VASCULITIS UK

NEWSLETTER JOURNAL

STRONG TOGETHER

Member of EURORDIS Rare Diseases Europe

SPRING 2019 ISSUE 57

The Old Chairman's Report

This report comes from the old chairman, John Mills, of the old charity Vasculitis UK Registered Number 1019983. Not to be confused with the New Vasculitis UK CIO (Charitable Incorporated Organisation), Registered Number 1180473, chaired by the not-so-old Dorothy Ireland. So this is mainly a report on decisions made and actions taken in 2018. Dorothy reports on the new CIO following this item in the newsletter.

For Vasculitis UK members nothing much will change except there will be a new charity number on forms. We have finally managed to change banks from the terrible TSB to the Coop Bank, so bank details on forms will change, but otherwise it's business as usual and old forms will still work for a while..

During the past year Vasculitis UK worked with the British Society for Rheumatology **(BSR**) on two projects. **RAIRDA** – the Rare Auto-Immune Rheumatic Disease Alliance and **Vasculitis Fellowships**. See reports elsewhere in this edition.

We are honoured that **Professor Charles Pusey** of Hammersmith Hospital has joined Professors David Scott, Richard Watts & Professor David Jayne as Medical Advisor on our Scientific Advisory Board. We are very grateful to these eminent doctors for their invaluable contribution to Vasculitis UK

The international Vasculitis Conference & ANCA Workshop will be held in Philadelphia this Spring. Vasculitis UK offered **5 travel bursaries** to assist doctors in training who are presenting abstracts or posters at the conference. We had 6 excellent applications, so trustees agreed to fund all six. (See report elsewhere in this edition).

Reports of drug shortages, even *before* Brexit are concerning for all, but especially those suffering from rare diseases. Some of these are due to problems in manufacturing, but others are artificial, caused by speculators, mainly in the US, buying the sole manufacturing rights on established essential drugs, then inflating the price such that in the US, a drug which used to cost $33 now costs $680. An almost identical drug in Europe costs €8. If, as part of a post-Brexit trade deal with the US, the NHS gets taken over by US business interests, we could see similar drug price-hikes in the UK.

The UK situation is made worse because the NHS strikes hard deals when purchasing drugs in bulk; thus the UK is often seen by international pharma companies as being an "unattractive market." To make matters worse, the Chancellor has made a drastic cut in NICE's budget. To be used in the NHS, each new drug has to be appraised & approved by NICE. NICE now has to make up for the loss of much of its Treasury grant by introducing charges on pharma companies for appraising new drugs. This will add £125,000 to the cost for the company of getting a drug approved by NICE - with no refund if it does **not** get approved. Thus the chances of getting new drugs for rare diseases on the NHS will be greatly reduced. Sadly, as I write this, The European Medicines Agency (EMA), which has been based in London for almost 25 years, has just settled into its new post-Brexit home in Amsterdam.. The UK's loss is Holland's gain. For the UK, so much lost and nothing gained.

In May, at Salford Royal, Drs Nina Brown & Dr Fiona Pearce are presenting the inaugural UK & Ireland Rare Disease Group **Vasculitis Education** day sponsored by UKIVAS. Vasculitis UK are supporting this event with a grant of £500 to cover speakers travel expenses and will have a table stand at the event. The event is aimed not at patients, but primarily at trainees & junior consultants, although it is open to any interested health care professionals.

In September, there will be the 3rd EUVAS (European Vasculitis Society) International Vasculitis Education Course, to be held at Downing College, Cambridge. This 3 day residential course is mainly aimed at both junior & established nephrology and rheumatology consultants who routinely see and treat vasculitis patients, as well as trainees & junior doctors. For more information see the EUVAS website.
www.EUVAS.med.cam.ac.uk

Vasculitis UK will, as usual, have a stand at the British Society for Rheumatology Conference in Birmingham at the end of April. We will for the first time have a stand at the Royal College of Nursing Annual Congress in Liverpool at the end of May.

New Insurance Sites.

Travel Insurance is a recurring topic for people with pre-existing medical conditions, especially rare conditions such as vasculitis. There is a list of suggested providers of specialised travel insurers on the Vasculitis UK website. A recently recommended addition to that list is Fit2Travel.

Life Insurance has long been a problem for people with vasculitis. **moneysworth.co.uk** are well-reviewed brokers who specialise in finding Life Insurance cover for people with existing health conditions. If you contact any of these suggested sites for a quote, we will be very happy to hear of your experiences, good or bad.

John Mills

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And the New!
Vasculitis UK Trustee News

Chairman's Report

I am Dorothy Ireland the new chair of Vasculitis UK, a Charitable Incorporated Organisation (CIO) Charity.
A few of you will be wondering what am I talking about and what has happened! For many years the UK Vasculitis Trust has wanted to upgrade to this new type of charity. It offers greater protection for the Trustees and our members. After a great many false starts and the Charity Commission changing the goal posts, we were finally accepted as the new Charitable Incorporated Organisation 1180473 in October 2018. This new number will start to appear on our leaflets and correspondence.
The UK Vasculitis Trust 1019983 will continue for a time while we transfer assets across. This is especially important as we need to trace the standing orders going into our old account. If you have one of these then please contact us.
We are therefore, at present, two boards. John Mills is continuing as the Chair of the Trust and I am Chair of the CIO.
Those who attended last year's AGM will know that I asked everyone present to complete a General Data Protection form, which also allows us to provide you with the newsletter. This is doubly important as now every member has a voting right, not just those who previously paid membership; although, donations will always be readily and gratefully received.
Who am I? I was first diagnosed with MPA in 2008, and joined the then Stuart Strange Trust. I then met John and Susan Mills. When I was retired due to ill health, Susan suggested I help set up the East Midlands Support Group. She then found out I had experience of fundraising and a long list of other voluntary roles. Before I had time to say no, I was a trustee and Fundraising coordinator. Many will know me from contact when they are organising fundraising events. There was no job description, I wrote my own. I was then asked last year if I would take on the role of Chair to guide us through the changes, as I had been the one (with help) to take us through the submission process.
The other trustees on the CIO are many familiar faces.
John Mills is my Vice Chair and Director of Operations. He will still be talking to the medical professionals and pharma companies and being a terrific advocate for Vasculitis but no longer has to worry about the day to day things. I don't know where vasculitis would be in the UK without John. In 2008 he became chairman of a small insignificant charity of a rare disease and turned us into a much respected big voice among the professionals.
Kelly Jefferies is our new Secretary. She has had a difficult time with not just Behcets, but is determined to make a difference. She is a very talented designer and has now had several books published for vasculitis.
Richard Remorino is our Treasurer. He runs his own accounting business and has GPA.
Susan Mills is our Web administrator, but so many other things. She is always in the background supporting both John and myself. I think Vasculitis UK would come to a standstill if Susan stopped.
David Newman is our representative on Genetic Alliance. He also runs the London support group and was diagnosed with rheumatoid vasculitis.
Gareth Garner is our representative on the Scientific Advisory Board with an overview of the applications for grants. He was diagnosed with Anti-GBM disease when he was 16.
Martin Makin will shortly be co-opted onto the board of trustees and his co-option be confirmed at the AGM. He has been a very active fundraiser usually with green hair running the London Marathon or Great North Run. Martin has GPA.

Dorothy Ireland

Vasculitis UK AGM.

The Vasculitis UK 2019 AGM will take place on Sunday 19th May at a new venue – the "Post Mill Centre" just off the M1. The guest speaker will be Dr Chetan Mukhtyar from Norfolk & Norwich Hospital. Chetan is also the secretary of the British Society for Rheumatology. For more details see the flyer accompanying this newsletter or see the Vasculitis UK website www.vasculitis.org.uk

From The Editor

Kevin Soper

Once again we present to you our readers a newsletter with some excellent articles from both the medical professionals and some very personal stories from you our readers and supporters of Vasculitis UK, stories like Heidi's on page 27.
This was a real hard read for me as it mirrored the same experience we as a family went through with my dear sister Clare back in 2010, which goes to show that there is still more to be done with an initial diagnosis at GP level. It also shows that no matter how much awareness and support we give, these kind of cases still come up where family and friends were not aware or had even heard of Vasculitis, until sometimes it too late, it is that what still drives me today to help get the message out to those who are not aware.

This is portrayed though awareness days like Rare Disease Day which is on February 28th every year and many of you got involved with that by sharing your rare star, which is also highlighted throughout the newsletter, It was also the day our very own Kelly Jefferies launched her booklet called " Switching on the light" on page 5. Talking of books Margaret Robertson also published a book called "A book of verses" which is a filled with some wonderful poems, it's theses kinds of things along with the other fundraising / awareness ideas that you and your family and friends do that help to raise the awareness to the many so thank you all for that.
(Front Cover Image runners from Great North Run 2018)

Kevin

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

Two Book Reviews

1) **"Are You the F**king Doctor" by Liam Farrell** (Tales from the Bleeding Edge of Medicine).

2) **"Seven Signs of Life" by Aoife Abbey**. (Stories from an Intensive Care Doctor)

These are both "Doctor" books, written by doctors, but quite different in character from each other and from the usual medical humour, "Doctor in the House" type stories. If you are a fan of Dr Kildare, Casualty or Holby City on TV these books are probably not for you. There's no hospital romance or glamourised medical life here, just the reality of daily life as a medical professional, with the unpleasant fluids and smells; with some smiles too, but death not too far away.

Before he retired, Liam Farrell was a GP in a rural practice in Crosmaglen in Northern Ireland, right on the border during the "Troubles". Liam tells very amusing anecdotes about the fictional "composite" patient "Joe" who is a hypochondriac, obsessed with his sex life (or lack of) and none too bright, but ever-present on the daily patient list; but there is also an underlying darker side reflecting the pressures of practice life in a time and place of political tension.

By contrast, Aoife is a young woman, an Intensive Care Specialist Registrar, originally from Dublin, now having been in the job for seven years.

This is not a series of patient cases & events like the TV programmes "Casualty" or "24 Hours in A&E". It is a thoughtful, sensitive and introspective reflection on life as a doctor in one of the most stressful fields of medicine. It is about the stress of working a week of 12-13 hour night shifts. Chapter headings like "Fear", "Grief", "Joy", "Anger", "Disgust" & "Joy" indicate that this is a book about the experience & personal emotions of both doctor & patient.

Both Liam and Aoife wrote regular columns for doctors in the BMJ. Liam is now a successful writer and broadcaster. Aoife is now a Fellow of the Faculty of Intensive Care Medicine.

These books are available from Amazon and proper book shops. *Reviews by John Mills. March 2019*

For information and advice about vasculitis you can Telephone - Emial or if you prefer Write

VASCULITIS UK

Helpline

john.mills@vasculitis.org.uk
susan@vasculitis.org.uk

Post: John Mills
West Bank House,Winster, Matlock DE4 2DQ

0300 365 0075

Rare Disease Day 2019

This year Rare Disease UK for Rare Disease Day February 28th 2019, called on patients suffering with a rare disease to share the their story to help illuminate the reality of living with a rare condition. Many of those diagnosed with Vasculitis took part by sharing their rare star. Look out for their rare stars throughout the newsletter.

