coordinated the course.

Zoi Anastasa

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) <https://rairda.org/> released a report in November 2022 highlighting 'alarming disparities in the quality of care and treatment' received by people living with rare autoimmune rheumatic diseases (RAIRDs).

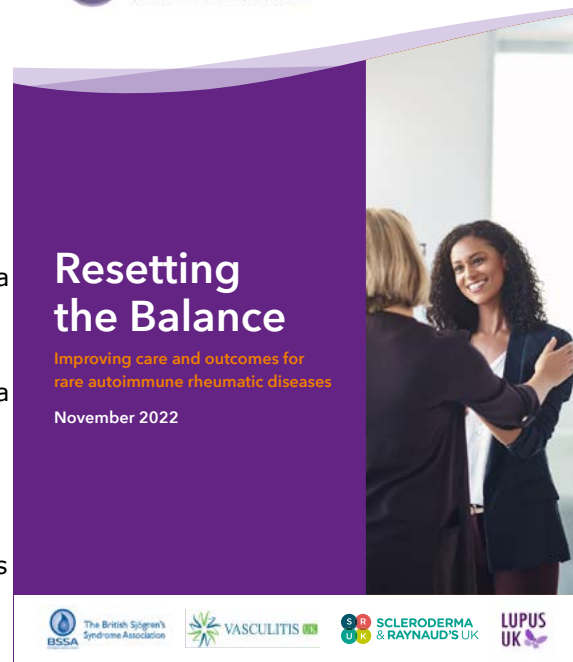
The Resetting the Balance report provides compelling evidence that late diagnosis and inadequate care of these diseases can significantly reduce a person's life expectancy and have a major impact on their quality of life.

Sue Farrington, Co-Chair of RAIRDA, said: "People living with rare conditions have too often been forgotten when it comes to policy or investment in health services. The Resetting the Balance report presents evidence and clear recommendations for how to improve care and services for people living with RAIRDs across the UK.

"We hope that the next few years will see policy developments that reflect the needs of people living with these serious illnesses, and real breakthroughs in important areas such as improving diagnosis and creating and accessing new treatments. We also hope that the experience of living with a RAIRD is dramatically improved as care and treatment reaches parity with other more common conditions.

"Finally, we hope this progress happens across the UK, with the treatment a person gets no longer being determined by which nation or region they live in."

In order to urgently address the care and treatment of people living with these rare conditions, RAIRDA is calling for quicker and more effective processes for diagnosis for people with RAIRDs, better access to treatments – including new and innovative drugs, an elimination in care and treatment inequalities and, due to the vulnerability of RAIRD patients, priority access to vaccines and treatments for Covid-19 and other viruses.



The report has received coverage in The Daily Mirror, Daily Express and Daily Record
Read the full report here.

<https://rairda.org/wp-content/uploads/2022/11/Resetting-the-Balance-Report-RAIRDA.pdf>

THE INCIDENCE OF KAWASAKI DISEASE USING HOSPITAL ADMISSIONS DATA FOR ENGLAND 2006-2021

Incidence of Kawasaki disease using hospital admissions data for England 2006-2021: results from the RECORDER project:

What?

Kawasaki disease

A childhood illness, 74% affects <5yrs

Inflammation & weakness of heart blood vessel walls

Why?

- Delayed diagnosis & treatment
- Damaged heart
- Immunoglobulin shortage

- Inform & plan services
- Early diagnosis & treatment
- Prevent heart damage

How?

2006 2021

Diagnosis checked in

Patient involvement

Findings?

5908 children in England 2006-21

Each year ~300 children <5yrs affected (1 in 12,500)

3 ♀ : 2 ♂

Non white & deprived socioeconomic groups

University of Nottingham
UK | CHINA | MALAYSIA

Odingo M, Rutter M, Bowley J, Peach EJ, Lanyon PC, Grainge MJ, Stilwell P, McPhail S, Bythell M, Aston J, Stevens S, McCormack R, Brogan P, Pearce FA.
Rheumatology 2023, <https://doi.org/10.1093/rheumatology/kead051>

Or Scan me

Rheumatology Journal Article

<https://academic.oup.com/rheumatology/advance-article/doi/10.1093/rheumatology/kead051/7009240>

Urticarial Vasculitis

Prof David Jayne

Director of the Vasculitis and Lupus Service, Addenbrooke's Hospital

Urticaria is the name used to describe a raised itchy rash, also called hives. There are a number of causes but the symptoms are usually short lived and subside within hours. When urticaria occurs for longer periods of time, days or weeks, the blood vessels under the skin can show evidence of vasculitis and the term urticarial vasculitis is used. Patients may experience a burning or painful sensation and there is skin discoloration when the rash subsides. It is a form of skin vasculitis.

Urticarial vasculitis can be seen as a skin manifestation of another form of systemic vasculitis, such as, EGPA (Churg-Strauss) or IgG4 related disease, and like other forms of vasculitis, urticarial vasculitis may be triggered by another disease process, infection or cancer, or a drug. It has particularly been associated with hepatitis virus infection but most cases have no identified cause. It is either limited to the skin or with evidence of systemic disease. The systemic disease is quite rare and not well characterised, but arthritis, glomerulonephritis (kidney involvement), lung and gastro-intestinal disease have been reported. Patients with systemic disease feel unwell, with fevers, muscle and joint pains and the CRP (inflammation) blood test is usually high.

Some cases of urticarial vasculitis are associated with changes in the blood complement system with falls in the level of complement components C3, C4 or C1q in the blood, or the presence of anti-C1q antibodies. This has been called hypocomplementemic urticarial vasculitis (HUV). These complement abnormalities can also be seen in SLE (lupus), although anti-nuclear antibodies are seen in some cases of HUV, this would further raise suspicion that the correct diagnosis is lupus. HUV has also been called MacDuffie syndrome, with one attempt at defining diagnostic criteria requiring 2 of, biopsy confirmed urticarial vasculitis, arthritis, eye inflammation, glomerulonephritis, abdominal pain and anti-C1q antibodies. Systemic disease is more common than when complement abnormalities are not present and the possible overlap with lupus has encouraged use of drugs effective in lupus such as hydroxychloroquine and rituximab.

