



VASCULITIS UK

Newsletter & Journal

Autumn 2013

Issue No. 46

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CHAIRMAN’S REPORT



Plus ça change.

A French phrase which translated literally means “it changes more”. Freely translated it means “there are even more changes on the way”. Since I am writing this whilst in France and it’s about reform and change and I was at the Paris International Vasculitis conference in April, a few words in French don’t seem inappropriate.

Most people will know that in England, the Primary Care Trusts have been abolished and replaced by GP-led Clinical Commissioning Groups. It was recognised that special arrangements needed to be made for treating those with rare diseases, such as vasculitis. These are the changes that I’m excited about.

It is normal to be distrustful of change. We prefer the familiar, warts and all, the tried and trusted, the status quo, fearing the unknown and suspecting that change will be for the worse, which it sometimes seems to be; but change can also be an opportunity for improvement.

GP-led Clinical Commissioning Group - “High quality care for all, now and for future generations”

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NHS England came into existence in March this year. It is effectively part of the Department of Health and is responsible for overseeing the planning, delivery and day to day operation of the NHS. One of the guiding principles is equality of access, as embodied in its slogan “High quality care for all, now and for future generations”. One of the principal aims is to make “best practice” available for all patients, wherever they live in England. (The equivalent bodies to the DoH in Scotland, Wales and Northern Ireland will make their own arrangements.)

These are lofty ideals, but there is great scope for delivering massive improvement in quality of care for people with vasculitis and other rare diseases. Much of the responsibility for turning ideals into reality rests with the new NHS Specialised Services Clinical Reference Groups that will set the national terms and conditions for awarding contracts to supply care for these groups of “special” patients to hospitals. In the case of vasculitis, it comes under Rheumatology Specialised Services.

Vasculitis UK is closely involved in the new Clinical Reference Group that will determine the future shape of NHS care for vasculitis patients. More details of this exciting change are to be found on page 8

NICE and Rituximab

Vasculitis UK representatives have been very heavily involved in the NICE appraisal of Rituximab for treatment of ANCA vasculitis. Vasculitis UK also made

representations to the Scottish Medicines Consortium on the use of Rituximab. We have also been involved in discussions with the All Wales Medicines Strategy Group about Rituximab, on equality of access and the problems associated with cross-border referrals to England.

Other Vasculitis UK Activities

You will read about the activity of our wonderful team of fundraisers elsewhere in this newsletter. Membership grows steadily. We welcome new trustees, Danni Brunwin, Richard Eastoe, Dorothy Ireland and Jacqui Moran and thanked retiring trustee Martin Thomas for his contribution over several years.

The new website has proved very successful, attracting attention worldwide. It has now passed its first birthday and is reported elsewhere.

The online discussion group “Vasculitis UK HealthUnlocked” now has over 1100 members. A new “Young Vasculitis UK” group on Facebook, run by Danni Brunwin, has over 60 members. A new “Vasculitis UK Bereavement Support” group, started by trustees and other members has attracted much interest.

Vasculitis Research Funding

Sponsoring and funding research into vasculitis is one of the core aims of Vasculitis UK. All “surplus” income after covering the day to day costs of running the charity is directed into research. Typically this is 60-75% of income, around £40k. The emphasis is on research for patient benefit. *Continued* ►

Chairman's report continued

However, even a modest research project can cost over £500k, so in recent years we have contributed small sums to support suitable projects where the main funding comes from other sources.

The trustees have recently conducted a review of the process for attracting applicants for research funding with a view to reaching a wider audience with a more transparent process.

Until next time *John Mills*

16th INTERNATIONAL VASCULITIS AND ANCA WORKSHOP - REPORTS BY JOHN AND SUSAN MILLS

In 1988, following the discovery of ANCA (Anti-Neutrophil Cytoplasmic Antibody), a group of excited medical researchers called an international conference in Copenhagen. Fifteen conferences have been held since, in different venues around the world.



This year it was held in Paris in April at the beautiful Institute Cordelier, a former monastery, now part of the Paris Medical School.

I was privileged to attend on behalf of Vasculitis UK. As it was Paris and Springtime, Susan came too. Travelling by Eurostar from London to Paris was very civilised and we

found a modest small hotel next to the Sorbonne University.

This event is the international showcase for vasculitis research and attracts all the top experts in vasculitis. There were 86 speakers delivering 52 lectures and 68 brief oral presentations of their research. Some of these were in the vast main lecture theatre, others in three smaller lecture theatres. Sometimes there were four presentations taking place simultaneously, so there were difficult choices to be made.

Over the three days of the conference, the lectures and presentations began at 8am and finished at 7pm, so it was certainly not a "holiday in Paris"! In addition to the presentations, there were 230 "posters" on display. These were written presentations of pieces of research printed on large (1m by 2m) boards displayed around the cloisters of this lovely building.

Thus, in total, there were 350 pieces of vasculitis research being reported on covering all aspects of **all** types of vasculitis. Fortunately for me, the language of the conference was English. I really did feel privileged to hear some of the top experts in the world talking about their particular field of vasculitis research. It is pleasing to report that UK research and UK speakers featured very prominently in the programme.

The conference was superbly organised by the French Vasculitis Study Group. The host was Professor Loïc Guillevin of Paris University, one of the pioneers of vasculitis research. A very hard act to follow for the next International Conference in London in 2015.

Continued on page 10

Diary Dates

SUPPORT GROUP MEETINGS

Polite note: For VSGs please book to help with organisation and for ordering refreshments. For contact details for Support Groups please see page 26.

East Midlands VSG

5th October at the Clock Warehouse, Shardlow, Derby

London - SE London/NW Kent

5th October - Informal lunch, The Stage Door, Dartford, Kent.

Merseyside, Cheshire, N.Wales VSG

7th October, Royal Liverpool Hospital.

All Ireland Vasculitis Conference:

12th/13th October at the Royal Marine Hotel, Dun Loaghaire.

West Midlands VSG (VSGWM):

13th October at the Hilton Hotel, Bromsgrove.

Yorkshire (North/West)

20th October at the Gomersal Park Hotel, Gomersal, Bradford.

London (North) VSG:

20th October at the Swiss Cottage Centre, London.

Yorkshire N&E Riding - 27th

October, Informal lunch, Huntington, York.

Beds, Bucks & Herts VSG

9th November - Informal lunch at The Papillion Restaurant, Hertford.

Cambridge VSG: Saturday 7th December, Holiday Inn, Impington.

South Wales VSG - New Year lunch

- 4th January 2014. Jenny Fulford Brown will be arranging this on behalf of Jackie. Please contact Jenny for full details after 14th October.

FUNDRAISERS

Team Clare - Julie Rose Ashford Half Marathon - 13th Oct

Philippa Fortescue - An evening of Scottish Country Dancing in Lyme Regis - 26th October. 01297 442181

Natalie - Mouldsdale - Halloween Event in St. Helens - 26th Oct

Claire Rounph, Rebecca Ledger & Joanne Hargreaves - Stow Half Marathon - 27th October

Full details about all the above visit: www.vasculitis.org.uk/events

VASCULITIS IN CHILDREN

Dr Paul Brogan, Reader in Vasculitis and Honorary Consultant Paediatric Rheumatologist, University College London, Institute of Child Health and Great Ormond Street Hospital NHS Foundation Trust, gives us an overview of the different forms of vasculitis affecting children

Henoch Schönlein purpura

Henoch Schönlein purpura (HSP) is the commonest form of vasculitis in children, affecting between 10 and 20 per 100,000 children every year. Half of all cases present before the age of five. HSP usually presents with rash (purpura, figure 1), usually on the legs but occasionally much more widespread, tummy pain, arthritis and joint pains. The most severe complication is kidney involvement (glomerulonephritis), affecting about a quarter of patients, albeit usually only mildly. Less than 10% will develop more severe kidney involvement.



Fig 1: Typical (severe) palpable purpura of HSP in 13 year old girl with renal involvement

Most children will not require specialist investigations or treatment; paracetamol and/or ibuprofen are helpful for relief from fevers, joint and abdominal pain. Children with severe abdominal pain, once intussusception has been excluded, may benefit from a short course of prednisolone, although the value of steroids in preventing renal involvement has not been proven. Steroids and other immunosuppressants, however, may have a role in children who develop severe kidney involvement. There are few clinical trials to guide treatment; corticosteroids help those with severe nephritis but there is scant clinical evidence into the role of other immunosuppressants.

Pitfalls in the diagnosis and management of HSP

The trick is identifying the rare cases with severe renal involvement, so that more aggressive treatment can be given earlier to secure better outcome. In general, children who present with evidence of kidney failure, lots of protein in the urine (sometimes with visible blood giving the urine a smoky red appearance), peripheral oedema and high blood pressure, have the worst long-term kidney outcome. A paediatric nephrologist should manage children with kidney involvement.

One pitfall is to diagnose "atypical" HSP when in fact the child has a more sinister form of vasculitis, requiring much more aggressive treatment. The rash associated with polyarteritis nodosa, or ANCA vasculitis can be very similar to HSP. Clinicians should be alert to this in children with unusually severe presentation of what initially looks like HSP.

Kawasaki disease

Kawasaki disease (KD) is the second commonest vasculitic condition of childhood, affecting approximately eight per 100,000 children under the age of five years, in the UK. The disease presents with prolonged fever, typically longer than five days, sometimes much longer,

unusual rashes (figure 2), red eyes, swollen lymph glands in the neck, red lips and tongue, swellings of the palms and soles with later peeling, and irritability. A quarter of untreated children develop coronary artery aneurysms (figure 3). Prompt treatment with intravenous immunoglobulin (IVIG) combined with high dose aspirin reduces this severe complication to approximately 4%; low dose aspirin in the convalescent phase may prevent thrombotic complications. Children with more severe disease have even higher risk of coronary artery aneurysms and benefit from the addition of corticosteroids to IVIG to prevent coronary aneurysms. A new UK guideline to help clinicians identify which patients require the addition of corticosteroids to IVIG will be published soon.



Fig 2: Kawasaki Disease



Fig 3: Coronary angiogram revealing a giant coronary aneurysm in KD

Pitfalls in the diagnosis and management of KD

It used to be said that if there was evidence of infection, then one could not diagnose KD. Now we know infectious triggers are relatively common for KD. Clinicians should not be put off a KD diagnosis if the clinical features fit and there is a lack of response to antibiotics, even if an apparent infection is discovered at the disease onset. If there is diagnostic uncertainty, children can receive antibiotics and IVIG to prevent severe coronary artery injury from missed KD.

Clinical features may present sequentially; clinicians should be alert to this, and enquire specifically about retrospective symptoms or signs that may fit with KD but have resolved by the time of clinical review.

Lastly, another misconception is that "treatment doesn't work 10 days after the onset of the illness"; this is incorrect and clinicians should treat if there is ongoing inflammation indicated by blood tests, and/or other inflammatory clinical features.

Polyarteritis nodosa

Polyarteritis nodosa (PAN) is a rare but serious form of vasculitis, involving predominantly medium and small-sized arteries. The clinical features may evolve gradually with non-specific features such as fever, rashes and joint pains. The disease can affect any organ in the body. PAN mimics many childhood diseases; chronic infection, malignancy, immunodeficiency, and other forms of vasculitis need to be excluded. Specialist tests such as skin/other tissue biopsy, nerve conduction studies, and specialist imaging including various forms of angiography are important to secure the diagnosis.

Continued ▶

Vasculitis in Children - continued

Some children develop a predominant cutaneous form of the disease, requiring less aggressive approaches to treatment. Children with severe forms of the illness should be treated aggressively with high doses of corticosteroids and immunosuppressants to induce remission. After three to six months, the treatment can be changed to lower doses of corticosteroids and milder forms of immunosuppression such as azathioprine to maintain remission for a further one to two years, depending on the clinical course. Although relapses can occur, unlike ANCA vasculitis there is a very good chance of curing PAN using this approach.

Pitfalls in the diagnosis and management of PAN

Severe systemic PAN can be confused with HSP, or the more benign cutaneous form of PAN. This leads to therapeutic delay and worse outcomes. Another misconception is that "non-invasive" forms of angiography are equivalent to catheter angiography; they are not (Figure 4) and clinicians should not be falsely reassured by a normal CT angiogram. Advice from centres used to doing this test in children should be sought if there is diagnostic uncertainty.