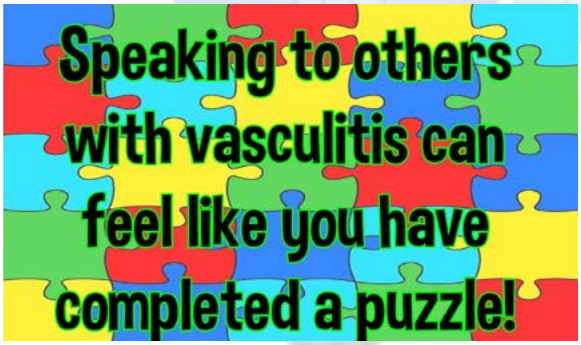
VASCULITIS UK

RAREDISEASEDAY.ORG

"Switching on the Light"

This is a new booklet created by Kelly Jefferies and illustrated by Kelly and by Shanali Perera. Having a rare disease can leave one feeling very confused & bewildered, alone & isolated. The chances of meeting another person with your disease, with whom you can share knowledge & experiences, are very small. We have about 20 local support groups, but they only meet one or twice a year, and the nearest one might be 40-50 miles away.

However the internet has changed all that – but you still need to know where on the web to find your fellow sufferers and once you've found that place, you need to feel secure before you can open up to others.



For all these reasons, Vasculitis UK has for several years, had 2 online discussion groups – or forums. One is a Vasculitis Support Facebook Group and the other is on a platform called Health Unlocked, which tends to be more medical whereas the FB group is more chatty. We also have a FB based "Bereavement " group, a "Young Vasculitis" group, a VUK "Hobbies, Crafts & Greenfingers" group. The "Young" group is for those under 25 & is very carefully monitored by a couple of young members

All the groups are closed groups, moderated by trustworthy & experienced members. There are set rules & those abusing the rules are censured or excluded. Members are encouraged to have a pseudonym & protect their privacy.

Recognising that these groups represent one of the greatest benefits offered by the charity, especially for those newly diagnosed, lost & bewildered by this mysterious disease, Susan put out a call for members of the groups to tell us their opinions of the groups & narrate their experiences, both good & bad. The results confirmed our suspicions that so many people found the online groups to be a lifeline.

So we collected together some of these "unsolicited testimonials" and gave them to one of our volunteers, Kelly, to make into a booklet, with illustrations by Kelly & Shanali – another of our volunteers. This is both for the benefit of people with vasculitis – especially those newly diagnosed, who are still in the confused, lost & bewildered phase – and for medical professionals, who are often not very good at understanding the psychological & emotional trauma experienced by many with this rare life-threatening disease.

Kelly herself has a particularly nasty form of vasculitis with other rare diseases alongside (quite a common scenario). She made the analogy between her experiences and PTSD (Post Traumatic Stress Disorder).

I think she has a point.

This new booklet contains a number of stories sent to us by people with vasculitis (or living with someone who has vasculitis) about their experience of using the online discussion groups and how helpful (or otherwise) they found it to be able to talk to their peers, others who understand about their problems & experiences. The booklet gives information on how to join the online groups as well as details of local support groups.

The booklet was launched on Rare Disease Day (Feb.28) and will be Vasculitis UK's contribution to Rare Disease Month in May. It will be available from the Vasculitis UK online shop at £2.50 a copy (to cover p&p). For £3.50 you can have both of Kelly's books - "Switching on the Light" and "A Fact a Day About Vasculitis.

FUNDRAISING 2019

It's another year of Fundraising. We started a little slowly but with warmer weather events are coming in.
The 2 events which caught my attention were both snow related. We have a snow boarder in March at Chamonix and in April a snow-kite 100km event Ragnarok. Hope it ends well for both events.
We also have a lot of individuals holding work-place events, coffee mornings and raffles for Rare Disease Day and to raise awareness of Vasculitis.
Sadly, we have a lot of fundraisers running or holding events for those family members or friends who have lost their battle with Vasculitis. As they say it's a good way to remember the person and also to fund research.
Our main event for the year will again be the Great North Run in September. We were allocated 20 places and all places went very quickly when posted on the website in October. Currently we have 21 (1 self-funded) runners but as ever some people drop out through injury, we had 4 last year, so I keep a reserve list.
To be added to the reserve list please email me, Dorothy@vasculitis.org.uk

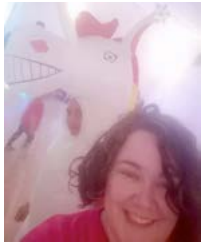
Some of you may ask why is fundraising so important. It funds the majority of our research studies and projects, and this year we have already put out a call for research, which are currently being processed and peer reviewed.
When I log onto Just Giving it says we have raised £455K since the account was opened. So thank you to everyone who raised, even £1, it will be well spent.

Some of the runners (Great North Run 2018)

Dorothy Ireland
Fundraising Co-ordinator

Some of Our Fantastic Fundraisers

All the staff at Keppie Massie (surveyors and property consultants) ran the Liverpool Santa Dash for VUK December 2018.



Matrix Circus fundraising in December for VUK on behalf of Kath Macintosh who has vasculitis.

Laura Matthews from Lutterworth High School Leicestershire, set off with the goal of running 1000 miles and raising £1000 in 2018 for VUK. But she ran more than 1000 miles and raised over an amazing £2,300.

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

Some of Our Fantastic Fundraisers

Norfolk Vasculitis Support Group Christmas Quiz. Thanks to Carol and Roy for doing the quiz and Maz Sayer, Susan Burrows, Hayley Marieand and Avril Orford for being Vasci Bear helpers, even Prof David Scott popped into visit, over £650 raised for VUK

Tracey Pollard ran the Bournemouth 5k for VUK and raised over £500

Sherry White who is in the North East Support Group was given Bingo Vouchers by Steve, the Manager at Mecca Bingo, Stockton. Sherry sold these to her friends and has made £450 for Vasculitis UK. She also received knitted goods from Maria Williams (who posts on the Vasculitis Support Group Facebook page) and has made a donation of £30 for the goods bringing the total raised to £480.

Jayne Hardman representing Vasculitis U.K., Clarry, Danny and Abby Bean - Illuminate My Life Concert in memory of Christine Bean November 2018
https://www.illuminatemylife.co.uk/about

Mark Sayer and members of the Norfolk Vasculitis Support Group have been fundraising and have donated an amazing £2000 to Vasculitis UK

Platinum Care Solutions, raised £400 over the Christmas period for Vasculitis U.K.

Richard Jones managed to complete the Ealing Half Marathons in 2.12.12 raising over £1100 for VUK

Tarn Kernahan on the right running the Yorkshire Marathon on behalf of Holly Hampshire for VUK

The Guisers Of Winster Have donated £100 to Vasculitis U.K. from their Christmas performances 2018

Keebles Solicitors Leeds office launched their charity partnership with VUK with a PancakeDay event raising over £290

Steroid Dosing in Giant Cell Arteritis

Dr Chetan Muktyar. MB BSc MSc FRCP(Edin);

Consultant Rheumatologist & Senior Lecturer,

Norfolk & Norwich University Hospital.

When I first became a consultant in 2009, I noticed two problems with the care of patients with GCA. Firstly, there was no standardisation for the dose, duration or tapering of prednisolone. It seemed to me that we were using this most potent drug in a very random way. This meant that most patients were on prednisolone and suffering toxicity for far longer than they needed to.

This of course led to even clinicians believing that patients with GCA need to be on steroids long-term and that should be the default position. Secondly, we were making short term plans for the regimens to last only till the next follow-up appointment (or in some cases, handing this out to primary care completely after diagnosis of GCA).

To address these issues, I spent several months searching all that was written about prednisolone use in GCA. This was not that difficult for me, because I had just written the EULAR recommendations for managing large vessel vasculitis, so a lot of this work had already been done. Next I had to look at these data and see if I could make any sense of it.

At first it all looked random till I plotted every regimen on a spreadsheet and then themes started emerging. I built 3 mathematical models (only the final one that worked actually made it to the published paper) and shared it around all my clinician colleagues and received a sense check on them. I finally had something that I could use. This only took me a few years.

Next I actually had to find a way to empower patients - so they knew what dose of prednisolone to take, when to take it, when to reduce the dose etc. Also, I had to build a fool-proof way to make a plan so that, should I or my colleagues decide to have a day away from the hospital (always working, never holidays - who ever in the NHS has a holiday), and the clinic was cancelled, the patients weren't left without a plan.

I certainly did not want to pass this problem on to my primary care colleagues who have enough on their hands besides worrying about a few mg of prednisolone reduction - because Dr Mukhtyar has decided to go and give another lecture somewhere.

Sometimes the simplest answers are the best. I devised a calculator which took the patients height, weight and gender and spat out a full 100-week plan - as long as you entered a start date. This meant, that irrespective of season, academic time of year, annual leave, natural disasters etc - patients would have a plan that meant the prednisolone was tapered in a sensible way and all patients were instructed to contact me if they had a problem with the reduction plan.

If you are interested in the historical aspects of GCA, where we came from, where does the 60 mg prednisolone dose originally come from - and where I'd like it to go, or if you want to learn how we use this age-old drug in a completely new way - hopefully more safely and more effectively - please read my paper in full at https://doi.org/10.1093/rap/rkz001

Research Grant Applications 2019

The Vasculitis UK trustees set a budget of £150,000 for research grant applications this year. Due to internal reorganisation, no awards were made in 2018. The grants are awarded on a competitive basis with a maximum per grant of £50,000. All applications are independently peer reviewed and "marked" by external experts. The final decision will be made by the members of the Vasculitis UK Scientific Advisory Board (SAB), guided by the points awarded by the peer review panel. The "call" for applications is made via the UKIVAS contact list and is open to medical research doctors & scientists based in the UK and Eire.

Eight applications had been received by the January 31st deadline. Seven were from the UK and one from Eire. The total of all 8 applications is £320,000. Subjects addressed include PMR & GCA, Takayasu Arterits, IgA disease (HSP) and ANCA vasculitis. Once all the peer reviews are in the SAB will make their final decision, hopefully in late May or early June.

A Potential New Disease Bio-marker for GPA

The lack of reliable disease activity markers in GPA has long been a problem for doctors treating patients with GPA and correspondingly for the patients being treated. ANCA levels have been found to be a poor marker for GPA and for the level of disease activity. This makes it very difficult for doctors to make valid decisions on the treatment requirements of individual GPA patients.

Research scientists based in Holland have been investigating the possibility of using the ratio of IgG4 : IgG RNA as a disease activity marker. In a small pilot study, this ratio accurately distinguished active disease from remission and gave an indication of the level of disease activity. A larger study is required to confirm these preliminary results.

Unreliable ANCA Results

A team at UCL (University College, London) including **Professor Alan Salama**, of the Royal Free Hospital, looked at records of 200 patients who had been recorded as MPO-ANCA positive and what proportion of those had later been diagnosed as having pANCA vasculitis – which is generally described as MPA (Microscopic Polyangiitis. They found that almost 40% of those testing positive for pANCA did NOT later turn out to have ANCA vasculitis, but about half of those 40% did have non-vasculitic renal disease. The eventual diagnoses of those 40% included gastro-intestinal tract disorders, infections and other connective tissue disorders.

The conclusion of the study was that a positive MPO-ANCA should not be considered as indicating vasculitis unless there are other significant signs and symptoms which corroborate vasculitic disease.

Medical Volunteer for VUK

Prof Charles Pusey will be joining Prof David Scott, Prof Richard Watts and Prof David Jayne on the Vasculitis U.K. Scientific Advisory Board from Spring 2019.

Charles Pusey is Professor of Medicine, and Head of the Renal Section in the Department of Medicine at Imperial College London. He is also Consultant Physician and Lead Clinician in the Renal Directorate at Imperial College Healthcare NHS Trust.

Charles Pusey is a clinician scientist with a particular interest in autoimmune renal disease, including primary systemic vasculitis. He runs a large multidisciplinary vasculitis clinic, and has made a major contribution to clinical trials in this area. He directs an internationally competitive laboratory research programme studying mechanisms of autoimmunity, inflammation and scarring in glomerulonephritis.

