



**VASCULITIS UK**

# Newsletter & Journal

**Autumn 2012**

**Issue No. 44**

**What's inside?**

**New Website**

**Vasculitis and the eye**

**Patient reported outcomes**

**ANCA-activated neutrophils**

**Interview with ....**

**Fatigue study**

**Vasculitis UK Shop**

## A view from the Chair



This really has been a momentous six months for Vasculitis UK. The two most high profile events have been the launch of the Vasculitis Routemap at the Vasculitis UK AGM in May, and the launch of the new Vasculitis UK website on the 1st September (see p4)

The Routemap was received with great acclaim from both patients and medical professionals – and so it should have been, as there has been nothing like it before.

The initiative for the Routemap project came from the Department of Health and was administered by Genetic Alliance. So there was a second Routemap launch before a large audience at the Genetic Alliance AGM in July in London.

The modest grant from the DoH allowed us to print 100 copies and distribute them to many doctors throughout the UK and to leaders of the Local Support Groups in the UK and Ireland.

We were overwhelmed by the demand for the Routemap and it is now on the second reprint. Copies have gone all around the UK and abroad. We are greatly indebted to Pat Fearnside for her dedicated work on this project and to Dr Matt Morgan, consultant nephrologist at Queen Elizabeth Hospital, Birmingham for his advice and support.

The Routemap gave the necessary boost to the long-planned new Vasculitis UK website. If you haven't already looked at it you should do so – [www.vasculitis.org.uk](http://www.vasculitis.org.uk)

Most of the content of the website was taken from the Routemap, but this is just a beginning. Freed from the constraints of the printed page, the website will get bigger and better and more interesting as we add more content, but already it contains more information about all aspects of vasculitis than any other website in the world. Again we have to thank Pat Fearnside for her dedication and hard work that made it all possible.

The good news doesn't stop there. Vasculitis UK now has representation on the influential Vasculitis Rare Disease Working Group and on the British Society of Rheumatologists' panel currently reviewing the "Guidelines for Treatment of ANCA associated vasculitis. In May we submitted a report to the Government's consultation on the provision of care for those suffering from rare diseases – the UK Plan for Rare Diseases. (see p9)

Vasculitis UK was represented on the NICE consultation in July on the use of Rituximab (see p10). Knowing of the distress and hardship caused to people with vasculitis by the ATOS assessment process, we recently submitted a report to Professor Malcom Harrington's review of the Work Capability Assessment.

Although we don't actively recruit new members, membership grows steadily. As I write this report we have no less than 41 kind and generous individuals carrying out various activities to raise money for Vasculitis UK (see p15). A year after its introduction, the Vasculitis UK Health Unlocked discussion group is proving so popular with a rapidly growing number of users. Several new local groups have started up, with assistance from Vasculitis UK.

The only real problem is that all of this is going to be a hard act to follow.

On behalf of Vasculitis UK, may I wish you all a rather early "Very Merry Christmas and a Happy New Year". On which note, don't forget your VUK Christmas cards (p23)

*John Mills*  
Chairman



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# Diary Dates

## MEETINGS

**Polite note:** Are you thinking of attending a Support Group meeting? Please book to help with organisation and for ordering refreshments. Please remember that once the organisers have ordered refreshments they will have to pay for them. **For contact details for VSGs see page 18 .**

Also see website: [www.vasculitis.org.uk](http://www.vasculitis.org.uk) for full details.

**West Country VSG** Lunch at the Mill on the Exe in Exeter at 12 noon on **Wednesday 3rd October**. Please contact Charlotte Stoner for full details and to book.

**All Ireland Vasculitis Conference** The first conference will be held at the Royal Marine Hotel, Dun Laoghaire on **Saturday 6th and Sunday 7th October**. Details from Julie Power. Also VSG meeting in Belfast on **3rd November**.

**Yorkshire (North) VSG New Sunday 7th October**. Gomersal Hall Hotel near Cleckheaton. Further details from Lynne Jacques.

**Oxfordshire VSG** Informal lunch at the Duke of Marlborough pub near Woodstock, **Sunday 7th October**, 12 noon.

Also: Advanced notice: **Oxfordshire VSG Seminar - Sunday 17th March 2013**. Further details for both events from Sue Ashdown.

**Cambridge VSG Saturday 13th October**. 2pm. Holiday Inn, Impington, Cambridge (off A14). £7 to include tea & scone. Further details from Jenny Fulford Brown .

**West Midlands (VSGWM) Sunday 14th October** at the Hilton Hotel, Bromsgrove. Talks by Drs Julie Williams and Matt Morgan. Further details from David Sambrook.

**South Wales VSG** Contact Jackie Thomas. Possible meeting in early October.

**Lincolnshire VSG** The next meeting will be held on 28th October. Further details from Pam Todd.

**Beds, Bucks & Herts VSG** The next informal lunch will be held on **Sunday 4th November**. The exact venue is not confirmed but is possibly going to be The Raven in Hexton, Beds. Full details from Chris Lee.

## Baby news

### Holly Hampshire

We are pleased to announce the safe arrival of Robyn Hampshire in May. Members will remember that Holly was a Trustee of Vasculitis UK and also a WG patient. The Trust sends congratulations to proud Mum and Dad — Holly and James.



### Dr Nina Brown

We are also pleased to say hello to Ewan who was born in August. Ewan weighed in at 8 lbs 4 oz. Congratulations to Mum (Nina). Members will know that Nina is one of the vasculitis doctors at Manchester.

**Merseyside, Cheshire & N.Wales VSG** The 2nd meeting will be held on **Tuesday 6th November** - 2.00—4.00pm, Royal Liverpool Hospital. Further details available from Keith Quinn or Susan Chance.

## FUNDRAISING EVENTS

**Sponsored walk — St Helens town centre to Southport** (18 miles) **Saturday 13th October**. In memory of Neale Mouldsdale. For more details contact Susan Mills.



**Charity Ball, West Wing, Ickworth House, Bury St Edmunds, Suffolk. "All Aboard with Little T".**

**Saturday 20th October**. Come along, join in with the nautical theme

and have a wonderful time. For full details please contact Tracy: 01284 704656

**Justgiving.com:** There are currently over 40 individuals or groups fundraising for Vasculitis UK at [justgiving.com](http://justgiving.com). Many of the fundraisers have inspirational stories to tell. You can read about them and their chosen events, and possibly consider making a donation at: [www.justgiving.com/VasculitisUK/](http://www.justgiving.com/VasculitisUK/)

## Discussion groups

Why not consider joining one of the Trust's internet discussion groups? There's "**Health Unlocked**" which is a "private" group where you can set your own levels regarding who is able to view your posts. All posts are relevant to the vasculitis patient. Currently there are over 560 members



To join the Health Unlocked discussion group go to: [www.vasculitis-uk.healthunlocked.com](http://www.vasculitis-uk.healthunlocked.com) and follow the links to join.



Then there's the **Vasculitis UK "Facebook"** site. This is an open group for those who are happy with the Facebook concept. Current there are over 600 members. To join simply go to the Trust's website: [www.vasculitis.org.uk](http://www.vasculitis.org.uk) and follow the Facebook link.





# Vasculitis UK - New Website



It has been a long time in the planning, preparation and execution, but on 1st September the new Vasculitis UK website was finally launched.

Much of the content for the individual disease sections has been taken from the Route Map for Vasculitis. Similarly the "Living with Vasculitis" sections are also derived from the Route Map. However, there are other new sections including "Inspirational Stories".

We also have a shop, although presently this is not entirely "on-line" shopping, but we will eventually be including an interactive shop with payment by PayPal.

The intention is to review each section of the website systematically, and add to and improve the present information over time. In addition plans are being formulated to add other completely new sections.

In the meantime there will be regular updates in our News and Events sections. So please keep visiting to keep up-to-date with what's happening in the vasculitis world, and for information on meetings and fundraising events.

We have tried to make the site as interesting as possible, with plenty of information and photographs. Clicking on the Home Page photographs will take you to those specific sections in the website, while hovering over the photos in the individual disease sections and in the photo galleries will show a legend related to the photo. So, why don't you pay us a visit at: [www.vasculitis.org.uk](http://www.vasculitis.org.uk) and take a tour.

Feedback on the site is important, and the Trust welcomes your comment. It is only with constructive feedback that the Trustees will know which sections work and which sections don't. Please send your observations to John Mills ([john.mills@vasculitis.org.uk](mailto:john.mills@vasculitis.org.uk)).

The Trust is indebted to Paul Townend of "OnScreen" for the design, development and hosting of the new website. ([www.onscreen.co.uk/](http://www.onscreen.co.uk/))



## Selection of photos from the new website



## Vasculitis UK - Trustees

The Trust is sorry to announce that Paul Bingham stepped down as a Trustee in May.

Paul was actively involved with the running of the Trust. It was Paul who administered the 2011 raffle. He also contributed to the Route Map for Vasculitis.

The Trustees wish to place on record their appreciation of the contribution Paul made to the Trust. Our best wishes are extended to Paul and to Maggie.

Paul still remains the Support Group Leader in Surrey, until such time as a replacement is found.



### New Trustees:

At the AGM three new Trustees were proposed and seconded: **Jann Landles**, **Anita Parekh** and **Lisa Ranyell**.

(Jann is also the Support Group Leader for the North West VSG).

During the past few months two further Trustees have been co-opted:

**Richard Eastoe** and **Lynne Jacques**.

(Lynne is also the Support Group Leader for the new Yorkshire (North) VSG).

Please see page 24 for the names of all Vasculitis UK Trustees.

# Vasculitis and the Eye - Dr Catherine Guly

## Consultant Ophthalmic Physician, Bristol Eye Hospital

Vasculitis can affect different parts of the eye. In some patients there is only mild inflammation which does not affect the vision and in others symptoms are more severe and the vision may become affected. With advances in the understanding of ocular inflammation it has become clear that the treatments for vasculitis elsewhere in the body are also useful for treating vasculitis affecting the eye. This article discusses the different forms of vasculitis and explains how they can affect the eye. A more detailed article with further medical information is available on the Vasculitis UK website.

### **How is vasculitis of the eye diagnosed?**

Vasculitis affecting the eye is usually diagnosed by an ophthalmologist (eye doctor). Ophthalmologists use a slit lamp which has a microscope that gives a magnified view of the eye. It is possible to look into the back of the eye by enlarging the pupil with dilating eye drops.

The eye examination can tell which part of the eye is inflamed but does not show what has caused the inflammation and so other investigations, such as blood tests, can be helpful in making a diagnosis. Blood markers of inflammation (including the CRP, ESR and plasma viscosity) are useful in diagnosing and monitoring giant cell arteritis. If there is inflammation behind the eye a CT or MRI scan can be useful. Rarely, a small sample of tissue is taken from the eye or around the eye to send for analysis in the laboratory to look for signs of vasculitis. In Giant cell arteritis a sample of artery from the temple (the temporal artery) is used to help with the diagnosis.

### **How do different forms of vasculitis affect the eye?**

**Giant cell arteritis (temporal arteritis)** can result in an optic neuropathy in one or both eyes. An optic neuropathy is a disruption of the function of the optic nerve, in this case due to inflammation of the arteries that supply blood to the optic nerve. The optic nerve joins the eye to the brain.

