



VASCULITIS UK

NEWSLETTER JOURNAL



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No Gnomes in Zurich. Until the banking crash, the powerful Swiss bankers of Zurich, nicknamed by the press "The Gnomes of Zurich", played a very influential role in the economies of Europe.

In March this year I was invited to join a group at the headquarters in Zurich of EULAR – The European League Against Rheumatism – as a vasculitis patient representative. Eular HQ is housed in an impressive late c19 building on the shore of Lake Zurich.

The purpose of the two day meeting was to agree new European guidelines for treating Adult ANCA Vasculitis. This group comprised all the leading specialists in vasculitis in Europe, plus Dr Peter Merkel from the US, Dr Janice Mooney and me.

The meeting was led by Dr Chetan Mukhtyar assisted by Dr Max Yates, both from Norfolk & Norwich Hospital. The process of drawing up the guidelines is very rigorous and strictly based on evidence, with each piece of evidence being weighted in terms of its reliability. The pace was brisk and there were some intense discussions.

Zurich is a large modern city, but on the evening of day one, Dr Thomas Hauser, an immunologist whose home town is Zurich, took us for a walking tour round the mediaeval old town of Zurich, which was built on a glacial hill at the end of the lake. The walk up and down the pretty, narrow, winding, cobbled streets lined with small but expensive shops was quite challenging for my WG damaged lungs, but we were rewarded with an excellent meal at a very old inn.

By mid-afternoon on day 2 everything had been agreed in principle and the meeting closed in time for us to stroll in the spring sunshine to the nearby Suchard chocolate factory, to buy Easter eggs and chocolates to take home. I can confirm that I saw not one single Gnome during my time in Zurich!

The final draft of the guidelines has at last been fully approved by the group but it awaits formal approval by the EULAR governing body before publication.

Charities in the news. Charities have had quite a lot of bad press in the past few months. First was the suggestion that an elderly lady had taken her life partly due to persistent pestering, by post and 'phone, by charities demanding donations. Next came the reports that some charity bosses were paid six figure salaries for their services. Most recent was the collapse of the "Kids Company" amidst complaints about gross mis-management and maladministration and implied corruption. These are all serious failings and responsibility for them rests wholly with the trustees of the charities.

Just to put Vasculitis UK in context, the most aggressive technique we use in soliciting donations is the inclusion of a donation form with this newsletter.

Vasculitis UK is run entirely by unpaid volunteers and trustees. Trustees are able to reclaim essential expenses, but they frequently re-donate part of their expenses to Vuk so the charity can reclaim the Gift Aid.



Chairman's Report

Most of the charity's income is used to fund research; details are to be found elsewhere in this issue. The charity's accounts are subject to rigorous professional audit and are made available for all to see on the Vasculitis UK website.

The Rise and Fall of Charities: Planning for the Future. The Stuart Strange Vasculitis Trust was founded in 1993. Like most charities it was set up by a small band of enthusiastic and highly motivated volunteers and supporters. By 2008, most of those pioneering supporters had died, become older or drifted away and the charity was set to be wound up for lack of enthusiasts to run it. This "waxing and waning" cycle is an oft repeated story in the charity world.

Fortunately, a few new enthusiastic volunteers came to the rescue and like a phoenix, "Vasculitis UK" was born from the ashes of SSVT and it flourished.

There are basically two alternative routes for charities; either they grow and become more successful or they fade and decline. The charity may continue being run by unpaid volunteers or the trustees may take on paid staff and even pay a director or chief executive to manage the running of the charity.

The first option depends on the energy and goodwill of a pool of volunteers who have the enthusiasm, energy and the time to carry out all of the admin as well as the intended aims of the charity. The advantage is that the charity's precious donations are not spent on paying for staff and premises and can thus be directed towards the aims of the charity.

The second option has the advantage that it does not depend on goodwill. Staff are paid to do the job and if they are not effective, they can be replaced. They have an incentive to keep the charity running well as their jobs depend on it. However, staff need salaries, offices and equipment, with heating, lighting and telephone lines. They also need pensions and insurance and they have employment rights. The charity now has ongoing financial commitments, so it needs substantial reserves to cover fluctuations in income and to cover the risk of collapse and redundancies.

All of these have to be paid for from those precious donations. So then the charity has to employ professional fund raisers to increase income from donations. It becomes a vicious circle and it's a quantum leap away from that first option.

In addition, the charity may start to exist for its own sake, to serve the interest of those who work there and might lose sight of its original aims and objectives.

continued on page 3

Chairman's Report continued from page 2

Vasculitis UK is a small charity, but growing - and the workload grows with it. At present, all the work is all carried out by a few unpaid volunteers, with a few "bought in" professional services such as IT and printing. As we are now experiencing, in the wake of the untimely death of Pat Fearnside, sometimes too much is demanded of too few. It's not good for the charity to have too many eggs in too few baskets and it's not good for those concerned, especially if they are not well themselves. So we need to spread the load more, even if it means employing someone; but as stated above, that solution brings its own problems.

Maybe there is a third way; to "buy in" even more services to supplement the work of volunteers, without actually employing people. These are the dilemmas currently facing the trustees of Vasculitis UK.

In addition to strong support from members and volunteers and a sound reliable income stream, an effective charity needs enthusiastic and effective trustees with vision, insight and experience of running a business; trustees who can understand important bigger issues and make carefully considered informed decisions.

The members of the Board of Trustees of a "normal" charity bear legal (and possibly financial)

responsibility for the running of the charity. In these days of blame culture and litigation, for an unpaid trustee, this is an unfairly onerous responsibility and a deterrent for some who might wish to become a trustee. For this, and various other practical reasons, the trustees are considering applying to the Charity Commission for a change of status, becoming a Charitable Incorporated Organisation, or CIO. This is a half way house between being a normal charity and a limited company. Members will be fully consulted and will be able to vote on the matter before any action is taken.

The Vasculitis UK constitution requires that nobody may hold the post of chair for more than six consecutive years, so at the AGM next year the members will need to elect a new leader for Vuk, someone with vision and knowledge of vasculitis, someone who feels really passionate about vasculitis and has time and energy to follow it through..

That new leader will need a strong and effective Board of Trustees to help in facing the challenges ahead. If you think you have the necessary qualities to be a trustee or you know of someone, please contact us. Without a strong leader and a strong Board of Trustees, Vasculitis UK could easily wane and fade away...

John Mills (Chairman)

An introduction from your new joint editors

As some of you will already know, Vasculitis UK recently suffered a great loss with the death of Pat Fearnside. One of the many tasks she took on was the setting up and producing this newsletter.

I never met Pat, but she was one of several individuals who provided much needed support at the dark time of my initial diagnosis. I think Pat helped many more through this newsletter, and when I heard of her passing I was pleased to offer my help in continuing the work she started.

As things have turned out I've been very lucky, and my condition is redefined as 'an unspecified auto-immune' condition (although I did get to enjoy the 'pleasures' of prolonged high dosage steroids and cyclophosphamide infusions as investigations progressed!) But in itself that demonstrates some of the challenges we face. Vasculitis is not a clear cut condition. Things are not always black and white. It's not well understood. Which is why this newsletter was such an inspired idea. To keep people in touch with new ideas and developments as well as recognise the wonderful work of the many fundraisers who help fund research into better understanding and treatment. (And based on some of the photographs to share a smile at some of their fundraising ideas!)

Hopefully Kevin and I will be able to help keep Pat's ideals going. We're already starting to appreciate just how much work that means. Please keep sending us your ideas to help make the newsletter even more useful.

Keep well, and thank you for your contributions so far. *Graham Baker*



Hi readers I would like to introduce myself to you all, I'm Kevin your joint editor of **your** newsletter and alongside Graham I'm sure we both will be able to serve you well.

Becoming a volunteer for Vasculitis UK gives me a chance to rest my legs from running and raising funds for various charities and replacing it with my services to help raise awareness.

VUK is a charity that is very close to my heart due to the sad loss of my sister to Wegener's Granulomatosis. My focus will be to raise awareness of Vasculitis by helping to inform you the readers, patients, medical professionals and the general public through **your** newsletter.

We welcome your input so if there is anything you wish to be included in future editions please contact either of us through Vasculitis UK and we will try our best to accommodate it.



Kevin Soper

CONFERENCE



The second half of April 2015 was just a bit hectic and challenging for the VUK team. Saturday April 18th was the Vasculitis UK Patient Symposium at the London Business Design Centre. In the same venue, Sunday 19th saw the opening of the amazing international vasculitis conference, Vasculitis 2015. That closed on Wednesday 22nd and the three day British Society of Rheumatology Spring Conference opened in Manchester on Tuesday 28th.

The Patient Symposium attracted 141 delegates to hear 17 world class speakers from the UK, Europe and the US. These included Dr Maria Cid from Barcelona, Dr Thomas Hauser from Zurich Dr Nataliya Milman from Toronto and Dr Peter Merkel from Philadelphia.

From the UK, speakers included Professors Justin Mason, Ann Morgan and Caroline Savage with Drs Neil Basu, Nina Brown, Rachel Jones, Janice Mooney, Louise Oni, Fiona Pearce, Jo Robson, Richard Watts and Sister Julie Ingall.

The theme in the morning was "Vasculitis, Diagnosis and Treatment", chaired by Dr Peter Lanyon and in the afternoon "Living and Coping with Vasculitis", chaired by Professor David Scott.



Delegates arriving for the Vasculitis 2015 Patient Symposium

The event was organised and sponsored by Vasculitis UK and supported by the US Vasculitis Foundation, the Lauren Currie Twilight Foundation and PMRGCAUK. The symposium was also supported by the organisers of Vasculitis 2015, Professors Charles Pusey and Alan Salama. Commercial sponsors were GlaxoSmithKline and Servier Pharmaceuticals.

The symposium would not have been possible without the wholehearted support of James, Emma and Kira of Innov8 Conference Services. On the day we were indebted to the enthusiastic team of Vuk volunteers, Christine, Clarry, Gareth, Jane, Jann, Sue and Susan and of course, the generosity of the seventeen speakers who gave so freely of their time.



*Kimberley - LCTF Joyce-VF
Susan and John - VUK
Vasculitis 2015 Conference*



*David Jayne - speaking at the Vasculitis 2015 Conference
talking about the "importance of peer to peer support."*

You can read more about the symposium elsewhere in this newsletter. As their contribution, Vasculitis Foundation paid for the professional video recording of the sessions. This material is now being edited and we hope it will soon be available on the internet, for all to view.