Professor Alan Salama
Professor of Nephrology and Honoray Nephrologist
Royal Free Hospitial London

What is Polyarteritis Nodosa?

Polyarteritis Nodosa (PAN) is a very rare relapsing vasculitic disease which affects medium sized blood vessels, such as those supplying the kidneys and bowel.
It can affect all ages although there may be differences in the main symptoms between children and adults. Men and women are almost equally affected.
PAN was a term first used to describe various forms of vasculitis, but with better understanding of the causes and associations of the disease we can now sub-classify the condition, which helps with its management, defining the likely outcomes, counselling of patients and relatives and initiating the most appropriate treatment. It may be that these subtypes are really different diseases, but with some similar clinical features which occur when medium sized blood vessels are damaged by various biological factors, and the more we understand about the causes, the better we will understand their relationships.

What are the symptoms?
It depends on the area affected and it can, like most forms of vasculitis, affect any organ in the body, but common symptoms include weight loss, muscle aches, joint pains, skin rashes or nodules, abdominal pains, sometimes with blood in the stools, and numbness or tingling in the hands or feet. Less often eye problems, breathing difficulties chest pains, or pain in the testicles can occur. In certain forms of PAN strokes occurring at a young age are common. Kidney involvement and high blood pressure is also often found but may be without symptoms.
A list of the common symptoms, in children and adults is in the table below

PAN Subtypes and associations:

a. **Infections:** PAN can be associated with Hepatitis B virus infection, and less commonly with other viral infections such as HIV or Hepatitis C. There may be a known history of contracting/carrying these infections.

b. **Genetic diseases:** PAN may be associated with inherited (genetic) forms of periodic fever syndromes, in particular a condition called Familial Mediterranean Fever (FMF), which is especially common in patients from the Eastern Mediterranean. In this form, abdominal pains, muscle aches and bleeding around the kidney are common features. Other genetic diseases which result in a PAN-like disease are found in patients with defects in a gene termed DAD2. In this form joint pains and strokes are common.

   In all these genetic cases there may be a family history of similar problems, although not always in immediate family members (parents, siblings, or grandparents), as the condition may be recessively inherited, so sometimes generations may be skipped.

c. **Classical PAN:** In those without an obvious (currently known) association we call them classical PAN.

d. **Cutaneous PAN:** This is a limited form of PAN that at least initially is confined to the skin**.** It seems that cutaneous PAN doesn't often lead to more widespread PAN, but there may be some limited symptoms apart from the skin problems. Some forms of cutaneous PAN may be related to exposure to particular drugs(such as minocycline , an antibiotic)

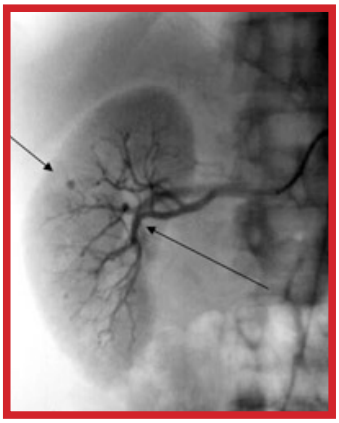
e. **PAN associated with other autoimmune rheumatic diseases:** medium vessel vasculitis can be found in other rheumatic diseases such as Sjogren's syndrome, and rheumatoid arthritis although these may be separate autoimmune diseases in the same patient or manifestations of a single rheumatic disease.

We therefore now qualify what form of PAN it may be, for example Hepatitis B associated PAN, FMF-PAN, classical-PAN or DAD2- PAN, and bearing in mind that we may discover new associations or causes in the future.
PAN is **always** ANCA negative, and the finding of ANCA in a patient suggests a different form of vasculitis (see ANCA associated vasculitis).

Who are affected?
Classical PAN is most common in middle age, but adults and children can have this disease. Many of the older series describing PAN did not adequately differentiate all the new forms and subtypes as they were not known about, with the exception of Hepatitis B associated PAN. As a result what we know about the particular subtypes is only now being truly appreciated.

What causes PAN?
The cause of classical or cutaneous PAN is not yet known. There is an attack on the blood vessel wall by the patient's own immune system. Why certain blood vessels are affected and in certain areas, and what provokes the autoimmune attack is still not clear. In those people with PAN and Hepatitis B virus infection, the reason for the blood vessel damage is also uncertain. Only a very few people with hepatitis B infection ever develop PAN and only a small proportion of people with PAN have hepatitis B infection. This form of PAN is becoming significantly less common as a result of vaccination for and treatment of hepatitis B infections.

Diagnosis
As with other types of vasculitis there is no one single diagnostic test.
Diagnosis is based on the symptoms described by the patient, physical examination, various laboratory tests (to exclude other causes of the symptoms and point to PAN) and possibly biopsy of the affected area. In the genetic forms of disease, specific genetic tests are required to make the right diagnosis. Blood tests will show evidence of inflammation. The blood vessels in the abdomen are commonly affected and angiography (x-rays of the blood vessels- see Figure) can show typical findings which help with the diagnosis. It is important to test patients with PAN for hepatitis B virus, HIV and Hepatitis C as these may require separate treatments.


kidney angiogram in a patient with PAN

Treatment
For classical PAN, high dose steroids and cyclophosphamide are often used to get the inflammation under control. Once under control treatment is often continued for 12 months using steroids and other immunosuppressants such as azathioprine, and then can be stopped in some patients. Disease relapses do occur and in some cases longer duration of remission treatment may be needed.
Patients with infectious causes will need specific treatment for the particular infections with anti-viral drugs, usually under specialist care.
For certain subtypes of PAN there may be other specific treatments - for example colchicine works well in suppressing the inflammation in FMF-PAN, while anti-TNF therapies, sometimes used in rheumatoid arthritis, are most effective in DAD2 associated PAN.

Drugs and Side effects
For information on the main drugs prescribed for Polyarteritis Nodosa see:
- Cyclophosphamide
- Steroids
- TNF blockade

For information on other drugs used in the treatment of vasculitis see Glossary of drugs and side effects
.
Prognosis
With treatment the prognosis is generally good. In most cases treatment can be stopped after 12 months. In some patients the disease relapses requiring longer term treatment.

Key Points
- PAN is a rare type of vasculitis.
- There are many different forms of what we call PAN

- It is known to be associated with various other conditions including hepatitis B virus infection
- Treatment depends on the severity and subtype of PAN.

Further reading

- Michael J Dillon, Despina Eletheriou, Paul A Brogan: Medium-size Vessel Diseases. Paediatric Nephrology 2010
- Sonmez HE et al .Polyarteritis nodosa: lessons from 25 years experience Clinical Experimental Rheumatology 2018

- Karadag and Jayne: Polyarteritis nodosa revisited:a review of historical approaches, subphenotypes and a research agendaClinical and Experimental Rheumatology 2018

- Lucidi et al Childhood versus adult onset polyarteritis nodosa: results from the French vasculitis study group registry. Autoimmunity reviews 2018

Table: Common symptoms in children and adults with PAN according to frequency

Symptoms	Adults	Children
Most Frequent	Nerve involvement	Skin –rashes, nodules, ulcers
	Skin –rashes, nodules, ulcers, muscle aches, weight loss	Fever, joint pains, muscle aches
	Joint pains, fevers,	Nerve involvement
Less frequent	Abdominal pains, high blood pressure, kidney damage	Weight loss, Abdominal pain, kidney damage, high blood pressure

Support Group Meetings

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

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

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

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 Trust 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 Trust 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.

facebook HU health unlocked

Norfolk Vasculitis Support Meeting

Mark Sayer and Specialist Nurse Sue Burrows organised the very first Norfolk Vasculitis Support Meeting held at Norfolk and Norwich Hospital on October 15th. It was so well attended with over 50 people including family and friends. Dr Chethan Mukhytar and Prof David Scott held a Question and Answer Session. Ruth Cookson and Jeryl Joy won both raffle prizes and almost £600 was raised for Vasculitis UK.(see fundraising page)

Beds Bucks and Herts Support Group lunch

The Beds. Bucks and Herts Support Group held a lunch on January 12th at The Cross Keys, in Pulloxhill, Bedfordshire, a nice time was had by all that attended.

East Midlands Vasculitis Support Group Lunch

New Vasculitis Support Group

There is new Vasculitis Support Group in Northamptonshire, please contact Maurice and Mel northantsvsg@gmail.com

Support Group Meetings

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

VASCULITIS SUPPORT GROUP WEST MIDLANDS (VSGWM) MEETING OCTOBER 2018

When I was diagnosed I was lucky to have a lot of support from my friends and family. We all know that this isn't always the case. If we travel back in time when internet wasn't an everyday tool, local support groups were the only source of information for many patients.

Margaret Gentle

At the VSGWM meeting I had the pleasure to meet Margaret Gentle who formed the support group in the early '90s. You can read about her in the spring 2017 newsletter. The West Midlands group meet once a year, in October. They always have guest speakers with special interest in vasculitis as well as coffee/tea time so members can spend time together.

Last October, the speakers were two Nurse Specialists from UHB (Queen Elizabeth Hospital) : Robert Carmichael, Clinical Nurse Specialist in Inflammatory Eye Disease/Intravitreal Injections, and Angela Murphy, Diabetes Clinical Nurse Specialist. Both presentations ('What's going on with my eye?' and 'Diabetes in vasculitis') captured our interest and the speakers gave practical advice as well as answering a lot of questions.

I would like to thank David Sambrooks and the other members of the group that organised this meeting for their hospitality!

Zoi Anastasa

Cambridge Vasculitis Support Meeting November 2018

The speaker on this occasion was Dr Lisa Willcocks Consultant Immunologist Addenbrooke's Hospital discussing ANCA Vasculitis Causes and Treatments.

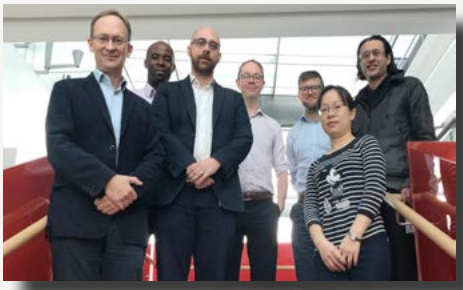
North East Vasculitis Support Meeting November 2018

Freeman's Hospital Newcastle

Speakers on this occasion Dr Jonathan Heaney Consultant Rheumatologist, Dr Alice Lorenzo Consultant Rheumatologist and Prof Bridgett Griffiths Consultant Rheumatologist.
Topics covered were ANCA, Connective Tissue Disease and Clinical Reference Group Specialised Services.

Plymouth Vasculitis Support Group Meeting

Vasculitis Fellowship



"Professor Justin Mason (left) with Vasculitis Fellows"

One of the many benefits British Society for Rheumatology (BSR) members can enjoy are fellowships. These unique learning opportunities are open to anyone looking to continue their professional development through practical, hands-on experience and teaching. They are held at specialist centres up and down the country.

After an initial very successful round of scleroderma fellowships in 2017, BSR agreed in 2018 to support a round of Vasculitis Fellowships which Vasculitis UK were privileged to co-badge.

The Rare Disease Fellowship in Vasculitis was held in Imperial College London. Running over three days, it was aimed at those coming to the end of their training, looking to develop their knowledge in the disease. In November 2018, five top-class practitioners won a place on the fellowship. Attendees included;

Dr Gary Reynolds is a Registrar Rheumatologist at Freeman Hospital in Newcastle, in his final year of training, as well as being a Clinical Lecturer at Newcastle University. He finishes training in October 2019.

