



VASCULITIS **UK**

NEWSLETTER JOURNAL



I started to prepare this report when we had a Queen. With 70 years of service to this country we will all miss a great lady. Now we have the first King in my lifetime.

We live in a world of change. On 15th May (World Vasculitis Day) we held our first AGM by webinar. All 9 trustees were present along with 45 attendees. Comments at the time and since indicate that it was a success. We had practised before and we do need to thank the gatekeeper John Geddes, who worked hard in the background. Also, Charlotte Smith who fielded the questions and Jen Harper who was taking notes. We need to thank the speakers, Fiona Pierce and Megan Rutter from Nottingham University talking about Covid related research and the MELODY study at Nottingham. We also had Peter Rutherford talking about AVACOPAN. We will make a decision next year about whether to try this again or to look for a Face-to-face venue.

For Vasculitis UK it has been a momentous year. We've been talking for years about needing someone to take on various roles on a full-time basis, rather than trying to cover things as volunteers in our own time, even for those of us who are retired. In a way it's our own success as a small charity that we are invited to professional events and to make presentations. The trustees decided that we needed to appoint an employee. The job description and person specification meant we had to look for someone ideally with knowledge of vasculitis. We concluded that one of Trustees fulfilled the requirements. Zoi Anastasa is now our Director of Operations and has resigned as a trustee.

As always, we are open to new trustees. If you're interested, please send a statement setting out your experience which would be beneficial to the charity to chairman@vasculitis.org.uk

I mainly organise the Great Runs. This year we had over 20 runners for the Great North Run and many have sent their photo-

graph for this edition and so far, they have raised nearly £6300. We also have runners for the Great South Run in October, this is the first time in many years and they have raised over £2000.

I will be seeking places for both events at the end of October, so please look at our website for entry details. We have one runner for the London Marathon, so if you're in the area cheer her on. Thank you to all who have donated or taken part in events this year.

I have also been involved in joining with other charities for Evusheld to be made available in this country for all immunosuppressed patients. We have again been active in funding research into Covid antibody response.

Our new trustees are settling into their roles. Charlotte Smith is increasingly taking the lead in fundraising. She thought of the "30 miles in May" and designed the T shirt, this has raised over £2000. Everyone seemed to enjoy it and put their own spin on it. We're working on the next.

Peter Rutherford has been a great help with documentation and procedures needed to take on an employee. He works with Zoi and myself on the medical information.

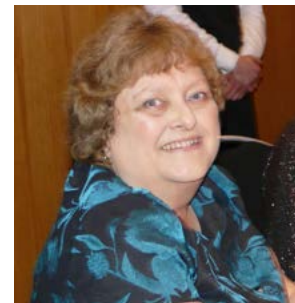
Jen Harper had a little boy, but is still running the shop.

Proud dad Charlie Harper has been developing the Young Group. He's also been working with Charlotte, Zoi and myself in designing the

new posters and leaflets. We felt it was time for a fresh look.

Charlotte, and Charlie are representing Vasculitis UK at the BSR case conference in Brighton at the end of the month. They will be joined on the stall by Tony and Giles Hart.

Heidi Pollard is the new treasurer and presented the accounts at the AGM. She also ran the Great North Run and has been running for us for a number of years. John Mills still keeps a close watch on what we're doing, sending emails and joining zoom



Chairman's Report

calls, even though he's not very well. Susan Mills on top of caring for John, still manages to post all the orders out and does a lot of work in the background, which keeps the charity running. She still has the helpline along with Zoi and myself.

Finally, I'd like to thank the volunteers who're not trustees. Kevin Soper our Newsletter editor who always manages to produce an attractive very readable product, even if we are sometimes late with the articles. John Geddes our website manager who learned new skills to make the webinar work. Duncan Cockrane-Dyett who keeps a close eye on our finances. Laura Whitty who manages the grant applications. Paul Townend our web designer. Just a reminder that it's the flu jab season and autumn covid vaccine booster time. When you get the text please have them done. We seem to have had a lot of members including myself who've had covid, its not nice. Take care.

Dorothy Ireland



PAGES	CONTENTS
FRONT COVER	
1	Front Cover Image credit to Charlie
2	Chairman's Report
3	From The Editor
4	Jayne Continues to Raise Awareness
5	Avacopan / Trustee News
6	A Cry For Support
7	ECRD 2022 / EULAR
8	Our Fantastic Fundraisers
9	Our Fantastic Fundraisers
10	International Vasculitis Workshop
11	Book Review / Melody Update
12	What Is Texas?
13	Lived Experience / Spring Crossword Answers
14	Research Update
15	Research Update
16	Support Group News
17	Cristmas Cards 2022
18	Tell Your Story - David
19	Tell Your Story - Wendy / Maxine
20	In Memoriam / Donations
21	Professor Justin Mason
22	Local Support Groups
23	Events
BACK COVER	
	Official Details

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



I hope you've all managed to navigate your way through the summer months and been able to appreciate some of the fair weather, and possibly even hotter climates if you were able to do so. As we start Autumn and prepare for the Winter months ahead, please take a few moments to have a read through this edition,

there are a few personal stories and as ever a focus on some of the charities wonderful fundraisers, which are the life blood for our charity.

We have had yet another fantastic turnout for the Great North Run and along with the 30 miles in May our much needed funds are the richer for it with thanks for everyone's contributions both in these and all the fundraising done since the last edition.

This years christmas cards are now on sale please see the details on page 17, and please have a browse at our online shop for any other items you may wish to purchase.

I would like to thank all those who have contributed to this edition and look forward to getting to grips with the Spring 2023 edition, keep safe and well.

Kevin Soper (Editor)



*Jayne Continues to
Raise Awareness
of Vasculitis*

On the 21st of September NICE published their recommendations for Avacopan (Tavneos) for treating severe active granulomatosis with polyangiitis (GPA) or microscopic polyangiitis (MPA) in adults. <https://www.nice.org.uk/guidance/ta825/chapter/1-Recommendations>

As a result of this Jayne Hardman was asked by Vifor Pharma the pharmaceutical company behind Avacopan to take part in a medical professional and patient vasculitis awareness campaign.

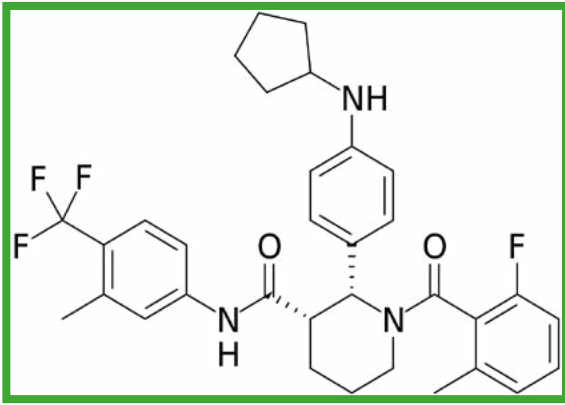


Filming began this last week and Jayne wanted to share some photos with you.

The campaign should be completed in the next few weeks and we will be able to continue Jayne's vasculitis awareness journey in the Spring 2023 newsletter.



Avacopan for treating severe active granulomatosis with polyangiitis (GPA) or microscopic polyangiitis (MPA)



On the 21st September NICE published their recommendations on Avacopan (Tavneos) for treating severe active granulomatosis with polyangiitis (GPA) or microscopic polyangiitis (MPA) in adults.

After many years a new medication has been approved for vasculitis.

