



VASCULITIS UK

Newsletter & Journal

Spring 2013
Issue No. 45

What's inside?

All ANCA aren't equal in vasculitis

Infection in people with vasculitis

Vasculitis and the ear

Vasculitis Masterclass

Urticarial vasculitis

A day at Imperial College, London

Interview with

Renal Patient *View*



CHAIRMAN'S REPORT - SPRING 2013

Vasculitis is a rare disease, consequently we vasculitis sufferers are rather thin on the ground. It is not unusual for people to go for years without meeting or speaking to someone else who shares their experiences. So I like to think that when someone contacts Vasculitis UK directly or through the Facebook and HealthUnlocked discussion groups, they are being welcomed into a friendly extended family, where they can talk freely about their vasculitis problems and maybe learn from others.

In addition, this Vasculitis UK newsletter helps to keep members informed about new developments in the vasculitis world. However this is no substitute for face to face contact so we encourage the formation of independent local support groups around the country.

“Through Vasculitis UK you are represented on influential organisations in the vasculitis and healthcare world”

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The “family” offers other advantages. As individual sufferers, we don't have much of a voice, but when united under the Vasculitis UK banner, our voice is much, much louder. “Together we're stronger”, as it says on the Vuk website! So, through Vuk, you are represented on influential organisations in the vasculitis and healthcare world, such as the Vasculitis Rare Disease Group, The UK and Ireland Vasculitis Study Group, Rare Disease UK, The British Society of Rheumatologists, NICE etc.

Instead of standing on the outside, this is working inside the system, where we are able to talk to the doctors and the policymakers and have influence.

So this is being “political” in the small world of vasculitis. Then there is the bigger world of healthcare, the NHS and the social security system. It is difficult to avoid being big-P “Political” about issues that impinge on the lives of so many people with vasculitis.

Some of us are fortunate in being able to go back to work (or like me, being retired) but many of our

members struggle with disabilities brought on by vasculitis, not to mention the fatigue that makes them unreliable as employees in what is already a shrinking job market. For many, just coping with vasculitis is a challenge.

It doesn't matter whether the Government is Labour, Conservative or Coalition, when money gets tight, those who are disabled and chronically ill and dependant on the State to provide a living, are an easy target. We know, we get the phone calls from people in tears because their benefits have been summarily cut off.

NHS reform is another great experimental leap into the unknown. We all know there's a lot of scope for improvement and some unforgiveable examples of total lack of caring principles. But will private companies do a better job? I don't know, but I'm inclined to think that changing the system we already know, working from the inside, is better than throwing it all out and re-inventing the wheel.

Your views are greatly welcomed.

John Mills

Stop press

NICE APPRAISAL We have now made the Vuk submission to the NICE Appraisal on the use of Rituximab in treating vasculitis. We would like to thank the 25 members who shared their experiences of Rituximab. Extracts from these form part of the submission.

ANCA VASCULITIS GENETIC STUDY Those who volunteered to take part in the ANCA vasculitis genetic studies at Cambridge will be hearing more shortly. There has been a delay while certain procedural details were being clarified.



DIARY DATES

Meetings

Polite note: Are you thinking of attending a Support Group meeting? Please book to help with organisation and for ordering and paying for refreshments. For full details see the "Events" section of our website:

www.vasculitis.org.uk

Vasculitis UK Annual General Meeting
Sunday 12th May - Novatel, Long Eaton - see attached flier for full details



Lincolnshire VSG Saturday 30th March. Contact: Pamela Todd

North/West Yorkshire VSG Sunday 21st April Contact: Lynne Jacques

New East Midlands VSG Saturday 20th April Contact: Susan Mills

Surrey VSG Sunday 5th May Contact: Paul Bingham

New York, North & East Riding VSG Sunday 5th May: Contact Jennifer Wormald

Essex VSG Informal meeting Wednesday 29th May Contact: Jules Darlow

Oxfordshire VSG Informal lunch Sunday 2nd June Contact: Sue Ashdown

West Midlands (VSGWM) Sunday 14th October Contact: David Sambrook.

For contact details for Vasculitis Support Groups see page 26

Fundraising



Vasculitis UK in partnership with the Jane Tomlinson Appeal — **"Walk for All" Sunday 9th September.** The Trust has purchased a number of places on this event which is suitable for all the family. For further details see page 8.

Photo - publicity launch in February with representatives of the partner charities, and Peter Rabbit, at the World of Beatrix Potter



Trans Pennine Challenge - 100 km — Walk it, Run it, Your challenge, Your way.

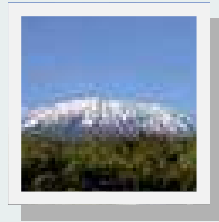
Manchester to Sheffield—**22nd-23rd June 2013**

Raise funds for Vasculitis UK. For full details visit:
www.transpenninechallenge.com/



18 runners are entering this prestigious event on Sunday 14th July to raise awareness of vasculitis and funds for Vasculitis UK: *Good luck to all these wonderful volunteers. Please visit Justgiving.com and support them as they do their best to raise funds for vasculitis research.*

FUNDRAISERS



Eleanor Barrett & Aimee will fearlessly bungee jump on 16th June.

Charlotte Birkett will don her running shoes in the Shell Chester Half Marathon on 12th May

Vincent Caldwell will be entering the BUPA Manchester Run on 26th May.

Emma Cremnitz is entering the Richmond 13.1 on 31st March

Tara Gami and friends are conquering Mt Kilimanjaro and have set their sights as high as the mountain, hoping to raise £5000 for V-UK. *Go Girls!*

Monica Hughes will Pedal for Scotland, in memory of her dear mum, Mary, on 8th September

Aimee Morrison is raising funds for Vasculitis UK by all means possible - which are legal and won't frighten the horses!

Julie Scott is walking in the Run for Life event in York on 2nd June

Martyn Wells with Hazel Chislett, Sophie Croft, Christopher Jewson, and Sarah Pittaway will be undertaking the Worcestershire Walk on 29th June. Why not join them or cheer them along?



Read the stories about our fundraisers and perhaps donate to the Trust at:
www.justgiving.com/VasculitisUK

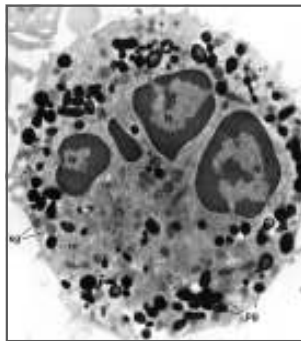
New fundraising stories are always being added

ALL ANCA AREN'T EQUAL IN VASCULITIS

Presentation given by Dr Julie Williams at the West Midlands (VSGWM) meeting in October 2012

To those of you new to Vasculitis the disease is associated with the presence of an antibody called ANCA, or antineutrophil cytoplasm antibody. This antibody is able to attach to a particular type of white blood cell called a neutrophil. Neutrophils are the cells responsible for fighting infections, like bacteria, and to do so release lots of toxic chemicals which kill the bacteria and digest it to get rid of it. So this is what happens normally.

When ANCA are present the neutrophil thinks that there is a bacteria around and releases its chemicals. As there is no bacteria to kill the chemicals attack the blood vessels instead which causes inflammation and damage. This is what Vasculitis is. As well as releasing these chemicals the neutrophil also sticks inside the blood vessel and where it sticks will determine what organs are affected, for example the kidneys and the lungs.



A highly magnified picture of a neutrophil

ANCA is a protein called an immunoglobulin (Ig). There are a few different types of Ig but ANCA are mostly of the G type, and so are called IgG. There are 4 different sorts of IgG; 1, 2, 3 and 4. These different sorts all have slightly different jobs in the body or are slightly better or worse at their jobs. Even though IgG is a protein it has little molecules of sugar on it which make it better at its job, as it can bind other proteins better. We know that ANCA IgG is mostly of types 1, 3 and 4 but not 2 and that there is something different about the sugar molecules on it which may make the antibody more efficient.

ANCA antibodies bind to certain parts of the neutrophil only. These are proteins called proteinase 3 (PR3) and myeloperoxidase (MPO). These proteins are quite big compared to the antibody so the antibody tries to find the best part to bind to. Different ANCA bind to different bits.

As well as differences in ANCA different people's neutrophils are different too. Some people may have more PR3 or MPO on their neutrophils. Also there are many other proteins on the neutrophil that are involved in Vasculitis and there may be different amounts or types of these too.

All of these differences make for a very complicated system.

We have developed tests in the laboratory to measure what neutrophils are doing. Amongst other things we can measure how much of the toxic chemicals are released (called superoxide production and degranulation) and also how much the neutrophil is likely to stick to a blood vessel. We get neutrophils from blood by a process which purifies them from all the other red and white blood cells present. We get our ANCA from patients who come to hospital when they first get diagnosed with Vasculitis. Most patients undergo a process called plasma exchange which cleans out all of the ANCA from their blood. We collect this and take out the ANCA to use in our experiments.

Over the last 10 years or more we have performed lots of these tests with lots of different patient's ANCA and lots of different healthy people's neutrophils. What we have seen is that there are lots and lots of differences between different ANCAs and different people's neutrophils. Sometimes an ANCA will cause one person's neutrophils to release chemicals but it may not do it to another person's neutrophils. Or sometimes an ANCA will cause the same person's neutrophils to be positive in one of our tests but not another. We tried to find a pattern but there was nothing obvious. There did seem to be certain people whose neutrophils generally seemed to be a bit more responsive than others.

The next question was whether, as all this work had been done in neutrophils from people without Vasculitis, patient's neutrophils may respond differently in our tests. So we tested 11 patients with ANCA from either themselves or other patients to see if they gave different results. In all of our tests there again wasn't any pattern and the patient's didn't do anything different from the non-patients. The only thing that was helpful was that the patient's neutrophils seemed to want to stick to things quite a lot and this led to them releasing their chemicals too. So it MAY be that patient's neutrophils stick to their blood vessels more than non-patient's ones do and this may cause more damage.

The future - we need to find out why this happens. Is it because the type of ANCA is different or is it because the neutrophils are different, or both?! We can look at this by analysing the types of ANCA present or by testing the DNA from patients that we have stored. Whatever it turns out to be we need to then think of a way that we can use this to develop new treatments in the hunt for a cure for Vasculitis.

Finally I'd like to take this opportunity to thank Vasculitis UK for all the support that they have provided to our research over the years. I will be moving on in early 2013 from Birmingham, the UK and from Vasculitis research. I wish you all well and will remember those of you whom I have met fondly.

Dr Julie Williams

Senior Research Fellow Renal Immunobiology
Birmingham (Hon)

INFECTIONS IN PEOPLE WITH VASCULITIS - DR MATTHEW MORGAN

Presentation given by Dr Matthew Morgan at the West Midlands (VSGWM) meeting in October 2012

As many of us know, if left untreated vasculitis causes significant health problems and can be fatal in some cases. The biggest change in the treatment of these diseases occurred in the 1960s and 1970s when doctors first started using the combination of cyclophosphamide and steroids to treat some serious types of vasculitis. We now also use medication such as azathioprine to reduce the risk of a recurrence of disease and allow us to use less cyclophosphamide. Before these drugs were used in combination around 80% of people diagnosed with ANCA associated vasculitis died within two years of diagnosis. Currently around 80% of people now survive at least 5 years and usually much longer.

