VASCULITIS UK

Newsletter & Journal

Spring 2012
Issue No. 43

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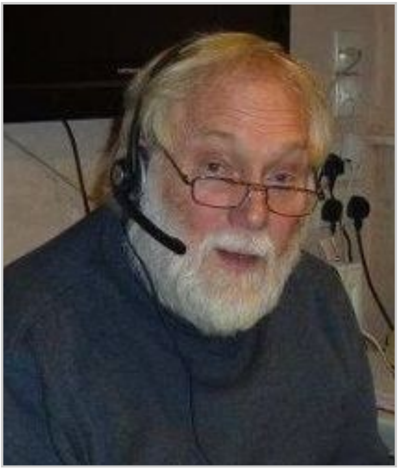


Chairman John taking part in a recent webinar

I hope you will agree that this edition of the Vasculitis UK "Newsletter and Journal" is even better than before in terms of both presentation and content. Editor Pat tries to ensure that there is a balanced mix of interesting and informative articles, not too frivolous and not too stuffy.

The newsletter is our showcase and it is well-respected for its content by doctors, healthcare workers and those in authority. Copies are often left by members in hospital waiting rooms so they are found by others seeking information about their illness. For this reason, we think that the printed copy sent by post is still the best method. For a small charity, producing a newsletter of this quality and mailing it out is expensive, and postal charges are about to rise. It is sent to all our members, many hospitals and many consultants who treat vasculitis patients. In its internet format, it is read around the world.

It costs about £5 to send each member a newsletter twice yearly. We do not charge for membership. So if you **don't** want to receive the newsletter, please do let us know. If you **do** like reading it and if you can afford to, please send a donation of at least £5 a year to Vasculitis UK to cover the cost. Please remember that after our admin costs have been covered, all extra income goes towards research funding.

Route Map and Website
Vasculitis UK is entering a very exciting phase. The Route Map for Vasculitis (see page 4) is to be published in May, to coincide with Vasculitis Awareness Month. This represents almost two years' work, mainly by Pat Fearnside. The content of the Route Map will be used as the basic material for the new Vasculitis UK website, which is also due to go "live" in May. This too will have involved many hours of work when it is launched, but it will not be complete.

The beauty of a website, compared to a book, is that it is not constrained by numbers of pages or cost of printing. It can have bits added and taken away or be updated at any time.

It is a "living" document and the content of the new website will be constantly evolving, so it is never going to be really "complete".

Research
At present Vasculitis UK is not giving financial support to any research projects. Most projects require funding over two or three years. As our income comes entirely from donations, it is unpredictable from year to year, so we have to accumulate sufficient funds to ensure we can cover the entire project. We are now registered with the NIHR (National Institute for Health Research) and will soon be members of AMRC (Association of Medical Research Charities). This will put our research funding on a much more formal and structured basis and allow us to be co-funders with other organisations.

Oh No! Not another new logo!!
You were introduced to Vasculitis UK's new logo in the Autumn edition. It looked very pretty and stylish with its multi-colours, but it was impossible or very expensive to use as a logo on a pen or a tee shirt. So it was back to the drawing board and the result is our new "new logo", the "hub". This is made up of many Vs joined together in a circle or wheel, which is symbolic of people with all types of vasculitis joining together in one organisation for mutual support and to fight vasculitis. It is a strong image, which sticks in the mind and can be used as a single colour or in black and white.

On that final note, may I wish you all a very happy and healthy Spring and Summer. The next newsletter will be out in early Autumn.

John Mills

VASCULITIS UK

Contents

Diary Dates

MEETINGS

Polite note: *If you are going to attend please pre-book so the organisers know how many are coming. Please be considerate to the organisers and let them know if, once booked, you are unable to attend. Food ordered has to be paid for!!*

Cambridge VSG Saturday 14th April, 1-4pm, Holiday Inn, Impington (off A14). Dr Rachel Jones (Addenbrook's) will be "Talking about Vasculitis". £7 per person. Full details from Jenny Fulford Brown. jenny.cambsvsg@hotmail.com or call 01223 565967

Lincolnshire VSG The next informal meeting (with coffee and cake) will be held on Sunday 15th April in Digby. All welcome. For further details contact: Pam - 01526 268106 ayla.todd@gmail.com

Yorkshire VSG This meeting will be held in Doncaster on Sunday 22nd April. For full details contact Pat: 01709 583722 pat.fearnside@vasculitis.org.uk

VASCULITIS UK - ANNUAL GENERAL MEETING
The AGM will be held on Sunday 13th May at the Novotel, Long Eaton near Nottingham. See flier for full details.

Surrey VSG The next informal meeting will be held on Sunday 20th May at the home of John & Maggie Bingham. For further details contact Paul: 01737-813389 paul.m.bingham@btinternet.com

Charity Golf Day at Benton Hall (Essex) in aid of incurable autoimmune diseases at Addenbrooke's Hospital. Friday 18th May. £55 per person. To include: refreshments, 18 holes, 3 course meal, trophies and raffle. ***Also*** from 10.30am there will be a **VSG meeting**, also at Bentham Hall. Full details on both events: 07789 113144 jules.essexvsg@googlemail.com

West Country VSG BBQ on Saturday 16 June at 1.00pm in Teignmouth. For further information please contact Charlotte on 01626 872420 the.stoners@talktalk.net.

Oxfordshire VSG The next local group lunch will be held on Sunday 15th July at The Duke of Marlborough Hotel, near Woodstock. For details contact Sue Ashdown. 01295 816841 oxonvsg@hotmail.com

West Midlands (VSGWM) The next meeting will be held on Sunday 14th October 2012 at the Hilton Hotel, Bromsgrove, Birmingham. Further details TBA. For details contact Dave Sambrook davsamuk@yahoo.co.uk

FUNDRAISERS

Janine Emma Brown ran the ING New York Marathon 2011. She is now entering the Virgin London Marathon on 22nd April.

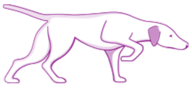
Jamie Flanagan entered the Rome Marathon on 18th March . He will now be entering the BMW Berlin Marathon on 3rd September.

Sarah Freestone along with **Caroline, Karin** and **Jamie** will be entering the Edinburgh Half Marathon on 27th May

Mo McBain VSG leader in Aberdeen will be entering the Balmoral 10K in April. Mo is raising funds for vasculitis research at Aberdeen University.

Francesca Saville & boyfriend Tim will be taking part in the Virgin London Marathon on 22 April 2012

Work and Benefit



The Trust has professional membership of "Work and Benefits" and this enables us to provide members with information to help them claim benefits or to prepare for an appeal.

If you are claiming or appealing about "DLA", "ESA" or "Incapacity Benefit" then contact: Susan Mills—sandjmills@btinternet.com

Alternatively you can obtain your own membership of "Work and Benefits", as an individual member, for a subscription of just under £20 a year: www.benefitsandwork.co.uk

Holly Hampshire - Trustee

The Trust is sorry to report that Holly is resigning as a Trustee, but we are absolutely thrilled with the reason why. Holly, who was diagnosed with WG nine months before her wedding to James in 2009, is having a baby in May.

Holly recently told her story "The Power of Hope" in the magazine "Pick Me Up" which appeared in the edition of 9th February.

Holly's final input as "Roving Reporter" is on page 10. For this she has interviewed her ante natal consultant. Holly's hope is that this will be of interest to all our members, but especially to the many young women who have vasculitis but also hope, one day, to have their own babies.

Discussion groups

Why not consider joining one of the Trust's internet discussion groups? There's "***Health Unlocked***" which is a "private" group where you can set your own levels regarding who is able to view your posts. All posts are relevant to the vasculitis patient. Currently there are over 240 members

To join the Health Unlocked discussion group go to: www.vasculitis-uk.healthunlocked.com and follow the links to "join".

Then there's the ***Vasculitis UK "Facebook"*** site. This is an open group for those who are happy with the Facebook concept. Current there are over 500 members. To join simply go to the Trust's website: www.vasculitis-uk.org.uk and follow the Facebook link.

The "Route Map" Project


Route Map for Vasculitis

After almost 18 months of blood, sweat, and many tears and tantrums, the Route Map for Vasculitis is now complete. The deadline was set for the end of March 2012 and this date was met with some weeks to spare.

The Route Map was commissioned and funded by the Department of Health as part of the "Route Maps for Rare Diseases" initiative, administered by Genetic Alliance (UK). Jessica Burke from GA helped, supported and encouraged the nine charities taking part in the project, who have each prepared their own Route Maps.

Putting together a project like the Route Map was something that the Trust had long wanted to do, but shortage of finance and personnel meant that it remained a pipe dream until the Department of Health stepped in.

"Route Map" seems a strange expression, but in plain English it is really a small (112 page) encyclopaedia of all things vasculitis. Included are individual pages on the actual diseases, and on the treatments and procedures. There is a "living with vasculitis" section which, amongst many other things, gives information on diet, oral hygiene, fertility, prescription charges and government benefits. There's so much in the Route Map that we call it our "Vascupaedia". We have aimed to make it an interesting resource and there are lots of photographs included. We are particularly grateful to our Members for sending photographs which show the effects of their disease or the effects of their treatment.

So, who is the Route Map aimed at? Well, firstly, the patient and their family and friends, to enable them to have all the facts about the conditions and where to obtain help and support (financial and pastoral), all in one document. Our Medical Advisor, Dr Matthew Morgan, has pitched the main thrust of the information on the vasculitides at a level which can be understood by the newly diagnosed patient. So, it isn't intended to be a text book for those who need to know everything about vasculitis — those already exist. However, for the informed and aware patient there are some excellent links to research papers — more than enough to get their teeth into.

As we know, many GPs and other medical professionals (including nurses and medical students) and social service professionals may rarely come into contact with a vasculitis patient. To this end there is an extensive section in the Route Map which contains references to a vast number of research papers published on the vasculitic diseases, which we hope will help raise awareness of vasculitis in these groups of professionals. Finally it is aimed at those doctors undertaking assessments for disability benefits. Many vasculitis patients feel that these doctors, like some GPs, do not understand the problems faced by vasculitis patients because the diseases are rare and because "we look so well".

None of us realised in the beginning exactly what a marathon task this was going to be. Whereas the other charities taking part had only one rare disease to deal with, "vasculitis" is a collective term for 15 or more rare diseases. However, what we did realise was that this would be a golden opportunity for us to raise vasculitis awareness and to ensure that Vasculitis UK, as an organisation, was one to be reckoned with.

What now? The Route Map will be available or all to read, but because of its size and the cost of printing as a complete document, it will mainly be available as an internet based resource for downloading. It also has another purpose. Most of the content of the new Vasculitis UK website, which is due to go "live" any day soon, will have been taken from the Route Map. The Trust will, however, obtain a limited number of printed copies for circulation to specific influential bodies.

Genetic Alliance (UK) will launch all nine Route Maps on 2nd July and they will ensure that adequate publicity is undertaken for this occasion. However, each charity will be able to launch its own Route Maps prior to July. The Vasculitis Route Map will be officially unfurled in May, to coincide with Vasculitis Awareness Month. We are currently working on our own publicity campaign for the Route Map to ensure that vasculitis, the Route Map and the Trust get widely mentioned during the month of May.