John Mills, from Vasculitis UK was quoted in the CLS Vifor press release about the recommendation from NICE: *“ANCA-associated vasculitis is a rare, systemic disease which can be rapidly fatal if not appropriately & promptly treated. The variable nature of the disease and its course along with challenging side-effects of current treatment options can severely affect subsequent quality of life for patients. We very much welcome NICE’s decision, which means that eligible patients and clinicians have another choice of treatment for this debilitating condition”.*

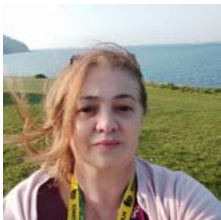
The outcome comes after years of hard work from the pharma industry, clinicians, researchers, and patients. Vasculitis UK was involved in the appraisal of the medication, and we worked hard behind the scenes to raise the patient’s voice. We must thank the members of our community who responded when we asked for quotes to support our submission.

Avacopan could be given instead of (or with a small dose) of prednisolone with cyclophosphamide or rituximab to treat severe, active GPA and MPA vasculitis. This makes having a correct diagnosis ever more important, as having a vague diagnosis like “small vessel vasculitis or ANCA associated vasculitis” may not be enough to give access to Avacopan, the guidelines are clear; at this point only patients of these two types of vasculitis are eligible to get prescribed this treatment.

This doesn’t necessarily mean that all patients will automatically receive it or will be given it immediately. Your individual treatment plan will be discussed with your doctor.

It is the first time, in the UK, that a medication gets approval and funding for vasculitis before it has been used in other rheumatic diseases. We are very happy that we played a role in this. One more treatment, one more option for vasculitis patients!

Trustee News



We would like to congratulate Zoi Anastasia on her job role as Director of Operations stepping into John Mill’s shoes. Unfortunately as John’s ill health has taken a step forward he has taken a step back. Zoi has now taken over more of John’s responsibilities. As you will read within this newsletter Zoi has been extremely busy this last 3 months and continues to be very busy, as you will read in the Spring 2023 Newsletter.

As some of you will know John Mills has been extremely unwell this last few months and has decided to take a step back from his role as Director of Operations. He is still lurking

in the background as vice chair and has been acting as mentor and advisor to Zoi and the other trustees.

Although Susan is caring for John she still continues to support Dorothy & Charlotte with fundraising. She also helps manning the helpline and is an admin for the online support groups.



We would also like to congratulate Jen and Charlie Harper on the birth of their little boy, Alexander, a little brother for Heidi.



A cry for support – Working across borders

Sometimes we don't realise how lucky we are to live in this country, not that it a bed of roses. The NHS is precious even when it's overworked as it is now. The care system is far from perfect, but it exists. And there are organisations like Vasculitis UK that offer advice and support to patients. Our online and local support groups can be a lifeline to many.

In one of the virtual European networking events I participated earlier this year I met a young lady from Cyprus who is working at the Cyprus Alliance for Rare Diseases (C.A.R.D.) and had a lovely chat with her. A few months later I received an email asking for support, they had a newly diagnosed patient with GPA vasculitis, but there isn't a patient support group, and they didn't know of anyone else with vasculitis to ask questions.

Fast forward to the beginning of September; I am in Cyprus for a short visit to family. A meeting is arranged, and we discuss the barriers rare disease patients face in Cyprus, the collaboration the alliance has with local support groups and the need of information about vasculitis as they have none. Knowledge is valuable when it is shared, so the next step will be to see what material we could share, what advice we could give them on how to organise a patient group and introduce them to Vasculitis International that could support them further.



Zoi Anastasa

British Society for Rheumatology 2022 Autumn Case Study Conference and Paediatric & Adolescent Rheumatology Conference.



This year both conferences were held in Brighton on the 28th/29th September. On this occasion Charlie Harper, Antony & Giles Hart & Charlotte Smith represented Vasculitis UK by having a charity information stand and Charlotte also gave a short presentation at the conference about VUK. Both Charlie & Charlotte have Vasculitis and are trustees of Vasculitis UK.

We would like to give a special thanks to Giles, who also has vasculitis and his dad Antony for volunteering to support with manning the stand. We believe it was quite a busy couple of days.

As copy date for this news letter is the 30th September Charlie and Charlotte will write a full report about their experience for the Spring 2023 Newsletter.

Susan Mills

ECRD 2022 - 11TH EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS

The ECRD is probably the largest patient-led rare disease policy event globally. This year the participants had the opportunity to learn about how to improve access to effective diagnosis, how to reduce inequalities for rare disease patients, to learn the importance of rare disease research and rare disease registries. This year the conference was held online from 27th of June to 1st of July 2022.

ECRD 2022's virtual platform gave the opportunity for collaborative dialogue to bloom and made the need of a new European collective strategy for rare diseases even more obvious. It was the second conference that took place fully online and the first one to be a 5-day event. This was the second time I participated in an ECRD conference, and the experience was very positive. It was difficult to choose between the parallel sessions and there were satellite meetings, language networking groups (where you could meet advocates from your country and speak in your own language), comfort breaks between the sessions where you could have informal chats with the speakers and a lot of opportunities for networking.

The first day started with the Opening Plenary Session and was followed by several Thought Leader sessions. The next three days were focused on how to reach the goals set by the Rare 2030 project. The Closing Plenary on the last day of the conference reminded us about the importance of addressing rare diseases across all of Europe (beyond the EU) and in global scale.

If you are wondering why it is important for us, a UK charity, to participate in EU events, the answer is simple. In rare diseases we don't have the luxury not to be involved. Progress towards better diagnostic tools, treatments, accessibility, and better care in general is something we all are working towards. Exchanging knowledge and opinions, having an open dialogue about the barriers we all face can only take us forward.

I took part in a focus group about the ECRD conference recently. Patient advocates from all over Europe were chosen to give their opinion on the agenda, the format and the networking opportunities during the event. Having the event online made it possible to more patients to participate as travelling is not always easy for rare disease patients. Having access to the recorded presentation for a year was something well received from the community as well. In general, the patient voice was raised through the whole conference, and we were given plenty of opportunities to ask questions, to voice our opinion and make this being a patient led event.

I am already looking forward for the next one!

Zoi Anastasa

EULAR 75

1947-2022 Anniversary

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

This year EULAR celebrates 75 years of contributing to rheumatology. A lot has happened in these years, let's have a look at some of the milestones:

1947

Birth of EULAR – first Congress in Denmark

1949

Cortisone is first used for the treatment of rheumatoid arthritis (RA)

1950's

Development of tests to detect Anti-Nuclear Antibodies (ANA)

Methotrexate synthesis

1960's

Cortisone low dose application becomes routine in many patients; side effects are described

First use of Methotrexate for RA patients

1970's

Magnetic Resonance Imaging (MRI)

"Invention" of monoclonal antibodies

1980's

Development of Anti-Neutrophil Cytoplasmic Antibodies (ANCA) test to help diagnose subtypes of vasculitis

1990's

TNF-alpha-inhibitors become available for many patients
Developments of outcome measures for RA: Disease Activity Score (DAS) and Radiological Score

2000's

Biologicals with other mechanism of action are introduced for rheumatic diseases e.g., rituximab and abatacept

2010's

Development of targeted synthetic DMARDs
First biologic agent that inhibits B-cell-activating factor (BAFF) approved to treat Lupus