Although these drugs undoubtedly save lives they have a number of side effects including increasing the risk of serious infections. Unfortunately the properties that make these drugs useful in treating vasculitis are the same properties that lead to increased infection - they suppress (dampen down) the immune system.

Our immune system is designed to protect us from infection by constantly monitoring our body for signs of trespassers (infections) which happen to all of us all the time.

The immune system can be divided into two main parts; the innate system and the adaptive system. The innate system is a bit like a burglar alarm. It knows when something sets it off but it doesn't know the difference between you coming home and getting the code wrong or the burglar coming in through the window. Whoever it is, it makes a noise, calls for help and might set the dogs loose on you. The adaptive system is more like the police. They turn up because the alarm has gone off but they can learn the difference between you as the homeowner and the man in the stripy jersey with a bag marked swag. What's more they can learn how to recognise the man in the stripy jumper so that next time they react more quickly and arrest him at the first sign of trouble.

These two parts of the immune system work in cooperation. The adaptive system has to be programmed to recognise different types of infection and make antibodies (sticky proteins) that stick to infections and signal to the innate system that these things need clearing away and destroying. Vaccines work by teaching the adaptive immune system to recognise infections before we are infected. Because the adaptive system can learn to recognise just about anything occasionally it goes wrong and starts to recognise parts of our own body and cause disease. This is how auto-immune diseases including vasculitis occur.

Drugs such as steroids and cyclophosphamide suppress the functions of different parts of the immune system leading to fewer cells in the innate and adaptive system and less antibody production. This is a good thing for treating vasculitis but a bad thing if you need protecting from infection.

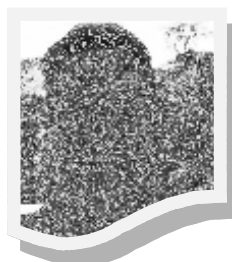
In Birmingham we have been doing some research into the problem of infection for people with ANCA vasculitis and whether we might be able to reduce the problem using vaccinations. We found that the majority of people attending our clinic had had serious infection at some point since being diagnosed with vasculitis. By measuring different bits of the immune system we found that having low antibody levels (antibodies that fight infection rather than the antibodies that cause vasculitis) was the biggest risk factor for infection. We also found that having fewer immune system cells was associated with having lower antibody levels. People taking azathioprine or mycophenolate (hardly anyone was taking methotrexate but it is probably the same) had lower antibodies, fewer cells and more infections. The more steroids people had had to take over the years was also associated with more infections.

Unfortunately the most obvious solution, use less treatment or stop immunosuppression, is not the answer for many people because their vasculitis will come back. We wanted to find out if using vaccines might help to reduce the risk of infection. We started offering routine vaccinations a few years ago and ninety two people agreed to us using their results as part of the research project. We measured the antibodies in the blood that were made after vaccination for various infections (including common causes of pneumonia) and found that after vaccination a significant proportion of people improved their antibody levels. Unfortunately the people who were at most risk of infection (those with the lowest antibody levels to start with) were least likely to respond to the vaccines. Our main conclusion was that we need to find better ways of using vaccines to reduce the risk of infection in people on immunosuppression.

Up to date advice on vaccination for adults over 65, people on immunosuppression or with specified underlying medical conditions is available from the Department of Health and the NHS and is contained in the "Green Book" (www.nhs.uk/Planners/vaccinations/Pages/Adultshub.aspx).

Vaccination against pneumococcus (a bacteria causing pneumonia and other serious infections) and 'Flu is recommended for everyone over 65 and individuals with chronic diseases including treated diabetes, some kidney disease, heart disease and liver disease and some types of immunosuppression (www.wp.dh.gov.uk/immunisation/files/2012/07/chapter-7.pdf).

Some people may require additional vaccinations in some circumstances and any concerns about vaccination should be discussed with your medical team.



Dr Matthew Morgan is Senior Lecturer in Renal Medicine at Birmingham University Hospital

VASCULITIS AND THE EAR - DR MARCOS MARTINEZ DEL PERO

Vasculitis can either affect the ear as part of a general illness, for example in Wegener's granulomatosis (now called granulomatosis with polyangiitis –GPA-), or can be a localised problem, for example autoimmune hearing loss. Problems with the ear can come before other features of disease in GPA and correct diagnosis is important in order to prevent hearing loss and more widespread illness. This article will discuss the different ways in which vasculitis can affect the ears and the different treatments available.

Ear anatomy and function

It is worth starting by explaining the different names doctors give to parts of the ear (Figure 1) and the different types of hearing loss. The outer ear extends from the part that one can see up to the eardrum. The middle ear is the space between the eardrum and the skull, it contains the hearing bones or ossicles (malleus/mallet, incus/anvil and stapes/stirrup) and it is drained by the Eustachian tube. The inner ear forms part of the bone of the skull where the sound is converted into electric stimuli for transmission by nerves to the brain. Next to it are the semicircular canals and the rest of the balance organ.

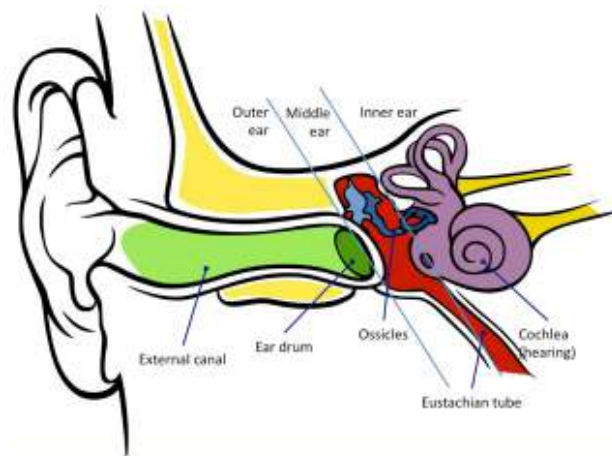


Figure 1. Anatomy of the ear (by M.Komorniczak published in Wikimedia commons)

In terms of hearing loss it is divided into 'conductive loss', when the ear drum and/or the ossicles are affected; and 'sensorineural loss' when the cochlea, the nerve and/or the hearing centre in the brain are affected. In some cases the hearing loss is a mixture of conductive and sensorineural loss.

How is vasculitis diagnosed in the ear?

Patients who present with vasculitis, which is limited to the ear, often have the same symptoms and show the same appearances as patients with infections and congestion in the middle ear. Very occasionally they have inflamed tissue behind the eardrum (Figure 2B). Another way vasculitis patients present is with sudden (over less than three days) nerve hearing loss.

The features that would point towards a diagnosis of vasculitis are an infection that does not respond to optimal treatment, greater pain than appearance of the ear would suggest and inflammatory tissue filling the middle ear. All patients that suffer from acute sensorineural hearing loss are treated with steroids. If the hearing responds well, an inflammatory process such as vasculitis is suspected, particularly if the hearing drops again on another occasion.

All patients suspected of GPA should have a urine dipstick done in the clinic and a chest x-ray as well as blood tests that include ANCA. However, in conditions such as Churg-Strauss syndrome (now called eosinophilic with polyangiitis –EGPA-) or limited GPA, these tests may not be helpful and biopsies may be required. The difficulty is that biopsies are often negative because vasculitis or granulomas may not be seen in the sample and what is seen could be caused by a number of inflammatory conditions. In these cases, close monitoring and repeat testing is required and occasionally treatment is started before having positive tests based on clinical findings.

How do different forms of vasculitis affect the ear?

Granulomatosis with polyangiitis (Wegener's granulomatosis)

Acutely, patients may present with a painful discharging ear, infection or deafness. They often have nasal symptoms as well, that cause scarring of the Eustachian tube and congestion behind the eardrum. Some of these patients may have grommets (ventilation tubes through the ear drum) inserted that unfortunately, can result in constant ear discharge and little relief of deafness or discomfort.

During remission up to 60% of patients with GPA have involvement of the ears. Their complaints include persistent/recurrent discharge and hearing loss. The abnormalities seen when examining the eardrums are shown in Figure 2. The type and level of hearing loss seen in GPA is usually different in each ear and does not have a characteristic pattern seen in other conditions (for example with increasing age we tend to see patients with hearing loss that affects the same frequencies in both ears).



Figure 2. Images of the tympanic membrane: A. congestion in the middle ear, B. Soft tissue mass in the middle ear, C. Chronically retracted tympanic membrane, D. Infected, retracted tympanic membrane with two small perforations inferiorly

Vasculitis and the Ear - continued from page 6

Eosinophilic granulomatosis with polyangiitis (Churg-Strauss syndrome)

Ear disease in EGPA, can be also limited to the ears or part of a widespread disease. The symptoms are similar to those seen in GPA, but these patients seem to have a higher incidence of chronic inflammation in the middle ear and pain in the middle ear. The appearances and type of hearing loss is the same as that seen in GPA i.e. no characteristic pattern.

Microscopic polyangiitis

Patients with this type of ANCA vasculitis do not suffer from the destructive effects that GPA patients do. However, they may develop sensorineural hearing loss as a consequence of inflammation of the small vessels supplying the hearing nerve.

Other symptoms

There are other symptoms that can affect the ear, but they are considerably less common and are not associated with a particular type of vasculitis or in most cases with a vasculitic process. These include tinnitus (a sensation of sound in the ear without a stimulus) and vertigo. Tinnitus can affect anyone, but it is often associated with hearing loss. Vertigo takes many forms and the different inner ear pathologies present in the same way as in the general population. Rarely vasculitis can affect the nerve of the inner ear balance organ and cause similar symptoms to labyrinthitis (nausea and vomiting and a sensation of movement that lasts for a few days).

How is it treated?

Once the diagnosis is made, the initial treatment consists of systemic immunosuppression either with steroids alone or with immunosuppressants such as cyclophosphamide or methotrexate.

Conservative

Infections with ear discharge with or without a hole in the eardrum are treated antibiotic drops. If the infection is not settling or the canal is full of pussy discharge, the treatment involves cleaning the ear with suction in the ENT clinic and antibiotic creams or different antibiotic drops. If the infection is in the middle ear and does not settle on its own, it may require oral antibiotics. The treatment is expected to work within a week, but in the case of deep infections it may take a few weeks of intense treatment. However, one should consider low-grade activity if the infections do not settle as expected.

Hearing aids are useful in patients with conductive (middle ear problems) or sensorineural hearing loss ('nerve' hearing loss). Patients with constant ear discharge, who require aiding, may benefit from implantable devices. Hearing aids can also be helpful in patients with very intrusive tinnitus and if the patient has hearing loss, they are the first line of treatment. In patients whose tinnitus does not let them sleep or concentrate a referral to a specialist in tinnitus may be helpful. The specialists are usually audiologists who will try and find the trigger, provide information and sometimes white noise devices.

Surgical

Generally surgery is avoided in patients with vasculitis, but in patients who have been in remission for over 12 months and have a persistent discharge, surgery to repair the eardrum may be considered appropriate. In patients with congestion in the middle ear (glue ear) who are also in remission, a ventilation tube (grommet) may be helpful. There is not much evidence to inform the management decisions, so each individual case is considered with the advice of the medical team. In addition, patients may suffer from conditions affecting the rest of the population, such as, cholesteatoma (a condition where the ear drum retracts into the middle ear and traps skin within it). In these cases surgery should be considered with the advice from the medical team on medications before, during and after surgery.

