

*"Ramfeezled Today"*



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***Autumn 2010***

**THE JOURNAL & NEWSLETTER  
OF  
VASCULITIS - UK  
(Stuart Strange Vasculitis Trust)**

**INCLUDED IN THIS ISSUE**

Meet your new Committee  
Alternative Therapies - Diane Patterson  
Anti-inflammatory Foods  
Research Report - Dr Neil Holden, Birmingham  
Rituximab –v– Cyclophosphamide - Recent Research  
Questionnaire - Your chance to win £25 M&S Tokens  
Rare Diseases Project

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



## NEWS ITEMS AND EVENTS DIARY

- 5th October            **West Country Vasculitis Support Group** - Talk on vasculitis by Dr Nick Viner, consultant rheumatologist, Torbay Hospital. Meeting starts at 6pm. Please contact Charlotte Stoner (details page 22)
- 10th October           **Kerry-Anne Orakwusi and Lizzie Deane** walks the Royal Park Half- Marathon for SSVT
- 7th October            **Craig Hill** runs in the Cardiff Half-Marathon in support of the Trust
- 24th October           **VSGWM Meeting** (See Below)
- 14th November        **Cambridge Vasculitis Support Group** meeting to be held at The Holiday Inn, Impington, Cambridge. The meeting will start at 11.00am, to finish about 3.00pm. There will be an opportunity to share experiences. A sandwich lunch will be provided and is included in the price. Dr David Jayne will host a questions and answers sessions. **All places to be booked in advance please.** For booking and full details (including price) please contact: Jenny Fulford-Brown (see page 22)
- 2nd January 2011      **Surrey Vasculitis Support Group**, Winter meeting. Details from Victoria Lown. 01372 727833 e-mail: vlownd@vasculitisfoundation.org
- 10th April 2011        **Francesca Saville** runs the Brighton Marathon to raise funds for SSVT



### VASCULITIS UK - SSVT ANNUAL GENERAL MEETING 2011 Initial Announcement



**The 2011 AGM will be held on Sunday 22nd May 2011 at  
Long Easton Novotel, Long Eaton, NG10 4EP (M1 Junct 25)**

**Further details, including Programme and Speakers will be published in the**

#### VASCULITIS SUPPORT GROUP WEST MIDLANDS (V.S.G.W.M.) MEETING

**SUNDAY 24th October 2010**

HILTON BIRMINGHAM BROMSGROVE HOTEL  
( [www.hilton.co.uk/birminghambromsgrove](http://www.hilton.co.uk/birminghambromsgrove) )

The Hilton Hotel directions - M5 at Junction 4 take the A38 towards Bromsgrove for about a mile, Hilton Hotel is on the right

Informal gathering from 12.00 in bar (snacks available, but quite expensive), or from 1.15pm in the Elgar Suite

PROGRAMME in ELGAR SUITE 1.30 pm to 5.0 pm

1.30 pm Welcome and news ... Margaret Gentle  
2.0pm to 5.0pm Talks, with break in middle for tea and biscuits

SPEAKERS BOTH VASCULITIS SPECIALISTS FROM UNIVERSITY OF BIRMINGHAM  
PROFESSOR C.O.S. SAVAGE, Professor of Nephrology, MRC Centre for Immune Regulation.  
"How industry sees development of drugs for rare illnesses."

PROFESSOR P.A. BACON, Department of Rheumatology, Medical School,  
"Vasculitis in India (including Takayasu's Arteritis)"

NOTES i) A Toby Carvery is just past the Hilton Hotel but on left side of the road at the traffic lights.  
ii) the 144 bus runs infrequently on Sundays between Birmingham and Bromsgrove

ENQUIRIES V.S.G.W.M. 15, Chepstow Grove, Birmingham B45 8EG, Phone. 0121 243 5621

*"Ramfeezled" = Old Scots expression - to be weary, fatigued or befuddled*

## AUTUMN 2010 - CHAIRMAN'S REPORT



How things do change! This time last year, following the resignation of Paul Pegg as secretary and the intended resignation of Richard Harris as treasurer, it looked as if the Trust was going to have to be wound up for lack of a secretary, treasurer and committee members to run it. However, the response to the questionnaire, which was sent out last November to all members, confirmed that you wanted the Trust to carry on.

Fortunately, a very able and committed new treasurer, Andy Bone, volunteered his services in time to save us from disaster. Then, at the AGM in June, several new, enthusiastic trustees came forward to help run the Trust. (You will find an article introducing each of us on page 4). So now we have to get together to make some decisions about the future of the Trust and its direction and how the aims and intentions are to be implemented. One of the new Trustees is Pat Fearnside, who has, to my relief, now taken over as editor of the Newsletter as well as helping out with many other administrative issues. This is her first edition as editor.

About 70 people attended this year's AGM in June where there were talks by Dr Neil Holden about his vasculitis research (see page 8), and from Dr Andrew McClean on new research into "Fatigue in Vasculitis and chronic kidney disease".

Dr Lorraine Harper also gave a very interesting talk on genetic factors in vasculitis "ANCA Associated Vasculitis: Genes or Environment? Or a little bit of both". For reasons of space in this Newsletter, her presentation will appear in the Spring newsletter.

Having now been on the receiving end for over a year of many 'phone calls, emails and letters, from those with vasculitis or suspected vasculitis, I have come to believe that the main problem that needs to be addressed is the failure to recognise and diagnose vasculitis sufficiently early and to treat it appropriately. I think many with vasculitis would now be suffering from fewer long term effects, have a better quality of life and an improved life expectancy if their disease had been correctly diagnosed and properly treated at an earlier stage.

So the change in government does give me some cause for alarm. Earlier this year, Sir Liam Donaldson, Chief Medical Officer, announced his intention to direct more attention and resources towards diagnosing and treating rare diseases. However he is no longer CMO and the new administration has announced its intention to devolve all the commissioning of medical services to GPs.

Unfortunately, most GPs have little or no knowledge or awareness of rare diseases like vasculitis, so one suspects they are hardly likely to direct a larger proportion of the reduced resources that are going to be available in the direction of those diseases. But these are early days and I hope my worst fears are unfounded.

However, there is hope on the horizon. The Trust has been invited by the highly respected "Genetic Alliance" to join a pilot scheme "a route map for rare diseases". It is hoped that this will give rare diseases, such as vasculitis, a higher profile. See report on page 20.

### PROFESSOR LORRAINE HARPER

I am sure all Members will join me in congratulating Professor Lorraine Harper (the Trust's medical advisor), who was officially promoted to Professor of Nephrology at the University Hospital of Birmingham on 1st October.

*John*

## INTRODUCING YOUR NEW COMMITTEE



### **JOHN & SUSAN MILLS - CHAIRMAN & HON SECRETARY**

We are your very own BOGOFs (buy one, get one free). We are partners in marriage and many other aspects of life. We usually work as a team, well, most of the time anyway!

John, now 67, was a dentist in a country practice for over 40 years until he retired in 2007. Susan also worked in the practice for many of those years, initially as a dental nurse and latterly as practice manager. In addition to her dental qualifications, she is also a qualified social worker, having worked at different times in the care of elderly and handicapped people as well as working with severely abused children.