Anti IL-17 treatment for spondylarthritis

Biosimilars enter the market

2022

75th Anniversary of EULAR
First hybrid EULAR Congress

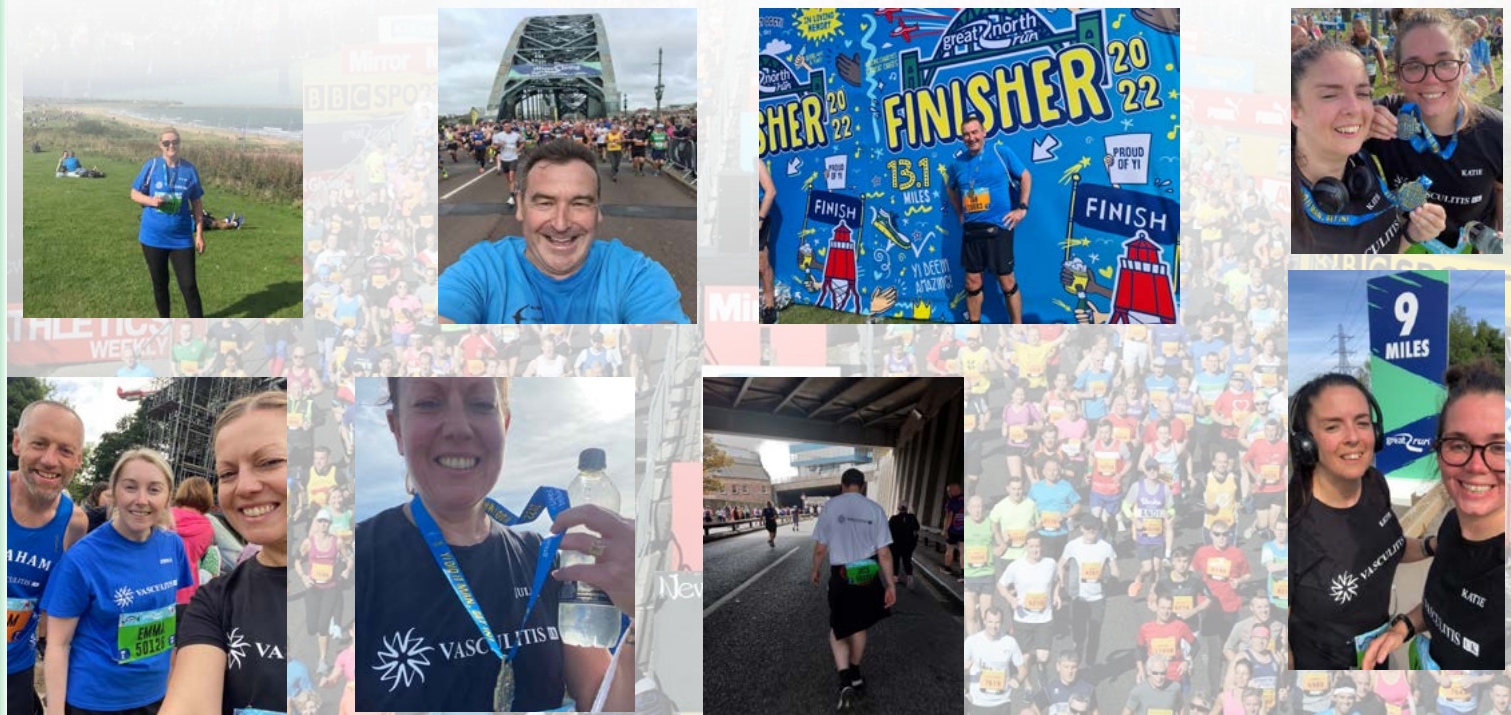
For the full timeline visit the EULAR organisation's website <https://www.eular.org/index.cfm> and choose EULAR 75th Anniversary Timeline.





Those who run the GNR raised more than £6200, and also all those who run the £30 miles in May raised over £2000. In this years Great North Run we had 26 runners with 6 having been deferred from the previous year. Here is a small collection of images some sent in - well done and thank you. Anna Mayhew, Ty Buckley, Sally Payne, Katie Pugh, Katie Manford, Jack Biggs Jack Biggs, Julie Brown, Jeremy Moore, Glynn Wallace, Rachel Thornton, Nicola Corbett, Andrew Thomson, Julie Black, Mike Elliott, Julie Sams, David Raggett, Emma Brady, Leanne Armstrong, Heidi Pollard, Elaine Grice, Graham Mully, Rachael Graham, Mahmood Nassar, Samh Elghazzawy, Julie Longdon, Jessica Randle.

Our Fantastic Fundraisers



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

Our Fantastic Fundraisers

Des Winks Memorial Football Match raised £730.
<https://www.deswinks.com/about-us/charity-events/>
 The score finished 3-3 and with a penalty shootout to decide the winner which was Roscoes Bar FC by 5-3.



At this year's Winstar Carnival Susan Mills, sister Janice and friend Audrey held a craft and produce store and raised £70. All crafts and produce were donated by those who have vasculitis or related to someone who has vasculitis. Even John Mills made a brief appearance.



The Scotland Coast to Coast race, September 10th.
 Caroline Meyrick, who has vasculitis writes



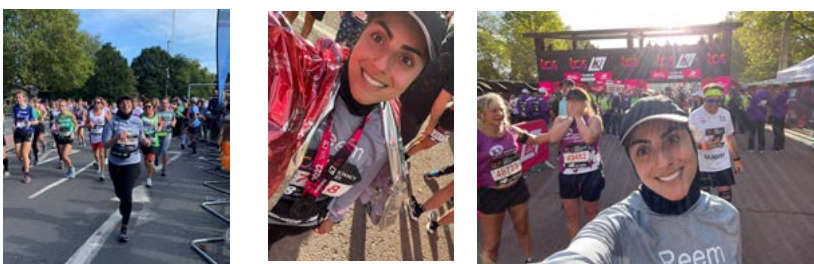
"The first photo is my son Oliver and his good friend Dan at the start of the race...it's 7.35 am and they are dipping their hands in the North Sea.
 The finish was at Loch Leven. The time was 18.36, so he did 105 miles in 11 hours.....and raised more than £1380 for VUK.
 It was a glorious day, and they are both so glad that they have finally completed the race after a three year delay."



Matt Smith (right) is our first ever fundraiser to climb to the Everest Base Camp – scheduled for October/November 2023. He's doing this in memory of his mother-in-law Janice Stevens, who sadly passed in 2021.

To read his full story and to donate please follow this link. <https://www.justgiving.com/fundraising/Matt-Smith150>

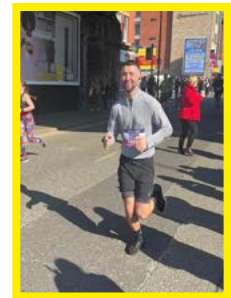
Reem Alkufaishi below who completed the recent London Marathon raising awareness and funds for VUK.



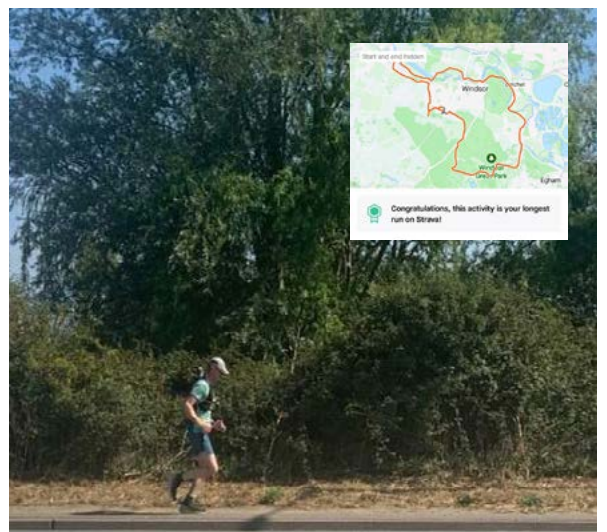
Jemma Jones, along with her step father, Gary, and her friend Maria, all completed the Essar Chester half marathon on Sunday 15th May, in memory of Jemma's mum Steph and have managed to raise £1440 for Vasculitis UK.



Elenia Tumini (below) ran the London Vitality 10K for VUK on May 1st 2022, raising over £550



Ryan Mouldsdale ran the Manchester Marathon in memory of his dad Neale who sadly lost his life to vasculitis. Ryan has raised an amazing £560



Michael Parry has been fundraising for Vasculitis UK. Michael's 15-year-old son became critically ill and was diagnosed Eosinophilic Granulomatosis with polyangiitis – EGPA Vasculitis, (formerly Churg-Strauss syndrome) a type of vasculitis & with secondary Mononeuritis multiplex.