Outcome

Nerve related hearing loss can recover with corticosteroids in some cases, particularly when treated within a few days, but in most cases it does not recover completely. Conductive hearing loss usually implies damage to the eardrum or the ossicles or congestion behind the eardrum. If there is only glue ear with no other damage, grommets can potentially return the hearing to normal or to the level the nerve functions. If a more extensive procedure to repair the eardrum or the ossicles is required, the chances of improved hearing to normal levels are lower (between 50-80% will benefit five years after the surgery). The chance of repairing the eardrum successfully is quoted as 85% in the general population, but there are no published case series in vasculitis.

Regarding tinnitus, most the time the brain learns to ignore it and it becomes part of the background noise. In patients whose tinnitus is very intrusive the therapies mentioned above can aid the process of reducing the tinnitus to the background.

Is there anything I can do to protect my hearing?

For patients who suffer from chronically discharging ears it is advisable to cover the opening of the ear canals with cotton wool smeared in Vaseline during showers or baths. If the patient is a keen swimmer personalised swimming moulds can be helpful. Cotton buds do not help to clean the ears and often cause more harm by traumatising the ear canal or pushing wax deep in the ear canal. No harm is done by using or not using hearing aids, but if people become withdrawn because they cannot follow a conversation, then this might be a good time to consider them.



"Vasculitis and the Ear" has been written for Vasculitis UK by Dr Marcos Martinez Del Pero, Specialist Registrar in ENT, East of England Deanery, Cambridge, UK

PREDNISOLONE AND INSOMNIA

Many of us experience disturbed sleeping patterns, particularly when on high dose steroids. Some of the symptoms encountered include:

- Difficulty falling asleep
- Waking up during the night and having trouble going back to sleep
- Waking up too early in the morning
- Waking up tired and not feeling refreshed

Here are a few useful hints which may help you get a good night's sleep:

- Consider taking your prednisolone earlier in the day.
- Try to keep to a regular sleeping-waking cycle - going to bed and waking up at the same times every day may help.
- Avoid caffeine, alcohol, and nicotine for at least four to six hours before bedtime.



- Avoid exercise within two hours of bedtime.
- Avoid large meals within two hours of bedtime.
- If you nap during the day try not to do so after 3.00 pm.
 - Try sleeping in a dark, quiet room.
 - Keep the room at a comfortable temperature.
 - If you still can't sleep after 20 or 30 minutes get up and undertake a quiet activity. Go back to bed when you feel sleepy.
 - Establish a pre-bedtime ritual 30 minutes before going to bed - try a warm bath, listen to soothing music, read a book, or drink some warm milk.

If you are taking prednisolone and your sleeping problems don't ease or are getting worse speak to your consultant or GP.

LAKE DISTRICT - WALK FOR ALL



VUK are excited to announce that we've just signed up to partner the **Jane Tomlinson "Walk For All"** fundraising festival in the Lake District. We'll be looking for fundraisers and volunteers to join us on **Sunday 8th September 2013**.

"Walk For All" caters for walkers of all abilities and offers three different walks, from the 5 mile "Lakeside Potter" to an exacting 22 miles "Colossal". All three take in the wonderful views of Lake Windermere and the beautiful Cumbrian Lakeside towns of Newby Bridge, Ambleside and Windermere itself.

We want this to be a really special event to raise both awareness and funds for Vasculitis UK. With your help we can make it a really memorable day. So if you'd like to take part and raise funds or even just volunteer to help please contact **Richard Eastoe** - e-mail: richard@eastoe.net or phone: 07941 139896 for further details.

You can read all about the Lake District Walking Festival at:
www.forallevts.co.uk/walk-for-all/events/lake-district/

VASCULITIS MASTERCLASS AND ANCA –VE GLOMERULONEPHRITIS MEETING

In November Richard Eastoe, Pat Fearnside, Lynne and Sam Jacques and Jann Landles (Vasculitis UK Trustees) attended the second Vasculitis Masterclass organised by ReMEC (the Renal Multidisciplinary Education Committee). The meeting was chaired by Dr Janice Harper (Nephrology) and Mr Ian Pearce (Ophthalmology) both from the Royal Liverpool.



Dr Janice Harper

Pat set up a small VUK stand in the assembly area where we had Route maps and leaflets available. One consultant was heard to say "This will be just great for the junior doctors" and a Neurologist who took a Route map was very interested in the proposed UK Vasculitis Register.

The first presentation was "**The Retina – A Window On Vasculitis?**" by Mr Nick Beare, an Ophthalmologist from Liverpool.

Mr Beare told us that because the retina is considered as part of the Central Nervous System they believe it is a useful guide in diagnosing and monitoring active disease.

At Liverpool they make use of new wide field imaging – a massive 200 degrees field of view as opposed to the normal 30. They have found that clinically well patients may show signs of active disease right at the periphery of the retina. This gives them early indication of disease activity.

The second presentation was by Dr Peter Enevoldson (an MD Neurologist at Walton Centre) and was entitled "**The Neurologists' Approach to Vasculitis (Made Easy!)**".

Dr Enevoldson gave us some insight into the difficulties for clinicians diagnosing Vasculitis and in particular Cerebral Vasculitis (or Central Nervous System Vasculitis - CNSV). Because CNSV is a particularly rare form, many other more likely conditions have to be considered first.

He thought that brain imaging could be misleading since many neurological conditions showed the same type of brain scans. He felt that clinical observations were more important in diagnosis and that the only way to be certain would be to undertake a brain biopsy. He felt that this avoided the potential risks from unnecessary treatment with Cyclophosphamide.

We noted that other consultants questioned his approach to diagnosis and felt a decision on treatment would often have to be made before a biopsy could be done.

It will come as no surprise to learn that some doctors do not always have the same opinions as their colleagues !!

Dr Elizabeth Graham, a Medical Ophthalmologist at Guy's and St Thomas', presented "**Optic Neuropathy – More Than Meets The Eye**". Her talk concentrated on diagnosing ischemia (restriction in blood supply) of the optic nerve due to Vasculitis.

The aim was to allow a less invasive treatment for Temporal Arteritis without optic involvement whilst treating the more severe form of the disease immediately with steroids.

Dr Anil Gholkar, a CD Neuroradiologist from Newcastle Upon Tyne, present "**Vasculitis Brain Imaging – More Questions Than Answers**" Interestingly, in opposition to Dr Enevoldson's views, Dr Gholkar told us that new techniques in brain imaging could show signs of inflammation, narrowing of veins and tissue death. He did however back up Dr Enevoldson's comment that a brain biopsy may still be the only way to confirm diagnosis of CNSV.

Professor Steven Harper from Bristol proved to be a stand-up comic with some very funny stories. This helped to make his difficult subject of "**Glomerular Biology and mRNA Splicing**" more palatable. The thrust of his presentation was to impress upon the student doctors present that gene splicing was the future of kidney (and cancer) research and treatment.

Dr Roshni Rathore from Preston then gave her "**Day Case Renal Biopsy: An Audit**" presentation. This was of personal interest to Jann who was one of the statistics! Dr Rathore explained how Preston record and monitor their kidney biopsy procedures with a view to improving patient outcomes.

Professor Lorraine Harper from Birmingham University Hospital presented "**An Expert Guide to Glomerulonephritis Trials and Patient Recruitment.**" Professor Harper explained that many trials are of poor quality and have low patient recruitment levels.

She believed that collaboration was the key to successful trials and told us that EUVAS had been very successful in recruiting patients. This was pertinent as VUK have recently confirmed we are supporting the new UK and Ireland Vasculitis Registry.

The final presentation was entitled "**Lupus Nephritis : What Can Adults Learn From Children**" by Dr Louise Watson from Liverpool. She compared Junior Systemic Lupus Erythematosus (JSLE) with the adult form and called for the use of non-invasive biomarkers in order to monitor disease activity. These allow clinicians to predict improved or worsened renal disease and may allow for early reduction in aggressive treatments. Her final word was of hope for future developments to treat the disease.

All in all a fascinating day. We had an insight into the research and clinical procedures going on "behind the scenes" that ultimately give us all hope for the development of improved treatments and just maybe, someday in the future, **a cure**.

Report prepared by Jann, Richard and Lynne

URTICARIAL VASCULITIS



Stinging nettle rash in Urticarial Vasculitis

Smoking is a major risk factor for fatal lung disease in HUVs and smokers should seek help to give up as soon as possible

SIDE EFFECTS OF THE SUBGROUPS OF URTICARIAL VASCULITIS

Normocomplementemic Urticarial Vasculitis (NUV)

The main symptoms of Urticarial Vasculitis combined with normal levels of C1q complements. NUV is generally the least severe form of Urticarial Vasculitis.

Hypocomplementemic Urticarial Vasculitis (HUV)

The main symptoms of Urticarial Vasculitis combined with lower than normal levels of C1q complements and raised levels of anti-C1q antibodies (antibodies that attack the C1q complements). Likely to include purple or dark red spots or rash on the skin (a typical vasculitic rash); arthritic joint pain; breathing difficulties such as asthma, and stomach pains.

Hypocomplementemic Urticarial Vasculitis Syndrome (HUVS)

Patients may have more extensive complement abnormalities (low circulating 3rd and 4th complement components). As well as the symptoms of HUV, patients will suffer from systemic problems such as: (bloodshot or inflamed eyes; kidney disease; inflammation of the membrane surrounding the lungs; swelling of the tissues under the skin; Chronic Obstructive Pulmonary Disease (COPD) (breathing difficulties), and cardiac involvement such as heart attack.

What is Urticarial Vasculitis?

Urticarial Vasculitis is a form of cutaneous vasculitis characterised by inflammation of the small blood vessels. Urticarial Vasculitis can be classified into three subtypes - Normocomplementemic Urticarial Vasculitis (NUV), Hypocomplementemic Urticarial Vasculitis (HUV) and Hypocomplementemic Urticarial Vasculitis Syndrome (HUVS). All are defined by a measure of the "complement" levels in the blood. The complement system is a set of proteins that contribute to and amplify immune responses.

Who are affected?

NUV is most common between the ages of 30-40 and is found in women more than men. HUV and HUVS are almost exclusively found in women.

What is the aetiology (cause)?

The cause of Urticarial Vasculitis is not known in 50 per cent of cases. However it can be associated with or triggered by autoimmune/connective tissue diseases like Systemic Lupus Erythematosus (SLE or simply Lupus) Rheumatoid Arthritis, or occur in the context of a systemic vasculitis syndrome, such as Churg Strauss syndrome (Eosinophilic Granulomatosis with Polyangiitis); infections or viruses such as hepatitis; a reaction to certain drugs such as ACE inhibitors; certain types of diuretics; penicillin and Non-Steroidal Anti-Inflammatory Drugs (NSAIDs); cancer; and Glandular problems, such as Graves' Disease (overactive thyroid).

What are the symptoms?

The main symptom is a recurring urticarial ("stinging nettle") rash that lasts for longer than 24 hours and "burns" rather than "itches", leaving marks behind on the skin when it clears.

Diagnosis

As in other types of vasculitis, diagnosis will depend on the doctor recognising the pattern of symptoms and examination findings. Blood is commonly taken to test for raised levels of "C-reactive protein" (CRP) and "Erythrocyte Sedimentation Rate" (ESR) which indicate inflammation in the body.

Skin and kidney biopsies may also be taken to confirm the diagnosis. Testing for C1q, anti-C1q, C3 and C4 complement components is essential to determine the type of Urticarial Vasculitis. Tests may also be done for Anti-Nuclear Antibody (ANA) levels (which are positive in 30 to 50 per cent of patients), and Anti ds-DNA levels may also be positive.

