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We feel the need to make the whole system of research funding much more structured, formal and transparent

The “Patient – Professional Partnership”

The recent success in the NICE appraisal of the drug Rituximab for treating vasculitis, as reported elsewhere in this issue, has demonstrated the effectiveness of a patient organisation such as Vasculitis UK working alongside the medical professionals to improve quality of care for people with vasculitis. Over the past two years there has been increasing collaboration between medical professionals and Vasculitis UK. The funding by Vasculitis UK of the Vasculitis Registry (or database) is another example of this collaborative relationship and the fruits of this cooperation will become increasingly apparent over the coming years.

Educating the Professionals

One of the main problems in vasculitis treatment is failure to recognise and diagnose vasculitis in its early stage, before serious damage is done, but symptoms are vague and unclear. Thus we try to focus on making doctors more aware of vasculitis, so that they are more likely to recognise it. This year we are having stands at both the British Society of Rheumatologists and Renal Association Conferences. The BSR conference alone attracts over 1000 delegates, so we will get a chance to meet the doctors and other health professionals and talk to them about vasculitis.

Research Funding

A major part of the work of Vasculitis UK is supporting and funding vasculitis research. Until now, this has been on a rather informal basis, but now that the charity has grown, with many more fundraisers and more money to spend on research, we feel the need to make the whole system of research funding much more structured, formal and transparent.

One benefit of doing this is that Vasculitis UK will be able to attract other “partners” with big budgets to spend on research, such as the National Institute for Health Research. So our research funding will be made much more effective.

The downside is that the whole process is much more complicated and long winded than we expected, so we have only been able fund a few small projects this past year and the bank balances have accumulated. But rest assured, once the proper processes are in place we will be launching a “call” for applications for vasculitis research funding and there will be a much more rigorous and robust selection process.

Volunteers and Trustees

We are proud that Vasculitis UK employs no staff, has no offices and almost all the work of running the charity is carried out by a few people who have vasculitis themselves. But as the charity grows and we become involved in more activities it gets more difficult for the few to do everything. If you feel you can contribute in a practical way towards the running of Vasculitis UK, do please get in touch. You don’t need to make a big commitment!

RIP “Ghostbuster” Harold Ramis

We seize every opportunity to raise general public awareness of vasculitis, so any news of somebody famous being associated with vasculitis represents an opportunity. The recent sad news of the death, due to vasculitis, of Harold Ramis, star of the 1980s children’s “Ghostbuster” films, has turned out to be one of those unfortunate “opportunities”.

The members of the UK fan club of the Ghostbuster films are now approaching middle age, but a group of them, “Ghostbusters UK” have fun by holding high profile events, dressing up in Ghostbuster outfits and raising money for charity. In memory of Harold Ramis, they have chosen Vasculitis UK as their chosen charity for the next year. This will not only raise money for Vasculitis UK, but will bring the term “vasculitis” to the attention of a wider audience.

John Mills
RITUXIMAB APPROVED BY NICE FOR THE TREATMENT OF VASCULITIS

In January NICE issued new Guidelines approving the use in the NHS of rituximab (MabThera) in treating the two most common types of ANCA vasculitis - GPA and MPA - but with certain provisos.

After a lengthy process of collecting and considering evidence, lasting almost a year, the National Institute of Health and Care Excellence (NICE) has announced their decision on the merits of rituximab in the treatment of ANCA vasculitis. Their decision is that rituximab, in conjunction with steroids, is recommended as an option for treating ANCA vasculitis. This completely reverses the original decision to reject the use of rituximab for ANCA vasculitis announced in July last year.

Vasculitis UK has been very actively working with leading medical professionals since the beginning of 2013 to show that rituximab is not just as good as conventional treatment, but in certain situations it is superior and for some patients it can be life changing. Two lengthy reports were produced and submitted by Vasculitis UK and representatives from V-UK were invited to be present and to speak as Patient Experts at three meetings of the Appraisal Committee.