Patients with an optic neuropathy due to giant cell arteritis may notice loss of vision or transient loss of vision in one or both eyes. This is often associated with a headache. There may be pain on eating if the blood supply to the jaw is also affected. Early treatment with steroids usually stabilises the vision but if there is damage to the optic nerve it does not always recover. Occasionally, giant cell arteritis disrupts the blood supply to the retina (retinal artery occlusion) or results in double vision (cranial nerve palsy).

**ANCA associated vasculitis (Wegener's granulomatosis and Microscopic polyangiitis) and Polyarteritis nodosa** can affect all the different parts of the eye. The most common symptoms of vasculitis are redness and eye pain. There may be increased sensitivity to light.

Some forms of inflammation are mild and do not affect the vision. For example, episcleritis is the inflammation of the outside coat of the eye, the episclera, and may result in a red, irritated eye. Other forms of inflammation are more serious and may affect the vision if untreated. These include

inflammation of the cornea which is the clear window at the front of the eye (keratitis), inflammation inside of the eye (uveitis) or inflammation of the sclera which is the white outer coat of the eye (scleritis). Scleritis in particular may cause severe pain around the eye, although this usually settles with treatment.

Orbital inflammation is inflammation in the eye socket. With orbital inflammation there may be double vision, the eyelid may be higher or lower than normal and the eye may protrude more than normal. The vision can become blurred if the optic nerve is affected. Orbital inflammation is most commonly associated with Wegener's granulomatosis.

**Churg Strauss syndrome** rarely causes inflammation in the eyes.



◀ Scleritis in a patient with WG.

The sclera is inflamed giving rise to a dark red colour, and the overlying inflamed episclera is brighter red.

### **How is vasculitis of the eye treated?**

The treatment will depend on the type of vasculitis and which part of the eye is inflamed. Eye drops can be used to treat inflammation at the front of the eye such as episcleritis and some forms of uveitis. Other types of inflammation usually require high dose steroid treatment with or without other immunosuppressive medications (such as mycophenolate mofetil, cyclophosphamide or methotrexate) or biological medications (such as adalimumab, infliximab and rituximab). Giant cell arteritis can usually be treated with steroids alone but sometimes other immunosuppressive medications are added. Patients usually require high doses of treatment initially to gain control of the inflammation and then the treatment is tapered to the lowest dose that will maintain control of the inflammation.

If the patient has inflammation elsewhere in the body the ophthalmologist will aim to work closely with the other physicians involved so that as far as possible the medicines chosen will treat the inflammation in the eye as well as any inflammation elsewhere in the body. The treatment will normally be dictated by the organ which is most at threat so if the eyes are inflamed and the sight is at threat then the ophthalmologist will need to guide the type of treatment required and how quickly the treatment can be reduced.

### **Is there anything I can do to protect my vision?**

If you have vasculitis you should report any new visual or eye symptoms to your doctor or your optometrist (optician), particularly if you notice any change in your vision. It is also a good idea to see an optometrist (optician) on a yearly basis as they will perform a thorough eye examination during your eye check.

## The inflammatory actions of ANCA-activated neutrophils

Research at Birmingham University, funded by Vasculitis UK, has shed light on the role neutrophils play in vasculitis.

Neutrophils are specialised white blood cells that fight infection. The ANCA blood test looks for antibodies against this type of white blood cell as their presence usually confirms if someone has small cell vasculitis. ANCA stands for antineutrophil cytoplasmic antibodies.

In one paper, the researchers led by Dr Neil Holden, the recipient of the Charity's bursary, found granules released from neutrophils, affected by ANCA, damage the endothelium, the lining of blood vessels. The release of the granules, known as azurophilic granules, occurs along a particular cellular sequence involving the enzyme diacylglycerol kinase and another chemical that is produced further along the pathway, phosphatidic acid. Damage to the endothelium is a fundamental process in small cell vasculitis and these azurophilic granules are often released into cellular environments that are highly inflammatory. Inflammation is, generally, a bad thing. Understanding the cellular sequence means further research can look at this pathway and see if it can be targeted to stop the release of azurophilic granules and, therefore, the damage they cause.

What is significant about this research is that the scientists found the release of azurophilic granules was dependent on the production of phosphatidic acid through the activation of diacylglycerol kinase. What the scientists think is that this pathway may be key to the neutrophils' ability to release

harmful proteins as well as their ability to stick to endothelial cells. If that is the case, then these molecular mechanisms are worthy of consideration as novel targets for treating vasculitic glomerulonephritis.

In the other paper Dr Holden and his colleagues established that neutrophils activated by ANCA are a primary source of the B cell survival factor B lymphocyte stimulator (BLyS), which promotes the longevity of B cells, an important immune response. B cells are lymphocytes that have matured in the bone marrow and play a significant role in the body's defences. They normally live for a few days so the finding that ANCA-activated neutrophils causes an extension in B cells' lifespan is of interest.

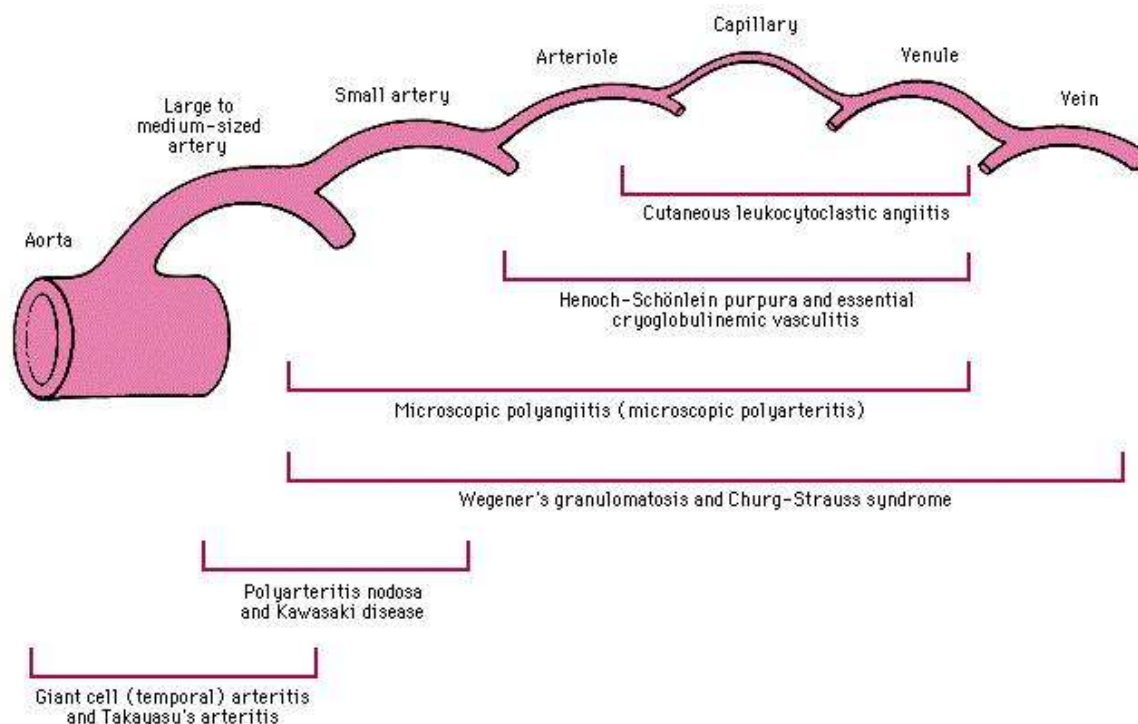
The researchers believe that by promoting the survival of B cells the neutrophils support ongoing inflammation, are capable of promoting further inflammation in sites already affected by vasculitis. This is important because at least one drug used by some patients with certain types of vasculitis -- rituximab -- may actually promote the production of BLyS and this could predispose patients to disease flares.

But, says Dr Holden and his colleagues, more work needs to be done to establish if maintenance therapy with rituximab, or other treatments that knock out B cells, really could be detrimental to vasculitis patients.

**Review prepared by Maya Anaokar, PhD**

## Vasculitis diseases (by size of arteries affected)

Vasculitic diseases are usually classified according to the predominant size of vessel involved as indicated in the diagram below:



## Patient reported outcome (PRO) questionnaire development for patients with ANCA-associated vasculitis

**Report by Dr Jo Robson, Clinical Lecturer in Rheumatology, University of Oxford.**

Patients diagnosed with granulomatosis with polyangiitis (GPA), microscopic polyangiitis (MPA) or Churg Strauss Syndrome (CSS); collectively known as the anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitides (AAV), have inflammation in the small blood vessels leading to disease in different body areas, for example, the kidneys, lungs and skin. Even with current treatment, patients often suffer from ongoing disease activity, damage or treatment side effects which can have a negative impact on their quality of life. Patients are currently monitored using laboratory tests and clinical questionnaires such as the Birmingham Vasculitis Activity Score, which is completed by their doctor, based on whether they have features of active disease (e.g. nasal crusting, or rashes) at the time of review.

However, we know that patients' views can differ significantly from those of their doctors in terms of what is important to them; for example, patients would rank fatigue as being more intrusive than their doctors may appreciate. This highlights the need to start from the patients' experiences when designing a questionnaire about patient's health related quality of life (known as a patient reported outcome or PRO), rather than basing the questions on what doctors believe is important.

A breakout session from the vasculitis workshop held at the 2012 Outcome Measures in Rheumatology (OMERACT) conference in May 2012, looked at several issues about the development of a PRO specific for patients with ANCA-associated vasculitis. The group felt that a combined approach involving patients from the UK, US and Canada was feasible and desirable due to the relative rarity of the disease and the ability to create a validated questionnaire that can then be used in all three countries.

**Report by Sue Ashdown – a patient perspective of the PRO. Sue is a “patient partner” for this project.**

I first heard about this project last year when The Oxfordshire Vasculitis Support Group was approached to get involved to help develop a tool which would be from the patient's perspective. As Dr Robson said in above article all current questionnaires are from the clinician's point of view, so one from a patient's perspective, taking into consideration all that a person with vasculitis has to deal with, is a great step forward.

Even so it was a surprise to get a call from Prof Raashid Luqmani asking me to become involved on a more personal level and to become a 'patient partner'.

Based on patient interviews from the UK, US and Canada we therefore plan to develop and pilot an AAV-specific PRO, to quantify patients' perceptions of the impact on their health related quality of life, which can then be used as an outcome measure in future clinical trials. Important themes related to quality of life will be taken from individual patient interviews, these themes will be then turned into questionnaire items, which will then be tested on a further set of patients. We plan to capture the broadest range of experiences possible, consistent with the spectrum of diseases seen. We will include patients with all three of the different diagnoses which comprise the ANCA-associated vasculitides (GPA, CSS and MPA), with different disease durations (more than or less than two years since diagnosis) and differing extent of body system involvement (for example generalised disease or limited to the sinuses).

This is a collaborative project funded by the University of Oxford, University of Ottawa and the Patient-Centered Outcomes Research Institute (PCORI), University of Pennsylvania, who kindly funded the first face to face steering committee meeting in August 2012.

This meeting was held in Pennsylvania, and included two patient participants from the US and two from the UK, as well as rheumatologists, epidemiologists and experts in the methodology of creating PRO questionnaires. The meeting was a great chance to meet the members of the team and start work together; monthly teleconferences will now ensure the smooth running of the collaboration. In the UK, patients diagnosed with AAV will be recruited for interviews through outpatient clinics or inpatient wards at the Oxford University Hospitals (OUH) NHS Trust, including the Nuffield Orthopaedic Center (NOC). Please see Sue Ashdown's report below. Sue gives her perspective as one of our expert patients on the collaboration steering committee.