If you would like a copy of the Route Map (as an internet PDF document) then please e-mail me at: pat.fearnside@vasculitis.org.uk If there is sufficient demand for them, printed copies might be available to buy.

Finally, I would like to place on record my appreciation of the support, encouragement and input given by Dr Matthew Morgan and Professor Lorraine Harper of Birmingham University Hospital, Trustees of Vasculitis UK, Jessica Burke of Genetic Alliance (UK) and, of course, the Department of Health for their funding.

Pat Fearnside - Editor, Route Map for Vasculitis

Selection of the Route Map content

Vasculitis basics

The vasculitis diseases

Glossary of drugs, procedures and blood test monitoring

Living with vasculitis

Health Service

Government benefits

Children and young people with vasculitis

FAQs

Weblinks

Further reading for medical professionals

Research

Book review

Videos and podcasts

Support Groups

Diagnostic Techniques in Vasculitis - Presentation by Dr David Carruthers (Consultant Rheumatologist Birmingham City Hospital)

Report on the presentation given by Dr David Carruthers to the West Midlands Vasculitis Support Group meeting in October 2011

Dr Carruthers spoke about the various tests for diagnosis and for assessing and monitoring vasculitis disease activity.

Blood tests such as CRP and ESR indicate levels of inflammation. The liver is driven to produce CRP inflammatory protein by pro-inflammatory cytokines. Cytokines are immunomodulating agents in the blood produced by other cells, especially macrophages, such as neutrophils. They can raise or lower the inflammatory response.

ESR (Erythrocyte Sedimentation Rate) indicates the amount of protein in blood serum. Inflammation causes more protein, which makes the blood thicker, more viscous, so the red blood cells take longer to settle out.

WBC – the count of different cells in the blood. Deficiency of red cells indicates anaemia. this can occur when bone marrow activity is depressed by drugs or due to renal disease. White blood cells are mainly Neutrophils, Lymphocytes and Eosinophils.

Neutrophils are the main defenders against infection. They can pass through the blood vessel walls to initiate inflammation in surrounding tissues. Lymphocytes can become plasma cells, which produce antibodies, such as rheumatoid factor, ANCA and ANA.

Eosinophils are more involved in allergic reactions and are raised in Churg Strauss cases (EPGA). They can also cause inflammation in the airways, resulting in narrowing.

Urinary Dipsticks can provide an indication of diabetes but also of blood and protein in the urine. This *may* be an indicator of kidney disease but can have other causes such as urinary tract infection or kidney stones. Monitoring normal kidney function is very important, but it is also used to check whether medication drugs are being excreted properly. Blood from the kidneys produces minute clots in the urine, which are visible under a microscope.

ANCA test determines if the patient's blood serum attaches itself to neutrophils. If it does, it indicates ANCA+ve and *can* indicate the level of disease activity. There are two types, binding to different proteins, cANCA (cytoplasmic) and pANCA (perinuclear). Both types can be present. In Wegener's 90% show cANCA. in Microscopic Polyangiitis (MPA) 70% show pANCA. There are ethnic differences, so Japanese WG patients are more likely to have pANCA.

Imaging *Conventional Xrays* of lungs can show thick walled cavities, possibly due to WG. Capillary vasculitis may also be due to WG and gives a diffuse cotton-wool appearance that can be confused with sarcoidosis.

CT Scans of lungs can show inflammation of bronchi causing narrowing, and can distinguish between current inflammation and scarring from past inflammation. It can demonstrate subglottal stenosis of the windpipe and the "nodes" of polyarteritis nodosa.

MRI Scans: Magnetic Resonance Angiography can show abnormalities in blood vessels without the need to inject dyes into the bloodstream.

Pet Scans can show the level of metabolic activity – an indicator of inflammation.

Ultrasound Scans can show how thick the wall of a blood vessel is and how much its flow is restricted. A national research project, co-ordinated by Dr Rashid Luqmani, is under way to determine the effectiveness of U/S scans in diagnosing Giant Cell/ Temporal arteritis as opposed to the traditional invasive and unreliable biopsy.

Dexa scans for bone density are helpful in establishing if there is osteoporosis but repeat scans are unnecessary.

Biopsy of the kidney is very invasive but can confirm diagnosis and distinguish PAN from other types of vasculitis.

Dr Carruthers concluded his talk by saying that it is essential for physicians to see the whole picture and not to rely just on tests. Also that the very best diagnostic tool is a physician who has seen a lot of cases and treated a lot of cases. Evidence shows that physicians with greater experience produce better outcomes.

Report compiled by John Mills

Correction:

In an item on the Route Map on p12 of the Autumn 2011 Newsletter, Dr Matthew Morgan was referred to as a Vasculitis Registrar. In fact Dr Morgan is an Honorary Consultant Nephrologist, working with Professor Lorraine Harper in running the vasculitis clinic at Birmingham University Hospital. He is also a senior clinical lecturer in Renal Medicine at Birmingham University and has a PhD in immunology.

We apologise unreservedly for having misrepresented Dr Morgan's status.

Why do patients with ANCA Associated Vasculitis Experience Fatigue - Presentation by Dr Andrew McClean

Report on the presentation given by Dr Andrew McClean to the West Midlands Vasculitis Support Group meeting in October 2011

Dr Andrew McClean is Renal Registrar & Research Fellow, at University Hospital, Birmingham.

Dr McClean detailed the comprehensive research study into this subject currently being undertaken at UHB under the guidance of Professor Lorraine Harper. This involves an initial detailed questionnaire then selected patients undergo extensive physical tests, designed in collaboration with sports scientists.

Patients are recruited from those with AAV in remission, those with chronic kidney disease (where fatigue is also a problem) and healthy volunteers as "controls". The groups are carefully matched and balanced in terms of ethnicity, gender and age. The mean age of the vasculitis group is 57. Some early results are shown below.

Survival in AAV is now about 80% after 5 years, but many have permanent damage to organs such as kidneys and lungs. 90% of AAV patients report chronic fatigue, even when in remission. There are three types of fatigue:-

<u>Muscular fatigue</u> - where muscles are weak or tire easily. (There is a theory that this could be due to reduced numbers or activity of mitochondria in the muscles. These tiny particles are responsible for producing energy in the muscles.)

<u>Cardio-vascular fatigue</u> – where fitness levels are reduced.

<u>Central fatigue</u> – due to the effects of vasculitis on the spine and the brain. This is not the same as "all in the mind" – but carries that stigma. Central fatigue can affect motivation, need for sleep and perception of effort. It may also be a side-effect of drugs used in treatment.

Even when AAV is in apparent remission there is evidence of continuing vascular inflammation. There can be muscle wasting and both a reduced or unresponsive blood supply and an impaired motor nerve supply to muscles.

Fatigue affects people differently. Some are fatigued all the time, others wake refreshed but deteriorate as the day goes on. For some it is mental fatigue causing difficulty in concentration. AAV patients generally have poorer concentration. In the research study, concentration and recall are measured using a computer programme.

Inflammation has been shown to be a risk factor in coronary disease, reducing the ability of the heart to pump.

It can also affect the central part of the brain that controls motivation and the perception of exertion, so one feels exhausted even though the muscles, heart and lungs still have reserves. This can also be a side effect of drugs used in treatment.

Those taking part in the research complete a questionnaire to assess their level of anxiety and depression. Most AAV patients show increased anxiety. There may be a link between depression and fatigue. They are also assessed using an exercise bike to determine their current level of fitness. So far this level seems to be very similar to the control group. Perception of effort is assessed by the "Borg" test. Again, this shows little difference between AAV and control groups. Muscle bulk is assessed using a dexa scan; again, so far, little difference has been found, however there is a **significant** difference in muscle strength.

Saliva tests are used periodically to assess the level of cortisol in the blood stream. Cortisol is the body's own steroid, produced in the adrenal gland. Production of cortisol is depressed when prednisolone medication is given and it does not always recover fully when the prednisolone is discontinued. Natural cortisol levels rise and fall as required to cope with physical and mental stress.

In order to assess the effect of Central fatigue, participants are tested for muscle endurance to determine how long they can sustain a muscular contraction. This is then compared to how long a contraction can be maintained using artificial stimulus. Results suggest central fatigue is a significant factor. Muscles are assessed to see if impaired blood supply is a factor, but this does not seem to be so. Some AAV are worse than controls but others are better!

Results so far indicate:-

1) high levels of fatigue in the AAV group, comparable to cancer patients, but this is mainly physical rather than mental fatigue,

2) higher levels of anxiety and depression in the AAV group, maybe due to cytokines in the blood, produced as a result of the vasculitis,

3) the AAV group is less fit and with weaker muscles,

4) there is no evidence that "pushing one's self" can cause a flare.

A further extension of the study is to assess if a structured graded exercise programme, with progressively increasing exercise, can improve the situation.

The research programme is still recruiting volunteers. You must have an AAV type of vasculitis (WG, MPA & some CSS) and be in remission. You must also be able to go to Birmingham for a full day of physical tests.

If you wish to volunteer for the research programme please contact John & Susan Mills – jandsmills@btinternet.com or 'phone 01629-650549.

Report compiled by John Mills

Fatigue: a principal contributor to impaired quality of life in ANCA-associated vasculitis (AAV)

The tiredness people with ANCA-associated vasculitis (AAV) experience is a greater cause of poor physical health than any other side effect of the condition, researchers in Aberdeen have concluded.

Their research will confirm what every person with a vasculitides knows first-hand; that the fatigue caused by vasculitis has far reaching consequences into every day life.

Writing in the journal *Rheumatology*, the researchers say: "Our study suggests that fatigue may be a dominant problem for patients." And they add it is the physical problems people with AAV experience, rather than any mental health issues, which determines reduced quality of life.

The researchers at the University of Aberdeen urge doctors and nurses working with patients with vasculitis to "take time to recognise and evaluate fatigue, a symptom that we have identified to be a principal contributor to impaired health status".

Their study is one of the first to specifically investigate fatigue in ANCA-associated vasculitis. It compared the experiences of patients with confirmed diagnoses of Wegener's granulomatosis, microscopic polyangiitis and Churg–Strauss syndrome to those of patients selected from general practice lists in Aberdeen, free from any form of vasculitis.

People were then asked to score themselves on scales that measure fatigue, depression, and their general health. In total, the scores of 72 patients with some kind of vasculitis were compared to those of 781 controls.

What the researchers found was that there was no difference between mental health scores but the people with vasculitis were two and half times more likely to report low levels of physical health and more likely to report fatigue than the matched controls.

The researchers warn that there are some limits to the study. The scoring tools used to assess depression, fatigue and general health have not been validated in people with AAV and the controls tended to be younger and male, which usually raises the general levels of health reported. They also said that while it was one the largest studies to look at fatigue in vasculitis it was still a small study and they caution against making comparisons between the patient sub-groups of Wegener's granulomatosis, microscopic polyangiitis and Churg–Strauss syndrome.