Testing for C1q, anti-C1q, C3 and C4 complement components is essential to determine the type of Urticarial Vasculitis

Treatment

Milder cases of Urticarial Vasculitis may simply be treated with antihistamines and NSAIDs such as Ibuprofen. Corticosteroids such as Prednisolone might be used for more persistent cases. However for the more severe forms of Urticarial Vasculitis, steroids such as Prednisolone are usually prescribed to reduce inflammation as well as immunosuppressants such as Azathioprine, Cyclophosphamide or Mycophenolate Mofetil (CellCept). In cases where a patient is unresponsive to treatment, intravenous immunoglobulin and anti-cytokine monoclonal antibodies or rituximab may have a role.

If the disease is very severe large doses of Methylprednisolone or Plasmapheresis (plasma exchange) may also be given. When the disease becomes quiet less toxic drugs are used to keep control and these include: Azathioprine, Methotrexate and Mycophenolate Mofetil usually in combination with low dose prednisolone.

Prognosis

The overall prognosis in Urticarial Vasculitis depends on the severity of the disease and the amount of damage that has been done to organs, especially the lungs. The main risk to patients appears to be Chronic Obstructive Pulmonary Disease (COPD). Smoking is a major risk factor for fatal lung disease in HUVS and smokers should seek help to give up as soon as possible.

Thanks to Richard Eastoe, Vasculitis UK Trustee, for researching into this topic

PERSONAL STORY — VIV DUNSTAN

I've been ill with cerebral vasculitis for a very long time. I was only 22 in 1994, had newly started a full-time funded science PhD. And I started to get ill, often nauseous and vomiting, battling severe fatigue, falling over, problems with my legs etc. Initially I was diagnosed with ME, but the symptoms changed over time to look more like multiple sclerosis. My vision and hearing became badly affected, I couldn't control my bladder properly and had to wear incontinence pads permanently and sprint to the bathroom.

I had to leave the science PhD, unable to put in the hours needed, but it prompted me to fight for a proper diagnosis. I had to fight at hospital level too, arguing with the consultant, and saying why I thought the ME diagnosis was wrong. He agreed to do a brain scan, but didn't think it would show anything. Wrong! There were multiple lesions in my brain, which should never be there in the brain of someone so young. He was shocked.

I was just relieved that finally something was showing up and I might be close to a new diagnosis. I had a raft of new tests, most on 5th November 1997.

I have a wonderful husband, who I married aged 22 shortly before the disease started. He has stuck by me throughout everything that has happened. He's a gem.

I remember coming home, in agony after a rather botched lumbar puncture, to the sound of fireworks and smell of bonfires. And I was re-diagnosed with cerebral vasculitis. It's in the small blood vessels in my brain, and is very similar day to day to multiple sclerosis.

My main symptoms are mobility, bladder incontinence, memory/cognitive problems, fatigue, and losing control of my arms and legs. However I also have problems with vision, hearing, speech, falling over, headaches (though not until a few years ago), sleeping for up to 17 hours day after day, etc. I always use one stick, often two, and have had my own manual wheelchair since the late 1990s.

Treatment-wise my disease has not behaved nicely. I didn't have Cyclophosphamide early on because I was newly married and hoping to have children, and though I said "Just give me the treatment!" the consultant was very concerned about fertility concerns. More recently it was ruled out again because it might worsen my very severe (off the urologist's scale) bladder problems. But I finally tried it in summer 2012. And it wasn't effective. I was very sick on it, on one day 20 times over a 12 hour period. More importantly, it didn't control my disease. My inflammation markers reached record levels on it, and we're now looking at an alternative biologic therapy. Over the years I've tried Azathioprine, Ciclosporin, Mycophenolate Mofetil, Methotrexate, Thalidomide, and of course steroids. And I'm still on quite a cocktail.

So there are downsides. But I think there are also positives. The main one is that I'm happy, despite everything. My memory problems really help with this. Each day is like a fresh start, and I take pleasure in the small things. For example I recently took up digital photography and am enjoying getting out and about to take pictures. Also, and perhaps most importantly of all, I have a wonderful husband, who I married aged 22



Viv & Martin's Wedding day



Viv's photography

shortly before the disease started. He has stuck by me throughout everything that has happened. He's a gem.

And I've been able to continue studying. After leaving the computer science PhD I started studying history with the Open University part-time in 1998. I was finding my new immunosuppression treatment horrific, being very nauseous every day on Azathioprine. I needed something positive to take my mind off it. So I signed up for one OU course. And that led to another course, and another, and soon, partly helped by my existing science degree and credit transfer, I had a new history degree. And then, still part-time, I went on to study a history Masters at my local university, followed by trying for a PhD again, researching reading habits in Scotland circa 1750-1820. I completed the PhD in early 2010. It wasn't easy: by the end I was managing on no more than five hours total a week, in one hour chunks spread throughout the week. But I did it. I got shingles in the weeks before my viva, the final oral exam PhD students must go through. That probably took my mind off the viva, but it wasn't the best timing in the world!

I can't work with my disease. I'm severely disabled from the cumulative brain damage over the years. But I've been awarded an honorary research fellowship by my university, and that's helping me slowly turn my research and my PhD thesis into more academic journal papers. That's very rewarding, and I recently had one paper published in the most eminent Scottish historical academic journal. To have a single-authored paper in that journal only two years post PhD would be a big achievement for any academic historian, but for me given my health circumstances and disability it's massive. I'm also planning new research, bringing records to me to work on at home, and hope to enjoy doing this for a long time to come.

Viv Dunstan

VASCULITIS DISCUSSION GROUPS

There are three Vasculitis UK discussions groups on the internet.

The first is **Health Unlocked**



This is a private group. Here you can set your own levels regarding who can see your posts. All the posts are relevant to the vasculitis patient. There are over 600 members in this group.

This site is particularly suitable for those internet users who do not like the concept of Facebook or Twitter.

To join **Health Unlocked** go to the Trust's website: www.vasculitis.org.uk and click on the HU link on the Home page.

Then there is the **Vasculitis UK Facebook** site. There are now over 700 members. To join go to: www.vasculitis.org.uk and click on the FB link on the Home page.



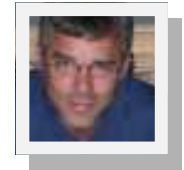
Finally you can open a **Vasculitis UK Twitter** account. As above, go to the Trust's website and click on the Twitter link.

P.I.Y.R.A. AWARD TO PROFESSOR MARK LITTLE

The immune system is pretty useful for keeping us safe from invading bugs, but why does it sometimes turn tail and attack the body's own tissues? Finding out the answers could offer clues about how to better diagnose or even eventually treat auto-immune conditions.

Two such projects were highlighted at Áras an Uachtaráin earlier this month when President Michael D Higgins met recipients of the President of Ireland Young Researcher Awards, otherwise known as PIYRAS.

Funded through Science Foundation Ireland, PIYRAS offer researchers support for five years to set up a group to investigate a particular area, and for these two awards, the immune system looms large. One of these awards was to Prof Mark Little, who is well known to the readers of this Newsletter.



Prof Little is using his PIYRA to develop research into ANCA vasculitis. About 1,000 people are currently living with the chronic, relapsing condition in Ireland, according to Prof Little, who is Professor of Nephrology at Trinity and is a Consultant Nephrologist at Tallaght and Beaumont Hospitals.

"About a quarter of the [PIYRA] grant is to support the development of a registry and a biobank to cover the whole country," he says. "The idea is that we try and pool the experiences of all the clinicians around the country [dealing with this condition] and that we obtain samples, blood, tissue, urine samples to allow us to study it."

Mark, who was previously at University College London, is also building up the research at the Trinity Health Kidney Centre, using a model that mimics the disease and that can help to identify which components of the immune system are malfunctioning.

"One aim is to investigate newer biomarkers in the urine that could be used to better diagnose when a person with the condition is relapsing"

One aim is to investigate potential new biomarkers in the urine that could be used to better diagnose when a person with the condition is relapsing. "We want to work out simple non-invasive markers to tell us when the disease is active," he says.

MAY IS VASCULITIS AWARENESS MONTH



May is the time when you can help make a difference and raise awareness of vasculitis in your community and further afield. There are a number of things you could consider doing, from the relatively easy to the more energetic. The main thing is the raise awareness of vasculitis in any way you can.

Last year a number of members held coffee mornings or a tea party in the garden. What about a cake stall?. Other ideas could be - a quiz night or a book sale. Why not hand out pamphlets at your place of work? What better way though, for spreading the word, than for those who would like to tell their story than by contacting your local newspapers.

Whatever you decide to do the Trust can provide you with free balloons, pens, stick-its and car stickers. Just contact Susan or John Mills.

We also have a selection of other "goodies" for sale in our shop if you think your friends and family might be interested. Wearing a t-shirt, hat or one of our new V-UK badges could be one way to help raise awareness.



Whatever you decide to do please let us have a few words and a photograph for the Autumn Newsletter. Many thanks and happy awareness raising.

RENAL PATIENTVIEW

Providing up-to-date medical information for patients and healthcare professionals

Renal PatientView **NHS**

Renal PatientView is a project of RIXD (the Renal Information Exchange Group) a UK group representing renal patients and the renal team. It aims to provide online information about renal patients' diagnosis, treatment and their latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world.

Many vasculitis renal patients are registered, and one of your Trustees found it invaluable for his emergency treatment when he was taken seriously ill on a cruise and had to be airlifted to Aberdeen Hospital.

PatientView is only available from some UK renal units, and for patients who have chosen to participate. The map shows green flags which are units in RPV, the red flags - it's on its way. To view a larger map showing these units please go to: www.renal.org/whatwedo/JointActivitiesSection/RIXGSection/RenalPatientView/RIXGWhere.aspx and click on "all UK units on this map". The information comes directly from existing databases within units, so if you suspect a mistake, you should check with your own unit.

RPV is funded by contributions from renal units in England and Wales and by the Scottish Government in Scotland. Development funding has come from the Department of Health in England, Scotland and Wales, and from NHS Kidney Care.

If you have any questions you will find an excellent "help" section at: www.renalpatientview.org/help.do



Rare Disease Registers - coming soon via RPV

If you have a rare disease, it can be trebly difficult -

First, it can be difficult to find reliable information

Second, it can be difficult to find other people who have it, and

Third, it can be difficult to find doctors who know much about it



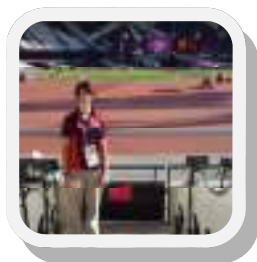
These aren't just frustrating, they can be dangerous. In response to this, a Rare Kidney Disease Initiative has been launched, based on Rare Disease Groups. At first there will be 11 groups of which vasculitis is one. The full list of groups can be found at: www.rarerrenal.org/groups/

Each rare disease group (RDG) will need lists of patients, ways to contact them, and ways to keep up with how they're doing. Most of this info is already in Renal PatientView, so if you want to join, the first thing you'll be asked to do is to sign up to sharing your info with the Disease Group.

This system is being called RADAR (Renal Rare Disease Registry). Your name and where you live won't be part of that, but they will be kept so that the group's organisers can keep you up to date with info and research, and get you together online or in person.

A lot of work has been going on behind the scenes to make this technically possible, and to make it as easy as possible for staff to get info into the system. We hope that the first new group, the Alport group, will launch very soon, closely followed by the others.