We are both on second marriages and have 4 children and a grandchild between us. John was struck down with Wegener's Granulomatosis in 2001, but was promptly diagnosed and suitably treated, so now leads a pretty normal and very active life. We have a second home in France, where we spend about 2 months a year.

Over the past 18 months, SSVT has taken over our lives, but the up side of that has been meeting and talking to so many nice, different, interesting and good humoured people who are determined to not let having a silly disease like vasculitis get them down.



### **VICE CHAIR - MARK GRIFFITHS**

Sarah (my Fiancé) and I live in Leamington Spa. She works for National Grid nearby, and I work for Network Rail. Sarah first started having the symptoms of WG in the summer of 2005 and was diagnosed with it in the December 2005. Before that, I was profoundly ignorant of what WG was, or about what it is to live and deal with such a condition.

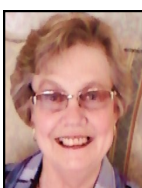
The past 5 years, seeing what she has gone through and the tenacity with which she deals with it have been a revelation and inspiration to me. I hope I can make some small contribution as a trustee to what Vasculitis UK (SSVT) can achieve.



### **ANDY BONE - TREASURER**

I'm Andy and I'm 40, I live in a small village in North Buckinghamshire and I am engaged to Lorna. My background is as Press Officer/Programme Editor at Buckingham Town Football Club, I was Press Officer at Buckingham Town Cricket Club and Secretary for ten years. My loves include being a fanatical Southampton Football Club supporter for 34 years, cricket and sports photography - I run a Facebook Group called "Sports Shots" which raises awareness of Vasculitis through my images. I am grateful to my parents, Lorna and friends for helping me through the past 20 years in my battle with WG.

I look forward to building on the excellent foundations of all those previously involved with the Trust and to continue their good work. I would like to give a big thank you to Richard Harris for all his ongoing help and support.



### **NEWSLETTER EDITOR - PAT FEARNSIDE**

I live in South Yorkshire and share my home with my constant companion Peter. I have Wegener's (trachea), diagnosed in 2003. I was a keen dancer and taught dance. I now help to publish a dance magazine, and recently this Newsletter. I love animals. Other interests include reading (historical novels and mysteries), crosswords, clothes and eating out. Pre-retirement I was the senior administrator for the Occupational Health Service of a now defunct nationalised industry.

My aims for the Trust are to continue to improve on the excellent work of my predecessors regarding the Newsletter, and assist with updating the website, and other initiatives. ⇨



**MEDICAL ADVISOR - LORRAINE HARPER**

Although most of my time is spent looking after patients and performing research I still have time to enjoy myself. You will often see me out on the hills with my other half on a mountain bike. I hope to bump into some of you there as I am sure you will agree exercise is the best form of medicine.

I graduated from Edinburgh University and trained in kidney diseases. I gained my PhD in 2000. I am currently Professor of Nephrology at Birmingham. My research interests include: improved outcomes for patients by using novel treatments and better understanding how to use current therapies in a safer manner. My department is currently studying fatigue in ANCA associated vasculitis, the role of genes, and possibly predicting those at risk. This work should allow us to tailor the drugs we use to treat the individual.



**TRUSTEE - HOLLY HAMPSHIRE**

I'd love to say I'm very exotic ... but I'm not. I'm 27 and diagnosed with WG in December 2009. I married James last September. We live in West Yorkshire and have just moved house, which has been a pretty crazy time. I'm a journalist and run a news team at a local radio station, which I love. I not only get to interview interesting/famous people but also read bulletins live on air.

I hope that the Trust can help spread the word about Vasculitis, both to the medical profession and the general public. One way is through media coverage and I am going to work to this end via my knowledge of the industry.



**TRUSTEE - CHRIS STAIT**

I live on the southern edge of the Peak District with my Partner. Between us we have 3 children and 5 grandchildren so we have a large house to keep us occupied. We enjoy walking and touring in our mobile home. We also used to sail a lot. I am now retired after 38 years with Rolls Royce, where I was involved in both the manufacturing and assembling of aircraft engines, including the testing of the "Trent 1000" for the new Boeing 787. One year after retiring I acquired WG, and am living successfully with renal failure awaiting a transplant.

I wish to bring to the Trust some of the process and disciplines that where a way of life in my career, and to help highlight the best practise of living with WG.



**TRUSTEE - PAUL BINGHAM**

I'm married (42 years) and have 3 sons and 7 grandchildren. I retired at 56 after 35 years in Marketing which took me all over the World. My interests are quite diverse but include family, travel, food & wine, music, opera, golf (I had to give up occasional tennis when I got WG in 2006). Manchester United are the team I support !! I have always been involved in voluntary work, charity activities and fund raising.

I am very supportive of the initiatives of the Trust. I have a strong patient perspective, and believe that some medical professionals need to be more knowledgeable about Vasculitis, should exchange experiences more and be more communicative with patients. I will support the Trust to attain a sounder financial base, to develop awareness, and fund important future research.

## ALTERNATIVE THERAPIES

### Out of adversity, an opportunity

I was diagnosed with Cerebral Vasculitis in 2004. This is a very painful condition which affects my arms, legs and nervous system. Initially I was even told that I could possibly die within three months which was difficult to deal with mentally and physically. For various reasons I could not commence treatment for six months so I looked for alternative therapies to help me cope. I tried hypnotherapy, which was interesting, but I discovered that my therapist also practised Reiki – a system of natural healing. I didn't know what was involved but decided to give it a go. Remarkable, after one session, I was able to do my shopping which I hadn't been able to do for ages.

Amazingly, a week later I received a prospectus from Dundee University which included a course on Reiki. Despite my own experience I was sceptical. Of course, my condition is not curable and I take immune-suppressants, but Reiki has enabled me to control my condition. It keeps me calm, peaceful, and it lifts my pain so that I rarely have to take painkillers. I now have energy to work and play, optimism for the future, and I live a very full and happy life.

Thanks to Reiki I was able to return to work and I decided to learn to practice Reflexology and Crystal therapy. On reflection it amazes me that despite my condition I was working and managing to attend evening classes to gain my diplomas.

I work part-time in a jobcentre as a lone parent adviser. My new skills do come in handy as I help customers who suffer with chronic conditions or severe depression.

If they are interested I show them how to access free courses by setting up an individual learning account for access to Dundee University. I even offer Reflexology, Reiki and Crystal therapy to my colleagues,

and my employer allows me to volunteer for the Princess Carers Trust where I offer reflexology for Carers on their "pamper days". In addition to the above I talk to lone parent groups and I offer Reiki and Reflexology at the local hospice.



There are several scientists researching these alternative therapies, including Dr David Hamilton

([www.drdavidhamilton.com/](http://www.drdavidhamilton.com/)). There are also paid healers within the NHS, one being Angie Buxton King who is doing brilliant work with staff and patients in London. An interesting DVD on research being undertaken is "The Living Matrix" ([www.cygnus-books.co.uk](http://www.cygnus-books.co.uk) (£17.99)).

I believe that in the future it will be common to use both conventional medicine and alternative therapies. I am sure there will be Members reading this article who are sceptical, and I completely understand. All I can say is please don't knock it unless you've tried it.