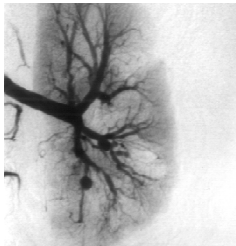


Fig 4A

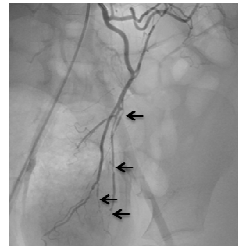


Fig 4B

More subtle changes, including calibre variation and beading of medium-sized mesenteric arteries are 4A: selective renal digital subtraction arteriography in an eight-year-old girl with polyarteritis nodosa. Large aneurysms, small aneurysms, renal, parenchymal perfusion defects, and calibre variation of intrarenal arteries demonstrated. Perfusion defects in the renal cortex are also present.

4B: selective mesenteric digital subtraction arteriography in a six-year-old boy with partially treated polyarteritis nodosa (arrowed) and these are unlikely to have been detected using non-invasive angiography such as CT angiography or MR angiography

ANCA associated vasculitis

Granulomatosis with polyangiitis (GPA, formerly Wegener's granulomatosis) occurs in children much more commonly than microscopic polyangiitis (MPA), although both are rare, probably affecting one per million children per year. Great Ormond Street Hospital sees two new cases a year.

The clinical features of GPA in children are virtually identical to those affecting adults, with ear nose and throat inflammation, airway involvement, lung involvement, and renal vasculitis, among other symptoms.

Children are treated in the same way as adults: induction of remission with high-dose corticosteroids combined with cyclophosphamide, rituximab, or mycophenolate mofetil (MMF), followed by maintenance of remission with low doses of corticosteroids combined with

azathioprine, MMF, or other immunosuppressants. Children are now being included in trials and soon we will have evidence of how MMF compares to cyclophosphamide and whether rituximab induces remission.

Pitfalls in the diagnosis and management of AAV in children

The main pitfall is delay in diagnosis leading to organ injury and even death before a diagnosis is made. Ear, nose, and throat symptoms are very common in the paediatric population, and GPA may not be considered. More widespread availability of ANCA testing and increased awareness will hopefully reduce diagnostic delay, leading to earlier treatment and better outcomes.

Takayasu arteritis

Takayasu arteritis (TA) is the only recognised large vessel vasculitis affecting children. The disease is very rare, probably affecting less than one in one million children per year. The disease is more common in the Japanese population. The disease presents very non-specifically with symptoms such as fevers, headache, fatigue, aches and pains. Hypertension may be the first indication of a problem in children. It is useful to consider the illness in two phases: the initial inflammatory vasculitic phase, followed by a later fibrotic stenotic phase of the illness, where large arteries become progressively narrowed leading to symptoms due to lack of blood supply to organs and limbs. Due to the non-specific nature and rarity of the condition, children are often well into the stenotic phase of the illness by the time the diagnosis is made, sometimes many years after the disease onset. Angiography and other forms of imaging are key to securing the diagnosis. Treatment usually involves corticosteroids combined with another immunosuppressant to induce remission, followed by tapering corticosteroids usually combined with methotrexate or azathioprine to maintain remission. Anti-TNF and anti IL-6 treatments are beginning to be used for resistant paediatric cases, but there is no clinical trial data to guide management.

Pitfalls in the diagnosis and management of TA in children

Clinicians should be alert to the possibility of TA in patients with unexplained inflammation and cardiovascular symptoms such as unexplained cardiac failure, hypertension, or other symptoms of vascular insufficiency affecting the limbs or organs. The disease can even present in infancy; the heart may be primarily affected in children with heart valve insufficiency, myocarditis, or even ventricular aneurysms. Another major diagnostic challenge is to differentiate TA from the many non-inflammatory forms of vasculopathy (sometimes with genetic cause) that can affect children, the commonest being fibromuscular dysplasia. Once the diagnosis of TA is secured, another challenge is how to monitor disease activity. Blood tests may not be reliable. Magnetic resonance scans of arteries looking for features of large vessel vasculitis are important, as are other approaches to imaging such as PET scans, but require specialist interpretation.

Unclassified forms of vasculitis

There are many other forms of vasculitis affecting children that don't fit into any single entity. It's essential that clinicians do not delay therapy if severe vasculitic manifestations are unfolding, even if they don't fit into any particular diagnosis. The sage advice of "treat now and ask questions later" may apply here.

THE UK HENOC SCHÖNLEIN PURPURA NEPHRITIS (HSPN) STUDY (SUMMARY)



Dr. Louise Watson who is leading the research at Alder Hey Children's Hospital has kindly prepared this summary of the study

What is HSP?

Henoch Schönlein Purpura (HSP; also known as IgA vasculitis) is the most common type of vasculitis seen in children with an estimated 20 cases occurring per 100,000 children in the UK. HSP usually presents with a classic vasculitic rash on the lower legs and buttocks, along with abdominal pain, joint pain and joint swelling and also kidney involvement.

For unknown reasons, it is more common in children than adults and generally the outlook for this condition is good with the majority of patients having a flare up of the disease that lasts only a few weeks with no long-term consequences. About a third of patients can get relapses of HSP that can occur even many years after the first episode and generally it presents with similar symptoms to the original episode.

HSP is the most common type of vasculitis seen in children with an estimated 20 cases occurring per 100,000 children in the UK.

Almost half of all patients will get kidney involvement, which ranges from mild to severe inflammation. It is the only long-term consequences of HSP as all other symptoms usually resolve with time. Some patients with HSP (about 1 in 10 patients) develop more severe kidney involvement; this is more often teenagers or adults with HSP rather than younger children. Severe kidney involvement can require intensive investigations (a kidney biopsy) to look at the inflammation within the kidney and depending on the results it is usually treated with steroids and/or immunosuppressive medication.

Kidney involvement is called HSP nephritis, or HSPN. It can lead to long-term health problems including the development of end stage kidney disease (in about 1 in 100 childhood HSP cases) that may require lifelong dialysis or a kidney transplant. In the UK HSPN accounts for 2% of all cases of end stage renal failure in children and this number has not changed despite advances in medicines and improved outcomes in other renal conditions.

Why do we need research into HSP?

Despite this being the most common type of childhood vasculitis there is a significant lack of research in this area, both within the UK and across the world, and therefore many of the management plans that doctors use to treat patients are based on their clinical experience of treating other patients but not from firm evidence. What are needed are robust clinical studies when medicines can be compared against each other and the best one selected.

What is the UK HSPN Study?

In order to try and improve the outcomes for patients with HSP, we plan to collect information on how the disease presents, how it progresses and particularly how it affects the kidneys. Additionally, we are working with paediatric doctors in the UK to develop agreement guidelines on when to do invasive kidney tests and the current best management of HSPN. Once we have developed these guidelines we can begin to use these to plan how we can go about comparing new medications. We are also planning some research to study the immune system in HSP by looking at markers of inflammation in the blood and urine samples that may give us early predictors of kidney inflammation and also see how these compare to samples from patients without HSP to learn more about the condition.

To take this forward we have formed the UK HSPN study group, made up of interested paediatric professionals from across the UK, and we have linked in with adult research groups who are studying similar renal diseases.



Last year we held a local parent/patient focus group to gather research ideas from our patients and these sessions helped us to formulate the priority areas that we have mentioned. We are currently undergoing regulatory approval for the study.

Once we have achieved these goals we can use the guidelines and immune system studies to begin to compare new treatments and work towards improving the long-term kidney outcome for our patients.

A HSP focus group was held at Alder Hey Children's Hospital to gather ideas for research from patients and parents

What do we hope to achieve?

The UK HSPN study group hopes to provide the foundation for research into developing better treatments for HSP in particular those that prevent permanent kidney damage. We hope to develop universal guidelines that will ensure each patient has similar management regardless of where they are cared for and these guidelines can then be used in clinical trials to compare new medicines. We understand the importance of listening to patients and we aim to continue to work with patients and parents who have experienced HSP to make sure that our research is appropriate to their needs.

We are grateful to Vasculitis UK for their support and we look forward to keeping the members up to date with the progress of this proposed study.

KIRA'S STORY

Kira is 9 years old. She has HSP and here is her story - in her own words.

"My name is Kira. I am 9 years old, I was born on October the 1st 2003. I have Henoch Schonlein Purpura which is also known as HSP.

I started to get HSP when I was 4 years old and I have still got it now. I always get it near my birthday which is not very nice as I miss out on my birthday parties.

To me it is the worst rash. It stings, hurts and itches I hate it! It gets really itchy but you can't itch it because it will go worse. My rash is mostly on my legs, arms and elbows. It is worse around my ankles and feet, it hurts on my feet and I can't get shoes and socks on when it is very bad but I can manage it sometimes. I DON'T like it when it infects my knees it gets really painful and I can't move my legs and I find it very painful to walk. Sometimes I need to stretch my legs to exercise them.

It hurts when the doctors and nurses put the needle in my arm and on my hand. They take blood out of me, so they can see if I am getting better. They have to keep checking my blood pressure and my temperature and check my urine, this is because it can affect your kidneys. It hasn't infected my

kidneys but it has infected my intestines. It is really painful. You can get different types of HSP. The type that I get is very bad and comes on very fast in a few hours. It normally takes around 6-8 weeks for it to clear up.



When the blisters pop sometimes blood comes out of them! It is gross. I don't like it when the blood comes out, it is freaky. It hurts when the doctors pop them in the bath and from outside the bath. I also get a special bath which is coloured pink. It is really cool and awesome I love it. The bath is for all the blisters, it also cleans them out, so I need a bath nearly every night, I can only put my slippers on.

When I am in hospital I make stuff, like today I made a Halloween sculpture, coloured in a plate and made it sparkle. I also made a monkey it was fun.

I would like to raise money for charity all over the world, to help other people that get HSP so they get better. I would also like to raise awareness because not many people know about it. For the charity I will do biking, climbing, rock climbing, and I ran in the Manchester run with my sister and family this Spring.

SHINGLES VACCINE FOR THE OVER 70'S

There is currently an NHS health promotion to offer shingles vaccination to those in the age group 70 to 79. Prof Harper and Dr Matt Morgan have provided this information for the benefit of vasculitis patients:

"The new shingles vaccine for people aged 70 and 79 is a live vaccine and may cause illness in some people whose immune systems are not working properly due to their disease or to some types of immunosuppressive medication. This includes people taking high dose steroids, chemotherapy drugs and some other immunosuppressants.

Current guidance from NHS England is that the vaccine should not be given to

- People who have been taking prednisolone 40mg per day for 1 week or more within the last three months

- People who are currently taking prednisolone 20mg per day or more
- People who have had cyclophosphamide treatment within the last 6 months

The advice for people taking azathioprine, methotrexate, mycophenolate, leflunomide, ciclosporin or other similar drugs alone, or in combination with prednisolone less than 20mg per day, is not clear and these people should discuss the possible risk of having the vaccine with their GP or Hospital Specialist.

There is no current specific advice regarding the safety of this vaccine for people being treated with therapeutic antibody drugs and similar "biologic therapies" (rituximab, infliximab, adalimumab, etanercept, abatacept, anakinra, campath/

alemzumab and similar drugs) and people who have received these drugs should discuss the safety of vaccination with their hospital specialist.

There is general advice that live vaccines should not be given to people currently being treated with most of these "biologic" therapies or within 6 months of receiving anti-cytokine drugs (anti-TNF, anti-interleukin 6, anti-interleukin1etc).

The vaccine can be given safely to people using only inhaled steroids (for asthma or other lung disease) or hydrocortisone steroid replacement therapy provided they do not also come under one of the groups above."

CLINICAL COMMISSIONING GROUPS

Dr Peter Lanyon is a Consultant Rheumatologist at the Queens Medical Centre, Nottingham. He is also the Chairman of the Rheumatology Specialised Services Clinical Reference Group for NHS England.

Dr Lanyon gives us an overview of the work of the Commissioning Groups and what they aim to deliver for the patient.



High quality care for all, now and for future generations

Specialised Commissioning

Most readers will be aware that major changes in the organisation of the NHS were introduced in April 2013. The majority of routine NHS care (including hospital care) is now "commissioned" locally by organisations called Clinical Commissioning Groups, which are usually led by General Practitioners.