Dr Tochukwu Adizie is a Consultant Rheumatologist at Wolverhampton's New Cross Hospital. He's been there 12 months.

Dr Adam Croft is a NIHR Academic Clinical Lecturer in Rheumatology at Birmingham University, and a Specialist Registrar in Rheumatology at the Queen Elizabeth Hospital, Birmingham.

Dr Reynold's clinical interest is Vasculitis, and he was hoping to find out how they manage the disease at one of biggest centres in the country - what research they do there, how they deal with vascular arthritis there. He was also hoping to see how the other delegates approach these problems.

The timetable included a mix of lectures, talks and hands-on observations. With such a detailed agenda, what did they find the most useful? What has stayed with them into 2019?

We asked each attendee to tell us what they've changed in their practice as a result of attending:

Benefits of holding multidisciplinary team meetings

Multidisciplinary team meetings are a make-up of other specialists combining to discuss patient cases. They will look through a scan together, and make plans about what to do next.

Delegates were able to sit in on some of these sessions. They were told about the practicalities of how to schedule something like that, which involves lots of doctors coming together to see patients at the same time, and can be a logistical nightmare. They also gave advice on the necessary people to have attend - "I hadn't considered radiologists and other relevant people. I wouldn't have thought to include them, but when I saw what they could contribute, that kind of made sense", thought Dr Adizie.

This was Dr Croft's main take away. "If I make a diagnosis, it's unlikely I'll be able to manage on my own - it involves kidney, lung, ENT (specialist in ear, nose and throat) involvement etc. My role is to initiate treatment, but then to send the patient on to see other centres. I need to develop my own networks within the hospital or region". Patients are seeing so many specialists, he wants to work on how to join up that care and "break down the silos to work together".

Dr Croft has now set up a multidisciplinary team meeting for large level vasculitis cases, and is seeing the benefit of receiving a range of opinions when treating difficult issues.

Running a specialist service

Attendees visited the large vessel vasculitis specialist service, to see how it was run. All mentioned how useful it was to observe the set-up, and learn about management decisions that have been made.

Dr Croft realised he couldn't take what he'd learnt about the treatment of specialist cases directly into his own practise, as he doesn't see that number of cases. "I saw the gold standard of practise", which he'll come back to when he's ready to set up his own.

A couple of weeks after the fellowship, Dr Reynolds applied for a research fellowship in a vasculitis clinic. He is going to start a specialist clinic in Newcastle and apply what he learnt, such as screening for large vessel vasculitis in vascular arthritis, how often they do it, how to treat patients as a result.

Speaking to patients about their experience

During the visit, attendees had the chance to watch clinics in session. Dr Adizie found it very helpful to "ask the Consultants questions about what they were doing in real time". It gave the opportunity for just two attendees to sit in clinic with a consultant, asking about the patient in front of them as well as very specific questions about their own cases. This also allowed them to ask questions of patients themselves.

Dr Croft valued the chance to discuss with the patient about their experience of the specialist clinics. He found out about their long-term expectations, and saw how important it was to build up a trusting relationship with them. He realised the need to make a connection rapidly. Patients with the disease are often misdiagnosed for long periods of time, so they come with hang ups, and can be mistrusting. One tip he took away was how to have frank discussions around uncertainty. Another was about making treatment choices individualised to patients, that and may not always be standard practise. "It's important to adapt, involve colleagues, get opinions, and work collectively across specialties".

During training, registrars only saw large vessel vasculitis cases a handful of times, and so Dr Croft saw twice as many patients in one day as he had ever done previously.

The chance to chat through cases with peers

All attendees mentioned how much they valued the chance to chat through current cases with people at the same career stage as them.

The specifically designed session was in an informal setting, where the delegates shared with each other how they managed cases and referrals. "You didn't feel bad about asking stupid questions" said Dr Reynolds, who enjoyed being able to "say what you think". It makes you "realise you're not the only one who has uncertainty, others are in same boat."

Large vessel vasculitis treatment audits

The group were talked through why and how to run an audit of treatments. Centres can vary from consultant to consultant, meaning not all patients can benefit from developments some have discovered.

Vasculitis Fellowship (continued from p14)

Dr Reynolds has begun auditing the way his department treat large vessel vasculitis, as a direct result of this session. He's found that "the way this condition is diagnosed and treated varies and can include prescribing strong treatments". At Hammersmith it was interesting to see how they managed these patients, particularly how they incorporate imaging in to their follow-up.

"They screen more at the start of the condition than we do at moment", Dr Reynolds reflected. He also learnt that they don't operate when vasculitis has been untreated, and from that recommended on a recent case not to do it in his practice, improving patient care as a result.

Other treatment protocols

Dr Adizie found it useful to hear about specific treatment protocols Imperial are using. The clinic treat large vessel vasculitis with Rituximab and Cyclophosphamide combination treatment, and the group learnt about what doses and schedules they put the patients on. They presented their data, showing how well their patients were doing. The results were very positive.

Main takeaways

In summary, each fellow has already made changes to their practice for the better.

Dr Gary Reynolds carried out an audit of the way his department treats large vessel vasculitis, and has started implementing standardisations to ensure patients don't receive too strong a treatment if not completely necessary.

Dr Tochukwu Adizie now prescribes Rituximab and Cyclophosphamide as a combination treatment, after seeing how it worked for patients at Imperial.

Dr Adam Croft has set up a multidisciplinary team meeting to discuss large vessel vasculitis, which means his patients will benefit from having their cases and treatment discussed by a group of specialists.

Everyone we spoke to said they wrote "copious notes", really enjoyed the experience, and are changing something about their practise as a result.

This fellowship was run in partnership with Vasculitis UK.

We are always looking for ideas for future fellowships. Would you and your colleagues consider hosting the next rare disease knowledge share, and create better outcomes for patients?

"Limited" Wegener's

This is Jayne. She contracted WG (GPA) several years ago, but as it had affected her nose and sinuses and not affected her lungs or kidneys it was considered to be not "life threatening" and was designated as "Limited Wegeners". Thus it was only treated with what we usually consider to be "maintenance" drugs, like methotrexate.
Unfortunately this treatment was not powerful enough to control the GPA effectively and Jayne's nasal septum continued to break down, until her nose broke off completely.
Jayne has since been treated with Rituximab to stop the disease and she now has a very convincing silicone prosthetic nose which is held in place by 3 magnets mounted on osseo-integrated implants fixed to the remaining bone.
If you have suffered from facial disfigurement due to ANCA vasculitis AND/OR been diagnosed with "Limited" Wegener's, I would like to hear from you – contact: john.mills@vasculitis.org.uk or see my contact details on the back of this newsletter.

Adverse Reactions to Biologics

The new "Biologic" drugs such as Rituximab & Tocilizumab have proved to be very successful and for some they have been life-transforming. But for others they have just added to their problems due to unexpected side effects. These can just be due to problems with the infusion, but in other cases there seems to be a reaction caused by the drug.
If you have been given any sort of biologic drug and you seem to have had an adverse reaction, we would be interested to hear your story. If you would like to "share" your story, please contact john.mills@vasculitis.org.uk or see my contact details on the back of this newsletter.

Vasculitis UK Chari

On Saturday March 2nd 2019, Emma from Innov8 Conference Service held her se
The event was attended by around 150 people of all ages and was such a fantas
yet but we will update you in the Autumn newsletter.

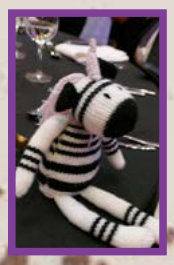
Guests arriving and chatting

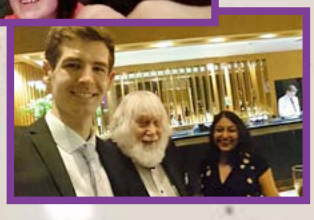
Auction Time

VASC

inno
CONFERENCE SE

Selfie Time

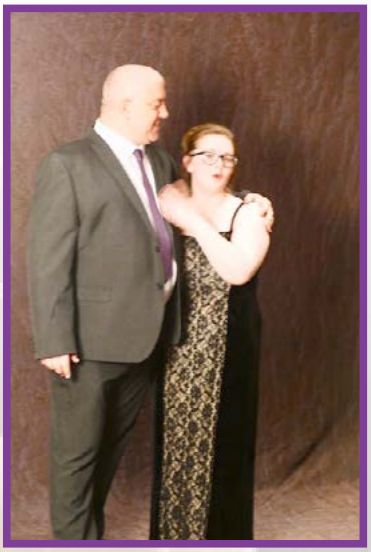




ty Ball March 2019

cond Charity Ball in Manchester, to fundraise and raise awareness of Vasculitis.
tic success, actually raising £4000 on the night, the total figure is not known

Photo session with the UK Ghostbusters



Professional photographs too

CULITIS UK

Dancing & Entertainment

RAIRDA UPDATE

Jack Feinmann

RAIRDA is the Rare Autoimmune Rheumatic Disease Alliance, a partnership between the **British Society for Rheumatology (BSR)** and several patient charities including Lupus UK, Behcet's Disease Society, Raynauds/Scleroderma UK and Sjógren's Society. All these diseases are AutoImmune diseases and share many common factors.

RAIRDA was founded 2 years ago, the brainchild of Dr Peter Lanyon, who was then President of BSR. The main aim was to provide a combined strong voice to ensure that the rare auto-immune disorders, which collectively affect many thousands of patients, were not drowned out in the Government's Rare Disease Strategy by the voices of thousands of congenital monogenic rare diseases, each of which affects only a handful of patients.

RAIRDA has the benefit of the services of **Jack Feinmann**, who works for the BSR in the policy and public affairs team, but is also the sole worker behind RAIRDA. Read here about the focus of Jack's work with RAIRDA, how he's working to increase the reputation of RAIRDA, and how he's lobbying to improve the quality of care for patients with rare auto-immune conditions.

In 2018 RAIRDA produced a report '**REDUCE, EMPOWER & IMPROVE**: Addressing the shared needs of rare autoimmune rheumatic diseases,' This was based on surveys of patients suffering from lupus, vasculitis etc.

It contained 12 recommendations altogether, focussing on different bodies and healthcare professionals, "but our overarching aims are to raise awareness of the importance of rare disease care and the need to improve it". We know that we face a range of challenges. With Brexit on the horizon and many in the voluntary sector fighting their cause, especially in the health field, policy recommendations don't typically provide immediate, tangible results very quickly. With this in mind, we ensured that the report's recommendations are very direct in targeting the bodies that can help us in our aims. Whilst we have made some significant advances, there have been peaks and troughs since publication on rare disease day 2018.

The report calls on the decision makers of the four nations to improve the care and lives of patients with rare auto-immune diseases. For example, the Strategy calls for high quality training on rare diseases and professional development. We've been promoting the importance of correct care of rare auto-immune rheumatic diseases amongst professionals, working with BSR on their training programme for members on rare diseases. (See report on Vasculitis Fellowships)

Our report calls for **alert cards** (similar to those for steroids**)** to be created for patients with a rare auto-immune rheumatic disease. Just under half (49%) of those surveyed reported having to make an unplanned hospital visit in the past year, with vasculitis patients the most likely to have been required to make multiple visits (34% of that group reported making 2 or more unplanned hospital visits). Alert cards should go some way to make unplanned visits much easier. This seems now to be part of the NHS England strategy.

