



**vasculitis uk**

**Autumn 2011  
Issue No 42**

**Newsletter & Journal**

**What's inside?**

**THE IMMUNE SYSTEM/AUTOIMMUNITY**

**MYCOPHENOLATE -v- AZATHIOPRINE**

**MYCROSCOPIC POLYANGIITIS**

**WALKING THE TIGHTROPE**

**AGM REPORT**

**“WHO GETS VASCULITIS - AND WHY?”**

**AN INTERVIEW WITH .....**

**STUART STRANGE & MARTIN LOCKWOOD**



## A view from the Chair



Susan & John  
(Victorian Musical Evening)

There was no audible trumpet fanfare, but at the AGM in May, the name of the Trust was officially changed to "Vasculitis UK". But have no fear, we won't forget our roots, or Stuart Strange, or our debt to his family for setting up the Trust almost 20 years ago. You will find the history of the Trust elsewhere in this newsletter. Now that the new name is registered with the Charity Commission, we can move forward with printing new literature and developing the new website.

In May, we said farewell to our Treasurer, Andy Bone, to whom we are very grateful for having taken over from Richard Harris. Personal commitments meant that he could not continue, so Pat Fearnside has, very bravely, added Acting Treasurer's role to that of Newsletter editor and vice-chairman - a

lady with many hats! Pat hopes that this is just a temporary measure, so we are still looking for a new permanent treasurer. Martin Thomas, from Cumbria, joined the Trustees at the AGM.

Vasculitis UK has recently contributed £12,000 to fund part of a research project at Addenbrookes Hospital, Cambridge. This research, into the use of a drug called Alemtuzumab in treating ANCA related vasculitis, is being undertaken by Dr Rona Smith and Dr David Jayne. This drug, like Rituximab, is a manufactured antibody.

We always welcome the setting up of new independent support groups and the new Lancashire and North West group had its inaugural meeting at Preston on September 4<sup>th</sup>. Much of the credit for that must go to Jenny Fulford-Brown and Jann Landles.

Many of the other changes that have taken place since the Spring Newsletter are discussed elsewhere in this edition, such as the new website and logo, Routemap developments, the new HealthcareUnlocked online discussion group and the Webinars launched by the Lauren Currie Twilight Foundation.

So it just remains for me to wish you all a (rather premature) Merry Christmas and a Happy, Healthy and Prosperous New Year.

*John Mills*

## Contents

- 3 Diary dates
- 4 The Immune System/ Autoimmunity
- 5 Mycophenolate -v- Azathioprine
- 5 Microscopic Polyangiitis
- 6 Walking the Tightrope
- 7 AGM Reports
- 8 "Who gets Vasculitis - and why"
- 9 Discussion groups
- 10 Stuart Strange/SSVT
- 11 Influenza vaccination
- 12 Website and Logo
- 13 An Interview with ....
- 14 Personal Stories
- 15 Healthy Eating
- 16 Fundraisers
- 18 Support Group reports
- 20 The Enlightened Patient

Cover photograph by kind permission of one of our Members, Anthony Falla.  
See more of Anthony's photos on Flickr: [www.flickr.com/photos/anthonyfalla/](http://www.flickr.com/photos/anthonyfalla/)

\* Formerly known as: *Vasculitis UK (Stuart Strange Vasculitis Trust)*

# Diary Dates

## SUPPORT GROUP MEETINGS

*Polite note: If you are going to attend please pre-book so the organisers know how many are coming, and, if food is included, that they don't under or over order. Please be considerate and let the organisers know if, once booked, you are unable to attend. Once food is ordered the organisers have to pay for it!!*

**VSG West Midlands (VSGWM)** The next meeting will be held on Sunday **23rd October** at the Hilton Birmingham Bromsgrove Hotel. The speakers/topics: Dr David Carruthers - topic TBA, and Dr Andrew McClean—Research into Tiredness. Contact: 4a Northbrook Rd., Shirley, Solihull B90 33NT 0121 744 0318 [davsamuk@yahoo.co.uk](mailto:davsamuk@yahoo.co.uk)

**Oxfordshire VSG** A local group lunch will be held at The Duke of Marlborough pub near Woodstock (OX20 1HI) on Sunday **6th November**. Details from Sue Ashdowne 01295 816482 [oxonvsg@hotmail.com](mailto:oxonvsg@hotmail.com)

The next seminar for the Oxfordshire group is being planned for **March 2012**.

**Cambridge VSG** The next meeting will be held on Sunday **20th November**. The speaker will be Dr Sapna Trivedi. Further details to be announced. Please contact Jenny Fulford-Brown 01223-565967 [jenny.cambsvsg@hotmail.com](mailto:jenny.cambsvsg@hotmail.com)

**Essex VSG** Jules Darlow (Support Group Leader, based in Colchester) has booked Benton Hall in Witham for an informal lunch-time meeting on **Wednesday 23rd November**. The venue is free but members are asked to purchase their own lunch/refreshments at the hotel. Please contact Jules:

## News in brief

**Professor Raashid Luqmani:** The congratulations of the Trust are extended to Dr Raashid Luqmani of Oxford on becoming Professor Luqmani.

**Work and Benefit:** See the column opposite if you are thinking of applying for or are considering appealing a decision on DLA, ESA or IB.

**Research grants:** The Trust has provided £12,000 funding to Addenbrookes hospital to part fund the research into the drug Alemtuzumab.

**What's in a name:** It was officially accepted at the 15th International Vasculitis and ANCA Workshop at Chappel Hill in May, that Wegener's Granulomatosis would be re-named "Granulomatosis with Polyangiitis (GPA)" and Churg Strauss Syndrome would be renamed "Eosinophilic Granulomatosis with Polyangiitis (EPGA)".

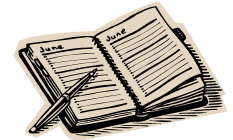
### Stop press

In the summer of 2012 the **NHS Direct** will change to **NHS 111**. For more information:

[http://www.dh.gov.uk/en/Healthcare/Urgentandemergency/DH\\_115054](http://www.dh.gov.uk/en/Healthcare/Urgentandemergency/DH_115054)

**Collection boxes** Did you know the Trust once had collection boxes? Neither did we. Recently we heard from Mrs Kerry Drew who had kept a SSVT collection box on the counter of her shop for years. She had diligently put the money in the safe but decided that, as no one ever collected the money, she would try to contact the Trust. We are grateful for Mrs Drew's investigative work and the kind people of Alfreton for donating over £200 to the Trust.

If any Member knows the whereabouts of other collection boxes please let John know.



[essexvsg@googlemail.com](mailto:essexvsg@googlemail.com) or ring 07789-381680

**Lancashire VSG** The next meeting will be on Sunday **4th March 2012**. The venue has yet to be agreed. Detail can be obtained from: Jann Landles or John Chadwick: [nwvasculitis@hotmail.co.uk](mailto:nwvasculitis@hotmail.co.uk)

**VASCULITIS UK—Annual General Meeting.** Will be held on Sunday **13th May 2012**. Further details to be announced.

## FUNDRAISING

**Elise Baxter** will be entering the Ashford 10K on **9th October** to raise funds for the Trust, in memory of her friend Clare Grossman who passed away in December 2010.

**Neil Holden** will be taking part in the BUPA Great Birmingham Run on **23rd October 2011**

**Janine Emma Brown** of the Ashford Athletic Club will be taking part in the ING New York Marathon on **6th November**. Janine will be dressed a Wonder Woman. Janine is also raising funds in memory of her friend Clare Grossman.

## GENERAL

**Lauren Currie Twilight Foundation "Webinar"** The 2nd "Webinar" will be held on Wednesday **16th November** at 5.30 pm.

**International Rare Disease Day 29th February 2012**



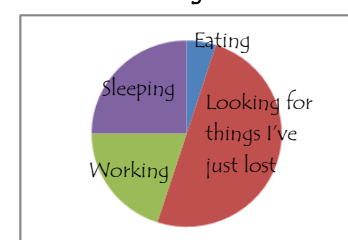
## Work and Benefit

"Work and Benefit" give advice to claimants on all aspects of claiming benefits and appeal procedures, eg "Disability Living Allowance", "Employment and Support Allowance" and "Incapacity Benefit".

The Trust has obtained "professional" membership of "Work and Benefit" which enables us to provide information to our Members **free**. If you would like details from this website please contact: Susan Mills in the first instance: [sandjmills@btinternet.com](mailto:sandjmills@btinternet.com)

Alternatively, you can join "Work and Benefit" as an individual member for a subscription of £19.45 a year at: [www.benefitsandwork.co.uk/](http://www.benefitsandwork.co.uk/)

### Life in segments



# The Immune System/Autoimmunity

*The following was prepared by Dr Julie Williams at Birmingham University Hospital. It is reproduced here for the benefit of Members who would like to learn a little more about the workings of the immune system and autoimmunity:*

The immune system is a large group of cells that protect us from the outside world (e.g. bacteria, fungi and viruses). The immune system can be split into two parts, the innate immune system and the adaptive immune system.

The innate immune system provides a basic and general form of defence against infection. A large component of the innate immune response is a group of cells termed phagocytes. Phagocytes are able to detect bacteria and other micro-organisms and kill them by eating and digesting them. The model phagocyte within the immune system is a cell called a neutrophil. The neutrophil is the most abundant white blood cell in the body and is found predominantly within the blood stream. Neutrophils are able to leave the blood stream to travel to sites of infection or inflammation. There, they readily detect and eat up any harmful micro organisms.

Neutrophils are also able to kill harmful micro-organisms through the release of anti-microbial granules. Neutrophils are powerful cells of the immune system and are fundamental to the immune system's response to infection. However, neutrophils are difficult to control and may promote inflammation by releasing their granules at the wrong place at the wrong time. The uncontrolled release of granules may also damage healthy neighbouring cells.

The adaptive immune system provides the body with a much more specialised and advanced response. One important contribution of the adaptive immune response is the generation of antibodies. Antibodies are produced by cells called B cells, and are generated against a specific threat. Antibodies are released into the blood stream and act like homing missiles. Once they have located their target they will lock on to it. The antibody then aids the innate immune response by attaching to a phagocyte (such as a neutrophil) which will then eat up the target or release

granules in its direction. The generation of antibodies is a powerful tool employed by the immune system, but sometimes it does get it wrong. Occasionally a B cell will generate antibodies that will be specific for cells or proteins of our own body. When this happens the immune system begins to attack itself, this is known as autoimmunity.

ANCA associated vasculitis is one form of autoimmune disease where B cells produce antibodies that are directed against proteins that are found on the surface of neutrophils. These antibodies are termed Anti-Neutrophil-Cytoplasmic Antibody or ANCA for short. ANCA predominantly bind to two major proteins found on the neutrophil called myeloperoxidase (MPO) and proteinase 3 (PR3). ANCA have been demonstrated to be involved in vasculitic diseases such as Wegener's Granulomatosis (WG), Microscopic Polyangiitis (MPA) and to some extent Churg-Strauss-syndrome (CSS).

In the laboratory a number of important studies have provided evidence that ANCA are actively involved in these diseases and from these experiments we can get some idea what is happening within the body during the onset of vasculitic disease. It is currently understood that ANCA circulating in the bloodstream are able to detect and bind onto neutrophils (also in the bloodstream). Neutrophils, doing their job, believe that the ANCA antibody is providing the innate immune system with a microorganism to destroy, and for this reason the neutrophil becomes activated. As a result of this process, the neutrophil acquires the ability to stick to cells lining the blood vessel around it and releases its harmful anti-microbial granules into the environment around it. This release of granules is likely to cause a large amount of damage to the cells lining the blood vessel and promote inflammation which is associated with vasculitic disease.