However, a new organisation, NHS England, has taken over the responsibility for commissioning care for people living with either very rare or very costly medical conditions. This is so that decisions about providing this care can be made at a national level, rather than at each local CCG level. This new process is called Specialised Commissioning.

Why have these changes been introduced?

For many years it has been recognised that people living with rare diseases (e.g. Vasculitis) can sometimes find it difficult to obtain the right specialised healthcare that they need, and this can often vary according to location, particularly for high cost drug treatments.

It is also thought likely that receiving care from hospitals which have a greater experience of a rare disease will result in a better outcome, compared to smaller centres which only occasionally treat a particular condition. So the ambition behind these changes is to ensure that NHS England provides the same access to high quality specialised care for all people with rare diseases regardless of where they live.

How will these changes happen?

NHS England has established Clinical Reference Groups for each branch of medicine, whose role is to advise on how specialised care should be provided in the new NHS. I was appointed this year to chair the Specialised Rheumatology CRG, which comprises senior doctors elected from each region of England, and Patient and Carer members recruited via a national selection process, and we are very pleased that John Mills successfully applied to join this team!

Although Vasculitis is primarily within the remit of the Specialised Rheumatology CRG, this care will require a team approach, and is likely to be led locally by either a Renal Physician, Rheumatologist, or Dermatologist depending on expertise and circumstances in each centre.

There is likely to be at least one specialised centre in each region of England, but at this time the exact number and location of these is not yet known. NHS England has recently asked all Hospitals for evidence of whether they meet the necessary requirements (which the CRG has defined) to be designated a specialised centre. When these results are known, these centres will have a contract with NHS England to provide this patient care from April 2014 onwards.

What will this mean for people living with Vasculitis?

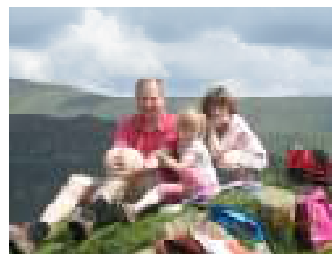
Each specialised centre will be expected to develop ways to lead improvements in the care of all patients (e.g. with Vasculitis) at all hospitals in their region. This doesn't necessarily mean that patients would have to travel or could not continue to be treated in their local hospital. However, these changes should lead to patients being able to readily access a greater level of expertise than is available locally, when needed. The exact circumstances will depend on local arrangements but are likely to include situations where there is diagnostic uncertainty, and either severe disease unresponsive to standard care or is frequently relapsing, or where access to novel treatments is required.

What progress has been made so far?

The CRG has formulated a national policy, published by NHS England on 1st April, which enables access to funding for Rituximab for any patient in England who meets certain criteria e.g. when other drugs haven't worked or would cause severe side effects, or where ongoing treatment with Rituximab is required to maintain remission. This has removed any "post code lottery" associated with obtaining treatment, although clearly this policy may need future revision depending on the results of an appraisal of this drug by NICE.

In parallel to this, there is a programme of ongoing work within the CRG to advise NHS England on standards of care and how to improve these, including better identification of how many people have Vasculitis, and the quality and outcome of their treatment, and there is significant involvement of UKIVAS members on this work.

So in summary, Specialised Commissioning is a new and ambitious process which started across all specialties, and this has never been done before!. We need to seize the opportunity that this provides, to try and shape future services to meet the needs of VUK members and all people living with Vasculitis and other rare diseases, and all of us involved in this process are working closely to ensure that we give the best advice to NHS England on how this should happen. We will provide further updates as this process develops.



Peter with his family enjoying some well earned relaxation between his hectic schedule.

LIVING WITH VASCULITIS: CAN TAI CHI BE HELPFUL?

ALICE MUIR - SPECIALIST NURSE - QUEENS MEDICAL CENTRE, NOTTINGHAM

In 2006 I was treated for breast cancer, and in 2009 it came back - my worst fear. It was during this treatment that I first became aware of the Tai Chi for Health Institute and its programmes. I was feeling unwell with fatigue, poor sleep, pain and generalised stiffness: all side effects of the chemotherapy I was receiving. I had lost my fitness and needed something to hang on to, and was lucky enough to be able to access some Tai Chi for Health classes, and these impressed me enormously!



Alice (2nd from Left) receiving her Tai Chi certificate

Tai Chi is an ancient Chinese martial art that dates back to the 15th century. Nowadays it is mainly practiced for its health benefits. There are a number of different forms or styles of Tai Chi requiring differing levels of exertion and some forms may take many years to learn. I was able to learn small sequences, based on Sun style Tai chi, which had been developed by Tai Chi and medical experts to be safe, effective, manageable by most people and relatively quick and easy to learn.

I found the movements to be a gentle form of physical exercise but unlike traditional forms of western exercise there was an additional meditative benefit, promoting relaxation and a 'calming of the mind'. It is thus an exercise for both mind and body i.e. 'moving meditation'. By training the mind to focus on the movement and concentrating on learning and practicing the moves, I found there was no space for gnawing worries, and some respite from the pain.

There is considerable evidence to suggest that exercise can promote health, prevent illness and aid recovery.

As a Nurse Specialist treating patients with Vasculitis I had spent many years studying and looking for strategies to help support people who are struggling to live with the debilitating effects of their illness and its treatment, particularly fatigue. There is considerable evidence to suggest that exercise can promote health, prevent illness and aid recovery. Regrettably, as I found when unwell, it can be difficult to do this.

Studying for a masters' degree I became very interested in guided imagery and relaxation but I was aware it is quite "abstract", can be difficult to grasp,

and not easy to practice when struggling with anxiety and pain. My experience of Tai Chi is that it combines both elements of exercise and relaxation, in a way which is tangible and manageable. The movement is slow, flowing and easy, and not difficult to do. I found a further benefit was the social aspect of the support, company and friendships that stem from attending a class. I have met some wonderful, inspiring people who I am now glad to call my friends.

In Chinese philosophy and medicine, Chi is a life force or energy. It is believed that Tai Chi generates and promotes the circulation of Chi enhancing health, wellness and vitality. This may be a notion that does not sit comfortably, but the idea that we can help ourselves is both empowering and comforting.



The ladies and gentlemen of Alice's Tai Chi class

On returning to work as a Nurse Specialist, it struck me how there are some similarities between living with cancer and living with Vasculitis. Both can threaten any organ in the body, causing symptoms that can require significant emotional and practical adjustment. Treatment can be arduous and disruptive and there is always a fear of relapse. Living with illness is stressful, and this stress can trigger harmful physical, emotional and social responses.

Tai Chi may not suit everyone, but I have found it an extremely practical and useful strategy to add to my armoury of resources! It is an extra tool that can be learnt and practiced, and complements the other things in life such as family and friends, a good book or film, a glass of red wine, home made cake and Ollie my dog (a strange idea of therapeutic but nevertheless he is!)

I have now learnt to teach these programmes and run a weekly Tai Chi class, overlooking the lake in my local park, which I enjoy and is great fun! If you would like more information on Tai Chi, there is a guide on the NHS Livewell website or the Tai Chi for Health Institute.

www.taichiforhealthinstitute.org/

<http://www.nhs.uk/Livewell/fitness/Pages/taichi.aspx>

Alice Muir

Report on the 16th International Vasculitis and ANCA Works - continued from page 3

Susan Mills' memories of the 16th International Vasculitis Workshop in Paris 2013

John asked me to accompany him to Paris where he was representing VUK at the workshop. I thought "brilliant - a little sightseeing and shopping, then mop John's tired brow in the evening after his long day". How wrong I was!

On the first day, I met John for lunch after spending a pleasant morning at Notre Dame. It was the end of the first session, he was so enthusiastic about his morning, he persuaded me to stay for the afternoon session. So I joined him in the main auditorium. I was amazed. There were over 300 doctors from all around the world listening to David Jayne speaking. We were sitting with Dr Mike Venning from Manchester. It was fascinating, so I stayed there all that afternoon.



Foundation in the US and Jane Dion from the US Churg Strauss Association. It was lovely to meet and chat with them all and have our photos taken together.

On the third day John persuaded me to attend a workshop discussing Takayasu Arteritis. He also wanted to attend a workshop on new and rare types of vasculitis. Both were scheduled at the same time. He went to his workshop. Armed with a note pad and pen I went to mine. I got a little lost on the way and a lovely guy with an American accent pointed me in the right direction. Later he came and sat next to me to listen to the presentation.

There were doctors from India speaking as well as the UK experts, Professor Paul Bacon and Professor Justin Mason from the Hammersmith. The guy next to me asked lots of questions and was very vocal. Later I learned he was Dr Peter Merkel one of the best known vasculitis doctors and researchers in the US.

The final workshop was in the main auditorium. Dr Peter Merkel, Dr Gary Hoffman also from the US, Dr David Jayne and many other well known doctors gave presentations about Vasculitis, past, present and plans for the future. The whole three days were an experience I will never forget and I am looking forward to the next International Vasculitis Workshop in London in 2015 .

There were over 300 doctors from around the world listening to David Jayne speaking

Day two and we met for lunch again and John introduced me to Bernard Piastra who has WG and set up the French "Wegener's Info" group.

We also met Peter Verhoeven, representing the Dutch vasculitis support group (of similar size to Vasculitis UK), Joyce Kulman the Director of Vasculitis

HELP RAISE AWARENESS OF VASCULITIS AND VASCULITIS UK

Did you know that you can do your bit to help raise awareness of vasculitis and of the work of Vasculitis UK?

Please "re-cycle" your Newsletter/Journal to good effect when you have finished with it. Here are two important ways to help raise awareness.

- ▶ The first is by taking your Newsletter/Journal to your hospital or GP's waiting room when you have finished with it.
- ▶ The second is to leave your copy with your consultant or GP. We are sure he or she will find the medical articles of interest. Hopefully this might prompt them to bring the Trust to the attention of any new patients attending the clinic or surgery.

DONATING TO VASCULITIS UK



The work of Vasculitis UK is undertaking thanks entirely to voluntary donations. Without **your** support we could not support patients, raise awareness and help fund research here in the UK.

Although we do not have an annual donations or a joining fee, please consider kindly donating at least £6 a year towards the cost of your two bi-annual Newsletters. This will enable us to use our finances for the benefit all vasculitis patients.

Please remember, unlike some charities, we have a Board of unpaid Trustees and we have no paid staff and no fancy offices.

You will find a Donation Form enclosed with this Newsletter or you can pay by card at: www.justgiving.com/VasculitisUK/donate

Thank you

VASCULITIS : THE PATIENT’S EXPERIENCE - DR NINA BROWN

There is increasing Government, NHS and public awareness of rare diseases. In particular there is focus on vasculitis as a set of diseases with strong public representation, led by Vasculitis UK. Recent Rare Disease Conferences / Study days have acknowledged the gold standard set for other diseases by the Vasculitis UK Route Map. There is also a planned move towards development of recognised Centres of Excellence, with accessibility to support the local clinical teams caring for patients. However, in order to inform improvements to care giving and co-ordination in this area, it is vital that we the clinicians understand the patients’ experience of the systems currently in place.

Therefore, to establish areas that may benefit from improvement we undertook a national survey of vasculitis patients with the support of Vasculitis UK. The initial drive to undertake this work came from patients in our Manchester Specialist Vasculitis Clinics who raised a number of different issues that we felt needed further investigation. These included: the sometimes lengthy time taken to receive diagnosis; being told they had a different health problem before vasculitis was recognised and differing levels of knowledge amongst patients, particularly regarding treatments and side-effects.

With the assistance of members of Vasculitis UK and a team of doctors, nurses and scientists with an interest in vasculitis, we designed a questionnaire that would cover these and other areas.

This was sent out in the Spring of 2011 to all members of Vasculitis UK, and we would like to take this opportunity to thank those of you who took the time to reply and also for the many supportive letters we received regarding this work. More than half of all members replied, which is a very high response rate for a postal questionnaire.

