

# vasculitis **uk**

Spring 2011 Issue No 41

## Newsletter & Journal

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# Welcome to the New Look Newsletter & Journal of Vasculitis UK \*



John

Susan

## A Few Words from the Chairman

Welcome to the first edition of this new-look newsletter. This is a trial of a new format. We hope members will appreciate the improved quality and content and that it will become the new standard. Credit for this must go entirely to Editor, Pat Fearnside, who has had to develop a whole new range of skills to produce it. We welcome your feedback please.

However, quality usually comes at a price and this newsletter does cost more, BUT we hope that the new layout, improved print quality and colour will make for a more pleasing and interesting read. There is also another motive. We want to reach those people with vasculitis who need help, but never find us.

So we hope that when you are sure you have finished with this newsletter, you will

“recycle” it by taking it to the waiting room of the hospital clinic where you get your treatment. Then, perhaps, with its new brighter cover and content, it will be picked up by someone who has just been told they have vasculitis and is in desperate need of support, advice and guidance. I’ve certainly been in that situation, and probably you were once there too.

## Going Forward

It’s amazing to think that only a year ago, the Stuart Strange Trust was on the brink of being wound up. Now, as Vasculitis UK, we have a strong new committee bursting with energy and ideas for making life better for current and future vasculitis sufferers. If you want to join them, put your name forward for election at the AGM in May.

Current projects are: development of the Vasculitis UK website, the Vasculitis Routemap (of which more elsewhere in this issue) and raising awareness of vasculitis and other rare diseases at a political level, in conjunction with the Rare Diseases Network. It’s an exciting time for Vasculitis UK!

Sadly, we are losing our “new” treasurer, Andy Bone, who helped to pick up the pieces of the dying SSVT and revive it. He brought to the team a refreshing and innovative approach. Unfortunately Andy’s increasing personal and work commitments prevent him from continuing as our treasurer, but we are very grateful for what he has done over the past year.

## Research

As you will read elsewhere, we are proud to be able to help in the funding of research to be carried out by Dr David Jayne’s team at Addenbrookes. For a small charity, the full cost of research funding is too great. In this case, we are collaborating with others to fund this small project. It is also applied research, so if it is successful it just might lead to a new treatment in the near future. This joint funding of research might become our new model for the future.

## Turning out the Light? Logo To Go??

It is now two years since the Trust was “rebranded” as “Vasculitis UK”, but being economical, we have been using up the existing SSVT stationery etc.

We have recently been looking at new logos to replace the SSVT Lightbulb. Some love it, some hate it. We really would like to hear **your** views, so do ‘phone or send a note, by email or post to Pat or John & Susan. (*see back cover for details*).!

John



## Other Trustees



Andy



Chris



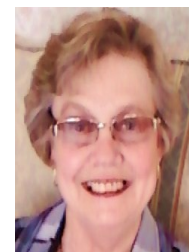
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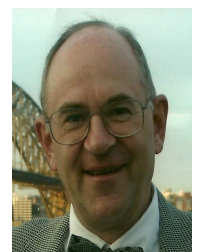
Lorraine



Mark



Pat



Paul

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

# News Items and Events Diary



## VASCULITIS UK

### ANNUAL GENERAL MEETING 2011

Sunday 22nd May 2011

at the

Long Eaton Novotel, Long Eaton, NG10 4EP



Speaker:  
Dr Richard Watts

### Topic: Who gets Vasculitis, and Why

For full details please see attached notification

**10th April 2011** - Francesca Saville runs the Brighton Marathon to raise funds for the Trust.

**10th April 2011** - Alex & Danni Brunwin of Oxfordshire will parachute jump to raise funds for the Trust.

**10th April 2011** - Cambridge Vasculitis Support Group Meeting. (see column below on Left)

**12th April 2011** - West Country Vasculitis Support Group Lunch at the Heathfield Inn near Honiton. For further details, please contact Kathleen on 01392 832231 or email: krawlinson@waitrose.com

**13th April 2011** - Vasculitis Meeting Manchester—see page 15.

**17th April 2011** - Emma Hayes runs the London Marathon

**23rd April 2011** - Holly Hampshire is organising a charity marathon in West Yorkshire for Rare Diseases Day. Run the full marathon, or pledge to run a certain amount eg. 6 miles. Details from Holly: 01484 863552. hollyemery82@hotmail.com

**6th May 2011** - Charity golf day in Essex—see details below.

**14th May 2011** - Surrey Vasculitis Support Group Meeting. This meeting will be held at Paul Bingham's home. There will be the usual delicious buffet lunch in a very friendly environment. Come along and chat with fellow sufferers and their partners/carers. All welcome. Contact Paul: 01737 813389 or e-mail: paul.m.bingham@btinternet.com

**22nd May 2011** - Vasculitis UK AGM. See column on the Left and the flier enclosed.

**5th June 2011** - Oxford Vasculitis Support Group Summer Lunch 12.30 The Duke of Marlborough Pub, near Woodstock, OX20 1HI. To book please contact: Sue Ashdown 01295-816841 oxonvsg@hotmail.com

**18th June 2011** - Vasculitis Conference, Portsmouth. Full details from Julie Ingall, Inreach Rheumatology Nurse Specialist. e-mail: julie.ingall@porthosp.nhs.uk

## Charity Golf Day Essex - for Vasculitis Research

Jules Darlow, Support Group Leader in Essex, is organising a Charity golf day **Friday 6th May 2011** at Benton Hall Country Golf and Country Club. All monies raised are to be donated to the otherwise unfunded research being undertaken by Dr. Jayne and Prof. Smith at Addenbrookes into the drug Alemtuzumab, for vasculitis which is not controlled with standard therapies.



Bacon roll,

18 holes, 3

course meal, coffee/mints with a raffle £55.00 per person

Please support Jules in raising money for this worthwhile research.

If you would like to attend or donate a raffle prize that would be fantastic. For full details please contact Jules:

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

### Cambridge Vasculitis Support Group Meeting. 10th April 2011

11.00 am to 3.00 pm  
The Holiday Inn, Impington,  
Cambridge

Speaker: Dr Rona Smith,  
Specialist Registrar,  
Addenbrooke's Hospital.

Dr Smith's topic will be  
"Talking about Vasculitis"

£10 per person (payable in advance please) to include a sandwich lunch. Please make cheques payable to: **Jenny**

**Fulford Brown**  
3 Church Street,  
Hilton,  
CB24 9JG  
01223-565967  
jenny.cambsvsg@hotmail.com

## Narborough Arms, Narborough near Leicester

We recently held our second Trustees meeting at the Narborough Arms and because of our charity status no charge was made for the use of the meeting room and facilities.

We are extremely grateful for the warm welcome afforded to the Trustees and for the generosity shown by Lynn & Nigel and their staff.

6 Coventry Road, Narborough, Leicester,



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## My Personal Journey with WG - "Nil Desperandum"

I read the Spring 2010 Newsletter and was touched by a story written by Holly. Touched, I suppose, because it reminded me very much of myself when I was diagnosed with Wegener's Granulomatosis back in 1995. I wrote to John Mills and asked if he would forward a letter on to Holly from me, which he very kindly did. He also asked me to write my story for the next newsletter, so here goes!

I had always been fit and healthy and I got married in 1994, when I was 26. Six months later, I woke up one morning with a bad back, over the next eight months or so the pain spread throughout my body and I got to the stage where I couldn't even get out of bed on my own. I had ulcers everywhere, I was constantly being sick and I couldn't eat. I've never been "twiggy", but I lost about 5 stone in weight. I was admitted to Stoke Mandeville Hospital in Aylesbury and diagnosed with Wegener's Granulomatosis. I will never forget that morning, it's now nearly 15 years ago, but in some ways it feels like only yesterday. The doctor told me what was wrong with me and told me that the treatment was cyclophosphamide and steroid pulses. The side effects sounded horrendous. He left my husband and me to talk and decide whether or not I wanted the treatment, having told me that without it, I would die. There didn't really seem to be much to discuss. But I do remember saying to Tony, "Oh my God, I'm going to lose my hair and we are never going to have a family" – something we had taken for granted when we got married the previous year.

I had 6 pulses of cyclophosphamide/steroids and felt instantly better. I returned to work, I was a Bank Manager with the Royal Bank of Scotland in the City. I was in remission for about two years, when unfortunately the disease flared and I again had 6 pulses of the same treatment. Things settled quickly again and I went back into remission. I was well and working full time (more than full time) and we decided that we would like to try and have a family. I knew that there may be problems as a result of the treatment. But I did get pregnant and Jessica was born in March 2000, followed by Madeleine in June 2004.

Quite soon afterwards, I started to suffer with violent headaches and vomiting – this would last about 24 hours and I could be sick up to 20 times, the pain was unbearable and I wouldn't be able to move or see very

well. For about 6 months the hospital kept telling me that this couldn't possibly be Wegener's – it must be migraine. Eventually they did a different MRI scan – a contrast scan – and it showed what they then called Wegener's Meningitis – it was Wegener's and it was back. It is apparently very rare for the disease to affect the brain. Initially I had high doses of IV steroids; this was fantastic but only for a couple of weeks and the pain returned. Following a five week spell in Stoke Mandeville, I was referred to UCH in London for a second opinion to see Prof Isenberg. He recommended Rituximab and cyclophosphamide together and I had two doses of that in 2005. It lasted really well and I was better for some time.

Unfortunately Wegener's had started to affect my vision at that time too, the optic nerve had shut down on the left side and I lost my sight in my left eye. I was referred to St Thomas Hospital in London and they recommended a shunt (a bit of plumbing to drain fluid from my head to my stomach) in an effort to preserve my vision on the right side. This was fitted at the National Hospital for Neurology in London in Jan 2008. Not long after that my headaches returned and I had another dose of Rituximab. At about the same time the hospital discovered I had a venous sinus thrombosis – a blood clot in my brain – as a result of all the swelling. I take Warfarin for that, and probably will do for the rest of my life, but it is under control.

Later on that year, the headaches became very aggressive and I lost my sight altogether, and I was admitted to the JR Hospital in Oxford. I was unconscious there for about three days. No-one really knows what happened, they suspected that the swelling just got so severe that it pushed down on the part of your brain that controls the consciousness, and I switched off. When I came round, I was having high doses of antibiotics and I started having Infliximab infusions and taking methotrexate along with my other medication. The infusions carried on for about a year. That was nearly two years ago now, and I am pleased to say that I am doing ok. Being diagnosed with Wegener's at any age is a complete nightmare, but when you are a young woman and want to have children it is even worse. On top of all the concerns you have about your health, you also have that to worry about. That's why I wanted to write.