At present it is not clear why ANCA are produced. A number of theories and factors have been suggested. There is a strong link between infection and disease and it has been put forward that ANCA are originally produced in response to infection. If this is the case it would mean that something in the process of making ANCA goes wrong,

leading to the production of antibodies that may also be harmful to the body. Exposure of individuals to certain chemicals may also be linked with disease. For example, over exposure to silica is considered an environmental factor associated with ANCA positive vasculitis. These, along with genetic factors may mean that some people are more at risk at developing ANCA associated vasculitis than others. As yet, there is not one single factor associated with ANCA-associated vasculitic disease and it is likely to result from a number of combining factors.

The presence of ANCA in the serum of patients is used to help diagnose patients with WG, MPA and CSS and, in a number of patients, the measurement of ANCA levels is an important way of predicting, and preventing relapse.

This usually involves the patient donating a small amount of blood which is analysed in the lab. The presence and type of ANCA is confirmed by two separate lab tests.

The first test measures the amount and type of antibody (MPO or PR3); the second test confirms whether the antibodies bind to MPO or PR3 by looking to see whereabouts the antibodies bind to human neutrophils when looking down a microscope.

The presence of PR3 ANCA is associated with WG, whereas the presence of MPO ANCA is more associated with MPA and CSS. These associations are not completely exhaustive, a small number of patients with WG may have MPO antibodies present in their serum and the same is true of MPA patients with PR3 ANCA. There is also a small percentage of patients suffering from these diseases that do not have detectable levels of ANCA in their serum. As the type and amount of ANCA can vary between patients with vasculitis, ANCA test results are usually used in parallel with tissue biopsies and other routine lab tests to diagnose disease.

## Mycophenolate Mofetil –v– Azathioprine

Review of an article in the Journal of the American Medical Association: "Mycophenolate Mofetil vs Azathioprine for Remission Maintenance in Antineutrophil Cytoplasmic Antibody-Associated Vasculitis: A Randomized Controlled Trial"—Thomas F. Hiemstra, Michael Walsh, Alfred Mahr, et al. *JAMA*. 2010;304(21):2381-2388.

Mycophenolate mofetil is not as good as azathioprine in preventing disease flare ups in ANCA positive vasculitis, a European study has found.

The findings led the researchers to state: "Although mycophenolate mofetil is frequently regarded as a potent alternative to azathioprine, we found no evidence to support its use as the initial remission maintenance therapy for patients with ANCA positive vasculitis."

The researchers say mycophenolate mofetil should only be considered in patients with ANCA positive vasculitis intolerant of azathioprine.

Azathioprine has traditionally been used in patients with ANCA positive vasculitis to maintain remission, in combination with glucocorticoids. But relapses occur in half of all patients within five years of diagnosis.

Doctors designed the International Mycophenolate Mofetil Protocol to Reduce Outbreaks of Vasculitides (IMPROVE), to test if mycophenolate mofetil was more effective than azathioprine for preventing relapses in people with ANCA positive vasculitis.

Doctors at 42 centres in 11 European countries recruited a total of 156 patients to the trial; 80 patients took azathioprine and 76 mycophenolate mofetil. They found that more than half the patients who took mycophenolate mofetil

had a relapse, compared to little over a third of patients taking azathioprine. The incidence of serious side effects did not differ significantly between groups. There were 22 serious events in 13 patients (16%) in the azathioprine group and eight serious events in eight patients (7.5%) in the mycophenolate mofetil group. The type of serious side effects noted in both groups included serious infections, very low white blood cell counts, and the diagnosis of a malignancy. Doctors also looked at patients' kidney function and did not find any real differences between the two groups.

Seven patients dropped out of the study because they could not tolerate the drugs. There were two deaths; one patient died from blood poisoning caused by a fungal infection after taking mycophenolate mofetil for three weeks and one patient on azathioprine died suddenly from heart problems after nearly six months treatment.

Commenting on the results, the authors of the study speculate that the dose of mycophenolate mofetil may have been too low. However, they note that the dose was similar to that used in other auto immune diseases, for the prevention of solid organ transplant rejection, and remission therapy in vasculitis.

IMPROVE was published in the Journal of the American Medical Association last December.

**This review was written by Maya Anaokar**

## Microscopic Polyangiitis

Microscopic Polyangiitis (MPA) is inflammation of the small and sometimes medium vessels. In the past MPA was thought to be a type of PAN and patients would have been told they had PAN. It is now recognised that they are separate diseases. In microscopic polyangiitis it is common for the smallest blood vessels (capillaries) or the lungs and kidneys to be damaged leading to reduced kidney function or kidney failure and breathlessness

MPA is commonest in middle aged people and affects both men and woman.

Occasionally MPA just affects the kidneys (sometimes called Renal Limited Vasculitis) so that an individual may only begin to feel unwell when the kidney function has deteriorated.

Some of the symptoms encountered, specific to various systems are:

Lungs - Breathlessness, wheeze, dry cough,  
Skin - Skin rashes and ulcers,  
Eyes - Blood shot/gritty eyes, visual loss, changes in vision,  
Nerves - Loss of sensation, weakness, pins and needles,  
Bowels - Diarrhoea, bleeding and abdominal pain.

As with other type of vasculitis the diagnosis depends on the doctor recognising the pattern of symptoms and clinical signs. The ANCA blood test and a biopsy from the kidney or other affected organ are very helpful tests for MPA.

Prednisolone (steroid) and cyclophosphamide are often used to get the disease under control in moderate or severe cases. In mild cases where the kidneys are normal milder treatment with prednisolone and methotrexate may be given. If the disease is very severe large doses of

methylprednisolone or plasmapheresis (plasma exchange) may also be given. When the disease becomes quiet less toxic drugs are used to keep control which include: azathioprine, methotrexate and mycophenolate mofetil usually in combination with low dose prednisolone.

The overall prognosis in MPA depends on the severity of the disease and the amount of damage that has been done to organs, especially the kidneys, when the disease was active.

Relapses can occur in MPA though less commonly than in some other types of vasculitis and usually require a temporary increase in treatment. It is not clear how long patients with MPA should remain on treatment for and this should be discussed with the doctors looking after the patient on an individual basis.

## Walking the Tightrope

**Richard A Watts DM FRCP Consultant Rheumatologist, Ipswich Hospital.**

The treatment of systemic vasculitis involves the use of powerful drugs which potentially have significant side effects. This inevitably poses the dilemma of benefit versus risk. As a doctor seeing patients with vasculitis and other long term autoimmune diseases I spend a lot of my time assessing this balance. In general the best principle is to use as little therapy as possible that controls disease activity without exposing the patient to unnecessary side effects.

For many patients it is like walking a tightrope – too little treatment and the patient may fall off with a relapse of disease, too much and the patient gets across but at a cost. So how do we make this assessment?

The key is an accurate assessment of the patient and their disease status. Has the patient active or inactive disease and which organs are affected? Active disease may require an increase in therapy. Some organs require more intensive therapy than others for example kidney disease is more intensively treated than purely skin disease. Inactive disease in remission may require no adjustment of therapy or possibly a reduction in treatment may be possible.

All drugs have side effects, some are more significant than others, and some concern the patient more than the doctor or vice versa. Many of the drugs used in the routine treatment of vasculitis have been used for several decades and therefore the side effects are well known. Cyclophosphamide for example is generally accepted to be a very good drug for controlling active disease. When it was

first introduced it radically changed the outlook for people with granulomatosis with polyangiitis (Wegener's granulomatosis). Because of this success, treatment was continued for many years. It then became apparent that this was causing unacceptable longterm side effects. Azathioprine was then introduced as an alternative for long term control of remission, because it has a safer side effect profile. Steroids which are the other mainstay of treatment are well known to have many side effects, some of which are dose dependent; that is the more you take the greater the side effects, hence why we are always trying to minimise the dose used. Modern treatment protocols use much shorter courses of cyclophosphamide and aim eventually to withdraw treatment.

None of the drugs currently available is ideal; therefore there is a continuing hunt for less harmful alternatives, which have the benefits of the present drugs but less of the risks. Rituximab is currently the new kid on the block and shows much promise being no less effective than conventional cyclophosphamide for gaining disease control and potentially less harmful. However, we do not know the long-term risk-benefit balance. Furthermore, we try to use drugs for which we have good evidence they work, hence the need for high quality trials of new therapies so that potentially promising drugs can be carefully evaluated, there are numerous drugs which have been used sometimes quite widely and then after careful study been shown to be ineffective or at worst harmful.

We therefore always assess the patient carefully to establish how severe the disease is and then tailor treatment accordingly so that unwanted side effects are minimised.

## Vasculitis Clinical Research Consortium



### What is the VCRC Contact Registry?

The Vasculitis Clinical Research Consortium (VCRC) has been established in the USA to collect information and perform research on vasculitic disorders including Takayasu's Arteritis, Giant Cell Arteritis, Polyarteritis Nodosa, Granulomatosis with polyangiitis (Wegener's granulomatosis) (GPA), Microscopic Polyangiitis, and Churg Strauss Syndrome.

The Contact Registry is a method by which patients with vasculitis can register themselves with the VCRC in order to be contacted in the future about clinical research opportunities. The contact registry is completely anonymous and free of charge. The registry will be a global registry of patients will to be contacted via email about potential new research projects.

Information contained within this registry will be used for recruitment to research studies directed at improving our knowledge and treatment of vasculitis. The continued efforts of researchers seek to improve the quality of life for all who are suffering from vasculitis. The work of the researchers cannot occur without the partnership with patients.

Patients who participate in research make it possible for researchers to find new treatments, create new studies, and work for the improvement of all our lives.

### Who Can Join the Contact Registry?

Any patient with a confirmed or suspected diagnosis of a vasculitis disorder (such as Giant Cell Arteritis, Takayasu's Arteritis, Granulomatosis with polyangiitis (Wegener's) (GPA), Microscopic Polyangiitis, Churg Strauss Syndrome, or Polyarterteritis Nodosa) can register.

### How do I join the Contact Registry?

You can join on line at [www.rarediseasesnetwork.org/vcrc/registry](http://www.rarediseasesnetwork.org/vcrc/registry) or contact John Mills for a form.

### How does the Contact Registry Work?

After you have read and agreed to the Authorisation, the Registry form will appear on your screen. This form asks you for information such as your name, address, birth date, place of birth, email address, and items relevant to your disorders.

Once you have entered and submitted this information online, the data will be stored in a secure, computerised database. No personal identifying information (such as your name, address, telephone number) will be given to anyone without your express approval.

Researchers seeking volunteers will simply email you anonymously with details of projects seeking volunteers.

*Some Members who attended the AGM or who receive the e-communications from the Trust may have already registered.*

**Richard A Watts DM FRCP Consultant Rheumatologist, Ipswich Hospital.**

# Annual General Meeting of the Trust - Chairman's Report

The AGM was held at the Novotel, Long Eaton near Nottingham on Sunday 22nd May. There was a tremendous turn-out with over 80 members and carers attending.



Pat Dr Richard Watts John

In my opening remarks I said that great strides had been taken since 2009, when it looked as if the Trust might have to be wound up because of apparent lack of support and the resignation of several Trustees. The Trust now enjoys a professional standing recognised by vasculitis professionals and other organisations, including government agencies. Membership continues to increase.

Some of the main items from the meeting are noted below:

**Routemap:** Thanks were extended to members for completing the questionnaire for the Routemap. The project is on course for completion by early 2012.

**Funding:** The Trust is primarily for the benefit of members and secondly to raise funds for research. As it was possible that the Trust might be wound up in 2009/10 the Trust made a final

payment for research at Birmingham. This large payment had depleted finances. Therefore, in order to ensure the Trust became financially viable, no research funding was made in 2010/11.