Finally, they say that a better understanding of the mechanisms of fatigue are needed to support the "new generation of AAV patients where long-term survival is considered the norm and issues related to quality of life take precedence".

Basu N, Jones GT, Fluck N, et al. Fatigue: a principal contributor to impaired quality of life in ANCA-associated vasculitis. Rheumatology (Oxford). 2010;49:1383-90

Review prepared by Maya Anaokar, PhD

Clinical review on the diagnosis and management of ANCA-associated vasculitis (AAV)

The *British Medical Journal* has published a clinical review on the diagnosis and management of ANCA-associated vasculitis (AAV), mentioning **Vasculitis UK** as "a useful resource".

Written for a generalist by clinicians from Leiden University Medical Centre, the Netherlands, Addenbrooke's Hospital, Cambridge, the University of Oxford, and Statens Seruminstitut, Copenhagen, the review provides information on incidence, how patients present, how to diagnose the condition, how to find a specialist and prognosis.

The review points out that vasculitis can present in many different ways but doctors should consider vasculitis in patients with general symptoms and signs of inflammatory disease. There are a number of tests GPs are able to do, including ANCA in a patient with unexplained illness that has lasted more than a few weeks and is associated with a raised erythrocyte sedimentation rate (ESR) or C reactive protein. If the ANCA is positive then GPs are advised to refer the patient to a consultant with experience in vasculitis.

In secondary care, further tests may be necessary such as biopsies of affected organs.

The review notes that in the 1950s, two fifths of AAV patients did not survive the first year after diagnosis. Now the situation is much different and most forms of vasculitis are "a chronic condition prone to relapse throughout life", thanks to modern treatments, which are evolving all the time.

The review outlines the kind of support general practice could offer patients with AAV, especially in relation to flares and the side effects of treatment, and concludes with a small section on causes.

Key points of the generalist

- Consider AAV when inflammatory disease cannot be ascribed to any other disease and inflammation progresses despite antibiotics
- Avoid diagnostic delay to prevent end organ damage, particularly renal disease
- Test for ANCA in patients with chronic destructive upper airway disease, pulmonary nodules, renal and pulmonary inflammatory disease, rapidly progressive glomerulonephritis, skin vasculitis with systemic illness, mononeuritis multiplex, subglottic stenosis of the trachea, and retro-orbital mass

Continued on page 8

Fatigue: a principal contributor to impaired quality of life in ANCA-associated vasculitis — cont. from page 7

- Patients should be managed by a specialist in vasculitides
- Remission is usually induced with high dose glucocorticoids and cyclophosphamide, followed by remission maintenance treatment
- Adverse responses to treatment are common, as are relapses, so long term follow-up is needed

Berden A, Göçeroglu A, Jayne D, et al.
Diagnosis and management of ANCA associated vasculitis. BMJ. 2012;344

Review prepared by Maya Anaokar, PhD

UKVAS: a registry for patients with vasculitis in the UK and Ireland

Members may remember that in the Autumn issue we asked you to consider registering for the American based "Vasculitis Clinical Research Consortium". Many of you did, so many thanks.

The American group continues and your membership is still important to that project. However, we are pleased to announce that there is now to be a registry specifically for the UK and Ireland.

Dr Mark Little explains about the registry below. We hope that Trust members will register and help to make this project a success.

UKVAS : a registry for patients with vasculitis in the UK and Ireland.

This exciting new project is soon to begin. The aim is to collect anonymised information about patients throughout the UK with different types of vasculitis in a uniform way. Our aim is that it can all be brought together in a database and the information shared more widely, with the aim of improving understanding, diagnosis and treatment. Hitherto, vasculitis data have been collected in different ways, so that it is not easy to analyse, compare and produce conclusions. So this new collaborative initiative is to be greatly welcomed by both medical professionals and vasculitis sufferers.

The UKVAS project involves the **Vasculitis Rare Disease Working Group**, a group of doctors which includes most of those with considerable experience and expertise in diagnosing and treating vasculitis in all its forms. It is led by Dr Richard Watts (Senior Lecturer and Consultant Rheumatologist, Norwich Medical School) and Dr Mark Little (Professor of Nephrology, Trinity College, Dublin). Further details of the project are given below:-

Systemic vasculitis is a rare disease, with less than 10,000 people affected by GPA (Wegener's granulomatosis) or MPA in the whole of the UK. Other forms of vasculitis are even rarer. Specific expertise in managing this devastating condition is concentrated in several research active centres. These groups of doctors have come together in an effort to share their experience in caring for patients with vasculitis so that this pooled knowledge can be used to help us better understand why some people get this disease, to identify ways to improve monitoring of patients and to allow us to test the effectiveness of new therapies. The result of this collaboration is "UKVAS", a registry where anonymised details of patients with vasculitis are stored and analysed (www.UKVAS.org).

Although very few people in a specific town or region will have vasculitis, when combined across the whole country there are enough to provide exciting insights that will lead to improved patient care. This endeavour is currently supported by **Kidney Research UK** and is linked to efforts of the recently established Vasculitis Rare Disease Working Group. The patient is at the centre of this project; we envisage that individual patients will be able to log in and see their own clinical data, as well as entering values themselves, in a manner analogous to RenalPatientView (www.renalpatientview.org). By linking this information to samples collected over time, researchers will have an unprecedented opportunity to study vasculitis in great depth.

If you wish to find out more or to register to take part in the project when it begins, please email mlittle@tcd.ie or talk to your vasculitis doctor.

Please note that we welcome family, friends and carers of patients with vasculitis to participate as well.

Also see page 12 for details of an important study "Diagnostic and Classification Criteria in Vasculitis Study (DCVAS)" which also requires the help of vasculitis patients in the UK.

Congratulations

Dr Mark Little has been appointed to the chair of nephrology at Trinity College, Dublin and to his new appointment as a consultant nephrologist at the Adelaide and Meath Hospital in Dublin.

The congratulations of the Trust are sent to Professor Little.

Rare Disease Day
29th February 2012

Trust members helped to make Rare Disease Day a success, raising awareness of vasculitis and a few funds for the Trust along the way. There were lots of innovative ideas, from a sponsored silence to a taxi driver handing out Trust pens, stick-its pens and leaflets to all his customers on the 29th.

Many thanks to everyone who raised awareness and funds.

Fertility and Vasculitis — Dr David Jayne

Introduction:
Vasculitis activity and its therapy are potential threats to the fertility of patients with vasculitis. Loss of fertility is an important consequence of the disease, but the risks of this occurring can be considerably reduced with newer forms of treatment. As a chronic disease, vasculitis also causes psychosexual and relationship problems due to effects on self-esteem and mental well-being. Chronic kidney disease is a common consequence of renal vasculitis and the depressed kidney function itself affects fertility in both women and men.

Fertility in women:
The major threat to women is cyclophosphamide exposure. This drug is used to control vasculitis activity and is directly toxic to the ovaries. This can result in permanent infertility, also known as primary ovarian failure. In addition to loss of menstrual periods, amenorrhea, blood levels of the hormones FSH and LH are elevated. Primary ovarian failure is related to the total amount of cyclophosphamide administered and to the age of the patient. Data from lupus nephritis suggests that a total cyclophosphamide exposure of 14-20g results in infertility in over 50% of women aged over 32 years. The risk of infertility in those under 32 years is lower, around 10% in one series. These risks can also be reduced by using short-term regimens or by intravenous pulse as opposed to daily oral administration. Three months of oral cyclophosphamide leads to an exposure of 9-14g, and an equivalent six dose course of intravenous pulse cyclophosphamide, 5-7g. Even if infertility is not induced, less severe ovarian damage leads to earlier menopause. Drugs that temporarily suppress ovarian function, such as zolodex, are used to reduce the risk of cyclophosphamide toxicity. Rituximab has been shown to be as effective as cyclophosphamide and can be used when cyclophosphamide avoidance is desirable.

Following cyclophosphamide withdrawal and return of a normal menstrual cycle, women can conceive and have children. There have been concerns that cyclophosphamide, through damage to DNA in the unfertilised egg, results in an increase in birth defects but this has not proved to be the case. However it is advisable to wait at least six months between stopping cyclophosphamide and attempting to conceive.

Women have a finite number of eggs and once lost, they cannot be replaced. For this reason, in cancer therapy, egg harvesting and preservation or even, preservation of ovarian tissue for subsequent re-implantation, can be considered when drugs toxic to the ovaries are used. This is rarely feasible in vasculitis due to the tempo of the disease, the need for rapid institution of therapy and the potential complications of the procedures.

Being unwell with vasculitis interferes in a non-specific manner with menstrual cycles and can cause periods to stop, amenorrhea. This can be differentiated from ovarian damage by an ultrasound scan of the ovaries which demonstrates the presence of healthy oocytes (egg follicles) and by measuring hormone levels in the blood. Periods will usually re-start spontaneously as the patient recovers. Direct damage to the ovaries or female reproductive tract by vasculitis is rare but has occurred.

The influence of other drugs should also be considered. Some immune suppressives, such as, methotrexate and mycophenolate mofetil, and thalidomide, damage the foetus and must not be used in pregnant women or those attempting to conceive. Certain antibiotics, such as rifampicin, interfere with the contraceptive pill. Anti-inflammatory drugs and high dose steroids also reduce fertility. The infective risks of the coil are increased in those receiving immune suppression. Sexually transmitted diseases can be more problematic in immune suppressed patients and *Chlamydia Trachomatis* can result in infertility in women.

Fertility in men:
Cyclophosphamide directly affects sperm production in men but there is more potential for recovery by the generation of new sperm forming cells when cyclophosphamide is withdrawn. However sperm production does not usually recover to pre-treatment levels and healthy sperm counts can remain depressed. It is likely that, in combination with non-specific effects of chronic illness, cyclophosphamide reduces male fertility. An alternative immune suppressive used in vasculitis, methotrexate, also reduces sperm formation but has a lower risk of sustained effects after drug withdrawal.

In contrast to the difficulties of egg preservation in women, semen preservation is quite feasible in men and can be considered before cyclophosphamide is commenced. It can be hard to advise on this, especially if there is a cost to the patient involved, because the risks of infertility are probably quite low with current cyclophosphamide regimens and if infertility occurs it is more likely to be partial rather than complete. Testosterone therapy has also been used to protect the testes from cyclophosphamide toxicity.

The testicles can be directly attacked by vasculitis in polyarteritis nodosa causing pain and swelling and subsequent loss of function. GPA (Wegener's) can affect the prostate gland but the effects on fertility are not well understood.

Drug effects, especially high dose steroids, vasculitic activity and chronic illness reduce testosterone levels that can lead to reduced libido and erectile failure. Testosterone levels in the blood are readily measured and testosterone supplementation can correct the problem.

Conclusions:
The protection and preservation of fertility are important issues in the management of vasculitis. Much is known about the effects of cyclophosphamide in women although there is a shortage of information about the longer-term effects in men and in children. The potential dangers of this and other drugs should be discussed in detail before their use, but it should be remembered that cyclophosphamide has been a truly life saving drug in vasculitis and a balanced approach to assessing both risks and benefits is needed.