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



The 20th International Vasculitis Workshop took place in April of this year and was held in Dublin. This year, for the first time it was decided to hold a hybrid conference - face to face and online. Around 500 medical health professionals attended. It is the largest international vasculitis congress focussing on vasculitis conditions. It is a cross disciplinary conference for all healthcare professionals and scientists who have a special interest in vasculitis.

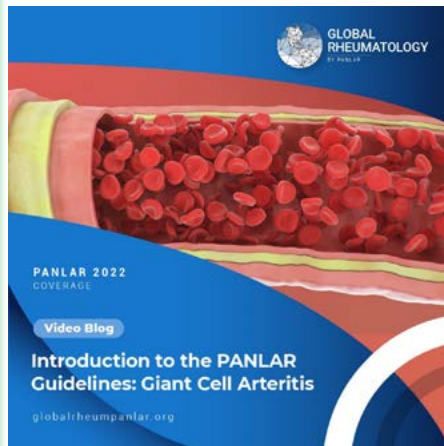
speakers but also offered engaging plenary sessions to keep up to date with the latest developments in clinical practise and research.

The Workshop this year was organised by Prof Mark Little and Dr Michael Clarkson and their corresponding teams of dedicated supporters.

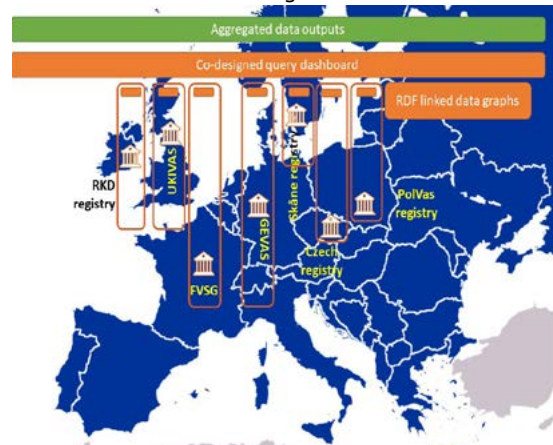


A Plenary Session discussing GCA

John and I were attendees on line and found all three days interesting, informative and exciting. We followed the workshop both as attendees and via Twitter https://twitter.com/vasculitis2022?s=21&t=_Xyly-4Igg_VeNRTj_PeJ1g we were multitasking.



EUVAS Vasculitis Registries slide



Vasculitis UK funded two special awards at the Workshop Best Oral Presentation



Small Vessel Vasculitis
Maintenance of Remission of AAV by Rituximab Based on B-cell Reconstitution vs ANCA Serology (MAINTANCAVAS)
 Dr. Reza Zonozi

Large Vessel Vasculitis
The Utility of Hybrid PET/MR Imaging for Disease Monitoring in Large Vessel Vasculitis
 Dr. Dan Pugh

Final Panel Session - Discussing New Horizons and Next Steps for Vasculitis.



The next International Vasculitis Workshop will be held in Barcelona in two years' time.
 Susan Mills

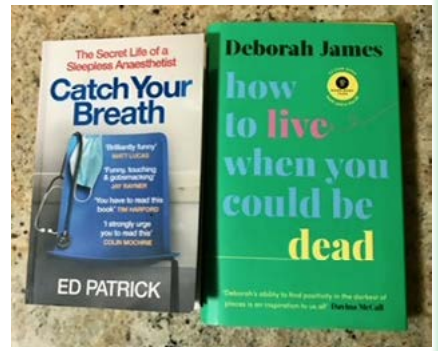
BOOK REVIEW **By John Mills**

How to live when you could be dead – by Deborah James (aka “Bowelbabe”)

Catch Your Breath – by Ed Patrick (The secret life of a sleepless anaesthetist).

Many of us who have suffered with vasculitis over the years feel that we have had quite sufficient contact with the medical profession however these are often the very people who are keeping us alive.

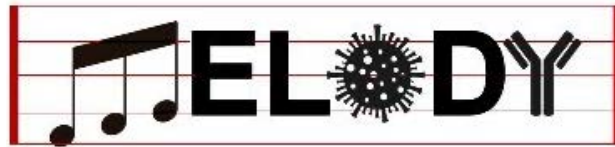
Here are books describing two very different experiences.



Deborah James was a very dynamic head teacher of a primary school who was diagnosed with incurable bowel cancer at the age of 35 and given a maximum 5 years to live. She was the mother of two young children but she used many of the techniques she had learnt in the course of her professional activities to help her deal with this overwhelming challenge. Deborah’s positive attitude was an inspiration to her colleagues and the members of her medical team. Nobody seriously thought that positive thinking was going to make Deborah survive for a long time but she did live to see both her children reach secondary school age and to celebrate her 40th birthday. She was the instigator and creator of the ‘Bowel Babe’ charity which aimed to raise awareness that young people can and do get cancer. Deborah started a blog and instagram platform to tell her story @bowelbabe to help and support others, this led to becoming an awarding winning columnist and author. She was awarded a Damehood in 2022.

In contrast Ed Patrick was a trainee anaesthetist learning how to cope with the problems which accompany a very sick patient. Ed’s baptism of fire came because he started his anaesthetist specialist rheumatology training just as Covid was causing chaos in hospitals throughout the country. The anaesthetist is the member of the team who is responsible for looking after the patient’s airway – a most critical role in any operation or life saving procedure.

Deborah’s story is inspirational but has an inevitability sad ending whereas Ed’s story has a lot of dark medical humour in its narration and the ending is not unpredictable but what we hope for, Ed becomes a fully qualified Anaesthetist. Both of these books offer plenty of food for thought and are stimulating in their different ways. Both books give a very satisfactory and enjoyable literary experience.



MELODY UPDATE FOR VASCULITIS UK

The MELODY Study (Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people) has been designed to find out how well the COVID-19 vaccine protects people with vasculitis and other immunosuppressive conditions. The study has recruited nearly 30,000 people in the UK and is soon to release its first results. It has been funded by Vasculitis UK in collaboration with UKRI Medical Research Council and other patient charities, Kidney Research UK, Blood Cancer UK and the Cystic Fibrosis Trust.

The study includes over 6000 people with vasculitis and other similar diseases such as Lupus, scleroderma and myositis, as well as groups with other immunosuppressive conditions, namely organ transplants and lymphomas (a type of blood cancer).

The initial results are expected in the next month or so. The study will provide information on the proportion of people who have no antibodies to COVID-19 after at least 3 vaccines, as well as the impact of COVID on people’s mental health. In a later analysis, it will investigate how effective having measurable antibodies against COVID-19 is in preventing COVID-19 infection, and subsequent hospitalisation and death.

COVID-19 vaccination study in Nottingham – update for Vasculitis UK

What is VEXAS syndrome and could I have it?

Dr Ben Mulhearn, Academic Clinical Fellow, Royal National Hospital for Rheumatic Diseases, Bath. Dr Sinisa Savic, Associate Professor, University of Leeds



Dr Ben Mulhearn



Dr Sinisa Savic

VEXAS syndrome is a disease caused by an acquired change (mutation) in the genetic code that makes certain immune cells created in the bone marrow overactive and dysfunctional. It can imitate a variety of rheumatological conditions, including vasculitis, cartilage inflammation (polychondritis), and cause joint pain and swelling (synovitis), painful rashes, and breathing problems. Because it is caused by an acquired change in the genetic code, VEXAS usually occurs later in life (typically over 50 years of age). The X of VEXAS syndrome signifies that the mutation occurs on the X chromosome, and since men only have one copy, they are much more likely to develop the disease. Patients with VEXAS syndrome do not typically respond to treatment in the same way as patients with other types of vasculitis, and in some cases, using immunosuppression may be detrimental. VEXAS also affects ability of the bone marrow to create other important parts of blood, such as red blood cells. Eventually the bone marrow might fail altogether, in which case regular blood transfusions might be needed and overall life-expectancy might be reduced.