The Trust has taken advice and future research funding will be by collaboration with other interested parties. This would mean that the Trust could pay for sections of particular research rather than having to fund the whole project. The first research project to benefit from funding in 2011 is into the drug Alumentuzumab being undertaken at Addenbrooke's. Several other projects were being considered for later in 2011.

Thanks were extended to Fundraisers and Members without whose donations the Trust would not be able to fund essential research.

**Treasurer's Report:** See separate item below.

**Revised constitution:** The Charity Commission required changes to the Trust's Constitution to ensure we operate legally and retain charity status. The Trust had now defined those Members who wished to be considered Full Members. Only Full Members would be eligible to vote at the AGM. The changes to the Constitution had been made available to Full Members prior to the meeting. The Full Members voted unanimously for the changes either in person or by proxy vote.

**Name of the Trust:** It was also agreed, by the Full membership that

the name of the Trust be changed from Vasculitis UK (SSVT) to "Vasculitis UK".

**Election of Officers and Trustees:** With the exception of Andy Bone (who had tendered his resignation) the present Officers and Trustees were re-elected. Mark Griffiths stood down as Vice Chair but remains a Trustee. Pat Fearnside was elected Vice Chair and retains her responsibilities for the Newsletter. Professor Lorraine Harper will become a co-opted Trustee and will continue to advise the Trust on medical matters. Two new Trustees were appointed—Martin Thomas, and Shirley Whileman (Treasurer).

**Spring raffle:** The Spring Raffle was drawn by the Guest Speaker, Dr Richard Watts. At the time of the meeting the full amount raised was not known, but it was in excess of £10,000. The cost of the raffle, printing, postage and licence was approx £806. All the prizes were donated. Winners were to be notified by post

**Guest speaker:** Dr Richard Watts was the speaker and he gave an interesting and informative presentation "Who gets vasculitis, and Why?" See report on page 8.

*John Mills*



After the meeting mini meeting  
Martin, Pat, John, Paul

## Treasurer's Report April 2010-March 2011

2010-2011 saw the Trust make a profit of £54,756.73 (income £59,397.91 - Expenditure £4541.18).

- Donations for the year were £48,463.25, with those donations via Justgiving.com increasing from £622.92 in 2009-10 to £14,406.63 in the current year.
- More members are using Easyfundraising and Easysearch, and income from these sources increased to £172.88,.
- Gift Aid increased from £2143.54 to £3521.23
- At the time the Accounts were produced the Spring Raffle had produced income of £5357.00. The setting up costs for the Raffle were £806.80 (licence, printing, postage) - all the prizes were kindly donated.

- No research grants were made in the financial year 2010-11 to allow the Trust to re-build it's resources.

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 2011 was circulated at the AGM. A copy is available by contacting John Mills.

**Andy Bone** Treasurer

As Members are aware, Andy has now resigned as Treasurer. The Chair and the Trustees are grateful for Andy's hard work, and wish him and Lorna well for their future together.

## Brief Report - Dr Richard Watts' Talk at the AGM



Renaming the vasculitides is a move away from naming diseases after eminent physicians to calling them after the blood vessels involved.

So now, we no longer suffer from Wegener's Granulomatosis but granulomatosis with polyangiitis (GPA). Churg Strauss Syndrome is now eosinophilic granulomatosis with polyangiitis (EGPA).

Dr Richard Watts of the University of East Anglia and the Ipswich Hospital NHS Trust, guest speaker at the AGM of Vasculitis UK in May 2011, admitted the change had controversial, but the ultimate goal of the name change is to advance research and clinical care for vasculitis, especially faster diagnosis.

### Why me?

As other physicians before him have explained to the members of the charity, Dr Watts reiterated that developing vasculitis appears to be the consequence of some kind of environmental insult in people with a genetic predisposition. As we age, so does the immune system and how it reacts to infections also changes.

"That may explain why we see this striking age distribution," said Dr Watts, with the vasculitides occurring at the end of the age spectrum, with the exception of Kawasaki disease, which affects infants, and Henoch Schönlein purpura, which affects children to their teens. About 60% of ANCA vasculitis is GPA, 30% MPA and 10% EGPA and the peak ages for onset are between 65-75. GCA is only seen in the over 60s with between 75-80.

### British studies

Epidemiological studies done in Norfolk over the last 23 years have identified 200 patients with a form of vasculitis; this means between five to ten cases a year in Norfolk. The conditions' rarity is one of the reasons they are so difficult to diagnose, although the incidence is increasing, which may be a consequence of increasing disease awareness.

"In many GP practices there isn't even a single ANCA vasculitis patient. Most GPs will never see a case," said Dr Watts, although most will have other forms, especially GCA. But what researchers have discovered is that GPA – the most common form of ANCA vasculitis – has a cyclical incidence with a peak every seven years. Whether there is a similar cyclical pattern for microscopic polyangiitis (MPA) is not discernible because there are not enough patients to enable doctors to tell. The reason for the peaks in GPA is not clear.

### Global epidemiology

Northern countries have more cases of GPA than southern countries, where MPA is most common. Dr Watts speculated that this may reflect different genetic backgrounds between the north and south, but he added that incidence of vasculitis was unknown across much of the globe because health systems were not equipped to study the conditions' epidemiology (figure 1).

Similarly, little is known about possible ethnic differences influencing the development of vasculitis although one French study has found it more common in people of European origin than non-European. Dr Watts' team in Norfolk is collaborating with Japanese researchers to explore

what lies behind the different clinical patterns to the diseases. In Japan the incidence of vasculitis is much the same as in the UK, about 22 people per million, but the types of vasculitis differ. Japanese sufferers are more likely to develop MPA than GPA.

### Genetic risk

Dr Watts explained that one of the challenges in this type of study is the lack of large numbers of patients; there being between 10,000 to 15,000 ANCA vasculitis patients in the UK.

Dr Watts said: "One project will be to get DNA from thousands of people with vasculitis to see if there is a clear genetic signal between GPA and MPA. Are they two distinct disease or a spectrum?"

What is currently known is that there is a familial association, similar to the likelihood of developing rheumatoid arthritis or type 1 diabetes if a first degree relative suffers from these conditions.

### Environmental insults

A whole range of external factors have been studied to see if exposure to them can cause vasculitis but little association has been found between some of the suspect substances or professions. There does seem to be an association between exposure to ultra violet radiation and the development of GPA and EGPA; the lower the exposure to UVR the greater the risk of GPA and EGPA (but not MPA).

### Current studies

Dr Watts also mentioned the work of The European Vasculitis Study Group – EUVAS – which works to improve understanding and treatment of vasculitides.

He noted that there were a lot of questions about rituximab, a drug being investigated in a number of trials. In the UK rituximab is licensed to treat Non-Hodgkin's lymphoma (NHL), Chronic lymphocytic leukaemia (CLL), and rheumatoid arthritis.

Dr Watts posed the following questions to the AGM: "How do we maintain remission? Rituximab can be used to treat relapses but do we use it at fixed intervals? If we do use it, how long can we continue to use it for? We need randomised trials to answer these questions."



Fig 1: North-South difference in GPA and MPA incidence

Watts et al ARD;60:115607

Report prepared by Maya Anaokar



## Connective Tissue Diseases Seminar – Portsmouth

On 18<sup>th</sup> June 2011, Paul Bingham (Trustee) and Anita Laycock (Surrey) attended a one day seminar for patients in the Portsmouth area with connective tissue diseases including vasculitis. The seminar was held at the Queen Alexandra Hospital. The seminar was organised by Julie Ingall the Clinical Nurse Specialist in the Rheumatology Department with some 80 plus people attending. Patients were joined by medical charity representatives and medical practitioners.

The medical charities set up their displays with a view to raising patients awareness and offering advice and assistance where required. The Trust displayed its new banner and the vasculitis patients who were non-Trust members showed considerable interest in the Spring Newsletter/Journal.

The seminar comprised 10 presentations covering various disease management aspects plus breakout sessions for individual diseases. The Vasculitis breakout session was attended by 10 patients and carers. Key outputs and

conclusions from this session included:

- \* Every patient is unique with a varying set of experiences and symptoms.
- \* Vasculitis patients require specialism and would normally benefit from being treated centrally within a hospital in order to enhance medical experience.
- \* Complexities often require a broader medical experience than is available in a small hospital.
- \* Patients, despite the difficulty involved, should never be afraid of seeking a second opinion from a more specialised hospital.

The Seminar was a success. Julie Ingall and her medical colleagues are to be congratulated on this initiative and for giving up their time for the benefit of patients.

## Internet discussion groups—Facebook and HealthUnlocked

Internet discussion groups are extremely useful, especially for those with a rare disease, who might feel lonely, isolated and uninformed about their illness. Vasculitis UK has a very lively social group on Facebook, with about 400 members. It is open to everyone who is a Facebook user and is particularly useful for newly diagnosed people and their families who are seeking help, advice and support. It is also very popular with people who already have vasculitis, for sharing information and discussing problems.

However, the drawback with an "open" group, like the Vasculitis UK one on Facebook is that any Facebook user can read the messages, including the "Facebook Friends" of the person posting the message, through the "newsfeeds". This can inhibit discussion of personal problems. To overcome this, it was decided to work with a company called HealthUnlocked so that we could set up a separate Vasculitis UK social network which is completely private for members and quite independent of Facebook, but can still be linked to Facebook and Twitter. There are various different groups (known as "Communities") on HealthUnlocked. They are run by charities devoted to specific medical conditions, such as Lupus UK, Heart UK, The Meningitis Trust, The Rheumatoid Arthritis Society and The Lung Cancer Foundation.

So you don't need to be a Facebook user to join this new group. As it is a "closed" group you do have to register with VasculitisUK/HealthUnlocked using your email address. You then join the group using your own name or you can be quite anonymous by using a pseudonym. After you have joined, you can connect with others with vasculitis who share your

health concerns. You can also read other members' reviews of services at their local hospital, ask questions of other members or the whole community, or contribute your own experience to answer other members' queries.

HealthUnlocked Communities was the idea of two overworked and caring doctors who wanted to create a safe, lively and supportive online forum designed around patient groups for patients, families and carers to share information on their health experiences. They believe that hearing directly from patients about what life is like with a condition expands the learning opportunities for healthcare professionals and researchers across the private and public sector. Patients are the experts in how disease management affects their lives and HealthUnlocked can gather anonymised insight for healthcare partners.

You can be a member of either the Vasculitis UK Facebook site or the Vasculitis UK HealthUnlocked site – or both. The links to both are on the Vasculitis UK website: [www.vasculitis-uk.org.uk](http://www.vasculitis-uk.org.uk)

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

**facebook**

To join the Facebook group, go to the Trust's website [www.vasculitis-uk.org.uk](http://www.vasculitis-uk.org.uk) and follow the Facebook link.



Arthritis Research UK have produced a 30 page booklet on Vasculitis. They briefly explain the main types of vasculitis, how it's diagnosed and treated, what you can do to help yourself and where to get more information.

You can obtain a copy of the booklet by writing to: Arthritis Research UK, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire, S41 7TD, or view the booklet in PDF format at: [www.arthritisresearchuk.org/](http://www.arthritisresearchuk.org/)



## About Stuart Strange, the Trust and Martin Lockwood

As promised in the Spring issue, we have been able to obtain more information about Stuart, Martin and the setting up of the Trust. We are grateful to Lillian Strange, Stuart's mother and our Life President for sharing her memories, and to Rachel Marsh for sending us copies of newspaper cuttings from the 1990s which have given us an insight into both men and of the setting up of the Trust.