Who are affected?

Urticarial vasculitis is most common between the ages of 30-40 and is found in women more than men. Very rare cases of HUV have been familial, more than one case in the family.

Diagnosis

As in other types of vasculitis, the diagnostic work up tries to define abnormal clinical, laboratory and X-ray features, identify any associated diseases and then classify the type of vasculitis that is present. A skin biopsy can be helpful as there are characteristic findings in urticarial vasculitis, a search for disease in other organs should be undertaken.

Key blood tests would include inflammation markers, CRP and ESR, testing for C1q, anti-C1q, C3 and C4 complement components and autoantibodies, ANA and ANCA. The oc-

currence of a rash and complement abnormalities would also raise suspicion for cryoglobulinemia. Chronic virus infections, other infections and inflammatory diseases and cancer should be looked for and excluded.

Treatment

There is no high quality evidence from clinical trials to help guide treatment in urticarial vasculitis. The skin manifestations of Urticarial Vasculitis may simply be treated with antihistamines and NSAIDs such as Ibuprofen. Hydroxychloroquine, an anti-malarial, dapsone and colchicine can be tried especially for relapsing disease. Corticosteroids work well but relapse can occur on withdrawal and they are more toxic. The presence of systemic disease usually demands the combination of higher dose steroids with an immune suppressant such as such as azathioprine, cyclophosphamide, mycophenolate mofetil or methotrexate. Other therapies that have been effective include high dose intravenous immunoglobulin, omalizumab (used in asthma), plasma exchange, anti-interleukin 1 biologics and rituximab.

A logical approach to treatment is required trying to avoid steroids as far as possible for skin limited disease. Without good data to help select drugs a sequence of treatments may be required until one is found that works well for that patient.

Patient monitoring to detect the emergence of systemic disease or another underlying diagnosis is important, although after 1-2 years patients often settle into a pattern of quiet periods and flares, that may be triggered by intercurrent infection, and treatment strategies for prompt flare management are worked out.

Procedures: Plasma exchange or plasmapheresis

This treatment is sometimes used in patients with severe vasculitis where antibodies in the blood are thought to be important in causing the disease. The treatment involves removing antibodies from the blood using a machine and returning the "cleaned" blood back to the patient. The treatment may necessitate giving blood products to the patient including plasma, albumin or immunoglobulin. It may also involve giving drugs to thin the blood and prevent it clotting in

Key Points

- Urticarial vasculitis can be a feature of another disease or a disease on its own.
- It can be limited to the skin or have systemic manifestations
- There may be complement abnormalities in the blood, in which case the term hypocomplementemic urticarial vasculitis is used.
- Treatment follows similar principles and drugs to other forms of vasculitis.

Our Fantastic Fundraisers



Nuffield Health Quiz Night for Vasculitis UK Tracey Pollard and friends raised £612.00 for VUK selling an amazing 500 tickets.



Denis McMahon being presented a cheque for £500 by Kevin Parker - General Secretary of the Manchester City Supporters Club. Denis has GPA and applied to the Supporters Club for a donation to the Vasculitis UK charity.



Helen Eleftheriou ran the London Marathon for Vasculitis UK in memory of her father, Paraskevas, who very sadly lost his life, in October 2021, to an extremely rare type of Vasculitis which affects the Central Nervous System. Helen raised an amazing £2930



Milton Keynes Rock Choir raised £287 for VUK on Thursday 23 March, 2023. This makes to date a total of £567 raised by Nick and Kathryn Collyer.

The name of our choir leader is Rob Baker and the four ladies who helped with the raffle, from left to right are Wendy Thompson, Joyce Easton, Katherine Johnson and Kathryn Collyer.



Ann Baron held their yearly charity event on Lady of Lee Valley barge at Lee Valley Boat Centre. Raised £165 for Vasculitis UK. It was a lovely day and the sun shined for them all!!

Poles Of Inconvenience Rally 2023

Team Bam Boo



We decided that we would sign up to an unforgettable and wild adventure this Summer on the 8th July which will span

until the 8th August on what is known as The Poles Of Inconvenience Rally. The un-routed journey will start and finish in Czechia but it's the Poles of Inconvenience that really creates the stupidity. Think of it as a curated network of chaos.



Some of the Poles may be inconvenient in the classic sense of being nestled in remote corners of wilderness areas. Others might be topographically inconvenient, like the top of a mountain, or in the middle of a sea of sand dunes in the Sahara. Some will be logistically inconvenient, and all of them will be comically unsuitable for our 20-year-old Fiat Panda.

There are only **3 rules** to this crazy adventure, and they are:

Small and Rubbish

Our vehicle had to be small in engine size, physical size and definitely not suitable for the roads we are about to take to make the rally as hard as possible. There may be just a few break-downs along the way, so we picked a Fiat Panda we bought for £600.

No Set Route

We must bag as many Poles of Inconvenience as we can in any order we like, in any direction we want. So, we have decided to make it even harder by getting as many as we can by travelling to as many countries as we can! On the worst roads we can!

We're on our own.

That means we have no support or backup following us and we are com-

pletely alone apart from other team members. If it's not dangerous and we aren't lost, we're not on an adventure!

We are doing all of this for a brilliant once in a lifetime experience but also to raise money and awareness to an amazing charity that helps so many people. We are also dedicating this adventure to our good friend Sarah who sadly left us way too soon due to Vasculitis. We will be taking photos of our car along the way and displaying Vasculitis UK everywhere we go!