Vasculitis 2015 (The 17th International Vasculitis & ANCA Workshop) was an amazing four day event, with a bewildering choice of lectures and presentations by eminent speakers from around the world. I was privileged to be given my 10 minutes of fame, speaking to an auditorium full of doctors under the title "Medical Professionals and Patients in Partnership for Better Outcomes"..



*Dr Mike Venning introducing speaker
Kate Gilbert chairman of PMRGCA -
Vasculitis 2015*

The conference involved 24 full lectures, 95 Short lectures and the presentation of 253 pieces of research in the form of "posters".

It is heartening to see that so much research is taking place.

Vasculitis UK had a stand at the conference, which attracted much interest from delegates coming from all around the world and was a good opportunity to make new acquaintances and renew old ones, such as Peter Verhoeven of the large Dutch Vasculitis Support Group.

Susan and I were also invited to take part in the conference social events for speakers, including the Gala Dinner.



*John Mills, Susan Mills, Danni Brunwin, Mike Patnick
Trustees of VUK manning the VUK stand at the
BSR Annual Conference April 2015.*

The British Society of Rheumatologists Annual Conference was held in Manchester from 28-30 April, with 2000 professionals attending.

There was a well-attended session devoted to vasculitis, led by Professor Raashid Luqmani and 14 vasculitis poster presentations.

Vasculitis UK had a stand at this conference, which once again attracted much interest. Over 2,000 medical professionals attended this conference, most being doctors. There were 96 Abstract Research Posters on display, including 18 Vasculitis research posters.

The Vasculitis Research Poster Tour was led by Dr Richard Watts.

The ninth Arthritis and Connective Tissue Conference was held in Portsmouth on 16th September. Vasculitis UK had a stand at this excellent patient-focussed event organised by the Rheumatology Department of Queen Alexandra Hospital. A brief report is to be found elsewhere in this edition.

The fifth "Vasculitis Ireland Awareness Conference" was held in Dublin on 3-4 October. This patient support group, run by the very energetic Julie Power, brings together patients and doctors from both Northern Ireland and the Republic. A full report on this conference will be in the Spring edition of the newsletter.

EULAR European League Against Rheumatism Meeting in Zurich March 2015. John Mills was invited to this meeting with Dr David Jayne, Dr Peter Merkel, Prof Mark Little, Prof Raashid Luqmani, Dr Chetan Mukhtyar.



More information and photos from all these events are to be found on the Vasculitis UK website.

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**

Some of Our Fantastic Fundraisers



Colour-me-rad

Michelle Dring and Katie Dring have raised over £4800 in memory of Rachel Dring.



Laura, Jemma, Hannah, Caroline and Therese at the Major Series 10-12K in Eridge



Lisa has Takayasu Arteritis - she and her family climbed Snowdon in May 2015



John Jon and Dave cycling for Vasculitis UK have raised over £800



David Golden cycling from Blackpool to Scarborough for his friend Carol Wadsworth. Raised over £320



Holly Taylor has raised over £5000 with the support of her employers, Activity Superstore Ltd



Paul England, Lands End to John O'Groats



Anna Higgins Worcester Half Marathon Sunday 12th April on behalf of her sister Lucy.



Dorothy, John, Martin Markin and Martin's son Joe aged 9. Taken at the East Midlands Vasculitis Support Group meeting in May. Joe gave a donation to VUK from selling some of his pictures.



Kevin Dunbar running in the Manchester Marathon in memory of Neal Mouldsdale

Manda Taylor, family and friends raised over £1000 in memory of Tanya, Manda's daughter who lost her life to vasculitis August 2014, aged 29.



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

Some of Our Fantastic Fundraisers

Three Peaks Challenge, with Alan and Claire Harry fundraising for Vasculitis UK on behalf of Alan's Dad.



Simon Coates is 9 years old and has been fundraising for VUK for two years now. His mum has Takayasu Arteritis. Simon has raised over £500 for VUK



Hannah's father was diagnosed with vasculitis in 2014. Hannah took part in the MK Marathon in May and has raised £200 for VUK.

Axe Cliff Golf Club in Devon are raising awareness of Vasculitis for the next two years 2015 - 2017



Gailhealthtatchd Champion Dog Show (Inverness) May 2015. In aid of Vasculitis UK and Help the Heroes



Ayrshire Referee Association cheque presentation, for £4700 to Vasculitis UK September 2015



The UK Ghostbusters raised over £360 at the London Film and Comic Convention July 2015



Louise and Tarn after the Leeds half marathon in May. Running on behalf of their friend Holly Hampshire who has WG (GPA)



The Valley Girls (Mad group of 20 ladies, who have taken on the challenge to cycle 470km across rural Rajasthan, raising money for Charities close to their hearts) presenting a cheque for over £17,000 to Sue Ashdown, Organiser of the Oxford Vasculitis Support group, who accepted the cheque on behalf of Vasculitis UK.

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

What's worse than being ill 24/7?

My journey started not long after I had turned 18, 6 years ago. At the time I had a good job, lived with my long term boyfriend and had a good bunch of friends, yet my life was slowly falling apart. I felt like a prisoner in my own body.

My symptoms started off as nothing major, just little individual problems. The first thing that happened was that I developed late onset of asthma which continuously had me in and out of hospital. Next I completely lost my smell and taste and partial hearing loss too. It was at this point the doctors were telling me it's just a cold and that I was making it out to be worse than it is. My body always hurt like hell, every step felt like I was climbing Mount Everest. My muscles would cramp all through the night. I seemed to pick up every infection going and had stomach pains that would have me crippled, bent over in agony.

I was a regular at my GP surgery, pretty much every week for about 18 months. It got to the point that the GP just wouldn't take me seriously and refused to give me anything to help. The only medication that I was prescribed was antidepressants. I refused to take them, I knew the problem wasn't in my head. I would break down to the GP but only because I was in so much physical pain not because I was depressed. Looking back I can sort of understand why they didn't think there was anything seriously wrong, they were looking at the problems on their own rather than as a whole.

April 2011 nearly 2 years since the symptoms started and at the age of 20, I have no idea how I had managed to carry on up to this point. By now I was sure something was seriously wrong and knew that I had a choice to make. I could either give up or take it into my own hands. I chose the latter.

My GP and A&E were both out of the question, I had received a letter from the hospital saying I was wasting the time of the A&E staff. The only option I had sadly came down to money. My mum was just as frustrated as I was so she paid for me to see a doctor privately. If I hadn't done this I'm almost positive I wouldn't be here today.

The private doctor took one look at me and sent me to St James hospital in Leeds. She could

see something was seriously wrong and I had finally made it into the hospital as an inpatient. There was no way I was leaving my bed until I had answers!

Things quickly spiralled out of control. I couldn't eat, even water made me vomit. I lost 2 stone in 4 weeks. My breathing deteriorated, the pain was unbearable. I eventually lost use of both my wrists and one of my feet. The funny thing is even though all of these things were happening the doctors seemed to still not believe me. I was accused of so much; some examples are an eating disorder, a drug addiction, getting abused at home. I was 20 years old and I was unable to go to the toilet on my own, how could I possibly have made this up?!

Just when I thought I had no more strength to carry on, I got what I had been waiting for, a diagnosis! Churg Strauss Syndrome, I'd never heard of it before but just putting a name to the problems made me feel relieved, it made me feel safe, although that didn't last very long. I was told to get my family to the hospital as soon as possible as it was highly likely I wasn't going to make the next 48 hours. I should have been terrified but more than anything I felt determined not to give up. I wanted to get married, buy a house, be a mum, how can I give up when I had so much ahead of me?

I was put straight onto Cyclophosphamide chemotherapy infusions. Day by day I was getting stronger, 4 weeks later I was allowed to go home. I had been in hospital for 2 months but I was finally free and best of all I had a diagnosis.

The last 4 years have been a rollercoaster ride.



My health has been up and down, constantly throwing new loops into the equation. I've been in and out of hospital more times than I can remember, the amount of CT and MRI scans I've had I should be radioactive. Some days I would be taking up to 30 tablets and be physically bed bound.

Being ill 24/7 yet nobody believing you!

It's hard to believe now that up until the age of 18 I had no health problems. I was fighting fit, I loved going on long walks, going to the gym and playing for a football team. But now that seems like a distant memory; even something as easy as going to the supermarket is a big challenge for me.

Although that's doesn't mean I'm going to sit down and settle with it, I'm determined that one day I will be able to do all those things again and more.

Last year was a major turning point in my life, when I first was told I had CSS I thought this one thing would be impossible. I walked down the aisle and married the love of my life, the person who was there from the beginning and has travelled with me on my journey and will continue to do so for the rest of my life. I wasn't able to have the big wedding that I had dreamt of as my body and health was not up to it. Instead we chose to get married in St Lucia, a quiet intimate wedding with only 2 guests. I only managed to be awake for 4 hours



of my wedding day but those 4 hours were the best of my whole life! I still dream of a big perfect wedding with all our family and friends,

when the day comes that I am well enough I would love to renew our vows and have the day just how I had dreamt it would be.

I also thought that I would never get the chance to own a home of my own but me and my husband now own a perfect little home which proves to me just how far I have really come.

Another thing is that all of the doctors had told me to give up work; the CSS would make it impossible for me to hold down a job. But guess what, they couldn't be more wrong! I work full time and have continued to do so throughout everything, my boss has been there and supported me all along the way, which has made the impossible possible.

Right now I am seen under the Vasculitis team at Addenbrookes hospital in Cambridge. It is a 7 hour round car journey from where I live but well worth the miles to be seen by one of the best Vasculitis specialists in Europe.

8 weeks ago I had a treatment called Campath that is in trial stages for CSS. I had been on Rituximab for the majority of the past 4 years but this hadn't controlled the illness successfully. I am positive that the Campath will finally take control of my health problems, even just after 8 weeks it has improved my health massively. In fact I do feel that in ways I am better than I have been since my journey began.

I want to have the chance to enjoy my life just like a woman in her 20's should be doing. There is just one more big dream I have, the biggest out of them all. I would love to become a mum; at this moment in time this isn't medically possible but I do have hope that one day my dream can come true.

As long as I carry on with my head held high and the smile on my face I am determined I will get to the life I deserve.

I will not let my illness define me!

Emma Smith, Leeds

Eosinophilic Granulomatosis with Polyangiitis

**Dr Thomas Jones (Wessex Research Fellow)
Respiratory Department, Portsmouth Hospitals
NHS Trust, supported by Professor Anoop Chauhan
(Respiratory Consultant and Director of Research
and Innovation) Portsmouth Hospital NHS Trust**

As Emma's story demonstrates and in common with other types of vasculitis, the journey for a person with EGPA is often complicated. The time it takes between symptoms starting and a person getting a diagnosis of EGPA is often prolonged. Once a diagnosis is made, it often takes time for treatment to be effective and side effects are common. Doctors and other healthcare professionals who care for people with EGPA recognise many problems with the "pathway" or journey for people with EGPA but we are attempting to improve this situation.