*Diane*

*Editor's note: The Trust is grateful for Diane providing this article. However, we and Diane wish to point out that alternative therapies should only be used after discussion with your consultant, and are not intended to be used instead of conventional medicine. If you wish to contact Diane personally please e-mail: [moon.harvest@btopenworld.com](mailto:moon.harvest@btopenworld.com)*



## ANTI INFLAMMATORY FOOD LIST

There are a number of books on the market recommending foods and supplements for weight loss and improved wellbeing. One such book is "The Perricone Weight-loss Diet" although other books are, of course, available. Pat Fearnside has used this book as a guide to sensible eating and in the process lost 2 stones which had been gained when taking high doses of Prednisolone. The book recommends organic where possible, but Pat used a mixture of organic and free-range. "Wild" and "organic" are preferable for wellbeing but not necessarily for weight loss.

Here are some of the recommended and non-recommended foods. Some of these foods may not be appropriate for certain vasculitis conditions or drug regimes, especially for those who have, of necessity, to adopt a particular diet. Such Members are recommended to speak to their nutritionist and/or doctor before considering changing any part of their diet.

### **RECOMMENDED FOODS**

#### **Omega-3 Seafood**

Wild Alaskan salmon (sockeye), Halibut, Herring, Black Cod (Sablefish), Trout, Anchovies, Sardine, Mackerel.

#### **Additional seafood**

Prawns, Scallops, Clams, Mussels, Oysters, Crab, Lobster, Bass, Cod, Flounder.

#### **Best poultry**

Organic/free range Chicken and Turkey, Turkey sausage and bacon (avoid products with nitrates).

#### **Best source of protein from dairy**

Plain low fat organic yogurt, Plain Kefir (fermented milk drink), Organic low fat cottage cheese, Organic free range eggs.

#### **Organic, unsalted nuts**

Almonds, Brazil nuts,

Hazelnuts, Macadamia, Pecans, Pine nuts, Pistachios, Walnuts, Organic unsalted seeds, Linseed (flax), Sesame seed, Sunflower seed, Pumpkin & Squash seed.

#### **Organic grains/legumes (use in moderation for weight loss)**

Non-instant oatmeal or whole oats, Lentils, Chick peas, Dried beans, Buckwheat, Barley.

#### **Fruit and Vegetables**

Apples, Artichokes, Asparagus, Aubergine, Avocado, All fruit berries, Broccoli, Brussels sprouts, Cabbage, Cauliflower, Melon, Celery, Cherries, Courgettes, Cucumber, Lettuce, Baby greens, Lemons, Grapefruit,\*\* Green beans, Peppers, Mushrooms, Onions, Pears, Peas, Spinach, Swedes, Tomatoes.

#### **Herbs & spices**

Most herbs & spices \*\*

#### **Beverages**

Organic green, white or black tea, Pure spring water, Acai,

Pomegranate juice, cocoa from pure cocoa powder.

#### **Healthy Fats**

Organic extra virgin olive oil, Linseed oil (flax), Avocado, Coconut, Nuts & seeds.

### **PRO-INFLAMMATORY FOODS TO AVOID**

All buns and cakes, Bread, Cereals except Oatmeal, Cheese, Chips, Croissants, Fast food, Fizzy drinks, Fried food, Fruit juice, Granola, Honey, Hot dogs, Ice cream, Frozen yogurt, Jams Jelly and preserves, Margarine/Butter, Pies, Potatoes, Puddings, Rice, Sorbets, Sugar, Sweets, Tacos, Tortillas, Waffles.

\*\* Grapefruit and Turmeric are not recommended when taking Cyclophosphamide

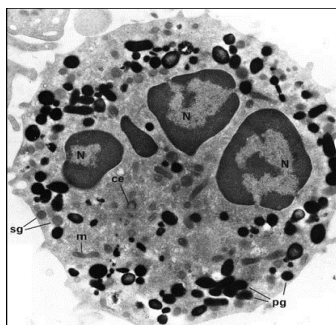
I am a post-doctoral research fellow with the Renal Immunobiology Research Group at the University of Birmingham. Over the last three years I have been researching disease mechanisms of ANCA associated vasculitis, work that has been kindly funded by the SSVT. Below is a short synopsis of my ongoing research projects in the lab.

### ***The immune system and basis of ANCA associated vasculitis***

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

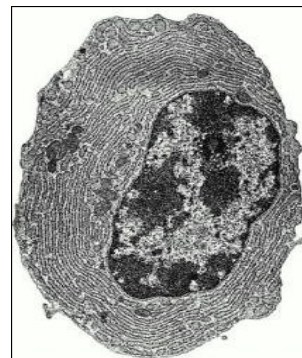
The innate immune system provides a basic and general form of defence against infection. A large component of the innate immune response is a group of cells termed phagocytes. Phagocytes are able to detect bacteria and other infectious agents and kill them by eating and digesting them. The model phagocyte within the immune system is a cell called a neutrophil. The neutrophil is the most abundant white blood cell in the body and is found predominantly within the blood stream. Neutrophils are able to leave the blood stream to travel to sites of infection or inflammation. There, they readily detect and eat up any harmful micro organisms. Neutrophils are also able to kill harmful micro-organisms through the release of anti-microbial granules. Neutrophils are powerful cells of the immune system and are fundamental to the immune system's response to infection. However, neutrophils are difficult to control and may promote inflammation by releasing their granules at the wrong place at the wrong time. The uncontrolled release of granules may also damage healthy neighbouring cells.

The adaptive immune system provides the body with a much more specialised and advanced response. One important contribution of the adaptive immune response is the generation of antibodies. Antibodies are produced by cells, called B cells and are generated against a specific threat.



A highly magnified picture of a neutrophil. The black dots throughout the cell are

Antibodies are released into the blood stream and act like homing missiles. Once they have located their target they will lock on to it. The antibody then aids the innate immune response by attaching to a phagocyte (such as a neutrophil) which will then eat up the target or release granules in its direction. The generation of antibodies is a powerful tool that the immune system employs, but sometimes it does get it wrong. Occasionally a B cell will generate antibodies that will be specific for cells or proteins of our own body. When this happens the immune system begins to attack itself, this is known as autoimmunity.



A highly magnified picture of an antibody-producing B cell

ANCA associated vasculitis is one form of autoimmune disease where B cells produce antibodies that are directed against ssproteins that are found on the surface of neutrophils. These antibodies are termed Anti-Neutrophil-Cytoplasmic Antibody or ANCA for short. ANCA have been demonstrated to be involved in vasculitic diseases such as Wegener's granulomatosis, microscopic polyangitis and to some extent Churg-Strauss-syndrome. Research in our lab has shown that ANCA are able to lock on to the neutrophils' surface. This action activates the neutrophil, causing the cell to become sticky and release its inflammatory granules. In patients suffering from ANCA associated vasculitis it is likely that ANCA, interacting with neutrophils in the blood vessels, cause the cell to stick to the side of the vessel and spill out their granules. This release of granules is likely to cause a large amount of damage to the cells of the blood vessels and promote inflammation.

### **Research at Birmingham**

At the University of Birmingham we are specifically trying to identify important processes and molecules that drive inflammation in ANCA associated vasculitis. In the lab, we are able to isolate ANCA from the serum of patients with ANCA associated vasculitis and study the ability of these antibodies to activate neutrophils.