At the time when I wanted to have a family, my doctors could not offer me any examples of anyone with Wegener's who had had

children. I know everyone is different and every case is different, but I did have two children after 12 doses of cyclophosphamide, and I am living proof that it is possible.

My children are an absolute joy and source of great inspiration to me – even if they are also very tiring – they make me very proud and make every day worth living!!!

I am now 41 and as you can see I've had a rocky road with my disease, I would be lying if I said it had been easy. But in some ways I wouldn't change anything. I've become a better person; I am far more appreciative of everything I've got. I've had fantastic support from my husband and my family and I could never have done it without them. My marriage is different than it was 15 years ago, we have been through so much together, but it has made us stronger.

Many doctors in many different hospitals have presented my case – some of which I have attended, and I hope that helps to get the message out there!! I was really touched by Holly's article and I really hope that this letter helps anyone else out there facing the same problems.

The photo (taken in Majorca in October 2009) is of my lovely family, my daughters Jessica, now 10 and Madeleine, now 6, and my very, very long suffering husband, Tony.

*Jenny Phillips*



# Healthy Eating by Catherine Cotter

Catherine is a fully qualified dietician. She also has WG having been diagnosed in 1994, so she is aware of the dietary problems many of us encounter. Catherine will give us the benefit of her expertise and experience in each of the forthcoming quarterly Newsletters. She will offer some general healthy eating guidance and occasional recipes.

If you have any dietary questions for Catherine please send them to the Editor. Unfortunately personal one-to-one advice will be limited as this would require a formal clinical assessment so that the advice is tailored and considered.



For this issue Catherine has provided the first of two articles covering:

## High and low potassium diets

Potassium helps regulate muscle function, digestion, metabolism and helps maintain a balance between the many electrical and chemical processes of the body (homeostasis). Potassium helps nerves and muscles communicate. It also helps move nutrients into cells and waste products out of cells.

Chronic kidney disease (CKD) is one disorder that can affect the body's ability to remove excess levels of potassium and can lead to hyperkalaemia, which means having higher than normal levels of potassium in the bloodstream.

Hyperkalemia often has no symptoms. Occasionally, people may experience the following: -

- Irregular heartbeat
- Nausea
- Slow, weak, or absent pulse

**Low Potassium Diets** are sometimes needed in people with CKD when levels in blood exceed normal values. (Normal values are usually 3.5 - 5.0mmols/litre).

Many foods contain potassium and so avoidance of foods **high** in potassium, form the basis of a 'Low potassium Diet'. Below

is a list of **High/Low** potassium foods within the main food groups.

**Starchy foods** - should form the basis of every meal.

'**Lower**': Bread, chapatti, noodles, pasta, rice, some cereals: e.g. cornflakes, weetabix, rice crispies.

'**High**': Chips (all types), Roast Potato unless part boiled first, Croquette potato, Jacket potatoes, Potato waffles. Cereals with dried fruit, chocolate or nuts e.g. fruit and fibre, muesli, coco pops.

**Fruit & Vegetables** – up to 2 portions per day allowed from the '**low**' in potassium list. Vegetables should be boiled first and the water thrown away – do not steam or use a microwave or pressure cooker

'**Lower**': Broccoli, Carrots Cabbage Cauliflower Cucumber Courgette Green Beans Leeks Mixed Veg (frozen) Onion Peas Swede Turnip. Apple, Clementine, small handful of Grapes, Kiwi, small Orange, Peach, 1 slice Pineapple, Plum, 8 Strawberries, all tinned fruit but drained first.

'**High**': Baked Beans, Broad Beans, Brussels Sprouts, Mushrooms, Parsnips, Red kidney Beans, Spinach, Sweetcorn, Tomatoes, Mushrooms, Okra, Karela. Apricot, Avocado, Banana, Blackcurrants, All dried fruit, Mangoes, Melon, Papaya, Pomegranate, Rhubarb.

**Protein** – moderate portion sides ~ 2 portions day.

'**Moderately High**': Meat & Poultry: 4oz for main meal or 2oz for snack meal. Fish: 6oz for main meal or 3oz for snack meal. Dahl: as meat replacement 2-3 times per week.

**Dairy** – '**Lower**' - Eggs – up to 5 per week.

'**Moderate**' - Yogurt: up to 2 pots per week, Cheese: up to 2oz (50g) week

**Soups**: All types likely to be '**High**' & should be avoided – even if homemade

**Snacks**: '**Lower**' - Corn, maize/wheat snacks: e.g. tortillas/Quavers, bread sticks, popcorn. '**High**' - Potato crisps, all nuts, ganthia, sev, Bombay mix

**Sweets**: '**Lower**' - Boiled sweets, jellies, mints.

'**High**' – Chocolate, toffee, fudge, Asian sweets e.g. Burfi.

**Condiments**: '**Lower**'- Fresh herbs, pepper, vinegar, salad cream, mayonnaise, mustard. '**Moderate**' - Pinch dried herbs, 1tbsp mint/apple sauce, 1tsp sweet pickle/cranberry

sauce. '**Higher**' – Salt-substitutes: e.g. Ruthmol, selora, Lo-salt, tomato sauce, brown sauce.

**Drinks**: '**Lower**'- Diluting squash/cordial (not high juice), fizzy drinks/pop, spirits, tea. '**Moderate**'- Milk – up to 1/3pint (200mls) per day; Coffee – up to 1 cup/day; Wine/stout/beer – 1 glass/day (if medical team allow).

'**Higher**' All fruit juices, high juice cordials, blackcurrant juice, chocolate/cocoa and malted drinks

There are a number of cookbooks that have been written specifically for the renal patient. Here are some that we know about: -

"*Enjoying Food on a Renal Diet*" edited by Marianne Vennegoor ISBN 0 951 9894 05, Ultrapharm Ltd, 23 New Street, Henley on Thames, Oxfordshire, RG9 2BP

"*Food for Life*" by Lawrence Keogh (a famous chef who has experience of renal disease) NBS Distribution, One House, Keats Close, South Wonston, Winchester, Hants, SO21 3HF

"*Eating Well with Kidney Failure*" by Helena Jackson, Annie Cassidy and Gavin James

Useful website:

<http://www.kidneywellbeing.co.uk/>

Acknowledgements: Leicestershire Nutrition and Dietetic Department October 2007 ©

*The second part of this article will appear in the Autumn Newsletter/Journal. Catherine has provided an easy to follow colour coded "traffic light system" appendix which contains allowable and restrictive elements for high and low potassium foods.*

*If you would like to receive a copy of this appendix, prior to the publication of the Autumn issue, please e-mail or write to Pat. (contact details on page 24)*

## Vasculitis and Oral Health

Vasculitis can affect all parts of the body and the mouth is no exception. Large, persistent and excruciatingly painful mouth ulcers are sometimes a characteristic of active Wegener's Granulomatosis as is severe toothache that moves around the mouth, especially in the upper jaw.

When patients are severely ill with vasculitis (or any other disease) it is essential that their dental care is not neglected, as a period of neglect can cause permanent damage to teeth and gums. This can also apply where patients are suffering from restricted use of their hands or upper limbs.

Obviously, those taking immuno-suppressing drugs must take care as the mouth is one of the places where invading bacteria can most easily gain the upper hand. Some medication, especially some types used to control high blood pressure, can have the side-effect of making the gum

tissues swollen so that they bleed and are more prone to infection.

Pre-existing dental disease, in the teeth or gums, may get worse due to steroids or immuno-suppression, so these need immediate attention by your dentist.

Do remember to tell your dentist that you have vasculitis. If you are taking steroids, immunosuppressing drugs or drugs to prevent osteoporosis, you **must** tell your dentist. The drugs used to counteract osteoporosis, such as the biphosphonates or alendronates, can cause serious problems if you need to have a tooth extracted.

Like in vasculitis generally, damage once done, cannot always be reversed. The best remedy, as usual, is prevention.

1) The **proven** most effective toothbrushing regime is to use an electric toothbrush with a rotary oscillating head, such as the Braun

Oral B.

2) Couple this with a toothpaste containing both fluoride and triclosan, such as Colgate Totalcare.

3) If possible use dental floss or dental tape regularly or interdental brushes.

4) If you do have gum problems, use an antiseptic mouthwash containing a low dose of chlorhexidine, such as "Corsodyl". This may be used daily for a short term, but in the long term, only as a weekly mouthwash as it can cause staining of the teeth, although this is easily removed.

*John Mills.* BDS, DGD UK.

## The Charity - How we began

We have been asked on several occasions how the Trust came about. We discovered the following article in the SSVT Newsletter, Issue 9, October 1996. This gives an insight into the origins of the Trust. We believe the article was written by our Life President, Lillian Strange.

"In September 1991 we had never heard of Wegener's Granulomatosis or any of the vasculitis diseases. By April 1992 we knew that come what may no one else was ever going to feel alone or isolated if we could help it.

Our reason for setting up the Trust was simple, Stuart's death could not be in vain. Our ambition, to raise as much awareness and funds as possible and to bring as many people together as we could.

Stuart started raising money whilst he was a patient in Papworth Hospital. He wanted to do more than just lay in bed. He wanted to know WHY, like so many of you. He started a sponsored cycle around the UK on an exercise bike. He managed to raise £36 before becoming too ill to continue.

Then Dr Lockwood suggested we might raise some funds to help with research into this awful disease. At first it was to be a one off. In the midst of the fundraising it was decided that we should try for charitable status. After a few sets backs with the constitution, charitable status was achieved on 16th April, 1993.

The Trust was born. We didn't know if we were going to falter and fall or if there were people out there who wanted to know. Soon letters started to pour in and donations were made. Fundraising was our primary aim at first, after all we had to and still wasn't to know How, What and Why?

The letters kept coming and eventually doctors, hospitals and clinicians were approaching us for information. As so many of you contacted us we knew we had a success on our hands.

To all of you we say thank you. Because not only have you helped yourselves but also us as a family. And, the rest as they say, is history."