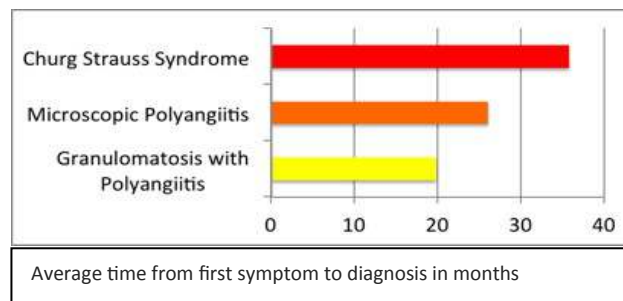
Of these (378 replies) we have initially looked at those who were completed by patients with a diagnosis of “ANCA Associated Vasculitis” or “Systemic Vasculitis” so that we could make some comparisons across the groups due to their similarities (particularly in treatment received). There were 306 responses which fitted this category and you can see a break-down of who responded in the figure 1. ►

If you filled in the questionnaire you will remember that it covered many areas, of which there are too many to present fully here. We will, therefore, describe a selection that we hope will be of interest.

We firstly wanted to know about time to diagnosis. We thought it would be helpful to split this up according to diagnosis given as the different forms of vasculitis present in different ways - meaning some patients may be diagnosed quicker than others. It can be seen in the graph below that the average time to diagnosis ranged from just under 20 months for patients with Granulomatosis with Polyangiitis (formerly known as Wegener’s Granulomatosis) to over 35 months for those with Eosinophilic Granulomatosis with Polyangiitis (EGPA, formerly Churg-Strauss Syndrome). However, many patients with EGPA have asthma before they develop vasculitis, and it may be that some people have regarded the onset of their asthma as the first symptom from vasculitis.

Demographics	Patient numbers (%)
Granulomatosis with Polyangiitis (Wegener’s Granulomatosis)	241 (79%)
Eosinophilic Granulomatosis with Polyangiitis (Churg Strauss Syndrome)	41 (13%)
Microscopic Polyangiitis	15 (5%)
Other "Systemic vasculitis/AAV"	9 (3%)
Total	306
Female	190 (62%)
Male	112 (37%)
Not specified	4 (1%)
Age	61.7 years (range 21-87)
White British	285 (93%)
White other	5 (2%)
Other	10 (3%)
Not specified	6 (2%)

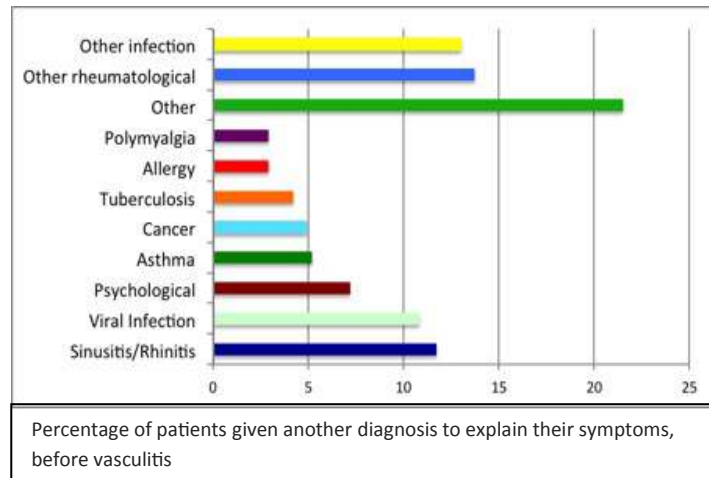
Overall it seemed that there is the potential for improvement in the time it takes vasculitis patients to receive a diagnosis, particularly with increased investment of attention and resources to rare diseases. See figure 2 ▼



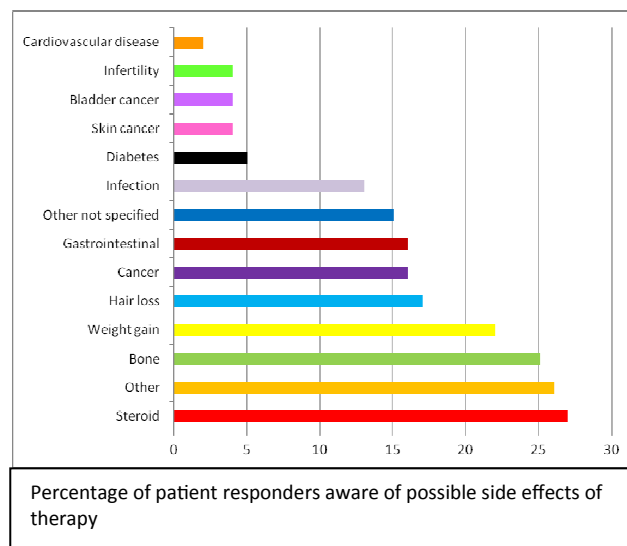
Continued ►

Vasculitis: The Patient's Experience - continued

We then wanted to know if people were told that they had something else to explain their symptoms before being diagnosed with vasculitis. This obviously may result in a delay to diagnosis for some. 71% of patients were told that they had another condition initially. A breakdown of these diagnoses are given in the chart below with people commonly being told their symptoms were due to infection, or another condition such as rheumatoid arthritis. See figure 3. ►



We also wanted to know about the awareness of potential side effects of medication often used to treat patients with vasculitis, such as cyclophosphamide, azathioprine and steroids. You can see from the graph below that this knowledge level was generally low, particularly with regards to fairly common side effects such as increased risk of infection, and less common but more serious long-term side effects such as cancer.



Overall we feel that the results of this study demonstrate that better education and awareness is needed regarding vasculitis, for both patients and medical staff, perhaps by aiming to provide more detailed and structured guidance for care across the UK.

The Vasculitis UK Route Map, published in 2012, is an excellent start to improving the standard of information that is out there and will benefit patients and their families, doctors and nurses alike. However, alongside that we need to ensure that we provide enough information for our patients in clinics regarding their disease and treatment.

Here in the North-West we are running a series of "Vasculitis Masterclasses" mainly aimed at doctors and nurses who may come into contact with those with vasculitis. The aim is to increase awareness and improve knowledge to allow vasculitis to be diagnosed earlier but also to

avoid some of those "misdiagnoses" which many of you have experienced.

For further information on this work, or any of the points raised in this article please contact nina.brown@cmft.nhs.uk.

With grateful recognition of the support and input from Vasculitis UK and the North-West Vasculitis Group, in particular Dr Mike Venning.

STOP PRESS - SCOTTISH MEDICINES CONSORTIUM APPROVE THE USE OF MABTHERA™ (RITUXIMAB) - SEPTEMBER 2013



On 10th September 2013 the Scottish Medicines Consortium approved the use of MabThera (Rituximab) for treatment of GPA (Wegener's) and MPA in cases where the disease is relapsing, or where use of cyclophosphamide is either unsuitable or found to be ineffective; although its routine use as an initial induction or for maintenance was not approved".

Vasculitis UK was the only patient organisation that made a submission to the SMC supporting the application and we are very pleased that patients in Scotland will have access to this valuable treatment.

V-UK has also been heavily involved in supporting a similar application to NICE by drug manufacturers Roche for approval of the use of Rituximab in England. The application was rejected at the first stage, but additional evidence was submitted to the committee for the second stage. We are now awaiting their decision.

PERSONAL STORY - JOHN ENGLISH

I was diagnosed with WG in April 2009, aged 43. I had been fit and active, competing in cycling time trials and triathlon events. However I was having random joint pain that would last for a few days and then move to a different part of my body. GP's tests were inconclusive and I was diagnosed with gout. I modified my diet but began to experience other issues. There were skin lesions on my torso and legs - diagnosis "impetigo".

I was training for the Great North Run but I felt really tired, I had no strength in my hands, and my wrists were hurting. I put it down to old age creeping on, did the half marathon and finished in a decent time.



I've now been in remission for three years and steroid free for two years, I'm planning to take part in fundraising for V-UK in 2014

As the winter passed the aches and pains appeared in different parts of my body. I was tested for diabetes and prostate cancer, thankfully I had neither. In February I was aware of my diminishing health and the 50-70 mile training rides I would normally complete were leaving me wrecked.

More tests - the results were puzzling and nothing was showing up. Why did I feel so dreadful inside when there was nothing showing on the outside or on the tests? My colleagues noticed I was finding work increasingly difficult and following nagging from my wife, Ann, I went back to the doctors. This time an appointment was made with the rheumatologist for possible migrating poly arthritis. Without a diagnosis all that could be prescribed was ibuprofen and paracetamol.

By late March work was becoming more difficult, I was very lethargic, suffering from pain in my joints, increasingly short of breath and having difficulty walking. One evening Ann took me to A&E at the Queen Elizabeth Hospital. I explained my symptoms but my joints were moving freely as I was lying down. There was no swelling and my muscles responded to resistance tests. As a cyclist I was used to working through the pain barrier and have a high threshold. My vital signs appeared to be normal with a healthy resting pulse of 88; however, this was double my normal rate, something they didn't appreciate.

After several hours still nothing to find. "Keep taking the ibuprofen and keep the rheumatology appointment". I was disheartened and felt like a fraud - but why was I feeling so dreadful when they couldn't find anything wrong?

It was too difficult to go to work. I was fatigued and in pain - the bottoms of my feet felt like they were being hit with a hammer when I tried to walk. When I was sleeping my breathing was twice the normal rate. Ann was becoming increasingly worried. By 6th April I was running a temperature, exhausted and had a small nodule on both elbows and had multiple joint pains. Another visit to the QE where one of the consultant rheumatologists assessed me.

Much discussion with colleagues and "rheumatic fever" was diagnosed. At last a diagnosis, what a relief.

That was short lived however and over the next few weeks I deteriorated further. Every day I kidded myself I was getting better. I became weaker, could hardly walk and the pain now involved all my joints, and my muscles were aching. My symptoms were now - red eyes, double vision, high temperature, multiple joint pains, coughing up blood, elbow nodules, malaise, breathlessness, anaemia, high pulse rate, a fast breathing rate, and then passing blood. Back to the QE.

Luckily, after three days in MAU (Medical assessment Unit) I was sent to the Newcastle RVI to see an eye specialist. Why luckily? The eye specialist had been a kidney doctor. He focused on my urine tests, and after what seemed like a lifetime said "you might have Wegener's Granulomatosis".

Then it was chemotherapy and high dose steroids. I started to feel much better within 24 hours. I must have looked a sight though. I had lost 16 lbs, hadn't shaved for days, had a patch over one eye and generally looked like crap. After reading about WG on the hospital internet I'm not embarrassed to say I cried myself to sleep on more than one occasion.

I continued to improve but developed a DVT (left leg, both veins, ankle to groin). More hospital visits for tinzaparin injections and now Warfarin was added to my daily diet of medication - oh joy!

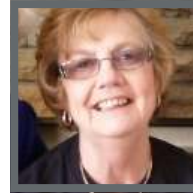
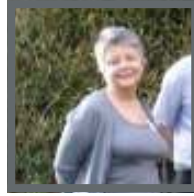
I've now been in remission for three years and steroid free for two years. I don't compete on my bike now but I cycled 9000 miles in the past year. I'm running again (slowly) and aim to do the Great North Run, or maybe a cycling event in 2014 when hopefully I will raise some money for Vasculitis UK.

I hope my story helps anyone out there with similar symptoms to get an early diagnosis.

Cheers. *John English*

MEET YOUR VASCULITIS UK BOARD OF TRUSTEES

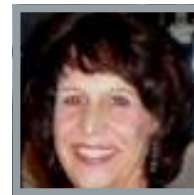
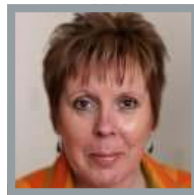
2012/13 saw a number of changes to the V-UK Board of Trustees. Here we introduce you to some you may already know and to some who have recently joined us. Apart from Professor Harper all the Trustees have vasculitis so we are proud to say that Vasculitis UK is run **by** vasculitis patients **for** vasculitis patients.



Left to Right: **John Mills** (Chairman), **Richard Eastoe** (Vice Chairman), **Jann Landles** (Hon Secretary), **Pat Fearnside** (Treasurer & Newsletter Editor) and **Professor Lorraine Harper** (Medical Advisor)



Left to Right: **Anita Parekh** (Assistant Treasurer), **Chris Stait**, **Danni Brunwin*** and **Dorothy Ireland***



Left to Right: **Jacqui Moran***, **Lisa Ranyell** (Lisa is on the Left !!), and **Lynne Jacques** (V-UK "Shopkeeper")

* **New Trustees**

ONE YEAR ON - THE VASCULITIS UK WEBSITE

The Vasculitis UK website went live on 1st September 2012. Since then we have been amending, updating and improving, and we are continuing this process.