### Stuart 26.1.64 - 19.4.92 - and the start of the Trust:

Stuart was born in 1964. He was a premature baby and he suffered from the normal childhood problems but he always had sinus problems. At the age of 16 he had pleurisy and it was subsequently found that he only had one kidney. However, this did not stop him leading a full and active life. In 1991 at the age of 27, Stuart was 6ft 5in tall and weighed 15 stone and was employed as a groundsman and greenkeeper. He was a keen sportsman and loved playing rugby. He was married to Rachel and they had an 18 month old baby (Matthew).

Stuart's WG problems began with headaches and sinus problems in August 1991. Eventually an x-ray at the local hospital showed a possible shadow on the lungs which was diagnosed as pneumonia. Treatment at Peterborough didn't improve matters and he was admitted to Papworth and subsequently to Addenbrookes where Dr Martin Lockwood diagnosed WG via an ANCA test. He received the most excellent treatment and care in Addenbrookes but, sadly, the disease had taken a tremendous toll on him physically and Stuart died in April 1992 aged 28.

During his time in Papworth Stuart had undertaken some local fundraising to purchase a television for the ward and his efforts raised £100. Following Stuart's death his sister Sue and his wife Rachel decided they would do everything they could to continue the good work Stuart had started and help other victims of this disease they'd previously never heard of. There had been no help for the family when Stuart died and Sue and Rachel wanted to ensure that if they could only give one other person some degree of comfort it was going to be worth it.

A support group was started and this received charity status in April 1993. Three years later sufficient money had been raised to pay one-third of the £50,000 needed for research into the disease by Dr Martin Lockwood's team at Addenbrookes. At the fifth anniversary of the Trust being set up there were over 500 Members - a remarkable achievement by any standards.

From the outset Stuart's family and friends worked tirelessly for the Trust, travelling throughout the country, raising funds, arranging meetings and seminars at postgraduate centres for medical students and ensuring that vasculitis became part of the training programme. Their aim was to raise awareness in the medical profession and to reach out to patients with vasculitis. Television and radio were used to good advantage in spreading the word about the Trust and about vasculitis and its associated problems.

Lillian has expressed her heartfelt gratitude to Sir Richard Branson who was instrumental in opening doors for the Trust, particularly with the media, which might otherwise have remained firmly closed. As she commented, "it isn't always what you know but who you know". She would also like to place on record appreciation of the early involvement of Dr Martin Lockwood, Dr David Jayne, Professor Caroline Savage and Professor Valerie Lund.

After 10 years the reigns of the Trust were taken over by Paul Pegg, whose wife Jill suffered from WG. Many members, who were diagnosed during the period of Paul's tenure, speak highly of the help and assistance he gave to them personally, and all the hard work he undertook on behalf of the Trust.

As Rachel subsequently commented "A lot of good has come out of Stuart's death and it is important for people to see that their donations are being put to good use". This sentiment remains the core of the work undertaken by the present Trustees.

### Dr Martin Lockwood - 2.12.45 - 10.9.99:

The death of Dr Martin Lockwood (in a sailing accident) robbed British clinical medicine of a gifted innovator who helped to lay the foundations of a new discipline - therapeutic immunology. He was among the first to recognise the need for understanding the mechanisms controlling immune responses, so that untoward immune responses could be better treated. His work led to the establishment of plasma exchange. Martin also played an important part in the application of genetically engineered monoclonal antibodies in the treatment of autoimmunity.

Martin graduated with first-class honours from Cambridge, where he was a Foundation Scholar at Queens' College and went on to University College Hospital where he won various prizes including the gold medal in surgery and pathology.

He graduated in 1970 and then joined Hammersmith Hospital, later acquiring a series of increasingly eminent research fellowships. For most of his professional career he was supported by the Wellcome Trust. In 1997 he moved to the University of Cambridge School of Clinical Medicine and in 1996 was awarded the title of University Reader in Therapeutic Immunology. He was a Fellow of the Royal College of Physicians and the Royal College of Pathologists.

Martin was married to Janet (a consultant radiologist) who he met when they were students at University College Hospital. At the time of his death in 1999 their son and daughter were both medical students.

Dr Lockwood was an excellent doctor and was admired by his many patients, many of whom had been sent to him when other standard methods of therapy had proved inadequate. His enthusiasm was infectious and he stimulated research by young physicians, many of whom now occupy leading positions in academic medicine in Britain and internationally.

**OOPS!**

In the report of Prof Savage's presentation to the Vasculitis Support Group in the West Midlands (reported in the Spring Newsletter/Journal, page 20), it states that the annual incidence of AAV is 20/24 per **thousand** of population. This should, of course, have read "20/24 per **million**".

## Improving outcomes for patients with vasculitis in Greater Manchester

On behalf of the North-West Vasculitis Group I would like to thank all of you for spending the time and effort to complete our questionnaire. We received over 300 responses which was more than we ever expected. The answers which you provided have given us an important insight into your experiences and allowed us to design a project which we hope will improve the care provided for those with vasculitis.

This project is entitled "A study aiming to improve the quality of care for patients with Primary Systemic Vasculitis: development and evaluation of a Vasculitis Care Optimisation Tool (VasCOT)". We have submitted a grant application to hopefully obtain funding for this project and should hear back in March next year. We will keep you all informed as to how we get on.

The results from the questionnaires will also be submitted to the national renal and rheumatology conferences in the UK over the next 12 months and we hope to publish our results in the next edition of this newsletter so watch this space!

Thank you again for all your support in this project, without which it would not have been possible.

Best wishes, *Nina Brown*

Central Manchester University Hospitals   
NHS Foundation Trust

## Influenza vaccination

The influenza season will be upon us shortly. Unfortunately as the majority of us are immunosuppressed we fall into the 'at risk' group where flu vaccination is recommended. Flu vaccinations are now being rolled out at your GP surgery.

At least one of our members cannot have the flu vaccine because of her drug regime. However, although her husband is not in the 'at risk' group he does have the flu vaccination as he is the main carer.

The Department of Health have issued the following guidance to doctors and patients:

"Following infection, flu has a usual incubation period of one to three days. The disease is characterised by the sudden onset of fever, chills, headache, muscle and joint pain and fatigue. Other symptoms include a cough, sore throat, nasal congestion and diarrhoea may occur. For otherwise healthy individuals, flu is an

unpleasant but usually self-limiting disease with recovery usually within two to seven days. A proportion of people infected may have very mild illness or no symptoms at all. However, for those that become sick, the illness may be complicated by bronchitis or pneumonia (either from the virus itself or a secondary bacterial infection) and, in children, otitis media (ear infection). In some rare cases, infection can cause cardiac problems, meningitis and/or encephalitis (inflammation of the brain). The risk of serious illness from influenza is higher amongst children under six months of age, older people and those with underlying health conditions such as respiratory or cardiac disease or immunosuppression.

For people with suspected flu who are not in the 'at-risk' groups, they should *stay at home, rest, drink plenty of fluids while they are recovering, and consider taking paracetamol/ibuprofen-based painkillers or cold remedies to lower their temperature and relieve their symptoms.*

The 'at risk' groups are more likely to suffer complications from flu, and the doctor may prescribe antiviral medication.

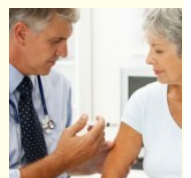
Antibiotics are not prescribed for flu as they have no effect on viruses. However, occasionally it may be necessary to treat complications of flu, especially serious chest infections or pneumonia, with a course of antibiotics."

Remember good hand hygiene is important and the "catch it, bin it, kill it" technique reduces the spread of germs.

If you are unsure about any aspect of flu vaccination you should discuss this with your doctor.

More information can be found at:

<http://www.dh.gov.uk/health/2011/09/seasonal-flu-vaccinations/>



## Webinar - American Autoimmune Related Disease Association

The AARDA will be hosting a series of three Webinars on vasculitis. The series aims to educate autoimmune disease patients on the commonality of vasculitis in autoimmune patients.

The first webinar will be held at 12am on Thursday 20th October and will last approx 45 minutes. However, it is hoped that the webinar will be available to download at a later date. To register for the Webinar go to: <https://www3.gotomeeting.com/register/992929230>

## Wrist bands

The Trust has now purchased a consignment of wrist bands. These are proving extremely popular especially with younger members.



If you'd like a band, or if you would like to sell them to raise funds for the Trust, please contact Susan: [sandjmills@btinternet.com](mailto:sandjmills@btinternet.com)

## The "Routemap" Project



Work on this big project has been continuing. Almost all of this has been done by Pat Fearnside. In order to ensure that the clinical information in the Routemap is correct, we have been fortunate in having help from Dr Matthew Morgan, Vasculitis Registrar at Birmingham University Hospital, who has been checking the relevant parts of the manuscript. We are very grateful to Matthew for all his hard work.



We plan to produce just a few printed copies, mainly for the benefit of Genetic Alliance UK and the Department of Health, who have been sponsoring the project, which should be completed by early next year. The plan then is to use the Vasculitis Routemap as source material for the new website and for a new range of advice leaflets for vasculitis sufferers.

## Logo and Website – Vasculitis UK



### Logo:

You may remember that in May, members were invited to vote on whether or not we should

keep the lightbulb logo or "switch it off". A clear majority were in favour of retaining it, but many of those also suggested it needed updating. Those we approached about redeveloping the website, were not keen on the lightbulb. So we had a problem.

The answer? A good old fashioned British compromise; we'll have a new logo, but the lightbulb will still keep popping up to remind us of our past. The lightbulb lives on too in the new logo. If you look at the sweeping "V" in the new logo, you will find that it almost mirrors the filament inside the old lightbulb.



### Website:

The Trustees finally agreed on someone to design the new website for us. Paul Townend of "On Screen" started his working life as a graphic designer and then moved into IT, so he can marry together the design element with the technical skills.

Now begins the big job of deciding exactly what will go into the website, how it will work and how it will look. We hope to have the new website open to the public in the early part of next year, if not before.

## Chickenpox and immunosuppressed people by Viv Dunstan

"If you haven't had chickenpox as a child and catch it later when on immunosuppressant drugs this can be a life-threatening situation. Chickenpox can kill healthy adults who don't have immunity to it. It can certainly kill immunosuppressed ones who haven't had it before.

I started Azathioprine and steroids in Spring 1998. A few weeks after I woke up one morning and was covered in spots. I feared they were chickenpox, I called the doctor's surgery right away and a GP came round within 15 minutes. She said yes, it was chickenpox, and phoned the infectious diseases unit at the nearby city, and arranged for me to be admitted immediately.

I was told I only just got there in time. My pulse was already stratospheric (every time a computer checked it an alarm would go off), but luckily I didn't develop anything worse. I was on anti-viral drugs, intravenously, for a week. That was actually very painful because I showed signs of vasculitis in my hands where the drips were going in - the only time I have ever showed signs of vasculitis outside my brain. But the drugs worked. After a week I was discharged, somewhat reluctantly on their part, because my pulse was still quite

impressively high. But I was desperate to get home, to my own bed, where I could sleep properly. Sleeping as an in-patient in hospital can be difficult as many of you know.

More recently I developed shingles, where the chickenpox virus reactivated. That was very painful, horrible nerve pain, running down a nerve from my waist down my left leg to my toes. Quite agonising. And a much nastier rash than I had with the chickenpox. People who are immunosuppressed are at a greater risk of the virus reactivating like this. They can also get shingles repeatedly. Be careful as shingles is infectious. You can't give someone shingles, but if someone hasn't had chickenpox before they can catch chickenpox from someone else who has shingles. Shingles is infectious until the rash starts to crust over and dry up. It should be covered up at all times.