*We will endeavour to obtain more information about our roots, about Stuart and the late Dr Martin Lockwood. We are aware that Dr Lockwood was a driving force with the setting up of the Trust. Unfortunately Dr Lockwood died in a tragic accident in 1999.*

# Blood Test Monitoring

In the Autumn issue we gave the normal ranges for the usual blood tests undertaken for vasculitis, together with a short Glossary of Terms. Below we have extended the Glossary and re-stated the normal ranges for the various tests:

## Alkaline phosphatase (Alk. Phos):

Alkaline phosphatase is an enzyme made in the liver, bone, and the placenta and normally present in high concentrations in growing bone and in bile. Abnormally high blood levels may indicate disease, eg in the liver or bone injury.

*Alk. Phos: 30-114 iu/l*

## Antineutrophil Cytoplasmic Antibodies (ANCA):

Autoantibodies found in some autoimmune diseases, recognized by their reactivity with cytoplasmic antigens in neutrophils; two groups are recognized: c-ANCA, reacting with proteinase 3, is found in Wegener Granulomatosis; p-ANCA, reacting with myeloperoxidase, is found in microscopic polyangiitis and Churg-Strauss syndrome

## Aspartate Aminotransferase (AST):

AST is an enzyme found in heart muscle, liver and skeletal muscle cells. To a lesser extent it is found in other tissues. It is raised in acute liver damage or muscle injury.

*AST: Male 16-50  
Female 12-34*

## Creatinine:

Creatinine is a breakdown product of creatine, an important part of muscle. A blood test evaluates kidney function. Creatinine is removed from the body entirely by the kidneys. In abnormal kidney function, creatinine levels increase in the blood. This is because less creatinine is released through urine.

*Adult Male about 60-110 µmol/L  
Adult Female about 45-90 µmol/L*

## C-Reactive protein (CRP):

C-reactive protein is produced by the liver. The level of CRP rises when there is inflammation present.

*CRP: 0.6 mg/l*

## Erythrocyte sedimentation test (ESR):

ESR is a test that indirectly measures how much inflammation is in the body. However, it rarely leads directly to a specific diagnosis.

*ESR: (under 50) <15 mm/hr  
(over 50) Male <20 Female <30*

## Haemoglobin (Hb):

Haemoglobin is a protein in red blood cells that carries oxygen. A blood test indicates how much haemoglobin there is in the blood.

*Hb: Male 13.5-18 g/dl  
Female 11.5-16.5 g/dl*

## Platelets:

Platelets assist in blood clotting. During normal blood clotting, the platelets clump together. Although platelets are often classed as blood cells, but they are, more accurately, fragments of large bone marrow cells called megakaryocytes.

*Platelets: 150-400*

## White blood count (WBC):

WBC count measures the number of white blood cells. These cells help fight infections. They are also called leukocytes. There are five major types of white blood cells: Basophils, Eosinophils, Lymphocytes (T and B cells), Monocytes, and Neutrophils.

*WBC: 4-11*

## grams per decilitre (g/dl)

A metric unit of volume equal to one-tenth ( $10^{-1}$ ) of a litre.

## International units per litre (IU/l)

An international unit is an arbitrary amount of a substance agreed upon by scientists and doctors.

## mg/dl = milligram per decilitre

A milligram is one-thousandth of a gram. A gram is about 1/30 of an ounce. A decilitre measures fluid volume that is 1/10 litre.

*The normal ranges quoted are from the "Disease-modifying anti-rheumatic drugs (DMARD) and Shared Care booklet" issued at Milton Keynes, and some other hospitals.*

Do not argue with an idiot. He will drag you down to his level and beat you with experience.

Light travels faster than sound. This is why some people appear bright until you hear them speak.

To steal ideas from one person is plagiarism. To steal from many is research.

The voices in my head may not be real, but they have some good ideas!

# ANCA-Associated Vasculitis - Are Genes Important?

Vasculitis is a disease that causes inflammation of the blood vessels. Wegener's granulomatosis, microscopic polyangiitis and Churg Strauss syndrome are all types of vasculitis that affect the smallest blood vessels and can also affect medium sized blood vessels. Small vessels include the capillaries, very small blood vessels that supply oxygen and nutrients to the body's organs. During inflammation these vessels become damaged which in turn damages the body's organs. This commonly results in damage to the kidneys, lungs, skin, nerves, ears and nose; indeed any organ can be damaged.

The symptoms may be non-specific (such as tiredness) or related to the organ damaged; in the lungs it may cause bleeding or symptoms similar to pneumonia; the skin can develop a rash; damage to nerves causes tingling, pain and lack of function of hands or feet; damage to the nose and ears causes deafness, nose bleeds and crusting.

## Why do these diseases develop?

These small vessel vasculitic diseases are usually associated with an autoantibody. An antibody is a protein that is normally important in fighting infection. It is produced by immune B cells and binds to the invading bacteria. The antibody flags the bacteria as foreign. Other immune cells, such as neutrophils, then recognise this flag and attack the bacteria. However in some people antibodies are produced against cells that are present in the body. This causes the immune cells to attack the body's own cells as foreign causing inappropriate inflammation and damage.

In vasculitis these antibodies are called ANCA and they are directed against the neutrophil. The ANCA not only flags the neutrophil as foreign (which they are not) but also causes the neutrophil to act in a dangerous manner causing additional inflammation. Studies in animals and in the test tube have shown that ANCA is important in causing the damage that occurs in disease. Due to the association with ANCA Wegener's granulomatosis, microscopic polyangiitis and Churg Strauss syndrome are called ANCA-associated vasculitis.

## Is ANCA-associated vasculitis inherited?

ANCA-associated vasculitis is an uncommon disease. Each year 20 people in every million are diagnosed with new disease (incidence). In the UK this roughly equates to 1000 new cases every year. However as people are surviving longer the prevalence (the number of people at any point with a diagnosis of ANCA-associated vasculitis) is increasing with approximately 150-200/million people affected.

There is a suggestion that disease is increased in family member of a vasculitis patient suggesting a small risk of inheriting disease. This does not mean that if you are affected your daughters or sons will be affected. It means that the chance of another member of your family being affected is slightly higher than average. If you have ANCA-associated vasculitis your relatives have a risk of 2.9 in 10000 of developing disease whereas the relatives of healthy people have a risk of 1.9 in 10000 of developing disease. As you can see this is a very small risk; 1 ½ times increased. This risk is much smaller than other diseases such as multiple sclerosis where the risk of having a relative affected if you have disease is increased 7 times. You would need to have 3500 children before one was likely to be affected with ANCA vasculitis.

## Why is disease inherited?

We each inherit a set of genes from both our mothers and fathers. Genes are organised into chromosomes, 23 chromosomes from our

mothers and 23 from our fathers. Each person has approximately 30,000 genes. The genes provide the code for our make-up, i.e. each protein in the body has a different gene that codes for the production of a protein. As we grow cells divide to produce new cells. As the cell divides genes are copied so that each cell has a copy of the protein code. Sometimes genes are not copied identically and this results in a mutation which forms a different protein. As genes are passed from one generation to another mutations occur. This is why we are all different from each other, why some people have dark hair and others red hair. However mutations can result in disease. Sometimes only one mutation is required to cause disease such as in sickle cell anaemia.

Diseases such as ANCA-associated vasculitis are not single gene diseases. It is likely that there are several genes which have mutations in them and that if inherited on their own they do not cause disease but when they are all inherited together they do cause disease. These are called polygenic diseases. In other settings these genes may have conferred some sort of advantage for survival but now in modern times they may be disadvantageous and increase the risk of disease.

## What genes are important in ANCA-associated vasculitis?

We don't know the exact genes that are important in ANCA-associated vasculitis. This is an area of active research. A large number of researchers across Europe have collected blood from patients and have isolated genes from this blood. These genes are being compared to the genes of individuals without disease. Clues as to some of the important genes are known. For example one of the targets for ANCA is a protein on the surface of neutrophils called PR3.

When neutrophils are activated by ANCA they release PR3 which then causes damage to the blood vessels. This is important during an infection as it allows the neutrophil to leave the blood vessel to reach the bacteria which are normally outside the blood vessel. However in ANCA associated vasculitis PR3 is released inappropriately. Normally another protein, A1AT, binds to PR3 and stops its action. In patients with ANCA-associated vasculitis there is an increased risk of patients inheriting a defect in the production of A1AT. Having less A1AT may allow the PR3 to cause more damage. There are also other immune proteins that control how active the immune system is. These genes are also inherited. Genes that make the immune system overreact may be inherited more commonly in ANCA-associated vasculitis.

We should have more results in the near future when a large research project studying over 2000 patients and healthy volunteers will report.

*Lorraine Harper*

Professor of Nephrology, University Hospital of Birmingham



# The Wellcome Trust Clinical Research Facility - Birmingham

*Dr Julie Williams, the Translational Scientist and Laboratory Manager at the Wellcome Trust Clinical Research Facility tells us about her department and the work that she and her colleagues undertake.*

The Wellcome Trust Clinical Research Facility (WTCRF) at Birmingham is situated at the front of the, now, old Queen Elizabeth Hospital. We are a dedicated research unit which was funded by a millennial grant from the Wellcome Trust.

There is an agreement between the Hospital and the University of Birmingham, next door, to run projects jointly and share the responsibility. Since the Facility opened in 2000 we have seen 57,000 patients, completed 183 studies and have 130 ongoing research projects. Our remit is to provide investigators with the physical space and staff to be able to run their individual studies. These projects can be from any discipline and require anything from a 1 hour visit right up to a 2 week stay. The renal team are one of our most active users and particularly with respect to Vasculitis research.

We have a dedicated staff of 22 nurses who are fully trained in a number of different specialities and then further trained in specific research protocols. We also have 3 laboratory staff who are specialists in a variety of different experimental techniques. To support this we have a number of admin staff and managers. As laboratory manager I have oversight of all of the projects in our labs but additionally I have a research interest in Vasculitis.

In the Facility we have a wide variety of Vasculitis research taking place. This is both at a 'wet bench' laboratory level as well as clinical trials of new drugs or ways of using standard therapies. As you will all know current drugs have a number of issues and are not perfect. In the laboratory we are trying to determine what happens at a cellular level.