Many other factors will influence the fertility of vasculitis patients that include the consequences of vasculitic activity, ongoing medications and the patient's general state of health. Pre-conception counselling should be sort by women with vasculitis wanting children so that any risks to the mother, pregnancy or future baby can be discussed and appropriate plans made.

David Jayne

Vasculitis and Lupus Clinic, Addenbrooke's Hospital, Cambridge, UK

Roving Reporter Holly Hampshire speaks to Dr Rob Siraj ...

I was diagnosed with Wegener's Granulomatosis in December 2008 and had my first round of cyclophosphamide in early 2009, with another eight sessions later that same year. My husband and I had been told my fertility could be affected but despite this six months after my last infusion we started trying for a family. In August 2011 I became pregnant! We were both thrilled and we can't wait for the baby to arrive in May, but being pregnant whilst having WG isn't plain sailing. Here I talk to my Antenatal registrar Rob Siraj about some of the issues we're facing ...

Of course I know who you are but for those who don't, can you fill us in on what it is you do?
I am a registrar in obstetrics and gynaecology at Barnsley Hospital in South Yorkshire; I supervise junior doctors, but I am also accountable to more senior doctors (consultants). On a day-to-day basis, I see patients in clinics (pregnant and non-pregnant) and perform both major and minor operations (like sterilizations or hysterectomies). After normal working hours I provide emergency care, for example performing emergency caesareans.

Could you also give me a brief summary of your career to date?
I hail from Norwich and graduated from Cambridge. I worked in East Anglia for a few years and then moved to South Yorkshire nearly four years ago. My main interest is obstetrics, particularly pre-existing medical conditions that complicate pregnancies like Wegener's granulomatosis.

Am I the first patient you've treated with vasculitis?
I have been involved in the care of a couple of other patients with WG. It is rare, but, having said that, it is being diagnosed more frequently in or before pregnancy as less severe cases are recognised and treated earlier.

I've been treated with cyclophosphamide in the past and was told it could affect my fertility, is that the case?
There is not a great deal of data about cyclophosphamide-induced sterility in patients with systemic vasculitides, probably because it generally affects older people. However, fertility after intravenous (IV) cyclophosphamide has been studied in patients with systemic lupus. Ovarian failure occurred in 11-59%; this complication was more likely the older one was when starting this medication and the higher the total dose given.

What are the main concerns with a pregnant patient who also has Wegener's granulomatosis?
WG, per se, probably does not have any direct effects on the unborn baby. However, active disease that makes the mother ill will in turn affect the baby. Most reports suggest that pregnancy is associated with worsening of the disease. Relapse in a pregnant patient with WG must be treated (usually with steroids and immunosuppression) because under treatment leads to poorer pregnancy outcome. Patients with WG are monitored, as usual, by paying attention to symptoms, blood tests and urine tests, and ANCA levels. The frequency of testing depends on symptoms, disease activity and treatment.

I'm on prednisolone and azathioprine, do those drugs have any influence on my baby's development?
Drugs used to treat WG may pose risks to the unborn baby, but those very same drugs do improve pregnancy outcomes too. Remember that under treatment of the disease does lead to poorer pregnancy outcomes.

Prednisolone is fairly safe during pregnancy as very little drug crosses the placenta. Doses in excess of 30mg/day are associated with breaking your waters early and premature birth. The baby may not grow properly either, so additional scans to check on the baby's growth are performed at 28, 32 and 36 weeks. If any growth problems were detected, more frequent scans would be performed. Prednisolone may affect the mother too, by increasing the risk of high blood pressure, pre-eclampsia and diabetes in pregnancy. Antenatal care is designed to monitor for these complications.

Azathioprine has a very low risk of foetal complications, and is considered safe in pregnancy.

Will there be any impact on the delivery?
Vaginal delivery would be recommended. Long-term steroid use prevents the body from producing its own natural steroid during a stressful episode, for example labour and delivery. Therefore steroid injections may need to be given during labour. If a caesarean section is necessary, steroid injections will need to be continued for a couple of days after the operation.

James, Holly and baby bump ▶

Welfare Reform Act 2012

Stop press

The Welfare Reform Act 2012 was enacted in March 2012 and will come into force on 30th April 2012. This Act amends many of the current procedures for disability benefits. For details of the proposed changes see http://www.direct.gov.uk/en/NI1/Newsroom/DG_201237

UK Plan for Rare Diseases : consultation document launched

On 29th February (Rare Diseases Awareness Day) the Department of Health published the first ever UK plan for rare diseases. To view the document visit: www.dh.gov.uk/health/2012/02/consultation-rare-diseases/

Lupus, Diet and Lifestyle—Is there any evidence?

Ani Richardson, BSc(Hons), MSc, RNutr

The effects of lupus are, in many ways, similar to those of vasculitis., with many patients being treated in a joint Vasculitis/Lupus clinic. Therefore, we thought members might be interested in the following article on lupus, diet and lifestyle much of which could easily relate to vasculitis.

Ani is a registered nutritionist with qualifications in counselling (psychosynthesis) and obesity management, she also has Lupus. Ani started to look at the scientific research behind diet, lifestyle and lupus after being diagnosed with 'lupus spectrum disorder'. She believes that what we eat can impact the body in many biological ways. After spending a few months reading published medical journals Ani began writing a scientific review of the evidence. In this article (recently published in a Lupus newsletter) she discusses some of her findings. More information and contact details can be found on Ani's website www.vitalitywithin.com

Vital Vitamin D

Research into Vitamin D has been intensive in the last 5 years. Data suggests that nearly all major human diseases are linked to the vitamin D status of our body. Only small amounts of vitamin D can be found in foods such as eggs and oily fish e.g. salmon, mackerel and sardines with most vitamin D in the body being synthesized from the action of sunlight on the skin. Many lupus sufferers cannot tolerate much sunlight and so their vitamin D levels may be particularly low and this could well be adding to lupus symptoms such as pain, fatigue and even depression.

Briefly I wanted to mention why vitamin D may be particularly helpful to lupus sufferers:

*Many studies have shown that individuals with lupus have low levels of vitamin D in the body and this is often correlated with severity of symptoms.

*Vitamin D can act on cells of the immune system in a variety of complex ways that can reduce inflammation in the body.

*Vitamin D is important for brain function and mood. Studies have linked depression and poor cognition (brain function) to lower levels of vitamin D in the body. Lupus sufferers often report problems with depression, anxiety and other mood disorders.

*Emerging evidence is pointing toward the benefits of vitamin D for those suffering with chronic pain, especially women.

* Hydroxychloroquinine, a medication typically used for treating lupus, can negatively impact vitamin D levels.

As yet experts have not come to agreement over what the most optimal levels of vitamin D in the body are but it is thought that blood levels of at least 30ng/ml (or 75nmol/L) are beneficial. Vitamin D supplements are inexpensive and widely available and are definitely worth talking to your doctor/rheumatologist about. Many rheumatologists are willing to do vitamin D tests so it is worth asking. These will need to be repeated every 4-6 months if supplements are given in order to track levels in the body. To achieve and maintain vitamin D levels of 30ng/ml usually requires a supplement of 2000-5000iu vitamin D daily (In the form of vitamin D3). Individuals with particularly low levels may need mega-doses of vitamin D to start with but your medical doctor will advise on this.

Fabulous Fats - Omega 3's

The notion that all fats are bad is a BIG FAT LIE! The benefits of long chain omega 3 fats, found in oily fish like salmon, mackerel, trout and sardines, is something I have been passionately researching since completing my masters degree (in nutritional medicine) in 2002. The long chain omega 3 fats which have the most potent biological activity in the body are eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA). The shorter chain omega 3 fat (alpha-linolenic acid ALA) found in flaxseeds, walnuts and green leafy vegetables is far less potent than EPA and DHA and doesn't seem to have the same benefits to health, though they are highly valuable to provide an overall balance of 'good' fats in the body.

Vegetable oils, processed foods and grain fed meats contain a lot of omega 6 fats. Currently in the western diet we have an imbalance between omega 6 and omega 3 fats, with far too many omega 6 fats and very low intakes of omega 3's. Both the omega 3 and omega 6 fats are used in the body to make potent immune chemicals (known as prostaglanding and leukotrienes). The immune chemicals made from the omega 6 fats are potent pro-inflammatory mediators which is obvious not what we want as lupus sufferers! The omega 3 fats, on the other hand, are used by the body to produce anti-inflammatory chemicals, which is great news!

Inflammation is linked to the production of free radicals, destructive chemicals, which cause oxidative stress in the body. Studies have shown that omega 3 fats may be useful in lupus sufferers by reducing the amount of oxidative stress in the body. Inflammation is also linked to depression, there is a lot of strong evidence that EPA and DHA (potent anti-inflammatory omega 3 fats) are highly beneficial in treating depression, and as mentioned earlier depression and low mood is common in lupus. Finally omega 3 fats are important for skin health and also protect against sun-damage.

Omega 3 fats from oily fish are important for the optimal health of most individuals and may be especially helpful if you are dealing with lupus. Eating oily fish at least 2-3 times every single week would help to boost levels but this is often difficult for people to stick to. EPA and DHA supplements can be very useful to boost levels. It is important to discuss their use with your medical doctor since omega 3's do interact with some medications, however if your doctor agrees then taking 1000-2000mg of EPA/DHA daily may well be worth trying. People often find that this can help with join pain/ mobility and feelings of fatigue, depression and food cravings. For vegetarians and vegans EPA/DHA supplements are now available from algal sources.

Anti-inflammatory Antioxidants

As mentioned earlier, inflammation can cause oxidative stress in the body which is implicated in the development of various clinical features seen in lupus patients. Free radicals can attack cells and cell membranes causing further inflammation, depression, sun damage and heart disease.

Continued on page 12

Lupus, diet and lifestyle - Continued from page 11

There are a variety of antioxidants in food which can quench the production of these free radicals and hence may be useful to reduce inflammation and damage in lupus sufferers. Vegetables, fruits and spices such as ginger, chilli peppers and garlic are rich sources of antioxidants (such as certain vitamins and flavonoids or plant chemicals).

Certain minerals such as magnesium and zinc are also antioxidant and anti-inflammatory. A diet rich in vegetables, fruits, nuts/seeds, beans/pulses and unprocessed wholegrains will go far in providing the body with an array of antioxidants.

Watching Weight

Currently studies suggest that overweight and obesity are common in lupus patients, especially women. It is an important factor to discuss because overweight is associated with chronic inflammation, impaired quality of life and increased risk of heart disease – all factors seen in lupus. Encouraging weight control is important in lupus patients, weight loss in the overweight can lead to significant lowering of inflammation in the body. Weight loss needs to be sustainable but need not be an arduous journey. Good support and good information are vital for the weight loss journey. Unfortunately it is not a topic I can expand upon here but having help from a registered nutritionist or dietician can be invaluable.