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

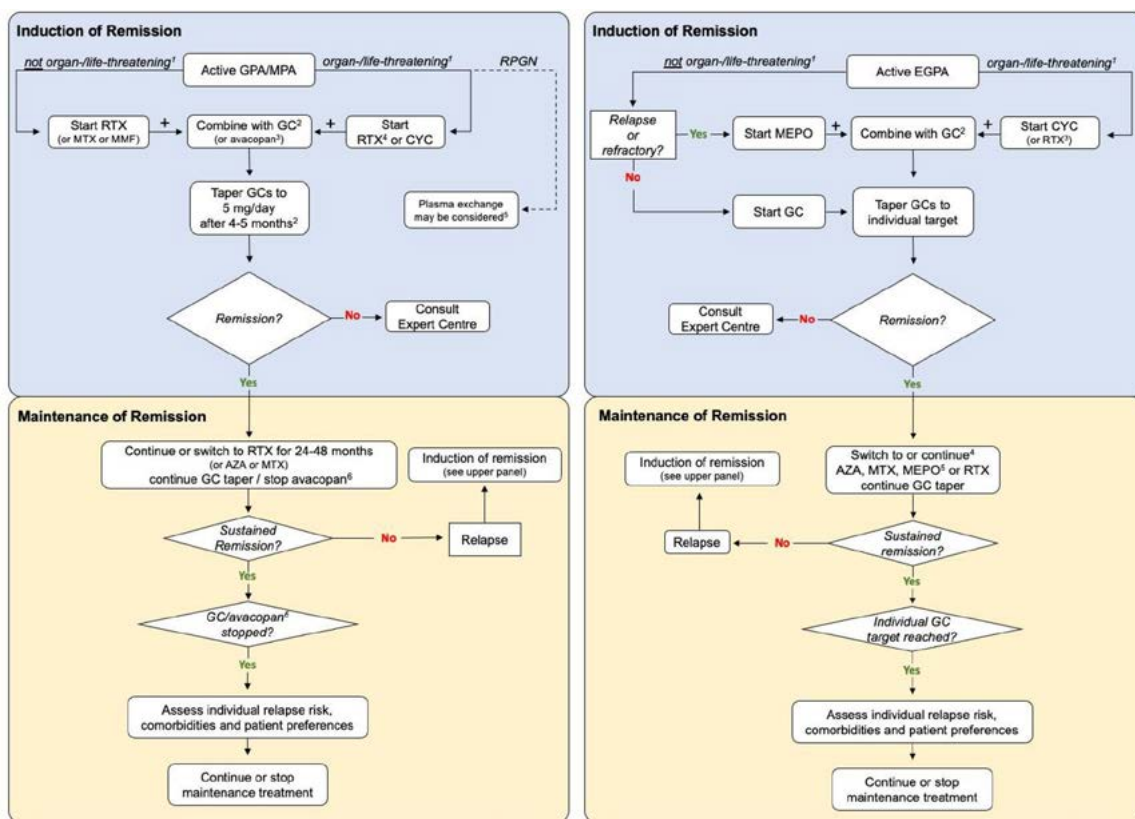
EULAR recommendations for the management of ANCA-associated vasculitis: 2022 update

EULAR is the European umbrella organisation representing health professional associations, scientific societies, and organisations for people with rheumatic and musculoskeletal diseases.

In 2016 they had published recommendations for the treatments of ANCA associated vasculitis. Now, we welcome the 2022 update that was published in the March 2023 issues of Annals of Rheumatic Diseases.

In a nutshell, in GPA and MPA the induction treatment is the same, regardless of the severity of illness. Rituximab is the most recommended treatment and patients should taper their steroids to 5mg in 4- months. For the first time EGPA gets its own recommendations and mepolizumab is part of the induction treatment in non-organ/life threatening disease.

The graphics below show the latest recommendations.



The graphics and information are from:

Hellmich B, Sanchez-Alamo B, Schirmer JH, *et al*

EULAR recommendations for the management of ANCA-associated vasculitis: 2022 update

Annals of the Rheumatic Diseases Published Online First: 16 March 2023. doi: 10.1136/ard-2022-223764



First data from the MELODY Study 9/2/2023

Antibody prevalence after 3 or more COVID-19 vaccine doses in 23,000 immunosuppressed individuals: a cross-sectional study from MELODY

Full Journal Article

<https://www.medrxiv.org/content/10.1101/2023.02.09.23285649v1>

AAV Pilot Workshop by CLS Vifor Pharma and Vasculitis International

A few years ago, Vifor Pharma (now CLS Vifor Pharma) and Vasculitis International co-created a project called "SEE ME. HEAR ME." aiming to make patients with ANCA associated vasculitis (AAV) to feel that their voice is heard.



This year they organised a two-day event in Madrid and Vasculitis organisations from Europe and beyond were asked to support the event and suggest patient representatives to participate. A

Vasculitis International meeting would be held during these days as well.

First meeting point for the UK representatives was Heathrow airport. Julie Power from Vasculitis Ireland, Sue Ashdown and I from Vasculitis UK flew together to Madrid and did our best to represent the UK vasculitis community.



There were long sessions and a lot of brainstorming. Patient representatives from Spain, Netherlands, Italy, Poland, and Canada found the common barriers vasculitis patients face during their journey and suggested best practices for the clinicians. The medical representatives attending had their own sessions discussing common problems across borders and sharing experiences with their colleagues.

A successful event, that will hopefully be the first of many! It was nice to see another face of pharma industry, one that has nothing to do with promoting their products. A big thank you to Peter Verhoeven, the chair of Vasculitis International, that worked endlessly for this event to be inclusive and fruitful.

Zoi Anastasa

I was invited, as an experienced patient, with GPA, to attend the AAV European event in Madrid last November.

Despite suffering from fatigue I thought I was an event worth travelling for. With me being able to learn more about Vasculitis International and being able to contribute as a GPA patient of 27 years.

The event was run by Vasculitis International, whose aim is to support Vasculitis Patient Advocacy Groups,

and CSL Vifor, who with this project aims to improve the lives of AAV patients with high unmet medical needs.

The attendees were other experienced patients and Clinicians from Europe and Canada. Over the two days we met and exchanged stories and knowledge.

The Chair of Vasculitis International, Peter Verhoeven, from The Netherlands presented a session on the Stages of a Patient's Journey, from diagnosis to planning for the future. From both the Clinician and patient perspective.