Over the years we have discovered a great deal about how the white cells function in vasculitis. One of the things we are interested in in my lab are what happens inside the cell that only occurs in vasculitis, as opposed to under normal circumstances such as when people get an infection. If we could find one event that was specific for vasculitis we could try to develop a drug which modified it and prevent some of the damage. Some of the studies that we run are in partnership with drug companies who come up with novel chemicals that we test to see if they switch off the white cell response to ANCA.

Another thing that we have shown is that there is a lot of variability in the way people's white cells respond to ANCA. We are currently starting a study where we will ask patients for donations of blood to purify their white cells and then we will mix them with their own ANCA and other patient's ANCA to see how they respond and if it is different to the responses we have shown in white cells from healthy volunteers. From this we are going to look to see what the differences are in the proteins in patients and try to link it to their DNA. This may give rise to a need for more 'personalised'

medicine.

Here at the WTCRF in Birmingham we have a large Vasculitis clinic that some of you probably know quite well! As a researcher this is of immeasurable value. There are many times that we have thought, 'oh if only I had some samples from a patient who had X or Y'. So as a resource we have now started a biobank. We have selected a number of patients from whom we collect a small amount of blood and some urine every time they come to clinic. We then process this in a very defined way, which is the same for every single sample – this ensures that any research finding is not due to the way we have dealt with the sample.

We are now slowly building the biobank up as a resource for future research. What will then happen is that anytime there is a research idea we will submit it to the renal research committee to decide if this valuable resource should be used. We also have a matching bank of DNA samples which dates back to 1999 and has been used in the recent country-wide DNA study looking for genes associated with Vasculitis.

Other studies that have passed through the laboratories here at the WTCRF have included looking for abnormalities in the balances of good and bad proteins in the circulation, looking at the types of ANCA there are during remission and relapse, looking at specific genes that may be involved in the disease and looking at the function of a type of white cell called T cells.

Here at the WTCRF we do a large amount of clinical trials in Vasculitis. These have included (over the years) comparisons of different types of drugs to see which is the best therapy for getting the disease under control and then the least harmful ones and the lowest dose for keeping symptoms at bay. This includes comparing MMF with cyclophosphamide, or looking at how effective plasma exchange is. Also we try out a number of new drugs such as the anti-B cell therapy rituximab or the anti-TNF infliximab. We additionally look at how life could be made more comfortable for patients by assessing their physical and mental well being and asking them to participate in a variety of tests.

All in all the WTCRF is involved in any aspect of research in Vasculitis at every level, right from cutting edge cell biology through to drugs that are now becoming more widely available as standard care. Here our ethos is to only perform work that is of an internationally high standard and we hope that we will be performing that for Vasculitis patients for many years to come.

*Best wishes Julie*

## An update on Rituximab

David Jayne, Vasculitis Clinic, Addenbrooke's Hospital, Cambridge writes:

There is a quiet revolution going on in the treatment of vasculitis with recent studies showing that rituximab is at least as good as cyclophosphamide for controlling ANCA vasculitis (Wegener's and polyarteritis). This means that there is a good alternative for patients who are not getting on well with cyclophosphamide or in whom it cannot be used. Also, for patients whose vasculitis has returned, rituximab appears a better option with a higher chance of obtaining remission again.

Attention is now turning to how to use rituximab to keep patients well and stop vasculitis returning. It seems clear that the effect of rituximab wears off in many patients after a year or so, and some after only a few months. Vasculitis clinics have

taken different approaches with some waiting for vasculitis to return and then re-treating with rituximab, some using the ANCA blood test to decide when to give more and, in Cambridge, we have chosen to give a rituximab dose every 6 months for two years. Because it is expensive and, although safer than cyclophosphamide, it can occasionally cause problems with repeated dosing, this has become an important question.

The European Vasculitis Study group (EUVAS) has now designed a new trial to examine these issues (RITUXVAS II). The next stage is to try to raise money to conduct the trial and a grant proposal has been submitted for this purpose.

We have been very grateful to patients who agreed to participate in our first rituximab trial (RITUXVAS) and hope to be in a

position in a few months to invite participation in this second trial. As well as assessing how well repeated rituximab can stop vasculitis returning, RITUXVAS II will also see whether a two year period of treatment with rituximab can have a lasting effect after it is stopped.

The current treatments of vasculitis have been much the same since the 1970s and most patients have experienced the side effects associated with them. The advent of a newer, safer, drug that is really effective is an important event which is directly helping patients now but also will encourage the future development of drugs for vasculitis that may be even better.

## Vasculitis UK to support research at Addenbrookes

Dr David Jayne's team at Addenbrookes Hospital, Cambridge, are undertaking research into a new drug, Alemtuzumab, which is one of the new generation of monoclonal antibodies, like Rituximab. Alemtuzumab has been used in treating MS, Rheumatoid Arthritis and other autoimmune diseases. It has also been used at Addenbrookes to treat 71 difficult or relapsing cases of ANCA Associated Vasculitis, (AAV), with very good results.

Alemtuzumab works by targeting auto-reactive T lymphocytes, which play a major role in causing damage to organs in AAV. However, the T lymphocytes are very slow to recover after treatment with alemtuzumab, taking months or years. Thus there is good reason to expect that Alemtuzumab would be effective in

inducing remission in AAV and that the relapse rate after treatment will be low.

Complications in some patients treated with Alemtuzumab have demonstrated that it is not suitable for use in the elderly and those patients with advanced kidney failure or bleeding in the lungs or in intensive care.

This study (called "Aleviate") is an initial trial, using a group of 24 selected patients, who will be very carefully monitored, to establish the effectiveness and safety of Alemtuzumab. If it proves successful it will lead to a much larger controlled randomised trial, comparing the effectiveness of Alemtuzumab to standard therapies.

As there is no outside funding available, the Clinical Research Unit at Addenbrookes are

funding Rona (who is carrying out the research) and the admin costs. Vasculitis UK are contributing £10,000 to provide nursing support for the study. Another charity is to fund the laboratory costs.

A further aim of the study is to develop new blood tests for assessing vasculitis activity. This could be of significant benefit for all current and future vasculitis sufferers.

## Denosumab for prevention of fractures

(Prolia™) Denosumab is a prescription medicine used to treat osteoporosis in women after menopause who: have an increased risk of fractures or cannot use other osteoporosis medicine or these do not work well.

A study into Denosumab by Cummings SR, San Martin J et al—*New Engl J Med* 2009; 361:756-65 "Denosumab for prevention of fractures in postmenopausal women with osteoporosis" had the objective to assess the efficacy and safety of Denosumab in reducing

the risk of fractures in postmenopausal women with osteoporosis.

The results showed that (Denosumab) significantly reduced the risk of new radiological vertebral fractures as well as hip and non-vertebral fracture, and significantly increased total hip BMD (body mass density) over 3 years. The incidence of adverse events, serious adverse events and discontinuation of treatment due to adverse events did not differ between patients who received (Denosumab and placebo

# Disability Living Allowance (DLA)



Disability Living Allowance - sometimes referred to as DLA - is a tax-free benefit for disabled children and adults who need someone to help look after them, or have walking difficulties.

You may get Disability Living Allowance if:

- you have a physical disability (including a sensory disability, such as blindness) or mental disability (including learning disabilities), or both
- your disability is severe enough for you to need help caring for yourself or someone to supervise you, for your own or someone else's safety, or you have walking difficulties, or both
- you are under 65 when you claim

Normally, you must have had these care or supervision needs or walking difficulties for at least three months and they are likely to

continue for at least a further six months. However, if you are terminally ill, there are special rules for claiming the benefit.

If you are aged 65 or over, you may be able to get Attendance Allowance.

You can view the complete details, including rates payable and how to claim, on the "Directgov" website: [http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG\\_10011731](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731)

Alternatively you can obtain a "claims pack" by phoning the Benefits Enquiry Line. They are open Monday to Friday 8.30am to 6.30pm and Saturdays 9.00am to 1.00pm: Telephone: 0800 88 22 00 Textphone: 0800 24 33 55

## NHS Prescription Exemptions/Pre-payment Certificates

You can get free NHS prescriptions if, at the time the prescription is dispensed, you:

- are 60 or over,
- are under 16,
- are 16-18 and in full-time education,
- are pregnant or have had a baby in the previous 12 months and have a valid maternity exemption certificate (MedEx),
- have a specified medical condition and have a valid medical exemption certificate (MedEx), eg (*note: some contain exceptions*)  
A permanent fistula (eg, laryngostomy), Diabetes insipidus, Diabetes mellitus, Hypoparathyroidism, Myxoedema, Epilepsy requiring continuous anticonvulsive therapy.
- have a continuing physical disability which means you can't go out without help from another person and have a valid MedEx,
- hold a valid war pension exemption certificate and the prescription is for your accepted disability,

- or you are an NHS inpatient.

You are also entitled to free prescriptions if you or your partner (including civil partners) are named on or are entitled to an NHS tax credit exemption certificate or a valid HC2 certificate (full help with health costs), or you receive either:

- Income Support,
- Income-based Jobseeker's Allowance,
- Income-related Employment and Support Allowance, or
- Pension Credit Guarantee Credit.

You are also issued with a MedEx if you are undergoing treatment for cancer. This includes treatment for the effects of cancer or for the effects of cancer treatments.

Full details on NHS prescription charges and exemptions, can be found at: <http://www.nhs.uk/nhsengland/Healthcosts/pages/Prescriptioncosts.aspx>

### Pre-paid Prescriptions

Where a patient does not qualify for free prescriptions, and is resident in England, it is possible to purchase a "pre-payment certificate (PPC). A PPC could save money where more than four prescription items are



required in three months, or fourteen or more items are required in twelve months.

Leaflet HC12 gives full details including charges and can be obtained from Job Centre Plus offices, NHS hospitals, GP, dentist or optician.

Full details, including current charges, can be found at:

<http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Aboutthehealthcosts.aspx>

Phone 0845 850 0030

# Giant Cell Arteritis (Temporal Arteritis)

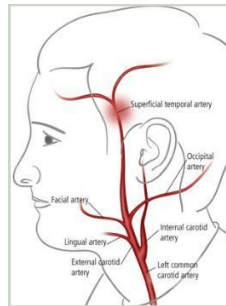
This new feature highlights some of the vasculitis diseases which rarely get mentioned in the Newsletter. In this issue we briefly discuss Giant Cell Arteritis.