Physical Activity

Evidence suggests that physical activity is important for lupus sufferers. Even 15 minutes of walking a day can be beneficial for mood, sleep, energy levels, weight loss, stress reduction and inflammation. Exercise can also reduce the risk of cardiovascular disease and osteoporosis. Sometimes the fear of feeling tired can stop us from taking any steps toward movement, for me personally I know that a walk a day really does help keep my flares at bay. Often I don’t think I can manage it but once I have my shoes on and I get going I feel invigorated and the rest of my day is more energised. Talk to your doctor about exercise and what you think you can or can’t manage, total exhaustion is certainly not the goal but many individuals find that they can manage 15-30minutes of walking each day (this can be broken up into 2 or 3 short walks).

Stress

Stress can be psychological (worries, anxiety), physiological (hormonal, damage from over exercising) and even nutritional (poor nutrition is a stress for the body and causes the production of certain stress hormones). Stress, stressful events and depression all impact inflammation in the body and as mentioned earlier inflammation is a huge part of lupus and its associated symptoms such as pain and depression. Stress can also produce general dysregulation in the immune system. Evidence suggests that stress plays a role in exacerbating lupus, although studies looking into this have produced mixed results. Needless to say life feels a lot easier and more joyful when stress levels are low.

Research suggests that yoga, meditation, cognitive behavioural therapy (CBT) a form of counselling, mindfulness and exercise can all help reduce the stress associated with chronic disease.

In terms of nutrition having a nutrient rich diet that keeps blood sugar levels stable can be highly useful in reducing physiological stress in the body. As mentioned earlier omega 3 fats can reduce depression and anxiety which are associated with stress, they also help stabilise blood sugar levels. To keep blood sugar levels stable a diet which is rich in vegetables, fruits, nuts/seeds, pulses/beans, unprocessed wholegrains and unprocessed meats and fish (especially oily fish) is a useful place to start. It is also very important to include a portion of protein with each meal (including breakfast), protein helps with blood sugar balance but also provides the body with certain amino acids needed to make neurotransmitters in the brain that keep us feeling good. Good protein sources include: nuts, beans/pulses, fish, unprocessed meat, eggs (although try not to eat too many eggs since they contain a type of fat that can be pro-inflammatory in the body).

For some good recipe ideas I find this book useful: “The everything anti-inflammation diet book” by Karlyn Grimes ISBN 978-1-4405-1029-8 For a full list of scientific references or to get in touch feel free to email Ani at vitalitywithin@gmail.com

Diagnostic and Classification Criteria in Vasculitis Study (DCVAS)

Launched in January 2011, DCVAS is a multinational observational study and aims to develop diagnostic criteria and update classification criteria in vasculitis.

There are currently no diagnostic criteria for vasculitis which has resulted in delays in making the correct diagnosis and starting appropriate therapy. The current classification criteria were developed before the availability of modern diagnostic tests and are not consistent with the present understanding of vasculitis.

Classification criteria are used to group patients into different types of vasculitis and are useful for studying patients in clinical trials with similar diseases.

The study is led and coordinated from the University of Oxford. Over 75 sites across 29 countries in Asia, Australasia, Europe, North America, South America and the UK will be included in the study. Sites will recruit a total of 3500 patients, 2000 with a new diagnosis of vasculitis and 1500 with similar symptoms to those with vasculitis.

In January 2012, 750 patients from 40 sites were recruited into the study and we plan to reach our target by December 2013. Further information is available from :
dcvas@nodorms.ox.ac.uk

Also see page 8 for details of a new vasculitis registry “UKVAS: a registry for patients with vasculitis in the UK and Ireland” which also requires the help of vasculitis patients in the UK.

Behçet's Disease

Behçet's Disease is very rare in the UK. It is a vasculitis that can affect both large and small vessels including both arteries and veins.

The disease can affect people of any age although it is commonest in the 20s-30s. Men and women are probably equally affected. The cause of Behçet's is not yet known.

Almost any organ can be affected. The commonest symptoms are recurrent crops of painful ulcers in and around the mouth and lips and the genitals. The joints may be affected with a painful arthritis. The most serious problems include inflammation in the front of the eye (anterior uveitis) which can result in cataracts and glaucoma and inflammation at the back of the eye (posterior uveitis) which can lead to blindness. Inflammation in the brain and nervous system may also occur. Inflammation may also occur in the aorta and major arteries leading to aneurysms and clots (thrombosis). Clots may also form in the veins of the skin (superficial phlebitis) or major veins (deep vein thrombosis).

There are no specific tests for Behçet's Disease. As with other forms of vasculitis making the diagnosis depends on recognising the pattern of symptoms and findings on examination. Blood tests may show evidence of inflammation.

One test that is partly specific for BD is the "Pathergy test". This test involves using a sterile hypodermic needle to make a deep prick in the forearm skin of the patient. A positive test is where a small swelling (papule) possibly with pus (pustule) is present at the site of the needle prick 48 hours later. If positive, the test is useful but a significant proportion of patients with Behçet's disease will have a negative test.

In cases where the brain is involved specialist scans such as magnetic resonance imaging scans (MRI) may provide useful information.

High dose steroids, possibly with cyclophosphamide, are often used in serious cases of Behçet's disease such as those involving the brain or eyes. For less serious cases milder treatment with drugs such as colchicine, non-steroid anti-inflammatory drugs (eg ibuprofen), azathioprine, methotrexate or ciclosporin A may be used.

The overall prognosis is very variable and depends on the severity of the disease and the frequency of relapses. Most patients will require ongoing treatment to control the symptoms of the disease and disease relapses.

Stop Press: The Behçet's Society have announced three Centres of Excellence for the diagnosis and treatment of Behçet's — Bart's and the London, Birmingham City and Aintree University hospitals. For more information contact: Chris Phillips +44(0)8451307328

info@behcetsdisease.org.uk
www.behcets.org.uk

Further Stop press:

Alemtuzumab (CAMPATH-1H) as Remission Induction Therapy in Behçet's Disease

Addenbrooke's have recently published the above paper in Arthritis Rheum 2010;62 Suppl 10 :1278
DOI: 10.1002/art.29044 To view on line go to:

http://www.blackwellpublishing.com/acrmeeting/abstract.asp?MeetingID=774&id=89925

"The outcomes of the research show that six months after treatment, 74% of patients were in complete remission. Many of these remissions have been sustained over years, but in those that did relapse, re-treatment with alemtuzumab was effective. There were significant reductions in prednisolone dose and BVAS after treatment."

Research funding: Members may remember that the Trust has awarded a research grant to Addenbrooke's to look into the question of whether Alemtuzumab (CAMPATH-1H) is beneficial in treating other vasculitis diseases where conventional drugs do not work.

If the results from the research YOU are funding are as good as those from the Behçet's research, then your financial support will benefit so many more vasculitis patients. So, please keep those donations coming in. The research we fund is research which, hopefully, will give early and beneficial results for vasculitis patients.

A new rituximab clinical trial

Rituximab is now established as an effective drug for ANCA vasculitis following major European and US trials reported in 2010. After a time, its effect wears off and the disease can return. This occurs in at least half of patients within 2 years of receiving Rituximab. A preliminary study in Cambridge has suggested that repeating rituximab every six months stops the disease returning and is safe.

The **RITAZAREM** trial will find out whether repeating rituximab stops vasculitis returning and whether it works better than the older treatments, azathioprine or methotrexate. It will also tell us how long patients remain well after the repeated rituximab treatments are stopped, and if repeated rituximab is safe. We should learn useful information about the effects of rituximab on quality of life and economic measures as well. The trial results will help decide the best treatment for future patients who have their vasculitis initially treated with rituximab.

RITAZAREM aims to recruit patients with established ANCA vasculitis whose disease has come back 'relapsing vasculitis'. All patients will be treated with rituximab and steroids and we anticipate that most will respond well. If their disease is under reasonable control after four months, further treatment with either rituximab (a single dose ever four months for two years) or azathioprine tablets will be chosen randomly. The patients in the rituximab and azathioprine groups will then be compared. Patients will be in the trial for four years.

The study has been designed by members of the European Vasculitis Study group (EUVAS) and the Vasculitis Clinical Research Consortium (VCRC). It will include 190 participants from 30 hospitals in Europe, the USA, Australia and Mexico. We hope to enrol the first patient in Cambridge in June 2012. RITAZAREM is being funded by Arthritis Research UK , the U.S. National Institutes of Health and by Roche/Genentech. Further information is available from the study co-ordinator, Michelle Lewin (michelle.lewin@addenbrookes.nhs.uk)

PERSONAL STORIES

My son Gareth's Goodpasture's journey

My son, Gareth Garner, was a fit healthy 16 year old boy, playing football, preparing for his GCSEs and with aspirations of studying medicine. Then in May 2011 he developed a bit of a cough and cold. However, as he had mild asthma in childhood and because I'm an over anxious Mum, I called my GP to be told that as a "non emergency" I should call back next day if I was still worried.

Early the following morning I was woken with a feeling of dread and checked on my two boys. Gareth was sitting up in bed, very breathless and coughing up blood! An ambulance was called and Gareth was rushed into Addenbrooke's Hospital. He was given oxygen and had a chest x-ray. This revealed severe bilateral pneumonia. We were assured after a few days with IV antibiotics Gareth would quickly recover.

However, it became evident over the next few days and weeks that he was becoming very ill. He was transferred to intensive care, literally fighting for every breath. He'd lost two stone and was terribly weak. An artificial coma was induced and a ventilator took over his breathing. He had further tests - CT scans and lung biopsy.

Finally a diagnosis - "Anti GBM (Goodpasture's) disease". This is a rare form of vasculitis which attacks the lungs and kidneys. Thankfully there was no apparent kidney involvement, but this would require monitoring closely. He was started on high dose IV steroids immediately. Our whole world was torn apart.

A few days later Gareth was woken and we gently explained the situation to him. He was also suffering from hallucinations and nightmares but the ICU staff were outstanding and supported both Gareth and ourselves.

Within 48 hours of starting the steroids he finally showed improvement. A week later he was moved to the high dependency ward where we met the wonderful Dr Jayne and his team. Dr Jayne explained to Gareth exactly what Goodpasture's disease was and how they planned to treat him. He explained, in no uncertain terms, that they were going to hit him with a sledge hammer, that the treatment was going to make him feel awful but it would work! The treatment consisted of plasma exchange for seven days in addition to six pulses of cyclophosphamide every other week.

It's been a rough ride and there have been a few hospital admissions due to infections. He also developed blood clots on his lungs, which is part and parcel of the vasculitis, but I truly believe that Dr Sivasothy, Dr Jayne and his team saved my son's life with their prompt diagnosis and treatment.

Six months on Gareth has a strict daily medication regime, weekly blood tests, and regular hospital appointments. He is still very breathless at times and has nightmares from his experience, but he is alive and slowly but surely improving.