We have had phenomenal results with the number of visitors far exceeding our wildest dreams.

Statistics

The main statistics from 1st September 2012 to 31st August 2013 are summarised below:

1. Approximate No. who visited on at least one occasion = 67,500
2. Approximate No. of actual visits made by the above = 98,750
3. Approximate No. of pages viewed = 423,000

Pages visited:

The majority of pages visited were in connection with vasculitis, ie Individual Diseases, Symptoms, Treatment, Causes and Diagnosis.

The most visited individual vasculitis disease pages were Wegener's Granulomatosis (GPA), Urticarial Vasculitis and Behçet's.

Also high on the list were the pages dealing with Living with Vasculitis, Inspirational Stories and FAQs.

Countries visiting:

Most visits were, of course, from the UK - approximate figures 78,000 but also the USA (7,500) Canada (1,500) Australia (1,450), India (1,250) and Ireland (1,100).



In total there have been visitors from 156 countries including countries such as - Philippines, Thailand, Egypt, Chile, Guatemala Macedonia, Ecuador and Uzbekistan.

The website has showcased the work of V-UK internationally

The website has boosted the reputation of Vasculitis UK here in the United Kingdom, particularly with medical professionals.

The website has also helped raise awareness of vasculitis and showcased the work of your charity on a truly international scale.

DEDICATED DOCTORS SHARE KNOWLEDGE OF VASCULITIS

Vasculitis UK trustee Richard Eastoe reports on the first vasculitis postgraduate education session in June at the newly formed Imperial Vasculitis Centre, Hammersmith Hospital, London.

Prof Charles Pusey opened the event informing us that the education session would contain a mixture of clinical and research updates and case study presentations. He outlined the purpose of the newly formed Imperial Vasculitis Centre of Excellence, their need for patient involvement and highlighted the work we do at Vasculitis UK with particular praise for the Route Map.

Prof Dorian Haskard, a Vascular Rheumatologist at Hammersmith, discussed Behçet's syndrome.

He noted that many treatments such as thalidomide and cyclophosphamide were outdated, superseded by the new biologic, anti-tumour necrosis factor (TNF) agents. Prof Haskard said cyclophosphamide had virtually no effect on the disease whereas infliximab, an anti-TNF agent, had brought on a good remission in some cases. Trials were currently on-going with anti interleukin 1 beta drugs and also interferon.

Prof Haskard explained Behçet's syndrome is usually more severe in men than women, with a correspondingly higher mortality rate. He suggested patients should not undergo any corrective surgery for aneurysms until any inflammation was under control. He also recommended against taking anti-coagulants, like aspirin, or undergoing dental procedures or arterial catheters. Dentistry can potentially cause ulcers and catheterisation may lead to aneurysms.

Prof Justin Mason, a Vascular Rheumatologist at Hammersmith, discussed Takayasu's arteritis.

He said the outlook for patients with Takayasu's was improving : diagnostic time is being reduced, imaging is getting better and immunosuppressive treatment is improving all the time. 80% of patients have only a short-term disease, lasting about two years, with 20% relapsing.

Prof Mason said typical symptoms of Takayasu's arteritis included stenotic lesions (narrowing of a blood vessel) in 90% of cases with aneurysms (bulge in a blood vessel) in about 25%. He said magnetic resonance angiography was useful in showing oedema (swellings in the blood vessels) before stenosis sets in.

The recommended treatment is currently prednisolone combined with methotrexate, azathioprine or mycophenolate. Prof Mason noted that with the advent of biologics, pulsed cyclophosphamide is being used less often. Professor Mason also advised that it was best to suppress disease activity before any corrective surgery was undertaken.

In the future, Prof Mason suggested that pentraxin 3, a protein that can be produced by cells in response to primary inflammatory signals, might be used as a biomarker for disease activity.

Finally, **Dr Alan Salama**, nephrologist at the Royal Free Hospital, discussed predicting relapse in ANCA associated vasculitis (AAV) and compared approaches to induction and maintenance of remission.



For induction he suggested cyclophosphamide was better than methotrexate, but equal to rituximab. Cyclophosphamide was not as good as rituximab for relapses but was equal to mycophenolate plus steroids.

For maintenance he suggested azathioprine was equal to methotrexate and better than mycophenolate. He said the role of rituximab in maintenance was still an unknown.

Dr Salama said that relapses were more common in ANCA-PR3 than ANCA-MPO vasculitis but ANCA was not a good predictor of relapse and other biomarkers may be the way forwards. New research showed monitoring the CD8 T cell signature can predict relapse in many autoimmune diseases, including AAV. He said that calprotectin may also be a predictor of relapse.

Finally Dr Salama talked about the possible role regulatory B cells may have in sustaining remission in AAV and possibly other forms of vasculitis. The Immune Tolerance Network is currently funding a trial into this.

Three case studies were also presented : a case of Henoch-Schönlein purpura (HSP) in an elderly patient, a case of an elderly patient with ANCA-MPO vasculitis plus anti-glomerular basement membrane (GBM) disease, and a case study about Microparticles found in Behçet's and cancer.

Note by Richard: As ever with these clinical seminars, I was impressed with the enthusiasm and interest that doctors, consultants and professors have for learning about vasculitis and treating the disease. But while the future is improving for patients with vasculitis, the rise in interest in vasculitis is having an unexpected effect on research. Prof Haskard told me that with the recent opening of the Behçet's centres of excellence he was no longer seeing new Behçet's patients. This means he will probably lose his funding and have to stop his research into the disease.

◀ The session was organised by Prof Mason.



More information about these case studies can be found in the full article on our website.

JIM BORNAC'S LETTER FROM AMERICA

It is with great excitement that I have this opportunity to write my first "Letter From America". My aim is to tell you a little about the vasculitis scene here in the US, and add a few cartoons which, hopefully will travel from this side of the pond to your side.

I've had "Central Nervous System Vasculitis" for about 25 years. Diagnosed in 1993 but started having symptoms in 1988. It's been a roller coaster ride just like anyone with Vasculitis. Some of you may know me from the V-UK Facebook site.



I live in Snelville near Atlanta in Georgia, the most populous state in the US, also known as the Empire State of the South or the Peach State. Atlanta was, of course the home of the 1996 Summer Olympics, and is the home of the Atlanta Braves, the Atlanta Hawkes and the Atlanta Falcons.



Coming up in September - The Atlanta Georgia Vasculitis chapter are looking forward to an exciting meeting on September 12 with a special guest speaker: Dr. Athan Tilakos, Assistant Professor, Division of Rheumatology, Emory University School of Medicine.

Since our last meeting, members of our group have been involved in several activities that have raised awareness about vasculitis. I'm especially excited about a new initiative that the Vasculitis Foundation has chosen our Atlanta group to be a part of the "Grass Roots Chapter Model Initiative".

We are very fortunate that Dr. Athan Tiliakos has agreed to partner with our group and work closely with the VF as this new plan is rolled out. It will bring medical centers such as Emory, and physicians who have an interest and expertise in vasculitis, closer to the patients that need their care.

Good news for patient care from the University of Florida.

A Vasculitis Unit is planned for the future in conjunction with new faculty recruitment. Through the Autoimmune Disease Center, they are developing disease management pathways that will serve to optimize the clinical monitoring and therapy of patients with systemic autoimmunity.

Vasculitis Awareness Month

Way back in May the Governor of Georgia, Nathan Deal, made a proclamation "Month of May



Proclamation: Vasculitis Awareness Month



Tim Tebow greets Bailey Knaub

designated Vasculitis Awareness Month". There I am on the left as part of the Atlanta Chapter receiving the Proclamation.

American football and Vasculitis

You can't get away from American football but an added bonus for raising awareness of vasculitis came when one of the top players with the Denver Broncos was given the "heave-ho" as I think you British might say.

"Heartbroken" is the word a 17-year-old girl from Loveland, Colorado used when her favourite player, quarterback Tim Tebow, was traded. Bailey Knaub who has had Wegener's since she was 7 years old has special reason to be faithful to the player. She was his guest at a recent celebrity golf classic. She also spoke at the gala. Like other Broncos fan, she has switched allegiance to Tebow's new team, and now she is chanting J-E-T-S like a life-long fan.

So for now, let me leave you with these two cartoons. One shows how we often react when taking Pred, and the other what we often think. So until next time, keep well, keep positive and keep happy. *Jim*



It is better to be roughly right than precisely wrong
John Maynard Keynes - 1883-1946

THE ROLE OF METACOGNITIONS IN ADAPTING TO LIVING WITH VASCULITIS

HELEN MAYOR—UNDERGRADUATE PSYCHOLOGY STUDENT

Helen has kindly provided V-UK with a summary of her recent PhD Dissertation. See Spring 2012 Newsletter, page 19, for an introduction to Helen’s dissertation:

Background

Elevated levels of depression and anxiety are found in people with long-term illnesses and this is also found in people with vasculitis. However, positive responses to long-term 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. As an undergraduate psychology student, I have had the opportunity to conduct a novel piece of research into the psychological impact of Vasculitis specifically looking at metacognitions and the role they may play in adapting to a long-term condition. Metacognitions are thoughts about thoughts, for example, worrying about worry. There is a link between high levels of negative metacognitions and anxiety and depression, both in the general and chronic illness populations. On the other hand, positive metacognitions are linked to positive outcomes, such as life satisfaction, and contribute to psychological well-being. In particular, three positive metacognitive factors are important to successful adaptation. These are; confidence in preventing negative cycles of thinking, confidence in controlling reaction to negative emotions, and confidence in setting realistic and flexible goals.

This project investigated if a presence of positive metacognitions and an absence of negative metacognitions can predict life satisfaction, reflecting successful adaptation in individuals with vasculitis. The project also investigated the impact of negative metacognitions on depression and anxiety.

Key findings

Higher levels of depression and anxiety were found in individuals with vasculitis compared to the general population. Individuals with vasculitis were also found to have lower levels of life satisfaction compared to the general population. (Figs 1 and 2).

Figure 1: The average level of depression and anxiety in Vasculitis patients compared to other patient population samples

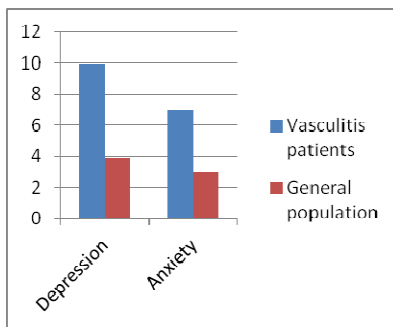
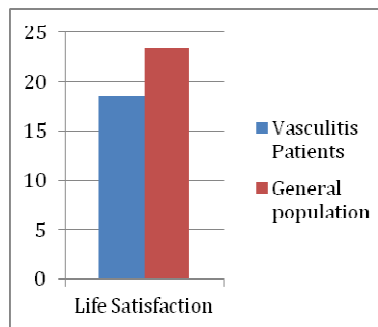


Figure 2 The average level of life satisfaction in Vasculitis patients compared to other patient population samples



Metacognitions and Depression and Anxiety

Individuals with high levels of negative metacognitions had higher levels of depression. The same was also found with anxiety, and levels of anxiety increased with higher levels of negative metacognitions.

On the other hand, high levels of positive metacognitions; confidence in preventing negative cycles of thinking, confidence in controlling reaction to negative emotions, and confidence in setting realistic and flexible goals, were associated with lower levels of anxiety and depression.

Continued ►

VASCULITIS AWARENESS MONTH

Vasculitis Awareness Month in May might have its origins in America, but Vasculitis UK members responded splendidly to the challenge and raised awareness in their local communities by newspaper and radio interviews.



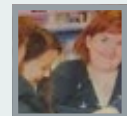
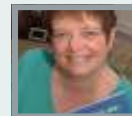
V-UK Trustee **Lynne Jacques** told her story in the local Bradford press and was interviewed several times by Leeds and Bradford radio stations.

Martyn Wells really got the ball rolling with his radio interview on BBC Worcester which was followed up with an interview in the Worcester News.