Next day brainstorming sessions were done with the clinicians and patients separately re this journey. Our group sat around a large table with a 'map' of the journey on it and went through the six stages: Pre-diagnosis, Diagnosis, Initial Treatment, Maintenance, Monitoring and Remission/Relapse. Each participant shared their own experiences at each stage, with experiences varying from country and from length of diagnosis, 2 to 27 years. We discussed what had worked well and at what stages improvements, with suggestion, could have been made.

The joint feedback session following this showed that both groups had come up with similar thoughts. The improvement of training and education for doctors, nurses, and patients, as well as the Public.

I found it a very interesting two days, learning about the work of Vasculitis International and their aim to have universal Toolkits, Brochures, and Website for all countries to use.

Meeting patients from other countries, mingling and swapping stories was great. It reminded me how well we are doing and lucky to have respected doctors in this country and Vasculitis UK.

Sue Ashdown

Clothing

 Vasculitis U.K. Hoodie £20.00	 Vasculitis U.K. T-Shirt £12.25	 Immune System T-Shirt £12.25
 Baseball Cap £10.00	 Running Vest £12.00	 Zip Up Hoodie £21.00
 Stigma T-Shirt £10.00	 Waterproof Jacket £21.00	 Sweatshirt £18.00
 Polo Shirt £13.75	 Cycle Top-Blue £27.00	 Vasculitis U.K. T-Shirt £12.25

<https://vasculitisuk.myshopify.com/collections/clothing>

Check out our online shop



20th January, 2023, Plenary Meeting followed by onboarding information event,

21st January, 2023 Hackathon 09.00- 19.00



Kraków City Centre at Dawn 20th January, 2023

“Hope you have plenty of warm clothes packed,”
 “You should visit the Salt Mines”,

the later comment was repeated several times as I travelled by car, bus, aeroplane and taxi to the hotel in Krakow. I was sceptical of having time to do this as I was on a mission to observe a hackathon on the second day of the meeting. I was right. I’m afraid I packed too many warm clothes and ended up roasted all day, every day.

We have been involved in the FAIRVASC project for almost 3 years now – VIA, Vasculitis UK, and Vasculitis Stichting – representing the patient voice. FAIRVASC started life as a means of addressing the facts that

- Vasculitis is a rare and life-threatening disease
- many registries are collecting valuable information that could improve the treatment and life quality of those living with vasculitis,
- these are not collaborating.
- The scientific data is siloed and not shared.

FAIRVASC was set up as a tool for researchers, clinicians, and patients to interact with research data. It is a research project of the European Vasculitis Society (EUVAS) and European Reference Network (ERN) RITA and has 10 partners representing all aspects of patient care with particular emphasis on data protection. The name comes from the acronym FAIR which means all information must be

F air, A ccessible, I interoperable, R eusable

The tool being used is semantic web technologies which get the registries to talk to each other, while protecting the identity of the participants – this never leaves the local registry.

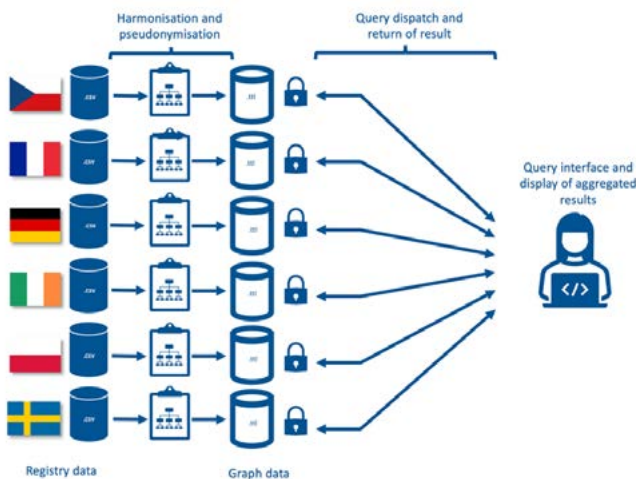


Image taken from talk by Karl Gisslander Kraków Jan 21st, 2023, to show how data is managed

To date, we have 6 registries on board, with 5279 AAV patients recruited and consented to interrogate their data to learn more about Vasculitis. The type of information stored is diagnosis, sex, age range, organ involvement, treatments used (for how long), organ damage, and co morbidities. An ontology has been created so that the same terms are used in each site, this means that the information is more easily shared and queried. The interface for this was showcased at the International Vasculitis and ANCA symposium which followed our successful International Patient event last April.

The future plans are to onboard more registries from Switzerland, Australia, Netherlands, Barcelona, Turkey, Italy, Portugal and the UK. Representatives from most of these countries attended the onboarding session on 21st Jan following our plenary meeting.

- Create a sustainability plan. A small amount of funds has been secured to help us explore this and create a business plan.

continued on page 12



HACATHON

I'm not sure about you, but when I hear this word, I think of lots of activity, brainstorming, problem solving and intense debates, so when I had a chance to attend one, I jumped at it. Lots of enthusiastic IT students and academics from Kraków come along to Jacochim University on Saturday in the hope of helping us with 2 aspects of our work and a chance to win a cash prize for their effort. We had 2 projects, 1 to help us redesign a more user friendly interface and 2. A greenfield project to design a more efficient way of getting our computer languages to speak to each other.

The day opened with a description of the FAIRVASC project, what we needed and some mock up resources for the participants to use to come up with their ideas. The participants were then divided into 2 IT suites where they had access to team members from all aspects of the FAIRVASC project and university IT staff.

I was in the room with those working on the interface design. We need an interface that will not only be easily used by researchers, academics and Healthcare professionals, but also by patients. The information in this federated registry can give us information on numbers and genders of those living with the different types of Vasculitis, the prevalence in the different countries, prognosis, organ involvement, drugs used and effectiveness of treatment. Ideally in the future, it would be nice for us to be able to see the data being held on us, but this would only be possible from the recruiting centre and would need very secure means of access.



4 teams finished in this project by the time allocated. All contributed new ideas for us to take away and refine our Interface - help section/most frequent queries, availability in different languages, suggestions to ensure security, scalability and accessibility of interface, resource section including recent research, link together button to combine results of several filters, results shown in different formats – graphs/charts. As one of the judges, it was difficult to decide one project over the other, but the winning team encompassed accessibility for all stakeholders with a valuable resource section.