ROVING REPORTER - AN INTERVIEW WITH HELEN MAYOR



Helen is a vasculitis patient and she was selected to help at the 2013 Paralympic Games in London. Helen speaks to our Roving Reporter about her vasculitis and about her role at the Paralympics.

Helen, first, could you tell us about your vasculitis?

I was diagnosed with WG in November 2007, just after I had started a physiotherapy degree. The first symptom I had was hearing loss. I suddenly noticed I was struggling to hear in lectures. It didn't take long before other symptoms started to appear though and I quickly became very ill.

This must have affected your studies

Not being able to do physiotherapy was a big blow as I'd worked hard to make sure I got the grades needed at A level and the work experience required. However, two years later I was finally well enough to start thinking about returning to university. Physiotherapy was out of the question because I wouldn't have been able to manage the physical nature of the degree. So I weighed up my options and decided psychology was a good choice at my local university of York St John. I was still attending a lot of appointments and in and out of hospital so started the course part-time. Since then things have improved, so much so that I was able to go full-time, I'm now in my final year.

So, to the Paralympics - How were you selected to help?

I applied online and waited for what felt like forever to hear that I had got an interview in Newcastle.

Did you have a fancy title?

I was an Events Services Team Member which was basically all the front of house customer service type roles. I was within the stadium so got to see a lot of track and field action!

And what were your duties?

The job roles were really well set up so that you got rotated each day. I did things like taking tickets, queue managing and showing people to seats. I also did mobility which meant having a wheelchair and a radio so that I could collect spectators in need of a ride! This was a challenge both for the breathing and my hearing trying to listen to where the person was over the roar of the stadium!

Tell us about the interesting people you met

I got a very exciting position one evening in the athletes' seating area so got to meet some of them. I also got to see bronze, silver and gold medals close up. Unfortunately I didn't get to meet any team GB athletes as they always seemed to be on the track!

Did you meet any royalty?

Unfortunately not, but I was extremely close to where the Queen was sitting during the opening ceremony. That was a wonderful experience.

Did you see any really memorable events?

I had an amazing position for the 400m final - I was

standing directly above the finishing line! I also got to see David Weir win three of his four gold medals and Johnnie Peacock win his 100m gold. Awesome.

Who was the athlete who stood out for you?

David Weir is an incredible athlete. He has consistently won athletics events and marathons for many years and it was a privilege to be able to see him on his home turf. He is unique in athletics terms, not many people can compete in the 800m, 1500m, 5000m and marathon and win them all! He has grit, determination and absolute focus when he's out there on the track.

Were you at any of the medal ceremonies?

Due to there being so many different categories in the Paralympics, medal ceremonies were happening all the time. I never lost the sense of awe at what the athletes had achieved and enjoyed watching them all in their moment of reward for all their hard work.

The atmosphere must have been amazing

It's difficult to put into words the buzz that constantly surrounded the game. The staff, the games makers, the athletes and the spectators were just having the time of their lives. Even though at times the work was hard, the shifts were long and jobs could be a bit monotonous, every games maker had a smile on their face as they knew how lucky they were to be part of something so special.

What do you hope that the lasting legacy of the games will be?

For me, I hope that the Paralympic legacy is one that sees more people being given the opportunity to achieve their full potential in sport regardless of disability and that para-athlete's achievements will continue to be recognised as much as other athletes.

Finally Helen, a little more about yourself. Are you an athlete?

I like to run, there's nothing quite like chucking your trainers on and going for a jog when things get a little stressful.

Were you running before the WG?

I've always loved running and athletics, however a subglottic stenosis and other lung damage meant that ever being able to run again looked really unlikely. But thanks to my amazing surgeon in London who widened my trachea, I've been able to get back to it. It was a very slow but steady road. The first time I managed just a 30 second jog on a gym treadmill. I punched the air with glee only to realise I was getting some strange looks!

You've entered a number of events. How did you do?

I entered the Great North Run in 2011 which was something that I had previously been meaning to do but never got round to it. Although I won't be beating Mo Farah any time soon, I finished it in a respectable time and had a fantastic day soaking up the atmosphere on my way round. I hope to enter some more races soon and raise some more money. I ran the GNR for the Vasculitis Foundation, so I think the next one most definitely should be for Vasculitis UK!

Thank you Helen, you are an inspiration to us all.

A DAY AT IMPERIAL COLLEGE LONDON

V-UK trustees, Richard Eastoe and John and Susan Mills spent a very interesting day at the beginning of November, at the Imperial College Biomedical Research Centre (BRC) Open Day. This event was held jointly with the National Institute for Health Research (NIHR).



Imperial College Healthcare Trust, NIHR and BRC have been partners in a healthcare research partnership since 2007. Much pioneering work, focussed on improving patient healthcare, has been carried out since then. The research frequently involves non-medical research workers in all disciplines, from engineering to electronics. There are several hospitals included in the extensive campus, including the Hammersmith Hospital where there is a clinical research facility.

Plans are well advanced for creating a new multi-disciplinary vasculitis centre there under the leadership of Professor Charles Pusey.



The showcase event was attended by local residents, patients, clinicians, health professionals and students. We were all there to see over twenty interactive exhibits and talk to the

clinicians and technicians who were there to explain their work.

Many of the demonstrations were of little direct interest to us, dealing with problems such as infertility or STDs. But some were very relevant such as one on a technique for collecting material from nasal passages without the trauma normally associated with biopsy, another one was for a relatively less invasive technique for kidney biopsy.

There was a study investigating the reduction in effectiveness of prednisolone in severe asthma over time, so requiring higher doses for longer. Another studied the effectiveness of a machine that could detect pneumonia by analysing the breath. Two genetics demonstrations involved in one case,

comparing millions of "strips" of DNA from patients with the human genome, looking for unusual patterns that did not fit. Another looked at how genes can behave differently when affected by environmental factors. To show how easy it can be to extract the mystical DNA, visitors were invited to crush a strawberry to pulp, then add a solution of salt and washing up liquid and mix briefly. The DNA appears as a gelatinous mass that can be scooped up.

The star of the show was the Magellan Robotic System. An amazing piece of biomechanical engineering that is being developed for treating aortic aneurysms with keyhole surgery, passing a catheter via the blood vessels through a small hole in the groin. This usually involves constant low dose x-rays as the catheter is guided on its route, so protecting the staff from radiation is a problem. This robotic machine allows the surgeon to carry out the operation whilst sitting in another room away from the radiation.



Magellan Robotic System

After viewing the exhibits we were taken on a quick tour of the Imperial Centre for Translational and Experimental Medicine (ICTEM). This consists of two fully equipped wards with thirteen beds, examination rooms and a negative air pressure gene therapy suite. Up to sixty studies may be running at any one time which are primarily sourced from Imperial College research but also from external academic and private research centres. The studies are often early stage or "first in man" (first time trialled with humans) and by all accounts only one or two in a hundred treatments will make it into clinical practise. This goes some way in explaining the expense of modern medicines and treatments.

Afterwards there was a question and answer session chaired by Ehsan Masood (editor of Research Fortnightly) which gave an opportunity to discuss points about clinical research. Following this we had the opportunity to introduce ourselves to Jonathan Weber (Director of Research) and Jean Cooper Moran (Senior Program Manager for Patient and Public Involvement). If they weren't familiar with VUK beforehand they certainly were by the end of the day!

Report prepared by Richard Eastoe

ONE PATIENT'S PERSONAL PERSPECTIVE ON DIAGNOSIS AND TREATMENT



Summary of My Illness

I have GPA formerly known as Wegener's Granulomatosis). My main problems are loss of kidney function, loss of sight in one eye, low lung function. leg numbness, and joint pains. I was diagnosed in February 2006 having presented

with flu like symptoms, which developed into the above symptoms in May 2006.

Diagnosis

My GP's initial diagnosis was flu for which I was treated for four weeks. I was then hospitalised for four weeks undergoing a range of tests, which showed a raised ANCA level. A week at home resulted in rapid physical deterioration and a further week in hospital for a kidney biopsy leading to the correct diagnosis. I believe that the delay in diagnosis made my GPA worse. I feel this is supported by the fact that my eyesight problem and leg numbness emerged when I was deteriorating at home.

The diagnosis phase is crucially important but, because of the rarity of vasculitis and the lack of awareness among parts of the medical profession, diagnosis can be delayed.

Treatment

A cyclophosphamide infusion course is the normal induction therapy to stabilise the illness. Thereafter, general best practice rules for on-going treatment include:

- steroids (prednisolone) at an appropriate level initially, reducing to a "safer" level over time. However, the optimal dose varies for each patient. My consultant sought to reduce the dose to 5mg daily because of the long term dangers of high steroid usage. However, working together we found that 7mg is the optimal level for my wellbeing. Therefore, it is to the patient's benefit to work closely with the medical team.
- immuno-suppressant drugs for maintenance therapy such as Azathioprine, Methotrexate or Mycophenolate. It is important to establish quickly which is best for you by appropriate monitoring and by patients reporting negative side effects. For me, Azathioprine was the ideal as the others produced some nasty side effects. Rituximab is increasingly used. It is expensive but many Trusts allow this drug to be prescribed where the consultant makes a reasoned case.
- other medication for high cholesterol, bone density problems, blood pressure problems, sticky blood (warfarin) etc., according to your detailed problems, are all part of managing the illness. I had a DVT and pulmonary emboli, therefore, I will be on warfarin for life, along with millions of others. My personal experience has lead me to believe that the following are important:-
- Optimal treatment is best via a consultant

knowledgeable in vasculitis and who has treated many vasculitis patients. If you are unhappy with your treatment ask to be referred to a vasculitis Centre of Excellence. Seek help from Vasculitis UK or your GP. Most patients with systemic vasculitis are treated by nephrologists (due to kidney involvement) or rheumatologists (as vasculitis is an inflammatory disease) or respiratory consultants (due to respiratory tract involvement).

- Ideally you should be seen by your consultant at least six monthly, and you should have blood tests undertaken regularly. You may find having a personal copy of the results helpful. Blood tests are important, long term, for the management of the illness generally and for medication purposes, but also to ensure that you are not relapsing. Even on appropriate medication the relapse rate in vasculitis is high.
- Prepare a list of questions prior to every appointment. Some of these may be raised by the consultant but if not ensure you raise them. Ask about your blood tests and other test results. If you don't understand then ask for clarification.
- Many consultants establish a communication mechanism for use between appointments (telephone, e mail etc) for important issues. My consultant is contactable via his secretary. He always calls me within two days.

Treatment is a team effort between you and your consultant. You know your body. He/she knows best the medical scenario around your Vasculitis.

There are over 1600 hospitals in England. It is impractical to expect all of them to optimally treat such a rare illness as Vasculitis. I believe therefore that the future treatment of vasculitis should be in specialist Centres of Excellence which would raise treatment standards. Addenbrooke's in Cambridge is one of the UK centre of excellence with almost 1000 patients being treated on a regular or occasional basis. There are others in the UK, eg Birmingham, but presently the majority of us are treated locally, some with excellent results, and some not so.

Finally

We all manage our vasculitis in our own unique way. I hope these few personal experiences and observations will help you to manage your vasculitis. Remember, it is your body, and as much your responsibility as your consultant to optimise your treatment - the informed patient is the empowered patient. Good Luck.