One cause of many of the problems that people with EGPA experience is the rare nature of the disease. It is estimated that 11-13 people per million have EGPA (approximately 850 people in the UK) and this means that neither the general population nor many doctors are aware of it. Even when doctors such as GPs or Consultants are aware of EGPA, very few of them will have experience of treating people with the condition.

Another cause of problems in EGPA is the difficulty in diagnosing someone. A diagnosis of EGPA is based on a combination of symptoms, blood tests and, ideally, a sample (biopsy) from an affected area. Biopsies can be uncomfortable and are not always conclusive, but there is no simple blood test that can give a firm diagnosis in all cases. Finally, treatment of EGPA is challenging. Monitoring the disease is most commonly done through blood tests to look at eosinophil (a type of white blood cell) levels, but this does not perfectly predict how active EGPA is. Treatment consists of steroids with or without additional treatment to dampen down the immune system.

Many readers of this newsletter will be familiar with the side effects of steroids and other immunosuppressive treatment.

This said, attempts are being made to progress in these areas. Research is needed into the best ways to diagnose, monitor and treat people with EGPA and this requires the help of people who have the condition. There is research going on in several hospitals across the UK (and worldwide) looking at new tests and treatments for EGPA. At Portsmouth Hospitals NHS Trust, we are starting a programme of research looking at diagnosis,

monitoring and treatment. Having participated in drug trials for our patients with EGPA, we decided that we could try to contribute more research ourselves.

In partnership with the University of Portsmouth and other UK hospitals, we are designing a series of studies; firstly to look at how people with different types of EGPA are affected, then to find new diagnostic tests and finally to try to find new options for treatment. We hope this research will improve the quality of life of people with EGPA, and would encourage patients to get involved in research into their condition for their own benefit as well as for other sufferers.



What is EGPA?

Eosinophilic Granulomatosis with Polyangiitis (EGPA), previously known as Churg-Strauss Syndrome, is an inflammatory disease of small and medium sized blood vessels. The lungs and skin are commonly affected but it can affect other organs including the heart, kidneys, nerves and bowels.

Eosinophils, a type of white blood cell that typically fights parasite infections and is related to allergies, are found in very high levels in EGPA, both in blood tests and in affected parts of the body.

Who is affected?

EGPA seems to affect men and women equally. Around 11-13 people per million are diagnosed with EGPA. The average age of someone with a new diagnosis is 40 years old, and it is very rare in children or those over 65 to be diagnosed.

What is the aetiology (cause)?

The cause of EGPA is not known. It is likely that a combination of factors lead to development of EGPA. Studies looking at genetics have shown some genes that are linked to EGPA, while some people have Anti Neutrophil Cytoplasmic Antibodies (ANCA) which may cause some types of autoimmune disease. Unusual levels of some types of hormone-like chemicals in the blood (cytokines) have also been found in people with EGPA, and this may contribute too.

What are the symptoms?

People who suffer with EGPA usually have severe asthma that may have developed as an adult. They often have sinus and nose symptoms and may have a number of other symptoms including: rashes, nerve damage including pins and needles or numbness, bowel trouble and blood loss, anaemia, heart problems, muscle and joint pain and tiredness. Symptoms often develop in phases:

First "prodromal" phase – People with EGPA often suffer allergies, asthma and sinus symptoms starting in their teens and twenties

Second "eosinophilic" phase – High levels of eosinophils are found in blood tests, and often in affected organs

Final "vasculitic" phase – Inflammation of small and medium vessels (vasculitis) begins, often in the twenties and thirties. Symptoms of tiredness, weight loss and fever often precede this.

How is it diagnosed?

The most up to date diagnostic rules, written by the European Respiratory Society (ERS), say that someone with EGPA should have:

- Asthma
- High levels of eosinophils in the blood (over 10% of all white blood cells)
- Damage from vasculitis to the skin, nerves, kidney, lung, heart or blood tests suggesting vasculitis

The ERS also suggested a sub-type of EGPA called Hypereosinophilic Asthma with Systemic Manifestations (HASM), where vasculitis itself was not present, but patients had other types of organ damage from eosinophils.

Diagnostic tests

Blood tests – Blood tests will show high levels of Eosinophil white blood cells in patients with active EGPA. Blood tests may also show damage to the kidneys, or may show a type of antibody related to vasculitis (ANCA).

Chest X-ray – People with active EGPA may have patches of vasculitic damage where eosinophils invade and damage the lung tissue (infiltrates) that may be visible on a chest x-ray.

Lung function – All patients diagnosed with EGPA have asthma, and this will almost always be shown through spirometry (breathing tests) that show an inability to breathe out as quickly as should be possible which improves when given inhaled treatment.

Biopsy – If biopsies (tissue samples) are taken, these may show high numbers of eosinophils, collections of immune cells (known as a granuloma), and damage to blood vessels cause by immune cells (vasculitis). Biopsies may be taken from any affected tissues (lung, nerves, skin, kidneys etc.) and are the most conclusive way of diagnosing the disease.

Bronchoscopic lavage – Camera tests may be performed to "wash out" areas of the lung. This fluid can show high numbers of eosinophils and may have blood in too. This test is most useful in making sure that other problems such as infection or cancers are not present.

Heart tests – People with EGPA can have damage to their heart, and so a heart tracing (electrocardiogram – ECG) and/or ultrasound test (echocardiogram) are often performed. This may be followed up with further tests where abnormal areas are found.

Treatment options

Corticosteroids – Steroids like prednisolone form the backbone of treatment of people with EGPA. Steroids are often needed at quite high levels initially, and should be tapered off although this can take many years. Reduction of steroid treatment should be done very carefully as dropping steroid levels too quickly can result in EGPA becoming more active or not having enough steroid within the body. Steroids can have multiple side effects.

Nasal and inhaled steroids – As well as steroid tablets, people with EGPA often need steroid sprays to treat their nose and sinus symptoms. These can help people breathe through their nose more easily and try to preserve their sense of smell. Steroid inhalers are used to control the asthma that almost all people with EGPA experience and prevent worsening of their breathing.

Cyclophosphamide – In people with severe EGPA and those who do not respond well to steroid treatment, medication like cyclophosphamide may be used. This can be given by mouth or into veins, and is continued for a limited period of time.

Azathioprine – Azathioprine is sometimes added into treatment for people who are struggling to reduce their level of steroids without their EGPA becoming more active. Blood tests are needed before starting azathioprine as some people react very badly to it.

Methotrexate – used similarly to azathioprine, methotrexate is sometimes used to help with reduction in steroid treatment.

Rituximab – A new injection treatment, Rituximab is occasionally used in severe EGPA that has not responded well to other treatment.

Other medications – New medication including other injectable antibody treatments are being researched and may become available over the next few years.

Alternative medicine – There is no evidence that any types of alternative medicines are useful in EGPA, and they should not be used in place of medical treatment.

Prognosis

Before treatment for EGPA was available, it was universally fatal. Half of patients diagnosed with EGPA died within 3 months of diagnosis. With modern treatment, this is much improved. We think that 8 in every 10 people diagnosed are still alive 5 years later. People who have involvement of the heart, kidneys, gut and brain seem to be at higher risk and may require more intensive treatment to prevent complications.

Report of Cambridge Vasculitis Support Group Meeting July 4th 2015

The 4th of July meeting of the group saw 40 of us gathered once more at the Holiday Inn. After lunch and lots of talking, we had more discussions looking at the big things that face vasculitis patients and then at the small things that annoy us. We didn't have quite enough time to explore these - although it was interesting how the two lists overlapped. The lists give us food for thought for subsequent meetings and perhaps the need to build in more discussion time.

We had two very different speakers starting with Vivien Turner who teaches the Alexander Technique - a method of learning how to move and especially to understand and correct our bad habits. One of our members - Caroline Meyrick - introduced Vivien, having found that her own sessions with Vivien always make her feel much better. Vivien stressed that she had no medical training and gave us some of the background to the Alexander Technique. She concentrates on very gentle and subtle changes, which she demonstrated on one of our members. She also made us realise just how big a weight we all carry on our shoulders, by passing round a box which, at just over 3 kilos, is the weight of a small head. It really demonstrated how easily we can get into bad habits - sitting at a computer for example! Vivien recommended the book "Body, breath and being" by Carolyn Niccholls - the first edition has a useful CD and the 2nd edition's Chapter 5 has the title Chronic pain - how to pace your life for more energy. Details of qualified Alexander Technique Trainers can be found at www.stat.org.uk.

After tea we were joined by Andreas Kronbichler, who gave us an insight into the Human Microbiome and in particular his own research, during his year as Honorary Research Fellow at Addenbrookes. The microbiome describes the complete habitat of part of the body - mapping all its micro-organisms and their genes. Andreas' particular interest is the microbiome in the nasal cavity - and especially the levels of the bacteria *Staphylococcus Aureus* (SA). 30% of the general population have SA in their nasal cavities - mostly with no ill effects. However this figure rises to 70% for patients with Wegener's (GPA). Andreas looked at swabs from vasculitis patients and other groups and also researched into the use of antibiotics. It is a hugely complex area, but with greater understanding and much more research, the microbiome could help doctors in the future to tailor treatment much more closely to the individual. A selection of Andreas' slides are available on the web site.

Finances

Thanks very much to Mike Ginn, who sold so many raffle tickets, and to everyone who brought prizes - our raffle made £112.50. This enabled us to cover the costs of the meeting with a small profit.

A big thank-you to everyone who helped and especially my husband Bill and my good friend Leonore.

Lesley Noblett



More local support group activity



The sun shone again this year for the West Country Vasculitis Support Group Summer BBQ - despite forecasts of dire weather 27 group members basked in beautiful sunshine on the South Devon coast! This is an annual event held by the group who also meet up throughout the

year for lunches and coffee mornings around the West Country. For information about upcoming events please email [Charlotte Stoner on the.stoners@talktalk.net](mailto:Charlotte.Stoner@talktalk.net) or visit the group website: vasculitiswest.wordpress.com

Mel Knight with Tricia Cornforth from the Leicester Vasculitis Support Group presenting John Mills with a cheque for £1000 donated from the Rokeby Lodge, Masonic Hall Rugby.



This photo is Dorothy, Lisa, John, Specialist rheumatology nurse Alice Muir and a visiting doctor from Nottingham at the East Midlands Vasculitis support meeting in May. Alice gave a talk

and interactive discussion and presentation about relaxation and coping strategies. John also gave a presentation and feed back from the Vasculitis Patient Symposium 2015. The meeting was attended by 30 members.