The genetic change that causes VEXAS was only discovered in 2020. We therefore believe that there are patients with VEXAS, who are undiagnosed and hiding in plain sight in rheumatology clinics. For this reason, our group has secured funding to identify such patients and invite them to join our study. VEXAS remains difficult to treat, and currently we do not know which are the best treatment options. Furthermore, there is no cure. Our study has been set up to answer some of these questions, but we require your participation to help us with this effort.

Many people may now ask, "have I got VEXAS syndrome?". The test for the genetic change is now easy to perform. If you are a man aged over 50, with difficult-to-treat vasculitis (or other rheumatic conditions such as polychondritis), have ever had a platelet count below 200, and/or an MCV (a marker of the size of red blood cells) above 100, please see your specialist and raise this question. Finding out will not only be useful to you, to ensure you are not on any treatments which may be harmful to you, but you may also be invited to join a study to research this new disease further. Please contact me on ben.mulhearn@nhs.net if you would like further information. The VEXAS foundation, which can be found at vexas.org, also has a wealth of information about the disease.

How many people in England have Takayasu Arteritis?

Mr David J Groves Research Fellow - National Disease Registration Service.
Dr Fiona Pierce - Nottingham University Hospitals Trust

Takayasu Arteritis is one of the rarer forms of vasculitis. There has previously been little known about how many people in England are affected. We are very pleased to report the results of this research we have conducted at the University of Nottingham and in collaboration with the National Disease Registration Service at NHS Digital, and Professor Justin Mason at Imperial College London. This work was funded by a Vasculitis UK research grant.

We used electronic health records in England to see how many people have Takayasu arteritis. We found that in 2020 there were 1094 people living with TAK in England, which is a prevalence of 19.3 people with Takayasu arteritis per million people in England. About 80% of people living with Takayasu arteritis were female, and about 77% of White ethnicity.

The annual rate of new diagnoses (incidence) of Takayasu arteritis, has been fairly stable over the past 15 years until the COVID-19 pandemic. Overall, about 1.2 people are diagnosed each year per million people in England, and about 75% are female.

Dr Michael Chen-Xu Specialist Registrar Rheumatology Norfolk & Norwich University Hospital

Dr John Mills (Vice-Chairman, Vasculitis UK) gave a lecture on his lived-experience of vasculitis and the role of Vasculitis UK to a group of approximately fifteen Speciality Registrars in Rheumatology (post-graduate doctors training to become Consultant Rheumatologists) from across the East of England region at their Vasculitis-themed training day, held at the British Racing School, Newmarket on Thursday 13th October 2022.



Dr Mills' presentation was very well received, with one of the attendees remarking that, *"The description of his personal experience of living with vasculitis was a good reminder of the fact that patients, such as John, are at the centre of what we are here for as Rheumatologists-in-training"*.

In addition, there were two case presentations from the Speciality Registrars: one on a patient with a vasculitic-looking skin rash eventually diagnosed with scurvy, and the other on a patient who had clinical and histologic features suggestive of a diagnosis of granulomatosis with polyangiitis but most likely had VEXAS (Vacuoles, E1 enzyme, X-linked, Autoinflammatory, Somatic) syndrome. VEXAS syndrome (<https://www.niams.nih.gov/labs/grayson-lab/vexas>) is a newly characterised syndrome, primary seen in males, characterised by inflammatory symptoms affecting multiple

organs (e.g., skin, cartilage, lungs, joints, blood vessels) and changes affecting the blood (e.g., anaemia, low platelets, and enlarged red blood cells).

Other presentations from the training day included Professor Richard Watts who gave a lecture on the approach to the diagnosis/assessment of vasculitis, Dr Chetan Mukhtyar on VEXAS syndrome, Dr Max Yates on an update in the management of ANCA-associated vasculitis, and Professor Nick Levell and Dr Ajay Kamath who spoke on the cutaneous and pulmonary manifestations of vasculitis respectively.

Overall, the training day received very positive feedback from the Speciality Registrars in attendance, with one stating *"Really great training day, nice mixture of interesting topics with good speakers"*,



while another remarking, *"Fantastic day, great talks which all worked very well together"*.

As a part of their continuing medical education and training, Speciality Registrars in Rheumatology from the East of England organise several training days a year on various topics in Rheumatology, featuring local experts from across the region.

Diagnosed with **VASCULITIS?**

Living in the **UK?**

Aged **18 to 39?**

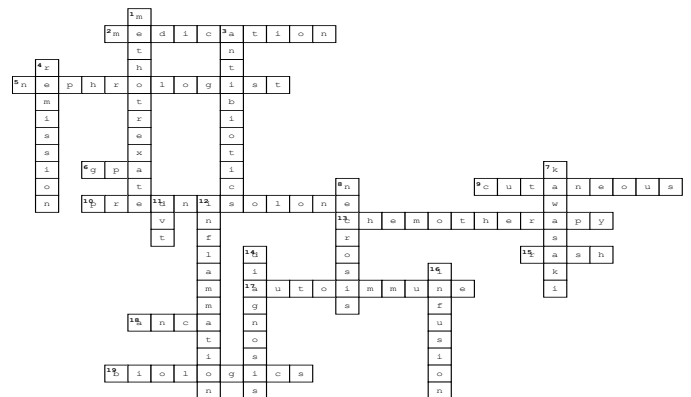
Vasculitis UK Young Adult Group is a new community aimed at supporting young people living with vasculitis

Join the community:

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

Email: Charlie@vasculitis.org.uk

Vasculitis UK crossword competition



Across

2. general name for the drugs you take
5. a type of consultant specialising in kidneys
6. type of vasculitis usually affecting kidneys, lungs, ears and nose
9. relating to the skin
10. a steroid commonly prescribed for autoimmune conditions
13. treatment that uses powerful chemicals to suppress the immune system
15. common general skin symptom
17. a condition where your body targets itself accidentally

Down

1. a strong chemotherapy treatment
3. prescribed for bacterial infection
4. the goal where your condition is controlled
7. second most common type of vasculitis in children
8. tissue death
11. a type of blood clot usually in the leg
12. your bodies natural response to injury or infection
14. confirmed nature of the illness or problem
16. the delivery system for many stronger drugs



RESEARCH UPDATE



Research Funding 2022

We had a fantastic batch of applications this year from all over the UK, covering both adult and paediatric research.

Following our usual peer review process, the Scientific Advisory Board (SAB) met in April and with the addition of two trustees to the group, they made the decision to fund 3 studies.

We would like to offer our sincere thanks to all of our peer reviewers, without whom we could not complete our grant calls.

We are delighted to announce that the following applicants received funding for their exciting and varied projects whose aims mirror Vasculitis UK's priorities.

1. **IgA Vasculitis: Do N-glycans play a role in pathogenesis?**

University of Liverpool - £49,822

Dr Andrew Chetwynd (Co-applicants; Dr Louise Oni & Prof. Claire Eyres)

This 12-month study will be the first study of its kind in paediatric IgA Vasculitis patients.

Immunoglobulin A vasculitis (IgAV) is the most common form of vasculitis in children. IgA is an antibody, a protein that the immune system makes to recognise and remove unwanted pathogens. In IgAV, IgA has an abnormal structure for reasons that we do not currently understand. This abnormal IgA settles in areas of the body and causes rashes, sore joints or, in more severe cases, kidney damage. In most children their immune system will clear the abnormal IgA, and they will make a full recovery. However, a few children (1-2 in every hundred) will go on to develop severe kidney disease. Unfortunately, at the moment we have no way of knowing who will get better and who won't.

The team plan to extend our understanding of IgAV by investigating changes in the N-glycan decoration of IgA in children with IgAV compared to healthy controls. Disease-dependent changes could be used to identify and monitor which children are at risk of developing kidney disease. If successful, this could improve disease outcomes for children that would otherwise have developed severe kidney disease, and reduce the need for long-term, potentially invasive, follow up of children who never would have developed kidney disease.