Giant Cell Arteritis (also known as Temporal Arteritis) is characterised by inflammation of the large and medium sized blood vessels ("arteries") with infiltration of small and large blood cells ("giant cell"). The blood vessels in the temple area of the head are commonly affected.

GCA is closely associated with Polymyalgia Rheumatica Syndrome which causes general weakness, and pain and stiffness in muscles and joints.

GCA is one of the commonest forms of vasculitis and is more commonly seen in older patients, seldom being diagnosed below the age of 50. Fatigue, loss of appetite, weight loss and fever are often found, with headache being a prominent

feature due to inflammation of the temporal vessels.



As with many of the vasculitides the cause of GCA is unknown although an infectious trigger has been suggested but no definite infectious organism has been found consistently in patients.

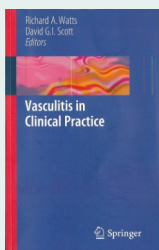
There is a predominance in the white

population with clusters of cases in some families and an association with genes called HLA-DR4. These favour an inherited predisposition to the disease.

Treatment for GCA is high doses of steroids lasting for one or two years. The relapse rate is about 50% and withdrawal of the steroids can lead to relapse. In such cases the steroids are re-introduced and are usually sufficient to induce remission. Many patients are maintained on a small dose of steroids indefinitely.

Prognosis is good with correct and early diagnosis and treatment, although untreated GCA can lead to permanent blindness.

## Book Review



### **Vasculitis in Clinical Practice.** Edited by **Dr Richard Watts & Prof. David Scott.**

This newly published book has filled a gaping void in terms of making vasculitis accessible and understandable, at least for those who understand basic medical terminology. The target audience is rheumatologists and other consultants who only encounter vasculitis occasionally. Unlike other vasculitis classics, such as the American Bailliere's "Vasculitis", which is written in the classical obscure language of a medical textbook, this is readily available and comprehensive source of knowledge.

It is described as a pocket book, but it is crammed full of essential practical information about all types of vasculitis and with a plentiful supply of excellent colour illustrations. This is not a book for the novice, but if you have some understanding of medicine, a medical dictionary and a thirst for knowledge about vasculitis, it is essential reading.

As well as an opening chapter which explains vasculitis in a most lucid way, there are chapters on general presentation of the vasculitic diseases and general principles of treatment. This is followed by a chapter each on the seven most common types of vasculitis as well as chapters on some of the very rare types of vasculitis.

Medical books are never cheap. This book comes in paperback format, available at £34.19 from Amazon. It might not be your taste in reading but it should definitely be on the bookshelf of every consultant who ever comes across cases of vasculitis. Ask **your** consultant if he or she has read this book. If the answer is "no" then you might suggest they get hold of a copy.

"Vasculitis in Clinical Practice" is published by Springer-Verlag 2010.

*Doctor Richard Watts is a Senior Lecturer at Norwich Medical School and a Consultant Rheumatologist at Ipswich Hospital NHS Trust. Professor David Scott is a Rheumatologist at Norwich University Hospital NHS Trust and an Honorary Professor at University of East Anglia School of Medicine. Both doctors have been involved in research into the causes and epidemiology of vasculitis.*

**Doctor Richard Watts will be the Guest Speaker at the AGM in May. His Topic will be "Who gets Vasculitis and Why".**

## The “Routemap” Project

Those who read the autumn newsletter and the winter e-news will know that we are currently engaged in the “Routemap for Vasculitis” project. This is part of an initiative instigated by the Department of Health, in conjunction with the charity Genetic Alliance UK.



Vasculitis UK is one of ten charitable organisations, representing those suffering from particular rare diseases, who were chosen to take part in a pilot project to develop a “Routemap” for their disease. If it proves to be successful, the project may be rolled out for other rare diseases. Completion date is the end of 2011.

It has long been the ambition of Trustees to compile a “Complete Guide to Vasculitis” for the benefit of patients, new and old, families and carers, physicians and other healthcare workers. This will cover all clinical matters, including recognition, diagnosis and treatment. In addition, it will cover family, social and psychological matters, as well as financial and aftercare issues, among others. It is a big, ambitious aim.

The “Routemap” project has now given a stimulus to this ambition and work is progressing well, thanks to the efforts of Pat Fearnside. It will be mainly internet based, as this will allow easy access for most people and will permit regular revising and updating – it is intended to be a “living” document.

We intend that it will be written on different levels, so it will be easy for those with little knowledge of vasculitis or medical terms to

understand, but there will be another level for those who have some knowledge of vasculitis, but want to know more, be they patients, GPs, other physicians or other healthcare professionals.

We know that for vasculitis sufferers, the key to successful treatment is early recognition and early diagnosis, followed by prompt and appropriate early treatment, with subsequent effective maintenance and monitoring. This results in a good quality of life and good life expectancy for those with vasculitis.

We hope that by informing and educating patients about their own disease, they will feel more in control of their destiny and that they will know what questions to ask and when to question the care they receive. We also hope that when faced with knowledgeable patients, the physicians will feel the need to address the gaps in their knowledge. The “Complete Guide to Vasculitis” will be a readily accessible source of information for them, as well as their patients.

Although principally an internet-based resource, we do intend that it should be available in printed format for those who prefer it that way. The whole document is already well over a hundred pages, but we expect that parts of it will be printed as information leaflets.

We see the “Routemap” as being the “tool” or navigation aid whereby those seeking information about vasculitis on the internet can be led quickly and easily though this “Vasculitis Encyclopedia” to the information they seek, or to find answers to their questions.

## Travel Insurance



**Freedom Insurance** of Cambridge are specialists in travel insurance for people living with pre-existing medical conditions. Freedom also give a small “commission” for each policy they transact to Vasculitis UK. It is important that you mention “Vasculitis UK” when taking out a policy with Freedom.

**Freedom Insurance, Richmond House, 16-20 Regent Street,  
Cambridge, CB2 1DB, UK**  
[information@freedominsure.co.uk](mailto:information@freedominsure.co.uk) Tel: 01223 446 914  
<http://www.freedominsure.co.uk/index.asp>



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.

Some **bank** accounts offer added benefits such as free travel insurance. Depending on the insurance provider some travel benefits do not apply in the case of pre-existing medical conditions. Others will provide cover on payment of an extra premium. The amount payable varies between providers. Details are available from individual banks.

The *Post Office* offers different levels of travel insurance.

# An interview with *John Mills* by our Roving Reporter *Holly Hampshire*



John Mills speaks exclusively to Holly Hampshire about his time as chairman of Vasculitis UK and what he hopes to achieve in 2011, as well as giving us an insight into the man behind the title.

We all know John as the leader of Vasculitis UK and as such the thought of him conjures up ideas of pomp and circumstance but that couldn't be further from the truth.

I've chatted to John over email many times and met up with him a few and one thing stands out amongst the rest ... he's determined to look on the bright side and tackle everything with a smile.

**Well John we all know you as the chairman of the Trust but what don't we know about you?**

I have a great many secrets in my past but I think it's best we don't delve into those!

**What made you decide to take charge of the Trust?**

I was elected to take over almost two years ago and when that happened I realised the Trust was about to die because the then secretary and treasurer both wanted to retire and no-one seemed to want to take their place. So the choice was whether to wind it up altogether or making sure it would survive. We had a consultation where I sent a questionnaire out to all members to ask if they wanted the Trust to continue and luckily we got an overwhelming vote of confidence and we set about trying to rebuild it.

**And has that effort paid off?**

Certainly yes. It's meant a lot of work for me and many others but I think we offer a very valuable service for people with vasculitis.

**I know a year isn't a long time but what are some of the things you'd like to achieve in 2011?**

Well at the moment we're working on this great project called the Route Map, where we're going to produce the complete guide to vasculitis. This is going to be aimed, not just at patients but also at doctors and it's going to be structured in such a way so that people can access it at different levels. My hope is that this will make a great contribution to understanding vasculitis.

**What keeps you going and striving to do even more for the Trust?**

One or two things motivate me considerably. I get phone calls regularly from people who do have vasculitis and some are in a fairly bad way and may not be getting the treatment they need.

I had an experience a couple of days before Christmas in 2009 where a man got in touch with me because his girlfriend was seriously ill, she'd been diagnosed with WG the previous October but hadn't had any treatment.

She was booked in to see a rheumatologist in February. I sent an email back saying she must be seen by a specialist immediately. I didn't hear from him until the end of January when he told me she'd been taken into intensive care just a couple of days after Christmas and she'd died, just a week after her 28<sup>th</sup> birthday. That really upset me but it motivated me with a burning desire to make things better. And that's what I'm trying to do now.

**What did you do before this?**

I used to work, I was a dentist during my career which was a full time occupation. It wasn't anything like this but I was a chairman of the governors at a local school. I suppose that has the same sort of public service element where you're trying to improve things. I learned an awful lot doing that but I think I got more out of being a governor than the school got out of me!

**Which do you find more demanding, the role you're doing now or when you were a dentist?**

That's a bit like comparing sheep and goats – it's very different. Dentistry is very intellectually and physically demanding, whereas what I'm doing now is intellectually demanding and not so physical. But I wouldn't say either is easy. I get a lot out of what I'm doing now because I don't have to do it to make money or anything; I do it for my own satisfaction.

**One of the things that must help is that you're a sufferer yourself and you've had WG for ten years now. So you've been through a lot of these experiences haven't you?**

Yes, I've experienced them first hand and because I speak to so many other people I see it from all different sides. I can empathise with people and understand what their problems are.

**If you could only give other vasculitis sufferers one piece of advice what would it be?**

I'd probably say: always look on the bright side of life. If you smile people smile back at you. If you laugh they laugh with you.

## Autumn questionnaire

**Thank you** to all those members who completed and returned the questionnaire. Your views are important in helping us prioritise our future activities. Here is a brief analysis of the results:

◆ Many members rated their Diagnosis score at a lower level than their Treatment score. *However, both scores leave room for improvement.*

◆ A significant proportion ranked working with the medical profession, to ensure quicker diagnosis and better treatment, as their highest priority.

*We are working towards raising awareness with the medical profession (and the general public) We hope that the Route-map will help play an important part in achieving this Aim.*

◆ Increasing membership, and updating and extending the website were also key priorities. *The Trustees are currently analysing the best methods of achieving these aims.*

◆ More information about vasculitis (medical/social etc) was seen as important. Also that information generally was limited and difficult to obtain. *Again we hope the Route-map will help deal with these points.*

◆ 84% of respondents have internet access and would like to receive updates electronically. However the majority still prefer to receive the main newsletter/journal in hard copy format.