A Delegate's Perspective by Lynn Laidlaw

It was with a great sense of excitement that my husband, 2 teenagers and I caught the train from Scotland to London on April 13th. We were going to stay in my sister's new house (no more hotel bills!) and I was particularly looking forward to attending the Vasculitis Patient Symposium.



After a week of beautiful London weather, a trip to see Billy Elliot, sightseeing and a lovely meal on the Friday night when I finally got to meet John, Susan and some other "Vascie" friends, the day of the Symposium dawned bright and clear. Everything was so wonderfully organised from the start. We received our name badges and delegate packs and got ready for the first lectures. After the obligatory "hitch" was sorted (oops, no microphones) we settled down for a wonderfully informative day.

The morning session concentrated on who gets Vasculitis and why, research priorities and details of a clinical study that we were invited to participate in. We then split into groups and I attended the Large Vessel Vasculitis Workshop led by Prof Justin Mason. We were treated to an entertaining and informative talk by Dr Maria Cid (all the way from Spain), Prof Mason and Prof Ann Morgan. We were given the opportunity to ask lots of questions which was great.

After a buffet lunch and a chance to greet some more vascie friends I attended the workshop on less common types of Vasculitis where Dr Louise Oni and Prof Morgan talked about HSP and Behcets Syndrome which was of particular interest to me.

After a coffee break it was back to the main hall for Dr Neil Basu's lecture on "Unravelling Vasculitis Related Fatigue". This was the lecture that generated the most questions and discussion, probably because fatigue is such a factor in all variants of Vasculitis. It was great to see it getting the attention that it deserves. Then followed a lecture from Prof Caroline Savage on future trends in treatment of ANCA associated Vasculitis and the wonderfully entertaining Prof Peter Merkel bringing us up to speed on Vasculitis International Clinical Research.



Gareth, Clarry and Jann welcoming the first delegates for the 2015 Vasculitis Patient Symposium

I realise this is just a whistle-stop tour of what was a long, exhausting but hugely enjoyable day. Whilst I may have forgotten the specifics of what was said on the day, what remains with me is a sense of being part of the worldwide Vasculitis family. I felt humbled that so many eminent, busy Dr's were prepared to give up their free time to come and speak to us and answer questions so honestly, it was a lovely example of the VUK mantra of patients and professionals in partnership. I also came away with a renewed sense of optimism at the hope of a cure for Vasculitis after hearing about how much research is being carried out worldwide.

Last, but not least, there is the efforts of all at VUK who worked so hard and tirelessly to make this day possible and such a wonderful success. My only question, when is the next Patient Symposium.....?

A Volunteer's Perspective by Gareth Garner

The vasculitis patient symposium in London was an extremely interesting experience for me, and a great opportunity to be involved as one of the volunteers, on the day, on behalf of Vasculitis UK. I threw myself enthusiastically into my role but I was also very keen to gain some invaluable knowledge.

The day began with a presentation from Dr Richard Watts who took a rather different approach to understanding vasculitis, by looking at the epidemiology of the disease, as well as why some people seem to get it. What appealed to me in particular about this presentation were the comparisons between countries such as England and Japan, where Dr Watts showed us how different types of vasculitis vary in prevalence, depending on what country is being studied.

After a short coffee break chatting and hearing people's stories about their experience with vasculitis, I attended the workshop on ANCA vasculitis lead by Dr Peter Lanyon. The presentation covered a huge amount of subject specific areas around vasculitis in great detail, but in an easy to digest way. To say I was engrossed would have been an understatement. I believe the whole room learnt a great deal about the role of ANCA in vasculitis and secretly left feeling like an expert of their own. I learnt that there are two different types of ANCAs (c-ANCA and p-ANCA) which I was very surprised about considering I've been learning immunology at university for a year now!

Following a delicious lunch and another opportunity to chat with others and give out information, two individual workshops ran in parallel. I attended the workshop on less common vasculitis.

The workshop focused on Behcets disease and Henoch Schonlein Purpura (HSP). In particular Behcets, which was very appealing to me, considering my mother suffers from this type of vasculitis. Professor Ann Morgan covered Behcets in a huge amount of detail from what causes the disease to treatment. What stood out to me was the affect the disease can have on the eyes and how dangerous it can be to sight.



John's Vasculitis "V" team - everyone worked so hard. Fantastic team work.

Dr Louise Watson, a Paediatric Nephrologist covered the whole of HSP in a very stimulating presentation. I learnt a huge amount on this disease considering I had very limited knowledge prior to the symposium.

One area of the symposium that stood out to everyone was the presentation on fatigue by Dr Neil Basu. He presented past findings and current research on using MRI to pin point why people with vasculitis suffer from fatigue so badly. For me this was the most absorbing lecture of the day. Dr Basu also mentioned a potential treatment which was music to a lot of people's ears in the room, as so many diagnosed with vasculitis suffer with chronic fatigue. However research is still ongoing.

The Q&A session, at the end of the day led by Dr Peter Merkel from the USA, was brilliantly done and Dr Merkel and his colleagues answered questions with a wonderful light humour which everyone enjoyed immensely. My personal favourite quote was "I'll never get tired talking about fatigue",

All in all I found it to be a very successful, informative and fun day which I hope was shared by all.

THE THIRD ANNUAL VUK THAMES

Back in September 2014, myself (Jacqui Moran) and Karen St. Ledger, began to plan the 2015 walk. This being the 3rd VUK Thames Walk lots of ideas were discussed and notes made on how we could improve the experience of the day and raise more money.

We decided the walk had to be financially



independent of VUK so that no costs were incurred by the charity. A registration fee of £12 would just about cover the walker's pack (including t-shirt) and all the administrative costs involved in organising the event.

At the end of the 2014 walk, The Hart family and I found a little oasis called The Kitchen@Tower, attached to All Hallows by the Tower, a stone's throw from the Tower of London. We popped in as we needed a drink or two to quench our thirst. We sat in the little garden, which was quite peaceful despite being in the centre of London, and relaxed with our drinks. We mentioned to the waiter that we had just completed a 6 mile charity walk and told him about VUK. Shortly after, Sally, the Manager of The Kitchen @ Tower came out and gave us a £20.00 donation for VUK and said the drinks were complimentary.

I had an idea that maybe we could use The Kitchen @ Tower as our end meeting point for the 2015 walk where we could all gather together to celebrate our achievement. I wrote to Sally in June 2014 to ask the possibility and cost of hiring her café for the 2015 walk. I was amazed and so pleased when she offered it to us free of charge; this would really make a difference to our event!

Over the next 12 months I met with Karen regularly to re-walk parts of the route to ensure

it was still wheelchair friendly. We also had to ensure our timetable of events was viable, so that our end time corresponded with access time to The Kitchen @ Tower.

We had made sure that VUK Chairman John Mills and his wife Susan were aware of everything we were planning from the start as this was to be a VUK event and when they said they would make the trip from Derbyshire to walk with us we took the opportunity to ask John as Chairman to give a post walk talk which he agreed to do immediately.

Jacqui Moran and Karen St Ledger who organised The Thames River Walk 2015 which to date has raised over £7,500 through individual Just Giving pages and sponsorship forms, and below some of the participants.

The next thing was to get an advertisement promoting the 2015 walk to appear in the Spring Newsletter 2015, this was kindly designed by Danni Brunwin. The advert was also placed on Facebook and Health Unlocked to ensure we had as wide a coverage as possible.

Every person that contacted us was sent a walk registration form with full details about the day. We gave the option to walk 3 or 6 miles to encourage everyone to get involved.



We encouraged each walker to try and raise money for doing the walk and gave them a sponsor sheet and details on how to open a JustGiving account. But the walk was also

THE THAMES RIVER WALK - 16 MAY 2015

about patients and family and friends having the opportunity to meet so fund raising was not a condition of the registration. (Unlike some charities!) A week before the event their Walk pack including the 2015 VUK t-shirt was sent out. When the day finally arrived we had 71 people registered to walk! Nearly double from the previous year.

It was great to finally put faces to names as they registered with us at the start point. We waited for everyone to join us before heading off from Victoria Station, all in our matching t-shirts holding yellow balloons, there was a real buzz of excitement in the group. We had arranged for a Marshall to lead the walk and be the point of contact in an emergency. There were also Marshalls in the middle of the walkers and at the back for the slower walkers in the group.

It had been decided this was a better option as in previous years we had stopped every 100 Metres or so to wait for the group to re-join.

This time everyone would regroup at the half way mark (Jubilee Gardens on South Bank) where we would also register the 3 Milers. Karen and I took the tube so that we could be ready and waiting for the walkers to arrive at the



midway point. Our first group of walkers could be seen with their balloons walking along the embankment after just one hour. We waved to them as they walked towards us over the Golden Jubilee

Bridge. The rest of the walkers arrived over the course of the next 30 minutes. There were lots of smiles and laughs I think new friendships had already been made in that short time.

After a short break they then set off again for the final leg which this time took a bit longer as they had to negotiate the tourists along South Bank! And also to stop and take pictures of the wonderful London Skyline. The second half of the walk is definitely mine and Karen's favourite as you get to see so many iconic buildings along the walk. The walkers were also lucky enough to see Tower Bridge raised!

As before Karen and I had taken the tube so that we could be ready and waiting to receive our walkers at The Kitchen @ Tower. And present them with their medal and certificate. We were so proud of them all no matter whether they came in first or last they had all achieved so much by taking part and for many it was a personal achievement to show they were fighting this disease and not letting it win.

Sally the manager at the restaurant was ready and waiting with her wonderful staff to seat everyone and take their food and drink orders, it really was the perfect place to recuperate. John Mills as promised gave his post walk talk explaining how the money raised would be used in research and thanking everyone for joining us.

Karen and I would like to say a massive thank you to all those that took part in the walk and made it such an enjoyable day. And on behalf of VUK a massive thank you to those that raised money for the event.

To date the 3rd Annual VUK Thames Walk has raised £7977.58.

Jacqui Moran

If you are visiting London we highly recommend a trip to:-

The Kitchen @ Tower, Byward Street EC3R5BJ
Sally the manager has promised us free use again next year.

If you are interested in joining us for the 2016 walk please email us at
VUKthameswalk16@btinternet.com

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

Postgraduate Educational Afternoon
Imperial Vasculitis Centre, Hammersmith Hospital, Imperial College, London
Wednesday the 17th of June 2015
(Attended by Richard Eastoe)

In June Richard Eastoe attended another vasculitis education session organised by Professor Justin Mason at Imperial College in London.