My son is an extraordinary and brave young man. Despite everything he has been through, at such young age, and everything he has had to give up, he still has his wonderful sense of humour and positive attitude. I am so proud of him. *Anne Sweeney*

Living with WG by Andrew Irving

I was born in October 1982 at a hospital that later would diagnose me with Wegener`s Granulomatosis. I grew up, as most kids do, playing out and riding my bike. I also had rally cars around me as my dad was into rallying and some of the local motor club cars were in the garage on the side of my house. At 12 I was cycling competitively mainly time trialing at 10 to 25 mile. By 17 I started training as a motor technician and I also started racing 100cc race karts which I raced for a few years. I became a fully qualified motor technician in 2003 but then had a small break from cars and worked at the Cumberland pencil mill. I also took up rallying with my dad coming out of retirement to navigate for me.

During summer 2010 I just didn't feel myself, always tired and feeling ill. By October 2010, whilst out rallying, I felt so ill and needed help out of the car at end of the day. I saw the GP next day and was told it was "just the flu". The following week I was feeling even worse. My sinuses where causing problems. Sinusitis was diagnosed and antibiotics prescribed. I returned to the GP feeling worse and she went through all my symptoms: pain from my sinuses, coughing up blood, bad nose bleeds, flu-like feeling, night sweats, sickness, and weight loss (3 stones). Blood tests were ordered, but later that week I was unable to get out of bed, was very weak and stared getting chest pains. An emergency appointment was arranged and they suspected I had pneumonia. However my blood had way too many white cells and very few red cells. I was admitted to Whitehaven Hospital. I underwent lung biopsies - internal with a camera and external. Unfortunately they punctured my right lung and so a chest drain was fitted. The biopsy confirmed what they suspected - Wegener's Granulomatosis. I started chemotherapy two weeks before Christmas.

I returned to work after four months having to take a week off every month for my chemo. This continued until May. I also started rallying again in March and came second in class in the ANECCC SG Petch Rally Championship in 2011.

Since diagnosis in 2010 I am continuing to learn to live with WG and it has been a bumpy ride. I don't like to admit it but I am ill at times, and sometimes it's a struggle. BUT **IT** WILL NOT WIN and I will fight on, hopefully into old age.

Andrew Irving

Music to Marathons with a little vino on the way — Jamie Flanagan's inspirational story

I was diagnosed with Wegener's Granulomatosis at the beginning of the millennium at the age of 17. A millennium bug I always call it! I'm going to start off with good news... went through the treatment and have had no flare ups since. Good place to start I think!

Unfortunately, being a musician, it was cruel that Wegener's chose to go for my hearing. In September 1999, after a particularly loud gig, I lost all hearing in my right ear. Initially I thought it was my fault, but visited my doctor anyway. I was told it had just been too much noise and that my hearing should return in a few weeks. Weeks passed, my hearing didn't return and my ear became badly infected.

Many a doctor and consultant treated this as a severe ear infection. It wasn't until I'd gone through a major fever over Christmas, severe weight loss (14 stone down to about 8), and eventually, after collapsing in January 2000, the ball started rolling. Many more consultant visits followed and eventually after Bell's Palsy had crippled the right side of my face my other ear went too. Then in April 2000 I found my saviour, Mr Hussain at Ninewells hospital in Dundee. He examined my ear and immediately knew something was seriously wrong, not just an ear infection. He ordered many tests, quickly consulted Rheumatologist Dr Morley, and performed emergency surgery on my right ear to relieve pressure and try to save my hearing. About a week or so later chemotherapy and steroids commenced and six pulses were scheduled. Aside from the mood swings and lack of sleep, I can honestly say the worst part was removing the sticky plaster they put on my arm during the chemo. Wasn't sick once and never lost a hair! Until now… I think age is creeping up on me.

I am thankful that the chemotherapy stopped the WG in its tracks. The Azathioprine and steroids which followed also helped put me into total remission within 3 years - which stands to this day. The hearing came back a fair bit too and, with the use of hearing aids, I was able to pursue my musical career, achieving a BA in applied music with honours from Strathclyde University. I've performed in many concerts across the country and was even part of a support act for Tony Bennett in Glasgow. The hearing loss didn't stop me playing, but I didn't enjoy it as much as I used to, the problem making performing more of a struggle than it needed to be. I don't regret continuing to study music as I have many great memories and friends from my musical endeavors. Drumming is still a part of my life, but I have since abandoned music to work with Majestic Wine as a trainee manager.

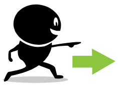
In July 2008 I also started running and completed my first marathon in Paris (April 2009). Since then I have continued running frequently completing many half marathons, and even a Kilomathon (26.2km) Most recently I completed the Marathon Du Medoc on the 10th of September 2011. It was without doubt a wine drinking marathon, and needless to say I was a little dehydrated at the end!

I run pretty much every day now (sometimes twice!), and I see it as one of the main reasons I have stayed healthy. My long term goal is to run an Ultra Marathon of 50 miles or more before 2014. However, 2012 will see me taking on the Rome Marathon (18th March 2012) and the Berlin Marathon (30th September 2012). I'm proud to be running both of these marathons raising money for Vasculitis UK.

If you'd like to sponsor me then please visit http://www.justgiving.co.uk/jamie-flanagan

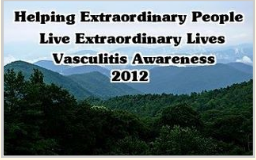
Many thanks, Jamie Flanagan

PS: Jamie is now signed up for the "Ocean Floor" race in Egypt in 2013. This is an ultra-marathon, 160 miles, non-stop across the rugged terrain of an ancient dried up sea known as the "White Desert". Jamie will be fundraising for a different charity, of his choice, for this event.



Follow Jamie's entertaining training blogs on the Vasculitis UK Health Unlocked site

▶Vasculitis Awareness Month — *May 2012*



This is a great opportunity to raise awareness of vasculitis here in the UK. Please consider raising awareness, and possibly also some funds for the Trust, during Vasculitis Awareness Month.

We aren't thinking of strenuous fundraising events, like abseiling down Mount Everest, but fun things you can do with your family, friends and colleagues.

Some ideas include:

- Coffee mornings
- Pamper parties (at your local beauty salon)
- Swishing parties (exchanging good quality clothes you no longer wear)
- A Bingo session or Quiz night
- A Book sale or Car boot sale
- A Dress-down day, or
- What about an Anne Summers' party !!!

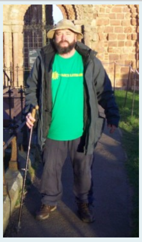
The list is endless if you think about it. Remember it's about raising awareness first and foremost and then raising funds - ***no amount is too small.***

The Trust will provide you with free balloons, pens, stick-it notes, car stickers and information about vasculitis. You could hold your own raffle, with a small prize. The winning ticket could then be sent to the Trust to go into a larger raffle to win M&S vouchers worth £100.

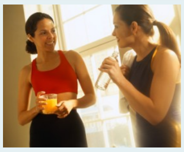
Together we can make Vasculitis Awareness Month 2012 really mean something here in the UK. You can help raise awareness and a little funding for the Trust to enable us to continue to achieve our aims of supporting patients and their families, raising awareness, and funding essential vasculitis research.

Please contact Paul Bingham for further details.
Redholme Cottage, Walton-on-the-Hill, Surrey, KT20 7AU.
paul.m.bingham@btinternet.com

Our Fantastic Fundraisers



James Apps - James undertook the Melrose to Lindisfarne Walk (St Cuthbert's Way Walk) between 21st and 24th February, a distance of 100 km. James' itinerary was: 21st – Melrose to Harestanes, 26km, 22nd - Harestanes to Yetholm, 27km, 23rd - Yetholm to Wooler, 21km, and 24th - Wooler to Lindisfarne, 28km. So far James has raised **£200** for the Trust.



Bakewell Methodist Keep Fit Group meet every week and donate their subscriptions to charity. On this occasion the Trust benefited from the Group's kind donation of **£100.**

Karen Brownbridge completed a sponsored diet in December. Over six months she lost an amazing 2 stones and in the process raised **£331** for the Trust.

Julie Bartoszyk took part in the Great Eastern Run on 9th October 2011. Julie raised **£10** for the Trust.

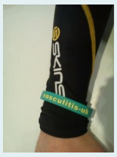
Elise Baxter - Elise Raised **£541** for the Trust by completing the Julie Rose 10K run in October. Elise ran the whole 10K in a very respectable time of just under an hour. She was raising funds in memory of Clare Grossman.

Andy Bone Sports Shots has raised **£60** for the Trust from the sale of his sports photographs.

Janine Emma Brown - Janine ran the ING New York Marathon 2011 on 6th November dressed as the female version of a "teenage mutant turtle". Her time was 3 hours 13 minutes, finishing the 216th female and 51st in her age group. There were over 47,00 entrants. This marathon marked the most personal one she had run to date because it was in honour and memory of a great team mate and friend. Clare Grossman, who lost her battle with WG in December 2010. Janine has raised **£770** for the Trust

James Clark (who has WG) and his nephew **Daniel** took part in the Lincoln 10K on 25th March 2012. So far they have raised **£97.50** for the Trust

Julie Daniel and Dawn Smith entered the Givaudan Ashford 10k on the 9th October 2011 (formally known as the Julie Rose 10k). Julie and Dawn were raising money for the Trust in memory of their friend Clare Grossman. They raised **£50**



Jamie Flanagan (see personal stories in this issue) entered the Rome Marathon on 18th March 2012. So far Jamie has raised **£645** for the Trust.

The family and friends of the late **Rupert Dickenson** (pictured) will be entering the Reading Half Marathon on 1st April 2012 raising funds for the Trust in Rupert's memory. Rupert had WG but sadly died after a four year battle with the disease. In total they have so far raised a magnificent **£7455**, as noted below, for the Trust and in Rupert's memory.

Atalanta (£1565)
Casper (£410)
Daisy (£885)
Felix (£2385)
Flora (£350)

Georgia Hick (£190)
India (£1520)
Milo Drake (£70)
Ben Winston (£80)

Emma Goodman raised **£52** for the Trust in memory of Clare Grossman. Emma raised the money by taking part in the Ashford 10k race.

Anna Gowing, Jessica Parsons, Richard Gowing, Francesca Gowing took part in the Old Dear 10K Challenge, in Richmond in November 2011 Between them they have raised **£525** for the Trust.

Tara Gami held a 24hr Sponsored Silence for Rare Disease Day in February. So for Tara has raised **£372.25** for the Trust.

Jenny Beale
1939-2011

Rebecca Hindley took part in the BUPA Great South Run on 30th October 2011 and also a half marathon in Vegas. Rebecca raised **£1405** for the Trust in memory of her mum Jenny Beale who sadly passed away in 2011 having been diagnosed with Wegener's. Rebecca works for Barclay's Bank who will match the fundraising amount of any of their staff. We are grateful for Barclay's generosity.

Paul Hughes took part in the Great North Run in September 2011. Paul's mum had recently passed away having suffered from WG. Paul has now managed to raised approximately **£1000** for the Trust.

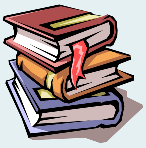
Holly Hampshire Just before Christmas Holly organised a "Pamper Party" at her local beauty salon for her family and friends. The had a wonderful evening and managed to raise **£82** for the Trust.