The more we learn about this activation process the more likely we are to identify drug targets that can be modulated to eliminate or reduce the inflammation and pathology associated with ANCA associated vasculitis. Below are two research projects the Trust is currently funding.

#### **Can B cells and neutrophils ‘talk’ to each other?**

We know from previous research that both B cells and neutrophils are important players in promoting inflammation in vasculitic disease. However, most research has solely investigated the action of either the neutrophil or B cell in isolation. We wanted to investigate further the possibility that either of these important cells could influence the other’s behaviour in an ongoing immune response.

As part of a healthy immune system neutrophils and B cells will rarely encounter each other. However when the immune system is activated, neutrophils and B cells are likely to travel to the same sites of inflammation, where they may interact. Currently in the lab we have evidence to suggest that neutrophils activated by ANCA are able to release proteins that have a direct influence on B cells. In our experiments, neutrophils, when treated with ANCA, released proteins that have the ability to ‘instruct’ neighbouring B cells to survive and divide. If this were to occur in inflamed tissue it would mean that activated neutrophils would be able to promote B cell activation and antibody production which would then ultimately prolong unwanted inflammation. The work so far provides an interesting insight into how these powerful cells may modulate each other’s behaviour in disease. We next intend to investigate the importance of these proteins in disease by looking to see if we can detect high levels of these proteins in serum from patients with ANCA associated vasculitis and whether its presence correlates with disease severity. Proteins that have the ability to modulate B cell behaviour are currently seen as exciting and novel drug targets for the treatment of a number of autoimmune diseases. Although the research here is preliminary in nature it suggests that these proteins may also be a useful target for the treatment of ANCA associated vasculitis.

#### **All ANCA are equal but some ANCA are more equal than others**

If we are to read current research reports on the actions of ANCA it would suggest that all ANCA, irrespective of the patient it once came from, do pretty much the same thing in all of our experiments. However, we know from our results in the lab that this is not the case; some ANCAs activate neutrophils readily whereas some do very little. Our experiments are also affected by the donor neutrophils. Some neutrophils are very responsive to ANCA in our experiments whilst others remain un-activated when treated with a number of different ANCA. In future research we are to investigate the key characteristics that make an ANCA reactive and make neutrophils responsive to ANCA. These are very big questions and require large and complex experiments.

There are many things we can study to try and discern differences between both ANCA and our neutrophils. For example for antibodies we aim to study differences in antibody structure and composition and for neutrophils, the expression of key molecules and differences in gene expression. We are also hoping to focus our attentions on studying patient neutrophils by looking in tandem at patient neutrophil responses to their own ANCA and ANCA from other patients. The ANCA associated vasculitides can take on a number of forms with different associated symptoms. This is something we need to remember when we are researching the mechanisms of the disease. In some ways the results we see in the lab may mirror the differences seen in the clinic between types of ANCA associated vasculitis. A clearer understanding of the results we see in the lab may enable us to predict more accurately the nature of disease in patients and help personalise effective therapy.

I would like to take this opportunity to thank the Stuart Strange Vasculitis Trust for all their continued support of projects here in Birmingham. It was lovely to see you all again at the AGM a few months ago. With your help we can learn more about the mechanisms of this inflammatory disease and possibly learn how to manage it more successfully.

Best Wishes, *Neil*

**In the next issue there will be a contribution from Dr Lorraine Harper on “ANCA Associated Vasculitis: Genes or Environment? Or a little bit of both?”**

## MONOCLONAL ANTIBODY NO BETTER THAN STANDARD TREATMENT

*This is a review of two articles published in the New England Journal of Medicine, 2010.*

The monoclonal antibody Rituximab is no better than intravenous cyclophosphamide for treating ANCA vasculitis, the results of two clinical studies published this summer show.

But Rituximab may be better for managing relapsing disease, according to one of the studies. And an editorial printed in the same journal as the studies said: "The practical implications of these two studies are substantial. Rituximab might be considered as an option for first-line therapy for induction of remission of ANCA-associated disease."

Researchers had hoped that Rituximab, which has led to remission rates of 80% to 90% in patients with difficult to treat ANCA-associated vasculitis, might be safer than cyclo-phosphamide, which is associated with serious adverse events.

In the **RITUXIVAS ([Randomized Trial of Rituximab Versus Cyclophosphamide for ANCA-Associated Vasculitis])** trial, led by Dr Rachel Jones from Addenbrooke's, 44 patients with newly diagnosed vasculitis and renal involvement were given either standard steroid therapy and either Rituximab for four weeks and two pulses of cyclophosphamide, or three to six months of intravenous cyclophosphamide followed by azathioprine. The second group were the control group.

Twenty five patients in the Rituximab group (76%) and nine patients in the control group (82%) had a sustained remission, but the difference was not statistically significant; this means the difference between the two groups may have been caused by chance. There was no statistical difference between the number of patients experiencing serious side effects because of treatment; 14 (42%) patients in the Rituximab group and four (36%) patients in the control group.

The researchers conclude: "A Rituximab-based regimen was not superior to standard intravenous cyclophosphamide for severe ANCA-associated vasculitis. Sustained-remission rates were high in both groups, and the Rituximab-based regimen was not associated with reductions in early severe adverse events." But they note that the study was small, they only followed-up patients for a year,

and the study did not determine the value of repeated use of Rituximab to maintain remission.

The other study, **RAVE-ITN (Rituximab for ANCA-Associated Vasculitis-Immune Tolerance Network Research Group)**, led by Dr John Stone, from Massachusetts General Hospital, was a bigger study of 197 ANCA-positive patients with either Wegener's granulomatosis or microscopic polyangiitis.

The patients, who were all equally ill, were split into two groups; around half were given Rituximab once a week for four weeks and the other group were given daily cyclo-phosphamide; this group was the control. In both groups the use of steroids was tapered down.

The researchers were investigating if the treatments could push the disease into remission without prednisone use at six months. At the end of the study in the Rituximab group 63 patients (64%) and in the control group 52 patients (53%) were in remission. The results led the researchers to believe that Rituximab may be better than cyclo-phosphamide for patients with relapsing disease. For patients with major renal disease or alveolar haemorrhage, Rituximab was as effective as cyclophosphamide and patients experienced the same level of side effects in both groups.

The researchers said the limitations of the RAVE study were that it was not possible to draw conclusions for patients with limited Wegener's granulomatosis or those who are ANCA-negative, the study's limited duration of follow-up, and the fact the study did not look at repeated use of Rituximab.

*Rituximab is more commonly used to treat a range of blood cancers. Monoclonal antibodies recognise certain proteins found on the surface of certain cells. Once recognised the antibody locks onto the protein. In cancer treatments this locking on may then trigger the body's immune system to attack the cancer cells and can sometimes cause the cells to destroy themselves. Rituximab locks onto CD20, a protein found on the surface of B-cell lymphocytes, one of the white blood cells.*

*This review was written by Maya Anaokar*



# VASCULITIS UK (SSVT)

## Questionnaire



**In order to help the Trustees plan the future direction of *your* Trust we would welcome feedback from Vasculitis Sufferers/Carers**

**\*\* Complete the questionnaire and return it by 31st October 2010 \*\*  
to be entered into the draw to win £25 M&S vouchers**

**Name:** ..... **Date** .....

**E-mail:** ..... Please print clearly

**Tel No.** .....

**Hospital where treated:** .....

**Type of Vasculitis:** .....

• **Your Treatment:** Please rate your   
**diagnosis**   
**treatment**  
by the medical profession within the range of 1 to 10, with 1 being very dissatisfied and  
10 being extremely satisfied.