Following the announcement, Vasculitis UK Chairman, John Mills, stated: "We are very pleased with this final decision, which meets with most, but not quite all of our objectives. We are proud to have been able to have a significant impact on the Committee’s decision. This demonstrates that the patient voice can influence decisions that will have far reaching benefits for many vasculitis patients who might otherwise have been denied the benefits of this beneficial new drug. It also demonstrates the value of working together with medical professionals – a perfect example of patient and professional teamwork”.

This is a perfect example of patient and professional teamwork

WHAT HAS BEEN APPROVED?
Rituximab is recommended for use:-
° as an induction drug only where there has already been one or more full courses of cyclophosphamide and further use of cyclophosphamide would exceed the maximum safe lifetime cumulative dose of 25 gms,
° in cases where cyclophosphamide is contraindicated for clinical reasons or is not tolerated by the patient,
° where the person has not completed their family. Cyclophosphamide can have serious effects on fertility in males and females,
° in cases where cyclophosphamide fails to control the disease,
° in cases of malignancy of the bladder or urinary tract.

WHAT HAS NOT BEEN APPROVED?
° Initial induction with rituximab in new cases,
° Treatment of relapse except where other immune suppressing drugs have failed and further cyclophosphamide would exceed the safe dose,
° Maintenance using rituximab.

Anyone already receiving the drug for uses not approved above may continue to receive it on the NHS as long as their clinician considers it necessary.

You can read more about the NICE decision on the V-UK website: www.vasculitis.org.uk/news/nice-rituximab-jan-2014

Diary Dates

VASCULITIS UK AGM
The 2014 Annual General Meeting of Vasculitis UK will be held on Sunday 11th May - See flier for full details.

SUPPORT GROUP MEETINGS

Polite note: For VSGs please book to help with organisation and for ordering refreshments. For contact details for Support Groups please see page 26.

5th April - East Midlands VSG - Contact Susan, Lisa or Dorothy
13th April - West Yorkshire VSG Contact Lynne
16th April - Merseyside, Cheshire, N.Wales VSG - contact Susan or Dave
20th April - London North VSG - contact Dave
27th April - West Country VSG Lunch - contact Charlotte
24th May - London SE/NW Kent - contact Jacqui
12th July - South Wales VSG - Contact Jenny
12th October - West Midlands (VSGWM) Contact Dave

FUNDRAISERS
6th April - Duncan Baxter & Chris Lee - Greater Manchester Marathon
Matt Mcilgrew - Brighton Marathon
Paul Allcoat - Lochaber Marathon
Richard Morton - Paris Marathon
13th April - Matthew Richards - London Marathon
19th April - Dawn Read - Skydives
4th May - David Elvidge - Grand East Anglia Run
Holly Hampshire’s “cycle and run”
10th May - Kelly Wright & friends - Rat Race Dirty Weekend, Burghley
17th May - Thames Riverside Ramble
Beds, Bucks & Herts - VSG lunch
18th May - Nicola Allan - Aberdeen Baker Hughes 10K
24th May - Natalie Moulds & friends - Walk up Snowdon
West Country VSG Volunteering in Health Fun Day - Bric-a-brac sale
29th Sept - Carol Bryant & Rachel Hulme - The Brighton Colour Run 5K

Full details about all the above visit: www.vasculitis.org.uk/events
Doctors at 11 hospitals in the UK are conducting this clinical research study for people with giant cell arteritis or GCA. This study is testing the safety and effectiveness of an investigational drug for GCA.

To qualify for this GCA study, you must:
- Have a medical diagnosis of GCA
- Have had signs or symptoms of GCA within past 6 weeks
- Are over 50 years of age
- Meet other specified criteria

The centres undertaking the research are:
* Aberdeen Royal Infirmary,
* Whytemans Brae Hospital, Kirkcaldy,
* Freeman Hospital, Newcastle upon Tyne,
* Chappell Allerton Hospital, Leeds,
* Barnsley Hospital,
* Haywood Hospital, Stoke-on-Trent,
* Ipswich Hospital,
* Colchester General,
* Queens, Romford,
* Prittlewell Chase, Southend on Sea,
* Royal Cornwall Hospital, Truro.