Paul Bingham

The above article is the personal view and opinion of the author. Publication in the Vasculitis UK newsletter/journal does not imply that all of the points raised necessarily reflect the policy of Vasculitis UK.

SUPPORT GROUP MEETINGS

NORTH WEST - SEPT 2012

There was a good turn-out for the meeting. Some of the regular attendees were delighted to see some new faces. Particular thanks go to the long-distance commuters who had made the trip from Cumbria, Yorkshire and Derbyshire.

The well informed presentation from Dr Elizabeth Macphie, a consultant rheumatologist at the Minerva Health Centre in Preston made the journey for all those attending extremely worthwhile.

Dr Macphie's talk covered the role of the rheumatologist in the treatment of vasculitis and also the various aspects of management of the diseases.

She gave a clear picture of the issues in both monitoring disease and the complications of treatment.



Anita Parekh & Dr Macphie

OXFORDSHIRE – INFORMAL LUNCH – OCT 2012



The usual good informal lunch was held at the Duke of Marlborough pub near Woodstock.

Many of the regulars attended and it was good to welcome a couple of new faces.

Along with the usual informal chat Sue gave an update about the PRO project and her trip to Philadelphia.

LINCOLNSHIRE INFORMAL GET TOGETHER – OCT 2012

Cheese, biscuits and cakes fortified 16 vasculitis patients and family at an informal meeting at Pam Todd's home on 28th October.

There were two new members present, one with suspected cerebral vasculitis and one with WG/GCA. Both said they found the meeting valuable and felt less isolated having met and spoken with those who understood.



MERSEYSIDE, CHESHIRE & N.WALES - NOV 2012

The meeting was held at the Linda McCartney Education Centre at the Royal Liverpool Hospital on 6th November.

Over 40 attended to listen to a talk given by Mr John Sexton, a pharmacist at the hospital.

Mr Seton's topic was "Steroids and their side effects".

This was followed by a talk by John Mills (V-UK Chairman) on "the history of vasculitis".

West Midlands October Meeting

The Autumn meeting of West Midlands Vasculitis Support Group on October 13th at the Bromsgrove Hilton, was attended by 51 people. The meeting commenced with a tribute to Margaret Gentle, who started the group in 1993. The first meeting was held in 1996 and the group has continued to hold meetings at least twice a year since then. Margaret is now stepping back and the group is being run by David Sambrook and Judy Ross.



After routine business, there were two excellent presentations. The first by Dr Julie Williams, research scientist at the Clinical Research facility in Birmingham, was titled "All ANCA are not equal in vasculitis" (see page 4). The second, by Dr Matt Morgan, consultant nephrologist at Queen Elizabeth Hospital, Birmingham, was on "Infection in people with vasculitis" (see page 5).



*Support Groups continued***Beds, Bucks & Herts informal lunch**

The November informal lunch was remarkable in that nearly everyone that should have attended was ill, including Chris.

However not all was lost. In December the Group met up with the Essex group for a meal at The Anchor Riverside in Hullbridge, Essex. The lunch was arranged by Jack and Carol Mcmenamin.

Everyone had a lovely time, in good company, oh yes, and the food was very good too.

In February a further lunch was organised this time at the Inn on the Lake at Bletchley. A splendid time was had by all.

West Country informal lunch

Lucky for some — 13 intrepid souls braved the dreadful January weather to meet for lunch at the Mill on the Exe in Exeter on the 22nd.

It was good to see new members in addition to many familiar faces and to have chance to share experiences—especially about the drug Rituximab which seems to have benefitted so many.

SE London/NW Kent

There was an excellent turn out and members welcomed guests John and Susan Mills of Vasculitis UK to the meeting.

John gave a talk entitled "Vasculitis, past, present and future" and members asked questions of the visitors and of Jacqui and generally had a good chat.

**NORTH YORKSHIRE - OCT 2012**

The first meeting of the Group was held on 7th October at the Gomersal Park Hotel.

John and Pat spoke about the Route Map, website and the current research being funded by Vasculitis UK.

Mr Alan Pollard, Lynne's rheumatology nurse spoke about "vasculitis after-care". His talk was very informative and he was happy to answer questions and to chat to people.

We all felt that we had made many new friends and there are now two willing helpers - Sandra and Richard.



Lynne Alan Pat John

VASCULITIS IRELAND – CONFERENCE – OCT 2012

This first conference was a great success, with 42 patients, carers, and interested Healthcare professionals attending from all over Ireland.

The speakers at the meeting were Dr Emanon Molloy who gave an overview of vasculitis and large vessel vasculitis conditions with particular emphasis on Giant Cell Arteritis and Takayasu Disease.

Dr Michael Power presented the results of our recent survey on vasculitis incidence and care in Ireland.

Professor Mark Little spoke on his work to improve services for vasculitis care in Ireland, and about the Science Foundation Ireland providing funding to facilitate setting up specialist regional vasculitis clinics.

Michael Clarkson, gave the Sunday morning talk, on recent advances in treatment for small vessel vasculitis (ANCA Diseases).

The enjoyable and plentiful buffet dinner was enjoyed by most delegates and was followed by lots of chat, sharing stories and fun.

CAMBRIDGE—OCT 2012

Sadly this was the last Cambridge meeting to be organised by Jenny Fulford-Brown before she moves to live in South Wales.

There were 41 members in attendance and they listened to Vasculitis UK Chairman, John Mills, deliver a talk on Vasculitis, Past, Present and Future.

Before the close of the meeting Jenny was thanked by the members and by John and Susan Mills for the excellent work she had done for vasculitis patients not only by organising the group meetings but also by offering help and advice to patients. A beautiful bouquet of flowers was presented to Jenny.



Jenny with son David (left) and husband Neils

The group will continue to hold meetings in the capable hands of Lesley Noblett. Lesley's first meeting will be held on 23rd March, when hopefully Jenny will be in attendance.

Contact details for Support Groups can be found on page 26

INTERESTING BITS

Genetic Alliance UK—Toolkit for Route Maps Jessica Burke, who was our lead in the production of the Vasculitis Route Map has helped produce a "Toolkit" for other organisations who wish to produce their own "condition specific " Route Maps.

The experienced gain by the founding Route Map producers, which included Vasculitis UK, have been used as examples of how to approach producing a Route Map and some of the pitfalls to watch out for.

A quote from the Toolkit: *"Our printed and pdf copies of the Route Map have proven highly successful in raising awareness and for patient enlightenment - Vasculitis UK"*



Jenny Fulford Brown (formerly of Cambridge VSG) is now the proud grandmother of twins. Odette and Imogen were born on 23 January, weighing in at 5lbs 8oz and 4lbs 11oz. Jenny's comment on telling the news "relieved and overjoyed, granny Jenny". The congratulations of the Trust are sent to the whole family.

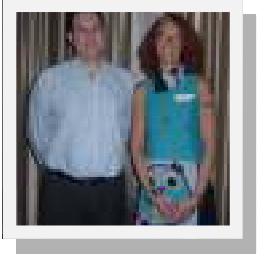
The photo shows Jenny and the new arrivals.



Dr Julie Williams On page 4 you will find a report by Dr Julie Williams on a presentation she made to the West Midlands group in October. Long standing members of the Trust will know that Julie has been a great supporter of the work of the Trust and has prepared several excellent and informative articles for the Newsletter/Journals.

Her work at Birmingham University Hospital has been extremely beneficial for vasculitis patients, not only those who attend the clinics there but to vasculitis patients throughout the UK. Julie has now resigned from Birmingham hospital and has taken up a post in Denmark. Unfortunately for us this is not in the vasculitis field.

We wish Julie every success in her new post and new country. She will be sadly missed. Denmark's gain is our loss. The photo shows Julie and Dr Matt Morgan at the West Mids meeting.



Helen Mayor *Psychological impact of vasculitis - Dissertation Article*

As an undergraduate psychology student, I have had the opportunity to conduct a novel piece of research in the form of a dissertation project. I chose to use this chance to investigate the psychological impact of vasculitis. The change in status of vasculitis from a fatal condition to a chronic illness due to increases in medical knowledge and improved treatments means that individuals are coping with disease symptoms such as pain and fatigue, side effects of medication and the remitting/relapsing nature of vasculitis on a long-term basis. Elevated levels of depression and anxiety are found in chronic illness populations and this finding is replicated in vasculitis populations. However, positive responses to chronic illnesses such as higher levels of life satisfaction and personal growth as a result of facing the challenges associated with illness have also been reported. Therefore, it is important to investigate the factors that may influence psychological adaptation to vasculitis.

One possible factor in the adaptation process is that of metacognitions, which are thoughts about thoughts. For, example worrying about worry. Research has identified a link between maladaptive metacognitions and anxiety and depression in the general population and also in other chronic illnesses. In addition, positive metacognitions and meta-emotions have been found to be associated with positive outcomes, such as life satisfaction, and to contribute to psychological well-being.

Therefore, the project is investigating whether a presence of positive metacognitive thinking and an absence of maladaptive metacognitive thinking can predict life satisfaction. It is also investigating whether maladaptive metacognitions can predict depression and anxiety. A better understanding of why vasculitis has a negative psychological impact in some cases and a positive one in others, will allow more specific and targeted help when seeking to address the problems of anxiety and depression in vasculitis patients.

Clinical trial of Tocilizumab for Giant Cell Arteritis

Pharma company Roche are planning a clinical trial of Tocilizumab for GCA. Tocilizumab has been used successfully in the treatment of rheumatoid arthritis. For details about the trial please contact: Polymyalgia and Giant Cell Arteritis UK at www.pmrcauk.com/ or ring 0300 999 5090

Patient Information Booklet

Jules Darlow — support group leader in Essex - is working towards her PhD. As part of this she is writing a Vasculitis Patient Information Booklet.

In order to do this, she needs to know about and understand the problems and experiences of people suffering from vasculitis. Jules will need to include a mixture of genders, ages and most importantly different vasculitis diseases

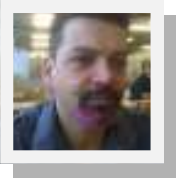
If you can help Jules with her thesis please contact John Mills who will pass on your details to Jules.

Thank you

OUR FANTASTIC FUNDRAISERS - WITH THANKS FROM V-UK

David and Marilyn Bentley

Following John and Susan Mills' interview on the BBC's "East Midlands Today" programme, the owners of their local pub, the Bowling Green in Winster, which dates back to 1472, David & Marilyn kindly donated £100 to V-UK (www.peakparkpub.co.uk/)



Ed Barton joined in with the spirit of "Movember" (grow a moustache in November). He also decided to grow a beard and for extra effect dyed the beard pink. Whether Ed is still hirsute or not isn't known but his kind efforts raised £265 for the Trust.

Helen Blackman of Wendover, Bucks held a Jamie Oliver Party in October 2012, and with the help of a number of friends raised £120 for the Trust. Helen's Dad passed away 10 years ago as a result of WG, and Helen was grateful for the help given to her Dad by the Trust and "wanted to give something back".

Karen Brech works for RBS and has organised two quiz nights to raise funds for the Trust. Karen raised £300. We are grateful that RBS have also donated £250 to add to Karen's donation

The **Buckingham Charity Cup Competition** was formed in 1927 at the Buckingham Hospital Cup. The charity donated to local charities and to those nominated by its members. Andy Bone (Vasculitis UK's ex Treasurer) nominated Vasculitis UK. The Trust has received £75.