So if you are immunosuppressed and haven't had chickenpox before and someone in your family develops either chickenpox or shingles please keep away from them. Also contact your GP for advice. You may be advised just to look out for signs of the disease developing. But if you do develop spots seek urgent medical help."

Probability of solving a computer problem:

- (a) Reconfiguring something, reimaging, anti virus, software, uninstalling programs, other jargon = 3%
- (b) Turning it off and on again = 97%



## An interview with Professor Lorraine Harper by our Roving Reporter Holly Hampshire



Lorraine Harper (PhD, MRCP) graduated from Edinburgh University and trained in kidney diseases. She gained her PhD in 2000 and is currently Professor of Nephrology at the University of Birmingham and is the head of Clinical Academic Training within the College of Medical and Dental Sciences. She's had over 70 research papers published as well as

reviews and book chapters in the fields of inflammation and nephrology.

Lorraine's research interests include: improved outcomes for patients by using novel treatments and better understanding how to use current therapies in a safer manner. Her department is currently studying fatigue in ANCA associated vasculitis, the role of genes, and possibly predicting those at risk. This work should allow them to tailor the drugs used to treat the individual.

Lorraine is also a non executive trustee for Vasculitis UK and has given us hours of her time and expertise, for which we're extremely grateful.

Over the years Lorraine has been a keen fundraiser and most recently took part in the Birmingham Half Marathon. Lorraine and Clive ran the marathon in 2 hours and 10 minutes and although it was very hard (Lorraine prefers to ride a bike) they managed to raise £282 for vasculitis patients.

Here she speaks to us about her calling to become involved in treating vasculitis, what patients can hope to see in the future and her ultimate goal.

### **We know you now as a prominent figure within the vasculitis world but what first sparked your interest in the group of diseases?**

That was when I was a very junior doctor working for Professor Caroline Savage when I first went to Birmingham. I became aware of how ill these patients were and how difficult and complicated their condition could be and yet there was a lot that could be done for them. Patients responded to treatment but there remained multiple complications afterwards and they needed to be treated in a holistic way.

They were very interesting people to deal with, both from a clinical but also a scientific point of view.

### **So once you became interested this opened up a whole new field to you then?**

Absolutely. There's so much unknown and so much potential for us to do things to improve care both from a scientific and clinical point of view. It's a relatively new field; the antibody associated with vasculitis was only discovered about 30 years ago, so the awareness of the disease has mushroomed in that time. We're now diagnosing people a lot earlier and therefore making significant improvements and progress.

### **So during the time you've been dealing with the condition you've seen progression?**

Oh yes, undoubtedly. We're completely changing the way we're treating patients from the time I started in 1994. We're reducing the amount of *Cyclophosphamide* people get, we're using *Rituximab* which is a new drug and the long term complications are much better.

### **What do you see happening in the future, say the in the next 5 years?**

I think the major research agenda for the future is reducing relapse and better understand why relapse happens. By doing this we can identify those patients at risk of a relapse and treat them more aggressively. We can also pinpoint those who won't relapse and reduce the amount of immunosuppressant they have. The idea is we'd tailor treatments to individuals.

### **At the end of your career, looking back, what would you like to say you'd achieved?**

Well hopefully I'm nowhere near the end of my career but I hope we will have improved the long term outcome for people. That way, patients will survive as long as the healthy population. At the moment we've improved the immediate disease but people are still dying younger than they should be.

## Healthcare travel costs scheme/accommodation

If a patient is travelling outside their NHS area for a consultation, ie an appointment at Addenbrookes, they may be able to claim travel and possibly overnight accommodation expenses.

For full details visit: [www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx](http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx)

In Scotland contact the Patient Expenses Officer (Finance Department) at your hospital.

**Accommodation at Addenbrooke's:** There is accommodation within the grounds of Addenbrooke's for

patients who have to travel some distance for their appointment and require an overnight stay: "[Pemberton House - Frank Lee Leisure and Fitness](#)" [www.frankleecentre.co.uk](http://www.frankleecentre.co.uk)

**Parking at Addenbrookes:** On production of an appointment letter, a patient can receive a special parking ticket (maximum cost of around £3.50 irrespective of the length of the stay). A visitor to the Addenbrooke's car park (run by NCP) can pay up to £9 a day!

## MY PERSONAL STORY (Mum knows best) by Rhian Murdoch

I'm 19 years old and I live in the Highlands of Scotland. I've always been a bubbly person, a mischievous toddler growing up into a very active person. I joined a highland dancing group at the age of 5, I loved it. I enjoyed games and sports in primary, and sport on a bigger scale at the Academy - cross-country, hockey, swimming, gorge walking, and a bit of football, netball and even badminton.

At 13 I joined the local Air Training Corps, (basically I wanted to be a female pilot). The main part of A.T.C is keeping fit and active, which was great for me. I took every opportunity of joining in more athletic activities - hockey, swimming and track racing. I have trophies and medals in my room which I love looking at. Looking is what I do now. I'm now lucky to do 100 meters, which I actually tried last year, without getting out of breath.

My problems started when I collapsed in school, but probably even before then. I was admitted to hospital, very ill. Tests couldn't pin-point the problem. I was extremely thin but I lost most of my muscle tone long before then. Mum organised many visits to the doctors, thinking that I was anorexic. The doctors put it down to "hormones". Nose bleeds - hormones, tiredness - hormones, headaches (and boy did I have those) - hormones. My mum started to keep a diary of my "feeling ill days". On one such day I developed a leg rash. Stupidly I kept the rash to myself but then my legs were swollen but before I could see the GP I collapsed and was admitted to hospital. Even though

Mum gave the hospital doctor her notes I was later sent home. The swelling and the rash were considered to be "a reaction" !! Next morning I was re-admitted and everything became a blur. I was so ill and remember very little about the tests or the rash all over my body and I was developing ulcers over the earlier rash. I remember being wheeled into the renal ward, where a lovely lady specialist arranged a scan and a kidney biopsy. My results came back "Wegener's Granulomatosis" I couldn't even pronounce it. "I'm 16 with a disease" and that's how I saw it.

Meds were thrown into me; I had drips and blood tests. A week later I'm in a wheelchair my legs still swollen my rash slowly breaking into ulcers but healing slowly. I could hardly speak without being short of breath, and then I'm on my way home to my own bedroom.

I managed the Memorial Day with my squadron and that was lovely, even though I was wheelchair bound. Three months later I'm out of the wheelchair, but even with my Mum's help I failed my last year in school, although I tried my best.

My poor Mum washed me, cleaned and creamed my ulcers and ran me back every week to the renal ward for blood tests. I was a wreck. I kept thinking "what next, what kind of life am I going to have?" My Mum gave me some good advice one night when I got scared "tomorrow when you wake up it will be the first day of your new life".

Information from the Stuart Strange Trust really scared me. So much to take in, "please Mum you handle this 'til I'm ready". Mum is made of sturdy stuff, made me pick myself up, dust myself down and get on with my new life.

I'm 19 now. I'm not in a wheelchair, and I'm doing my highers for sports in college. OK I won't be a female pilot but I've just past my flying scholarship in the Corps. I'm a cadet sergeant and I'm raising money for vasculitis through the A.T.C. All my colleagues know I have a medical condition that will stay with me for my entire life but I am my own person again, I love my life, even though it will never exactly be the same, but I'm doing my very best to make the most of it.

Mum's other advice: "Life is full of sxxt and sxxt gets thrown back at you. It's what you make of life and how you reach your goals that's more important than the sxxt itself". I'm still reaching for my goals. I love goals. Goals are the biggest part of achieving a reachable score in sports. This is me, this is my story, I'm *Rhian Murdoch*



Rhian (centre) with friends, and a cheque for the Trust

## My Personal Story (Find your hidden talents) by Ray Smith

My WG story began about five years ago. I was having problems with my hearing and I was going slightly deaf. I saw my ENT consultant who subsequently referred me to the Rheumatology clinic. By this time I was completely deaf and this lasted for about six months. I wasn't able to watch TV so I filled my time by reading, doing puzzles and practicing the chords on my keyboard.

I was subsequently found to have Wegener's in my kidneys and was prescribed the usual cyclophosphamide and prednisolone. After about three months I started to feel the benefits of the treatment and my hearing began to

return. I could have just felt sorry for myself, but I decided that I would achieve something and not let this disease stand in my way. I went to college for five years, undertaking projects and taking exams, and I passed my NVQ2. I also studied music and at the time of writing I am playing, and enjoying, all the old Elvis and Sinatra tunes and blues music.

It hasn't all been plain sailing. I've had a number of relapses, chest infections, scarring, bronchiectasis, kidney disease and pulmonary fibrosis. Thankfully my physicians understand my problems and I receive prompt and appropriate treatment.

Like most vasculitis patients, the disease changed my life completely, but I found that it helps not to dwell on the past but to embrace the present and look forward to the future. Our lives may never be as they were previously, but I believe that it helps to be proactive. If you can't do what you did before, then accept that you can't, but find something which interests you and which is within your capabilities. Who knows, you may find, like me, that you too have hidden talents.

Best wishes

*Ray Smith*

# Healthy Eating by Catherine Cotter

## High and low potassium foods - part 2

(to be read in conjunction with part 1—see Spring 2011 edition, page 5)  
Any significant changes to diet should be discussed with your dietician or consultant.

• Food Group	Low in Potassium	Moderately high in Potassium	High in Potassium so AVOID
<ul style="list-style-type: none"> <li>Starchy foods</li> <li>Potatoes, yam or cassava should be boiled and water thrown away – do not steam or use a microwave or pressure cooker</li> </ul>	Bread Chapatti Noodles Pasta Rice Cereal eg: Weetabix, puffed rice, cornflakes etc	Up to 3 egg sized - potatoes, cassava <u>or</u> yam /day	Chips (all types) Roast Potato <b>unless part boiled first</b> Croquette potato Jacket potatoes Potato waffles Cereal with dried fruit, chocolate or nuts eg fruit and fibre, muesli, coco pops
Vegetables – up to 2 portions per day allowed from the 'low in potassium' list.  These should be boiled and the water thrown away – do not steam or use a microwave or pressure cooker	Broccoli Carrots Cabbage Cauliflower Cucumber Courgette Green Beans Leeks Mixed Veg (frozen) Onion Peas Swede Turnip		Baked Beans Broad Beans Brussels Sprouts Mushrooms Parsnips Red kidney Beans Spinach Sweetcorn Tomatoes Mushrooms Okra Karela
• Meat & Poultry		4oz for main meal 2oz for snack meal	
• Fish		6oz for main meal  3oz for snack meal	
• Dahl		As meat replacement 2-3 times per week	
• Dairy	Eggs – up to 5 per week	Yogurt: up to 2 pots per week, Cheese: up to 2oz (50g) week	
• Fruit	Apple, Clementine, small handful of grapes, Kiwi, small orange, peach, 1 slice pineapple, plum, 8 strawberries, all tinned fruit <i>but drained first</i>		Apricot, avocado, banana, blackcurrant, <i>All</i> dried fruit, mangoes, melon, papaya pomegranate, rhubarb
• Soup			All soups: packet, tinned & homemade
• Snacks	Corn, maize/wheat snacks: e.g. tortillas/Quavers, bread sticks, popcorn.		Potato crisps, all nuts, ganthia, sev, Bombay mix
• Sweets	Boiled sweets, jellies, mints		Chocolate, toffee, fudge, asian sweets e.g. Burfi
• Condiments	Fresh herbs, pepper, vinegar, salad cream, mayonnaise, mustard	Pinch dried herbs, 1tbsp mint/apple sauce, 1tsp sweet pickle/cranberry sauce	Salt substitutes: e.g. Ruthmol, selora, Lo-salt, tomato sauce, brown sauce
• Drinks	Diluting squash/cordial (not high juice), fizzy drinks/pop, spirits, tea.	Milk – up to 1/3pint (200mls) per day, <b>coffee</b> – up to 1 cup/day, <b>wine/stout/beer</b> – 1 glass/day if medical team allow.	All fruit juices, high juice cordials, blackcurrant juice, chocolate/cocoa and malted drinks

## Our Fantastic Fundraisers

*giftaid it*

Once again, our fantastic fundraisers have been working hard to raise much needed funds for the Trust. Many thanks and congratulations to all fundraisers and their sponsors, for raising such amazing amounts for the Trust.