RAIRDA aims to work collaboratively with Royal Medical Colleges, NICE and the Department of Health to ensure the best possible care for patients with rare autoimmune rheumatic diseases. Additionally, we've worked with The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), which records those people with congenital abnormalities and rare diseases across the whole of England. We want them to prioritise rare rheumatic diseases when creating national rare disease registers. NCARDRS helps identify and register people with rare autoimmune rheumatic diseases, including promotion of self-registration, to better identify their needs, outcomes and variation in care.

A further aim is to develop Quality Standards of Care for rare auto-immune rheumatic disorders. So, a year on from the report, we've held discussions with NICE, NHS England Specialised Services, the Royal Colleges and Public Health England's NCARDRS (and equivalent bodies in the devolved nations). We're using our report to put RAIRDA at the forefront of healthcare planning, seeking opportunities to promote our work and raise awareness of rare auto-immune diseases.

There is still a long way to go, and our discussions are still in their initial stages, but we're ambitious in our aims and are motivated to provide a single and strong voice that will raise the profile and improve the quality of healthcare for patients with rare auto-immune conditions.

Jack Feinmann. March 2019

UKIVas

UKIVAS REPORT

The UK & Ireland Vasculitis Study Group held a meeting in London in December. Dr Pani Gopaluni spoke about Alemtuzumab (Campath) for Behcet's Disease and for ANCA vasculitis. Campath causes an increase in immunomodulatory T cells. A new trial (Aleviate) is studying its use for refractory ANCA vasculitis.
Professor Alan Salama spoke about a Dutch study which shows ANCA levels are not a reliable predictor of relapse.
Dr Sarah Mackie described a new trial aimed to decide if steroids are the best follow-on from a 12 months course of tocilizumab for GCA.
Professor David D'Cruz reported a new trial (the HAVEN trial) to review the benefits or otherwise of Hydroxychloroquine (HCQ) as an adjunctive therapy (ie.alongside other medication),in ANCA vasculitis. HCQ has shown reduced relapse in systemic lupus and so far 77% of AAV patients have reported benefits with no side effects.

The Role of Carers in ANCA Vasculitis – Dr Janice Mooney

Myself and Professor Richard A Watts were awarded a research grant from Vasculitis UK, to explore the experience of people with ANCA-associated vasculitis (AAV) and their informal carers about the impact of managing these conditions. We are interested in this subject because up until now, there was no knowledge about the role played by informal carers in the treatment and lives of people with AAV and as health care professionals we need a better understanding of their role.

Background

The ANCA-associated vasculitides (AAV) Granulomatosis with Polyangiitis (Wegener's) (GPA), Eosinophilic Granulomatosis with Polyangiitis (Churg Strauss) (EGPA) and Microscopic Polyangiitis (MPA) are a group of rare, potentially life-threatening conditions which if untreated can be fatal. Many organs can be affected such as the kidney, heart, lung, upper and lower airways and the nervous system. Modern immunosuppressive therapy, has changed the outlook for patients with AAV from being very poor with a high mortality to a chronic disease associated with a need for long-term treatment [1]. Despite improvements in survival, patients must often manage substantial burdens related to chronic illness and treatment-related side effects, requiring help from informal carers.

Informal carers are people who actively participate in the care of a patient on a practical and/or emotional basis, usually partners or family members. We interviewed 18 pairs of patients with AAV and their informal carers. The interviews were used to explore the experience and effects of caring. Patients and carers were interviewed separately in order to obtain their views on the role of caring. As these issues are often not discussed with each other. The interviews were recorded and transcribed as verbatim text and analysed using the framework technique.

Results: 18 patients (seven female) [disease: ten granulomatosis with polyangiitis (GPA); four microscopic polyangiitis (MPA); four eosinophilic granulomatosis with polyangiitis (EGPA), age range 34-78, disease duration 1- 20 years. Caregiver and patient perspectives were shared. The three emergent themes were the physical and psychological impact of the disease, the need for constant vigilance and fear of the future (Figure 1).

Figure 1Emergent Themes

Physical and psychological impact of the disease

This theme describes the physical and emotional impact of the disease particularly during the acute phase of the illness. Patients reported extreme tiredness and weakness, being unable to walk and needing help with dressing and bathing. Carers told of the physical help they provided and the psychological and emotional toll of caring for someone with a serious rare illness.

Need for constant vigilance

This theme describes the constant background monitoring that carers and patients expressed. In the context of a potentially serious illness, 'keeping an eye on' meant permanent vigilance for signs that the disease might be returning. Carers found this constant monitoring draining since they were concerned about the potentially serious consequences for the patient if they did not act appropriately.

Fear for the future

This theme describes the fear that individuals experienced, particularly when they did not know what to expect. For those patients admitted to intensive care, their partners described emotional turmoil, especially dealing with the uncertainty of whether or not their partner would survive this life- threatening illness. Both described triggers of emotional distress about what the future held and the inability to plan ahead.

Conclusion: Both patients and carers faced a range of challenges in managing a rare condition, from the seriousness of the illness, dealing with the emotional toll and knowing what to expect. This study offers insight into the experiences of patients and informal carers, and health care professionals should address individuals' fears and expectations for recovery.

This is the first study of the role informal carers provide to patients with AAV, and it makes a significant contribution to our knowledge. The study suggests that the role of carers is under-recognised, in particular the emotional toll. All the carers in our study experienced high stress levels relating to their partner's diagnosis and the need for constant vigilance was draining. Health care professionals should address individual's fears and expectations and ask carers how they are coping and if they require any support.

We would like to thank VUK for funding this work and the patients and carers who participated in the study.

In Praise of Love - Terence Rattigan

Polyarteritis Nodosa is an extremely rare type of vasculitis and does not really have much awareness as the ANCA types occasionally do.

This play was performed October and November 2018 at the Theatre Royal in Bath, it is a Terence Rattigan play from the 1970's about Sebastian and Lydia Crutwell who live in a small flat in Islington.

Sebastian, once a promising novelist, is now a cantankerous critic. Lydia, an Estonian refugee, has recently discovered she is seriously ill, news that she confides to a family, Mark, but not to Sebastian.
Over the course of two evenings, a series of heart-breaking revelations changes the facade of Lydia and Sebastian's relationship forever.

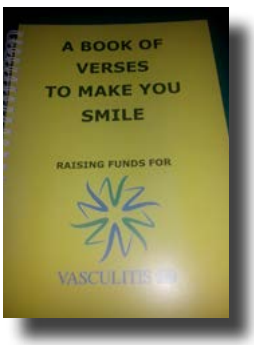
The illness is Polyarteritis Nodosa.

You can read about the play here:
https://www.theatreroyal.org.uk/event/in-praise-of-love/

The photos below are of the programme from the play where it describes Polyarteritis Nodosa and also mentions Vasculitis U.K.

A Book of Verses to Make You Smile

After having a previous poetry book printed via a publisher and being disappointed with the result and the amount raised I decided in a moment of madness to publish my own! I wanted to produce a book that was fun to read and would put a smile on people's faces and also raise awareness of Vasculitis.



I contacted the poets I knew and those who had been recommended by friends and relatives. Thankfully they agreed to allow me to use their work and Karen Thompson a local artist kindly illustrated the book free of charge.

I held a Beetle Drive to raise the money needed for the book to be printed and it was launched on the 10th November, 2018. The event was attended by 70 + people and the poets each read one of their poems and a local band named See-Saw played. The night was a great success and 52 books were sold
I initially had 100 books printed however, they soon sold out and a further 100 were ordered. (The cost of printing for these books was raised through donations and a raffle) 144 copies have now been sold and £1,022 raised for Vasculitis UK. If you would like a copy of the book the cost is £6.50 plus £2 p+p. I can be contacted via email:- mgtrob@talktalk.net

Margaret Robertson

Trustee and Volunteer News

RePAG meeting, Madrid, December 2018

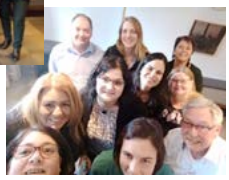
Eurordis, ERNs, ePAGS, RITA and RePAGs...what are all these and what do they have to do with us, vasculitis sufferers?

When I was asked to represent Vasculitis UK in the European network for rare diseases I was honoured but overwhelmed too. It is a huge responsibility to represent all of you, be your voice, advocate for our best.

In a nutshell, Eurordis is an alliance of 826 rare disease organisations working together in order to improve the life of the people living with a rare disease in Europe. The ERNs (European Reference Networks) give ground to clinicians and researchers to share their knowledge, expertise and resources across the EU. There are twenty four (24) ERNs representing different therapeutic areas. Every ERN has an ePAG group (European Patient Advocacy Group) optimising the involvement of patients in the ERNs.

Vasculitis UK is one of the patient organisations in the RITA ERN (European Network on Rare Primary Immunodeficiency, Autoinflammatory and Autoimmune Diseases), so I am a RePAG representing you in the RITA network.

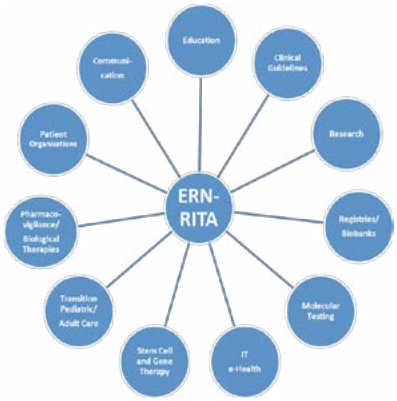
This is new for me and I have a lot to learn. I have taken part in a few web conferences and last December I travelled to Madrid where I met other RePAGs. It was the first face to face meeting since new patient advocates started to participate.
In the first part of the meeting there was an introduction about the RITA ERN, the eleven (11) different working groups and how we will participate in all of them. A lush lunch was offered and the break was welcome - a small opportunity for a walk in the garden of the hotel, to enjoy a bit of sun.



Brexit and its implications was the major subject of the second part of the meeting. Andrew Cant the RITA Network Co-ordinator (UK, Great North Children's Hospital Newcastle Upon Tyne) was asked to step down as UK research centres will not be able to be funded from EU after Brexit and Nico Wulffraat a pediatric rheumatologist from Netherlands will be the new Co-ordinator. We had the chance to speak to him - technology can be amazing - and hopefully this will be the start of a productive collaboration.

Vasculitis is very well represented as four (4) of the nine (9) Repags that attended the meeting represent Vasculitis organisations and one represents Behcet's syndrome. Every one of us have to participate in two (2) working groups, patient organisations being the one of them. My choice was the Education working group. I strongly believe that educating the medical world about the diagnosis, treatment and monitoring of rare illnesses is the step towards early diagnosis, treatment by the guidelines and better outcomes.

A new exciting chapter of my life has just begun!
I really hope that the UK government will rethink and won't cease to participate in the ERNs in case of a no deal Brexit. The benefits of this collaboration are away to important to be lost in a political battle.



by Zoi Anastasa
VUK patient representative in Europe

Laura Whitty: Our New Research Awards Administrator

Laura has experience of administration and management in every sector, including the NHS, local government and education. As a result Laura has a raft of skills that are utilised by the team at the EATC4Children. Projects undertaken so far include the launch of a new website and logo, building the team's social media presence, organising fundraising events for Lupus UK, co-ordinating PPIE involvement in an upcoming animation, assisting the team in grant applications across all work streams and acting as study co-ordinator for the Juvenile Localised Scleroderma PRIOR study.

She has a passion for improving the lives of children, whether that be through education, safeguarding or medicine and is continually inspired by the work of the clinicians and scientists that make up the Experimental Arthritis Treatment Centre for Children (EATC4Children)
Laura tells us .... In my spare time...
"I support my parents as a connected carer for their foster children, enjoy travelling during my holidays, see as much live music as I can and failing that (especially in the winter!) read as many books as I can get my hands on."