This was to involve a trip to America for a Steering Committee meeting with Dr Peter Merkel and the rest of the team at Penn University, Philadelphia, with whom the team at Oxford were collaborating. As I work as a part-time Practice Nurse I had to sort out my clinics, which my colleagues kindly covered, so I was able to go.

It was a brief trip, flying out on a Tuesday, staying one night and back overnight on the Wednesday. This in itself was a challenge for someone with GPA, not only juggling when to take your meds with the different time zones, but also the fatigue the trip caused. However Jackie Peck, the other UK patient partner, and I felt it was worth going, as we will be having monthly teleconferences and knowing who is who and what their roles are to

be, will be much clearer. This will make our role more useful as we will be able to contribute and participate in the discussions much better.

We met with the two American patient partners, Don who had flown in from Iowa and Georgia from Boston. I had met Don in 2007 at The Vasculitis Foundation Symposium in Cambridge, so it was nice to see him again. We all feel it is a privilege to be involved in this project from its beginning and in fact this had been a stipulation as part of the US funding. It is exciting as patients to be part of the development of a tool that will incorporate our perspective into the assessment of our disease, which will hopefully be used throughout the world.



## Roving Reporter — An interview with Professor Mark Little

Professor Little took up the Chair in Nephrology in Trinity College Dublin earlier this year having been awarded the Science Foundation Ireland President of Ireland Young Researcher Award five-year programme grant. During his distinguished career he has maintained a focus on academic medicine having over 50 research papers published in prestigious medical journals. His academic career has taken him through Imperial College, University of Birmingham and University College London. Mark has a special interest in ANCA-associated vasculitis and in particular in identifying new markers of disease and in discovering better ways of modelling the condition in the laboratory.



Mark, together with his colleagues, has received a number of grants towards research into the vasculitides since 2002 including one from Vasculitis UK (or SSVT as we were in 2004).

### Perhaps I could start by asking why you decided on nephrology and particularly vasculitis as your chosen speciality?

I was drawn to nephrology as it fed a then unconscious love of data and number crunching. It is very driven by numbers and measurements... how high is the creatinine? what is the rate of change? how much acid is in the blood? why is the potassium level high? As time went by, the love affair shifted to another aspect that is very relevant to nephrology: the immune system, and in particular, autoimmunity. That is to say, destruction of organs when the immune system turns on itself, like a snake biting its own tail. My PhD focused on ANCA associated vasculitis under the mentorship of Charles Pusey (one of the leaders in vasculitis research) and my post-doctoral period was with Caroline Savage in Birmingham, where my path in academic medicine was cemented. My move to Birmingham came about when Lorraine Harper spent a year in the US and I did her locum; if I hadn't had this break I would almost certainly now be a full time clinical nephrologist.

### Your new post is in Dublin and you were educated at Trinity College Dublin. Is that why you have returned?

I grew up in Dublin and moved to the UK in 1998 (most Irish specialist trainees have to emigrate). I always imagined I would move back to Dublin if given the opportunity, but that desire lessened as time went on. By the time I was offered the chair in nephrology in Trinity College Dublin last year, I was very settled and happy in London, and working in an amazing institution: UCL (Royal Free), with a great partner in crime: Alan Salama. I would have stayed in London had it not been for our two young daughters Sarah and Maggie, and their 15 cousins in Dublin.

### Could you tell us something about your new role as a Professor and what that means to you?

Actually, as a title it means little; I view my move to Dublin as a lateral move professionally rather than a promotion. However, I have found that the title is useful to open doors and maximise research funding.

### What do you hope to achieve now you are in Dublin?

I am currently setting up a research group in Trinity and Tallaght Hospital; I have obtained €1.5m of funding to set up a vasculitis biobank, registry and translational research lab. Naturally, this registry will feed directly into UKVAS. We have set up an Irish vasculitis research group (with Matt Griffin,

Mike Clarkson, Eamonn Molloy and Con Feighery) and the endeavour is growing alongside the Vasculitis Ireland Awareness patient group, led by the highly motivated Julie Power.

### About your honorary roles. Could you tell us something about these?

My main honorary role is as co-founder and co-chair (with Richard Watts) of both the UK Vasculitis Study Group's Vasculitis (UKVAS) Registry and the Vasculitis Rare Disease Working Group; this has been made possible by the cohesive nature of the vasculitis research community in the UK, who have a history of working collaboratively on the European Vasculitis Study Group (EUVAS)

trials, which have largely defined how we now treat vasculitis. The registry aims to collect clinical information over a period of time and at numerous treatment centres across multiple units in the UK and Ireland, with the goal of recruiting 2000 patients.

The UKVAS Registry should be live by the time this Newsletter goes to press. So could I ask your readers to speak to their vasculitis doctor about participating? Most major centres are on board. We are also interested in recruiting unaffected family members. Also, please become involved with the Rare Disease Working Group (<http://www.rarerenal.org/diseases/primary-vasculitis/>).

The UKVAS initiative has gained a lot of momentum and represents an excellent opportunity for patients to become involved in both clinical research and in deciding how vasculitis services are configured around the country. One of the main remits of the registry and working group is to examine how medical care for vasculitis cases is managed to ensure that patients with this rare disease get "joined up" care from the multiple specialties they encounter. **So, I would strongly encourage your readers to approach their doctor and ask to be enrolled so that we can obtain as complete a picture as possible from all parts of the UK and Ireland.**

The Rare Disease Working Group (should be live by Autumn 2012. See the article in the Spring 2012 Newsletter - page 8.

### So, which do you prefer, patient contact or the research side?

I must admit that the research side is what really makes me tick. Since becoming an academic clinician I can't remember a time when I've thought "Ugh, time for work" on a Monday morning...it has been exhilarating and fun the whole way. However, I can't imagine a professional life without looking after patients, working out the cause of what ails them and sometimes doing something to make them feel better. Besides, it is in the course of caring for patients that the most important deficiencies in that care become apparent.

### What changes you've seen with vasculitis treatment in your career?

Increased awareness of the adverse events of therapy, and an attempt to get the balance between immune suppression and infection right. Rituximab should help with this; it does appear a very safe drug, but unfortunately the RAVE and RITUXVAS trials didn't show a safety benefit. Most people blame the steroids for this failure to reduce adverse events, so the focus is now quite rightly on these, in an effort to reduce or get rid of them.

*Continued on page 9*



*Roving reporter—continued***What good things would you like to see for the vasculitis patient in the next 5 to 10 years?**

The abolishment of steroid use, a proper biomarker that tells us when the disease is active (ANCA levels are very poor at doing this) and the establishment of centres of excellence where joined up care between the various specialties can be achieved.

**Finally, what about Professor Mark Little when he finds time from his busy schedule for a little relaxation?**

As for hobbies, I have twin passions for cricket and scuba diving (and underwater photography in particular). The attached photographs were taken during two of my 200 dives.



## Vasculitis UK - Important initiatives

Vasculitis UK Chairman (John Mills) has been very active during the summer and early autumn representing Vasculitis UK on two important initiatives which will, hopefully, bring the vasculitic diseases to a wider medical audience, and improve the lives of vasculitis patients.

**Consultation on the UK Plan for Rare Diseases**

This is a rather exciting time for rare diseases in general and for vasculitis in particular. Having been regarded for years as "Cinderella" diseases the spotlight is currently shining on them.



In February this year, the UK government produced a consultation document "Consultation on the UK Plan for Rare Diseases". This outlined the

problems involved (including financial considerations) and some of the many ways of addressing them. Responses to the document were invited before 25th May.

Vasculitis UK submitted a response, as did other organisations such as Rare Diseases UK (who produced an excellent report) and the National Alliance for People with Rare Diseases. Vasculitis UK is a member of RDUK.

**Improving NHS services for rare auto-immune disease**

In April there was a meeting of the newly formed UK Vasculitis Rare Disease Working Group attended by most of the senior doctors working in vasculitis. Vasculitis UK was represented. This group also submitted a response to the consultation.

On 21st May another group met at the HQ of the Royal College of Physicians in London. This was a meeting between the members of the Independent Expert Clinical Group on Rare Auto Immune Diseases (led by Dr David Jayne) and representatives from MHP (the consultants who advise the government on health policy), NICE (National Institute for Health and Clinical Excellence), the National Specialised Commissioning Team and representatives from Vasculitis UK, Lupus UK and the Myaesthesia Gravis Association.

This meeting saw the launch of the Independent Expert Group's report and recommendations "Improving NHS Services for Rare Auto-immune Diseases" - which is an excellent, comprehensive and readable document.

One of the consistent themes that came through in all of these meetings and reports was the need for central registries (or databases) of patients suffering from rare diseases. Because these diseases are rare it is essential that all the information about these patients should be brought together for sharing clinical experience and for purposes of research.

The Rare Disease UK document "Improving Lives, Optimising Resources" is available at <http://www.raredisease.org.uk/>

The Department of Health consultation document on the "UK Plan for Rare Diseases" can be found at <http://www.dh.gov.uk/health/2012/02/consultation-rare-diseases/>

If you want to see the Vasculitis UK response to the consultation or the very interesting Independent Expert Clinical Group report, or if you cannot find the other documents online, then please contact John Mills (contact details page 24).

## Work and Benefit

Claiming government benefits or having to undergo re-assessment can be an ordeal, particularly when you are ill. The Trust has professional membership of "Work and Benefits" 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 "DLA", "ESA" or "Incapacity Benefit" then contact: Susan Mills—[susan@vasculitis.org.uk](mailto:susan@vasculitis.org.uk)



## Research Funding 2012

The Trust is currently part funding research at Birmingham University Hospital into Cytomegalovirus in ANCA-associated vasculitis patients.

Cytomegalovirus is part of the *herpesviridae* (herpes virus) which may be found throughout the human body and is typically unnoticed in healthy people. However, it can be life-threatening in the immune compromised patient.

The research proposal is to undertake an investigation into the use of valaciclovir to reduce the proportion of T cells which are required to be committed to



fighting the resident population of Cytomagaovirus (CMV) in those who have contracted the virus and who suffer from ANCA Associated Vasculitis.

It is hoped that by using valaciclovir to reduce the CMV burden this will lead to a reduction in committed T-cells which could in turn could lead to a treatment regime for those with AAV that will reduce opportunist infections in these patients, who already have compromised immune systems.

As this treatment might also benefit the elderly in general, and as the majority of surviving AAV patients are aged over 50, we might see a benefit on both counts!

## Vasculitis UK, NICE and Rituximab

The National Institute for Health and Clinical Excellence (NICE) is an independent organisation that provides national guidance and standards on the promotion of good health and the prevention and treatment of ill health. This role was set out in a 2004 white paper "Choosing health": making healthier choices easier, and is intended to help people to make well-informed choices about their health.

NICE guidance is produced by healthcare professionals, NHS staff, patients and carers, members of the academic world and other members of the wider healthcare and public health community.