◆ 86% of members support a small annual membership fee. *This has been discussed by the committee. It is not without administrative and financial implications. Further investigation is required before any decision can be taken.*

◆ Other comments made are very helpful as they will broaden our perspective in the future.

**To Mr Ian Dennis of Lea Valley, Hertfordshire the lucky winner**

*Congratulations!*

of the £25 M&S Voucher.

*We are very grateful to Ian who kindly donated the prize money back to the*

**Trust**

Wegener's has caused varying degrees of narrowing, scarring, and

## Breathing Tests (Are you left in the dark?)

inflammation to my lungs, but I've always been in the dark regarding the results of any breathing tests I've undergone since diagnosis. One of my breathing tests results stated: *"This gentleman's breathing is stable and he keeps active. His FEV was 2.27 which is 58% of predicted"*

These figures meant nothing to me so I did a bit of searching on line. I found the following table produced for sufferers with COPD.

MILD COPD: 60% - 79% predicted.

MODERATE COPD: 40% - 59% predicted.

SEVERE COPD : Less than 40% predicted.

I know these findings are for people with Chronic Obstructive Pulmonary Disease (COPD) but they gave me some idea as to what the report meant...at 58% predicted I am just a tad worse than someone with mild COPD.

I continue to keep active having recently walked 10 miles, over two days, of the quite taxing Hadrian's Wall. I hope for the third year running to manage 'Catbells' in the Lakes again this year.

Hope this helps. *Jack McMenamin* (WG 2005)

## Stop press

### Vasculitis Projects Your chance to help

◆ **Manchester Project:** The Trust is collaborate with the renal team at Manchester Royal Infirmary on their pilot project *"Improving outcomes for patients with vasculitis and lupus in Greater Manchester"*.

It will greatly assist their work if our members agreed to complete an anonymous questionnaire. *You don't have to live in the Greater Manchester area to complete the questionnaire.*

◆ **Routemap for Systemic Vasculitis:** As part of our remit for the Routemap project it is our intention to ask you, our Members, for your input.

It seems sensible, therefore, for us to produce a joint questionnaire which will, hopefully, cover both the Manchester project requirements and those of the Trust for the Routemap.

Please look out for the questionnaire which should be with you in the early summer.

### 'Health Bus' Begins First Clinical Research Studies

Read about this pioneering mobile medical facility developed by the UK's University of Birmingham. You can view the news-cutting at:

<http://www.medicalnewstoday.com/articles/218967.php>

or contact Susan if you would like a copy of this interesting article.

### Vasculitis Masterclass

The North-West Renal Multi-disciplinary Education Network is holding a "Vasculitis Masterclass" open to anyone who has an interest in vasculitis.

This will be held at Birchwood Park in

Warrington from 1.30pm to 5.30 pm on Wednesday 13<sup>th</sup> April.

If you are interested in attending please RSVP to Nina Brown at [nina.brown@cmft.nhs.uk](mailto:nina.brown@cmft.nhs.uk) or on 0161 2767987.

A copy of the programme can be viewed on the Facebook Vasculitis UK site, and on the Trust's website: [vasculitis-uk.org.uk](http://vasculitis-uk.org.uk)

**University of Dundee : Press Office**  
[www.dundee.ac.uk](http://www.dundee.ac.uk)

Researchers at the University of Dundee have developed new insights into the operation of white blood cells which play a vital role in fighting viral infections and dealing with organ transplants.

# Spring Raffle

We have had an excellent response from Members regarding the sale of tickets for the Raffle and for offers of great prizes. So many thanks to our generous Members their families and friends.

If you haven't already done so, it isn't too late for you to ask your family and friends to purchase tickets to support Vasculitis UK.

**It would help us if you could return any unsold tickets asap. Please ensure your counterfoils and money are returned to Paul by 13th May.** If you still wish to donate a prize, please contact Paul:

phone: 01737 813389 or e-mail: paul.m.bingham@btinternet.com

The draw will take place at the Annual General Meeting on 22 May.



*Some of the fabulous prizes include:*

- ◆ **A holiday for 4 in Portugal**
- ◆ **£600 cash**
- ◆ **Champagne tea for two at The Dorchester Hotel**
- ◆ **£150 wine voucher**
- ◆ **Houses of Parliament Visit and Tour**



We are grateful to:  
 the Jack Petchey Foundation,  
 the Reuben Foundation;  
 the Really Useful Group;  
 other organisations who requested anonymity; and  
**all our members**  
 for donating money or prizes and selling tickets

## 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 are currently donating £10,000 to the "Aleviate" trial being undertaken at Addenbrookes (see page 10).

As some projects take place over 2-3 years we need to know that there are sufficient funds available before considering supporting any future research projects. Fortunately the Trust's reserves are now increasing but we have to ensure we have sufficient funds and reserves before contemplating offering funding for any new projects.

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.

- 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% or more.

## "Do It For Charity.com"

Are you thinking of exciting new ways of fundraising for Vasculitis UK? If so please consider checking out "Do It For Charity.com". They have details of various fundraising events, from the relatively easy to the more challenging and exotic. You can undertake any of the events as an individual or part of a group



Here in the UK there are walks, runs and cycle rides, or you might fancy something more adventurous, such as skydiving or white water rafting.



There are overseas events such as cycling and treks - what about a trek in Peru, China or up Kilimanjaro? The opportunities are almost endless.

**"Do It For Charity" website:** <http://www.doitforcharity.com/home.aspx?ad=events1&adentry=true>  
**Or write to:** [doitforcharity.com](mailto:doitforcharity.com), 31 Corsica Street, London, N5 1JT



# “Easy Fundraising” “Easysearch” “Justgiving”

If you use the Internet then you can *safely, painlessly, and at no cost to yourself*, help raise funds for the Trust. *If you haven't yet joined please do so. It only takes a few minutes to register.*

⇒ **SHOP ONLINE AND RAISE MONEY OR VASCULITISUK (SSVT) with:**



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

vasculitisuk

Shop at your favourite stores and we receive a percentage from the store concerned.

⇒ **RAISE MONEY AS YOU SEARCH THE WEB with:**



<http://vasculitisuk.easysearch.org.uk>

This is the simplest way to raise funds for the Trust. Use “easysearch” instead of your usual search engine and we receive 1/2p for every search you make. *Every little helps.*

*Please join one or both schemes and help us increase the amount received. The total raised since the Trust joined the Scheme is approx £240, but we need more members to join.*

One further way of helping us to raise funds is via:



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

There you can sponsor any of our Fundraisers.

*If you are going to take part in an event or organise some form of fundraising, you can open your own page quite easily.*

## Our fantastic Fundraisers



### Rachel O'Neill, Swansea: Skydive (7th August 2010)

Rachel did a skydive in memory of her school friend Kayley who had Wegener's. Kayley was only 13 when she was diagnosed with the disease and sadly she passed away at the tender age of 20 on 1st September 2006. Rachel's brave endeavour raised £196 for the Trust. Here are Rachel's words to describe the experience:



"I sat in the doorway, on the edge, and in a split second I was flying. It was as if my breath had been taken away. Anything I had imagined now felt like an insignificant spec in comparison with reality. As the clouds opened below me, and the ground came into vision, I felt that I was the luckiest person in the world. I'd achieved a dream that day.

Every single moment was amazing. After freefalling for 8,000 feet, even though we were still thousands of feet high, I could hear, over my own shrieks of pure delight, the cheering of my wonderful support network of friends and family who were waiting to greet me, including Sharron (Kayley's Mum) and my friend Kat. There was a picnic, there was laughter, and I made new friends. I'd like to thank every family

member, friend and sponsor for putting their own fears aside, believing in me, and helping make my skydive possible.



Kat Rachel Sharron

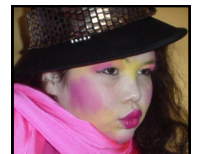
Skydive

Swansea and my instructor, Ryan, were great. They were so friendly and helpful. I was told of the significance of every stage we reached. So, I can't wait to go skydiving again and help raise more funds for the Trust. However, I doubt that the first thrill of putting on that jumping harness, the plane ride, and jumping out at 13,000 feet will ever be beaten.

It was Kayley's inspiration that spurred me into doing the skydive. She would say 'Go for your goals, try for your dreams and nothing is too big to achieve if you want it badly enough'. I remember her telling me 'feel the fear and do it anyway Rach'. I did and I hope Kayley is proud and knows that

she will always be missed, but her friendship lives on every day."

*Rachel*



Kayley  
1986-2006

### Increase in Donations:

We are pleased to report that sponsorship money has increased for the fundraisers/volunteers mentioned in the Autumn issue:

Jayne Coulson	Lizzie Deane
Sue Bowan Gray	Holly Hampshire
Craig Hill	Vivienne Kerr
Kerry-Anne Orakwuski	John Potjewy
Francesca Saville	

The combined total from these wonderful volunteers now stands at over **£8000**.



## Our fantastic Fundraisers - continued

**Gemma Lowe - Pep Rally, Lincoln University - 6th October 2010** Gemma and friends held a Pep Rally event which was a great success. They had lots of fun and kindly raised awareness of vasculitis and money for our charity £98.

Gemma also took part in an interview for the



University radio station 'Siren FM' again to raise awareness of vasculitis and of the work of the Trust.

### **Prof Lorraine Harper—Birmingham Half Marathon, October 2010**

Lorraine and Clive ran the Birmingham half marathon in 2 hours and 10 minutes, and it was hard. Running is not Lorraine's natural habitat. She is much happier on two wheels, BUT she did it and raised £282 for vasculitis patients. Well done.

### **Kerry-Ann Orakwusi and Lizzie Deane** walked the Royal Park Half Marathon on 10th October 2010

We are grateful to Kerry-Anne and Lizzie who have raised nearly £1200 to date for the Trust.



**Jeanette and Tommy Thomson** In December 2010 Tommy celebrated a "special birthday" and

they held a "Heroes and Villains" party. Instead of presents he kindly requested donations for vasculitis research. They raised over £750 for the Trust. Their daughter, Jayne, was diagnosed with WG

three years ago at the age of 21.