• Do you have access to the Internet?

• Would you prefer to receive your Newsletter electronically?

• Would you like to receive updates via e-mail?

• **Your Opinions:**  
Please prioritise 1 to 5 from the following work areas for the Committee/  
Trustees - 1 is your lowest priority, 5 is your highest:

1. Update and extend the Website.

2. Develop Facebook/Twitter and other communication channels.

3. Reprint Vasculitis leaflets and produce new ones.

4. Recruit new members.

5. Work with the medical profession/rare disease organisations  
towards quicker diagnosis and better treatment

• Please nominate any other area(s) that you would like your Committee to consider:

.....

Questionnaire continued from over:

- National Fundraising Raffle (see notice below)

Would you be willing/able to donate a prize, eg timeshare, villa week, cash, shopping tokens, theatre tickets etc .

YES / NO

- Membership Fees

Do you think it would be a good idea for Members to pay a small annual fee for Membership of Vasculitis UK (SSVT) eg £10

YES / NO

- Do you prefer to keep the present donation system?

YES / NO

- Newsletter

Would you prefer to receive a colour copy of the Newsletter, even though this will involve increased printing costs?

YES / NO

- Are you a Member?

YES / NO

With many thanks. Your answers will help us to plan the future direction of *your* Trust. All questionnaires received by 31st October will be entered into our prize draw to be held on 6th November 2010. Winners will be notified by e-mail or phone.

Please return this questionnaire to Paul either electronically or by post. Your input is very important to us. Should you have any other views about the future direction of your Trust, please communicate directly with John Mills (Chairman) at any time.

*With kind regards, Paul*

Paul Bingham, Trustee

☎ 01737 813389

💻 paul.m.bingham@btinternet.com

**\*\*\* COMING SOON – VASCULITIS UK (SSVT) SPRING RAFFLE \*\*\***

Please help us to raise essential funds to enable Vasculitis UK (SSVT) to continue to support important vasculitis research.

We are hoping to hold a Spring Raffle, to be drawn at the 2011 AGM. Tickets will be sent out to Members in January 2011. You could win yourself a prize and help to solve some of the mysteries of vasculitis. So please be as generous as you can and make the Raffle a success.

To keep costs down we are hoping that the prizes will be donated. Perhaps you have something you could offer as a prize – use of a holiday home, a timeshare you don't always use, theatre tickets, money, shop vouchers, Apple i-phone etc. Unfortunately we can't accept heavy articles. *If you can help please contact: Paul Bingham, Trustee*

☎ 01737 813389

💻 paul.m.bingham@btinternet.com

## DONATING TO THE VASCULITIS TRUST

You will read elsewhere in this newsletter, about the many people who 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 five years, the Trust has put over £125,000 into vasculitis research projects at Birmingham University. These usually take place over 2-3 years and require a commitment to support the project for the full period. So we need to know that there are sufficient funds available before considering supporting any future research projects. The Trust's reserves are now exhausted so we cannot contemplate starting any new projects until they have been rebuilt.

The Vasculitis Trust (SSVT) 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 form overleaf. 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 on both sides. This will effectively increase the value of your donation by 20% or more.

-----  
**Please note, if we are to obtain tax relief on your donation it is essential that you complete BOTH sides of this Gift Aid form, to include full details requested.**

### NOTES ON GIFT AID

Please send the **whole** form to SSVT Hon Secretary, Susan Mills, West Bank House, Winster, Matlock, DE4 2DQ.

Title ..... Forenames ..... Surname .....

Home address .....

Postcode .....

Please notify the Trust if (a) you want to cancel this declaration (b) you change your name or address (c) you no longer pay sufficient income or Capital Gains Tax. If you pay tax at Higher Rate, you may claim further tax relief in your Self Assessment return. If you are unsure if your

**DONATION TO VASCULITIS UK (SSVT)**

I wish to donate the sum of £ ..... to Vasculitis UK (SSVT)  
 (Please make cheques payable to "SSVT" and send to Susan Mills, West Bank House, Winster, Matlock. DE4 2DQ)

**OR** I would like to make a regular payment to Vasculitis UK., as shown below:-  
 (please fill in this form and send it to Susan Mills, Secretary, Vasculitis UK, West Bank House, Winster, Matlock, DE4 2DQ)

**Instructions to your Bank or Building Society to pay by Standing Order.**

Name & full postal address of your Bank or Building Society To: The Manager (Bank or Building Society) _____ Address _____ _____ Postcode	Name(s) of Account Holder(s) _____ Your Branch Sort Code <table border="1" style="width:100%; height: 20px;"> <tr> <td style="width:33%;"></td> <td style="width:33%;"></td> <td style="width:33%;"></td> </tr> </table> Your Bank/ Building Society Account Number <table border="1" style="width:100%; height: 20px;"> <tr> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> <td style="width:12.5%;"></td> </tr> </table>											

Please make the following payments to the account of The Stuart Strange Vasculitis Trust as shown below:-

Please pay	Lloyds TSB	Long Causeway, Peterborough	30 - 96 - 60
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For credit of	Stuart Strange Vasculitis Trust	A/c No. 0 4 0 4 9 9 9	Ref.
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	AMOUNT	AMOUNT IN WORDS
The sum of	£	

	Date of first payment		Please select how often (circle clearly)
Commencing On		And thereafter every	Month / Quarter / Year

And debit my/our account accordingly until further notice in writing.

Signed ..... Date .....

**Gift Aid : Stuart Strange Vasculitis Trust** (Reg Charity No. 1019983)

I am a UK taxpayer and would like to claim Gift Aid tax relief on my donation to the Stuart Strange Vasculitis Trust (Vasculitis UK). *Please see conditions overleaf.* I wish this to apply to:- (Please Tick)

- ..... The enclosed donation of £.....
- ..... All donations I make today and in the future until I give further notice.
- ..... All donations I have made in the past six years and from today until I notify you otherwise.

**You Must ENTER YOUR NAME AND ADDRESS ON THE REVERSE OF THIS FORM**

Signed ..... Date .....



## MORE HELP TO LOSE THOSE EXTRA PRED POUNDS

*As originally recommended by Sylvia Lennon*

1. Decide on a sensible eating regime (no fad starvation diets allowed)
2. Exercise every day (if you are able) even if it's only to walk round the block
3. Co-opt a family member or friend to join in so you can compare notes
4. Keep a weekly record of your weight loss (and don't cheat)
5. Set a realistic weekly weight loss target – say 1 or 2 pounds
6. Set a target date for the duration of the programme – eg 20 weeks
7. Weigh yourself only once a week – same day, same time, same scales
8. An occasional treat is essential to help you keep focused

## BLOOD TEST MONITORING

Jack McMenamin has told us about the “Disease-modifying anti-rheumatic drugs (DMARD) and Shared-care” booklets issued to vasculitis patients attending the Rheumatology Department at Milton Keynes Hospital. A number of other hospitals also have a similar system. DMARDS like Azathioprine, Methotrexate, Rituximab and others are used to dampen down the activity of cells in the immune system.