**Elise Baxter and her sisters Jessica and Tara** presented a cheque for **£3600** to the Trust - the proceeds of their charity disco in memory of their dear friend Clare Grossman. Clare was 38, diagnosed with WG in July 2010 but sadly she passed away on New Year's Eve 2010, leaving a husband (Richard) and two children (Kiera 11 and Callum 7). The photograph is of Clare's sister-in-law, Mum, Brother and Elise.

**Susan Bowen** recently held a quiz night at the Hockley British Legion, Essex. There were ten teams of eight making for a very entertaining quiz. Local businesses provided the raffle prizes. The evening's income (£863) was split between the British Legion (£170), a new electric wheelchair for Susan's sister Ann (£508), and **£185** to the Trust.



**Danni & Alex Brunwin** of Oxfordshire did a parachute jump on 10th April. Danni has Wegener's. They raised **£1727** for the Trust.



**Craig Callander, Audrey Callander and Carolyn Wilson** Craig's friend, Vivienne Kerr, has WG diagnosed in 2009. Craig was unable to join Vivienne in her marathon last year because of work

commitments, but entered the RENO 5000 10K on 16th July whilst on holiday in America. He was joined by Audrey & Carolyn. The ladies completed the 5k run in Reno on rather a warm dry morning, in a respectable 41min. Craig did the 10k in 59min 28sec and somehow managed to come 3rd in the men's age group 40 to 49. Between them they raised **£558** for the Trust.

**Jayne Coulson** organised a further Mary Coulson Memorial Walk on 12th June, raising **£135** for the Trust.

**Nicola Dehaes** is a consultant for NYR Organics and in July raised **£181** for the Trust from the sale of her organic beauty products, proceeds from a raffle, and donations raised at the Kimbolton Fete. Nicola also donated part of her profit from sales during July. Please visit Nicola's website at: [uk.nyrorganic.com/shop/NicolaD](http://uk.nyrorganic.com/shop/NicolaD)



**Jules Darlow** held a charity golf day in Essex during May and raised **£1220** which was presented to Dr David Jayne towards the Alemtuzumab research project at Addenbrooke's.

**Fujitsu Bracknell** recently held a business meeting where the members made a charitable donation every time they used a series of cliché phrases. Over 4 hours they raised **£20** for the Trust.

**Catriona Gibb** took part in the Big Fun Run in Aberdeen on 25th September. So far Catriona has raised **£1075** for the Trust.

**Holly Hampshire** (who has Wegener's and is a Trustee of Vasculitis UK) organised a "marathon" in Huddersfield on a

very warm Saturday in April 2011. Martin Richardson (pictured) was the only one to run the full marathon. Holly's mum (Annabelle) managed 13 miles, and the other competitors made up the miles between them, including youngsters Charlie Coope, Eva Thompson and Nell Thompson who ran the last mile. In total Holly and her friends raised over **£1350** for the Trust.



**Gill Harvey** of Bungay, Suffolk recently reached a milestone birthday and instead of presents kindly asked for donations to Vasculitis UK which totalled **£160**. Gill's husband Andrew has vasculitis.

**Emma Hayes** ran in the London Marathon in April and raised **£458** for the Trust.

**Paul Hughes** took part in the Great North Run on 18th September to raise funds for the Trust and to increase awareness of vasculitis. Paul's mum recently passed away, she had WG. Paul has so far raised **£450**.

**Hopton Primary School**, Norfolk held a non-uniform day and raised **£85** for the Trust.

**Jo Jones** entered the "Run to the Beat" half marathon around Greenwich, London on 25th September. This event of 13 miles took in 13 different musical stations. It was Jo's first half marathon. So far she has raised **£485** for the Trust in memory of Clare Grossman.

**Mansell Construction Services, Doncaster** held a "dress down" day in August at the Yorkshire Regional Business Unit in Balby. They kindly donated **£54.20** to the Trust.



**Rachel Marsh** of Hopton, Norfolk has raised **£610** from a Quiz Night held in March. The photo shows Rachel (far right) at the quiz night with family and friends.

**Susan Mills, Steven, Danni (and John)** succeeded in cycling the 30 miles of the Tissington High Peak Trail in Derbyshire on Saturday 20th August. They enjoyed the experience but they were jiggered at the end, having only managed 15/16 miles in practice. John joined them for the last 15 miles which was an even greater achievement. So far they have raised **£290** for the Trust.



**Rhian Murdoch** raised **£663** selling raffle tickets to the Air Cadets in Scotland.



**Ciara Newman**—took part in the Glasgow half marathon on 4th September and raised **£80** for the Trust.

**The Patel Family (Pearson Driving Assessment, Salford)** sold 363 raffle tickets and kindly matched the amount raised making a further donation of **£363** to the Trust



## Our Fantastic Fundraisers (continued)

**Potters Leisure Resort**, Hopton-on-Sea, Norfolk ([www.PottersHolidays.com](http://www.PottersHolidays.com)) kindly raised **£140.30** for the Trust at their "give a book or donate a £1" mini library

**Kala Rabadia** held a "sponsored 24 hour silence" in June. We are pleased to report that Kala managed her marathon. So far she has raised **£405** for the Trust.

**Zoe Reade**—Entered the Mary Coulson Memorial Walk on 12th June. Her gallant efforts have raised **£165**

**Claire Roumph** entered the Running to the Beat event on 25th September. Clare's mum has WG. Claire is proud of her uncle who recently donated a kidney to his sister. Claire has raised nearly **£560** for the Trust

**Catherine Salmon** of "The Angel Inn", North Shoebury, Southend-on-Sea ([www.angelinn.org/](http://www.angelinn.org/)) raised **£580** as proceeds from another Quiz Night. Catherine's aunt has cerebral vasculitis.



**Francesca Saville** ran in the unseasonal heat of the Brighton Marathon on 10th April. Francesca's efforts have raised **£3102** for the Trust. Francesca's sister Alexandra was diagnosed with WG five years ago, at the age of 19.

**Kevin Soper**—On 25th September Kevin took part in the Running to the Beat event (in memory of Claire Grossman nee Soper). To-date Kevin has raised **£500** for the Trust.

**Unison National Delegate Conference** At the June Conference in Manchester the chosen nominated charity was Vasculitis UK where the delegates kindly donated **£576.86**.



**George Willis** ran in the Edinburgh Marathon on 23rd May 2011. His gallant efforts raised **£117** for the Trust.

**Jennifer Wormald** of Wetherby makes exquisite bead jewellery which she kindly sells to raise funds for Vasculitis UK. Jennifer recently presented the Trust with **£100** from her sales.

**Jamie Wray** took part in the BUPA Great North Run on 18th September raising nearly **£1300** for the Trust. Jamie ran for Vasculitis UK because his granddad Des Winks passed away in 2007, aged 58 after suffering from Vasculitis. Jamie wanted to raise awareness and help the Trust which had given help and support to Des. Jamie's time was 1 hour 27 minutes, beating his target. He finished 503rd overall, out of over 54,000 runners—a wonderful achievement.



**Frank Haslam Milan** Many thanks to the Doncaster company for donating stationery to the Trust which will help us to reduce our operational expenditure.

### Andy Bone - "Sports-Shots"



Andy, is a sports fanatic and keen photographer. He 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/sportshots](http://www.facebook.com/sportshots)) or visit his new website [www.sportshots.org.uk](http://www.sportshots.org.uk) or his JustGiving page.

### Jennifer Wormald & Rita Allen - Bead Jewellery

We are grateful to Jennifer Wormald of Wetherby, near York (01937-586734) and to Rita Allen of Essex (01255-820307). Both ladies make 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 Wormald** has Christmas cards she is selling to raise funds for the Trust. Please contact Jennifer on the number above for details.

**Thank you** to all our gallant volunteers and to their very generous sponsors. Best wishes to those still to take part in their events.

Also to everyone who supports the Trust with their one-off or regular donations. You are too numerous to mention but we are extremely grateful for your support.

Without your generosity the Trust would not be able to continue to do what it does for the benefit vasculitis sufferers and their families, and in raising funding for vasculitis research.

### Entering or promoting an event?

Are you entering or promoting an event, or undertaking some fundraising activity? Don't forget your Sponsorship form (from Pat or Susan) - **better still, start a JustGiving page and ask your friends to sponsor you there.** <http://justgiving.com/VasculitisUK>

Please send a short report and if possible, a photograph from the event for inclusion in the Newsletter.

## Gift Aid

**Do you donate to the Trust by Direct Debit? If so, and you are a UK Taxpayer, have you signed a Gift Aid declaration form? This ensures the Trust receives an extra 20p in the £ from your donation.**

**Contact Pat Fearnside if you would like to complete a Gift Aid form or check your Gift Aid status with the Trust.**

**Don't forget, even with "one off" and "sponsorship" donations it is possible to Gift Aid your donations.**

**Individual Gift Aid and sponsorship Gift Aid forms are available from Pat Fearnside or Susan Mills.**

**See page 24 for e-mail and postal address details.**

## Regional Support Group Meetings

### Yorkshire Support Group (New)

The Yorkshire Group held its first meeting on 20th March in Clayton West, Huddersfield. The afternoon was a great success, with the format being a chat, coffee and a buffet.

On 9th October the Group expanded its horizons and held a formal meeting in Doncaster at the Innkeeper's Lodge Hotel. The guest speaker was Dr Robert Stevens, Consultant Rheumatologist, Doncaster Royal Infirmary. His subject was: Vasculitis and its Treatment.



Members at the March meeting

### Cambridge Support Group

This meeting, led by Jenny Fulford-Brown took place on the 10<sup>th</sup> April at Impington, Cambridge. The speaker was Dr Rona Smith who has been at Addenbrookes Hospital for 8 years and worked with Dr David Jayne for the past 2 years.

Rona spoke about the diagnosis and treatment of vasculitis then moved onto refractory and relapsing cases and the use of Rituximab and related drugs such as Alemtuzumab in these cases. These drugs work in a different way to conventional drugs by targeting the B cells that produce ANCA.

She also discussed the use of clinical trials in research and the importance of patients volunteering to take part.

Cambridge members



**New Group:** Jacqui Moran of Dartford, South East area would be interested to hear from members who would like to form an informal group, meeting for coffee and a chat. If you are interested please phone Jacqui (after 2pm) on 01322 400777 or e-mail: jacqui.moran@ntlworld.com

### Oxfordshire Support Group

The Oxfordshire seminar was held at the Four Pillars Hotel in Abbingdon in March and was a great success.

Dr Raashid Luqmani, gave a very informative talk on new Vasculitis research. He also discussed the renaming of some of the Vasculitis diseases, with Wegener's Granulomatosis becoming Granulomatosis with Polyangiitis (GPA). The photo shows Barbara Engstrom, Dr Luqmani and Sue Ashdown.



The Group would like to send their congratulations to Dr Luqmani on becoming a Professor.

### Lancashire Support Group (New)

The inaugural meeting of a new vasculitis support group took place at the Preston Marriot Hotel on Sunday 4<sup>th</sup> September

About 40 people attended including several Trustees from Vasculitis UK and a representative from the local Kidney Patients support group. The meeting was chaired Jenny Fulford-Brown who welcomed the speakers and guests and started proceedings with a small group exercise designed to enable people to get to know each other.