**Rita Allen** Thanks to Rita of Essex who continues to make beautiful jewellery which she sells to raise funds for the Trust. This has resulted in a donation of over £70 from individual commissions for Mrs J Morris and Mrs G Norman and her daughter plus a donation from Mrs Morris as her daughter has vasculitis. Other funds raised were from jewellery made and sold at Addenbrookes.

**Laura Carter** Laura's sister was recently diagnosed with vasculitis. Thank you to Laura and the Learning Disability Team at Tunstall, Stoke-on-Trent raised £72 from a Christmas card appeal.

**Linda Flegg** We are grateful to Linda and her colleagues at the Operations Area of Mizuho Corporate Bank Ltd who raised £174 for the Trust at their Charity Dress Down Day on Christmas Eve.

### **Hopton Primary School, Norfolk**

Our thanks to Hopton Primary School who raised £66 in lieu of Christmas cards and donations.

**Lune Ladies - Cumbria** We are grateful to Mrs Carole Clayton (Secretary of Lune Ladies, and to all the other ladies who kindly donated £50 in honour of one of their members - **Mrs Joan Best** - who has vasculitis. The donation was made to acknowledge the help and encouragement that Joan has given to the other members.

**Clive Currie** Mr Currie, a solicitor for 50 years, is soon to retire from Southern Solicitors in Colne, Lancs. Clive's late wife had vasculitis, and it is his desire that the Trust benefits from a gift to mark his retirement.. The firm has donated £500 to the Trust. We are very grateful to Southern and to Mr Currie.

**Francesca Saville** runs the Brighton Marathon to raise funds for Vasculitis UK on **10th April**. So far Francesca has raised £1620.

Also on **10th April Alex & Danni Brunwin of Oxfordshire** will parachute jump to raise funds for the Trust. To date they have raised £385.

**17th April** sees **Emma Hayes** run the London Marathon. So far Emma has raised £453



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.

### Entering or promoting an event?

*Are you entering or promoting an event, or undertaking some fundraising activity? If so please write or e-mail Pat with a brief note before the event. Afterwards please send a short report and, if possible, a photograph from the event.*

### **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.



## 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 probably a family member did.

We are extremely grateful for these kind donations and other bequests which help the activities of the Trust and especially our research projects.

Due to an error in the Autumn Newsletter, the kind donation we received, which was recorded at the passing of "Mrs Sadie Smith" should have read "**Mrs Sadie Hicks** of Machen". Mrs Hicks was 85. We sincerely

apologise to her family and friends for our mistake.

**The following kind and generous donations have recently been received, for which the Trust is extremely grateful. Our sympathies are extended to the families and friends of those mentioned below**

**Ron Archer** Further kind donations were received from Mr A Archer, Mr & Mrs M Crockford and Mrs DM Brown in memory of the late Ron Archer of Bognor Regis. The total now donated is £910

**Catherine Banks** The friends and family of Catherine kindly donated £425 in her memory.

**Allan Beveridge** A kind donation was received from the family and friends in memory of Allan of Chester who passed away in September 2010 after an eight year struggle with Churg Strauss Syndrome

**Peter Bullock** of Leicester, passed away in September 2010 aged 52. Peter had been ill with Wegener's for five years, but was only diagnosed three years ago. The Trust is grateful to Peter's mother Irene, his sister Liz and his family and friends for the donations, in his memory, of £756.

**John Cook:** A seasonal memorial donation of £80 from Mrs Eunice Cook and her daughter of Smethwick marked the passing, in January 2010, of Eunice's husband John. Although John had several medical conditions, including Wegener's, Eunice says he hardly complained and remained cheerful to the end.

**James Douglas Coull** James, of West Ferry, Dundee, passed away in October 2010. James had Polyarteritis Nodosa. A kind donation to the Trust, in his memory, of £482 was made by his family and friends.

**Barbara Dicks** Barbara passed away on 12 January. Barbara had Wegener's having been diagnosed at the age of 61 in April 2001. Despite several setbacks over the years Barbara managed to potter in or sit and admire her garden. She also enjoyed days out with her late husband Ron and later with her daughter. Barbara's daughters Ruth,

Gill and Bev, and family and friends kindly donated £156 to the Trust.

**Leslie Robert Gower** Robert recently passed away at the age of 63. His family and friends have kindly donated £228.50 to the Trust in his memory.

**Maggie Jennings** As we mentioned in the Autumn Newsletter, Maggie (the late leader of the West Sussex VSG) passed away in September 2010. Her family and friends have kindly donated £700 in Maggie's memory

**Ivan Leonard Siviter** Ivan, of Knighton, Powys passed away suddenly in March. He was 82 and had WG. Ivan leaves a wife Jo (married over 50 years) and a son and a daughter.

**Marion Sloan** of Annan, a vasculitis patient, passed away in October 2010. Mrs Sloan's husband, daughter Helen and family and friends kindly donated £805 to the Trust in Marion's memory.

**Glenys Williams** We are grateful to Mrs Louse Jones, and to family and friends, who donated £755 in memory of her mother Glenys who passed away, aged 82, in October 2010 following a brain haemorrhage. Although Mrs Williams did not have Vasculitis her daughter Sarah has WG having been diagnosed at the age of 17. Sarah is now 53.

**Keith & Hilda West** The Westonbirt Golf Club, Gloucestershire, held a charity golf competition and kindly donated £82 to the Trust in memory of Keith & Hilda.

### A tribute to Author, Diana Norman, who has died due to Cerebral Vasculitis



The death occurred, at the end of January of the well-known author, Diana Norman.

Her early career was in journalism. In 1957, as a reporter for the Daily Herald, she was the youngest journalist on Fleet Street. It was there that she met the man who was to be her husband for over 50 years and the

father of their two daughters, fellow reporter Barry Norman, who later became famous as a TV broadcaster and TV film critic.

Under her married name, Diana Norman, she wrote a series of highly acclaimed historical novels. Later, under the pen-name Ariana Franklin, she wrote several award winning thrillers, set in the 12<sup>th</sup> century.

In the Spring of 2010, she became very ill and was diagnosed with cerebral vasculitis, which is still one of the least recognised form of vasculitic disease. She died from heart failure as a consequence of the vasculitis.

As Barry Norman wrote in a very moving tribute to his late wife, "I lost my wife and the best friend a man could ever hope for".

You can read Barry Norman's tribute to his late wife at: <http://www.dailymail.co.uk/femail/article-1356228/Barry-Normans-moving-tribute-late-wife-soulmate-50-years.html>

# Regional Support Group Meetings

## Vasculitis Support Group West Midlands (VSGWM)

The autumn meeting of VSGWM, on 24<sup>th</sup> October 2010, was held, as usual, at the Bromsgrove Hilton, with around 75 people attending. Margaret Gentle introduced the two visiting speakers.

**Professor Paul Bacon**, formerly a rheumatologist at Birmingham University Hospital, spoke about Vasculitis in India, with particular emphasis on Takayasu's Arteritis. Although very rare in the UK with only 200 existing cases, is relatively common in India, with Takayasu and Kawasaki disease each making up 20% of vasculitis cases. In Mumbai alone there are 50 new cases a year. It affects females more than men with a ratio of 3:2.

He spoke of the possible link between large vessel vasculitis such as Polyarteritis Nodosa (PAN) and hepatitis B and hepatitis C infection. Antivirals and immunisation have reduced the incidence of this in the affluent West. Takayasu's causes restriction of the major blood vessels, including the aorta. It is known as the "Pulse-less Disease" because restricted flow in an arm results in loss of pulse. The damage to the arteries can result in stroke or gangrene in a limb.

Initial treatment can be with steroids. There is little evidence of benefit from immunosuppressants. Subsequent treatment can involve dilating blocked vessels using catheters and balloons, using stents to keep vessels open or diverting blood flow to bypass blockages. Expertise in this

treatment has developed to a high level in India, due to the high incidence of the disease, and success rates are high.

Answering questions, Prof Bacon said that of the immuno-suppressive drugs, Methotrexate is the mildest and safest, followed by Azathioprine, but they are correspondingly less intensive and less effective in controlling vasculitis diseases. He said that there was no evidence that the 'flu' vaccine induced flares and he recommended vasculitis patients to have it.



Profs Bacon and Savage

**Professor Caroline Savage**, was the second speaker. Formerly professor of nephrology at Birmingham University Hospital and a major contributor to the early development of the SSVT, she is now Head of Discovery Medicine at Glaxo-Smithkline, with an honorary post at Addenbrookes Hospital, Cambridge. She spoke of two new treatments, now on trial, that promise to be as effective as present drugs, but safer.

The *incidence* of ANCA Associated Vasculitis (AAV) in the UK is 20/24 new cases a year per million population. The *prevalence* is 180 per million, thus there are over 11,000 people with vasculitis in the UK. AAV is regarded as a "Rare" or "Orphan Disease" as it affects less than 5 in 10,000 people in the EU.

There are several hundred "Orphan Diseases", so the total number of people affected is quite high. So there is now a new initiative among EU governments to give incentives to drug manufacturing companies to develop drugs for these orphan diseases. In return for this "uneconomic" activity, they get tax credits, practical assistance, reduction in licensing fees and marketing exclusivity for 7-10 years.

Many current vasculitis drugs were developed to treat other diseases. Methotrexate and Azathioprine to treat Rheumatoid Arthritis; Cyclophosphamide to treat cancer and Rituximab to treat lymphoma by reducing the number of lymphocytes. Evidence suggests that many of the side effects of treatment are mainly due to the steroids, so ways of reducing their use are being sought. There is also a need for more targeted therapies. There is a new drug being developed to replace the biphosphonate, Alendronic Acid, that many people on steroids take to avoid osteoporosis.

## Cambridge Vasculitis Support Group Meeting



This meeting took place at the Holiday Inn, at Impington, near Cambridge on Sunday 14<sup>th</sup> November 2010 with about 30 people attending. Following a Welcome by Jenny Fulford-Brown, the meeting formed into groups for round-table discussion and

exchange of views and experiences.

For the second part of the meeting, Jenny introduced Dr David Jayne of Addenbrookes Hospital. His topic was "The Psycho-Social Side of Vasculitis". He began by discussing the history of treatment of vasculitis, starting in 1947 with the recognition of the therapeutic effects of the adreno-cortico steroid drugs that led to the development of prednisolone. They were found to be adequate for the treatment of Temporal and Giant Cell Arteritis.