You can read about the research and find contact details on the Vasculitis UK website at www.vasculitis.org.uk/news/giacta-gca-study or contact John Mills (see page 28 for details) and he will provide you with further information.

The study is receiving funding from F. Hoffmann-La Roche

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**GiACTA**

**Giant Cell Arteritis Clinical Research Study**

The prestigious 17th ANCA and Vasculitis Workshop will be held in London from 19th to 22nd April 2015.

Discussions are currently taking place with other interested parties for Vasculitis UK to co-host the Vasculitis Patient Symposium which is planned to take place on Saturday 18th April 2015.

This will be a wonderful opportunity to hold an international class vasculitis Symposium for patients here in the UK.

Vasculitis patients from the UK and abroad will have the opportunity to hear some of the world’s experts in the vasculitis field, who will be in London for the main Workshop, speaking on the latest in the international vasculitis field.

Further details will be available later in the year.

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**GSK START PHASE III TRIAL OF MEPOLIZUMAB**

On 14th February 2014 GlaxoSmithKline announced they are to start the Phase III trial of Mepolizumab.

This trial will be to evaluate the efficacy and safety of Mepolizumab antibody to treat patients with Eosinophilic Granulomatosis with Polyangiitis - EGPA (formerly known as Churg Strauss Syndrome - CSS).


The Centres involved in the trial are: Portsmouth Hospital (Prof Anoop Chauhan), Addenbrooke’s University of Cambridge (Dr David Jayne), University of Oxford (Prof Raasheid Luqmani) and University Hospital Leicester (Prof Andrew Wardlow).

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“Idealism is fine, but as it approaches reality the cost becomes prohibitive.”

William F Buckley Jr, American editor and journalist
GOVERNMENT UNVEILED RARE DISEASE STRATEGY

On 22nd November 2013 the UK government unveiled a new plan designed to improve support, treatment and research for people in the country who are affected by rare diseases. John Mills, Chairman of Vasculitis UK and Trustee of Rare Diseases UK, was part of the consultation process for this initiative.

Key features of the Strategy include:

- a clear personal care plan for every patient that brings together health and care services, with more support for them and their families,
- help for specialised clinical centres to offer the best care and support,
- better education and training for health and social care professionals to help ensure earlier diagnosis and access to treatment,
- promoting the UK as a world leader in research and development to improve the understanding and treatment of rare diseases.

View the Government policy document at: https://www.gov.uk/government/publications/rare-diseases-strategy

PAEDIATRIC FOR PROFESSIONALS PAGES

The Vasculitis UK website now has a new ‘Paediatric for Professionals’ section.

Currently included are pages on:

- Vasculitis in Children,
- the Management of Kawasaki Disease,
- Systemic Polyarteritis Nodosa in the Young, and
- the Guidelines for treatment of all forms of Paediatric Vasculitis.

The Trust is proud to have been chosen to host the Vasculitis Paediatric Guidelines which have been prepared by Dr Paul Brogan of Great Ormond Street Hospital, London.

The Guidelines are from the Oxford Handbook of Paediatric Rheumatology (with permission from OUP):


You can view the Paediatric pages at the V-UK website: www.vasculitis.org.uk/professionals/paediatric-vasculitis

RARE DISEASES DAY - FEB

Rare Diseases Day took place as this Newsletter was going to print. However, Jenny Fulford Brown attended an Action Day reception in support of Rare Disease Day at the Welsh Assembly in Cardiff on 11th February.

Here is Jenny handing over a Victor the Vasculitis UK white rabbit to Dr Chris Jones, Deputy Chief Medical Officer for the Welsh Government.

BENEFITS AND WORK

Vasculitis UK has professional membership of “Benefits and Work” an organisation who provide information which helps with all aspects of claiming benefits.

This membership allows us to provide members with information to help them preparing their claim or for an appeal.