Laura Whitty
Awards Administrator

Bio – Emma Leacy

Emma Leacy is a graduate of Trinity College Dublin with a B.Sc. in Human Health & Disease. Having spent a number of years working in product and business development for various technology startups, she joined an Enterprise Ireland-funded project to commercialise a prostate cancer biomarker test, and was introduced to mass spectrometry. From there Emma returned to Trinity College to pursue her own PhD in immunometabolism and metabolomic. Her project aims to uncover the metabolomic perturbations that drive inflammation in ANCA stimulated monocytes.

Abstract

The effect of anti-MPO and anti-PR3 on neutrophils in AAV has been extensively studied. The role of another immune cell type – monocytes – in AAV is less well understood, although these cells can be activated by ANCAs to produce pro-inflammatory signalling molecules and drive tissue damage. Changes in cellular metabolism have recently been shown to be important in the innate immune response, and targeting metabolic pathways may be a potential treatment in autoimmune disease.

We aimed to investigate the metabolic effects of ANCAs in monocytes. Monocytes isolated from whole blood of healthy donors and stimulated for 4 hours with anti-MPO and anti-PR3. Changes in glucose and oxygen metabolism were measured using a Seahorse XFe24 analyser and interleukin-1β (IL-1β) release was assessed by ELISA. After stimulation cells were processed for metabolomic profiling by liquid chromatography mass spectrometry (LC-MS) to detect changes in metabolite levels.

ANCA stimulation rapidly upregulated both glucose and oxygen consumption in monocytes. Anti-MPO treated cells showed more substantial increases in metabolism than anti-PR3, and also produced significantly more pro-inflammatory IL-1β. Metabolomic profiling by LC-MS revealed significant increases in the intracellular amino acids phenylalanine and threonine in anti-MPO stimulated cells. Relative increases of a number of amino acids also correlated with the upregulation of glycolysis. Another amino acid – glycine – was associated with the increased IL-1β production in monocytes. These results indicate an important role for glucose and amino acid metabolism in the pro-inflammatory monocyte response to ANCAs, particularly anti-MPO. Further work is needed to determine how these changes in metabolism influence the inflammatory response in AAV.

Jennifer Scott – Vasculitis UK Travel Bursary

Jennifer is looking forward to attending the Vasculitis 2019 conference in Philadelphia this year, with the very generous assistance of a travel bursary from Vasculitis UK. She will present the results of a retrospective cohort study, investigating the sex-specific differences in ANCA-associated glomerulonephritis outcomes. To date, there is a relative paucity of data surrounding this aspect of ANCA-associated vasculitis (AAV). Jennifer's group, using national data from the Irish Rare Kidney Disease Registry and Biobank, sought to validate the findings of a recent Norwegian study (Bjorneklett et al, 2018) demonstrating that males have significantly higher risk of progression to end-stage renal disease (ESRD), particularly in those with crescentic Berden class.

Jennifer is a Nephrology specialist registrar, and a Wellcome-HRB Irish Clinical Academic Training (ICAT) fellow, based in Beaumont Hospital, Dublin (Ireland). She is currently preparing to commence her PhD in July, which will be based at the ADAPT-SFI centre (Trinity College), under the supervision of Professor Mark Little. She is very excited to explore the environmental factors that trigger AAV relapse, using novel data analytic approaches.

Evaluation of PR3-ANCA status following rituximab for relapse prediction in ANCA-associated vasculitis

In this study, we looked at 58 patients from Addenbrookes Hospital who received rituximab for ANCA-associated vasculitis to assess 1) the effect of rituximab on the ANCA level and 2) if the response of ANCA could be used to predict remission (i.e. turning off vasculitis activity) or relapse (i.e. return of vasculitis activity). We specifically looked at PR3-ANCA.

We found that remission occurred long before the ANCA became negative in most cases and remission was still possible with very high ANCA levels. Therefore, the ANCA response was not able to predict remission.

However, patients who became ANCA negative after rituximab had a longer time in remission, i.e. took much longer to relapse. This suggests that if that ANCA goes away following rituximab then you are less likely to have a relapse. There has been an ongoing debate in the vasculitis community about the use of

ANCA measurements to assess disease activity or to predict relapse. The general feeling is that ANCA is not particularly helpful. However, there may be a suggestion from recent studies that PR3-ANCA testing may be more useful after rituximab compared to other broader spectrum immunosuppressive drugs (e.g. cyclophosphamide). Our findings provide further support for this concept. However, as our small study uses retrospective data from just one hospital, the findings must be interpreted with caution as studies like this sometimes do not reflect what happens to the wider vasculitis population.

This manuscript for this study has been accepted for publication in the Journal of Clinical Rheumatology.

***Mark McClure** is a nephrology trainee currently doing a PhD in Cambridge with Prof. David Jayne and Dr Rachel Jones. Mark was awarded a Vasculitis UK travel bursary to present his paper at the 2019 International Vasculitis Conference in Philadelphia USA next month.*

Low density granulocytes in ANCA vasculitis: phenotype and function

***Aisling Ui Mhaonaigh**. Aisling, from Trinity College, Dublin, has been awarded a Vasculitis UK Travel Bursary to attend the 2019 International Vasculitis Conference in Philadelphia, USA, where she will present this abstract.*

I am interested in the role of a particular type of neutrophil (a white blood cell) in ANCA Vasculitis called low density granulocytes (LDGs). Normal neutrophils are the first responders to the site of infection; they are produced in vast numbers, billions per day and only live for 6 to 8 hours. They release a toxic arsenal of enzymes and proteins that destroy bacteria and viruses on contact.

However in ANCA vasculitis, neutrophils are primed by auto-antibodies to attack proteins called MPO and PR3, which causes collateral damage at the site. This damage is what causes kidney failure in ANCA Vasculitis and is the focus of this project.

We have shown that a subset of these aberrant neutrophils (LDGs) is elevated in the blood of ANCA vasculitis (AAV) patients and that levels correlated with disease severity. It would be tempting therefore, to assume that these neutrophils are implicated in the etiology of AAV. However, these cells are also found in unrelated conditions such as sepsis, HIV and pregnancy. We suggest in this abstract that these cells are a non-specific emergency response rather than a specific cellular response in AAV. We are very interested in further understanding the phenotype and function of LDGs. We examined several cellular markers and compared them to normal neutrophils. On this basis we identified two subtypes based on surface markers alone.

We then examined the shape of their nuclei and concluded that LDGs are in fact mixed mature/immature cells, perhaps released as a non-specific cellular response to inflammation. To test this further we used a mouse model of generic inflammation and detected LDGs in the blood of mice. This supports the hypothesis that LDGs are a generic response to illness.

Functionally we then tested the response of LDGs to the ANCA antibodies and unexpectedly found that they are unresponsive, unlike normal neutrophils. This coupled with the fact that these cells are found in unrelated conditions such as cancer, sepsis and pregnancy leads us to suggest that LDGs may not be contributors to vasculitis pathogenesis but merely a generic response to severe illness. Future work will further elucidate the role of these cells in AAV and beyond.

Aisling Ui Mhaonaigh

I graduated from UCD with an honours degree in Biochemistry, then spent four years in the London Hospital Medical College working in Clinical Biochemistry with Prof Chris Price.

After taking a career break to raise 3 children I decided to study for an MSc in Immunology at Trinity College Dublin. Inspired by the ANCA vasculitis story I have elected to undertake a PhD on the role of aberrant neutrophils in AAV with Prof Mark Little at Trinity College Dublin.

UP AGAINST THE BENEFIT SYSTEM - Patient Personal Experiences

A record 72% of people who appealed after being denied Employment and Support (ESA) and Personal Independence Payment Allowance (PIP) won their cases. Both sets of figures were recorded between July and September 2018 and released in December 2018 by the Ministry of Justice.
Some people with Vasculitis rely on these financial lifelines to live independently and be part of their community.

In this article we thought we would share 3 personal stories by those suffering from Vasculitis, giving their accounts of going through the benefits assessment and appeal system and how it affected them both physically and emotionally.

Tara's story

I have had a very rocky life since getting first poorly in 2006. Although, a few times I have been "well" it always seems to end in another flare. Due to how unpredictable this illness can be and how poorly I can get, I was awarded DLA indefinitely. This relieved a lot of stress and worry. This money helped me afford to get to hospital appointments, helped me move into my own house with my family, pay bills and rent. It helped me become a "normal" adult, without being a burden on those closest to me. It took a lot of financial strain off my family too, who have had to take time off work unpaid, to care for me.
Then one day, the dreaded PIP letter landed on my doormat. Before even opening it, I was panicking and worrying. The stories I'd heard in the news, the stories I'd heard from other people who had already been through the dreaded process.
How was I going to be able cope? My partner and I and our 3 young children wouldn't have anywhere to live because we can't afford to pay the rent and bills. The stress was already making me ill. The worry of explaining my illness, the effects of my illness to a complete stranger who probably couldn't even say Polyarteritis Nodosa let alone even understand it. I'm not the type of person to complain and allow the people closest to me know just how hard every day can be. Struggling to dress myself, struggling to make a hot drink, to cook a hot meal.
I went through the process, I attended the face to face assessment, I sent in letters from consultants, I was as honest as I could be. I was lucky, I lost the enhanced rate and although I lost my car, I was awarded Standard Rate, for two years. Yet, I will have to go through this process again in just 12 months because every case is assessed 12 months before your current award ends.
The worst part is because I look well, I look okay, I look perfectly normal, the assumption is I am fit to work when the reality is… I have an invisible illness which is only invisible to the outside eye.

Holly's story

I am 23 years and having been living with GPA since I was 19 years old. Since diagnosis I have been off and on benefits numerous times as Vasculitis unfortunately left me unable to continue my studies at university. The only way I have been able to survive this last 3 years is through the help of my very supportive mother and grandmother, who understand the extent to which my illness has an effect on my day to day life carrying out the simplest of tasks. The same cannot be said for the welfare system, sadly. I have been forced to take my case to a tribunal on more than one occasion, a process which is anxiety-ridden and trauma inducing.
When I won my appeal, I had been without benefits for over 7 months, I did eventually receive the back payments. If I had not the support of my family I would have undoubtably been unable to pay for the very basic things such as food, bills and rent. The assessments themselves are largely pointless as every time I have had incorrect information recorded and even been told by my assessor that written information from my consultant "does not matter". Becoming so ill to the extent you are unable to work is heartbreaking but having to worry about the financial implications of such a thing is even worse.

Steve's story

My whole life had been turned upside down when at the age of 25 I found out I'd been diagnosed with Vasculitis , a long-term Autoimmune condition. I went from being fit and healthy to now walking with a stick and struggling to get about. I walked into the assessment with a walking stick. I was asked to do some physical tests which didn't seem to make much sense.
I was asked how far I could walk. I said that depends on whether I'm having a good or bad day. But she could only take one answer, she seemed to only take into account my good days. I felt as though she was not listening to me and just following her tick box.
She didn't seem to have any knowledge or understanding of my condition and was not interested in any information from my doctors.
I was turned down but went on to appeal and I won my appeal, which was a very long and stressful process. Without the support of my family both financially and emotionally I would never have coped. It's bad enough feeling so poorly, plus the anxiety of coming to terms with this condition and its treatments without having to come up against the benefit system, which I believed was there to support you when you needed it the most.