New Book Release

“Finding Me Beyond Illness”



Scan this code to view



Becoming someone new

“I am not the illness – I am a person first.”

<https://shanaliperera.wixsite.com/digitalart>



Onwards, 2020

RARE DISEASE DAY 2023 GLOBAL CHAIN OF LIGHTS



Diagnosed with **VASCULITIS?**

Living in the **UK?**

Aged **18 to 39?**

Vasculitis UK Young Adult Group is a new community aimed at supporting young people living with vasculitis

Join the community:

<https://www.facebook.com/groups/vasculitisukyoungadult>

Email: Charlie@vasculitis.org.uk



Rare Disease Day 2023



JOHN MILLS AWARDED MBE IN HIS HOME VILLAGE

John Mills was recognised in the New Year Honours 2023, but because he is too ill to travel to London the decision was taken to have the ceremony in his own village at his local pub.

Mr Mills was awarded the MBE "For services to people with rare diseases through his role as Vice Chair and Director of Operations at Vasculitis UK" The honour was presented by the Lord Lieutenant of Derbyshire, Elizabeth Fothergill.

Mr Mills was also recognised for his work setting up the internationally-recognised charity Vasculitis UK in 2010. He did this after being diagnosed with a rare condition Granulomatosis with Polyangiitis, in 2001. He was joined by members of his family, colleagues and friends in the village pub.



You can read full coverage of the ceremony here <https://>

LLAGE IN DERBYSHIRE



Johns honour, is very much well deserved, he said that he accepts it on behalf of all those involved with VUK, but in all

honesty if John hadn't taken the reins along with Susan none of us would be benefiting from all that this wonderful charity provides, and yes, it is true that all those now involved and those that came before us, there are many thanks to go round for helping this charity to be where it is today, but in my own opinion John has been the catalyst that drives this charity forward, his knowledge of Vasculitis and rare diseases is all self taught albeit triggered by his own diagnosis.

Both John and Susan should rightly be proud of this honour bestowed to him, his passion dedication to the cause is immense and a inspiration to us all and I sincerely thank them both for that.

Kevin Soper (editor)



[/www.bbc.co.uk/news/uk-england-derbyshire-64341107](https://www.bbc.co.uk/news/uk-england-derbyshire-64341107)

SUPPORT GROUPS



Vasculitis in general is a rare disease and some types are extremely rare. People with vasculitis often feel very alone and isolated because few people properly understand their problems and they know nobody else with vasculitis. Local groups provide an opportunity for people to meet and share knowledge and experiences.



The North East Vasculitis Support Group enjoyed a welcome “Get Together & Reunion” on Saturday, 11th March at The Mill Inn, Houghton-le-Spring. Margaret Robertson sadly announced her retirement as group organiser but will still be a member. Dan, Claire and Val will take over running the group and you can find their contact details here

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

Margaret received flowers from members of the group to say thank you for all her support over the last few years.

You will find details of support groups throughout England and Wales on page 27. Some groups are large, holding formal meetings with invited speakers, others are very small, perhaps meeting for coffee in someone’s house, or at a cafe or pub. The most important part of any meeting is the sharing of experience.

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

We, at Vasculitis UK, do our best to ensure that support group meetings are well attended by advertising them in the “Dear Diary” section in the Newsletter, the e-News, on our Facebook and Health Unlocked discussion groups, and here on our website.

For new groups the charity will advertise your endeavours by checking our main database for all members in your area and writing to them with details of the meeting. We can supply you with posters for your local hospitals/GP clinics etc., and send loads of “goodies” – balloons, pens, stick-it notes, car stickers etc. We also have a leaflet available to give you ideas about how to set up a Group.

We do not believe that anyone setting up a group should be out-of-pocket if they are willing to organise and run support group meetings. The charity can offer some financial assistance towards funding at least the initial meeting.

Why not check the Support Groups? If there isn’t a group in your area then email John Mills to discuss setting up a group.

4th EUVAS Course - Stazione Leopolda, Florence Italy 2022

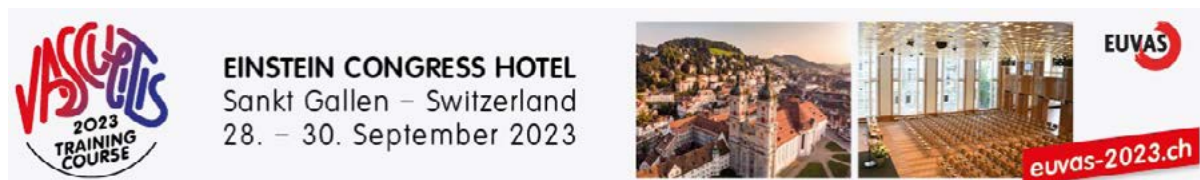


On October 13 -15th 2022, the beautiful architectural venue Stazione Leopolda, in Florence, Italy was the venue for the 4th EUVAS Vasculitis Course, affirming a return to in-person gatherings for the Vasculitis Community.

The three-day educational extravaganza gathered health-care professionals from around the globe to discuss discoveries, advances, and challenges across the breath of Vasculitis in both adult and paediatric populations.

Emerging themes for ongoing development and implementation of advances across the vasculitis syndromes included improving ways to make a diagnostic, refinement of classification, and assessment of how the disease affects different parts of the body from bed-to -bedside.

A combination format of auditorium lectures, parallel symposia and specialist group meetings proved an educational delight for the large audience. The opportunity to meet in-person once again, coupled with the vibrancy of the occasion ensured a wonderfully sociable atmosphere. Access to the lectures on-line, in addition to expert interviews on the Fondazione Internazionale Menarini website, continue to provide a very rich educational resource for the vasculitis community.



Opening the program, Meeting Presidents Professor David Jayne, President of EUVAS and Professor Domenico Prisco welcomed the audience, setting the scene for the coming days. The Organising committee and Scientific program Chairmen Professor Giacomo Emmi, Professor Carlo Salvarani and Professor Augusto Vaglio, along with the EUVAS Council and Local scientific committee choreographed a wonderful program that underscores the importance of education in vasculitis.