Two consultants, Dr Ajay Dhaygude from Royal Preston Hospital and Dr Michael Venning from Withington Hospital attended to give a talk about Vasculitis. They covered the accelerating advances in treatment and care of vasculitis patients. This was followed by a lively question and answer session.

Dr Dhaygude and Dr Venning thanked Trust members for completing the questionnaire sent out recently which would help them with their pioneering work to improve the outcomes for patients with vasculitis. They also spoke about the joint vasculitis clinics held in Manchester



See Diary Dates (page 3) for details of the next meeting.

### Surrey Support Group

Paul and Maggie Bingham hosted the Surrey Vasculitis Support Group informal luncheon on Saturday 14<sup>th</sup> May. Present and new members enjoyed chatting about vasculitis and their particular symptoms.

The photo shows some of the members waiting for Maggie's delicious homemade strawberry cheesecake. A guided tour of their newly renovated cottage and of Maggie's lovely garden followed.



## Support Group Contact Details

### Aberdeen & Grampian

**Mo McBain** 01224-862226  
[mcbain.moian@btopenworld.com](mailto:mcbain.moian@btopenworld.com)

### Beds, Bucks & Herts VSG

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

### Bristol VSG

**Jackie Sullivan** [morwenna29@yahoo.co.uk](mailto:morwenna29@yahoo.co.uk)

### Cambridge VSG

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

### Canterbury area (Contact person - *not* a group)

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

### Cheshire (Contact person: - *not* a group)

**Susan Chance** 01244-381680  
[susanchncc@yahoo.co.uk](mailto:susanchncc@yahoo.co.uk)

### Essex VSG

**Jules Darlow** 07789-113144  
[jules.essexvsg@googlemail.com](mailto:jules.essexvsg@googlemail.com)

### Lancashire VSG *New*

**Jann Landles** 07795547217  
**John Chadwick** 07743476539  
[nwvasculitis@hotmail.co.uk](mailto:nwvasculitis@hotmail.co.uk)

### London VSG

**Vincent Fernandes** 0208-8660602  
[vincentf51@hotmail.com](mailto:vincentf51@hotmail.com)

### Norfolk (Contact person: *not* a group)

**Brian Hart** 01263 512165

### Northern Ireland VSG

**Vacant.** Joe O'Dowd (ROI) will be happy to offer support until a new leader volunteers



Republic of  
Ireland:  
Joe O'Dowd

I was diagnosed with Vasculitis in 2008. The web site/newsletters were very helpful. However, I felt the need to talk with someone with first-hand experience. In the absence of any support group in the

Republic of Ireland I contacted John Mills. He was extremely helpful and supportive. His response was just what I needed at that point in time.

I believe it is important that newly diagnosed people should be able to talk to or meet up with someone in their locality who has an understanding of what they and their families are going through. In addition I feel a local contact has the added benefit of an understanding of some of the wider issues, such as how, here in the ROI, the Irish healthcare and health insurance system works.

I am based in Dublin and would be more than happy to help out anyone, in any way I can. My contact no is: 086 2345705 or e mail: [dwodo@iol.ie](mailto:dwodo@iol.ie)

### North West (Cumbria) VSG

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

### Oxfordshire VSG

**Sue Ashdown** 01295-816841  
[oxonvsg@hotmail.com](mailto:oxonvsg@hotmail.com)

### Republic of Ireland (Contact person - *not* a group)

**Joe O'Dowd** 00353 (086) 2345705 [dwodo@iol.ie](mailto:dwodo@iol.ie)

### South Wales VSG (Contact person - *not* a group)

**Jackie Thomas** 029-2089-2403  
[creigiau20@yahoo.co.uk](mailto:creigiau20@yahoo.co.uk)

### Surrey VSG

**Anita Laycock** 01372-750667  
[anitalaycock@gmail.com](mailto:anitalaycock@gmail.com)

### Vasculitis Support Group West Midlands (VSGWM)

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

### West Country VSG

**Kathleen Rawlinson** 01392-832231  
[krawlinson@waitrose.com](mailto:krawlinson@waitrose.com)

### West Sussex VSG

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

### Yorkshire VSG

**Holly Hampshire** 01484 863552  
[hollyemery82@hotmail.com](mailto:hollyemery82@hotmail.com)

### Jennifer Wormald

01937 586734 [jenw@bethere.co.uk](mailto:jenw@bethere.co.uk)

### Pat Fearnside

01709 583722

[vasculitis.uk@btinternet.com](mailto:vasculitis.uk@btinternet.com)

**The Ring** is a support group in Norfolk for RA patients. Lively monthly meetings and excursions. **Judith Virgo**  
[jvirgo@fsmail.net](mailto:jvirgo@fsmail.net)

## Spotlight on Support Groups/Leaders

Susan Chance  
Cheshire

I am 57 and am married with two grown up children. I live in Chester and was diagnosed with WG in 2004. I had to have a tracheostomy in 2005 and thereafter retired from work as an Insurance Claims Negotiator.

My husband took early retirement to help look after me though he now has a part-time job. I seem to have spent a lot of my time in hospitals around the UK, including Addenbrookes and London. I am pleased to say that I have had a tracheal reconstruction and life is at long last looking stable, thanks to medical progress.

I now manage to go to easy aqua aerobic classes which I love and have helped to lose some of those prednisolone pounds. I try to go for small walks (weather permitting) providing there are no slopes or stairs!

We have made some good friends by joining the SSVT, West Midlands Group and Oxfordshire Support Group. I have recently met a couple of local ladies with vasculitis and am always pleased to listen to anyone about their experiences.  
**Spotlight on Support Groups continued on page 22**

**Spotlight on Support Groups continued from page 21****West Midlands:  
Margaret Gentle**

The Group originally started in 1993 with two lists-the Polyarteritis Contact List (National) and VSGWM (Regional) list. The inaugural meeting was held in 1996.

VSGWM was set up to provide support for patients and carers by circulating information and ideas.

An introductory leaflet is available and ongoing support is provided by means

of the Contact List, Newsletter and annual meetings.

The meetings are relaxed and friendly. Our speakers are specialists in vasculitis, often from Birmingham University, who give excellent talks and allow lots of time for question and answer sessions.

Numbers attending the meetings gradually increased from about 30 to 50 and for the last two years have been between 70 and 80.

Any patient or carer is welcome to attend the meeting and we have had visitors from as far afield as Guernsey, Ireland, Yorkshire, Somerset.

The next meeting of the Group will be held on Sunday 23rd October. See page 3 for further details.

Margaret continues to take an active part in the activities of the Group. After several requests for assistance other members have kindly volunteered their services and the workload has now been more evenly spread.

## Vasculitis Masterclass

On 13th April the North West Regional Educational Committee held a Vasculitis Masterclass in Warrington. The majority of those attending were medical professionals but the Trust was out in force with eight Trustees/members/supporters in attendance.

After a rather splendid lunch the first speaker of the afternoon was Dr Peter Hewins, Consultant Nephrologist at Preston who gave an overview on ANCA associated vasculitis. Dr Hewins was followed by Dr Martin Laudien, ENT surgeon from Kiel in Germany. Dr Laudien's interesting presentation was on surgical techniques used in Germany for the correction of saddle nose.

Dr Pasupathy Sivasothy, Chest Physician at Addenbrooke's topic was "Lung disease and ANCA associated vasculitis".

The final speaker of the day was Dr Steve Powell, Radiologist at Liverpool. "The role of the interventional radiologist in managing vasculitis complications" was Dr Powell's topic.

He freely admitted he knew absolutely nothing about vasculitis per se, but his extremely interesting and amusing session highlighted the specialist and intricate radiological work he and his colleagues undertake in order to rectify some of the problems which had been caused by vasculitis.

Those who attended were very impressed by the quality and content. The Trust will endeavour to encourage other areas to offer similar masterclasses for professionals and vasculitis patients.

## The enlightened patient

The vasculitis patient may be the only such patient on the GP list. Where possible the patient should arrange to see the same doctor at each visit to ensure continuity of treatment and advice given.

Many vasculitis consultants advise patients to contact them (via their specialist nurse, secretary or clinic) regarding new symptoms and problems encountered as a result of changes in medication.

As the patient becomes more educated in the disease process they understand what is normal in their particular case. However, it is often difficult to detect whether any change in condition is due to the onset of a flare or relapse, or whether it may be attributable to a simple infection. Consultation is advisable under these circumstances

As part of the consultation process, the physician will discuss their findings and ask general questions. It is important to take a written note, as an aide memoire, of matters which need to be brought to the attention of the physician. Where the patient does not understand any aspect then clarification should be sought. Taking a family member or friend (an advocate) into the consultation can be helpful to enable the patient to recall any important instructions given.

Patients may not wish to mention a particular problem they may be encountering mistakenly thinking it is of no importance or they fear that the medication or treatment regime may be increased or changed. The physician requires the full facts if he/she is to provide appropriate care.

Changes to treatment regimes are not made solely on test results. The physician will consider recent blood/urine tests etc., how the patient looks and the history given. Blood tests are only a diagnostic tool and a guide for the physician. A negative ANCA test does not automatically mean the disease is quiet, whereas a positive ANCA does not automatically mean the patient is not responding to treatment.

The patient should never be afraid to ask any questions regarding their disease, possible symptoms or treatment. The physician should be happy to discuss any changes to enable an informed decision to be made. If a patient is not happy with the explanations given, the suggested treatment or changes in treatment they should never be afraid to ask for clarification.

Where the patient is unhappy with the treatment received they should not hesitate to request a second opinion with a consultant experienced in treating the vasculitides.

## 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.

**Jennifer Bannister** of North Luffenham, Rutland passed away on 3rd July. Jennifer's husband, Ken, has had WG since 1994 and Jennifer had been his support and help until she became ill with cancer. Jennifer had requested the donations in lieu of flowers be made jointly to Cancer Research and the Trust. Family and friends donated £286.59 to the Trust in her memory.

**Sandra Hughes** of Stroud, who had WG, sadly passed away in May, aged 63. Sandra loved reading books and especially gossip magazines. She was also an avid radio listener. Sandra leaves three children (Owen, Medina and David) and three adored grandchildren. Sandra's family and friends kindly donated £272.64 in Sandra's memory.

**Ethel Kirkpatrick** of Castle Douglas passed away recently. Ethel's husband, family and friends have kindly donated £433 to the Trust in her memory.

**Brenda Moore** of Barnes, London passed away in May 2011. Brenda was diagnosed with Takayasu's in July 2010 at the age of 68, but despite this she remained positive and actively engaged with life, regularly seeing her family and friends. She was even planning to open her garden under the National Garden Scheme in June (as she had done for 10 years in loving memory of her late husband Norman). Family and friends have kindly donated £662 to the Trust.

**Professor Frank Neil** passed away in September 2011. He had a long fight with WG and Good Pastures. The Neil family have donated £455 to the Trust in Frank's memory, and have started a "justgiving" page to help raise further funds for the Trust.

**Evelyn May Newton** of Sutton, Alfreton passed away recently aged 92. Mrs Newton had previously been a deputy registrar for Sutton, a member of Teversal Women's Institute and a Daffodil volunteer at Kings Mill Hospital. Evelyn did not have vasculitis but her son William had WG and passed away, aged 59, in 2006. It was Evelyn's wish that donations in lieu of flowers be made towards vasculitis research. Her family and friends kindly donated £130 to the Trust.