2. **Beyond the IL6/CRP axis: a systems-based approach to identify novel pathogenic pathways associated with disease activity and arterial progression in Takayasu Arteritis**

Imperial College London & University of Leeds - £49,099

Prof. Justin Mason (Co-applicants: Dr Robert Maughan, Dr James Peters, Dr Charis Pericleous & Prof. Ann Morgan)

This collaboration between Imperial College and Leeds University will use a systems analysis approach, utilising targeted proteomics and mass spectrometry-based flow cytometry in plasma and cellular samples collected from patients with Takayasu arteritis.

Their aim is to discover disease-specific changes in the blood and patient cells that may represent targets for new therapies, and/or have potential for development into new blood tests for patients. These can then be assessed and validated in large future prospective studies and clinical trials of new treatments.

3. **Ageing and ANCA: Investigating ageing-associated inflammation in response to drivers of ANCA-Associated V pathology**

Trinity College Dublin - £49,961

Asst. Prof. Nollaig Bourke (Co-applicant; Dr Mark Little)

The fact that vasculitis typically has a later life age of onset makes vasculitis unique among autoimmune conditions. There have been significant advances in understanding why inflammatory responses are altered as people age in the field of 'inflammageing', but this has not been investigated in vasculitis.

This study represents an innovative and novel approach towards understanding the causes of vasculitis and could spawn new areas of research in this field. This enhanced understanding of the early pathology of vasculitis could inform new therapeutic approaches and targets. The data generated from this proposal could also form the basis of larger national and international grant applications to further investigate age-associated changes to immunity and vasculitis pathology.

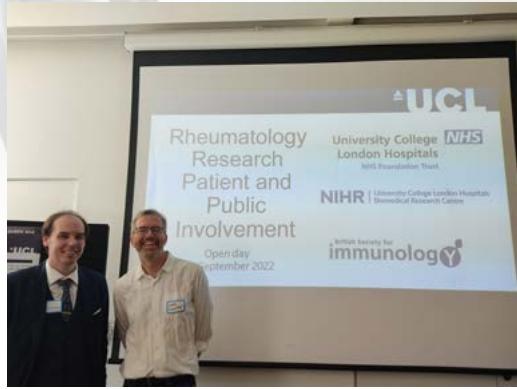
Laura Whitty

RESEARCH UPDATE

UCL Rheumatology Research PPI Open Day Autumn 2022

In September 2020 I received an email from John Mills forwarding an invitation to the virtual UCL Patient Partners in Rheumatology launch event. I was introduced to the PPI groups' world, and I have only missed one meeting in 2 years.

Patient and Public Involvement in Research (PPI) means that patients and members of the public work alongside and are actively involved in contributing to the research process, mostly as advisers. Our group meets virtually monthly (or sooner if needed) and we discuss research ideas and projects that are applying for funding.



On Saturday the 24th September we met in London for the first Open Day event. I had the pleasure to meet some of the team in the BSR conference in Glasgow last April, but this was the first time I met some of the other patients I have been working with for almost 2 years.

Professor Isenberg opened the event with a presentation about Lupus and the history of University College London Rheumatology Research. I loved his card analogy explanation of why some patients get diseases like lupus and vasculitis: we are dealt 'a bad hand of cards', genetic, hormones, environmental etc. It is like there is 'a conspiracy' in our body.

Then it was my turn to speak about us, patients, and what we can contribute to research. I cannot understand why they laughed when I told them that they wouldn't have a job if we didn't exist, it is true. Unfortunately, many of

us wouldn't be here if they didn't exist.

Dr Su-Ann Yeoh introduced us to her research about Immune cell aging and rheumatoid arthritis disease activity. Lucia Martin-Gutierrez shared a video of what happens to our blood when it is taken for research and shared the views of Sjögren's syndrome patients on research. Why don't biological therapies work all the time? Dr Clive Metcalfe talked to us about the ongoing research on this topic. Dr Shipa Muhammad presented his successful trial BEAT Lupus. Pregnancy in rheumatic diseases is something that interests a lot of young people getting diagnosed with RMDs. Professor Ian Giles has a special interest in management of rheumatic conditions in pregnancy and talked about 'improving our knowledge of how rheumatoid arthritis affects pregnancy'. Dr Thomas McDonnell came out of his lab and introduced us to the Beta-2-Glycoprotein I (anti-B2GPI) antibodies, their structure, function, and failure.

I would like to thank the team and especially Ellie Hawkins, the Rheumatology Research Lead Nurse at University College London Hospitals NHS Foundation Trust for giving me the opportunity to speak on behalf of the patients and for their hospitality.

Why should vasculitis patients get involved in research? What can they offer?

There are many ways patients, carers, parents can be involved in research participating in a PPI groups, taking part on surveys, studies and trials are the most common.

But why should we participate?

The patient perspective is extremely useful to researchers, by sharing our personal experiences and our need we give them a valuable and novel insight. Furthermore, it can make research more relevant and useful to patients, carers, parents etc.

Research in a rare disease like vasculitis is difficult and becomes almost impossible if patients don't participate. If we don't take part in PPI groups, surveys, studies, and trials what will the outcome be and how will it affect us? Take a minute to think about it and if you would like to be involved in any way ask your doctor.

What can we, the patients, offer?

In a PPI group we can share our expertise (after all we are experts on living with our disease), we can ensure that any research questions are relevant and that the needs of the patients are reflected in the research project. We can take part in survey's – most of them are online nowadays and we can complete them from the comfort of our sofa, studies, and clinical trials.

Patients, carers, parents etc can work alongside clinicians and researchers to make the future better. We can work together towards new treatments that can improve the quality of our lives and give us better outcomes.

Patients in research – Zoi Anastasa



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.

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.

West Country Vasculitis Support Group summer barbeque

After two years plus of 'hibernation' the vasculitis local support groups are slowly starting to hold face to face meetings.

Some of the groups met online, during the last 2 years, for a coffee and a virtual chat – not the same as meeting at a café, first of all you have to make your own coffee.

In August, Charlotte Stoner, the leader of the West Country Support Group invited the local members for a barbeque at her house, an annual tradition. The weather was glorious, the food was good, but the company was the best. A group of vasculitis patients and family members enjoyed the warm weather and the opportunity to share their experiences of shielding, the vaccines, the worry of not having covid-19 antibodies, but also their hopes of being able to do more things with family and friends, travelling plans and the bliss of doing something 'normal'.



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/>**

EVUSHELD

RAIRDA (Rare Autoimmune Rheumatic Disease Association) Press Release August 2022.



Over 120 clinicians representing 17 different clinical specialities, across all 4 nations, have released a clinical consensus statement saying that there is sufficient evidence that the Covid-19 preventative Evusheld would have clinical benefit to people who are immunocompromised, and a protective antibody treatment program should be delivered as soon as possible.




VUK Christmas Card Bundle 24 cards
 £2 + £1.50 postage
 Message reads :-
 Merry Christmas & Happy New Year
 Contact Susan Mills
susan@vasculitis.org.uk




For many immunocompromised people, the first lockdown in 2020 never ended, which is why in addition to the clinical consensus statement, alongside 18 charities, including our member charities Vasculitis UK & Lupus UK we have signed an open letter to Steve Barclay MP, urging the Government to buy Evusheld to protect the people they represent who remain vulnerable to Covid-19.

You can read the letter here <https://rairdaorg.files.wordpress.com/2022/08/evusheld-open-charity-letter-28.07.22.pdf>

The UK Government told the BBC it won't make Evusheld available until a decision has been made around its use by NICE. NICE decides what treatments are available on the NHS. They look at the cost of a treatment and how effective it is.

NICE are currently consulting around the effectiveness of Evusheld. Vasculitis UK is one of the charities involved in this consultation. This process usually takes a number of months, meaning a decision is unlikely to be reached until sometime in early 2023.