Barry & Jayne Coulson held another successful annual Mary Coulson Walk in June 2012 which is held in memory of Barry's wife Mary. On this occasion the participants raised a wonderful £500 for the Trust



Catherine Fowler had only ever run a bath, now she has taken part in several 8K and 10K events in the Brighton area. She laced up her shoes again on 17th February. So far Catherine has raised £410 for the Trust

Paul Hammond "Hammy" was a keen runner until 2000 when he was diagnosed with WG. Although running is out of the question Paul keeps in touch with the running scene by taking photos which he sells and raises funds for the Trust.



Paul has also given his permission for his photographs to be used for Vasculitis UK promotional purposes. So far Paul has raised £263.

You can view Paul's photographs at: www.flickr.com/photos/hammy8241/collections/

In October **Hopton C of E Primary School** near Great Yarmouth, held a "non-uniform day" and raised nearly £75 for the Trust.

IBMS London Regional Virology Discussion Group

This group carry out courses, symposia and lectures and every year they choose a charity to support. This year their chosen charity is Vasculitis UK. Despite atrocious weather in December, when numbers attending the meeting were depleted, they managed to raise £113.

IPM Global Specialists of Peterborough make quarterly charitable donations. In 2012 they presented Vasculitis UK with a cheque for £75



Our intrepid rally driver, **Andrew Irving**, is still raising awareness and funding for Vasculitis UK. Many thanks Andrew for the £80.

Midland Kickboxing

The Midlands Kickboxing Club held a special event in November to raise funds for Vasculitis UK. They raised a wonderful £1300, and the photo shows the cheque being presented to John Mills, in December. Mark and Lindsey Whitehead are members of the club - Mark has WG.



Lions Club of Dursley Thanks to the Charlie William bringing the Trust to the attention of the club. They kindly raised £2110. on behalf of Vasculitis UK. As a thank you Charlie spoke to the club members about vasculitis.

Midland Mencap's Chief Executive, Dave Rogers, has GPA. To celebrate Dave's 50th birthday the staff at Mencap have kindly donated £273 to the Trust

At **Holly Moore's** recent wedding £70 in donations was made to the Trust. This collection was in loving memory of Holly's dear late mother and father.

Natalie Mouldsdale

and 30 friends and family walked from St Helens to Stockton in October 2012. The walk was in memory of Natalie's Dad, Neale, who passed away in 2007 at the age of 46.

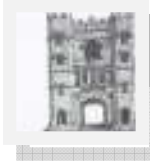


The walkers had a fantastic day. They were walking for 7 hours and there were lots of sore legs. They took the easy way out to get home though, and caught the train!! These wonderful people have raised over £3200 for Vasculitis UK.

Fantastic fundraisers continued ►

Fantastic fundraisers (continued)

The young at heart "The Old Girls" of South Derbyshire District Council still meet up for lunch and use the opportunity to raise funds for charity. Lynne Cotton, one of our members is one of the "young at hearts". This year they have kindly donated £55 to the Trust.



Newgate Club is a small group of friends who meet to have lunch and raise money for charity. This year the Club has raised a magnificent £4000 for their charity of the year - Vasculitis UK - which was selected by the current Principal Eddie Botham.

The money was raised through a system of "fines" and charity donations. In February Mr Botham presented the cheque to Barry Coulson whose wife Mary sadly passed away in 2009 as the result of WG,

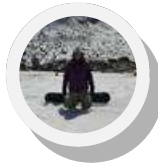
Potters Leisure Resort of Norfolk run a book stall for visitors who pay £1 towards borrowing books during their holiday. This has resulted in £143 being donated to Vasculitis UK.

Lucy Riveiros very kindly made her own Christmas cards to sell to family and friends and raised £342 for V-UK.

Isabel Rodriguez. Thank you Isabel for once again organising a dance session to raise funds for the Trust

Allison & George Tattersall of Whitby kindly donated £20 to the Trust, which was money saved from not sending Christmas cards by post.

Georgia Upjohn and her friend Abbie entered the Bath Half Marathon on 3rd March. They were asked "what's vasculitis then?" and they replied "people not knowing is why we are doing this". They have so far raised over £1000.



Mark Wakeman - Mark took part in the Coniston 10K trial in October 2012. His gallant efforts resulted in £250 being raised for the Trust in memory of his father Stuart

The Westonbirt Golf Club have once more kindly donated to the Trust in memory of Keith and Hilda West. On this occasion the Club has raised £75

Jennifer Wormald has again donated the profits from the sale of jewellery to the Trust. In addition Jennifer sold Christmas cards and her total donation is £112.50.

Dr Julie Williams, formerly of Birmingham University Hospital, made a presentation for the Werfen Group's Instrumentation Laboratory at their November 2012 Autoimmune Focus Group. Julie kindly donated her fee £150 to the Trust.

Winster Morris Men quiz night was held in January. Following John's BBC appearance they generously donated £140 from the quiz to Vasculitis UK

**Don't forget:**

Andy Bone's "Sports-Shots" Andy sells his sports photographs, which you can view at: www.sportshots.org.uk

Rita Allen (Essex) **01255 820307** and **Jennifer Wormald** (Yorkshire) **01937 586734**

These two ladies make exquisite jewellery which they sell and the profits come to Vasculitis UK

LITTLE T'S HOLIDAY COTTAGE**HOLT, NORFOLK**

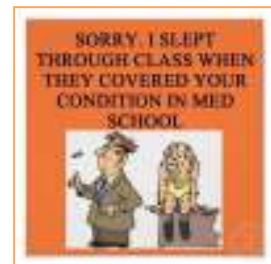
Tracy Martin has raised awareness of vasculitis and several thousand pounds for Vasculitis UK with her themed balls. To show our appreciation we are happy to give details of Tracy's holiday cottage in Holt, Norfolk.

Tracy's late partner Gordon (also known as Motty) died from complications due to Wegener's. He loved the cottage, Albert's fish and chips and the North Norfolk coast.

If you would like to hire the cottage, sample the fish and chips and visit this lovely part of the country, please contact Tracy: 01359 233343 (answer machine).

You will find full details and photographs at: www.littletscottage.co.uk

Alternatively e-mail: littlel@lineone.net, or write to: Tracy Martin, 10 St Mary's View, Pakenham, Suffolk, IP31 2ND

**ALL ABOARD WITH LITTLE "T"**

Tracy Martin's "All Aboard with Little T" charity ball in October 2012 was held at the magnificent National Trust property at Ickworth House. The ball was a resounding success. This was the second ball that Tracy had organised to raise funds for Vasculitis UK and was in memory of her partner Gordon

Mott who died in 2006. Gordon had WG but he lived life to the full even after being diagnosed.

A few brave souls dressed in a nautical theme, and there were a few "hello sailor" to John (Captain Pugwash) Mills and to Susan (the lady pirate) Mills.

"Captain" Dr Matthew Lockyer (Gordon's GP) opened the proceedings. Dr Richard Watts (Gordon's consultant) was the guest speaker. There was a delightful jazz band which consisted of Tracy's friends. The vocalist was Lynda (Dr Lockyer's daughter). Over 130 of Gordon and Tracy's friends attended the ball.

Vasculitis UK is grateful to Tracy and all her guests who raised a magnificent £2575 for the Trust.



ALEVIATE TRIAL

In 2012 Vasculitis UK helped to part fund a trial at Addenbrooke's Hospital, Cambridge, of the drug Alemtuzumab (Campath) for treating vasculitis which was not responding to normal therapies.

The trial is on-going despite slow recruitment and difficulties with supply of the drug over the past year. However, on a promising note Addenbrooke's have secured sufficient alemtuzumab to treat a further 22 patients to complete the study.

They are awaiting approval from the ethics committee to allow the team to broaden their inclusion criteria and, therefore, recruit patients with Churg Strauss Syndrome and Behçet's Disease as well as patients with Granulomatosis with Polyangiitis (GPA) and Microscopic Polyangiitis (MPA)

Our aim is to fund more essential vasculitis research in the UK but we can only do that if members and fundraisers continue to make donations to the Trust

WHERE HAVE YOUR DONATIONS GONE?

CYTOMEGALOVIRUS (CMV) IN ANCA-ASSOCIATED VASCULITIS

Cytomegalovirus (CMV) is a virus that usually does not cause symptoms in healthy individuals. Most people pick up the infection in childhood or early adulthood and it remains in the body for life. It can undergo periods of reactivation particularly at times of stress. The body's immune system tries to keep the virus in check. However this means that a large proportion of T-cells (part of the immune system important for fighting infection) are 'committed' to responding to CMV. Some of these T-cells appear not to work well and recent research has shown that previous CMV infection in the elderly is linked with a poorly functioning immune system.

The Birmingham research team have shown that people with ANCA-associated vasculitis (AAV) who have a lot of these CMV 'committed' T-cells also suffer from an increased number of infections. It may be that the already compromised immune system in people with AAV 'allows' more frequent reactivation of CMV leading to a vicious circle of further damage to the immune

system and a greater burden of infections.

Vasculitis UK is helping to fund an investigation into the use of a well-established anti-CMV drug called valaciclovir. The Birmingham team believe that treatment with valaciclovir may be able to reduce the number of CMV 'committed' T-cells in people with both AAV and CMV and allow the immune system to improve. They are conducting a clinical trial to see if this hypothesis is correct.

If the hypothesis that valaciclovir reduces CMV reactivation and in turn decreases the number of CMV 'committed' T-cells is correct, this could lead to a treatment that reduces the frequency of infections by improving the immune system in people with AAV.

At present the research team are optimizing and validating all of the different laboratory assays that will be used in the clinical trial and are hoping to start recruitment by May-June 2013.

In the past five years Vasculitis UK has funded over £200,000 in research, and presently the Trust has earmarked at least £50,000 for research during the next few years

UKIVAS REGISTRY

Starting in the Spring of 2013 this exciting project will be benefitting from a five year funding package from Vasculitis UK. The Registry will be a UK wide initiative with all the major vasculitis centres, and other centres being involved to build a database of vasculitis patients in the UK - something which has not been possible in the past.

This is an excellent opportunity for patients to become involved in both clinical research and in deciding how vasculitis services are configured around the country.

One of the main remits of the registry and of the working group involved, is to examine how medical care for vasculitis cases is managed to ensure that patients with this rare disease get "joined up" care from the multiple specialties they encounter.

If you wish to be enrolled in this unique project then approach your vasculitis doctor and ask to be enrolled so that from the registry data the project team can obtain as complete a picture as possible from all parts of the UK and Ireland.

IN MEMORIAM

Often donations or funeral collections are made and given to the Trust in memory of a particular individual. Most, but not all, suffered from vasculitis themselves, or possibly a family member did. Many of us with vasculitic disease are past the first flush of youth and may have been living with the disease for many years. It is sad, but not altogether surprising, that we do get a few deaths to report each year.

Our sympathies are extended to the families and friends of those mentioned below. The Trust is extremely grateful for the kind and generous donations and bequests received. These will help us with the activities of the Trust, especially our research projects.



Roy Edwards of Bournemouth



Roy passed away on 24th July 2012.

Roy's family and his friends, particularly those from his scoutmaster days, have kindly donated £250 to the Trust in Roy's memory.

John Gardner

John passed away in late 2012 having suffered from vasculitis. John's son Peter, family and friends have kindly donated £105 to the Trust in his memory.