Professor Charles Pusey welcomed everyone and gave a brief report on the success of the international vasculitis conference that he and Prof Alan Salama had organised in London back in April. He told us that Imperial had made one of the largest submissions of abstracts for the conference. He also mentioned the patient symposium and patient related outcomes section of the meeting at which Vasculitis UK chairman John Mills had spoken.



Professor Charles Pusey
Hammersmith Hospital
London

The first presentation was "The Assessment of Activity and Damage in ANCA Vasculitis" by Prof Raashid Luqmani from Oxford University.

Prof Luqmani discussed the immediate risks to patients due to the disease and side effects of immunosuppression. He said that relapse is a big issue in ANCA Associated Vasculitis (AAV) and that repeated flares can accumulate damage leading to greater risks for patients.

Prof Luqmani said that neuropathic and cardiovascular risks were now better recognised in AAV, particularly for Microscopic Polyangiitis (MPA). He said that the ANCA test could be useful for where the kidneys were involved but the benefits were dubious for certain disciplines such as neurology, which rarely test positive.

He went on to tell us about the Birmingham Vasculitis Activity Score (BVAS) and the Vasculitis Damage Index (VDI), BVAS is a measure of vasculitis disease activity. It can help predict patient survival with low scores indicating resistance to treatment. VDI is more important than BVAS as it documents accumulated damage. VDI is a good way to predict risks for patients.



Professor Luqmani

Prof Luqmani told us that many clinical trials now use BVAS as a measure of disease activity and response to treatment. In fact NHS England now requires monitoring of vasculitis activity via BVAS during treatment with Rituximab.

Groups such as the British Society for Rheumatology (BSR), the European League Against Rheumatism (EULAR) and the Outcome Measures in Rheumatology (OMERACT) all recommend a standardised disease assessment using BVAS, VDI as well as patient reported outcomes.

Prof Luqmani then talked about patient reported outcome measures or patient quality of life. He said

that this is diminished for AAV with many unable to work. He told us that the VDI was a useful measure of the ability to work.

There are online tools available for clinicians to train and become certified to use the BVAS and VDI measures. Certification must be renewed every 2 years. He told us that the test is not easy and requires an 85% pass for BVAS and a 75% pass for VDI. Only a third pass the certification on the first attempt.

Prof Mason asked about cardiovascular risks. Prof Luqmani thought that it was possible that AAV damages cardiac arteries which leads to cardiac events. However he was not aware of any studies to confirm this.

Prof Pusey said that NHS England also required patients on Rituximab be registered on the UKIVAS database. He felt that all patients should eventually be registered.

I asked about patient reported outcomes. Prof Luqmani told us that he was developing 25 questions that will feed into a US database along the lines of the RUDY one in the UK.

Finally Prof Pusey reported that NHS England will be funding the setup of specialist centres that will work with smaller hospitals. He said that Imperial is already happy to do this via phone or email.

We then heard Dr Philip Ind talk about "Vasculitis and the Lung". He described some of the symptoms and explained that lung involvement is very common in Granulomatosis with Polyangiitis (GPA). Dr Ind said that x-ray and particularly computerised tomography (CT) scanning was able to show nodules and "ground glass opacities". This was very useful in diagnosing lung involvement in GPA. CT shows many lesions that you can't see in x-rays but clinicians have to consider the accumulated radiation dose from repeated scans. Although he said that an x-ray was equivalent to the natural radiation you might get from taking a transatlantic flight or spending four days in Cornwall !

He said that biopsy is desirable for diagnosis but not essential and has associated risks. However imaging is very useful when monitoring disease progression and allows you to differentiate the disease from cancer. Equally, lung function tests repeated over time are useful and can predict upper airway blockages.

Dr Ind said that with repeated scanning over time you can see nodules improve, although new ones can appear in other places. He said you can even see this in patients who are relatively well under Rituximab (which can effectively shrink some types of lung lesions). Prof Pusey said he thought these patients had "grumbling" disease activity. Dr Ind said that there was a broad relationship between B cell depletion with lesion shrinkage and recurrence.

Dr Ind said he had seen two cases of lung limited GPA, which was fairly rare. Bleeding in the lungs could have a high mortality and recurrence, although blood is reasonably benign in the lung and dissipates pretty rapidly. He concluded that lung disease can commonly occur in vasculitis.

Next came a research update with Dr Tabitha Turner-Stokes from Imperial talking about "Positive ANCA Serology in Lupus Nephritis".

In 2003 lupus nephritis was redefined in six classes. Dr Turner-Stokes spoke about research that had found that patients with class IV-S lupus nephritis (with segmental lesions) were much more likely to be ANCA positive than those with class V.

She said that tissue death and crescentic glomerulonephritis (leading to loss of kidney function) were also more common in ANCA positive patients. ANCA patients had more active lupus and poorer outcomes. Their blood results showed higher creatinine levels and ds-DNA with lower C4 complements.

The conclusion was that ANCA positive patients had a different pattern of disease with different associated outcomes.

Dr Allan Kiprianos then spoke about research into "Microparticles as Potential Biomarkers for Takayasu's Arteritis".

Microparticles are small structures that are shed from cells. Dr Kiprianos spoke about microparticles released into the blood stream from endothelial cells (cells that line the interior of blood vessels). The study had shown that there were larger amounts of endothelial microparticles in patients with Takayasu's and that there were fewer after treatment.

He said they now wanted to carry out further research to assess the role of microparticles as markers for disease activity in Takayasu's.

This topic led to some very interesting discussion. Prof Matthew Pickering asked where microparticles end up - are they excreted through the kidneys? Dr Kiprianos said that no one knew at the moment. Prof Mason said that there is a huge increase in microparticles in sepsis patients and that those who have lower levels do worse. So he felt there was

probably a protective element to microparticles. Dr Ind wondered if microparticles could be loaded with drugs and used to deliver them to blood vessels and into the lungs.

After the break there was a case study by Dr Katie Bechman from Imperial.

Dr Bechman described a complicated case of large vessel vasculitis in a 30 year old lady. The patient had improved with treatment but then relapsed with severe cardiac problems. Following more treatment she stabilised and had an aortic valve replacement leading to some improvement. But subsequent MRA scans showed further constrictions to the arteries in her neck and kidneys as well as increased risk of aortic problems.

Dr Bechman's conclusion was that patients with large vessel disease require regular monitoring and scanning. Patients may require long term renal angioplasty to relieve blockages and protect kidney function. Problems with the heart are a major risk with Takayasu's so immunosuppression and conventional cardiac treatment is recommended. Where possible, surgical intervention should only be done when the disease is quiescent.

This was another interesting session at Imperial and for me it was one of the first times I've heard much said about vasculitis and the lungs. In the break Prof Pusey told me that this was one reason they had asked Dr Ind to speak. The talk about microparticles was also very interesting, although very technical. But it created some considerable discussion amongst the group and struck me as something to watch out for more research on.

As always it was a privilege to attend this event and to hear presentations by some of the UK's leading vasculitis specialists.



Hammersmith Hospital



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*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.

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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



Patient Engagement and Education Evening Lupus and Vasculitis Royal Free Hospital, London Monday 6th July 2015 6-8pm

The event was held in the Sheila Sherlock Centre at the Royal Free hospital. The attendance by interested patients was very good with over 80 people coming, we even had standing room only.

The event was opened with introductions from Dr Sally Hamour and everyone was made welcome.

Dr Aine Burns next took up the podium and spoke about how treatments for Lupus and Vasculitis had changed over the last 20 years with great advantages from new medications such as Retuximab coming to the fore. When we look back to the 1950's survival rates for vasculitis patients was very poor but today most patients reach remission to some degree and live a normal life. Some, however, do have recurring relapses but these are becoming fewer and fewer in number as treatments are modified to suit each patient with the emphasis being "Treat, but cause no harm." So the minimum dosage necessary is applied in each case. She also spoke about some of the contraindications of these medications, in particular that of Cyclophosphamide, Prednisolone (oral) and Methylprednisolone (I.V.) but that it was deemed that in using these the benefits gained far outweighed the other negative factors. She then spoke about the new drug Retuximab and how this was very effective in treating vasculitis and other auto-immune diseases.

Professor Alan Salama then spoke about new research and trials in lupus and vasculitis and how they would benefit patients. The Royal Free hospital has done much research itself and together with Great Ormond Street and Imperial College work closely with each other in this.



In particular he mentioned that with the standard initial treatment of Cyclophosphamide and steroids, while good at halting the onset of the disease and followed up with a maintenance with immunosuppressants such as MMF or Azathioprine was in most cases sufficient, it was with the introduction of the new biologic drugs such as Retuximab better response from treatment came about. Initially the trials involved using both Cyclophosphamide and Retuximab together with Steroids and most patients responded well initially but over the long term quite a few had relapses. This concerned the doctors and the treatment was modified so much so that today is

primarily done using Cyclophosphamide and Retuximab alone without use of steroids. This increased the amount of patients staying in remission over the long term. Today, research is also being done in paediatrics with the youngest patient at the Royal Free being just 8 years old!

Much humour was generated in the audience as Professor Caroline Ashley introduced the role of the specialist pharmacist in the treatment of patients with lupus and vasculitis. She spoke of the interactions of medications and alternative remedies and how most of the drugs we use today are derived from plants and fungi. In fact she said that in her garden she grew plants that could kill you. Please come around for tea.

She invited questions from the audience and also said that she was always available to answer queries from patients at the hospital. Just give her two or three weeks notice!

Next to speak was Dr Christine Hanson. She related the role of the clinical psychologist in the treatment of patients and how they helped patients overcome phobias such as needles and the worry and fear of having such diseases. She also spoke about how she and her colleagues could help patients cope better during the onset of the disease and treatments.

A short refreshment break followed and the meeting continued with a discussion on Patient perspectives: questions from the Kidney team to the audience. The clinical team referred to the work that Vasculitis UK did and also to support groups such as The London Vasculitis Support Group.

This was followed by questions from the floor and a lively Q&A session followed. The meeting over ran the 8pm finish and closed at 8:30 instead with Dr Sally Hamour rounding up the night's event.

All in all, as a first time event, it was very well received by all and it is intended to repeat these in the future.

Footnote.

All the VUK's booklets and newsletters were taken up during the refreshment break (we could have used more) as was the London VSG's pamphlets.

Comments received from others so far:-

"I was very impressed by the meeting last night, surprised a bit that there were so many people there! I was also very glad to hear about your organization, so thank you for setting it up! I think my daughter managed to spot the Vasculitis UK spot at some point."