Jack was diagnosed with Wegener's in 2005 and has taken Azathioprine for 5 years. He uses the booklet to record the results of the blood tests, initially every month, now three monthly. This allows both the Rheumatologist and the patient to monitor any changes in the blood.

For those vasculitis patients who are unaware of the **Normal Ranges** for blood monitoring these are reproduced below from Jack's Shared-Care Booklet:

Hb: <i>Male</i>	13.5-18 g/dl	ESR: ( <i>under 50</i> )	<15 mm/hr
<i>Female</i>	11.5-16.5 g/dl	( <i>over 50</i> )	<i>Male</i> <20 <i>Female</i> <30
WBC:	4-11	CRP:	0.6 mg/l
Platelets:	150-400	Creatinine: <i>Adult Male</i>	0.5-1.1 mg/dl
Alk. Phos:	30-114 iu/l	<i>Adult Female</i>	0.6-1.2 mg/dl
AST: <i>Male</i>	16-50		
<i>Female</i>	12-34		

### Glossary of terms:

Hb = Haemoglobin.

WBC = White blood count.

Alk. Phos = Alkaline phosphatase.

AST = Aspartate aminotransferase.

ESR = Erythrocyte sedimentation test.

CRP = C-Reactive protein.

g/dl = grams per decilitre.

## METHOTREXATE BOOKLET

A very informative booklet on *Methotrexate treatment* is currently available from:

<http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=60033&type=full&servicetype=Attachment>

The booklet contains information on pre-treatment and has a patient-held blood monitoring and dosage record book. The booklet is already available to patients attending Addenbrookes. If you are unable to download the pdf document please e-mail the Editor who will be happy to send you an e-mailed copy. The Trust will endeavour to obtain copies of the booklet should any member not have internet access.

## **MONEY MATTERS BY ANDY BONE (SSVT TREASURER)**

### **Financial Year Report**

The 2009-10 audited accounts saw the Trust record a loss of £29,073.52 - Total Income @ £41,342.50 and Total Expenditure @ £70,416.02. The reason for this was due to the "Research Grants" amount of £61,511.00 being paid in full. The day-to-day running costs including newsletters, stationery and postage and website accounted for the remaining amount.

On the income side, the two "Donation" categories increased - Gift Aid £11,479.50 (£7,216.78 in 08/09) and Other £20,379.78 (£9,977.68 in 08/09). As a result of the Gift Aid donations in 2008/09 the Trust were able to reclaim the sum of £2,143.54.

If you require a copy of these accounts then please contact Andy (Contact details on page 24). A copy will be placed on our website shortly.

The Trust would like to thank outgoing Treasurer Richard Harris for his hard work in this area.

### **Closure of the William Godfrey Vasculitis Patient Support Group**

It is with great sadness the Trust was informed of the closure of the William Godfrey Vasculitis Patient Support Group. This group has been a lifeline for many people in the Essex area and beyond, with their information packages and meetings. Many thanks must go to all the people who have been a part of this.

The Trust would like to thank Aidan & Tina Dorr and Jill Morris, the three remaining Trustees of WGVPSG, who have kindly donated all of their funds to the Vasculitis UK (Stuart Strange Vasculitis Trust). The total amount is £4,924.01. The process has taken time and effort by the three Trustees in ensuring the amount has been transferred.

## **PARACHUTE FOR FREE! and raise money for Vasculitis UK**



If you've ever wanted to do a parachute jump here is your chance. "Skyline Professional Events Organisers" gives volunteers the opportunity to make a fundraising parachute jump and raise money for Vasculitis UK (SSVT).

There are three types of jump available – an "Accelerated FreeFall" where you can experience the thrill of skydiving solo from up to 12,000 feet, a "Tandem Skydive" from 10,000 feet attached to a professional instructor and a "Static Line" jump which is performed solo from up to 3,000 feet – and you can jump from any one of over twenty British Parachute Association approved airfields across the UK. No experience is necessary as all training is given and if you raise from £360 (depending on the type of jump you choose) you will receive your jump free.

So, if you would like to make one of these thrilling skydives please give me a ring or e-mail and I'll send you a full information pack and everything you need to take part in the "experience of a lifetime".

*John*



## ?? NEW! FREE, SAFE AND PAINLESS FUNDRAISING ??

Every Vasculitis UK (SSVT) Member who uses the Internet can **safely, painlessly, and at no cost to themselves**, 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 FOR VASCULITIS UK (SSVT) with:**

**easyfundraising**  
.org.uk

“**easyfundraising**” is the easiest way to help raise money for Vasculitis UK (SSVT). If you already shop online with retailers such as Amazon Tesco, Argos, John Lewis, M&S, Comet, iTunes, eBay, HMV or any of more than 2000 major retailers, then please sign up, for free, to raise money while you shop!

### **So how does it work?**

- First, go to:  
**www.easyfundraising.org.uk/vasculitisuk**
- Sign up.
- Bookmark the site. Use the links on the site to take you to the retailer you have chosen.
- You shop and order directly with the retailer, as you would do normally.
- It's the retailer you pay not "easyfundraising". “easyfundraising do not have access to your credit card details.

A small percentage of whatever you spend with the retailer comes directly to the Trust at no extra cost to yourself. Just Bookmark and use the site every time you shop. *Simples!*

**How much can you raise for Vasculitis UK (SSVT)?**

This depends on where you shop, but can range from £2 if you spend £100 with WH Smith to £5 with M&S.

You'll also get access to exclusive discounts and voucher codes. Our “easyfundraising” members are growing, but we need your help to keep the donations coming in. Please sign up at: **http://www.easyfundraising.org.uk/vasculitisuk** and make a difference .... *simply by shopping.*

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

**easysearch**  
.org.uk search

Instead of using engines such as Google, you can now help to raise money for Vasculitis UK (SSVT) by using “**easysearch**”. This search engine combines the results of most of the usual search engines, so you will always find what you are looking for.

- Go to: **http://vasculitisuk.easysearch.org.uk**
- Bookmark the site
- Use this search engine instead of your usual one.

EVERY time you search, half a penny is raised for the Trust. *Not a lot, but every little helps !!* Searching just 15 times a day can raise around £25 a year for us. Next time you need to find something online, please use: “**easysearch**” and raise money for Vasculitis UK (SSVT). *You know it makes sense.*

**Please help us increase the amount received. The total for April-September = £60.00.**

## ?? MORE WAYS TO RAISE FUNDS FOR THE TRUST ??

The income for Vasculitis UK (SSVT) comes entirely from voluntary donations, bequests and fundraising activities. Most of this money goes towards sponsoring clinical research into the causes of and treatments for vasculitic diseases. In the past five years, the Trust has paid £125,000 for Vasculitis Research Grants and Research Travel Bursaries.