Mrs Debbie Gregson

Debbie was a mother, partner of Nick and sister to Veronica, Mathew and Sammy. Debbie was taken very cruelly from her family, and in Debbie's memory her family and friends have donated £140 to the Trust.

In memory of Laura Heraghty's uncle

Laura's uncle died in 2012. Laura made a kind donation to the Trust of £30 for her 30th birthday in memory of her uncle.

In memory of Ian Johnson

Ian passed away in December 2004 just two weeks after being diagnosed with WG. Ian's widow, Deborah, has donated £105 to the Trust in Ian's memory from a football reunion evening.

Mrs Betty Kasmir

Betty, a WG patient, passed away in August 2009. Her daughter Mrs Sue Sherrard kindly donated £100 to the Trust in her Mum's memory.

John Kealey of Kilmarnock, Scotland

John passed away in late 2012. John was husband to Wilma, a Dad and an uncle. His family and friends have kindly donated £860 to the Trust in his memory.

Mark Anthony Knott of Butts Hill, Frome, Somerset

Mark passed away in September 2012. Mark's wife and his family and friends kindly donated £130 to the Trust

Mrs Geraldine Llewellyn of Oswestry, Shropshire

Geraldine passed away in November 2012 after a short battle with vasculitis.

Geraldine's daughters, Caren and Ruth, and her family and friends kindly donated £670 to the Trust in her memory.

James Maitland of Oban

James Maitland, a long-time resident of Oban, on the west coast of Scotland, sadly passed away recently due to WG, aged 60. Although a joiner by trade he had several occupations over the years, from bus driver to chip van owner, but for 36 years he also served with Oban Retained Fire and Rescue Service, becoming Officer in Charge. James was a very popular local character. He was survived by his wife Catriona, children Ross and Marie and two grandchildren.



The funeral collection of £2190 was given in support of Vasculitis UK. However, James's widow, Catriona, requested that the Trust donate half of this amount to the Lauren Currie Foundation.

Mrs Kathryn Laws of Walton-on-Thames, Surrey

Kathryn was diagnosed with an extremely rare form of vasculitis 11 years ago. She sadly passed away in January 2013 as a result of a chest infection and complications with her vasculitis. She was only aged 40.

Although she spent the last six months in hospital her husband Chris was able to take her to some of the Olympic games and for a short break to France

Both Kathryn and Chris were members of the Surrey VSG. So far nearly £2000 has been kindly donated to the Trust in Kathryn's memory.

In Memoriam continued on page 24

In Memoriam (continued)

David Robert Smith of Aylesbury, Buckinghamshire

David passed away in late 2012. His wife Brenda and family and friends have donated £115 to the Trust.

Whilst David did not have vasculitis his son-in-law, Paul Pender was diagnosed with WG 18 years ago, and Paul kindly requested the donation be made to Vasculitis UK

Mrs Jenny Waters of Blackwood passed away on 28th June 2012 two days before her 58th birthday.

Jenny's daughter Leanne has kindly donated a further £500 to the Trust in Jenny's memory.

Mrs Glenys Margaret Williams of Llanelli

Glenys was a retired librarian and faithful member of Zion Welsh Baptist Church, Llanelli. She had been widowed for 28. Glenys was diagnosed with vasculitis over 20 years ago having previously survived breast cancer.

Glenys was appreciative of the care she received from the NHS in Wales and at Ty Mair Care Home in Felinfoel near Llanelli, and from her family and friends who helped her to retain her independence for so long. They have kindly donated £500 to the Trust in Glenys's memory.

The Trust now has a simple and sensitive Just Giving page for those who may wish to raise funds for the Trust by celebrating the life of a loved one. Please visit: www.justgiving.com/VasculitisUK/Remember

PERSONAL INDEPENDENCE PAYMENTS (PIP) - CLAIMS ON PHYSICAL AND MENTAL GROUNDS

Often the first question asked is what are the differences between the Disability Living Allowance (DLA) and PIP? This is Vasculitis UK current understanding of the similarities and differences. These may change as more information becomes available. Like DLA the PIP will not be means tested and it does not require national insurance contribution. This means it can be claimed if you are working or not. It is non-taxable and acts as a passport to other benefits.

PIP differs from DLA in that there will be only two rates. There will be a lower standard rate and a higher enhanced rate. The DLA has three rates.

PIP award will differ from the DLA as it will be based on a points system.

Like the current system there will be special rules that apply to people with terminal illness. Also like the DLA, PIP can give some claimants access to Motability scheme and automatic entitlement to a Blue Badge.

Unlike the current system the majority of awards are intended to be time limited. The majority will be for either two years or five years. There is likely to be regular reassessment for as long the benefit is being claimed.

Like the current system people who qualify for benefit below the age of 65 can continue receiving it beyond 65 provided they are still eligible.

PIP will have two components. They are the daily living component and the second is the mobility component. Each component has two rates. The first is a standard rate and the second is an enhanced rate.

The claimants who are assessed as having "limited ability daily living activities" are paid the standard rate of the daily living component currently £53.00. "Severely limited ability daily living activities" will be paid the enhanced daily living component currently £79.15.

Similarly those who have "limited ability to carry out mobility activities" are paid a standard rate of the mobility component current £21.00. Those who are "severely limited ability to carry out mobility activities" will be paid the enhanced rate £55.25.

The next question is when will I be affected? The transfer of all claimants from DLA to PIP is expected to take 5 years. It will not be completed until March 2018 and those claimants with indefinite awards will be the last to be assessed. The current timetable:

April 2013

A pilot will begin on 8th April 2013 for **new** claims for PIP in the North West and part of North East England.

PIPs continued on page 25

*PIPs continued***June 2013**

All new claims from anyone 16-24 will be PIP throughout the UK. The exception will be renewal claims from fixed-term DLA award which are due to expire by the end of February 2014. These cases the renewal claim will still be for DLA.

October 2013

From October 7th the following will have to claim PIP: Any children turning 16 when their fixed term award is coming to an end will need to claim. The next group are people reporting changes of circumstances that might affect their rate such as a change in their condition. Lastly people with fixed term DLA award which expires from the end of February 2014.

October 2015

From this date all other working age DLA recipients will have to claim for PIP. Claimants will be selected

randomly rather than by area or age although the DWP say they will "invite claims as early as possible from recipients who have turned 65 after 8 April 2013 when PIP was first introduced".

What needs to be remembered it that it is early days and thing will change as the PIP programme is rolled out and as claims are processed and assessments are challenged. It is important to be aware of the changes but claimants should not worry.

Vasculitis UK volunteers, along with other groups who support people, are undertaking training to understand the changes and will be there to offer support if required.

You can always follow updates yourself on www.benefitsandwork.co.uk

Report prepared by Jann Landles

Don't forget that by donating at least £5 a year to the Trust you will help us to cover our printing and posting overheads for YOUR Newsletter/Journals and enable us to use more of the donations we receive to fund essential vasculitis research and meet our other aims here in the UK. Many thanks.

TRAVEL INSURANCE

Goodtogo Insurance have been recommended for offering a high level of cover for pre existing conditions at a reasonable price. **0844 334 0160**
www.goodtogoinsurance.com

JustTravelcover: Chris Newton and his staff offer "a service where member's interests are paramount" whether this is cover for pre-existing medical conditions or for clients over 65. The Trust would be happy to hear of your experiences when using this company. Please mention the Trust when requesting details from JustTravelcover: www.justtravelcover.com/
0800 294 2969

Medici Travel: Offer travel insurance to cover pre-existing medical conditions. e-mail: customer.services@medicitravel.com, phone: **0845 8800168** or visit their website: www.medicitravel.com

The **Post Office** offers different levels of travel insurance. Some conditions may not be covered, others may require an additional premium. Details are available from any Post Office.



Virgin Insurance: Cover for pre-existing conditions and for over 65's. A number of members have used this service and have commented on the efficiency and cost effectiveness of the cover. **0844 888 3900**
www.uk.virginmoney.com/virgin/travel-insurance/

The Trust would be pleased to hear of your experiences - good or bad - when using any of these travel insurance providers.

"Connoisseur: A specialist who knows everything about something and nothing about anything else"

Ambrose Bierce (1842-1913)

**Please stay in touch****Keep your details up-to-date****e-News**

The e-News is sent to all Members where we have an e-mail address. If you don't receive the e-News then we don't have your current or correct e-mail address on file.



If you wish to receive the e-News or to change your e-mail address e-mail the Editor - pat.fearnside@vasculitis.org.uk

**Newsletter/ Journal**

To update your home address or other details on the database, please e-mail John Mills - john.mills@vasculitis.org.uk or write to John - Contact details on page 28.

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The Ring A support group in Norfolk for RA patients. **Judith Virgo**
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* **Vasculitis patients offering support — *not a Support Group***

New Groups for 2012-13



East Midlands



Liverpool/Cheshire



North London



N.Yorks



York

VASCULITIS UK SHOP

We have now extended our range of quality goods which we are selling to raise awareness of vasculitis and to boost the Trust's funds. All profits will go towards meeting our aims. Clothing is made from good quality 100% cotton.

All prices include VAT and p & p.

Route Map for Vasculitis £10

t-shirts/v necks £11 each

Running vests £11

Sweatshirts £15

Polos £11.50

Hoodies £18.50

Waterproof coat with hood

Green or black £25

Sizes — small 36, medium 38/40, large 40/42, X-large 42/44.

Baseball hats one size. £8

Wristbands £1.60

Beaded bracelets £4.00

Beaded key-rings £4.00

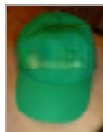
Vasculitis UK "Winston" teddy bears—two sizes £12 or £10 each

Vasculitis UK "Winston" teddy bear key rings £6

Waterproof draw-string back-pack—green or black £8

New Vasculitis UK lapel badge £2

Remember our prices INCLUDE postage and packing



Name: _____ Phone No. _____

Address _____

Post Code _____

Description + colour (if applicable)	Size	No.	Unit Price £	Total £

Sub Total	£	
Opt. donation	£	
Total	£	

To purchase from the Trust's shop please photocopy the order form and return to: **Vasculitis UK, West Bank House, Winstanley, near Matlock, Derbyshire, DH4 1DQ** with your cheque payable to Vasculitis UK. Please print clearly and include your phone number, in case of query. If you are not satisfied with your purchase, just return it unused and we will refund your money, less the cost of p&p.

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LIFE PRESIDENT – LILLIAN STRANGE

Vasculitis UK ♦ is the UK's No. 1 Vasculitis charity, established in 1992. We are an independent organisation funded only 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

Registered Charity No. 1019983

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



♦ formerly known as : **Stuart Strange Vasculitis Trust**

SOME OF THE VASCULITIDES

Anti GBM (Goodpasture's Disease)

Henoch-Schönlein Purpura

Behçet's Disease

Hypersensitivity Vasculitis

Central Nervous System Vasculitis/
Primary Angiitis of the Central
Nervous System

Kawasaki Disease

Cogan's Syndrome

Microscopic Polyangiitis

Cryoglobulinemia

Polyarteritis Nodosa

Eosinophilic Granulomatosis with
Polyangiitis
(Churg Strauss Syndrome)

Polymyalgia Rheumatica

Granulomatosis with Polyangiitis
(Wegener's Granulomatosis)

Relapsing Polychondritis

Giant Cell/Temporal Arteritis

Takayasu Arteritis

Urticarial Vasculitis

**Have you visited our
new website?**



www.vasculitis.org.uk



◀ Scanning this QR code will take you directly to our new website

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