NICE convened a meeting in Manchester on 23rd July with the aim

of continuing the process of considering whether Rituximab should be licensed in the UK for the treatment of two of the vasculitides - Granulomatosis with Polyangiitis (Wegener's), and Microscopic Polyangiitis. Those invited to attend were vasculitis medical experts, representatives of the drug company (Roche), Vasculitis UK and other organisations with an interest in the use of Rituximab as a front line treatment for vasculitis.

Lisa Ranyell and Martin Thomas (Vasculitis UK Trustees and also patients currently being prescribed Rituximab) attended the meeting to give a first-hand patient account of Rituximab and its benefits. Clearly any decision will be primarily based on peer-reviewed scientific evidence submitted

by the drug company but medical opinion and anecdotal accounts, such as those given by Lisa and Martin, will hopefully play a part in the final decision.

The application will now be considered further by NICE, taking in account cost benefits both in financial outlay and on quality of life. Should NICE decide that approval would be beneficial the final decision would rest with the Minister of Health. It is not anticipated that any final decision will be taken until later in 2013 at the earliest.

In the meantime Rituximab is being prescribed for vasculitis patients but with individual Trusts opting for different protocols.

## Shingles

This extract is reproduced from "NHS Choices" <http://www.nhs.uk/conditions/shingles/Pages/Introduction.aspx>



Shingles rash

### What are shingles?

Shingles is an infection of a nerve and the skin around it. It is caused by the herpes varicella-zoster virus, which also causes chickenpox. Shingles usually affects a specific area on either the left or right side of the body and does not cross over the midline. It causes a painful rash which develops into itchy blisters.

### Who are affected?

It is estimated that three in every 1000 people in the UK will have shingles every year. It can occur at any age but is most common in those who are over 50. Shingles is much less common in children.

### What is the cause?

If you had chickenpox as a child the virus remains dormant, and the immune system keeps the virus in check but it can be reactivated and cause shingles. Why the shingles virus is reactivated in later life is not exactly known but may be the

result of being older, being stressed or having a condition which affects the immune system. It is not possible to catch shingles from someone with the condition, but you can catch chickenpox if you've never had it before.

### Is there a cure?

There is no cure for shingles. It can be painful and the rash lasts between 7 and 10 days and takes between 2 and 4 weeks to heal. In some patients the after-effects can last several months.

### What is the treatment?

There are tablets and cream which your GP can prescribed to ease the pain and reduce the rash. Your GP may prescribe pain-killing medication and an antiviral such as Aciclovir. It is best to start the antiviral treatment within 72 hours of the rash appearing.

Wearing loose fitting clothing will help, and calamine lotion has a soothing and cooling effect. There is a shingles vaccine but this is a live vaccine and is not recommended in a number of cases, particularly if you are taking immune system suppressing drugs such as steroids and cyclophosphamide.

## Volunteer testing at Birmingham QE Hospital – Fatigue Study

I saw a post on the VUK Facebook page by John Mills that really caught my attention. Dr. Andrew McClean was still recruiting volunteers to take part in his research into fatigue.

I have Wegener's granulomatosis which caused kidney failure. A 25% kidney function and WG leaves me badly fatigued most days so I gladly offered my services as a volunteer and attend Queen Elizabeth Hospital, Birmingham on 5<sup>th</sup> March 2012.

As I live in London Andrew said he would do the testing, usually done over two days, in one day. I travelled to Birmingham the day before so I could be at the hospital on time as I was due the hospital between 9.00 – 9.30 a.m. Unfortunately, I was engrossed in a book when I heard Birmingham announced over the train tannoy and duly got off the train when it stopped. I made my way towards what I thought was the New Street exit and wondered why I could see air stewardesses then I realised I had got off at Birmingham International which was one stop early! Got on the next train for New Street but when I eventually arrived at the correct station I went out the wrong exit and got myself lost when I was looking for my B&B – it wasn't going to be my lucky day I felt. I did find my B&B ..... after going round in a complete circle.

The next morning I was really looking forward to getting to the hospital, which I did with no mishaps or delays. I was very warmly welcomed by Teresa, one of the Nurses, and she took me to meet Andrew who is friendly and made me feel very at ease straight away as he explained exactly what would be happening during the day.

The first test was a DEXA Scan (Dual-emission X-ray absorptiometry) to measure the amount of muscle, bone and fat in my body. The machine made all sorts of disturbing noises and the bed moved, it was all very strange as it made clunking and clanging noises and I kept my eyes closed but didn't last too long. After that was finished, I had a cannula inserted in my right arm so that bloods could be taken before I did any exercise test and taken again after tests. I was then given breakfast and a cup of tea which was very welcomed as I had been asked to fast from midnight the day before.

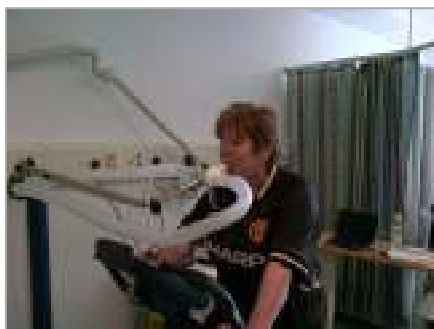
Next test was to be on the exercise bike where I had to pedal for nine minutes. I was to start very low resistance and the workload was increased, by a small amount, every three minutes. Six leads, not unlike ECG leads, were attached to stickers on my chest and back to monitor my heart rate and how much blood my heart was pumping around my body. I had to breathe into snorkel like tube and wear a peg on my nose.

Again, Andrew explained exactly what he wanted me to do. He kept a close monitor on what readings were showing and constantly gave me encouragement. Teresa held up a chart every so often with words such as "easy", "quite hard", "very difficult" etc. on it and I had to point to the one I felt closely resembled how I was finding the test as I peddled as fast as my little legs would allow. Andrew was giving Teresa the readings he was getting so she could record them.

I didn't find the peddling as difficult as I thought it would be but my heart was beating very, very fast when I finished as I could here the 'beep, beep, beep' from the machine before I was disconnected from the computer but I felt OK.

I had to fill in a small tick box questionnaire after every exercise to score how I was feeling, both mentally and physically.

It was now time for lunch and a cup of tea and a chance for me to get my breath back and for my heart rate to slow down. After lunch, it was time to have what Andrew called a PASAT test. This was to test my memory and concentration. This involved listening to a computer reading numbers in sets of two. I had to add up the two numbers but remember the last number to add to the next one, but NOT the total number from the two before. Oh my, this was so confusing especially when the voice got faster. I ticked the 'very anxious' box on the questionnaire at the end of that test I tell you.



I was taken to the School of Sport & Exercise Sciences for the final two tests and involved testing my leg and arm muscle strength. For the first part of the test I put on a specially designed chair in what resembled a kind of large cage or weighing scales (unfortunately, I do not have any photos of the contraption). Two electrical pads were put on my left thigh and a mild electrical stimulation was put through the pads, which was a bit of uncomfortable, not painful but enough to make me jump. My left ankle was chained to the cage so it couldn't 'kick' out too far and I was given a 'shock' and I had to push and hold my leg out against the strap as far and for as long as I possibly could. I found it difficult to do for too long as my leg muscle started to tire very badly and quite quickly so I had to stop after a short while.

For the second part of the test, I had the opportunity to lie down, which was very welcome. I had some kind of device attached to my right arm that would measure the oxygen levels in my arm muscle and a blood pressure cuff inflated on the same arm. I then had to hold and squeeze a handgrip as hard as I could for one minute. I could see a screen to the left of me and my aim was to squeeze the handgrip until it registered and went over a grey fixed line on the screen. Did a few of these, again, I did find it a bit difficult to sustain for too long. I felt I did OK at this one, but maybe the result would show different.

This concluded my day of testing, it was now almost 4.00 pm and I was beginning to feel very, very tired. I certainly slept well that night I tell you. I went home the following morning. Andrew gave me a set of salivettes to take home into which I had to give a sample of my saliva during different times of the day and post back to him.

I certainly enjoyed my day even though it was really very tiring but Andrew, Teresa and Selma certainly looked after me and all staff were extremely friendly and really made me feel welcomed. Andrew said he would continue testing volunteers, both people with Vasculitis and people who do not have the condition, until August this year and he hoped to have the results of his research early 2013.

I do hope that this research is able to help find suitable treatment and possible cure for fatigue as I am sure it will help 1000's of people ..... myself included.

*Jacqui Moran*



## Volunteer testing at Birmingham QE Hospital — Fatigue Study “Healthy Control”

It wasn't my idea at all. I was “volunteered” by husband, John Mills, to take part in Dr Andrew McClean's research study “Fatigue and ANCA Associated Vasculitis”.

Andrew asked for volunteers, not only people who had Vasculitis but people who did not have Vasculitis too. These were called “Healthy Controls”. He wanted to compare their performance with people with vasculitis and each group had to be matched, like for like.... age, sex, ethnic origin.



Like Jackie. I arrived not knowing what to expect but I also had my husband John accompany me as a spectator! First problem we got lost in the hospital complex, so Andrew kindly came to find us and escort us. He then introduced us to Jenny, the nurse who

would be looking after me for the day. Andrew and Jenny were extremely kind and made me feel at ease immediately. The first thing they did was to take a fasting blood test, then give me breakfast - I was starving!

My day progressed much the same as Jackie's with John by my side, except for the memory and concentration test. This particular test I had to do alone without the enthusiasm of my husband behind me! As the day progressed, John was enthusiastically taking photos, including those shown on the left of me with Jenny and Dr Andrew McLean and of me sitting in what John referred to as “the electric chair”.



Despite the electric shocks, I enjoyed my day and found the whole process to be very interesting. So did John. Jenny and Andrew looked after us both very well. We now await the final results of the research study in about May 2013, with great interest...

*Susan Mills.*

## Cogan's Syndrome

### What is Cogan's Syndrome?

Cogan's Syndrome is a rare inflammatory disease characterised by inflammation of the inner ears and eyes. It can lead to vision difficulties, hearing loss and dizziness. Commonly there is also inflammation in other organs as well, particularly the heart and large blood vessels, nervous system and bowels,

### Who are affected?

Although any age can be affected the syndrome is commonest in young adults (20's and 30's). It affects males and females equally.

### What is the aetiology (cause)?

The cause of Cogan's Syndrome is not yet known.

### What are the symptoms?

The most common symptoms include red, painful, light-sensitive eyes or blurred vision; hearing loss (which may become profound and permanent); vertigo (dizziness); poor balance; nausea and vomiting; fever, fatigue and weight loss.

### Making a diagnosis

There are no specific diagnostic tests. The diagnosis is made on clinical examination and history where a combination of problems in the eyes and inner ears are described. Other infections/diseases, including Wegener's Granulomatosis and Rheumatoid Arthritis need to be excluded.

### Treatment

There are no clinical trials of treatment in Cogan's Syndrome. Most people with Cogan's Syndrome will need treatment with moderately high doses of prednisolone or other types of steroids. A few patients with very mild eye disease may be treated with anti-inflammatory drugs including steroids and nonsteroidal anti-inflammatory drugs (NSAIDs) which are applied to the eye. Many patients will also require additional treatment with other immunosuppressive drugs including Methotrexate, Cyclosporin, Azathioprine, Tacrolimus or Cyclophosphamide.