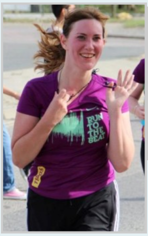
Continued on page 17

Our Fantastic Fundraisers (continued)

Dr Neil Holden of Birmingham University Hospital ran in the BUPA Great Birmingham Run on 23rd October 2011. Neil raised **£330** for the Trust.

Penny Hilton of Sheffield kindly raised a magnificent **£835** for the Trust by holding a 'Book sale'.





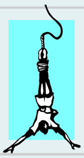
Joanne Jones competed in the "Running to the Beat" half marathon on 25th September 2011. Jo raised over **£530** for the Trust in memory of Claire Grossman (nee Soper).

Lindsey Sutton celebrated a special birthday in 2011 and she requested donations to the Trust and to her church in lieu of presents. Lindsey kindly donated **£190** to the Trust.

Margot, Nicole and Roy Palmer of Moycullen, Co. Galway kindly donated **£100** to the Trust

Emily Sutton and the family and friends of the late Professor Frank Neil have now increased their donation to the Trust, in Frank's memory, to **£565.**

Charlotte Williams bungee jumped in February to raise funds for the Trust. So far Charlotte has raised **£245.**



Jennifer Wormald has again been busy on behalf of the Trust by making and selling her bead jewellery and by selling her Christmas cards. From both sales Jennifer has raised **£230.**

Andy Bone - "Sports-Shots"

Andy, is raising awareness of vasculitis and funds for the Trust via sales and donations from photographs. Details can be found on his "Sports-Shots" Facebook site: (www.facebook.com/sportsshots) or visit his new website www.sportsshots.org.uk or his JustGiving page.

Jennifer Wormald & Rita Allen - Bead Jewellery

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

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.

Gift Aid — worth an extra 20p in the £ to the Trust

Whether you are making a one-off donation, a regular standing order, direct debit or a sponsorship donation please use Gift Aid if you are a UK tax payer.

giftaid it

Disability Living Allowance & Attendance Allowance

If you are in receipt of DLA or AA you may be entitled to various other types of help. *Sometimes the entitlement will depend on you being in receipt of a particular component of DLA or a particular rate of AA.*

Some of these entitlements include:

Possible increase in other means tests benefits or tax credits,

Energy efficiency grants

Exemption from road tax (vehicle excise duty)

Blue badge (contact your local council)

Public transport concessions

Companion Entitlement (Scotland only)

Motability scheme - (allows you to exchange part or all of your allowance to lease a car of your choice) www.motabilitycarscheme.co.uk/main.cfm?type=CHSW

For more information on DLA use the "search this site" box at: www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10018702

For more information on AA: www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10018710

A complete list of benefits can be found at:
www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/index.htm

www.direct.gov.uk/en/DisabledPeople/FinancialSupport/index.htm

Regional Support Group Meetings

West Country VSG: In October the West Country group arranged a talk by Dr Lucy Smyth, Consultant Nephrologist at Exeter's RD&E. It was an extremely interesting and informative evening with plenty of lively interaction between Lucy and the audience! We would like to thank Dr Smyth for her time and for putting information about a very complicated disease into understandable, layman's terms!

West Midlands (WMVSG) Over fifty people attended this meeting at the Bromsgrove Hilton. The group, probably the first of its kind, was started by Margaret Gentle in 1993. Margaret is still very much involved, but much of the organisation is now undertaken by David Sambrooks and Judy Ross, with the aid of newcomer Tom Osborne.

The meeting received two very interesting presentations. (These are reported elsewhere in this issue.). The first, by Dr David Carruthers was on "Diagnostic Techniques" (see page 5). The second, by Dr Andrew McClean was on "Fatigue in Patients with ANCA-Associated Vasculitis". (see page 6).

Surrey VSG: The photo shows some of the members at the October meeting. You can see by their attire what a wonderful day they had — the sun shone. Maggie and Paul hosted the informal lunch at their home. New and present members and their carers enjoyed chatting to one another about their particular type of vasculitis.

The 2nd meeting of the **Yorkshire VSG** was held in October 2011. The guest speaker was Dr Robert Stevens, Consultant Rheumatologist at Doncaster Royal Infirmary. About 40 vasculitis patients and their partners/carers attended the meeting. The majority present had WG but, there were also patients with Microscopic Polyangiitis, Cryoglobulinemic Vasculitis, Giant Cell Arteritis and Takayasu's. A number of members were newly diagnosed.

Dr Stevens' presentation was a one-man tour-de-force which held the attention of the members throughout. To begin the session Dr Stevens ascertained which types of vasculitis the members had. The next step was to ask about their main areas of concern. These included: difficulty of diagnosis, life expectancy, fatigue, fear of relapse, muscle weakness, hereditary problems, choice of treatment, infections, self help, and remission. Dr Stevens then ensured that throughout his presentation he dealt with all these concerns. He went through the individual vasculitis diseases in some detail, with the emphasis on the practical aspects and patient perspective.

On diagnosis he said that the earlier the patient was seen by the appropriate consultant the better the outcome. He said that nationally there was increasing awareness of vasculitis amongst medical professionals which would help speed the diagnosis process. Asked about Rituximab he said that many Trusts were not funding this drug routinely but this was gradually changing, particularly where other therapies were not appropriate or in the case of relapse.

In all it was not only a very comprehensive overview of the vasculitis diseases, but a most interesting and enjoyable presentation, set at a level understandable to all.

Northern Ireland VSG: The meeting was held in November 2011 at the Premier Inn, Dublin Airport and was very interesting and enjoyable, (and the soup and sandwiches afterwards were very good!). Ten people attended, (6 patients and 4 carers), and a good mix of vasculitis diseases, Polyarteritis Nodosa, Takyasu's, Giant Cell Arteritis, and Granulomatosis with Polyangiitis.

There was informal discussion about diagnosis, treatments experienced, hospitals/consultants attended, and the Irish Healthcare system. Adjusting to lifestyle changes were also discussed, some have had to retire while others still work. In fact one lady has just been made permanent in her job which was very encouraging to hear.

The group hope to hold an all Ireland meeting over a weekend in May - Vasculitis Awareness month - with speakers and social elements.

The **Cambridge VSG** held a well-attended meeting on 4th November 2011. Dr Sauna, Specialist Registrar at Addenbrooke's gave an update on exciting research into genetic links with ANCA associated vasculitis.

The two vasculitis conditions currently being investigated are GPA (WG) and MPA. The research has involved co-ordination of many patients across numerous sites within the UK and Europe. This co-operation has achieved a large enough sample to make conclusions valid. The outcome of the first stage of the current investigation is due to be published shortly. It is hope that further research will allow the better targeting of treatment for individuals in the future.

Thanks were extended to Jenny Fulford-Brown and family members for their time and efforts in arranging the event.

Lincolnshire VSG The first meeting of the group took place in Digby, Lincolnshire on 12th February. Despite the recent cold and snowy weather, everyone who had promised to come did indeed manage to make it.

The small group proved to be a friendly and informed set of people with much to offer. Medical histories were exchanged, as were hospital and drug therapy experience. Three members had Wegener's, the fourth Microscopic Polyangiitis and there was much common ground.

There were questions and observations about a possible viral link, transitory psychiatric problems, seasonal variations, links with familial auto immune histories, etc. All agreed it was good not to feel alone with this disease.

A further meeting is planned for the Spring. (See Pam's details below.) Please join us if you can, you will be made very welcome!

North West VSG

The 2nd meeting of the group was held on 4th March. A full report will appear in the Autumn issue. Meanwhile the photo shows the group leaders — Jann and John, with Drs McDowell and Dhygude in the centre.

Oxfordshire VSG

The photo shows the Oxfordshire group at their meeting held on 4th March. The speakers were Dr Jo Robson and Prof Raashid Luqmani. A full report will appear in the Autumn Newsletter

Support Group Contact Details

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Cambridge VSG
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margaretmcgrathfmsj@yahoo.com

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Lincolnshire VSG *New*
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ayla.todd@gmail.com

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vincentf51@hotmail.com

Norfolk (*Contact person: **not** a group*)
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Oxfordshire VSG
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oxonvsg@hotmail.com

Republic of Ireland (*Contact person - **not** a group*)
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dwodo@iol.ie

South East London/North West Kent VSG *New*
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jacqui.moran1@ntlworld.com

Surrey VSG
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West Country VSG
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krawlinson@waitrose.com

West Midlands (VSGWM)
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mgvsgwm@blueyonder.co.uk

West Sussex VSG
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johnbee4@googlemail.com

Yorkshire VSG
Pat Fearnside 01709 583722
vasculitis.uk@btinternet.com
Jennifer Wormald
01937 586734 jenw@bethere.co.uk

The Ring A support group in Norfolk for RA patients.
Judith Virgo jvirgo@fsmail.net

Starting a Vasculitis Support Group

Have you ever considered starting a Vasculitis Support Group in your own area? You don't have to start big with a venue and speaker, it could be a small gathering at home or in a local pub. This is an excellent way to support other vasculitis patients, and much less stressful for the organisers.

All the Support Groups are autonomous in that they are not "administered" by the Trust. However, it is one of the aims of the Trust to help and support the Support Groups.

We do our best to ensure that meetings are well attended by advertising them in "Dear Diary" in the Newsletter, the e-News, on the Facebook site, on the Health Unlocked site and the website. For those wishing to start a group the Trust will advertise their endeavours. We will check the main database for all members in that area and write to them with full details about the meeting. We can supply posters for the local hospitals/GP clinics etc, and send loads of "goodies" - balloons, pens, stick-it notes etc. We also have a leaflet available to give you ideas about how to set up a Group.

If small groups wish to branch out and arrange meetings where venues have to be booked, speakers arranged and maybe food ordered, then the Trust will be willing to consider making a donation to ensure that the organisers are not out-of-pocket for the first meeting and that they have a small float for further meetings.

Why not check the Support Group list on page 19. If there isn't a group in your area then contact John Mills or Pat Fearnside (details on page 24) to discuss setting up a group.

Travel Insurance

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

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

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

POST OFFICE®

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

Please stay in touch

Keep your details up-to-date

e-News

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

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

Newsletter/Journal

To update your home address or other details on the database, please write or e-mail John Mills.
Contact details on page 24.

Raising awareness of vasculitis and of the Trust

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

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

Statue found lurking in the snow.
Who does this remind you of?

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

Autumn deadline — 31st October 2012

In Memoriam

Often donations or funeral collections are made and given to the Trust in memory of a particular individual. Most, but not all, suffered from vasculitis themselves, or possibly a family member did. Many of us with vasculitic disease are past the first flush of youth and may have been living with the disease for many years. It is sad, but not altogether surprising, that we do get a few deaths to report each year.

Our sympathies are extended to the families and friends of those mentioned below. The Trust is extremely grateful for the kind and generous donations and bequests received. These will help us with the activities of the Trust, especially our research projects.