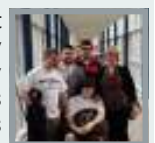


Kevin Soper and friends organised two teams of parents to battle it out on the football field and the report appeared in the Kentish Express.

The York Press interviewed **Julie Scott**, and **Sarah Thomas’** story appeared in the Brentwood Gazette.



Finally we must mention **the Family Hart** whose story about Giles appeared in "This is Local London".



Well done to everyone who helped raise awareness of vasculitis. Thanks to your endeavours a few more people will at least have heard the word "vasculitis".

If you have internet access you can read the full articles, together with other later articles which have been published, at: www.vasculitis.org.uk/about/newspaper-magazine-articles



You can now support the work of Vasculitis UK simply by using your phone.

Switch to Donate Mobile – a complete mobile phone service offering everything you'd expect, with one BIG difference – each month 10% of your mobile spend goes directly to Vasculitis UK at no extra cost to you!

So call now for further details:
0203 463 1386

Charged at standard local rate

www.donate-mobile.com/vasculitis-uk/



BENEFITS AND WORK

Are you making a Disability Living Allowance (DLA) or Employment and Support Allowance (ESA) claim or appeal? Or are you being transferred from Incapacity Benefit to ESA?

Claiming government disability benefits or having to undergo re-assessment can be an ordeal particularly when you are ill. Vasculitis UK has professional membership of "Benefits and Work" (a respected organisation in the benefits field) and this enables us to provide members with information to help them claim benefits or to prepare for an appeal.

If you are claiming or appealing about any of the government disability benefits then contact our Hon Secretary: Jann Landles. secretary@vasculitis.org.uk

The Role of Metacognitions in adapting to Living with Vasculitis - continued

Metacognitions and Life Satisfaction

A similar analysis was carried out between metacognitions and life satisfaction. Individuals with high levels of negative metacognitions had lower levels of life satisfaction. The opposite was true for all three positive metacognitive factors and life satisfaction. Further analysis found that the positive metacognitive factors of *confidence in preventing negative cycles of thinking* and *confidence in setting realistic and flexible goals* were most important in predicting higher levels of life satisfaction.

Conclusions

The research highlights that psychological distress, in the form of anxiety and depression, is a significant problem for people with vasculitis. It has also shown a possible link between high levels of negative metacognitions and poor adaptation to the illness in terms of depression, anxiety and low life satisfaction. The results also suggest positive metacognitions are important in successfully adapting to living with vasculitis.

High levels of *confidence in preventing negative cycle of thinking*, may enable individuals to move forward and increase determination to overcome difficult situations. This then provides the opportunity for personal growth, which is reflected in life satisfaction. The other positive metacognitive factor, *confidence in setting realistic and flexible goals*, has previously been found to support adaptive coping by identifying step by step goals. Multiple short-term goals can be effective in assisting positive adaptation to long-term illness.

The findings of this research could inform therapy or coaching interventions. Interventions such as metacognitive therapy aim to reduce negative metacognitive thinking and so, alleviate anxiety and depression. Although, there is no specific intervention developed for positive metacognitions, mindfulness is thought to be conceptually similar to positive metacognitive functioning. Mindfulness is being aware and accepting of current thoughts in a non-judgemental way. While this research is preliminary and requires corroboration, it does suggest that metacognitions are important in adaptation. By seeking to understand both successful and unsuccessful adaptation we gain insight into how psychological distress can be prevented in vasculitis and also how benefits such as positive growth and life satisfaction can be achieved.

VASCULITIS WEB DISCUSSION GROUPS

HealthUnlocked - A private group where you can set your own levels regarding who can see your posts. All posts are relevant to vasculitis. Join at: healthunlocked.com/vasculitis-uk

Facebook - There are now four *Vasculitis UK Facebook group pages* - the original "open" group for general discussion. Join at: www.facebook.com/groups/16351007695/

and now:

Young Vasculitis - for patients aged 16 to 30ish, join at: www.facebook.com/groups/5052015

Bereavement Support - for those who have lost loved ones because of vasculitis:, join at: www.facebook.com/groups/184007648435810/

Timeline information - Up to date information, news, photographs and much more. View at: <https://www.facebook.com/VasculitisUK>

Twitter - Join at: <https://twitter.com/vascuk>



*There are only a few copies of **Debbie's Delicious Cake and Bake Book** left. All proceeds for V-UK. The books cost £5 + £1.50 p&p and would make a great Christmas present for any bakers in your life. Over 50 delicious recipes. The books are available from: Debbie's Recipe Book c/o Mrs Sam Cunningham, 29 High Street, Great Doddington, Northants, NN29 7TQ. Please make cheques payable to "Debbie Gregson Fund".*

OUR FANTASTIC FUNDRAISERS

V-UK would like to thank all those who fundraised for the Trust during the Spring and Summer. Also many thanks to those who sponsored their gallant efforts, including those kind employers who matched part of the amount raised by their employees. We start off with some of the Team events:

KILIMANJARO Mount Kilimanjaro in Tanzania was conquered by Jitesh and Tara Gami, Ashok and Nisha Ladhani and Hiral Lakhman in June. This tested their endurance both mentally and physically. Tara's mum has vasculitis and the climb was for her. The photos show the group at Gilman's Point (at an altitude of 5681 meters). The "Fab 5" raised a high altitude £5174 for Vasculitis UK.



Thanks to Ashok's employers, Economic Group's Charitable Trust who matched his fundraising with a £1000 donation.

LONDON 10K—July 2013

There were a number of teams and individuals ran in this event in temperatures over 30°C to raise awareness and funds for V-UK:

Stephen Barry & Mary Wallace - their friend Des has vasculitis. Between them they have raised £354.



Tavis, Henry, Mark & Duncan Cockrane-Dyett - Tavis has vasculitis but with the others he finished the race and they raised £1390.

Louise & Natalie Cull - Louise and

Natalie's Dad has WG. He was diagnosed in January 2013 after being ill for 8 years. The girls raised £1280. Louise's gran also raised £582 from a cake sale and raffle at her home.



Elliott Darlow - raised £150.

Jolene Rollins' sister has CSS and the race was in her honour. Jolene raised £215.



Daniel Downer also raised £100.

Alexandra Saville, Nikola and Tim ran for Alex's sister and Tim's fiancé Francesca who has vasculitis. Between them they raised £1948.



Team Clare — During the year Janine Brown has been running for Team Clare (remembering Clare Grossman) and for the 10K she joined the other members of Team Clare - Kevin and Stephen Soper and Jo Jones. Janine raised £226, Kevin £313, Stephen £225 and Jo £255.

In addition Kevin & Stephen's employers Premier Foods donated £250. Further donations were made to the Team of £210.

LONDON MARATHON

Rory Scott, Giles Morland and Peter Krens might not have triumphed like Tsegaye Kebede and Priscah Jeptoo, but in their own way they triumphed on 22nd April. The trio completed the London Marathon in memory of their friend Rupert Dickenson, and raised £860 for V-UK

JAMES MAITLAND RUN - Marie Muir & Ross Maitland together Jim (Marie's husband) and the Oban Saints players ran the various sections of the 94 mile West Highland Way in June to raise funds in memory of their Dad, James Maitland who passed away in 2012.



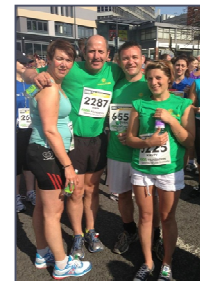
The WHA starts in Milngavie, following the shores of Loch Lomond to the head of Glencoe, finally finishing in Fort William. Not one for the

faint hearted with the terrain ranging from lowland moors, to dense woodland, rolling hills and high mountains.

The efforts of the 22 strong group have resulted in £4280 being raised for Vasculitis UK. The photo shows 9 of the team, with Ross in the front row, 2nd from the left.

LEEDS 10K—TEAM OLYMPUS

Team Olympus comprises Emma Hayden (who has CSS), Natalie Bishop, Adrian Brown, Rick Camm, Steve Cartwright, Steven Gilfoyle, Mark McCarthy, Sean McEvoy, David Ponton, and Kirsty Robinson Together they took part in the Leeds 10K in the heat of 14th July. Between them they raised £2432 for V-UK.



THAMES RIVERSIDE WALK - A large group had a fantastic time as they rambled along the side of the Thames on 22 June.



The walkers were Jacqui Moran and Karen St Ledger (who organised the walk), the Harts & Co (Anthony, Sally, Jack, Edward, Giles, Helen Richards & Gemma Essen, not forgetting doggies Millie and Monty, who raised £2005, Zoe Lovatt (£80), Jane Symonds (£275), Sarah & Deane Thomas, Debbie & Tom Hewitt with Lee, Ann Erin & Jack Brewer (£1530).

Jacqui raised £575. A big thank you to Karen St Ledger and her husband. Karen raised the magnificent sum of £8450. Karen and Vasculitis-UK are grateful to ICAP plc for their generous donation towards Karen's fundraising. The total raised by the Thames walkers was £12915

TOUGH MUDDER — Frank McDonald together with Suzanne, Jan & Steve McBurnie, David Irvine, Christopher Harrison, and Robin Bourne entered the "Tough Mudder" in August.



Continued ►

Our fantastic fundraisers - continued

The event challenges both physical and mental endurance. Frank's mum has vasculitis. The team have raised £1762 for the Trust.

DAVID TYZAC & WILKINSON'S STAFF—

David (who has vasculitis), his mum and dad (Barbara & David) and the staff of Wilkinson's in Barnstaple, organised and took part in a coast to coast cycle ride from Plymouth to Ilfracombe.



The cycling team raised £1106. The Furniture Warehouse donated and sold a suite which raised £550, and a skittles night raised a further £290.

Other donations made the total to £2037. The photo shows David centre with the cheque for V-UK.

WORCESTER WAY WALK - It took many months to organise but, on 29th June, Martyn Wells (who has vasculitis) and 13 happy wanderers set off from Bewdley to walk the 31 miles of the Worcester Way Walk - not only 31 miles but climbs of over 1000 meters. The team members included: Martyn who raised £2444, Hazel Chislett (£325), Kelly Fee (£325),



Chris Jewson (who also has vasculitis) raised £1540.

Andy Mayhew raised (£98), Sarah Pittaway (£1054). Lucy Roberts and Sophie Croft couldn't do the

walk but donated £110.

The charitable Trust of Martyn's employers (Wright Hassall) donated a further £500 and Ella (Martyn's daughter) raised £50 at a bake day at school. The combined total raised for the event was approx. £6450.

YORKSHIRE DALES WALKING FESTIVAL

There was a marvellous turn out for this Jane Tomlinson Walk for All event on 18th August.

Taking part and raising awareness of vasculitis and funds for Vasculitis UK were David Winlo and Ruth Winlo who raised £650. The "Wormald" team were: Amalia Shaw and Lochlan Shaw, Fiona Rowland and John Wormald with two of his friends have so far raised about £300.



Also taking part were Annabel Bolton, Deborah Hall and her husband, and Derek Scott. The individual amounts raised are not yet available but combined are understood to be approximately £1000

Derek (pictured here with his wife Julie who has vasculitis)

undertook the 14 mile Blockbuster section and came home in 1st place.

Beverley & District Sorority. V-UK was nominated as the charity of choice by retiring President Mrs Margaret Moulds. The society raised £130.

Carre's Grammar School in Sleaford, Lincolnshire held their annual 12 mile sponsored walk. Vasculitis UK was selected by Key Stage 5 pupils as their history teacher, Miss Tracey Mills, has vasculitis. The staff and pupils raised £950 for our charity.

Martin Charlton - Martin's mother-in-law has vasculitis. He took part in the Castle Series Triathlon at Castle Howard, Yorkshire on 21 July. The event involved a 400m swim in the Castle Howard lake, a 23k on a bike and finally a 4k run. Martin's endeavours raised £480.



Suzanne Coombs - Suzanne's mum has CSS and she is "one brave lady". So Suzanne became a brave lady on 10 August and undertook a sky-dive and raised £565 for V-UK.

Kira Conroy and sister **Jade**, together with James Caldwell, Bernie Fielden and Phil Smith took part in the Great Manchester Run on 26 May. Kira is 9 years old and has had HSP since she was 4. Together they raised £580.