**You will find a Donation form on pages 13/14 of this issue.**

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



Vasculitis UK (SSVT) is a member of the “JustGiving” scheme ([www.justgiving.com/ssvt](http://www.justgiving.com/ssvt)). Please visit the site. Once there just scroll down to find Fundraisers who are raising money for the Trust. Monies donated come to the Trust.

*If you are going to hold an event you can open your own page quite easily.*

Below are some of the valiant volunteers who have recently expended, or will be expending, their energy to support Vasculitis UK (SSVT). You will find some on the “JustGiving” site:

## OUR FANTASTIC FUNDRAISERS

**Holly Hampshire:** Holly (one of your Trustees) organised a “Swishing Party” in April 2010 where, with the help of family and friends she raised **£700** for the Trust. Great fun was had by all, and everyone came away with at least one nice new (to them at least) thing.



**Remembering Mary.** Jayne Coulson organised the **Vasculitis UK Hadleigh Country Park Sponsored Walk on 12th June 2010**. Sadly, Jayne’s Mum, Mary, died from Wegener’s last year after a 17 year battle with vasculitis. Jayne has so far contributed **£1500+** to the Trust in memory of her Mum. The photo (left) shows Dad (Barry), Jayne and Mary’s parents.



Mary Coulson  
1946–2009

**John Potjewyd:** Bath Sky Ride on 25th July 2010 - John rode in the 5 mile Bath Sky Ride. He used the event to raise awareness of vasculitis and to raise funds for the Trust. John’s friend has Wegener’s. So far John has raised **£185**.



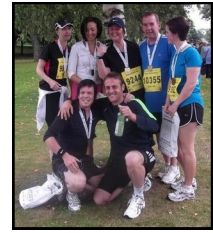
**Sue Bowen Gray:** Colourthon Sponsored Walk on 30th July 2010. Sue walked the 13 miles with “Ann’s angels” Jess Bowen and Sarah Rowland, and raised **£324** for the Trust. Sue’s sister Ann Barker was diagnosed with cerebral vasculitis in 2009. Sue’s daughter (Jess, aged 14) also raised £80 for the Trust from a sponsored car wash. Pictured are Jess, Sarah and Sue.

**Ms S Ross:** Raised **£95** for Vasculitis UK from her Open Garden Day.





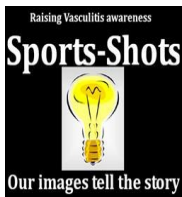
**Vivienne Kerr: 10K Great Scottish Run on 5th September 2010** - Vivienne was diagnosed with WG in October 2009. Her husband and four friends ran along with Vivienne to offer support. One of her friends who works offshore ran the 10k on a treadmill in a boat in Angola as he couldn't get home in time. Vivienne participated to prove to herself that she could do it, even with Wegener's, and to raise awareness of WG. So far Vivienne has raised **£2506**.



**Kerry-Anne Orakwusi and Lizzie Deane: Royal Park Half Marathon, London on 10th October 2010.** Kerry-Anne's Mum has WG. Kerry and her friend Lizzie have decided to walk the Half Marathon rather than run. To date Kerry-Anne and Lizzie have raised **£801** for the Trust. The photograph shows Kerry (left), Lizzie (Right)

**Craig Hill** will be running the **Cardiff Half Marathon on 17th October 2010.** Craig's wife Gwenllian, has Wegener's. Craig is running to raise funds for Vasculitis UK (SSVT)

**Francesca Saville:** Francesca will be taking part in the **Brighton Marathon on 10th April 2011.** Francesca's sister, Alexandra, has WG, diagnosed 4 years ago (aged 19). Francesca is hoping to raise awareness of vasculitis and also to raised money for the Trust. Todate Francesca has raised **£70**



**Andy Bone:** Vasculitis UK Treasurer, 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 on his "Sports-Shots" Facebook site: ([www.facebook.com/sportsshots](http://www.facebook.com/sportsshots)). Please visit Andy's site and JustGiving page.

#### 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.

**INCREASE IN DONATIONS:** We are pleased to report that sponsorship money has increased for the volunteers mentioned in the Spring issue - **Neville Homer, Tony & Michael Norris, Caroline Speers, Guy Hayes** and **Annie McGregor**. The combined total from these six wonderful volunteers now stands at over **£5000**.

#### 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 a photograph from the event.*

**Deadline for next issue - 28th February 2011**

*Thank you*

**To all our gallant volunteers and to their very generous sponsors. 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**

## IN MEMORIAM



Many of us with vasculitic disease are past the first flush or two of youth and may have been suffering with vasculitis and its consequences for many years, so it is very sad, but not altogether surprising that we do get a few deaths to report each year.

Very often, donations or funeral collections are made and given to the Trust in memory of a particular individual. Most, but not all of those listed below actually suffered from vasculitis themselves, but probably a family member did. We are extremely grateful for these generous donations and other bequests, which go to help the activities of the Trust and especially our research projects.

Donations totalling £464 were received in memory of **Margaret, Lady Allen**.

A donation of £500 was received in memory of **Jean Wenborn**.

We received £855 in memory of **Ron Smith**.

Donations totalling £140 were made in memory of **Ron Archer**.

Numerous verbal tributes were made in memory of **Graham Maslen** of Caerphilly as well as donations totalling £400.

A further £120 was received in memory of **Gordon Mott**, formerly of Norfolk.

£117.50 was received in memory of **Jean Bartram**.

Donations in memory of **Sadie Smith**, who died at age 82, totalled £360.

A total of £724 was donated in memory of **Ron Arrowsmith**.

**Dr John Hartley** of Truro donated £15 in memory of his father who had CSS.

**George Sutton** passed away in June. His family have kindly donated £1037 in his memory.

## GENETIC ALLIANCE UK - AN EXCITING PROJECT

Genetic Alliance UK is an organisation dedicated to investigating genetically related diseases and supporting those suffering from such diseases. Most rare diseases have a genetic element behind them.

They are hoping to develop "Road Maps" for different diseases, identifying how the diseases can best be diagnosed, how they are best treated, how they affect those with the disease and their families and what are the special needs of those with the disease. This information is intended to help patients, healthcare professionals and social care professional to understand more about the disease and how to deal with it and its consequences.

They are planning an initial pilot project involving just ten groups representing and supporting those with particular rare diseases. Vasculitis UK was fortunate to be selected as one of those ten who will take part in the pilot project, out of 22 applicants. The project is expected to take three years. We will keep members informed on progress with this exciting project.

We believe that it would be helpful to produce a booklet on the 100 most frequently asked questions

## 100 MOST FREQUENTLY ASKED QUESTIONS

### *WE NEED YOUR HELP*

relating to vasculitis. It is hoped that this might be particularly useful to the newly diagnosed patient.

Please submit any questions you would have liked answered when you were first diagnosed, or on any vasculitis issues since diagnosis. We will then do the rest. Please send your questions to John.

## REGIONAL SUPPORT GROUPS

### West Country Vasculitis Support Group

This July saw the West Country VSG hold their first ever Summer BBQ. The event gave an opportunity to spend a sociable afternoon with others with vasculitis and their partners. Eighteen people attended and the event was a great success - despite the rain!