Jean Moyra Bazeley

Jean of Leighton Buzzard passed away on 26th June 2011. Jean's family and friends kindly donated £90 in her memory to the Trust.

Ruth Merrick Harley

Ruth of Kislingbury, Northants passed away on 26 November 2011 aged 76 years. Her family and friends kindly donated £711.23 to the Trust in Ruth's memory.

John Hurry

John of Billingham, Cleveland was diagnosed with WG in February 2011. He was responding well and enjoyed a holiday in Florida with his family. Unfortunately John's health deteriorated and he passed away on 8th November aged 68.

John was a caring family man and leaves behind his wife Yvonne, twin sons Steven & Mark, grand-daughters Megan, Georgia, Imogen & Keira and his faithful Great Dane, Scooby. John's family and friends have kindly donated £600 to the Trust in his memory.

Dorothy (Bun) Claybrough

Dorothy, known affectionately as Bun, passed away on 27th October, following a massive stroke. Only four weeks earlier she had celebrated her 50th birthday with her darling husband David.

She struggled with WG for over 32 years but had progressively got worse over the past few years.

Bun's family and friends have kindly donated £696 to the Trust in her memory.

Winifred Gertrude Pritchard

Winifred of Hereford passed away on 17th October 2011. Winifred was diagnosed with vasculitis in 1996. She was born in 1934 and was a farmer's daughter and farmer's wife. Winifred had 4 children, 10 grandchildren and 8 great grandchildren.

Her family's memories will be of clicking knitting needles, apple pies, amazing Welshcakes, and Christmas poultry feathering and dressing. Her husband, Wilfred, predeceased her by 4 years. Family and friends kindly donated £656 to the Trust in Winifred's memory.

Peggy Cooper

Peggy of Cosham, Portsmouth, the sister-in-law of one of our members (Gwenda Cooper) passed away recently. Peggy's family and friends kindly donated £30 to the Trust in lieu of flowers.

Carl Thomas

Carl of Exmouth, Devon passed away on 28 July 2011 aged 63. Donations of £144 were kindly made to the Trust in Carl's memory.

Peter Wakeman

Peter of Brockworth, Gloucestershire passed away on 20th November 2011 after a long battle with Polyarteritis Nodosa.

Peter was aged 41 and leaves behind his partner Catherine and their children Daniel aged 10 and Jasmine aged 6. Peter's family and friends have kindly donated £146.20 to the Trust in his memory.

Winston's Wish is the leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families in the UK.

They offer practical support and guidance to families, professionals and anyone concerned about a grieving child. They believe that the right support at the right time can enable young people to live with their grief and rebuild positive futures.

Contact details:
http://www.winstonswish.org.uk/ Helpline: 08452 03 04 05 **Winston's Wish Head Office:** 4th Floor, St James's House, St James Square, Cheltenham, Gloucestershire, GL50 3PR. General Enquiries: 01242 515157 Fax: 01242 546187 Email: info@winstonswish.org.uk

David Booth died last year from complications due to WG. His widow, Karen, has started a blog on Facebook. To view the blog go to Facebook and search for "David Booth In Loving Memory" or copy this rather long link:

http://www.facebook.com/pages/David-Booth-In-loving-Memory-My-unfortunate-journey-to-becoming-a-widow/227434810682169

Donating to Vasculitis UK

Important note to Members As you know, the Trust does not have a joining fee or an annual subscription fee for Associate Members. Therefore, we rely ***entirely*** on ***voluntary donations*** from Members and Supporters. It is only with such donations that the Trust can continue to:

- ***support patients,***
- ***help raise awareness,***
- ***fund research,***
- **and, of course,** ***produce, print and post these twice yearly Newsletter Journals.***

DID YOU KNOW that you can now make a ***one-off*** donation to the Trust by ***Credit*** or ***Debit card*** or even by ***PayPal*** simply by using *Justgiving.com*?

You can also set up a ***monthly Direct Debit*** to the Trust by using *Justgiving.com* Simply go to: **www.justgiving.com/VasculitisUK/donate**

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

Vasculitis UK does not pay for offices and we have no paid staff, the Trust being administered by nine unpaid volunteer Trustees. Therefore, the majority of income received goes to those things which are important to you.

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

www.justgiving.com/VasculitisUK/

and follow the instructions.

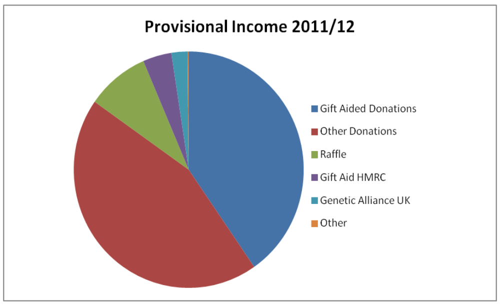
Raise funds for the Trust whilst you search the internet. To join, just go to www.vasculitisuk.easysearch.org.uk

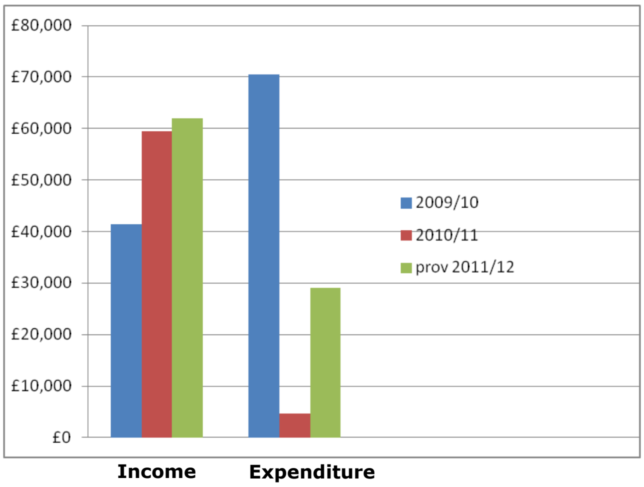
Shop online at your favourite supplier, eg John Lewis, M&S, via "easyfundraising" and raise funds for the Trust. It won't cost you a penny and it is safe and easy to use. You pay the supplier, no third party is involved with the payments.
www.easyfundraising.org.uk/vasculitisuk

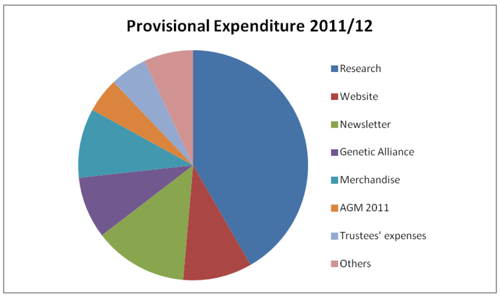
Financial Report

The Trust's financial year runs from 1st April to 31st March. Therefore, there are still a few weeks to go before the accounts can be finalised. However, I thought members might like to see how the Trust is doing financially. Below I have compared the income and expenditure results for 2009/10 and 2010/11 with the provisional results for 2011/12. Also shown are pie charts giving a segmental breakdown of provisional income and expenditure for 2011/12. A further research grant is presently being considered, to be funded from current and future income. The actual financial status will be reported at the AGM in May.

Patricia Fearnside ***Treasurer***







t-shirts, baseball hats and other goodies

NEW In addition to the wristbands, which are proving extremely popular, we now have other merchandise for sale to help boost the Trust's funds and to raise awareness. These include good quality 100% cotton t-shirts sweatshirts, running vests and baseball hats.

t-shirts £9.99 each

Running vests £11.99 each

Sweatshirts £ poa

Hooded tops £ poa

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

Baseball hats are one size. **£7.99 each**

Wristbands £1.60 each **Car stickers .99p**

Cost includes VAT and postage and packing

Name

Address

Postcode Phone No.

Item	Size	No.	Unit Cost	Total Cost

Optional donation: £

Total amount enclosed: £

Please make cheques payable to: **Vasculitis UK**

▲ To purchase the Trust's merchandise please photocopy this order form and return to: ***Susan Mills, West Bank House, Winster, near Matlock, Derbyshire, DH4 1DQ*** with your cheque payable to Vasculitis UK. Please print clearly and include your phone number, in case of query

If you are not entirely satisfied with your purchase (which we doubt) we will gladly refund the cost of the merchandise (minus postage and packing costs of course).

If you would like to sell any of our merchandise please contact Susan:
sandjmills@btinternet.com or 01629 650549

Promotional material for Vasculitis UK

One of the objectives of Vasculitis UK is to raise awareness of our rare diseases and to draw attention to the existence of ***Vasculitis UK*** both within the world of medicine and among those who suffer from vasculitis. One way to achieve this is to spread our promotional materials around the target audiences. To this end, we have purchased some very eye catching promotional material and would like to offer them to you.

Presently we have STICKY POST IT NOTES, BALL POINT PEN, and BALLOONS, all in a striking yellow/green colour combination. If you would like any of these materials to help promote our aims, perhaps by distributing them to your consultant and his/her team, or your GP, please contact Paul - details below. You may even be interested in obtaining some of the promotional items for your own or family use.

There is no charge. However, should you wish to make a donation, perhaps to cover the cost of postage and packing, that will help reduce the Trust's expenditure. Also, should you be able to use some materials in a fund raising capacity then again this will help to raise awareness and hopefully a few funds.

We hope that you will use the free CAR STICKER we have enclosed with this issue of the Newsletter/Journal.

Supplies of these materials will be distributed to the Regional Support Groups for use at their meetings.

All you have to do is to contact Paul:
paul.m.bingham@btinternet.com
01737 813389

Christmas cards 2012

Gosh, Christmas 2011 was only a few months ago and here we are mentioning Christmas 2012.

The Trust is going to venture out this year and obtain Christmas cards from a charity card manufacturer. Further details will be available during the year. We will ensure these cards are reasonably priced and good quality and hope that Members will consider purchasing them to raise awareness of vasculitis and funds for the Trust.

If you would like to sell cards on behalf of the Trust please let us know as this will affect the number we eventually order.

Life president: Lillian Strange

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

The aims of the Trust are:

- To offer support and advice for those with vasculitis and their families
- To support and promote research into the causes and treatments of vasculitis
- To increase awareness of vasculitic diseases among both the general public and health professionals
- To support the development of local vasculitis support groups
- To develop an advisory network for health professionals working in the field of diagnosis and treatment of vasculitic disease
- To encourage the development of centres of excellence in the treatment of vasculitis in the UK

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

Registered Charity No. 1019983

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

Some of the vasculitides

Behçet's Disease

Central Nervous System Vasculitis

Eosinophillic Granulomatosis with Polyangiitis (EGPA)
(Churg Strauss Syndrome)

Cryoglobulinemia

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

Giant Cell/Temporal Arteritis

Henoch-Schönlein Purpura

Kawasaki Disease

Microscopic Polyangiitis

Polyarteritis Nodosa

Polymyalgia Rheumatica

Relapsing Polychrondritis

Takyasu Arteritis

Find us on the web

Our current address is: www.vasculitis-uk.org.uk

We will soon be changing to: www.vasculitis.org.uk

Officers and Trustees

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