The EUVAS 2023 Training Course will take place on September 28th-30th, at the Einstein Congress Hotel, Sankt Gallen Switzerland. Eagerly anticipated, early registration is advised for the excellent program in-store.

See you in Switzerland....

Dr Allyson Egan

Tell your story

Send your story to kevin@vasculitis.org.uk

Is this what dying feels like?

I guess to fully explain my story I need to start right at the beginning, after living an illness free life until I was into my 40's, my first health issue rose its head in my early 40's. After feeling very tired most of the time I went to my GP, who said let's do some blood tests and after emphasising how tired I felt the last box he ticked was TSH levels last. As hypothyroidism (under active thyroid) is 10 times more likely in females than males it was quite a surprise that my TSH were very high indicating hypothyroidism, so that was me on pills for the rest of my life.

Then I in my mid 40's after my long-suffering wife, Jill complained that my snoring was getting worse, and I woke up gasping for breath a couple of times, so back to the GP let's do a sleep apnoea test. It was less of shock to find out I had sleep apnoea considering the choking, you cannot imagine what it's like to wake up gasping for breath with your wife shouting "what's wrong!" And you can't answer because you are choking! So that meant I needed a CPAP machine, fortunately these machines have moved on leaps and bounds from the "hoover" type machines of the past to sophisticated quiet machines of the today.

As I entered my 50's I thought well this decade can't possibly be as bad as the last one, little did I know...

As an almost aside my 50's started with bouts of severe constipation and I tried many things to combat this including a gluten free diet, which is about the most unfun I think I have ever had! Although I did become almost an expert on gluten free beer, which to my surprise is much better than you might think! This ended in me having a colonoscopy which did discover that I had some anal polyps, which of course wasn't helping! More on polyps later.

Perhaps fortunately in my mid 50's Jill and I relocated back to the UK after having lived in Alberta Canada for over 16 years. My journey towards vasculitis started, I now realise with asthma type issues, for most of my life I have been a keen runner doing usually three 5kms a week to keep me fit for my real passion of mountain hiking. I started to find my runs getting harder and often mention to my Jill, that they shouldn't be this hard and should be getting easier not harder! Then the chest infections started this was towards the end of 2020 and into 2021 this continued for over 6 months, getting a chest infection then taking antibiotics then repeat, they rather randomly prescribed some inhalers, a brown one and a blue but gave me no instructions at all on how to use them properly. Finally in July 2021 a Nurse practitioner diagnosed asthma and prescribed prednisone. I was relieved that I finally had a diagnosis and it was being treated and even more relieved when the steroids worked wonders and cleared up my crackerlike chest. Little did I know that an asthma diagnosis over the age of 50 is very rare, and also didn't know how much very rare would be in my future.

Despite the treatment and diagnosis of asthma it kept returning and I think from Oct to Dec I had antibiotics and prednisolone every month. In December I went back to my GP complaining of sinus issues and (for those of you with a delicate dispossession look away now) nose slugs! Yes,

blowing out huge nose slugs! He referred me to the ENT consultant who diagnosed chronic sinusitis and confirmed I had nose polyps, and remember I had polyps somewhere else in the past and I'm told there could be a connection, get them in one place and you might get them in another? So, surgery was arranged and for the first time in my life I heard the word vasculitis, as he stated that they would do a biopsy to ascertain the cause which was more than likely just an infection and there was a 5% chance it could be vasculitis.

On the day of the surgery although it got delayed a week which was very annoying, but it meant I when "down" first, and to my surprise I was under for around 3 hours. Can you imagine someone poking, cutting and prodding around in your nose for three bloody hours! The last time I was knocked out with general anaesthetic I was fortunate enough to be in a BUPA hospital so the coming around was very peaceful and almost stress free, nothing could be further from the truth coming around from a general anaesthetic in an NHS hospital! Firstly, I remember feeling all the Vaseline on my eye lids and the all the shouting and puking in the recovery room and then the blood pressure cuff crushing my arm. Not surprisingly I think I started to thrash around a bit and remember the nurse saying no please lay still and then how was the pain, how the hell should I know I was trying to work out where the hell I was and what the heck was going on! Eventually I could see again after wiping my eyes a few times and then realising that the screaming was a young person clearly suffering the same as me but with nausea added in! I also remember a semi naked very old person right in front of me and thinking WTF! Eventually my blood pressure returned to a level that the nurse said we will now return you to the ward, which compared to that recovery room appear to be a slice of heaven!

This is how I looked at the end of day, pretty right?

Once my blood pressure returned to its full normal level my nose just exploded, squirting blood everywhere, you know it's quite bad when even the nurses, who I assume see this every day, sympathise. I also remember the consultant who visited that afternoon saying well when you left surgery your nose was lovely and dry but then your blood pressure increases.



The recovery was pretty horrendous, lots and lots of pain, discomfort and then the nose douching and if you have never done this and or don't know what it is consider yourself very lucky!

It was about a month after surgery I started to feel unwell, it mainly centred around my stomach and just a general feeling of being unwell. I lost my appetite and started to lose weight quite a lot of it, my heart rate also went up and I often had a temperature and I was very tired and slept a lot. My wife, bless her, was convinced something was not right and in the end called an ambulance, they couldn't find much wrong but said I did have a temperature so would take me to hospital. Once there I was warned the wait could