### Prognosis

The course of the disease varies significantly from patient to patient. In some patients there is an initial flare, which may last several weeks to months. Following this there may be a slowly progressive course in some patients while others have a course of complete remission with intermittent episodes of disease activity. Fortunately blindness occurs in less than five per cent of patients. Deafness is a frequent and debilitating outcome occurring in up to 54 per cent of patients.

### Key Point

- Cogan's Syndrome commonly affects the eyes and ears causing vision, hearing and balance problems.
- Treatment will depend on the disease severity.

## Behçet's syndrome - A Patient's Journey

*This article was originally published in the BMJ 2009;339:b3876. Vasculitis UK is grateful to the BMJ for giving permission to reproduce parts of the article here.*

"I was 18 and had just returned from a trip to Australia when lumps started to appear on my legs. The doctors thought it was deep vein thrombosis caused by the long flight and prescribed anti-inflammatory drugs, which seemed to calm things down. However, over the next few months I was very unwell - one week with tonsillitis, the next with an infection in my testicles, then back to tonsillitis, and so on. I also had bad mouth ulcers that made eating difficult. All of this was accompanied by flu-like symptoms, whereby my bones ached and I had very little energy.

During the two years when I had repeated infections, I was admitted to hospital nine times. My mouth and genitals were ulcerated and lumps kept appearing. During one of these days, I was taken for tests and found myself in the genitourinary medicine clinic. They suspected AIDS or something similar, and I was terrified. In my mind I had gone from being just a nuisance to the doctors to someone who could have a life threatening disease.

My tonsils were removed but the ulcers and lumps continued unabated. Then I started getting headaches which were excruciatingly painful - so bad that I was vomiting and couldn't sleep. Six months later I visited the accident and emergency department because of these headaches and underwent a computerised tomography scan because of a suspected brain tumour. I was very scared but agreed to have several medical students examine me to try to find an answer. They put me on steroids to calm things down and I waited nine days as an inpatient to see a professor who immediately diagnosed Behçet's syndrome.

Receiving the diagnosis gave me an enormous sense of relief because somebody knew what it was. I started going to Bangor Community Hospital but I never managed to see the same professor again, even though I attended his clinic. I saw a different

junior doctor every time so I had to repeat my medical history with each one. I still had many of my symptoms because they kept changing the dose of my steroids to find the right balance. I was becoming depressed. I thought that now they knew what was wrong with me surely they could make me better and put me back on track - but that didn't seem to be happening. I started wondering if this was what the rest of my life would be like.

I became depressed and started taking antidepressants at the age of 22 when my GP told me that the job I was doing was too physical and was probably making my condition worse. I thought my life had ended - I didn't want to go out and face the world and eventually I didn't even see the point of getting out of bed in the morning. My fiancée and my family were all that kept me going through this time, and they tried endlessly to encourage and motivate me. They tried to stop me feeling sorry for myself and also helped me through my feelings of embarrassment at having depression. I don't like to think what would have happened without them.

It was one of my family who found the Behçet's Syndrome Society who were more than helpful. What a relief to know I was not alone. It was through the Society that I learnt about the Behçet's clinic at the University Hospital Aintree, Liverpool run by Professor Moots.

The treatment I received there was very different from that I had received previously. Professor Moots understood the illness, as did all the nurses, and they all took an interest in me. I tried several different drugs including Azathioprine, which caused chest pains and breathing difficulties. In January 2006 I started on Tacrolimus but this triggered an epileptic fit and had devastating effects on my personal life. At that time I had a good job as a financial adviser and had learnt to drive during the previous year. Suddenly my independence was taken away because I could no longer drive and had to rely on others.

Later that same year, on holiday in Turkey, I had another fit. I was taken

to intensive care where they suggested I needed a further computerised tomography scan. I signed myself out thinking it would be best to do this back in the UK. On my return home I phoned the local hospital for an appointment and was told it would be six months before I could see a neurologist. Again I used the services of the Behçet's Society who arranged a private appointment with a neurologist in London - Dr Kidd. He diagnosed the epilepsy, prescribed suitable treatment which meant that I haven't had another incident. In May 2007 I regained my driving licence.

In June 2007 I became really ill. I was planning to get married and wanted to enjoy our big day. I was admitted to hospital by Professor Moot and given infliximab. This changed my life and my outlook. I generally felt so well. My symptoms were under control and my outlook was much more positive.

At the time the article was published (2009) I was married, had a job I enjoyed and we were hoping to start a family. My worry was what would happen if infliximab stopped working, but I hope there will be alternatives by then.

Update at 2012:

### **What worked well?**

- Attending the specialist clinic at Liverpool,
- Infliximab,
- Support of family, friends and the Behçet's Society.

### **What didn't work so well?**

- Changing job twice,
- Waiting too long for a diagnosis,
- Patronising doctors who do not know anything about the illness,
- Tacrolimus"

The full article, including "The Clinician's perspective" by Professor Robert J Moots, can be found at: <http://www.bmj.com/content/339/bmj.b3876>

**Behçet's Syndrome Society** <http://www.behcets.org.uk/menu/main.asp>

One should always keep an open mind, but not so open that your brains fall out.

The danger with familiarity is that it can breed discontent. The danger with familiarity is that without it you can't breed anything

## PERSONAL STORIES — An actor's life for me !

For this issue, Ayden Callaghan, a young actor, tells a slightly different personal story. Many of us have one of the vasculitic diseases but Ayden played the part of a Churg Strauss patient in a fairly recent episode of Casualty, and he tells us something of his acting career and his part in Casualty.

"My TV career started with a British TV Legend....Basil Brush. I played a Nurse (male of course) working on Basil's injured tail, which is one of those weird coincidences considering I'm writing this because of an appearance on Casualty. I have since appeared in many TV shows, films and theatre productions and as the regular character Miles De Souza in Emmerdale from 2007-2008.

The part of Mick Statham the Churg Strauss patient in Casualty came up as most other jobs. My agent secured me a meeting with Steve Hughes a director on Casualty and casting director Derek Barnes. I always enjoy visits to the BBC in this case Elstree Studios where Eastenders and Holby City are filmed.

A few days after later I was booked and I had two stints of filming in Cardiff just before Christmas. I was pleased that I had scenes with my friend Steve Miller a regular (he plays Lenny). We have worked together before, so that was fun and, of course, we tried our best to put each other off. It's a small world the acting industry, and I was also pleased to be working with Sam Anderson (History Boys, Gavin and Stacey) as he had joined Emmerdale when I did, so it was great to see him again.

My character in Casualty was unaware of his condition and it only came to light after a minor car crash in which he injured his thumb. I was fitted up with a full plaster cast for this by one of the onset experts. The other actor involved in the crash was Michael Byrne, one of my favorites who starred in Indiana Jones and the Last



Crusade, Braveheart, and Sharpe to name just three of his incredible credits. Like an excitable child I asked him about his career and he entertained me with some excellent stories, a lovely man and a fine actor.

Back to my character, Mick — Some tests are ordered by Dr Dylan played by William Beck. Then, during the routine examination he picks up on what appears to be some insignificant information, like occasional shortness of breath. The story then starts to unfold. Mick is more concerned with getting home and seeing his wife. They are trying for a baby. She has pushed him too far he gets very upset and has an attack. The doctor then reveals that Mick is suffering from CSS. This helps put everything into perspective for the couple.

I had never heard of CSS before but clearly the writing team were very clued up, as was the director, and there was always a medical expert on set to give advice or information on anything we needed.

It was important to me that I got it right and didn't just give a generalised performance. I always research for my parts and auditions, so with Casualty I was able to read up on CSS.

The help and support afforded to me by the team and experts at Casualty was first class. They take what they do very seriously, whilst of course having fun doing it. They are always looking to raise awareness about conditions that may not be in the public consciousness as much as others. I think they do a fine job and produce an entertaining programme at the same time.

At the time of writing I am learning a script for a horror movie I am shooting in September. You can find me and regular updates on my career and shenanigans on twitter @aydencallaghan."

## GSK drug halves attacks in hard-to-treat asthma

*An extract from Reuters on 17<sup>th</sup> August, which may have relevance to patients with asthma and, of course, to Churg Strauss Syndrome (Eosinophilic Granulomatosis with Polyangiitis)*

"An experimental drug for treating severe asthma from GlaxoSmithKline nearly halved the number of attacks suffered by patients with a hard-to-treat form of the disease in a clinical study, boosting hopes for its commercial success.

Britain's biggest drug maker - already a world leader in respiratory medicine - said as a result it planned to move the new drug into final Phase III development before the end of 2012.

The injectable antibody treatment mepolizumab is designed to help a small group of people with asthma in which white blood cells called eosinophils cause inflammation of lung airways. It reduces the number of eosinophils by inhibiting an immune system signaling chemical called interleukin-5.

A year-long study involving 621 patients found that the rate in patients on mepolizumab of clinically significant exacerbations - defined as episodes requiring oral corticosteroids or a hospital visit - was around half that of those on placebo.

But while monthly intravenous injections of the drug cut attacks they failed to produce consistent improvements in symptoms or lung function, suggesting that this aspect of the illness might require different treatment.

GSK is also assessing the drug as a treatment for Churg-Strauss syndrome, a rare systemic autoimmune disease. Earlier plans to win approval in hypereosinophilic syndrome were abandoned after European regulators asked for more data in 2009."



## Our Fantastic Fundraisers

We are pleased to announce that the amounts raised by the fundraisers mentioned in the Spring 2012 Newsletter/Journal have increased considerably. Our grateful thanks go to all fundraisers and to those who have donated.

Our biggest joint fundraisers to-date remain the Dickinson family who ran in memory of Rupert Dickinson. The total raised by the family now stands at a magnificent £20,000.

### Balmaclellan Village Hall Committee

- In July the Committee held a dance in memory of Mrs Ethel Kirkpatrick. Mrs Kirkpatrick passed away in August 2011. She had been diagnosed with Wegener's 10 years previously. Jim, Ethel's husband is a member at the Village Hall. The Committee presented the Trust with a cheque for **£500**. The photo is of Ethel before her final illness.

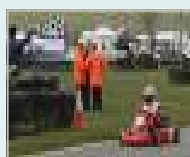


**Amanda Brammer** is a qualified reflexologist and she also holds Body Shop beauty parties. At a recent party Amanda raised £40 for the Trust. Amanda's Mum (Maureen Lakin) has WG and she has tried some reflexology. Her recent blood counts showed an improvement which Maureen hopes was due to the reflexology. [www.amandabrammer.co.uk](http://www.amandabrammer.co.uk)



**Janine Emma Brown** has continued to raise funds for the Trust in memory of her friend Clare Grossman. This time Janine entered the Folkstone 10. Here is Janine (left) presenting a cheque for **£1000** to Jacqui Moran (representing the Trust) at the Julie Rose Stadium in Essex.

**Samantha Carlin and Marion** - On 26<sup>th</sup> May Sammi and Marion undertook the gruelling Ben Nevis Challenge in order to raise funds for the Trust. Sammi's mum has Churg Strauss Syndrome. Together the duo raised almost **£800** for Vasculitis UK. The photo shows them braving the elements at the top of Ben Nevis.



**Tom Constable** - On 8<sup>th</sup> September Tom entered his first Triathlon at Tatton Park. Tom raised **£1260** for the Trust for his friend Martin who has CSS. Tom and Martin have been friends since meeting during 11 years ago through their mutual love of karting.