"Definitely was nice to be on a room with nearly 100 people going through the same things as you and one person after come to me for advice so at least I've helped one person and maybe more by mentioning what I did so that's the most important thing and to feel a sense of we are all uniting together to move forward with this. Definitely wouldn't mind going to another one."

A good night! Can't wait for the next one.

Written and attended by David Newman organiser of the North London Vasculitis Support group.

Welcome to our new trustee and new treasurer

I am Jennifer Fulford-Brown, I was born in 1947, and was diagnosed with Churg Strauss Syndrome (EGPA) 12 years ago and consider myself fortunate to continue as a patient at Addenbrookes, Cambridge paid for by the Welsh NHS.



*Jenny Fulford Brown
elected trustee of
VUK May 2015.*

My working life has been split between business and charity work. My current businesses include property development, public relations and marketing. On the charitable side, I worked for Relate, latterly providing couples with specialist therapy, my thesis explored the effect pain has on relationships.

In recent years, since moving to Wales, I have been involved in various meetings about improving the Welsh National Health Service. I also took over the Vasculitis support group in Cardiff, having set up the support group in Cambridge.

I enjoy gardening, and belong to an organic gardening club. I am a volunteer at Cardiff Castle. My partner and I have a caravan and travel abroad. We have 3 sons and 4 grand-daughters.

I am Richard and 42 years old.

I live in Worthing, West Sussex and am proud to be Treasurer of Vasculitis UK.

I first contacted Vasculitis UK in 2012 having been diagnosed with GPA, quite frightened and unsure what this meant for me and my family and what we had in front of us. The invaluable help and support I received then and to this day is the reason I wanted to be part of the team. Having spent 20 years in the accounting profession it wasn't until my diagnosis and treatment that I decided to start my own accounting company. Vasculitis did change my life in many ways but this has been one of the best decisions I have made; it is now an honour to help and support in any way I can.



*Richard Remorino
VUK Treasurer*

I personally enjoy all sports, including skiing, running and being an Everton Football Club season ticket holder. However all of these are second to my children and family.

Book Reviews

Vasculitis in Clinical Practice. (2nd edition) Pub. Springer International 2015

Richard A.Watts; (Ipswich) :David G.I.Scott & Chetan Mukhtyar. (Norfolk & Norwich)

Publication of the first edition of this book in 2010, was most timely for the fledgling charity, Vasculitis UK. We were just embarking on the development of the Vasculitis Routemap – and we didn't know where to start. The available books on vasculitis at that time were very academic, very dry – and very large and expensive! **This** book was an eye-opener. Clear, concise, well set out and illustrated. Aimed primarily at doctors and other health professionals in hospitals it was written in clear plain English that was accessible to most people with moderate understanding of medical terms. Not only that, but it is under 200 pages, pocket sized and under £30.

In addition to introductory chapters on classification, presentation and diagnosis and general treatment principles, there are 13 chapters on individual types of vasculitis, with valuable chapters on secondary vasculitis and vasculitis mimics.

Chetan Mukhtyar has joined David Scott and Richard Watts in this new 220 page revised edition, which is updated to reflect the new nomenclature of the diseases and includes details of treatment with rituximab. There is an additional chapter on IgG4, a newly identified

fibro-inflammatory auto-immune disease.

If you want a compact comprehensive and understandable book on vasculitis without paying a fortune, this can be yours for £43 if you shop around.

Textbook of Clinical Vasculitis. (1st edition) Pub. Jaypee Brothers Ltd 2015

Editor: Aman Sharma, Chandigarh, India.

This 420 page hardbacked textbook is remarkably good value at £37 from www.alibris.co.uk

Although it is a medical textbook it is very readable for anyone with a reasonable understanding of medical terminology. Unlike most medical textbooks, it could almost be bedtime reading for an enthusiast. Professor Sharma is both editor and co-author of several chapters. As one might expect, most of the contributors are from India, but there is a liberal sprinkling of names familiar to us in the UK – David Jayne, Paul Bacon, Justin Mason, Richard Watts, David Scott, Chetan Mukhtyar, Mark Little and several others from Europe and the US.

The layout is pleasing, well ordered, not crowded and the illustrations are many and of excellent quality. If you have a serious interest in all types and aspects of vasculitis and you can only afford one book, this book is an absolute must.

To tattoo or not to tattoo

In the online discussion groups, we get questions from people with vasculitis about the advisability of tattoos and alternative therapies. Of course, I'm an old and out of touch fuddy-duddy, so I have some difficulty with the current fashion for piercings and tattoos. To me, tattoos were simple, crudely drawn pictures of anchors and scantily clad girls that sailors and sometimes soldiers brought back from "The War", not the elaborate artworks that young (and even older) people have on their torsos, limbs and elsewhere.

However, if you have an auto-immune disease, your immune system is misbehaving and it needs to be suppressed, thereby leaving you open to infection by a variety of routes.

Infection is the commonest cause of death among people with vasculitis, so why gamble by having an unnecessary procedure that breaches the protective layers of the skin and has the potential to allow numerous unknown bacteria and viruses in to challenge your rather wonky immune system.

When you have any illness, it is important to have a healthy balanced diet. On the other hand, some people are keen to promote diets and alternative medications that are intended to "boost the immune system". Whether or not they work is open to conjecture, but it does seem contradictory to take pills to suppress the immune system whilst at the same time taking other pills, or eating a special diet, intended to boost it.

Chronic pain- What can I do to help myself?

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

The booklet covers many topics to help you understand your pain, covering issues such as how it is assessed and how to manage your pain, including complementary medicines. You can view the booklet at: www.vasculitis.org.uk/living-with-vasculitis/dealing-with-pain



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

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

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

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

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

Take medication regularly: To achieve good pain control, it is usually important that you take your medication every day, as guided by your healthcare professional, even if your pain doesn't feel as bad.

You should not change the dose of the medication or when you take it until you have discussed this with your healthcare professional.

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

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

Prednisolone predisposes us to weight gain, fluid retention, diabetes and redistribution of fat. Excess weight puts strain on already sore joints. Auto immune/ inflammatory disease isn't good for the cardiovascular system as the heart doesn't like inflammation. But there are a number of things we can all do to help ourselves by improving our diet.

Cut out sweet and fizzy drinks which are empty calories, and fruit juices are very high in sugar as well. Instead drink water, herbal teas or make your own flavoured waters. Fill a jug or pint glass with water and add fruit or veg, nice combinations include cucumber and mint, lemon and ginger, strawberry and kiwi, pineapple or watermelon.

Eat less meat and more veg or starchy carbohydrate like beans and pulses. Designate 1 or 2 days to be meat free. Add finely chopped veg (eg carrots, celery, aubergine, courgettes etc) to dishes like spaghetti bolognese to up the veg content and make the meat go further. Put a tin of chick peas as well as kidney beans in chilli.

Home made soups are tasty, filling and relatively low in calories, and most veg can be made into soup. Use in season veg to cut costs and look out for offers (eg Aldi super 6). Nice soup combinations are roast red pepper and tomato, carrot and celeriac, lentil and vegetable (carrot, turnip, potato and leek) and butternut squash, ginger and apple. Make a big pot and freeze leftovers.

Don't forget eggs, they are relatively cheap and a good source of protein. Spanish tortilla is a great way of using up any bits and pieces of veg eg onion, potatoes, cabbage, mushrooms, carrots, courgettes etc. Par boil the potatoes and cut them into slices, fry in a little oil with onions and then add any leftover veg. Whisk 4 to 6 eggs and pour over veg in frying pan. Cook the top

under a hot grill and serve warm or cold with salad. Leftovers make a great packed lunch.

Watch your sugar intake as it has no nutritional value and too much sugar leads to obesity. Purge your cupboards of sweets, biscuits and chocolate so you won't be tempted. When baking cut the amount of sugar in recipes, for example if the recipe calls for 4 oz of sugar use 3 oz. It doesn't affect the quality of the finished article and you won't notice any difference in taste! Snack on almonds, seeds and keep ready cut veggie sticks in the fridge. Substitute flavoured, sweetened yoghurts with plain yoghurt (Greek is particularly nice) and add fresh fruit to sweeten. It's also a good source of protein and calcium, I did this recently and I quickly got used to the taste.

Think about incorporating anti inflammatory foods such as ginger and turmeric into your diet; they taste good as well.

Above all enjoy what you are eating. a little bit but

not too much of what we fancy does no harm. I love cake and bake every week, a small piece of home made cake most days is my daily treat. Everything in moderation, no point in worrying about the nutritional value of every little thing that we eat. You also don't need a lot of expensive cook books, there are lots of recipes available on line or in magazines. My favourites are Deliciously Ella (gluten, dairy, egg and meat free), BBC Good Food magazine website and A girl named Jack for cheap, nutritious recipes. If you are a member of Facebook then join us in the Vasculitis Healthy Eaters group where we share recipes and post food related topics.

Lynn Laidlaw

Vasculitis and diet

Some great tips on good eating



All Vasculitis sufferers know it is a long-term condition. They also know that whatever their Vasculitis condition it can have a substantial impact on the quality of their lives. Vasculitis can affect every aspect of a person's life: from performing every day activities to getting a good night's sleep, it can influence the work you can do and it can dictate your social activities.

Like other conditions, early diagnosis of Vasculitis improves the quality of life for both us patients and our family. However, the many of the different types of Vasculitis diseases are difficult to diagnose as they share symptoms with other common disorders. Many patients do not receive a diagnosis or are misdiagnosed. Vasculitis patients experience is one they share with other rare condition. A Rare Disease UK (2010) report, highlights that of patients with a rare condition, including Vasculitis:

- 30% of patients received more than three incorrect diagnoses;
- One in five waited longer than five years for a correct diagnosis;
- 52% felt they did not receive enough information on their condition after being diagnosed.

How is Vasculitis UK working to change the situation in Vasculitis often find themselves? Hopefully, the activities our members and us are undertaking throughout the year are helping to raise awareness of our condition. A runner wearing one of our T-shirts or vests and a stall with Vasculitis UK goods on offer or just putting a few leaflets in your local surgery or consultants waiting room all go to promote a greater awareness. However, during May Vasculitis UK joined with other Vasculitis charities, both within the UK and USA, to promote awareness. Using social media, a poster campaign, the support of Vasculitis UK members and their families with various events and of course word of mouth we work to improve knowledge about our condition both with the public but also with the medical profession.

This year our message was "What do these people have in common". One of our Trustees, Danni Brunwin, produced a series of thought provoking posters. Many thanks to Danni for all her efforts. Perhaps you had seen one of these posters on display in your local hospital. If not we still have some available.