be 12 hours and it pretty much was but as there couldn't really find anything they said we can keep you in for observation or you can go home, I of course opted to go home who wouldn't? Unfortunately, the next day I was back as I was still feeling unwell and the GP had said to my wife take him back and I'll print off his history to take with you. I was admitted pretty quickly and then moved to a dreadful ward which I think was like the AE overflow. The bed was in a walled cubicle with a curtain at the front, the place was loaded with people coming and going plus you couldn't get any cell phone signal or WIFI. Fortunately, the next day they moved me to what was the equivalent of the Ritz! Top floor, my own ensuite room, with a TV and a window that opened. This was pretty good, perhaps things were looking up. The next day they came in and said sorry but we need to move you as this for short stays only and it looks like you will be here for longer, what! So down into the bowels of the hospital I went to ward 23 and by this time they had registered that I used a CPAP machine even though I didn't have it with me, so I was put in a plastic cube! Yep the same ones that they had used for covid patients and in this area there were 4 plastic cubes sharing one toilet, in which there were three other people that I can only describe as almost dead! That maybe sounds unkind but that is how they looked, mouth open, not moving and at least 30 years older than me! Then the one next to me left not sure why and not sure if they were still breathing when they left and was replaced with my first moaner. That's my best description because they just randomly moaned throughout the day and night! So, it would all quiet in the middle of the night then he would start, freaked me right out to start with. Then he left and I thought great at least I can get a reasonable night's sleep. At 2am the next occupant arrived, screaming and shouting at the top of her voice and a f-ing and jeffing as well. At that point I was somewhat pleased to be in my plastic "bubble" with the doors closed.

The next night my neighbour made a "fatal" error by banging on the wall that separate our plastic cubes, this was interpreted by the staff as threatening to another patient so with a police escort she was moved. Peace at last, well that is a relative term as any of you who have been in hospital will now, because they do a vitals check pretty much every 4 hours, so if one is done around 11-12 at night the next one is 4-5am! I got pretty good at only half waking up as I hung my arm out of the bed for a blood pressure and oxygen saturation check, it was a bit tougher when they had to take blood as well, which for me was very regular. Most of the nurses were pretty polite and gentle realising you were only half awake but I remember one which I was told after was agency staff they just said "arm" took the vitals and left! Good morning to you too!

So am getting a little off track, during all this time my symptoms increased and so did the testing, at one point I started to feel sorry for lab rats, because that is what I felt like! As I mentioned blood test most days sometimes twice a day, ultra sound test on my heart my now very numb leg, nerve tests on all my limbs, CT scans and an MRI which I hated with a passion. The rash on my hand, see photos was now getting worse and the ulcer on the end of my finger was also getting worse.



Then I had a very frightening episode of losing most of the vision in my right eye! It just went all blurry and grey and this happened twice, for up to 45 minutes which prompted one of the eye consultants (I'm sure they have a posh name), to come to my bed to do some tests. Fortunately, he couldn't find anything wrong and at this point vasculitis EPGA had been diagnosed and he said that that must have caused the vision issues.

Just when I thought things couldn't get any worse Norovirus hit the ward, I had never had Norovirus and I hope I never get it again! After visiting the toilet before going to sleep I started to throw up and then bounced between the toilet and throwing up for the next 24 hours! The only thing I could find to be sick in was a Tesco carrier bag, which I almost filled by the morning! Because of norovirus and also covid had found its way on to the ward no visitors were allowed and when Jill was allowed to visit me a few days later I still looked deathly ill! I distinctly remember lying in bed, feeling dreadful and wiped out and my wife looking at me with a startled glazed look in her eyes. I think she was at her most worried at this point.

I had also seen what I felt like was every consultant in the hospital and most of the registrars. I felt some of the registrars were most helpful as they were so keen to learn and to try and find out what was causing my issues. Unfortunately, the Rheumatology consultants weren't based at the hospital I was in but in a nearby one and towards the end of my stay they had to give the go-ahead or not for all my treatments, which was a little frustrating as it often took a while to reach them.

I have to mention one consultant who came to see me on one of the last days I was in hospital, she was a nephrologist or someone who studies kidneys. To put it in straightforward terms she could have walked onto a Hollywood set and not been out of place if she had sat next to Eva Green and Kylie Minogue, you get my drift. She wanted to do a kidney biopsy, which despite her stunning looks I wasn't very keen on and fortunately was saved from that procedure by my Rheumatology consultant who didn't think it was necessary as nothing had showed up in my blood results that indicated any kind of kidney issue. But I was glad she came to visit me anyway.

So with a diagnosis confirmed I was finally given my get out of plastic cube card but in true NHS style even that took all day! Firstly, it was going to be today then no it will be tomorrow for certain, ok great we just need to wait to get your discharge meds from the pharmacy Ok sounds pretty straight forward. Lunchtime arrived and went and still nothing, I enquired, the meds were on their way but got lost somewhere so we have had to reissue the request, ok so how long will that take? Maybe a couple of hours, so back to the iPlayer I went, two hours later nothing, I enquired, they have the order but not sure when it will be dispatched but it will be soon, two more hours passed and a nurse finally said you know what I will go and get them and just as she did they arrived! Then soon after I was out, I got to the see the sky again and I got to go home!

So the next stage in trying to deal with this awful disease is a treatment of 6 iv treatments of cyclophosphamide. This is done as an outpatient and you have to go and have blood tests the day before to make sure everything is Ok so you can have this treatment, which is used to treat cancer amongst other things. But I'll leave this story for the next chapter.

Robert J. Mitchell



Bequests - In Memoriam



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

Funeral Donations of £206 in lieu of flowers were made in memory of Mrs Linda Breakwell of Nether-ton, Liverpool

Funeral Donations of £90 were made in memory of Ms Nicola Susan Monaghan of Bristol

Funeral Donations of £250 were made in memory of Robert Taylor, Ann his wife said that Robert was diagnosed with GPA in 2008 and with the care of his consultants and medical team they gave me 14 more happy years with him. He was one of life's greats, a wonderful husband, father, grandfather, and friend. He will be missed by all who knew him.

Funeral Donations of £190 were made in memory of Mr Geoffrey Garner of Northampton.

Donations to the total of £965 were made in memory of Richard Samuel Eling Butler. Richard very sadly passed away on August 29th, 2022, from ANCA Vasculitis. His wife Fran told us that Richard was the most kind, gentle and precious husband.

Funeral Donations of £355 were made in memory of Michael Neil Gladstone of Axminster, Devon

Funeral Donations of £700 were made in memory of Michael Dring who passed away at the age of 52. Nicola, his wife said that Michael was a beautiful caring person, who used to like spending time with his family, making plans and doing DIY around the house. He was very much loved and thought highly thought of by all who knew him.