**Roderick James Rose** of Norwich passed away in May (aged 67) having been diagnosed with vasculitis a few months earlier. Rod's life-long passion was music, particularly the violin and he was renowned locally for his encyclopaedic knowledge of all things musical. Rod leaves his wife (Vivien). He was a much loved step-dad and granddad. Rod's family and friends kindly donated £580.50 in his memory.

**Ivan Leonard Siviter** of Knighton, Powys. Ivan passed away in February 2011, aged 81. Ivan had WG for 10 years. He was a patient at the Queen Elizabeth Hospital, Birmingham and his wife Joan and family are appreciative of the care and support he was given at the QE. Ivan's family and friends have kindly donated £400 to the Trust, in his memory.

**Hazel Thomas** of Coventry was diagnosed 10 years ago with WG aged 71. Sadly, she passed away in May 2011. Hazel was very well known in her neighbourhood as she had lived there for over fifty years. She was warm and friendly and was known for her beautiful smile and blue eyes. She leaves Bas, her husband of 57 years, and daughters Julie and Helen. Hazel shared a very special bond with her granddaughter Jessica. A donation of £355 was made by family and friends in Hazel's memory.

**Jean Wenborn** of Cheltenham passed away in June 2009. The Trust is extremely grateful to Jean's husband who has donated £600 to the Trust on the anniversary of Jean's passing.

**Harold Pixley Willey** of Grantham passed away in July. Harold's family and friends kindly donated £558 to the Trust in his memory.

**Westonbirt Golf Club, Tetbury** Once again the members of Westonbirt Golf Club held a charity golf competition in memory of Keith and Hilda West. The club has kindly donated £115 to the Trust.

**RON SMITH of Bognor Regis 9.6.30–30.5.10 - A LIFE LESS ORDINARY** a précis from the recollections of Ron's friends and colleagues.

Ron was born and raised in Sheffield. At 18 he was the youngest of only two Regimental Sergeant Majors in the Boys' Army. In 1948 he joined the regular army as a "squaddie" - a big change from RSM. He was involved in bomb disposal and Bailey bridge building. Ron could even speak Arabic (useful whilst in the desert). He was

demobbed in 1953 with the rank of Warrant Officer.

He first worked in the film industry but joined IBM in 1955 where he had a long and distinguished career.

His management style and interpersonal skills encouraged superb teamwork, ensured a commitment to business goals and made work enjoyable.

It was said of Ron "He didn't always do the right thing, but usually did the thing right".

Ron was a DIY enthusiast. He enjoyed the mental stimulus of solving problems whilst his hands did the decorating or maintenance.

He was diagnosed with WG in January 2009, but sadly passed away in May 2010, aged 79.

Marion, Ron's wife of 50 years, predeceased him by nine years. They had two sons, Martin and Peter and four grandchildren.



The Trust's Spring Raffle was drawn at the AGM on 22nd May. We would like to thank all our Members, their supporters and everyone who donated prizes. The raffle raised just over £10,000 which gives a significant boost to the Trust's finances. The lucky winners were:

**1ST PRIZE Portugal Holiday**

Mrs H Stroudley, Oxford

**2nd £600 cash** Mrs C. Sones, Lincolnshire

**3rd House of Parliament tour**

Mr J. Frost, Caerphilly

**4th £150 Wine Voucher** Mr G Williams, Beeston, Nottinghamshire

**5th Dorchester Hotel Champagne Tea** Mr J Gribben, Surrey

**6th Caravan Holiday** V. Culham, Ipswich

**7th Chewten Glen Hotel lunch**

Annette Potter, London

**Other prize winners were:**

George Willis, Chester

Georgina Ross, Ross-shire

V. Haymer, Sutton Coldfield

A&W Newland, Leamington Spa

E. MacDonald, Invergordon

Kelly Croucher, Midhurst, Sussex

All winners have been notified. A full list of prize-winners is available. Please contact Paul: (paul.m.bingham@btinternet.com)

## Donating to Vasculitis UK

Many people donate and raise money for the Trust. But how does the Trust use that precious money? Most is spent on supporting research projects. Over the past few years the Trust has donated over £125,000 into vasculitis research projects and travel bursaries at Birmingham University. We have recently donated £12,000 to the "Aleviate" trial being undertaken at Addenbrookes.

The Trust depends entirely on **voluntary** donations from members and supporters. We don't like anyone to feel pressured into giving money that they can ill-afford, but we do want to make it easy for those who do want to donate. People donate money to support the work of the Trust in a variety of ways as follows:-

- One-off donations, usually by cheque,

## EasySearch and Easyfundraising

"Up North", where I live, there is an expression "You don't get owt for nowt". But that's not always quite true. I spend ages on the computer and I make several internet "searches" every day. My computer is set so that every search goes through "**Easysearch**" rather than Google or other "Search Engines". Five searches a day means £10 a year for the Trust and it won't cost you a penny.

Being lazy, and living in the country, I just love online shopping. My favourite shopping stops are Amazon, Screwfix and John Lewis and for all of these I go through "**Easyfundraising**". For each purchase done this way, a small percentage, maybe 2%, is given to Vasculitis UK. So for example, a new washing machine and a new oven, bought online from John Lewis this summer, through "Easyfundraising", resulted in donations to Vasculitis UK totalling £20.30 – at no extra cost to me.

Since starting to use Easyfundraising, my own personal online shopping has resulted in £80 being donated to Vasculitis UK – and it cost **me** nothing extra. In total, Vasculitis UK has received £92.50 through members using Easysearch and £320 from Easyfundraising. That is from only

- Regular monthly or annual donations by banker's order,
- Bequests, or collections in memory of a loved one,
- Fund-raising events such as sponsored walks etc. There are some excellent and varied examples of fund-raising in this issue.

**If you want to make a single donation or set up a regular payment, please use the donation form enclosed with this Newsletter.** Regular payments can be cancelled at any time. Whichever method you use, make sure that if you are a UK taxpayer, you also complete the Gift Aid Form. This will effectively increase the value of your donation by 20%.

40 Vasculitis UK supporters using them. So imagine how much could be raised by 500 supporters. Make life Easy, do your online Christmas shopping through Easyfundraising at your favourite stores.

If you don't already use these fundraising schemes, please do sign up. There are over 2000 top name retailers to choose from, including Asda, Argos, Boots, Currys, Debenhams, Tesco, Sainsburys and so many more, not to mention insurance, hotels and travel companies. Almost every type of goods or service you might want. Your family and friends can join in too and help to generate more funds for Vasculitis UK – without it costing **them** a penny!

To join, just go to [www.easyfundraising.org.uk/vasculitisuk](http://www.easyfundraising.org.uk/vasculitisuk) for online shopping, or to [www.vasculitisuk.easysearch.org.uk](http://www.vasculitisuk.easysearch.org.uk) Add these links to your "favourites" list and you're there in one click. It's just **so Easy** to raise money for Vasculitis UK!



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: <http://www.justgiving.com/VasculitisUK> Give the address to your friends and life is easy for you and for the Trust as the JustGiving site do all the necessary administration. *Simples.*

## Lauren Currie Twilight Foundation



In October last year Lauren Currie, a bright and bubbly 14 year old from near Glasgow, the only child of Adrienne and Grant Currie, developed a severe cough and could barely eat or sleep. She had been suffering from various strange symptoms, with skin rashes and rhinitis since a bout of glandular fever in 2008, but nothing serious was suspected.

Lauren was taken to hospital and into intensive care with suspected pneumonia. Only then was it suspected that the condition might be Wegener's Granulomatosis. Tragically, despite all efforts, Lauren's condition deteriorated and within 48 hours she had died, just 15.

Lauren's grief stricken parents realised that life for them could never be the same again. They were determined that their loved daughter should not be forgotten and that her memory should be maintained in a positive way. So they set up a charity in her memory. Lauren had been a great fan of the "Twilight" series of films. So the "Lauren Currie Twilight Foundation" was set up to campaign for better awareness of vasculitis, especially Wegener's.

The Lauren Currie Foundation has now held several fund-raising events to raise money for vasculitis research and to support their awareness campaign. A dvd about vasculitis is

being prepared with the help of several doctors and a professional production team. When completed, this will be distributed to doctors and be available for all to view online.

### WEBINARS

An innovative "Webinar" was held on 30<sup>th</sup> August. Anyone with an internet connection could register and take part. There were presentations, with slides, by Dr David Jayne on "Understanding Vasculitis, Dr Paul Brogan on "Vasculitis in the Young" and Dr Marcos Martinez del Pero on "Vasculitis in the Upper Airways". It was interactive, so participants could email their questions for the panel. It was a great success. 60 people registered to take part on the night and another 250 have viewed the replay on the website, demonstrating that this really is an excellent way to share information.

You can view the replay of the August Webinar presentations and discussion if you visit the Lauren Currie website. You can also find out there how to register for the next Webinar on 16<sup>th</sup> November. The topic is Wegener's Granulomatosis (GPA) and Vasculitis UK chairman, John Mills, who has WG, will be one of the panel members. The plan is to hold these Webinars roughly once a quarter, with 15 planned over the next 3 years.

## Travel Insurance



**Freedom Insurance** of Cambridge are specialists in travel insurance for people living with pre-existing medical conditions. Please mention "Vasculitis UK" when using the services of this company.

**information@freedominsure.co.uk Tel: 01223 446 914**  
**www.freedominsure.co.uk/index.asp**



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.

**Just Travel Insurance** is a specialised Insurance Agent who have provided specialist Travel Insurance nationally for over a decade. By using a carefully selected panel of Insurers Just Travel Insurance are able to arrange Insurance to meet your exact requirements. Many medical conditions attract no additional payments. They provide in house medical screening to enable clients to complete the insurance arrangements with just one FREE phone call. Not only that but 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/**

Please contact the Editor to suggest a topic for the Newsletter or if you wish to submit an article for consideration.

To keep costs to the minimum, please inform John if you no longer wish to receive the Newsletter.

**Deadline**  
**Spring Newsletter/Journal**  
**4th March 2012**

**e-News** After careful consideration the Editor and Trustees have decided to make changes to the **e-News**. Instead of two 8-page electronic issues per year we will now only send out a one page e-mail (via dotMailer) which will contain Trust news in brief, diary dates etc. These e-mails will be sent between publication of the Newsletter/Journals, as and when information is available.

If you haven't already done so, please put **vasculitis.uk@btinternet.com** in your address book to make sure you do not miss the e-mails. If you wish to receive these electronic updates please let us have your e-mail address: **vasculitis.uk@btinternet.com**

**Newsletter/Journal** The twice yearly **Newsletter/Journal** will continue to be printed and posted to Members. The next issue will be published in Spring 2012.

If you prefer to read the Newsletter/Journal on your computer just log into the Trust's website: **www.vasculitis-uk.org.uk** and follow the link.

## Life president: Lillian Strange

**Vasculitis UK** ♦ is an independent organisation funded only by voluntary contributions from members and supporters.

The 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
- To develop an advisory network for health professionals working in the field of diagnosis and treatment of vasculitic disease
- To encourage the development of centres of excellence in the treatment of vasculitis in the UK

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

**Registered  
Charity No.  
1019983**



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

### Some of the vasculitides

Beçhet's Disease  
Central Nervous System Vasculitis  
**Eosinophilic Granulomatosis with Polyangiitis (EGPA)**  
(*Churg Strauss Syndrome*)  
Cryoglobulinemia

**Granulomatosis with Polyangiitis (Wegener's) (GPA)**  
(*Wegener's Granulomatosis*)  
Giant Cell/Temporal Arteritis  
Henoch-Schönlein Purpura  
Kawasaki Disease

Microscopic Polyangiitis  
Polyarteritis Nodosa  
Polymyalgia Rheumatica  
Relapsing Polychondritis  
Takayasu Arteritis

Find us on the web:

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

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