Behcet's In A Day – A Patients Perspective

I was privileged in my role as a trustee for Vasculitis UK to attend an educational conference on the presentation and treatment of Behcet's syndrome at the Behcet's Centre of Excellence at Aintree University Hospital in Liverpool on 29th November 2018. It was an enlightening day packed with an abundance of information by a broad spectrum of specialist speakers discussing state of the art care including;

Children with Behcet's, Behcet's eye disease, Musculoskeletal involvement with Behcet's, The skin in Behcet's, Gynaecological aspects of Behcet's, Oral and gastrointestinal manifestations in Behcet's, Neurological features of behcet's, Psychological impact and patient-centred care in Behcet's, Patient experience of living with Behcet's pre and post stem-cell transplant and four thirty-minute workshops.

I found the personal experience of Behcet's, presented by a patient of the Behcet's Centre of Excellence at Aintree, both moving and powerful, probably because I was able to draw parallels against my own personal journey. I was particularly interested to hear his account of having had a bone marrow transplant as a last resort in 2016. He was refreshingly honest, explaining it was a painful experience and that he was very ill for around five weeks but, since then, apart from some minor flares that were dealt with quickly, he has gone from strength to strength and feels like he has had a new lease of life. I sincerely hope he continues to stay well and enjoy his life to the full.

As a Behcet's patient myself, I learned a few things I hadn't previously known which I'd like to share for other Behcet's patients who may be suffering:

I have been suffering with numbness/tingling in my fingers, my tongue feeling too big without any actual swelling and a stiff neck, followed sometimes (not always), by a headache around the back of my skull. The neurologist explained these symptoms can be migraines in the occipital nerves around the back of the head which can be treated easily if you let your consultant know about them.

If you're suffering with mouth ulcers and finding it difficult to brush your teeth, try using toothpaste that is free from sodium laurel sulphate (SLS), which you can buy from most pharmacies, online and even on prescription in some instances.

Topical treatments for genital ulcers should be prescribed in ointment form as they sting much less than cream apparently – I will definitely be storing this little gem away!

Post traumatic stress disorder (PTSD), normally associated with having experienced a "traumatic event" – such as military personnel – was covered by the psychology team. I was heartened to hear this as I've been experiencing PTSD type symptoms myself and it was nice to hear we shouldn't underestimate how Behcet's affects us psychologically and emotionally as well as physically!

I had a thoroughly eye-opening day and felt hopeful to see so many medical professionals eagerly taking an interest in one of the rarer forms of vasculitis, even more so when I spotted a rheumatologist and three nurses from my own hospital in attendance! I hope, as a trustee for Vasculitis UK, that I can use this information and put the knowledge I have gained to good use by being able to support other Behcet's patients and creating more of my awareness graphics.

Kelly Jefferies

In Memory of Holly

Very sadly Holly Hampshire lost her very long battle with Granulomatosis with Polyangiitis on the 11th December 2018.
Throughout the 10 years of having Vasculitis, Holly actively tried to raise awareness of Vasculitis and to support Vasculitis UK. Over the 10 years, Holly and her family raised thousands of pounds for Vasculitis UK for research.

I first met Holly in 2010. In the Spring of 2011, Holly became a trustee of Vasculitis UK. She also became the "Roving Reporter" for the Vasculitis UK Newsletter. Holly was a reporter for her local radio. Her first interview was with John Mills, my husband and chair of Vasculitis UK. I remember that day so very well; we had so much fun carrying out the interview and we laughed so much.
http://www.vasculitis.org.uk/content/downloads/spring-2011-Newsletter.pdf

In the Spring of 2012 Holly resigned as a trustee of Vasculitis UK, but we were all thrilled with the reason why. Holly was expecting a baby, which was amazing news for both Holly and her husband James as Holly was unsure she would be able to have children after all the aggressive treatment for the GPA. Robyn , Holly's beautiful daughter was born summer of 2012. You can read Holly's own personal story via the VUK website http://www.vasculitis.org.uk/living-with-vasculitis/hollys-story

In 2016 Holly became an admin for the Vasculitis UK Facebook "Parenting and Pregnancy" Support Group and was so very supportive to others who had been through the same experiences as herself.
It was such a shock and with sadness to learn of Holly's death, just before Christmas at such a young age and she will be missed by so many people , not only her own, very close family but by so many friends and colleagues too.

So far Holly's Just Giving, In Memory page, has raised over £2700 pounds for Vasculitis UK.

Susan Mills

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" ,"Pregnany & 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/

In Memory of Sarah

Sarah Pierce is my sister. She was 49 years old when she died, on 23rd August 2018, of heart complications as a result of systemic vasculitis (GPA). Her vasculitis diagnosis came less than 24 hours before she died.

Sarah's story is sadly a tragic one. Sarah was a fit and healthy 49 year old who exercised regularly and had practised yoga for 30 years. 10 weeks before she died Sarah was enjoying a 2 week holiday in Croatia with her husband and the only indication of any impending issue was the onset of painful joints during the trip.

6 weeks before she died, Sarah, Mum, Dad and I were in Sorrento for a long weekend to celebrate mums 70th birthday. It was a place mum had always wanted to visit and we had a fantastic time together, though Sarah's joint pain persisted.

Three weeks before she died Sarah was out with friends in Leeds watching a Bananarama concert, and spent the night singing, dancing and enjoying herself. 11 days before she died we were out for a family meal to celebrate my birthday, by then Sarah was starting to feel extremely tired and the joint pain was getting to her a little more.

1 week before she died she was still going to work, as she had been throughout. However, by now she had developed flu like symptoms. The last week of Sarah's life was a worrying blur of hospital admission, discharge, readmission, differing diagnoses; ending with relief, the day before she died, that a firm diagnosis of vasculitis had been made and treatment could at last begin.

This finally turned into a nightmare less than 24 hours later, when Sarah died.

I read all your amazing uplifting and encouraging stories both online and in this magazine and I wanted to share Sarah's story, not to bring worry and despair to those suffering from vasculitis but to highlight how fast this disease can take hold and to urge people to seek help and advice from the charity and to push the medical professionals, in order to get a diagnosis and treatment quickly.

As a family we are not ones to have time off work for minor aches and pains and tend not to bother doctors unless we really have to. Sarah did have several GP appointments, June to the week before she died, but no diagnosis was made. Neither Sarah, nor we, her family, had heard of vasculitis before Sarah died and put our faith in the medical professionals treating her. We all believed she would get better but sadly that wasn't to be the case.

In the days after Sarah's death, I set up a just giving page in her memory to raise money for Vasculitis UK. To date we have raised almost £9500 (including gift aid) for the charity, have 70 family and friends attending the Vasculitis UK ball on March 2nd 2019, my cousin and her daughters are running the Hackney Half Marathon in May and I'm planning to run the Great North Run for the charity in September.

Sarah was described many times in the days and weeks after her death as a 'beautiful person inside and out'. She saw the good in everyone, loved people and people loved her. She would be amazed and humbled by the generosity shown in her memory. I truly hope that the money raised so far and that we hopefully continue to raise will go some way to help support those of you living with the disease day to day, towards earlier diagnosis, better treatment and to raise awareness both to the public and the medical professionals for the future.

Heidi Pollard

£1085 was donated by family and friends in memory of Brenda Tempest. Brenda and her husband Derek were both active members of the East Midlands Vasculitis Support.

Brenda was diagnosed with an extremely rare type of vasculitis, Cryoglobulinemia many years ago and coped extremely well with her condition until late last year when she became very poorly and very sadly died. Brenda will be sorely missed by all her family and friends.

Family and friends have donated £2,577.50 to VUK in memory of Paul Best who sadly lost his life to complications of Takayasu Arteritis , a particularly rare type of vasculitis.

Bequests - In Memoriam

Funeral donations totalling £980 were received in memory of Mrs Joan Dymond of Glasgow, who passed away in the summer of 2018.

Donations to the total value £780.00 were received in memory of Garry John Robbins of Bristol.

Mrs Lynn Elise Brogan of Redditch passed away last year. Funeral donations totalling £444.60 were received in her memory.

Funeral donations of £155 were received in memory of Jeanette Margaret Martin of Dorset, who passed away in early autumn last year.

Donations totalling £310 were received in memory of Mr Byron Bater of Tonbridge, Kent. Bereaved are his wife, Elizabeth and daughters Catherine, Sian, Ruth and Sarah.

The friends and relatives of Sarah Pierce of Halifax, West Yorkshire donated a total of £8,724 (including Gift Aid) to Vasculitis UK in her memory. Sarah died tragically due to vasculitis at the age of 49.

Donations to the value £326 were received in memory of Timothy Godfrey Townsend of Stoke Rochford, near Grantham, Lincs. who passed away last autumn.

A donation was received in memory of the late Rhona Dales.

Numerous donations, totalling £505 were received in memory of the late Maurice Conn of Portrush, County Antrim who sadly died on 28th October, in part due to pulmonary vasculitis. Having grown up in Northern Ireland, Maurice spent early years in New Zealand & Rhodesia, before returning to work in the dairy & animal feed business. A keen rugby player & rugby fan, he left a widow, Joan, 2 children, 4 grandchildren, all of whom play rugby.

Donations totalling £180.00 were received in memory of the late David Charles Poole Of Chesham in Buckinghamshire.

A cheque for £135 was donated to Vasculitis UK in memory of Walter Edward Seagraves of Gravesend, Kent, who died in 2016 due to vasculitis. A former merchant seaman, Walter left a widow, Jo, a son and two daughters, 6 grandchildren and 9 grandchildren.

Funeral donations totalling £280 were received in memory of Tony Marron of Middlesborough, who died age 80 due to vasculitis after only a short illness. Tony was a loving husband, father of 4, grandfather of 4 and great- grandfather of 5.

Donations to the value £170 were received in memory of Alan Churchill of Bicester, Oxfordshire, who passed away in July last year

Brenda Tempest of Chesterfield sadly passed away last November, due to cryoglobulinaemia. A mum of two children, she was a lady of many talents from being a skier to a pianist. Married for 53 years to Derek, she is sorely missed. A funeral collection in lieu of flowers resulted in donations totalling £735 for Vasculitis UK.

David Raggett took part in the Kielder Marathon, raising funds for Vasculitis UK in memory of Lydia Moxley, wife of Tim Moxley, who was a dear friend. David raised £820 in sponsorship and his employers, Innogy Renewables, donated an additional £500 in matched funding.

Funeral donations totalling £261 were received in memory of the late John Middleton of Nottingham.

A donation of £32.50 was received in memory of Roger Barry Pink, who died in November last year.

Donations totalling £481 were received in memory of Mrs Marlene Honan of Dorset, who passed away in the autumn of 2018.

Funeral donations totalling £40 were received in memory of Terry Farebrother of Honiton, Devon, who passed away in November last year.

Mr J E Chesson of Ashford, Kent, suffered from vasculitis. He passed away in late 2018. Donations to Vasculitis UK in his memory totalled £348.

Tina Heath donated £50 to Vasculitis UK in loving memory of her sister, Lorna Wright, who sadly passed away in January 2014 after suffering from Wegener's for only a short time.

Donations totalling £123 were received in memory of Robin Nelson, of Kendal in Cumbria, who sadly passed away on 16th December last year.

A donation of £240 was received in memory of Edna Vane Loudon, who sadly passed away on 20th January only shortly after being diagnosed with vasculitis.

Donations totalling £191 were received in memory of Margaret June Sidebottom who passed away in January.

A donation of £40 was received in memory of Mark Flegg, who sadly died two years ago, in February 2017

Donation totalling £320 made by family & friends were received in memory of Mark Pearson who sadly passed away in January this year, following a long illness. Despite the difficulties presented by his condition, Mark, supported and cared for by his loving wife Debbie and his family, was always cheerful.