In the 1960s, cancer drugs were tried for treating vasculitis. Cyclophosphamide with steroids was the first one, achieving very significant results. This is still the definitive

initial induction treatment for several types of vasculitis, but long-term oral treatment causes side effects. The total dose given over time seems to be the critical factor.

Many other vasculitis drugs are "borrowed" from treatment for other auto-immune diseases and Rheumatoid Arthritis. Rituximab is a "targeted" drug therapy that affects the B cells in the immune system. Thus it is safer, but recommended under NICE guidelines.

Continued on page 21 ⇨

## Regional Support Groups (continued from page 20)

### Cambridge VSG continued:

There is early convincing evidence that it works but a longer trial is needed to prove its effectiveness so that it can be recommended under NICE guidelines. Therefore a 4 year trial is starting to determine the long-term effectiveness of Rituximab. (Anyone wanting to take part in these trials should contact Dr Jayne\*).

Discussing maintenance treatment, Dr Jayne said that Azathioprine was better and safer for long term maintenance than Mycophenolate (Cellcept) which shows a 60% relapse rate after 5 years. When reducing the dose of Cellcept, there seems a threshold where it suddenly stops working and relapse may occur. WG patients who had predominantly nasal symptoms are at greater risk of relapse. ANCA is the best indicator of relapse although not entirely reliable.

Long-term use of steroids and immune-suppressing drugs is not good, but reduction **must** be gradual. Only one drug should be reduced at a time. When reducing the dose of steroids, occasionally the body fails to start making its own supply, so care is needed.

**Even if in apparent total remission, vasculitis patients should never be completely discharged from hospital.**

Surprisingly, relapse is less common in cases where there has been kidney damage, but it is more dangerous for elderly patients.

\* Please contact Dr Jayne by e-mail: [dj106@cam.ac.uk](mailto:dj106@cam.ac.uk)

**The West Country Vasculitis Support Group Lunch**

The West Country group held their January lunch at the Devon Hotel near Exeter. There was a good turnout despite some of the members succumbing to colds and viruses!



The next lunch is planned for Tuesday 12 April at the Heathfield Inn near Honiton. For further details, please contact Kathleen on 01392 832231 or email [krawlinson@waitrose.com](mailto:krawlinson@waitrose.com).

## New Regional Support Groups



We are pleased to announce that four new Regional Support Groups are being set up. The new leaders will be starting slowly offering advice and hoping to hold informal meetings, chatting over a coffee and a cake, at their own homes or at a suitable venue. If there is sufficient interest then eventually meetings with speakers might be possible.

The new Group details can be found on page 23. They are in the **Bristol, Cumbria, Southern Ireland** and **Yorkshire** areas.

The Yorkshire Group held its first meeting in late March and a report will appear in the next Newsletter.

If you would like to join with the new groups please contact the appropriate leader(s).

Where a Support Group has been running for a while in your area please use the facility and join in with their meetings. No need to be shy, you will be made more than welcome.



## Spotlight on two of the Support Group Leaders

### London: *Vincent Fernandes*

The London support group was formed and had its inaugural meeting in January 2010. The next meeting was planned for autumn 2010 but the speaker chosen could not be pinned down to a date and the meeting did not materialise. Currently it is hoped to hold a meeting in spring 2011 and more information will be released as soon as the plans are more advanced.

To date the group has provided telephone supported to a number of people newly diagnosed with vasculitis and members of their family. The group has been run by Vincent Fernandes (who has WG) and has recently been joined by Carole Watson\*

(who has CSS).

\*Tel: 01923 836015 email: [cwatson@hillingdonrid.org](mailto:cwatson@hillingdonrid.org)

### West Sussex: *John Bailey*

Our meetings tend to be informal and quite social affairs, generally just before Christmas.

I recently took over the Group following the sad passing of Maggie Jennings. Meetings were always held in Maggie's apartment but we are now considering holding them at the RAFA Club. We have a ballroom that is used for various gatherings, caterers who will provide a buffet at a reasonable cost

and a bar that provides various liquid refreshments including tea and coffee. We met in December to remember Maggie and all the work she did for the group. I am hoping to find a volunteer to take over the general admin.

I am a supposedly retired electronics consultant but the requests for help with computers, DVD recorders etc. etc. are never ending. I keep telling myself that I am going to have some "John Time" but it never seems to happen.

# Support Group Contact Details

**Aberdeen & Grampian**  
**Mo McBain** 01224-862226  
 mcbain.moiain@btopenworld.com

**Beds, Bucks & Herts VSG**  
 (Bedfordshire, Bucks, Herts and surrounding areas)  
**Janine Davies** 01525-372733  
 family.davies@btinternet.com  
**Christine Lee** 01480-869162

**Bristol VSG** **NEW**  
**Jackie Sullivan** 01275 398710  
 morwenna29@yahoo.co.uk

**Cambridge VSG**  
**Jenny Fulford-Brown** 01223-565967  
 jenny.cambsvsg@hotmail.com

**Canterbury area**  
 (Contact person: this is **not** a group)  
**Margaret McGrath** —  
 margaretmcgrathfms@yahoo.com

**Cheshire**  
 (Contact person: this is **not** a group)  
**Susan Chance** 01244-381680  
 susanchnc@yahoo.co.uk

**Essex VSG**  
**Jules Darlow** 07789-113144  
 jules.essexvsg@googlemail.com

**London VSG**  
**Vincent Fernandes** 0208-8660602  
 vincentf51@hotmail.com

**Northern Ireland VSG**  
**Karen Gallagher** 028-7138-4454  
 ni.vasculitis@gmail.com

**North West (Cumbria) VSG** **NEW**  
**Martin Thomas** 07765 888987  
 nwukvsg@gmail.com



Anita



Holly



Kathleen



Margaret



Martin



Pat



Sue



Susan



Vincent

**Oxfordshire VSG**  
**Sue Ashdown** 01295-816841  
 oxonvsg@hotmail.com

**Republic of Ireland** **NEW**  
 (Contact person: this is **not** a group)  
**Joe O'Dowd** 00353 (086) 2345705  
 dwodo@iol.ie

**South Wales VSG**  
 (Contact person: this is **not** a group)  
**Jackie Thomas** 029-2089-2403  
 creigiau20@yahoo.co.uk

**Surrey VSG**  
**Anita Laycock** 01372-750667  
 anitalaycock@gmail.com

**Vasculitis Support Group West Midlands (VSGWM)**  
**Margaret Gentle** 0121-243-5621  
 mgvsgwm@blueyonder.co.uk

**West Country VSG**  
**Kathleen Rawlinson** 01392-832231  
 krawlinson@waitrose.com

**West Sussex VSG**  
**John Bailey** 07752-122926  
 johnbee4@googlemail.com

**Yorkshire VSG** **NEW**  
**Holly Hampshire** 01484 863552  
 hollyemery82@hotmail.com  
**Jennifer Wormald** 01937 586734  
 jenw@bethere.co.uk  
**Pat Fearnside** 01709 583722  
 pat.fearnside@btinternet.com

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

# Newsletter & Journal and “e-Newsletter”

## New Layout / New Image:

I hope that you like the new look for the Newsletter/Journal. In his Chairman’s Report (page 2) John has detailed why we feel that this is the correct approach as we take the Trust forward.



*Please take your Newsletter/Journal to your consultant or hospital or GP waiting room when you have finished with it. This will, hopefully, help us increase awareness of vasculitis generally and of the Trust, and its activities. YOUR FEEDBACK WOULD BE APPRECIATED.*

## New initiative - e-Newsletter:

Our new initiative is to publish two e-Newsletters a year - Winter and Summer. The first, our prototype, was the Winter 2011 issue.

The “e-News” is only available to Members by e-mail.

The e-News will be an additional means of keeping in touch with Members. It will contain news items and an events diary, details of forthcoming fundraising, interesting web-based videos and research.

We appreciate that not all Members have internet access. Therefore, the e-News will not contain research articles, personal stories or detailed reports from Support Group meetings, although the social side of such meetings may be reported with photographs, to help make it an interesting

small package.

Our intention is that future e-News will be relatively short and “punchy”

*If you would like to receive a copy of the first e-News, and future issues together with periodic updates from the Trust, please let me have your name and e-mail address:*

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

*You will be able to unsubscribe at any time if you want.*

**Pat** Editor

## Letter to the Editor

Dr Editor

My husband has ANCA positive renal specific vasculitis. Generally his treatment has been fairly good, but there seems to be longer now between appointments. The hospital agree with me that he should be seen more frequently, then next time we see someone different, who gives an appointment for 2 months again.

My husband is feeling much better apart from horrendous dizziness and sinus like symptoms. This is mainly due to his diabetes which is

somewhat out of control because of the steroids. He now takes insulin which is helping.

There is, however, a good point, which I have made on several occasions. When a diabetic patient is diagnosed with something requiring steroids, short-term insulin should be an early treatment. This ensures that the diabetes doesn't start more problems. My suggestion met with agreement, but why can't the medics work things like that out?

Yours Mrs LM

## Problems with the Autumn Newsletter

*Unfortunately, there was a problem with the mail addressing system when we sent out the Autumn edition, so some addresses were a little jumbled. We know that some members definitely were not sent the Autumn newsletter. We must apologise for this error, which did not immediately become apparent.*

*If you did not receive your Autumn Newsletter and you would like to receive a back-copy please contact John & Susan Mills by 'phone, e-mail or letter. (Contact details are on the back cover).*

*The Autumn issue can also be viewed on-line:*

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

## Update of the Trust’s Website

Updating the Website is now an urgent priority. We are conscious of the cost of doing this work and are actively seeking a sponsor or sponsors to keep expenditure to a minimum.

Without additional funding the work will have to be undertaken “in-house” where possible.

If you are a **Web designer** or a **Graphics designer** and would like to offer your expertise and

time to the Trust please contact John (*details on the back cover*).

We would be willing to pay towards this assistance and/or to pay any necessary expenses.

<p>Please contact the Editor to suggest a topic for the Newsletter or if you wish to submit an article</p>	<p>To keep costs to the minimum, please inform John if you no longer wish to receive the Newsletter/Journal.</p>	<p><b>Deadline for the Summer e-News - 10th June 2011</b></p> <p><b>Deadline or the Autumn Newsletter/Journal - 26th August 2011</b></p>
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# 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



The vasculitides		
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