**Jayne & Barry Coulson, Louise Whale and Leanne Goessen** took part in the Mary Coulson Memorial Walk and raised **£1000** for the Trust.

**Jules Darlow** Jules held another successful Golf Tournament in Essex and the profits from the day, **£1200** were presented to Dr David Jayne at Addenbrooke's to be used towards vasculitis research.

**Pamela Edwards** - A fabulous afternoon fundraiser was held in March which included a "bake sale", and a make-up, handbag and jewellery display. This raised **£200** for Vasculitis UK. Cakes and jewellery can be viewed by visiting the Facebook pages of Sundae Kitchen and Tania Hewitt. The fundraising was dedicated to Amanda Hodges a WG patient

who sadly lost her vasculitis battle on the day of the fundraising.

**Jamie Flanagan** - Following on from his success in the Rome Marathon, Jamie continues to raise funds for Vasculitis UK. In August it was the Speyside Ultra finishing in 7 hours 51 minutes, and in September the BMW Berlin Marathon. So far Jamie has raised over **£1050** for the Trust.



**Sarah Freestone with Caroline and Karin** - Having decided to put down their wine glasses to train, the three ladies took part in the Edinburgh Half Marathon on 27<sup>th</sup> May. They raised **£1500** for the Trust.

**Stuart Govan** took part in the Great Scottish Run Half Marathon on 2<sup>nd</sup> September. His friend Bob Morrison recently passed away following complications with his vasculitis and the run was undertaken in Bob's memory. Stuart ran in 1 hour 46 minutes. He had hoped for a quicker time but had a viral infection before the event. Robert's brother John and his partner Melissa kindly donated £250 of the **£550** already donated.



**Candy Hawkins** - During 2012 Candy has entered several races including the Ashford 10K, the 28th Hastings Half Marathon and the Darwent Valley. 10K where she finished a commendable 13<sup>th</sup> in the ladies section and 155 overall and raised **£100** for the Trust in memory of her friend Clare Grossman.



**Hopton School in Norfolk** donated **£72** to the Trust from a number of fundraising events.



**James and Neville Horner** - Together, as Team Horner, James and Neville undertook what James describes as "Jim's birthday stroll", which actually involved walking up Ben Nevis. Their joint total for the Trust stands at **£350**.

**Hannah-May Jones-Leyshon** - H a n n a - M a y ' s "Bampi" (Grandfather) passed away in March 2012. Hannah May wanted to raise funds for the Trust. In June she, and her friends, took part in a sponsored walk from Cowbridge, through Ystradowen to Pontyclun and back to Llanharry. In their fancy dress and sponsorship buckets, and via JustGiving.com Hannah-May and friends have raised almost **£1565**.



*Fundraisers continued ►*

*Our Fantastic Fundraisers (continued)*

**Kirsty Landles with Bobby, Kaisa, Bea and Rafa** (with the help of Dad) undertook the "Three Peaks Challenge" between 18th and 19<sup>th</sup> July. This involved climbing Ben Nevis in Scotland (1344 meters), Scarfell in England (978 m) and Wales in Snowdon (1085 m) and

hiking 42 horizontal kilometres. To do all this in 24 hours was a marvellous achievement. Mum, Jann, has Wegener's. Together the group have raised over **£650** for the Trust.

**Maureen and Reg Lakin** recently celebrated their Golden Wedding Anniversary. Instead of presents they asked for donations for Vasculitis UK. Their family and friends raised **£225**. Maureen has Wegener's Granulomatosis.



**Lorna Lewis** - In March Lorna held a coffee morning at her home in Edinburgh and raised **£300** for the Trust.

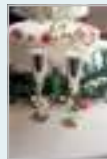
**Neville Macdonald** held a sale of books, postcards, LPs and her Mother's vintage furs, and raised **£150** for the Trust.



**Carly Martin** was another entrant into the Great Scottish Run Half Marathon in September. To date Carly has raised **£580** for Vasculitis UK.

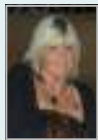
**Susan Mills** - For Rare Disease Day in February, Susan held an Open Day at West Bank. Friends and family came along and enjoyed a wonderful buffet and helped to raise **£300** for the Trust.

**Liz and Brian Moore** celebrated their Silver Wedding Anniversary on 2nd May. Their eldest daughter organised a surprise party for 80 guests. They kindly donated **£310**, in lieu of presents to the Trust. Liz has Churg Strauss Syndrome.



**Pension & Benefit Services Ltd** of York held a Cake Sale and Dress Down Day in March and kindly raised **£112** for Vasculitis UK.

**Posse Western Dancers (Sheffield)** - Jean Gibson's friend John Hardie has vasculitis and the ladies of the linedance class held a social evening and kindly raised **£100** for the Trust.



**Danielle Potter** - Sadly Danielle's mum Jacqueline (pictured left) had MPA and passed away in May (see In Memoriam). Danielle has been raising funds for the Trust in Jacqueline's memory, and has donated **£110** to Vasculitis UK.

**Mrs M Robertson** of Chester-le-Street raised **£62** at a fundraising event in August.

**Andy Bone - "Sports-Shots"**

Andy, is raising awareness of vasculitis and funds for the Trust via sales and donations from photographs.

Details can be found on his "Sports-Shots" Facebook site:

([www.facebook.com/sportsshots](http://www.facebook.com/sportsshots)) or visit his new website [www.sportsshots.org.uk](http://www.sportsshots.org.uk) or his JustGiving page.

**Jennifer Wormald & Rita Allen - Bead Jewellery**

Jennifer Wormald of Wetherby, near York and Rita Allen of Essex make

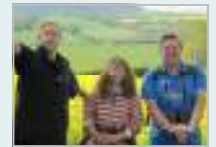
**Isabel Rodriguez** held a "Zumbathon" in Worcester during April. She raised **£170** in memory of her father Gonzalo Rodriguez Revoltos.

**Francesca Saville & Tim** - Following her success in the Brighton Marathon in April 2011, Francesca and boyfriend Tim entered the Virgin London Marathon in April and so far have raised over **£4,530**. Francesca's sister Alexandra has vasculitis. At the end of the marathon Tim proposed to Francesca, and tearfully, but happily, she said "Yes". Our congratulations and best wishes go to Francesca and Tim.



**Kevin Soper** kindly organised a disco in Ashford, Kent to raise funds for the Trust, and in memory of his sister Clare Grossman. Everyone had a wonderful time and, thanks to the hard work of Kevin and his team, managed to raise awareness of vasculitis and **£1,100**.

**Liz Upperdine** - Liz's close friend Dilys Powell has vasculitis. To thank the Trust for the support given to Dilys, Liz undertook a sponsored walk the "12 Mile Pound" and raised **£788**. Her employers, Barclays Bank kindly donated a further **£750**.



**Vasculitis Awareness Month (May)** - Rita Allen, Patricia Fearnside, Lynne Jacques, Kelly Jeffries and Lorraine Murton held either a tea party, a coffee morning, an auction or a dress down day at work. Between them the ladies raised over **£1000** for Vasculitis UK.



**Jimmy Walker** And his colleague Roger Mitchell undertook the 79 mile Scottish Highland's Lochinver to Tongue walk. This challenging "walk" included three mountains and some "wild camping". Jimmy has vasculitis. Together Jimmy and Roger raised almost **£500** and their employer, Scottish Power, kindly donated a further **£200**.

**Lindsey Whitehead** - Lin, together with Mark and Ian entered the Yorkshire Three Peak's Challenge on 14<sup>th</sup> September. All three admit to liking a good walk but this was a huge challenge, involving the three highest peaks in Yorkshire. Mark has Wegener's diagnosed in July 2010. Unfortunately, during training Lin received an unwanted gift - a parking ticket in Edale. So far this gallant trio have raised almost **£600** for the Trust.



bead jewellery and are happy to sell it on behalf of the Trust. If you are having an event where it could be sold please contact Jennifer or Rita direct. Jennifer can be contacted on (01937-586734), and Rita on 01255-820307.



## Regional Support Group Meetings

**Oxford VSG:** On Sunday 4<sup>th</sup> March the members of the Oxford Support Group were privileged to hear presentations from Dr Jo Robson and Professor Raashid Luqmani. They expertly covered what research was current at the Oxford Hospitals Trust, This research included better diagnosis beyond the familiar methods of blood tests and biopsies, which are not always reliable. Also under review are the newer



methods of ultrasound and PET scans, which are often more reliable as a first step in the diagnostic process, particularly for some types of Vasculitis and where raised ANCA levels are not present.

Professor Luqmani also spoke of the UK and European research currently being undertaken into optimal treatment including Rituximab, with patient samples from across many countries.

**North West VSG:** The second meeting of the group place near Preston in March.

About 30 people attended including several Trustees from Vasculitis UK and a representative from the local Kidney patients support group.



Two consultants, from Preston Royal Hospital, Dr Ajay Dhaygude and Dr A MacDowall gave talks about Vasculitis which were followed by a question and answer session. Dr MacDowall's talk included a summary of the experience of vasculitis patients who had taken part in studies during the period 2006 2011. The next meeting will be on 16<sup>th</sup> September at the Ticked Trout Hotel Preston.

**Yorkshire VSG:** The third Yorkshire meeting was held in Doncaster on 22<sup>nd</sup> April. Thirty members attended the meeting which, on this occasion was a buffet lunch with plenty of time to socialise with other vasculitis patients and their family and friends.



After a delicious lunch, which had been kindly prepared by Jennifer Wormald, Pat Fearnside and John Mills gave an overview about the Route Map for Vasculitis and hosted a Q&A session with included audience participation from members.

**Cambridge VSG:** held a well-attended meeting in April 2012.

The attendees heard presentation from Dr Rachel Jones. Since 2005 Dr Jones has been working as an Honorary Consultant Nephrologist with Dr David Jayne at Addenbrooke's hospital.

Dr Jones talk covered the impact of long term vasculitis and its treatment. She covered many aspects of having



the condition including psychological impact, tissue damage, and the side effect of the treatments. Dr Jones also mentioned the impact on the quality of life for all the family.

Once again the informative afternoon was all thanks to the work of Jenny Fulford-Brown with support from her family.

**Vasculitis Ireland Awareness—Meetings in Belfast and Dublin:** This has been an extremely busy time for the Group. Meetings were held in Belfast in June and September, and Dublin in July. The Group have recently obtained charity status.



The *All Ireland Vasculitis Meeting* is being organised and this will take place on 6<sup>th</sup> and 7<sup>th</sup> October (see "Diary Dates", page 3). The Group are working towards having their own website up and running in the not too distant future, and they recently became members of the Specialised Healthcare Alliance. The aim of the SHCA is to improve services in the NHS for people with rare or difficult disease. See: [www.shca.info/index.htm](http://www.shca.info/index.htm)

**Lincolnshire VSG** met in June in Digby for a summer BBQ. Despite the threat of rain, 21 people attended (vasculitis patients, friends and family) and enjoyed a memorable meal. As if on cue, the sun came out just in time to allow everyone to mingle outside.

There were several new members, and their partners, and they were particularly glad to be able to share experiences, compare medical care and the effects of therapies. As one of

them said, "it is so good to talk to people who understand and now I don't feel so alone anymore!"

The next meeting is to be on 29<sup>th</sup> October. Further details from Pam Todd.