Vasculitis UK was the recipient of donations totalling £123 in memory of Robin Nelson of Kendal in Cumbria, who sadly passed away in December last year.

Ray Jeffrey of Rixton, near Warrington sadly passed away in January age 81 due to complications following vasculitis. Funeral donations totalling £835 were made to Vasculitis UK. Ray was formerly an industrial chemist. He leaves a widow, Brenda, 2 daughters and 4 grandchildren. Ray was a strong supporter of the local Methodist church and a keen student of local and family history.

William (Bill) Harrison passed away in February at the age of 86 due to pneumonia resulting from vasculitis. He had suffered from vasculitis for 8 years. A funeral collection in his memory raised £150 for Vasculitis UK.

Donations totalling £112 were received in memory of Joy Mary Pfander of Colchester, who sadly passed away in December, aged 76.

Donations & Funraising

Linda Andrewes of Barnstaple, Devon, raised £60 from Vasculitis UK Blue Collecting Box donations.

Melanie Percival, of Leicester, raised £201.50 in sponsorship by taking part in the 2018 Great North Run.

Jayne Coulson raised a total of £1,906 for Vasculitis UK by taking part in the London Marathon.

Richard Jones raised an amazing £1107 for Vasculitis UK by taking part in the Ealing Half-Marathon in September last year.

Yvonne Orchard & Friends held a "Flamingo Card Party", which, with donations, raised a total of £250 for Vasculitis UK.

Norfolk & Norwich Vasculitis Support Group kindly donated £500 to Vasculitis UK.

Stewart Else of Crich, Derbyshire recently celebrated his 70th birthday and requested donations in lieu of gifts. This raised £350 which was split between Vasculitis UK and Derby Royal Hospital Renal Unit.

George Tattersall raised £620 for Vasculitis UK by taking part in the North York Moors Coastal Cycle Ride in September last year.

Paul Heron of Washington, Tyne & Wear, raised a total of £345 for Vasculitis UK by taking part in the Great North Run last September.

Sureen Osler of Bristol donated £100 to Vasculitis UK.

Pauline has several blue Vasculitis UK collecting boxes which she has on display at church and the various clubs she attends. These raised £70 for Vasculitis UK.

Gillian Hewitt of Birmingham kindly donated £250 to Vasculitis UK.

An anonymous donor living in Birmingham kindly donated £20, to Vasculitis UK to fund further research into vasculitic diseases.

Ian Dennis of Hoddesdon in Hertfordshire kindly donated £150 to Vasculitis UK.

In her spare time, Charmian Kayes, of Ambergate, Derbyshire, is a potter – a ceramicist. She created & hand painted some small porcelain pots as Christmas table decorations and sold them in aid of Vasculitis UK, raising £75.

Mr R Lowe of Shepshed, Leicestershire, kindly donated £100 to Vasculitis UK.

The staff of Close Brothers Motor Finance of Doncaster held a charity dress down day. This resulted in a donation of £127.24 for Vasculitis UK.

Donations & Fundraising

Margaret Robertson of Chester le Street, County Durham, published, in aid of Vasculitis UK, an anthology of humorous verse, written by herself and others. By the end of 2018, sales had raised £1022. The book is still available from the Vasculitis UK online shop, on the website.

Rachel Marsh has vasculitis and has been a long-term supporter of Vasculitis UK. Her mum, Cheryl, was a teaching assistant at Hopton School (where Rachel had been a pupil) for 34 years. On Cheryl's retirement, one of her teaching colleagues, who had been Rachel's first teacher, presented Cheryl with a cheque for £50, in favour of Vasculitis UK, as a retirement gift.

The members of the newly formed Norfolk Vasculitis Support Group, led by Mark & Maz Sayer and rheumatology nurse specialist Sue Burrows, held a Quiz Night and other fundraising efforts in support of Vasculitis UK. This resulted in a cheque for £1500.For full report;see elsewhere in this newsletter.

Mrs C G Loughran of Cleethorpes requested donations to Vasculitis UK in lieu of gifts for her 70th birthday. This resulted in a total donation of £135.

Sherry White of Stockton, Teeside, was given Bingo vouchers by the manager of the Stockton Mecca Bingo. She sold these to her friends & raised £450 for Vasculitis UK. She raised a further £30 by selling knitted goods donated by Maria Williams, bringing the total raised to £480.

Margaret Playfoot of Dentdale near Lancaster, donated £50 raised from "Carols in the Barn" at Christmas time.

"Tranquility with Hospitality" Masonic Lodge No.274 in Rossendale, Lancs, kindly donated £274 to Vasculitis UK.

Some members of Romsey Test Rotary Club donated to charity in lieu of sending Christmas cards. This resulted in a donation of £31-25 to Vascultis UK.

The "Guisers" of Winster village in Derbyshire Perform their centuries-old traditional Mummers' play in various venues (Mainly pubs!) around the area at Christmas time, collecting pints & donations for charity as they go. This year they have once again donated £100 to Vasculitis UK.

The Hebrew Order of David (Lodge 4) very kindly donated £500 to Vasculitis UK.

The staff at Lake House office of Liberata kindly raised £56 in support of Vasculitis UK.

The Church Guild of St Cuthbert's Parish Church donated £35 to Vasculitis UK in lieu of paying a guest speaker who refused payment!

The members of the Norfolk Vasculitis Support Group and the Rheumatology Team at Norfolk & Norwich Hospital, including nurse specialist, Sue Burrows, donated £1500 to Vasculitis UK.

Joyce Blackwell of Sidmouth kindly donated £100 toVasculitis UK.

The staff of Keebles Solicitors in Leeds held various fundraising activities in aid of their chosen charity for 2019, Vasculitis UK. This resulted in a cheque for £293 representing money raised so far.

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**

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

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

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

Virgin money giving Donate here

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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
Lisa Ranyell - 01664 857532 - lisa.ranyell@ntlworld.com
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

Essex Group
Jules Darlow - 07789 113144 - jules.essexvsg@googlemail.com

Leicestershire Group
Leicestershire Group Website https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home
Tricia Cornforth – lvsg@btinternet.com

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

London
North London Group
Dave Newman - 07429137670 - david.newman@londonvsg.org.uk

Merseyside, Cheshire and North Wales Group
Susan Chance - 01244 381680 - susanchance53@icloud.com
Dave Birch - 0151 7229049 or 07968226230 - davebirch@talktalk.net

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

Norfolk Vasculitis Support Group
Mark Sayer **- m-sayer@hotmail.co.uk**

The North West Group
Jann Landles - jann@vasculitis.org.uk
Anita Parekh - anita@vasculitis.org.uk

Northamptonshire Group
Maurice - northantsvsg@gmail.com

Northumberland and Cumbria (Contact person)
Martin Thomas - 07765 888987 – nwukvsg@gmail.com

Oxfordshire Group
Sue Ashdown - 01295 816841 – vsgoxford@gmail.com

Plymouth Group
elaine203@live.com

Scarborough Group
ruth.newton@york.nhs.uk

Solent/Portsmouth Group
Julie Ingall - Julie.ingall@porthosp.nhs.uk

Surrey Group
Group under discussion

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 - mgvsgwm@blueyonder.co.uk

West Country Group
Website https://vasculitiswest.wordpress.com/
Charlotte Stoner - 01626 872420 - the.stoners@talktalk.net

West Sussex Group
John Bailey - 07752 122926 – johnbee4@googlemail.com

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 :
Jennifer Wormald - 01937 586 734 email jennifer@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 - susanchance@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 - james-walker@outlook.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/
Julie Power - 028 44 842889 - vasculitisireland10@gmail.org.uk

EVENTS CALENDAR

British Society for Rheumatology
Annual Conference April/May 2019 Birmingham

VASCULITIS UK

Vasculitis UK Annual General Meeting
May 19th 2019 South Normanton Alfreton

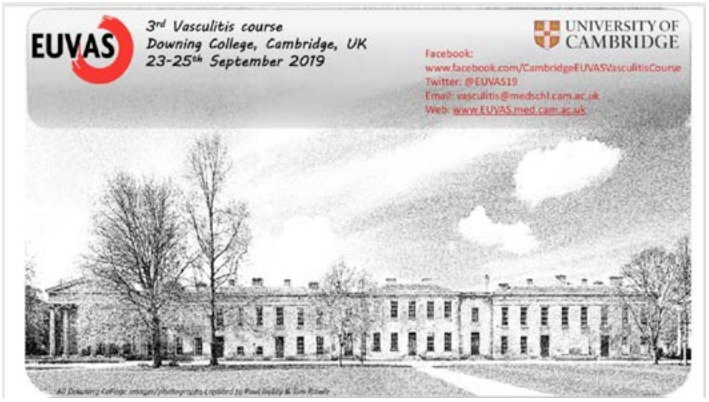
UKIVas

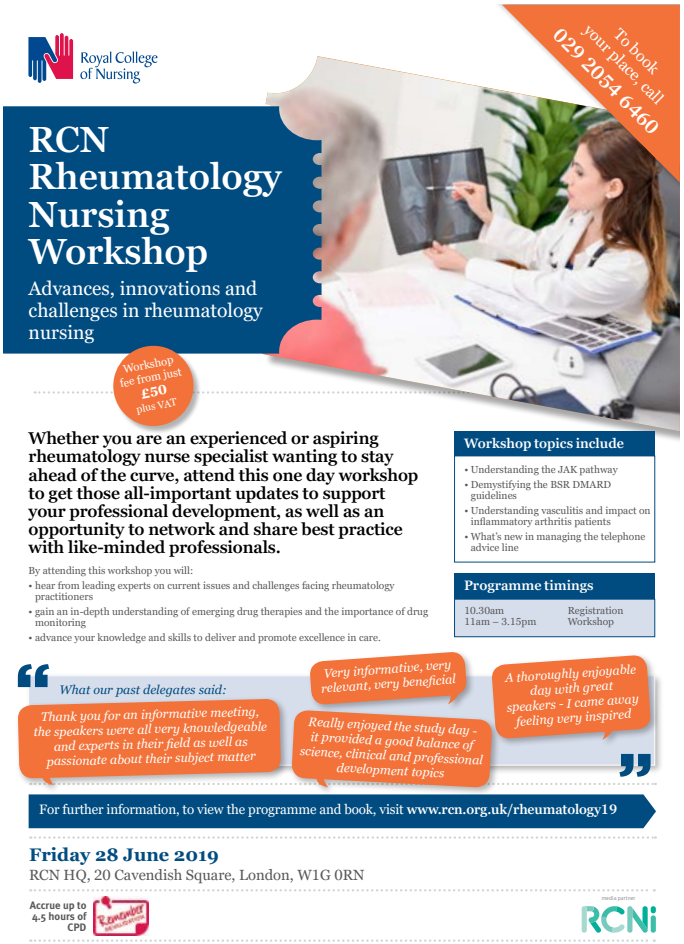
UKIVAS Education Day May 16th 2019
Salford Manchester

United Kingdom & Ireland Vasculitis
Study Group Meeting Ipswich June 6th 2019

VASCULITIS UK
Newsletter

If you would like something to be considered for future newsletters please contact:
kevin@vasculitis.org.uk





TRAVEL INSURANCE

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

Details are available on the VUK website:

www.vasculitis.org.uk/living-with-vasculitis/insurance

or contact John or Susan Mills details on page 28

HONORARY LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

Established in 1992 by the family and friends of Stuart Strange, in his memory.
Formerly known as the Stuart Strange Vasculitis Trust
Registered Charity No. 1180473

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