Susan Mills





Tell your story

Send your story to kevin@vasculitis.org.uk

Wegeners Granulomatosis (GPA) – 30 Years On

30 years ago I had never heard of GPA Vasculitis. I had also never considered the cataclysmic effect a debilitating disease can have on your life. I was 36 and doing OK. I had a good job (as an IT Consultant) that included plenty of travel and a decent salary package; all that was soon to become far less relevant.

I was on holiday in the USA – a fly drive. I remember the moment my life changed. I had jumped in a pool in a motel in Mariposa, California. I thought nothing of getting water in my ears. A few days later I'd arrived in L.A. and noticed a popping sensation in my left ear as I went up in the lift at the hotel. I thought little of it and got some OTC ear drops. I was flying home from LAX the following day.

I was finally diagnosed with GPA Vasculitis in December 1992 – 4 months after my ear problems started. I had been bounced around by medics until finally being admitted to the Infectious Diseases Unit at Churchill Hospital in Oxford. I had seen ENT Consultants all over Europe (I was still somehow working!) They thought I'd picked up an obscure bug on my travels. My joints had stiffened up and I felt really very ill and incredibly tired. Both my ears were now affected. My kidney function was going through the floor. I was scared. I also suffered Scleritis in both eyes and a most unpleasant 'extra' – a condition called Orchitis**. (Subsequently there was a slide presentation to Oxford University Medical School. One of my doctors had asked for my permission to use a slide showing my condition. The title slide was 'Goodness Gracious') ** Editor's note: Orchitis is the medical term for inflammation & swelling of the testicles.

Eventually a Radiologist and a team of Immunologists diagnosed Wegener's Granulomatosis. The assumption was that it had been 'triggered' by the ear infection though nobody could be certain.

I spent the next month in The John Radcliffe being administered Cyclophosphamide (I had double the normal dose and my hair fell out) and high doses of Prednisolone along with various other drugs to control the side effects. I was incredibly well looked after by a Medical Professor and his team. I was still absolutely terrified.

I was eventually discharged after about a month. For many following months I was reviewed weekly in Outpatients. I felt 'safe'. I had managed to return to work although I was battling both Depression and Anxiety. The monitoring and regular blood tests continued for years.

Eventually, about 14 years ago, I was told by my Consultant (a Medical Professor) that it was conceivable that this dreadful disease had 'burned itself out'. It was time to get on with life. My health slowly started to improve and, having lost a bit of weight I felt so much better and more capable. I had met my wife, Ann 9 years ago and our future was looking bright. Vasculitis was in the past.

Then in 2019 things changed. I was diagnosed with Double Pneumonia and a number of quite unpleasant infections (including cysts). I was being prescribed antibiotics almost bi-weekly. I was struggling. I was suffering fatigue and my breathing was dreadful. At this point I was under the care of the Respiratory Medicine Dept. In August 2019 I was admitted to hospital for IV antibiotics which still didn't resolve matters.

In January 2020 I was admitted again and diagnosed as having relapsed with my GPA Vasculitis – this time seriously affecting my lungs and also my shoulder joints. I spent a month in hospital and was given my first Rituximab infusions.

I was devastated I really had believed Vasculitis was behind me. Sadly, it doesn't look like it ever is.

Since then, my hearing has taken a further big hit and, due to Covid, we've barely left the house. My Respiratory Consultant had made it very clear that Covid would probably kill me. We've barely had any support from family although a few local people helped us at the start of Covid. Ann has been truly amazing throughout but it's exhausting caring and doing pretty much everything. Friends and family, with just a few exceptions, have disappeared. The loneliness of chronic illness is very real. Thankfully, Vasculitis UK have always been impressive and very supportive. Although our future looks a bit different now, we're not giving up.

UK Healthcare now is less impressive. Everything has been cut back and the medics no longer have time to talk. It's a battle getting vital blood tests scheduled as my GP is definitely less 'involved' than my first time round in the 1990s. Budgets are squeezed and we're all suffering. I honestly don't believe my GP fully understands my situation – he doesn't have time.

My Vasculitis-related blood results show that the disease is 'under control' but I still feel pretty dreadful, struggle with my breathing and suffer widespread joint pain. This is clearly exacerbated by being immobile. I can barely walk. My Consultant believes I also have Fibromyalgia!!

Vasculitis at 66 is considerably harder to deal with than it was 30 years ago!

The one glimmer of hope for me, after 2½ years of being removed from Society, is the emergence of Evusheld – a ground-breaking prophylactic antibody treatment. Unfortunately, it's quite expensive and the UK government appear to be dragging their feet. Our MP has been involved but she's not fighting for us either. She's just toeing the Government line.

BUT, somehow we'll get there – although I could do with a new pair of lungs!!

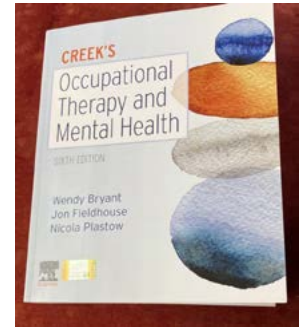
Dave Howard
August 2022



In 2017 I was diagnosed with GPA. My PR3 ANCA results were off the scale and stayed that way for many months despite having cyclophosphamide, then azathioprine, then mycophenolate and then rituximab. While all this was going on I was trying to work as a senior lecturer, leading a team of occupational therapists. I had PhD, MSc and BSc students.

I was also involved in preliminary talks about editing another edition of a textbook on occupational therapy and mental health. I'd done the previous one and signed the contract to do the new one in early 2018. Despite the rituximab I had a bad relapse that summer. In addition to my problems with my eyes, lungs and joints, I developed new damage to the nerves around my temples, giving me constant pain. The high dose prednisolone made me suicidal. And I had to take early medical retirement. Editing a textbook takes years, so fortunately I was able to slow down the pace while I recovered from the relapse. I got established on five monthly rituximab infusions and withdrew from the prednisolone.

We recruited 56 authors for 29 chapters. I co-authored two of the chapters, which turned into three, and then four as the pandemic disrupted everyone's lives. Many of our authors were working on the frontline of services trying to keep things going if they weren't redeployed. I had three friends to help me: one with checking the drafts as my eyes don't like prolonged screen time and another to put the glossary together.



The third friend helped me with recruiting and supporting people with mental health problems to write commentaries on the chapters. Summer 2021 was so busy with the book: by September when it was rituximab time again, I was so glad to be spending a long day in the chair doing not very much. The book was published in June. I'm still ANCA positive, but it's still falling. My vasculitis grumbles and flares, but with the support of the Addenbrookes team and my GP I haven't relapsed. So I've signed another book contract to write about managing fatigue: watch this space.

Wendy



Back in 2015 I was so unwell with Vasculitis. I had headaches, and head pain which would shoot from the back of my head to the front. The shooting pains occurred when undertaking tasks such as taking clothes out of the washing machine.

My arms felt like heavy weights, and I would use one arm to lift another arm up to hang out the aforementioned washing. I ached and then started with temporal pain. At fifty-six years of age, I was too old to be diagnosed with Takayasu, my symptoms were not typical of Giant Cell Arteritis. I then started to faint due to my blood pressure being so low, being blue lighted to hospital on several occasions. My blood pressure recordings were different in both arms, and I had absent radial pulses. The fatigue was dreadful, overwhelming. I would shower, then need to go back to bed for another couple of hours to recover. A repeating pattern throughout the day, which I am sure some of you recognise. Medical investigations revealed damaged subclavian and axillary blood vessels. Luckily despite my having transient sight loss symptoms my temporal artery remains intact.

My temporal artery remains intact.

I won't bore you with my roller coaster of a journey, my investigations and medication, these will be all very familiar to you.

It was over six months visiting every possible 'ologist' before a local Rheumatologist recognised my symptoms as Large Vessel Vasculitis, partly due to my absent radial pulses. (At my wrists)

I remain grateful to VUK to this day. The knowledge, information and resources John and Susan Mills offered gave me hope. It enabled me to educate myself and others to understand what it meant to have and live with Vasculitis.