Billy Crossland - Billy is only 8 years old. His granddad has vasculitis and he is also waiting for a lung transplant. As the photo shows, Granddad was thrilled that Billy ran in the 3km on 17th August at the British Transplant Games in Sheffield. There were all ages taking part and Billy came 6th, and raised a wonderful £165 for Vasculitis UK.



Paul Dubenski raised £100 for V-UK in memory of Debbie Gregson. Paul's employers, BP, kindly matched this amount.

Linda Flegg - The Manx Telecom Parish Walk took place over 22/23 June The 85 mile walk takes in all the parishes on the Isle of Man. Our ace walker was Linda whose husband Mark has WG. She didn't quite manage 85 miles but gave it her best shot and raised £535. V-UK would also like to thank Mark's employers C Brewer & Sons Ltd for donating a further £250 to boost the amount Linda raised to £785.

Hogg Robinson Charity Committee of Hampshire (The 50/50 Club) are nominating a few new charities to support, and this includes V-UK. The committee donated £600 in June.

IPM Global Management have again nominated V-UK as their charity of the quarter and donated £75.

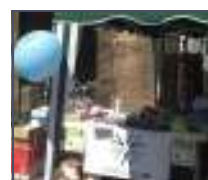
Ann Jackson - In August Ann and Merv undertook a 3 day "145 coast-to-coast cycle ride" and so far raised £10.

Lynnett Judd of Northampton held a "sweet and savoury stall" and raised £100 for V-UK

Marios Kakos - On 14 April Marios completed the Brighton 10K. Marios undertook the event for his mother-in-law, Linda Herriott, who has had WG since 2008. Marios raised £540 for V-UK

Lincolnshire County Council (Customer Services Centre) holds regular office events to raise money for charity. In March they raised £51 for V-UK.

Cheryl Meads and **Lynne Ford** - on 22/23 June Cheryl and Lynne completed the hilly 100km challenge "The Trans Pennine Challenge". They are justly proud of their achievement "Seriously tough, blisters and aches and pains galore, but huge grins of success." The girls raised £1040 for the Trust.



Susan Mills opened her stall at the Winstar Wakes fete in July and raised £100 for V-UK. Many thanks to Jean Morrison, Margaret Butler, Lynne Jacques and Sandra Bingham for donating knitted items and hand made cards.

Our fantastic fundraisers - continued

Aimee Morrison is taking on various challenges to raise money for V-UK including selling her old clothes on e-Bay. So far Aimee has raised £401.



◀ **Alex Morton** ran in the Berlin Half Marathon in April. It was bitterly cold, but Alex finished much to his relief. He raised £255 for V-UK with an additional £230 being donated by his employers Deloitte LLP.

Aasma Rasul ran the Birmingham Half Marathon course in May and raised £125. Barclays kindly matched

Aasma's fundraising amount.

Julie Scott has vasculitis but it didn't stop her taking part in the Race for Life 5K in York. However, in Julie's case it was more a "walk for life". With the encouragement of her husband and family Julie managed the "walk" and raised £273 for the Trust.

Paul Simpson, encouraged by the others members at the Slimming World club in Clayton, Bradford, undertook a six weeks slimming challenge with the aim of shedding 13 lbs. Paul actually lost over 19 lbs during the challenge and raised £230 for the Trust.

Rachel Marsh (right) is pictured receiving a cheque for £200 on behalf of V-UK from Diana Loveland, President of **Seroptimists International Great Yarmouth branch**.



The presentation took place at Diana's end of year cheque giving evening where Rachel gave a little speech. Rachel has suffered from WG since 1994.

The pupils and staff of **Stowe School** in Buckinghamshire held two fundraising activities to raise funds for V-UK. In April the pupils raised £180 and then in May the Cobham Housemaster and his House Pupils held a charity football marathon, and then the whole school participated in an "own clothes day". This resulted in a further £1,183 being

raised. Our charity was chosen because, sadly, the mother of one of the pupils passed away due to her vasculitis.

Taoist Tai Chi Society of GB - Stamford & District Branch have kindly donated £100.

Under 9's Park Farm Rangers Football Club, Ashford, Kent - The Under 9's raised a magnificent £475 for V-UK. One of their members is Callum Grossman whose mum Clare lost her battle with vasculitis a few years ago. The donation was made in memory of Clare.



Walsall Manor Hospital - As part of their Apprentice Framework, to work as a team and raise funds for charity, Claire Martin, Emily James, Sarann Duffy and Sean Morris held a cake sale in the atrium of the hospital.

They raised £365 for V-UK - their chosen charity - and they presented the cheque to Pat Fearnside, representing V-UK at a special event at the hospital.

West Country Vasculitis Support Group -

Philippa, Brenda, Angela and Charlotte had a bric-a-brac stall on a lovely Spring afternoon at the Funday in Teignmouth, Devon and raised £180 for V-UK. The Editor understands the ladies made a big splash with the lads of the local fire brigade and above is the proof.



Jackie Williams entered the Wolf Run in April. This was no ordinary run but involved 10 miles of wild running through mud and over obstacles. Jackie raised £40 for V-UK.

YORK SPRING CHARITY BALL

It was a miserable, wet and cold weekend, not the best of weather to view the wonderful landmarks that York has to offer. However the gloom of the weather disappeared at the Spring Charity Ball held at the DeGrey Rooms on Saturday 16th March.

The Ball was organised by Amelia Crossan (whose brother has vasculitis) to raise funds for Vasculitis UK and for York Against Cancer.

Representing the Trustees of Vasculitis UK were Richard Eastoe and his partner Suze, Pat Fearnside and her friend Kath Edwards, and Lynne and Sam Jacques



The beautifully restored DeGrey room was colourfully decorated with pink and blue balloons. The ladies were resplendent in their evening dresses and the gentlemen in dinner jackets.

A drinks reception was followed by a superb meal and wine after which Amelia (pictured left) explained all the wonderful ways she had devised to garner as much money as possible from the guests. There was a auction, raffle and a roulette wheel - all to raise money for these two special charities. Our own Lynne won a rather splendid bottle of champagne and Kath won a fantastic basket of fresh fruit. In addition there was lots of time for dancing to Vibetown.

It was a wonderful evening, but over far too soon. Amelia, her family and friends worked extremely hard before and during the event to make it a tremendous success. A wonderful £950 was raised for V-UK.



VASCULITIS SUPPORT GROUP MEETING REPORTS

SE London/NW Kent VSG

Nine members attended the meeting in May.

Jacqui told them about the news from AGM. Also discussed was the format of future meetings, and the possibility of getting a speaker to attend meetings. Everyone enjoyed this social gathering

East Midlands VSG



Twenty-three members attended the first East Midlands meeting in May.

There were patients with CSS, WG, MPA, and two who had never received a proper diagnosis. The members were of all age groups from early 30s to late 60s.

A pleasant social afternoon was held, and the format for future meetings discussed.

Beds, Bucks & Herts VSG

The George at Buckden, Cambridge was the lovely setting in August for the latest of the group's informal lunches. The food was really good and the company was excellent.



Lincolnshire VSG

A small group met for a splendid lunch on 1st September at the Thorald Arms. Small they may have been but they were big on friendship and support.



Oxfordshire VSG Seminar 2013 and August Lunch

The 2013 Seminar was held in March. Miss Stella Hornby, Associate Specialist Ophthalmologist at OUH and Lecturer at Oxford Hospitals, gave an interesting and informative presentation on Vasculitis and the Eye - Tips for Looking after Your Eyes. This was followed by a further interesting talk by Dr Jo Robson on the update of the Patient Reported Outcome Research.

On 18th August there were 21 of the group who met for a delicious roast dinner at Sturdy's Castle.

North & West Yorkshire

In April there was a good turn out to hear Alan Pollard (Rheumatology Nurse) chair a questions and answers session at Gomersal Park. Richard Eastoe also spoke about forthcoming fundraising events for Vasculitis UK.

Lynne and Sam also hosted a Sunday lunch and chat in June which was very well received.



Vasculitis Awareness Ireland - Charity Launch

On a beautiful May day the grounds of Stormont looked stunning. This was the venue for the official launch of VAI. An impressive presentations was given by speakers, Dr Eamonn Molloy and Prof Mark Little, and then Minister for Health, Edwin Poots launched the

charity. Julie Powers the leader of VAI's final comment "We have to keep this ball rolling if we want to make a difference.". See the Support Group list to contact Julie.

London (North) VSG

Two meetings of this new group have now been held with members travelling from Cambridge, Chingford, Woodford and Tufnell Park. The members exchanged information on their medications and diseases and enjoyed the social aspect of the meetings. David is hoping to arrange a speaker at future meetings.

West Country VSG BBQ

Well, the sun shone and members old and new spent a lovely afternoon together, drinking cold wine and beer and enjoying a scrumptious array of food at the BBQ held at Charlotte's home during June.



York, North & East Riding VSG

Back in May, Jennifer Wormald hosted the first York, North and East Ridings Support Group at Huntington Memorial Hall in York. About 20 people came along to hear Dr David Border, a Consultant Nephrologist at York and Harrogate District Hospitals, give an excellent talk about "The Renal components of the Disease and Current Advances in Treatment".

A big thanks must also go to Jennifer's family who helped out with tea and coffee and provided some excellent cakes for everyone.



Merseyside, Cheshire and North Wales VSG

Approximately 30 members attended the Meeting at The Royal Liverpool on Monday 22nd July.

Dr Glen Russell, Medical Director at Broadgreen Hospital, who is also a Vasculitis patient, talked about the future of Vasculitis care at the Royal. This was followed by a presentation by Dr Harper, Vasculitis Consultant, about patient satisfaction with the facilities. Members of the Group requested that Vasculitis UK contact both Doctors with a view to further discussions about the way forward.

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.

Mrs Sheila Bird of Dorchester

Mrs Bird sadly passed away in May 2012. Her daughter Jane and son-in-law Richard Sutton together with family and friends kindly donated £215 to Vasculitis UK in Sheila's memory.

Mr Roger Stuart William Boyes of Irthlingborough, Northants

Mr Boyes was 74 years old when he sadly passed away in February 2013. Roger's wife Esther and his family and friends kindly donated £325 to the Trust in his memory.

Mrs Jean Brotherton of Streetley, Sutton Coldfield

We were informed of the sad passing of Mrs Brotherton in April 2013. We are grateful to Jean's son David and her family and friends for the kind donation to Vasculitis UK of £256 in her memory.

Mr John Victor Day of Epping, Essex

The Trust would like to thank Mr Day's wife, family and friends for the kind donation of £310 made in memory of John who sadly passed away in Spring 2013.

Mrs Ivy Rose Dronsfield of Cheltenham

Sadly, Mrs Dronsfield passed away in February 2013. Mrs Dronsfield's daughter, Anne Kealy has Wegener's Granulomatosis and Ivy was always interested in research into vasculitis. Her family and friends, therefore, kindly donated £215 to help the Trust fund further vasculitis research.

Mrs Valerie Gardner of Ross-on-Wye

Valerie passed away on 6th May, having bravely fought the effects of severe vasculitis in her kidneys and lungs. She was a wonderful wife, mother and grandmother who cared deeply for her family and friends; and she is very much missed by her husband Michael, four children, four grandchildren and everyone who knew her. £490 has been donated to V-UK in Valerie's memory.

Mrs Deborah Katherine Gregson of Wilby Northants

Debbie was only 49 when she sadly passed away on 26th January 2013 from the complications of vasculitis. Debbie left her partner Nick and their four amazing children - Natalie, Georgia, Evie and Joe. Debbie was a passionate baker and her specialities were cakes and desserts.

Debbie's passing was mentioned in the Spring Newsletter but the Trust would like to record our gratitude to her family and friends who have kindly raised over £1200 in her memory.

Ms Barbara Hamilton of Scarborough

Mrs Hamilton passed away during the late Spring of this year. Barbara's family and friends kindly donated £430 to Vasculitis UK in her memory.

Mr William Charles Henshaw of Bilbrook, South Saffordshire

In January we were informed of the sad passing of Mr Henshaw. William's wife Sarah and his family and friends kindly donated £194 to Vasculitis UK in his memory.

Mr Kenneth Jones of Bolton passed away on 7th June aged 67. Kenneth's family and friends have kindly donated £232 in his memory.