" Vasculitis UK would also like to say a special thank



you to Kelly Jefferies for contributing a "fact a day" about Vasculitis for all of Vasculitis Awareness Month in May"

It is not too early to think about next year's campaign. So if you have any suggestions for this year's theme, something you think will resonate with other Vasculitis patients and their families e-mail me at secretary@vasculitis.org.uk

London 10K 2015



This was my first year organising the event for Vasculitis UK, taking over from the incredible "Team Mills".

When I first put the notice on Facebook and The Vasculitis UK website, I thought it will be ages before I would receive any response. Within hours I had 12 out of 18 signed up. There were two main groups; the Loughborough contingent led by Martin Makin and the London group led by Annouska Bowtell. Martin has GPA, but can't stop running.

There were also several individuals and many family groups all with their reasons for supporting Vasculitis UK. The last 6 places were harder to fill, but we got there. Getting the registration forms back from some of those taking part was certainly a struggle, you know who you are! Then with the help of Talie Hewitt, I managed to get the race packs out, well she did!

Martin wanted everyone to meet before the start for a group photo and various emails later it was organised. We had 17 entrants, in the end, as someone injured their foot.

These were Martin Makin, Andrea Makin, Roger Clarke, Peter Le Rossignal, Craig Sharp, Amy Waller, Rebecca Waller, Jo King, Kristina King, Adam Whalley, Alexis Pope, Natasha Hadfield, Duncan Bowtell, Annouska Bowtell, Zoe Tansey, Steve Griffiths and Ebenzer Lawson.



A big thank you to all those who ran for us this year, next year we only have 12 places so be quick to respond.

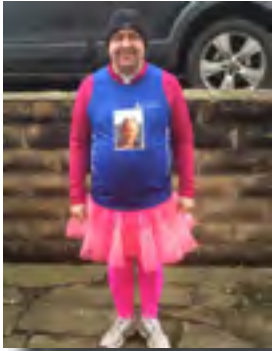


Dorothy Ireland

Joanna King, after the London 10k, with Mum who has Vasculitis

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

More of Our Fantastic Fundraisers



Samuel McMahon taking part in the Huddersfield 10k in memory of his father Keith. Samuel has raised over £1400 for VUK. Keith sadly lost his life to Vasculitis, August 2014. He was 61 years old



Susan Mills raising awareness and fundraising at Winster Carnival Summer 2015



Faye has taken part in 8 half Marathons for VUK this year and raised over £1000. Faye's son has Vasculitis.



Jackie Peck has WG, diagnosed 5 years ago, she cycled The Wiltshire Big Wheel and raised over £1200.



David swam the Henley Classic for VUK, his son Dan has WG (GPA) This is the second year Dave has taken part in this event. He has raised over £750 this year.



The OsterByrnes, Mike, Bernadette, Louis, Jack, Keiran, Erin and Olivia.



Bob Williams "Toastmaster" and "Ladies who Lunch" raised over £1000 for VUK.



Natalie Mouldsdale and her Mum Jackie Mouldsdale have been fundraising for Vasculitis UK for three years now. In memory of Natalie's dad, Jackie's husband Neale. Up to date they have raised over £4000



Amelia aged 7, with her medal after the 2k mud obstacle, Nuclear Rookies race, in May for her Uncle Paul



Andy Willows Football Day has now raised over £420

Tali Hewitt (Fundraising Volunteer) held a cake sale on Sunday 30th August and raised £165 for Vasculitis UK



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

Research Report

The trustees of Vasculitis UK were very conscious that there was no clearly defined research strategy or formal process for advertising and awarding research grants, so there was a need to make it more competitive and transparent. Setting this up proved more complex we expected, but we were fortunate in recruiting Mike Patnick to take charge of Research Governance. Mikes previous experience working with Arthritis Research UK proved to be invaluable. (See Newsletter, Autumn 2014).

After much preliminary work in drawing up the necessary policies and procedures and setting up a Scientific Advisory Board (SAB), a "call" for applications for research funding was launched in November 2014 among the UK vasculitis community of clinical and scientific researchers. The trustees agreed a total budget of £150,000 with no single grant to exceed £50,000. By the closing date of 31st January, ten applications had been received, totalling £386,000

Each of these applications was then sent to three independent reviewers for assessment. In the small world of vasculitis, finding 30 experts with no connection with any of the applicants or the institutions involved was challenging and involved finding suitable experts from Europe, the US and Canada. All 30 assessments were then reviewed by the SAB at a meeting convened in London at the end of the International Vasculitis 2015 Conference.

The Scientific Advisory Board is chaired by Professor David Scott and comprises Drs David Jayne and Richard Watts, with Vuk trustees, Jane Elsom, Mike Patnick and John Mills. On this occasion, Professor Paul Bacon replaced Dr Watts who was involved in one of the applications. The decisions of the SAB were guided by the results of a survey of Research Priorities carried out among Vuk members under the direction of Dr Janice Mooney.

All the applications were of a high standard of relevance and quality, making decisions very difficult. After much discussion, the SAB agreed that five applications totalling £155,000 should be recommended to the trustees for approval. This was agreed by trustees. The five approved applications are listed below. For greater detail please consult the website:- www.vasculitis.org.uk/research/funded-research

- 1) Dr Clare Pain & Prof. Michael Beresford; University of Liverpool.
British Paediatric Surveillance Unit study on Behçets syndrome in children and young people in the UK, £10,000 over three years
- 2) Dr Richard Watts & Dr Janice Mooney; University of East Anglia.
A study to investigate "The informational needs of carers of people with ANCA Associated Vasculitis".
£19,477 over one year.
- 3) Dr Sarah Mackie & Dr Emma Harris; University of Leeds
An investigation into the "Management of fatigue in large vessel vasculitis and its overlaps". £30,000 over 18 months.
- 4) Prof. Richard Hubbard & Dr Fiona Pearce; University of Nottingham.
"Improving early diagnosis of Granulomatosis with Polyangiitis (GPA/Wegener's) in primary care: development of a risk prediction model.
£48,000 over one year.
- 5) Stephen McAdoo, Dr Ivor Kwame; Imperial College, London.
SYK (spleen tyrokinase) as a novel therapeutic target in systemic ANCA associated vasculitis.
£48,000 over one year.

For more details of these and other projects see the Vuk website under "Research"

More 'Thank You's



Big Thanks to Antony, Sally and the Hart family of Gryphon Harvester, London for fundraising, representing and supporting Vasculitis UK over the last few years. All the trustees wish them all the best for the future.



Clare Witch and George pictured on the left have raised over £800 Fundraising Gig and joint hair shave for VUK. Clare's mum was diagnosed with Vasculitis in July of this year.



In Memoriam

Vasculitis UK receives donations from bequests and funeral collections in memory of particular individuals who have suffered from vasculitis, or where vasculitis affects a family member. Our sympathies are extended to the families and friends of those mentioned below.



The Trust is extremely grateful for families remembering us in this kind and generous manner. All donations received will be used to fund activities of the Trust, especially our research projects.

Gerald Barnham kindly donated £500 in memory of his late wife **Margaret Lilian Barnham**, who passed away on 30th March 2005, aged 52.

Paul French, aged 69, passed away suddenly on the 20th September 2014. He was diagnosed with Vasculitis just 10 days prior to his death. A wonderful husband to Pat for 45 years, loving Dad to Tina & Maria, 'super hero' Grandad to Leah, Holly & Taya and loving brother to Susan. A total of £6,297 has been donated to Vasculitis UK in the past 12 months from Paul's family and friends

Kirit Patel very sadly passed away July 2014, aged 21 years old, shortly after being diagnosed with Churg Strauss Syndrome (EGPA). A keen poker player, his many friends described him as a true gentleman, always polite and well mannered and very good company. Kirit's family and friends have donated £1852.50 to Vasculitis UK, this last year, in his memory.

Lydia Moxley passed away on 2nd April a Donation of £100 was given in her memory.

Charles Joyce passed away on 9th May a Donation of £50 was given in his memory.

Barbara Evans, very sadly passed away 19th February 2015 from complications of vasculitis. **Barbara** was a much loved wife, mother, grandma, great grandma, auntie and friend to many and will be greatly missed by all. Family and friends very kindly donated £260.

Mrs Norma Mackness of Leicester, passed away 23rd June. Donations totalling £320 were given in her memory.

Donations totalling £492 in memory of the late **Elizabeth Mary Williams** after a very long battle with Polyarteritis Nodosa.

The Football Day in memory of the late **Andy Willows** raised £260 for Vasculitis UK and The "Rowdy Boyz" of Ormonde Fields Golf Club at Codnor raised £420 also in memory of **Andy**. This includes £100 each from sponsors, Plantscape Ltd of Hulland Village and Firth Rixson of Darley Dale.

Donations of £67 were received in memory of **Trevor Hudson** of Boston Spa, near York.

A bequest of £1000 was received from the estate of the late **Mr Brian Hunt** of Wootton Bassett, Wilts

Donations & Fundraising

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

Vasculitis UK was nominated to receive a donation of £75 from Buckingham Charity Cup Competition.

The J Paul Getty Jnr Trust kindly donated £1000 to Vasculitis UK

The staff of CABA (The Chartered Accountants' Benevolent Association) kindly donated £500, this being the proceeds of their "charity snack box".

The employees of SSP Ltd, Halifax, held a charity event which raised £136 for Vasculitis UK.

The congregation of the Church of the Holy Family in Failsworth, Manchester, kindly donated £202 to Vasculitis UK.

Thanks to Winster village shop for all their support this last year. Over £100, for 2015 has been collected in the collection box they have on the counter.

Donations of £300 were received in memory of John Higson of Oldham.

The funeral collection for Mr R Sherburn of Manor Farm, Eastington, East Yorkshire resulted in donations in support of Vasculitis UK totalling £541.

At their Autumn meeting, Vasculitis Support Group West Midlands donated £100 to Vasculitis UK.

A donation of £35 from Buckingham Charity Football Club

A donation of £103 from Hannah Patterson following her fundraising for Vuk

Mr & Mrs Dave Griffiths of Crewe celebrated their Ruby Wedding Anniversary and requested donations to Vasculitis UK in lieu of gifts. This raised £245.

Laura Challoner raised £205 in a Parachute Skydive on 8th August.

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.



Pat Fearnside

Sadly, Vasculitis UK lost one of its most energetic and enthusiastic trustees and supporters in June this year, when Pat Fearnside passed away after a short but unpleasant fight with a rare form of cancer.

Pat joined Vasculitis UK as a trustee in June 2010, having been diagnosed with WG in 2003. Until her retirement due to ill health, Pat had worked for the National Coal Board as an administrator in the NCB Occupational Health Radiography Department, monitoring miners for the effects of pneumoconiosis (miners' lung disease).