The icing on the cake was a suggestion from John and Susan of a second opinion for my disease management. In early 2016, I met Professor Justin Mason for the first time. I embarked on shared care between him and my local Rheumatologist. I felt safe and had total confidence in that he believed everything I discussed with him. He 'got it' and what was more, he understood me. The Professor was a true gentleman, he treated me with respect and as an equal partner in my Vasculitis journey. In May I was shocked and devastated to hear of his death. I was due a clinic appointment with him in August. Like many others I am waiting to hear what next, who will take over not only my care, but the research I am part of. I know I sound selfish for even thinking of myself, but such is the impact of his loss. I now feel frightened and uncertain about my care again.



I was looking forward to telling the Prof that, this year on September 11th, now at the age of sixty-three I am running in my first ever formal running event. Albeit only 5k, of the New Forest Marathon, but for someone who has never run before and thought I would not live to see 2016, it feels amazing.

I know am in drug induced remission, I know I have a chronic illness, I know I am one of the lucky ones. So, in the event programme I have dedicated my 5k run to Professor Justin Mason, whose loss will be felt by many in the Vasculitis world.

Maxine
19



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

Donation from Lisa Collyer and family of £250 in memory of her dad Michael Beasley, who passed away in January. His granddaughter Chloe has vasculitis.

Donation of £30.00 from Rita Allen

Donation from the Gurney family of £205 on the sad loss of Mrs Diane Gurne

A donation has been received from the family of Robert Ernest Smith of £135

Donations totalling £127 were received in memory of Mr Roy Stowe of Hinckley, nr Coventry, who died in January 2022 age 84.

£315 was donated in memory of Anne Howard, of Banks, Lancashire. She died age 79 having battled with GPA & kidney failure for 24 years.

Donations totalling £139 were received in memory of Mrs Valerie McCarthy of Barnet who died recently after being ill for several years with vasculitis. A separate donation of £50 was received from her friend Sheila Levi.

Cheques totalling £220 were received in memory of the late Anwen Mai Read of Bangor, N.Wales who died in March this year having suffered from GPA for over 30 years.

Donations totalling £381 were received in memory of Mrs Patricia Bunnell of Leicester – including £50 from Colette & Robert Keyworth in New South Wales, Australia.

Further donations totalling £284 were received in memory of the late Mrs Valerie McCarthy of Barnet, North London who died due to interstitial lung disease caused by vasculitis.

Funeral Donations totalling £280 were received in memory of Mrs Betty Bellenger of Norwich, who sadly died in May this year, at the age of 84. She is survived by a daughter, Tracy.

Valerie Elizabeth McCarthy was a very popular lady and active member of Barnet U3A. The Queens Arms in Barnet held a fund – raising tea & cake morning in her memory, for friends & family. This raised a total of £511.65 in her memory for Vasculitis UK.

Donations totalling £177 were made to Vasculitis UK in memory of Mr Thomas Brown of Peacehaven, Brighton.

Donations totalling £150 were made in memory of Mr Gary Olsen of Rugby, who died late last year age 59 due to an aortic aneurysm. He leaves a widow and six children and numerous grandchildren.

Donations amounting to £440 were received in memory of David Roy Deaves.

After a long spell in hospital due to vasculitis and a variety of other conditions, Veronica Willis, of Witham Cheshire, sadly passed away in April this year. She was very much loved and will be sorely missed.

A collection for Vasculitis UK in lieu of flowers, at the funeral of Marilyn Todd of Durham, raised £228 in her memory. Marilyn died in July this year, age 63.

James Barry Gibson of Crawcrook, Tyne & Wear sadly passed away recently. Vasculitis UK received cheques totalling £353 in his memory.

Michael Gledstone of Axminster sadly died in August aged 72. Bereaved are his wife, Theresa and his three children, Max, Sophie and Helena. Vasculitis UK received a donation of £50.00 in his memory.

At the funeral of Robert Taylor of Okehampton, Devon, a request for donations to Vasculitis UK in lieu of flowers resulted in a total donation of £250



Jilly Holmes, made a donation of £280 in memory of her wonderful mother & father in law Joyce & John Holmes.

Donations & Fundraising

The North West Craven branch of the Royal Scottish Country Dance Society donated £473 to Vasculitis UK.

Katharine Philips-Smith - Albright International Ltd made a donation of £300 to Vasculitis UK

Professor Justin Mason



It's not often that true giants emerge in the vasculitis academic world. In May, this year the vasculitis world was devastated by the loss of one of its true giants, at the age of only 61, Professor Justin Mason. Justin was Professor of Vascular Rheumatology at Imperial College & Hammersmith Hospital. Not only did Justin seem to have a brain the size of a planet but he was also a wonderfully understanding

and empathetic human being, greatly loved and admired by his colleagues and patients. He was renowned for his gentle humility and quiet sense of humour, which put even the most nervous patient at ease.

Justin was an outstanding researcher, expert clinician and Internationally respected expert on all types of large vessel vasculitis, especially Takayasu's Arteritis.

His loss to medicine will leave a huge void that will be hard to fill.



Susan and I first met Justin at the International ANCA Workshop in Paris in 2013. We were over-awed by this his presence but we need not have feared, he came across as a wonderfully easy companion.

We were greatly privileged to be invited to attend Justin's formal inaugural address in 2014 at Imperial College. This gave us an insight into the true nature of Justin Mason as both a clinician and as a person. You can see Justin's Inaugural Address "From East Acton to East Asia" here <https://youtu.be/hPCspnupfus>

Over the years the bond and support between Justin and Vasculitis UK strengthened greatly. He will be greatly missed by so many, family, friends, work colleagues & patients.

John & Susan Mills

Donating To VASCULITIS UK

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

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

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

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

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



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

Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group

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

Cambridge Group

Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

Canterbury area (Contact Person)

Margaret McGrath - 01227 638469 - margaretmcgrathfmsj@yahoo.com

East Midlands Group

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

Dorothy Ireland - 01332 601303 - Dorothy@vasculitis.org.uk
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

Lincolnshire Group

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

London

North London Group
susan@vasculitis.org.uk

Merseyside, Cheshire and North Wales Group

TBA

North East Group

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

Northampton Group

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

Norfolk Vasculitis Support Group

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

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.org.uk



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

EVENTS

UKIVAS Vasculitis Education Course December 12/13th 2022
Cambridge (Medical Professionals only)



UKIVAS
UK and Ireland Vasculitis Society



World Kidney Day Thursday March 9th 2023



British Society for Rheumatology Annual Conference
24 - 26th April 2023 - Manchester (Medical Professionals only)

Monday May 15th 2023
International Vasculitis Awareness Day

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

Fundraising Co-Ordinators:

Dorothy Ireland
Dorothy@vasculitis.org.uk

Charlotte Smith
Charlotte@vasculitis.org.uk

Independent Advisor:

Duncan Cochrane-Dyat

Medical Advisors & Scientific Advisory Board

Prof David Scott
Prof David Jayne
Prof Richard Watts
Prof Charles Pusey

Research Awards Co-Ordinator:

Laura Whitty

Trustees:

Dorothy Ireland
Susan Mills
John Mills
Charlotte Smith
Charlie Harper
Jennifer Harper
Peter Rutherford
Heidi Pollard

Volunteers:

Kelly Jefferies
Kevin Soper
Vivienne Dunstan
Janice Mather
Kath Macintosh
Jayne Hardman
Gareth Garner

The VUK Shop Manager:

shop@vasculitis.org.uk

Web Admin:

Susan Mills

CONTACT US

Helpline:

0300 365 0075

Website:

www.vasculitis.org.uk

Address:

West Bank House
Winster
Matlock
DE4 2DQ

Phone:

01629 650549



Published by:

VASCULITIS UK