The group's next event is a talk on vasculitis by Dr Nick Viner, consultant rheumatologist at Torbay hospital, the talk will start at 6.00pm on Tuesday, 5<sup>th</sup> October – for full details please contact Charlotte Stoner on 01626 872420 or email [the.stoners@talktalk.net](mailto:the.stoners@talktalk.net).

### Surrey Vasculitis Support Group

Led by Anita and Graham Laycock

Anita & Graham held the Summer meeting of 2010 at their home in Bookham on the 21<sup>st</sup> April. There were many new members attending together with familiar faces. Altogether 25 people enjoyed a delicious buffet lunch in an informal friendly setting.

Paul Bingham, our Vasculitis UK Trustee, came along with his wife Maggie. He carried out his own brief survey about the Trust.

Victoria Lown, a Board Member of the US Vasculitis Foundation, came along with her baby Alexander now 5 months old together with her mum and sister. Victoria has recently returned from the American 3 day symposium in Los Angeles and talked to members about her trip.



**The Summer meeting at Bookham**  
Anita centre, middle row. Graham back row, far right. Victoria front row, far right

They were also fortunate in having Sue Ashdown, who leads the Oxford Vasculitis Support Group, attend. Also thank you to Anita's mum Betty who assisted her with the catering on the day.

The Winter meeting is scheduled for Sunday, 2<sup>nd</sup> January 2011 with the venue to be confirmed. The Surrey Group have now outgrown meeting in Anita & Graham's house and they are now looking at a function room in a local hotel. This meeting is being organised by Victoria Lown and if you would like further details please contact her on 01372 727833 or email [vlownd@vasculitisfoundation.org](mailto:vlownd@vasculitisfoundation.org)

The Surrey Group featured in the July/August edition of the US Vasculitis Foundation Newsletter and in their local Surrey Advertiser papers. Christine Sharp, Anita and Graham also attended April Turner's (Victoria's mum) art exhibition during Vasculitis Awareness Week. This raised £200 and April even had the Mayoress of Epsom and Ewell Council pull out the winning tickets!

Anita and Graham are happy to visit anyone in their own home for a personal one-to-one meeting. If you would like to join the Surrey Group, contact Anita on 01372 750667 or at 53 Dowlans Road, Bookham, Surrey, KT23 4LF or email: [anita.laycock@dsl.pipex.com](mailto:anita.laycock@dsl.pipex.com)

### Maggie Jennings

It is with great sadness that we report that Maggie (leader of the West Sussex VSG) passed away in September 2010 at the age of 80. Our condolences are sent to Maggie's family and friends. She will be



## UK SUPPORT GROUP CONTACTS



### **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

### **Cambridge VSG**

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

### **Cheshire** (*Contact person: this is **not** a group*)

Sue 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

### **Oxfordshire VSG**

Sue Ashdown 01295-816841 oxonvsg@hotmail.com

### **South Wales VSG** (*Contact person: this is not yet a group*)

Jackie Thomas 029-2089-2403 creigiau20@yahoo.co.uk

### **Surrey VSG**

Anita Laycock 01372-750667 anita.laycock@dsl.pipex.com

### **West Midlands VSG (VSGWM)**

Margaret Gentle 0121-243-5621 mgvsgwm@blueyonder.co.uk

### **West Country VSG**

Kathleen Rawlinson 01392-832231 krawlinson@waitrose.com

### **West Sussex VSG**

Position vacant

## SOME USEFUL WEB SITES

**Jackie Sullivan** is hoping to set up a Support Group in the **Bristol area**. If you are Interested please contact Jackie direct at: [morwenna29@yahoo.co.uk](mailto:morwenna29@yahoo.co.uk)

### **Facebook**

Look for "Vasculitis-UK" on Facebook. A very lively site, mainly for younger people with vasculitis. Currently there are over 300 members.

### **Voice-4-Vasculitis**

A very informative UK based internet discussion group. You can join at: <http://sites.google.com/site/voice4vasculitis/>

## YOUNG PEOPLE WITH VASCULITIS

We have been asked whether there is a UK support group catering for young patients. Unfortunately we don't. However, the Vasculitis UK (SSVT) Facebook has a number of young vasculitis patients who will be happy to exchanged information with other young people. See above for Web details.

If you are aware of a UK support group specifically for younger vasculitis patients, please let us know.

## TOPICS FOR FUTURE NEWSLETTERS

As we have a packed Newsletter this time we were unable to add some suggested topics from the last issue. Items for the next Newsletter include:

- Dr Lorraine Harper's report on genetic research at Birmingham - "ANCA Associated Vasculitis: Genes or Environment? Or a little bit of both"
- Disability Living Allowance
- Exemption from Prescription Charges
- More on the Rare Diseases project
- Letters to the Editor (please submit your letters)
- *Please contact the Editor if you wish to suggest other topics, or submit an article.*

*Deadline for the Spring issue - 28th February 2011*

## TRAVEL INSURANCE

**Freedom Insurance** of Cambridge are specialists in finding travel insurance for people living with pre-existing medical conditions. Several members have commented very favourably on the service they received. Freedom also give a small "commission" for each policy they transact for Trust members. It is important that you mention "Stuart Strange Vasculitis Trust" when taking out a policy with Freedom.

Freedom Insurance Services, Richmond House, 16-20 Regent Street,  
Cambridge. CB2 1DB. [www.freedominsure.co.uk](http://www.freedominsure.co.uk)  
Tel. 01223-454-290 email: [information@freedominsure.co.uk](mailto:information@freedominsure.co.uk)

## NEWSLETTER/JOURNAL

I hope that you have enjoyed this Autumn edition of the Newsletter that you found the content interesting and informative, and that you approve the "new look". If you wish to comment on any aspect of this issue please write/e-mail. Your opinions are important.

We aim to provide Members with the best publication we can - but this has to be within the bounds of available finance. Your Committee is considering further changes - so please watch this space.

Don't forget that you can receive a colour copy of the Newsletter electronically. This would help us to reduce our costs particularly for postage. If you would prefer this option, please e-mail **me** ([pat.fearnside@btinternet.com](mailto:pat.fearnside@btinternet.com)). Please include your name, postal address and e-mail address.

When you have finished with your Newsletter perhaps you could consider taking it to your hospital waiting room next time you visit. It could be one way to increase awareness of vasculitis, and may bring the Trust to the attention of other vasculitis patients.

*Pat - Editor, "Ramfeezled"*



# Vasculitis UK

(Stuart Strange Vasculitis Trust)



Life President: Lillian Strange

## Registered Charity No. 1019983

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

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

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

- ◆ Wegener's Granulomatosis
- ◆ Churg-Strauss Syndrome
- ◆ Polyarteritis Nodosa
- ◆ Microscopic Polyangiitis
- ◆ Henoch Schonlein Purpura
- ◆ Giant Cell Arteritis
- ◆ Temporal Arteritis
- ◆ Other Vasculitis Conditions

## Aims of the Trust

- 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 vasculitis diseases.
- To encourage the development of centres of excellence in the treatment of vasculitis in the UK.

*To help us to keep our databases up-to-date and reduce our costs:*

*\* Please inform **John** if you no longer wish to receive our Newsletter (in any form), or*

*\* Please inform **Pat** if you would prefer to receive the Newsletter, as a colour copy, by e-mail.*

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