## Support groups continued

**Beds, Bucks & Herts VSG:** Carol and Jack McMenamin organised a Support Group lunch in June at the Magic Mushroom in Billericay, Essex. As can be seen from the photo they had a wonderful time. They were even given a private room, as Chris says "maybe they remembered us from the last time!".



The **West Country VSG** braved this summer's rain to hold a bbq in June. During the event the group presented Kathleen Rawlinson with a gift to thank her for all her hard work in setting up and running the group over many years.



When it first started the group

consisted of a handful of people who met for lunch. Now there are over 20

members, and events arranged include talks by specialists, bbqs and, of course, those friendly lunches! Kathleen has decided to pass over the reins and Charlotte Stoner is now the main contact for the West Country.

Contact: [the.stoners@talktalk.net](mailto:the.stoners@talktalk.net) — 01626 872420

**New Merseyside, Cheshire and North Wales VSG:** The inaugural meeting of the Group was held at the Royal Liverpool University Hospital in Liverpool on Thursday 12th July. It was attended by approximately 40 people including partners/carers.

There was an introduction by Dr Janice Harper, who is a Consultant at the Vasculitis Clinic at the Royal Liverpool, aided by Sarah Hardy who is a specialist Vasculitis nurse. Both are dedicated to providing treatment for Vasculitis on a

local basis. This was followed by a good and informative talk by Pat Fearnside about the Route Map and the aims of Vasculitis UK.

Many of those attending had never met others with the same condition before so they were able to have a chat and compare notes. A raffle was held to raise funds for the future Group meetings. A further meeting will be held on 6th November in Liverpool.

## Support Group Contact Details



### Beds, Bucks & Herts

**Janine Davies** 01525-372733 [amily.davies@btinternet.com](mailto:amily.davies@btinternet.com)  
**Christine Lee** 01480-869162  
[chrislee0307@btinternet.com](mailto:chrislee0307@btinternet.com)

### Cambridge

**Jenny Fulford-Brown** 01223-565967  
[jenny.cambsvsg@hotmail.com](mailto:jenny.cambsvsg@hotmail.com)

### Canterbury area \*\*

**Margaret McGrath** 01227 638 469  
[margaretmcgrathfmsj@yahoo.com](mailto:margaretmcgrathfmsj@yahoo.com)

### East Kent \*\*

**Brian Hart** 01227 369774

### Edinburgh, Lothian & Central \*\*

**Jimmy Walker** 0759 118225  
[sirjimmywalker@hotmail.com](mailto:sirjimmywalker@hotmail.com)

### Essex

**Jules Darlow** 07789-113144  
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### Lancashire/North West

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**John Chadwick** 07743476539  
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### Lincolnshire

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### London

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[vincentf51@hotmail.com](mailto:vincentf51@hotmail.com)

### Merseyside, Cheshire and N. Wales

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### Northern Ireland

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[vasculitisireland10@gmail.com](mailto:vasculitisireland10@gmail.com)

### North Wales \*\*

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### North West (Cumbria) \*\*

**Martin Thomas** 07765 888987  
[nwukvsg@gmail.com](mailto:nwukvsg@gmail.com)

### Oxfordshire

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[oxonvsg@hotmail.com](mailto:oxonvsg@hotmail.com)

### Republic of Ireland \*\*

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[dwodo@iol.ie](mailto:dwodo@iol.ie)

### SE London/NW Kent

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### South Wales

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[creigiau20@yahoo.co.uk](mailto:creigiau20@yahoo.co.uk)

### Surrey

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[paul.m.bingham@btinternet.com](mailto:paul.m.bingham@btinternet.com)

### West Country

**Charlotte Stoner** 01626 872420  
[the.stoners@talktalk.net](mailto:the.stoners@talktalk.net)

### West Midlands

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[davsamuk@yahoo.co.uk](mailto:davsamuk@yahoo.co.uk)  
**Margaret Gentle** 0121-243-5621  
[mqvsgwm@blueyonder.co.uk](mailto:mqvsgwm@blueyonder.co.uk)

### West Sussex

**John Bailey** 07752-122926  
[johnbee4@googlemail.com](mailto:johnbee4@googlemail.com)

### Yorkshire (South)

**Pat Fearnside** 01709 583722  
[pat@vasculitis.org.uk](mailto:pat@vasculitis.org.uk)  
**Jennifer Wormald** 01937 586734  
[jenw@bethere.co.uk](mailto:jenw@bethere.co.uk)

### Yorkshire (North) **New**

**Lynne Jacques** 01274 412378  
[lynne.jacques@sky.com](mailto:lynne.jacques@sky.com)

**The Ring** A support group in Norfolk for RA patients. **Judith Virgo** [jvirgo@fsmail.net](mailto:jvirgo@fsmail.net)

\*\* Contact person - Not a group

## Innovative hearing aid helps Jamie

Siemens Hearing Instruments is doing its bit to help a hearing loss sufferer, vasculitis patient and current Vasculitis UK fundraiser Jamie Flanagan. The manufacturer has come to Jamie's rescue by developing a fully waterproof, dust proof and sweat proof digital hearing aid – The Aquaris.

Jamie will use the device, the only one of its kind in the world, when he takes part in the first of five marathons, covering a total of 160 miles across the Egyptian desert. He will be aiming to undertake these arduous events in under 96 hours in a bid to raise money for a charity of his choice, and demonstrate the ability of those suffering from hearing loss and from vasculitis.

Previously a musician, Jamie lost his hearing in 2000 as a result of Wegener's Granulomatosis. (Jamie's story was highlighted in the Spring 2012 Newsletter and is one of our Inspirational Stories on the new Vasculitis UK website—[www.vasulitis.org.uk](http://www.vasulitis.org.uk)).



He completed his first marathon in 2009 and now runs 100 miles and trains almost 20 hours a week.

To date, he has never been able to run with a hearing instrument for fear of sweat damaging the electronics. Since he was fitted with Aquaris he reports that for the first time he is able to hear traffic, other runners, and bikes, making his training safer and more enjoyable.

Jamie commented "My boring, tedious miles have become interesting with sound and my hearing instruments enrich my running. I never thought there would be a hearing solution that suited my

active lifestyle and I'm delighted to take this exciting product to the edges of the earth and demonstrate that it is as tough as I am."

Vasculitis UK wish to thank Jamie for fundraising for the Trust during 2011/12 and wish him every success with the hearing device and in his future marathon events.

## Slimming couple of the year—an inspirational story

Prior to 2005 Tracy and her husband Simon were active and enjoyed camping holidays, walking, fishing and visits to the cinema. Then she became ill and when her condition deteriorated she was referred to the Royal Brompton Hospital in London where a diagnosis of Churg Strauss Syndrome was made. By 2009 Tracy had gained 7 stone in weight, due to the effects of the Prednisolone and as a consequence of enforced inactivity, and she was caught in what she describes as "a self-destructive cycle". She was miserable about her health and her increasing weight gain, so she would eat and then try to cut down to a level she couldn't sustain. Tracy became a bit of a recluse and Simon stayed at home too. During this time Simon also gained a considerable amount of weight.

After encouragement from a friend they decided to join *Slimming World* in January 2011. Tracy didn't think weight loss was possible, and having looked at the *Food Optimising* book thought that if she ate all that food she would gain weight. After the first week Tracy had lost 7-1/2lbs and Simon 6lbs. From then their weight loss steadied to around 1 or 2 lbs per week.



As the weight reduced Tracy took her first tentative steps towards light exercise, then walking their collie dog and after six months, and a weight loss of 5 stone, they managed to hike 12 miles.

At the start of their slimming experience Tracy weighed 18 stone and is now 9 stone in a target time of 16 months despite still taking steroids. Simon's starting weight was 18st 7-1/2lbs and now 11st 12lbs in 11 months - a combined total of over 15 stone. This was achieved by sticking to the *Slimming World* plan and eating healthy food such as fruit and vegetables, pasta, rice, potatoes, lean meat, fish, eggs and low fat dairy produce. They are enjoying life to the full and Tracy's health and wellbeing has improved remarkably.



As Tracy says "by the time you read this we may well be white-water rafting or parasailing. There's no stopping us now".

Our thanks are extended to *Slimming World* and to Tracy and Simon Bartlett for their kind permission to reproduce extracts from the Aug/Sept issue of *Slimming World* magazine.

You can find details of a local meetings at [www.slimmingworld.com](http://www.slimmingworld.com) or call 0844 897 8000

Worry is a misuse of imagination - Dan Zandra

A wise man speaks because he has something to say; a fool because he has to say something - Plato

Nobody can make you feel inferior without your consent - Eleanor Roosevelt



## 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.

### **RICHARD BOYCE**

Richard of Birdham, West Sussex was a late diagnosis of WG in December 2002. Sadly he passed away, aged 59 in April. Richard was a loving family man, he was interested in motor racing, motor bikes and rugby. He was always ready to help in the community. He leaves his wife Jacky and daughters Natalie & Nicola who miss him very much. Richard's family and friends donated £1030 to the Trust in his memory.

### **EDITH CAREY**

Mrs Carey passed away in Spring 2012. She was the grandmother of one of our members, Catherine Cotter. Catherine and her family and friends kindly donated £100 to the Trust in lieu of flowers and in memory of Edith as they knew that this is what she would have wanted.

### **TED FLETCHER**

Ted was much loved by his family and friends. He was diagnosed with Wegener's in 2006 and after being seriously ill, but with appropriate treatment, his life returned to almost normal. Sadly in early 2012 his condition deteriorated and he passed away on 24<sup>th</sup> April aged 85 of autoimmune hepatitis. Ted's family and friends kindly donated £335 to the Trust in his memory.

### **LYNNE HARGREAVES**

Lynne, of Stockport, passed away in May, within a few weeks of diagnosis of WG. Lynne's husband Alan made this moving tribute. "Lynne was a beautiful person; good natured, dependable, selfless and always happy and great fun to be around." She leaves two children (Steven and Claire) and two adored grandchildren aged 3 and one. Lynne will be greatly missed by Alan and her extended family who have kindly donated £560 to the Trust in her memory.

### **RONALD JOHN HUGHES**

Ronald was diagnosed with Wegener's in 2010 and passed away on 28<sup>th</sup> May. His wife Janet and his family and friends kindly donated £100 to the Trust in Ronald's memory.

### **HUMPHREY (FRED) JONES**

Humphrey was the dear Bampi (Granddad) of Hannah-May. Humphrey had vasculitis and passed away earlier this year. His family and friends kindly donated £250 to the Trust in Humphrey's memory. Hannah-May has since undertaken fundraising for the Trust in memory of her Granddad.

### **ETHEL KIRKPATRICK**

Mrs Kirkpatrick of Castle Douglas, Kirkcudbrightshire passed away in August 2011 and her family and friends kindly donated £433 in her memory. The Trust must apologise to Mr Kirkpatrick that reference was not made in the Spring Newsletter to Mrs Kirkpatrick's passing. Ethel suffered from Wegener's for over ten years and subsequently had a long battle with cancer. Ethel was great fun to be with; she loved a laugh and a joke. She was so proud of her family, especially her grandchildren. Ethel is loved and sadly missed.

### **NEVIELLE MACDONALD**

Nevielle of Dingwell, Scotland passed away in August. She had Wegener's and had been battling cancer for some time. Nevielle was a very positive person and made her final arrangements, including holding a sale to raise funds for the Trust, and also purchasing a wicker coffin for her funeral. Her cousin Stanley Lamprey kindly donated in Nevielle's memory.