£500 donation received by Barry Coulson and daughter Jayne in memory of Mary Coulson.

£90 a donation was received by Katy Bradley & Elaine Millington in memory of Norman Shaw

Funeral donations of £287.14 were received in memory of Mr Thomas Newton Elwick.

Funeral donations of £58.96 were received in memory of Jennifer Childs

£45 donation received in memory of Mrs Janet Moreen Bowen

Funeral donations of £112.30 were received in memory of Mrs Ann Denwood

Funeral donations totalling £1,200 were received in memory of Mrs Lois Warren of Valley Road, Ipswich, who died due to vasculitis on 18th August 2022 aged 79 years.

Donations totalling £487.50 were received in memory of the late Daniel William Goodrum of Norwich

A funeral donation of £35 was received in memory of the late Mr Kevin Michael Tudor of Bury St Edmunds.

Funeral donations of £128 were received in memory of Mrs Brenda Coleby Surrey.



Funeral Donations of £606 were received in memory of Mrs Emma Brown, Sheffield. Emma had a long battle with Takayasu Arteritis. Emma was a beautiful lady and will be so missed by her wife, son, family and friends.

Peter O'Toole and family donated £670 in memory of Pilar O'Toole.

Bhavisha Vagajiani and family donated £3598 in memory of her beloved husband Sachin.

Ciaran Cradden and family donated £630 in memory of Barbara Anne Cradden.

Leanne Fryer and family donated £630 in memory of Chris Malkin

Seran Davies and family donated £565 in memory of Steven Taylor-Haywood

Nigel Aspden-Harland donated £870 remembering Hamish Aspden

Jade Toomer donated £522 in celebration of Audrey Harland

Donations & Fundraising



Lewis Naggs and all the family held a fundraising music live show and raised an amazing £5844 in memory of Lewis's father Chris who very sadly lost his life last year, to Microscopic Polyangiitis.



Thank you to Osiris Lodge Freemasons, Queen Street - donation for £232.08

A Donation of £50 was paid in Memory of Reginald Frederick Robert Wood, a retired member of the Hampshire Constabulary, made by his former colleagues of NARPO, North Hampshire.

Donation received of £100 from Philippa Fortescue of Lyme Regis

Donation received of £100 from RF Cook

Ken & Gladys Edwards of Rayleigh, Essex, very kindly donated £100.

Donation received of £62.50 from the Turnstone Pub Christmas Raffle, Hopton, Norfolk plus £25 donation from Donna Akerman - all friends of Rachel Marsh

Donating To VASCULITIS UK

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

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

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

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

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



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



VASCULITIS UK ISSUE 65 SPRING 2023

Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group

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

Cambridge Group

Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

East Midlands Group

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

Lincolnshire Group

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

London

North London Group
susan@vasculitis.org.uk

Merseyside, Cheshire and North Wales Group

TBA

North East Group

Dan Hughes dfhuk@yahoo.co.uk
Claire Phillips clairealps@icloud.com
Val Farnsworth val.f@the-madhouse.co.uk

Northampton Group

Mel Alexander - 07884257123 - northants-vsg@outlook.com

Norfolk Vasculitis Support Group

Mark Sayer - msayer1502@gmail.com

The North West Group

TBA

Oxfordshire Group

Sue Ashdown - 01295 816841 - vsgoxford@gmail.com

Plymouth Group

elaine203@live.com

Solent/Portsmouth Group

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

Surrey Group

Peter surreyvsg@gmail.com

Sussex by the Sea Vasculitis Support Group

Antony Hart - Antonyghart@outlook.com

Swindon Support

Wendy and Lisa swindonvsg@mail.com

West Midlands Group

David Sambrook - davsamuk@yahoo.co.uk
Margaret Gentle - 0121-243-5621 - mgentle128@gmail.com

West Country Group

Website <https://vasculitiswest.wordpress.com/>
Charlotte Stoner - 01626 872420 - westcountryvasculitisgroup@outlook.com

West Sussex Group

John Bailey - 07752 122926 - johnbee4@googlemail.com

North and West Yorkshire Groups :

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

East Yorkshire Group :

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

North East Yorkshire Support Contact :

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

South Yorkshire Social Group Contact :

Jenny Gosling - email jenny@yorkshirevasculitis.org.uk

WALES

North Wales - (Contact Person)

Pat Vernalls - 01766 770546 - patvernalls@btinternet.com

North Wales Group (group also covers Merseyside and Cheshire)

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

South Wales Group

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

SCOTLAND

Edinburgh and Lothian (Contact Person)

Jimmy Walker - 07725 770103 - jamzywalker@gmail.com

Republic of IRELAND

(Contact Person)

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

Ireland - Vasculitis Awareness Ireland

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



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

EVENTS



British Society for Rheumatology Annual Conference
24-26 April 2023 Manchester



RCN Annual Congress
Brighton 14-18 May 2023



UKIVAS Meeting Glasgow 25th May 2023

TRAVEL INSURANCE

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

**Details are available on the VUK website:
www.vasculitis.org.uk/living-with-vasculitis/insurance
or contact John or Susan Mills details on page 28**

Chronic pain- What can I do to help myself?

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

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

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

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

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

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

Learning about your pain and understanding it can help you manage it well.

Healthcare professionals can help you find a self-management programme that suits you.

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

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

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



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. 1180473**

Officers, Trustees and Volunteers

Chair:

Dorothy Ireland
Dorothy@vasculitis.org.uk

Vice Chair:

John Mills
john.mills@vasculitis.org.uk

Director of Operations

Zoi Anastasa
Zoi@vasculitis.org.uk

Temporary Secretary:

Susan Mills
susan@vasculitis.org.uk

Treasurer:

Heidi Pollard - Director of Finance

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Independent Advisor:

Duncan Cochrane-Dyat

Medical Advisors & Scientific Advisory Board

Prof David Scott
Prof David Jayne
Prof Richard Watts
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