In her leisure time she was a Line Dancing instructor and caller, editing the Line Dancing magazine. This, combined with her clerical and administrative experience, meant she was the ideal candidate to be the Vasculitis UK newsletter editor. She soon rose to the challenge, learning new desktop publishing skills. Her first edition, in Autumn 2009, was in the same style as previous editions, but she was not satisfied and set out to improve it. The first glossy full colour newsletter was published in Spring 2011, setting a new standard for the future with stylish layout and photographs.

At this time, Vasculitis UK was also embarking on the "Routemap for Vasculitis" project. Pat embraced the challenges of this ambitious project and it was thanks mainly to her energy and dedication that the Routemap was eventually published in May 2012. It was a ground-breaking professional looking document, full of comprehensive medical and more general information. It rapidly acquired acclaim amongst both patients and medical professionals, greatly enhancing the reputation and status of Vasculitis UK.



Patricia Fearnside receiving an award on behalf of Vasculitis UK at the Genetic Alliance UK headquarters for the Rare Disease UK awards ceremony for Rare Diseases 2012 - for the publication of the "Route Map for Vasculitis"



Following the overwhelming success of the Routemap, attention turned to a major redevelopment of the very inadequate website that had been inherited from the Stuart Strange Vasculitis Trust. Once again, Pat rose to the challenge, working with website developer Paul Townend and acquiring yet more skills in IT. The new website went live in September 2012. The result was an impressive source of reliable information about vasculitis that was available to anyone who has access to the internet. Today, almost a thousand people from around the world visit www.vasculitis.org.uk every day.

As if this was not enough, in addition to these responsibilities, when Vasculitis UK was desperate for a new treasurer in 2011, Pat took on the onerous task of being treasurer for a rapidly growing and developing charity. In recognition of her essential role in the development of Vasculitis UK, the trustees elected Pat to be Honorary Vice-President, alongside our Honorary Life President, Lillian Strange.

Pat led an active life despite the restrictions imposed by WG. She lived alone apart from her pets, Merlin the dog and Peter the parakeet. She was devoted to both.

Pat became unwell in spring of this year, but kept this very much to herself. The serious extent of her cancer only became apparent to others in May, shortly before she passed away.

For Vasculitis UK, Pat Fearnside will be very hard to replace.

John Mills – Chairman.



Patricia, Dr Richard Watts and John - Vasculitis UK AGM 2011



Jann, Pat, John, Jenny and Colin at the South Yorkshire Vasculitis Support Group Meeting 2012 - Jenny, Jann and Colin were very supportive to Pat when she ran the South Yorkshire support group. But sadly VUK have now lost both Pat and Colin.

New Carers Support Group - Lisa Pearce

At the recent Vasculitis UK Patient Symposium held in London in April, the spouse, of one of our members, suggested that a carers' group was required within the umbrella of Vasculitis UK. The aim of this group would be to ensure that information, advice, practical and emotional support were available to partners and the families of those unpaid carers of Vasculitis patients, across the UK.

Generally, one can find a carers' group just by searching on Google or perhaps within a local directory but these generic services cater for those unpaid carers of patients with a variety of diseases and illness. However, with a rare and complex group of disease like vasculitis, we felt there was the need for a specific type of caring group.

Lisa Pearce is the wife of one of our own members, David Pearce. David has Granulomatosis with Polyangiitis and has been in and out of remission with this disease for 15 years. Lisa arranged the first meeting of our carers' group and has offered to help Vasculitis UK in organising future meetings. She said, at times, life has been very difficult for them both, especially for her as David's carer. Other carer groups which she joined just didn't understand the complexities of vasculitis and the stress and strains it had put on their marriage.

The first meeting was held on the 2nd August in Suffolk. A small number gathered for lunch to meet one another and discuss all type of issues and concerns. The meeting was very successful.

The next new "Carers" group in Meriden, Coventry, is having its inaugural meeting on 28th November, 2015. This informal meeting, with food, will take place at Berryfields Farm Shop, Meriden, Coventry. Afternoon tea there at 2pm. The cost of the afternoon tea is £10 for two. Carers and patient are also welcome together, there will be an opportunity to separate to eat and talk during the afternoon tea, then afterwards meet up again before saying our goodbyes and discuss how useful our discussions were.

Dr Richard Watts, Consultant Rheumatologist from Ipswich Hospital will be attending this meeting. Dr Watts is currently carrying out research, along with Dr Janice Mooney, for the informational needs for carers who care for those diagnosed with ANCA Associated Vasculitis. This 12 month study is being funded by Vasculitis UK. Please do come along to this meeting,

not only to support Lisa but to support research too. Berryfields Farm Shop (<http://www.berryfieldsfarmshop.co.uk/>)

The group meeting venues are based on numbers attending and their individual locations. Lisa tries to organise the meetings in venues central to all attendees. This new group is for carers and carers with patients, not patients alone who have vasculitis. If you are a carer of a vasculitis patient and you would like to join the group, then, please call Lisa on 01652 678848 Lisa@vasculitis.org.uk



Financial Report

Our late treasurer Pat Fearnside usually wrote a report on the past year's accounts. Before she died, she was able to complete the accounts to the year end and send them for audit. We are once again extremely grateful to our auditor, Duncan Cochrane Dyett, for carrying out a rigorous audit and providing a comprehensive and comprehensible report. The full annual trustees' report and audited accounts can be found on the Vuk website; www.vasculitis.org.uk/about/accounts and on the Charity Commission's website. Below is the headline summary.

	2015	2014
Income	£206,000	£168,000
Expenditure	£ 67,000	£84,000
Reserves	£363,000	£224,000

Notes:

- 1) The charity is committed to keeping sufficient reserves to support all pre-committed expenditure, in addition to the running costs for a year. Thus no new commitments are taken on unless there are reserves to match them..
- 2) During this period a budget of £150,000 was allocated to fund research grants. Most of this will be spent during financial year 2015-2016.
- 3) If reserves permit, there may be a budget allocated for a further round of research funding grants in the financial year 2015 - 2016.

Arthritis and Connective Tissue Patient Conference

On the 16th September, John and Susan Mills, on behalf of Vasculitis UK, attended the 9th Arthritis and Connective Tissue Patient Conference at Portsmouth Hospital.

Topics covered on the day were Inflammatory Arthritis, Ankylosing Spondylitis, Psoriatic Arthritis, and Connective Tissue Disease. (Vasculitis, Scleroderma, Raynaud's, Sjogens and Lupus.)

Also discussed and covered were Fatigue Management, Pain Management, Gout, Understanding Medication, Exercise, Foot and ankle problems and pain,

Behind Closed Doors (personal and emotional problems), for Carers, there were drop in sessions Support and relaxation. It was an extremely interesting and informative day.



Susan Mills

MERRY CHRISTMAS

Christmas is fast approaching, and this year we are going to sell two Christmas card designs, with all profits going to Vasculitis UK. They will come in packs of 5 single designs at £2 each or packs of 10 mixed for £3.50 each. (Postage is extra)



They have been designed by hand with pencil and paint by Lucy Riveiros, the shop coordinator, especially for this year's cards.

Email lucy@vasculitis.org.uk for orders and postage discounts when ordering large amounts, or see www.vasculitis.org.uk/shop for more details.

Get in touch with your local Vasculitis Support Groups

Beds, Bucks & Herts

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

Cambridge

Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

Canterbury area **

Margaret McGrath - 01227 638469 - margaretmcgrathfmsj@yahoo.com

East Kent **

Brian Hart - 01227 369774

East Midlands

Dorothy Ireland - 01332 601303 - irelanddot@hotmail.com

Lisa Ranyell - 01664 857532 - lisa.ranyell@ntlworld.com

Susan Mills - 01629 650549 - sandjmills@btinternet.com

Edinburgh, Lothian & Central **

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

Essex

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

Glasgow **

Patricia Henderson - 0141 581 1711

Ireland - Vasculitis Awareness Ireland

Julie Power - 028 44 842889 - vasculitisireland10@gmail.com

Lancashire/North West

Jann Landles - 07979 180145 - nwvasculitis@hotmail.co.uk

Anita Parekh - 07921 682232 - nwvasculitis@hotmail.co.uk

Leicester NEW GROUP

Tricia Cornforth lvsg@btinternet.com

Lincolnshire

Sandra Lee - 0754 514 4777 - sandralee_506@famail.net

Caroline Meyrick - 01780 460354 - cmmeyrick@gmail.com

London Support Group - North London

Dave Newman - 07429137670-david.newman@londonvsg.org.uk

London - South East/North West Kent

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

Merseyside, Cheshire and N. Wales

Susan Chance - 01244 381680 - susanchance53@icloud.com

Dave Birch - 01517229049/07968226230 davebirch@talktalk.net

North Wales **

Pat Vernalls - 01766 770546 - patvernalls@btinternet.com

North East (Cumbria) **

Martin Thomas - 07765 888987 - nwukvsg@gmail.com

Rebecca Winlo - rebecca.winlo@gmail.com

Oxfordshire

Sue Ashdown - 01295 816841 - oxfordvsg@hotmail.com

Republic of Ireland **

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

Solent - Portsmouth

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

South Wales

Jenny Fulford-Brown-029-2021-8795- jenny.swvas@gmail.com

Surrey : Contact position vacant

West Midlands

David Sambrook - davsamuk@yahoo.co.uk

Margaret Gentle-0121 2435621 - mgvsgwm@blueyonder.co.uk

West Country <https://vasculitiswest.wordpress.com/>

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

West Sussex

John Bailey - 07752 122926 - johnbee4@googlemail.com

Yorkshire website www.yorkshirevasculitis.org.uk/

North Yorkshire

Richard Eastoe-01423520599-richard@yorkshirevasculitis.org.uk

Lynne Jacques-01274 412378-lynne@yorkshirevasculitis.org.uk

York, North & East Ridings

Richard Eastoe-01423520599-richard@yorkshirevasculitis.org.uk

Jennifer Wormald - 01937 586734 - e-mail jennifer@yorkshirevasculitis.org.uk

Yorkshire (North/West)

Lynne Jacques 01274 412378 - lynne@yorkshirevasculitis.org.uk

The Ring : support group in Norfolk for RA patients

Judith Virgo - jvirgo@fsmail.net

** Contact person - not a Group

LIFE PRESIDENT - LILLIAN STRANGE

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

The main aims of the Trust are:

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

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

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

Officers, Trustees and Volunteers

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john.mills@vasculitis.org.uk

VICE-CHAIRMAN:

Mike Patnick

Hon Secretary:

Jann Landles
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Medical Advisors:

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

Trustees:

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