### **GLYNIS ANN MASON**

Glynis of Colchester passed away in June. Glynis was a vasculitis patient. Her brother, family, friends and colleagues at Family Support, Colchester donated £230 to the Trust in memory of Glynis.

### **ROBERT (BOB) MORRISON**

Bob had Wegener's and also had Stephens Johnsons Syndrome. He regularly posted on the Trust's Facebook site and amused members with his witty postings. It was with great sadness that we heard that Bob had passed away suddenly. Bob's mother, brother, family and friends kindly donated £321 to the Trust as funeral donations in his memory.

### **PETER JAMES MYATT**

Peter, of Salisbury passed away in March 2012. His daughter, Mrs Burr and family and friends kindly donated the funeral collection on 26<sup>th</sup> March to Vasculitis UK (£403).

### **EDITH NORRIS-SHERBORN**

Edith, of Bardney, Lincolnshire passed away on 11 March 2012. Edith's husband Frank and her daughter Jan and son Andrew have kindly donated £250 to the Trust in her memory.

### **JACQUELINE ALICE POTTER**

Jacqueline had a long battle with MPA and also suffered a major stroke. She passed away on 15<sup>th</sup> May aged 56. She still managed to smile, and in October became a Nan for the first time. Jacqueline was so looking forward to looking after baby Luci. Her family and friends kindly donated £66 to the Trust in lieu of flowers and in memory of Jacqueline.

### **HUGH REID**

Hugh, of Camberley, Surrey would often phone John Mills for a chat. It was with great sorrow that we heard of Hugh's passing on 12<sup>th</sup> June. Hugh's wife Jill says "he was very brave and a lovely person and he appreciated the help he received from John and from the Trust". Family and friends have kindly donated £150 in Hugh's memory to enable the Trust to continue to support others with vasculitis.

### **JENNY WATERS**

Jenny of Blackwood sadly passed away 10 days after being diagnosed with WG, and just before her 58th birthday. Jenny's family and friends kindly donated £180 in her memory.

### **JEAN WENBORN**

Jean, of Cheltenham, passed away in June 2009. The Trust is extremely grateful that Jean's husband Donald has again kindly donated £600 to the Trust in her memory on the anniversary of Jean's passing.



## Donating to Vasculitis UK



Your voluntary donations to Vasculitis UK help us to achieve our aims—to **support patients, help raise awareness, fund research**, and, of course, **produce, print and post these twice yearly Newsletter Journals**.

Please remember, your two annual Newsletters now cost the Trust over £6 a year with printing costs and the increased cost of postage. So please consider making a donation of at least £5 a year towards the cost of your Newsletter. **If you no longer wish to receive the Newsletter please let John Mills**



**know. This will help reduce the Trust's administrative costs. Thank you.**

There are now a number of ways to donate:

A **one-off** donation or **monthly direct debit** by **Credit** or **Debit card** or even by **PayPal** simply by using [www.justgiving.com/VasculitisUK/donate](http://www.justgiving.com/VasculitisUK/donate)

Alternatively, If you would like to make a **single donation by cheque** or set up a **regular standing order payment**, please use the donation form enclosed with this Newsletter.

giftaid it

### Gift Aid - worth an extra 25p in the £ to the Trust

Whether you are making a one-off donation, a regular standing order, direct debit or a sponsorship donation please use Gift Aid if you are a UK tax payer. It doesn't cost you a penny to Gift Aid your donation, all you need to do is complete a Gift Aid form and send it to the Treasurer.

Want to check your Gift Aid status with the Trust? Contact Pat Fearnside (Treasurer). Remember Gift Aid means 25p extra for the Trust for every £1 you donate.

giftaid it



If you are entering an event or raising funds for the Trust, the easiest method is to start your own **JustGiving** page and ask your friends to sponsor you through **JustGiving**. Starting a page is easy — just go to:

[www.justgiving.com/VasculitisUK/](http://www.justgiving.com/VasculitisUK/)

and follow the instructions.



Shop online at your favourite supplier, eg John Lewis, M&S, via "easyfundraising" and raise funds for the Trust. It won't cost you a penny and it is safe and easy to use. You pay the supplier, no third party is involved with the payments.

[www.easyfundraising.org.uk/vasculitisuk](http://www.easyfundraising.org.uk/vasculitisuk)

There's even a "Find & Remind" prompt to remind you about "Easyfundraising" when you are shopping on line: <http://www.easyfundraising.org.uk/find-and-remind/>



Raise funds for the Trust whilst you search the internet. To join, just go to:

[www.vasculitisuk.easysearch.org.uk](http://www.vasculitisuk.easysearch.org.uk)

## Travel Insurance

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

**Just Travel Insurance** is a specialised Insurance Agent who have provided specialist Travel Insurance nationally for over a decade. Many medical conditions attract no additional payments. Their Insurance policies **have no upper age limit**. Please mention "Vasculitis UK" when using the services of this Agent. **Phone: 0800 231 5535**  
<http://www.conditionscovered.co.uk/>

The **Post Office** offers different levels of travel insurance. Like many insurers they have specific rules regarding pre-existing medical conditions. Some conditions may not be covered, others may require an additional premium. Details are available from any Post Office.



**Goodtogo Insurance** have been recommended for offering a high level of cover for pre existing conditions at a reasonable price. **Phone: 0844 334 0160**  
[www.goodtogoinsurance.com](http://www.goodtogoinsurance.com)

Further travel insurance providers can be found at the Trust's website: [www.vasculitis.org.uk](http://www.vasculitis.org.uk)

## Treasurer's Report 1st April 2011-31st March 2012

The Treasurer reported on the Trust's financial year 2011/2012 at the AGM in May.

Income for the financial year increased appreciably when compared to 2010/11 - (£74,498.24 compared with £59,397.91). The largest increase in income was due to fundraising and other donations received via JustGiving.com (see below).

- Donations for the year were £64,234.26, with those donations via Justgiving.com increasing from £14,406.63 in 2010/11 to £28,899.23 in the current year.
- Gift Aid, as claimed by the Trust, showed a slight fall - £3,212.69 compared with £3,521.23. However, the overall amount of Gift Aid increased via JustGiving.com who collect Gift Aid on donations on behalf of the Trust. The amount of Gift Aid received via JustGiving.com is included within the £28,899.23 and was approximately £5,800.
- The income from the Spring Raffle during 2011 totalled £10,802, £5,445 being received in the financial year under review.

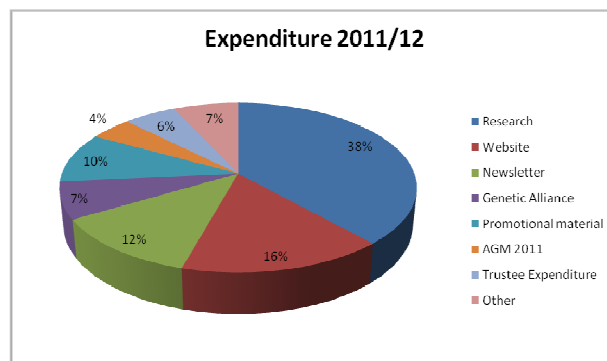
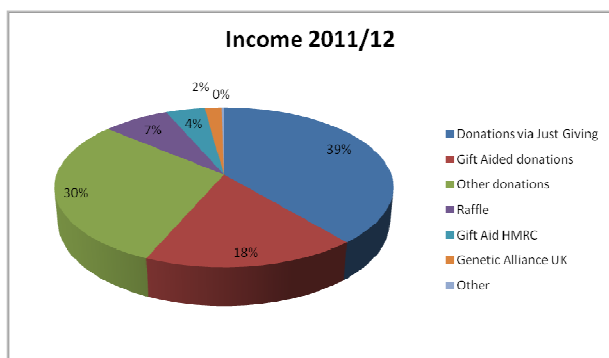
Expenditure showed a considerable increase (£31,745.34 compared with £4,641.18). Increased expenditure included a large increase in the number of Newsletter/Journals being printed, together with costs incurred to produce the Newsletter in colour and subsequent postal costs; the initial costs of the new website, and purchase of merchandise.

The main expenditure during the year was a donation of £12,000 to Addenbrooke's Hospital in Cambridge to part-fund research into the drug Alemtuzumab.

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

A copy of the Accounts of the Trust for the year ending 31st March 2012 was circulated at the AGM. A copy is available by contacting the Treasurer.

**Patricia Fearnside** Treasurer



### Please stay in touch Keep your details up-to-date



#### e-News

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

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

#### Newsletter/Journal

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

Contact details on page 24.



## Raising awareness of vasculitis and of Vasculitis UK

▶ Please help to increase awareness of vasculitis and of the activities of the Trust by taking your Newsletter/Journal to your hospital or GP waiting room when you have finished with it. Or why not hand it to your GP or consultant? Help to spread the word about vasculitis and about the Trust.

▶ **If you no longer wish to receive the Newsletter/Journal please let John Mills know. This will keep our administrative costs down.**

**If you would like to submit an article for consideration for publication in the next Newsletter/Journal, please contact the Editor (details page 24)**

**Spring 2013 deadline — 1st February**

# Vasculitis UK Shop

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

**All prices include VAT and p&p.**

- Route Map for Vasculitis £10**
- t-shirts/v necks £11 each**
- Running vests £11 each**
- Sweatshirts £12**
- Polos £11.50**
- Hoodies £18.50**

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

- Baseball hats one size. £8 each**
- Wristbands £1.60 each**
- Beaded bracelets £4.00**
- Beaded key-rings £4.00**



**New Vasculitis UK teddy bears 11" (28cm) height. £12 each**



## Christmas cards New for 2012



Our quality charity Christmas cards come in four different designs. Each pack contains 10 cards of one design with the greeting "Best wishes for Christmas and the New Year". Card sizes 125 x 125mm for the dove/robin and Santa, and 145mm x 100mm for the penguins. Price: **£3.95** per pack (to include p&p).

Name: \_\_\_\_\_ Phone No. \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_ Post Code \_\_\_\_\_

Description + colour (if applicable)	Size	No.	Unit Price £	Total £
			Sub total £	
			Opt. donation £	
			Total £	

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



# Life president: Lillian Strange

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

The main aims of the Trust are:

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

**Registered Charity No. 1019983**

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

♦ formerly known as : **Vasculitis UK (Stuart Strange Vasculitis Trust)**



## Officers and Trustees

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PROFESSOR LORRAINE HARPER**

**Trustees:**

**Richard Eastoe Lynne Jacques  
Jann Landles Anita Parekh Lisa Ranyell  
Chris Stait Martin Thomas**

## Some of the vasculitides

**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)**

**Granulomatosis with Polyangiitis  
(Wegener's Granulomatosis)**

**Giant Cell/Temporal Arteritis**

**Henoch-Schönlein Purpura**

**Hypersensitivity Vasculitis**

**Hypocomplementic Urticarial Vasculitis**

**Kawasaki Disease**

**Microscopic Polyangiitis**

**Polyarteritis Nodosa**

**Polymyalgia Rheumatica**

**Relapsing Polychondritis**

**Takayasu Arteritis**

**Have you visited our new website?**

**[www.vasculitis.org.uk](http://www.vasculitis.org.uk)**

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



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