Mrs Barbara Rose Lloyd of Hessle, East Yorkshire was a V-UK member and keen supporter. Barbara had WG but passed away recently following complications after a stroke. Her nephew and family and friends have kindly donated £125 in Rose's memory.

Mrs Susan Marlow (1955-2013) of Bradford, Yorkshire

Susan was a wife (married to Stewart for nearly 40 years), mother to Alex, grandmother, daughter, sister and friend to many. She had a zest for life but sadly lost her long battle with vasculitis in the Spring of 2013.

In a touching tribute to her Nan, granddaughter Beth wrote the words: "I never thought this day would come. Or maybe it was just that I didn't want it to, I feel cold. Not outside but inside." Susan's passions, apart from her family, included swimming, theatre, music and her lovely garden. Stewart, Alec and all her family and friends kindly donated £1200 to the Trust in her memory.

Mrs Janet Eva Pauling of Burgh le Marsh, Skegness

Mrs Pauling was 72. She passed away in February within a week of being diagnosed with Wegener's Granulomatosis. Janet leaves her son Stephen and his wife Amanda and a brother Malcolm and his wife Joan. Janet had spent a good part of her career as a midwife. She was loving, caring and very generous. She will be sadly missed by her family. Janet's family and friends kindly donated £130 to Vasculitis UK in her memory.

Mrs Constance Richards of Reading

Mrs Richards passed away in May 2013 aged 64. Connie was a vasculitis patient and her son Brian, daughter Linda, niece Jan Appleton, together with Pam and George Middleton and other family and friends kindly donated £180 to the Trust in her memory.

*In Memoriam - continued***Mr Fred Sterling of East Sussex**

Fred sadly passed away on 27th March 2013 aged 62. He had been diagnosed with vasculitis three weeks before he died. He was a wonderful husband of 42 years to Sally and father to four children and grandfather to six grandchildren. He was admired and loved by many family friends for his positive attitude and great sense of humour.

Fred was a builder by trade, a semi-professional footballer and coach. Latterly he and Sally built up a small-holding caring for animals. He touched so many people and his family and friends very kindly donated £1802 to Vasculitis UK in his memory, and a similar amount to The Stauros Foundation.

Mr Gordon (Delme) Thomas passed away in August. Gordon was diagnosed with CNS in January. His daughter Paula (of Skipton, North Yorkshire) has opened a JustGiving Remembrance page for her father, and Gordon's family and friends have so far raised £2000 in Gordon's memory.

Mrs Jean Wenborn - Mrs Wenborn passed away in June 2009. We are once again grateful to Jean's husband, Donald, who has kindly donated £700 to the Trust in his dear wife's memory.

Mrs Edna May Wheeler of Berkshire - Mrs Wheeler was 88 years old when she sadly passed away on 3rd February 2013. The Trust is grateful for the kind donation of £210 from Mrs Wheeler's niece Susan Dawn Niblett and family and friends, made in Mrs Wheeler's memory.

Mr Brian Philip White of Ickenham, Middlesex Sadly, on 3rd March 2013, Mr White passed away. Brian's wife, family and friends kindly donated £617 to the Trust in his memory.

Mrs Jean Wilson of Stoke-on-Trent passed away during the summer. Her grandson, Mario Booth has had vasculitis for 15 years, since he was 7 years old. Jean's daughter, Angela, Mario and family and friends kindly donated £41.50 to V-UK in Jean's memory.

Mr Robert Worthington passed away due to vasculitis. His daughter works for Liverpool Social Services in the Careline Department. Her colleagues have donated £50 in Robert's memory.

From JustGiving

The Trust would like to thank the family and friends of Mr Terry Carley and Mrs Joyce Livingston for their very kind, but anonymous donations.

A tribute to - Mrs Margaret Davies of Oldbury, West Midlands

It was with great sadness that Margaret's son, Rob, informed me that my dear vasculitis friend of many years had passed away in early September. Margaret was diagnosed with MPA several years before I was diagnosed with WG. Exactly how we met though is lost in the mists of time.

Although Margaret was in her mid 80's she was a wonderful correspondent, confidant and friend. She was my rock in times of illness and stress, and I will always be grateful that we found each other all those years ago. I will miss her, as I know Rob and his family will.

Pat Fearnside (Newsletter Editor)

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

VASCULITIS UK FUNDS ANOTHER RESEARCH PROJECT — MYPAN RESEARCH STUDY

The Trustees of Vasculitis UK are very pleased to be associated with and part funders of this international trial, which is being led by Dr Paul Brogan (pictured above) of Great Ormond Street Hospital for Children and University College, London.

The investigation is into the relative effectiveness of Mycophenolate in treating PAN (Polyarteritis Nodosa) in children. This is a rare condition, especially in children, hence the need to make it an international collaborative study involving other centres throughout Europe. In research terms, you need to have numbers of participants to make the

results meaningful and significant.

The standard treatment for PAN is with an aggressive immune suppressing drug - Cyclophosphamide. As we all know, although it is very effective, cyclophosphamide has numerous undesirable side-effects. For children these are potentially so much more serious. Mycophenolate is also very effective but has fewer serious side-effects. So if Mycophenolate is found to be at least as effective as Cyclophosphamide in controlling PAN in children, they would be spared those side effects, as the known side effects of this drug are relatively mild.

The main funding for this research study is being provided by Arthritis UK. The other participants in this Europe-wide study are paying their own basic costs, but participation also involves approval by the different regulatory bodies in each country involved.

Vasculitis UK is providing £15k to help in funding this part of the project and the LCTF in Scotland are also funding £15,000. If the trial proves to be successful, children suffering from PAN throughout the world may be safely spared the harmful effects of Cyclophosphamide.

TREASURER'S REPORT – APRIL 2012 TO MARCH 2013

The Treasurer reported on the Trust's financial year 2012/13 (1st April 2012 to 31st March 2013) at the AGM in May.

Income

Income increased appreciably when compared with 2011/12 – £102,192 (£74,498). The largest increase again being fundraising and donations via JustGiving.com.

Donations for the year were £93,105 with those from JustGiving £37,500.

Gift aid claimed by the Trust increased slightly to £3,312, with Gift Aid claimed by JustGiving (on behalf of V-UK) in the region of £7,500.

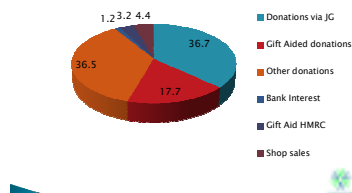
Expenditure

Expenditure increased considerably when compared with 2011/12 to £63,851 (£31,735).

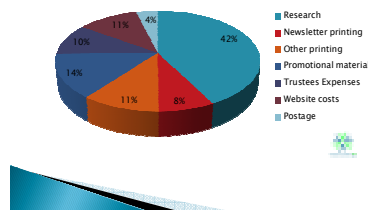
Income & Expenditure 2006/07 to 2012/13



Main Income



Main Expenditure



The main expenditure was £25,000 for research funding at Birmingham University Hospital.

Other increases were for the printing of the Route Maps, additional fundraising costs, promotional material (including purchases for the shop), and the final payment for the design and development of the new website.

The accounts were examined and accepted by an independent examiner (in accordance with the Charity Commission's requirements).

A copy of the Accounts was circulated at the AGM. A copy can be obtained from the Treasurer (contact details page 28) or can be viewed at:

www.vasculitis.org.uk/about/accounts

Patricia Fearnside
Treasurer

TRAVEL INSURANCE

Freedom Insurance Services Ltd Richmond House, 16-20 Regent Street, Cambridge, CB2 1DS. information@freedominsure.co.uk or ring **01223 454 290**. www.freedominsure.co.uk

Goodtogo Insurance - ring **0844 334 0160**
www.goodtogoinsurance.com

JustTravelcover - Cover for pre-existing medical conditions or for clients over 65. www.justtravelcover.com/ or ring **0800 294 2969**

Medici Travel - customer.services@medicitravel.com, phone: **0845 8800168**. www.medicitravel.com

The **Post Office** - Details are available from any Post Office or phone **0844 888 3900**

Virgin Insurance - Cover for pre-existing medical conditions or for clients over 65. Phone: **0844 888 3900**. www.uk.virginmoney.com/virgin/travel-insurance/

More travel insurers can be found on the V-UK www.vasculitis.org.uk/living-with-vasculitis/insurance

The Trust would be pleased to hear of your experiences - good or bad - when using any of these travel insurance providers. When booking please mention Vasculitis UK as some of these companies pay a small commission to the charity.

Please stay in touch

Have you changed your e-mail address recently?

Are you moving home?

Don't forget to let us know so that we can keep in touch.

e-News

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

Newsletter/Journal

To update your home address or other details on the database, please e-mail John -

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**

THOUGHTS TO PONDER

“The worst thing about medicine is that one kind makes another necessary.” Elbert Hubbard

“The art of medicine consists in amusing the patient while nature cures the disease.” Voltaire

“The good physician treats the disease; the great physician treats the patient who has the disease.” William Osler



VASCULITIS UK SHOP



Winston the V-UK Bear recently re-launched the new-look Vasculitis UK shop with new photographs and some new items. We have a wide 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.

Winston invites you can view the full range of the goods we have for sale, including special offers, on the V-UK website.

Did you know that you can still pay by cheque or you can now pay by **PayPal**. To order and pay using **PayPal** please visit our on-line shop: www.vasculitis.org.uk/shop



Prices INCLUDE Postage & Packing except for Special Christmas Card Pack

Clothing

t-shirts & v necks	£13.25	Running vests	£14.00
Sweatshirts *	£17.50	Polo shirts	£14.75
Hoodies*	£23.00	Zoodies* (hoodies with zip)	£24.00
Waterproof hooded coat**	£ 24.00	Baseball hat (one size)	£11.00

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

Colours: green, royal blue or black expect for * = grey or black , and ** = black only

Other items

Route Map for Vasculitis	£10.50	V-UK White Rabbit	£15.75
Wristbands	£2.00	Enamel V-UK lapel badge	£2.00
Beaded bracelet	£4.00	Beaded key-ring	£4.00
"Winston" V-UK Bear	£15.75	Waterproof backpack	£8.95
"Winston" baseball hat - white or black	£3.50	V-UK 4 pen pack	£3.00

SPECIAL OFFER VASCULITIS UK CHARITY CHRISTMAS CARD PACK



12 Assorted quality cards + free Vasculitis UK pen = £2.00 per pack + £1.50 p&p. Two packs for £6.00, saving £1.

Each pack contains four of each card - Peace Dove, Robin, Santa (125 x 125cm) and Penguins (145 x 100cm).

Greeting: Best wishes for Christmas and the New Year. All the proceeds from the sale of the cards will help V-UK raise awareness and fund research in the UK.

When you buy this special pack of 12 cards you will receive a free Vasculitis UK pen. You will really help to raise awareness of vasculitis with every Christmas card you send.

To order by post please send a note of your order, including the item name, size, colour, and number required. Don't forget your name and address + a phone number in case of query, and send the order and your cheque to: **Lynne Jacques, Vasculitis UK Shop, c/o 37 Pinfold Close, Swinton, South Yorkshire, S64 9BJE**

Your cheque should be made payable to **Vasculitis UK**.

If you are not satisfied with your purchase, just return it unused and we will refund your money, less the cost of p&p.

Please allow up to 14 days for delivery of clothing, bags, Winston the Vasculitis UK bear and the V-UK rabbit.

Lynne Jacques — V-UK Shop Manager



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

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

♦ formerly known as:

Stuart Strange Vasculitis Trust



**Registered Charity No.
1019983**

***Have you visited the
Vasculitis UK website?***



www.vasculitis.org.uk

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SOME OF THE VASCULITIDES

Anti GBM (Goodpasture's Disease)

Behçet's Disease

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

Cogan's Syndrome

Cryoglobulinemia

Eosinophilic Granulomatosis with Polyangiitis (Churg Strauss Syndrome)

Giant Cell/Temporal Arteritis

Granulomatosis with Polyangiitis (Wegener's Granulomatosis)

Henoch-Schönlein Purpura

Hypersensitivity Vasculitis

Kawasaki Disease

Microscopic Polyangiitis

Polyarteritis Nodosa

Polymyalgia Rheumatica

Relapsing Polychondritis

Takayasu Arteritis

Urticarial Vasculitis

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