If you are claiming or appealing about PIPs, or any other government benefit, then contact: Jann Landles - jann@vasculitis.org.uk
PHYSICAL ACTIVITY IN PATIENTS WITH GIANT CELL ARTERITIS (GCA)

Joanna Robson, Karolina Lada, Anne Miller, Wilby Williamson, Natasha Jones, Julia Newton and Raashid Luqmani. Oxford University Hospitals NHS Trust.

Giant cell arteritis (GCA) affects patients over the age of 50. It is caused by inflammation of the blood vessels and is the most common form of vasculitis, affecting one or two persons per 10,000 people in the UK. It most commonly presents with headache, scalp tenderness, jaw claudication (pain in the jaw muscles brought on by eating) and may lead to visual loss in one or both eyes, which is usually permanent. Treatment of GCA is with high dose corticosteroids. Although an effective treatment to bring the inflammation under control and protect eyesight, treatment with steroids is associated with important symptoms including muscle cramps and weakness, psychological symptoms such as insomnia, irritability, and anxiety and can increase the risk of heart disease and high blood pressure. Patients with GCA have a two-fold increased risk of heart disease compared with other people of the same age and gender.

Studies of physical activity in other inflammatory conditions, for example rheumatoid arthritis, have shown that increased physical activity supports disease control and also improves quality of life, fatigue and muscle strength and self-confidence. Many patients are nervous about taking physical activity but there is good evidence that it is beneficial. For adults, taking part in 30 minutes of at least moderate intensity physical activity on at least 5 days a week helps to prevent and manage over 20 long term conditions, including heart disease, stroke, type 2 diabetes, cancer, obesity, mental health problems and musculoskeletal conditions.

We investigated levels of physical activity in patients with a diagnosis of GCA, who were all treated with steroids, and the advice given to patients. We identified the 102 most recently diagnosed patients with GCA from hospital records. We sent questionnaires to each patient to ask about recent physical activity using the International Physical Activity Questionnaire. We also sent a questionnaire to explore reasons why patients did not participate in physical activity, and what advice they had received from healthcare professionals, family and friends. The levels of physical activity reported by the group of patients were compared with the Department of Health 2011 guidelines on the amount of physical activity required to achieve general health benefits (see Table 1). A description of the different types of physical activity- light, moderate and vigorous is given in Table 1.

Fifty-one patients responded; participants were an average age of 74 years and 65% were female. Presenting features included headache (74.5%), polymyalgia rheumatica (51.0%), fatigue (31.4%), temporary visual loss (21.6%), permanent visual loss (5.9%) and stroke (3.9%). Twenty two (43.1%) patients reported that they walked for more than 10mins each day, 7 (13.7%) reported moderate physical activity and 1 (2.0%) vigorous physical activity every single day. Eleven (21.6%) performed a total of more than 2.5 hours a week of moderate physical activity and only 1/51 (2.0%) of these performed a total of more than 75 minutes of vigorous physical activity per week.

Symptoms including fatigue, pain, muscle weakness and stiffness were agreed to be reasons for limiting physical activity, whilst a fifth of patients were concerned about safety (Table 2).

<table>
<thead>
<tr>
<th>2011 DoH advice</th>
<th>Levels of intensity of physical activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim to be active daily</strong></td>
<td>Light - walking/strolling at 2 mph, ironing, cleaning and dusting</td>
</tr>
<tr>
<td><strong>Over course of a week, activity should add up to ≥2.5 hours of moderate intensity activity or ≥75 minutes of vigorous activity</strong></td>
<td>Moderate - walking at 3-4 mph, cycling at 10-12 mph, doubles tennis, painting/decorating, hoovering, golf, social badminton</td>
</tr>
<tr>
<td><strong>Guidelines are applicable for all adults, even those who have a chronic disease</strong></td>
<td>Vigorous - running at greater than 6 mph, cycling at 12-14 mph, singles tennis, aerobic dancing, swimming at a slow crawl at 50 yards per minute</td>
</tr>
</tbody>
</table>

Table 1. 2011 Department of Health Guidelines on physical activity for all adults.
The majority of patients did not receive any advice from health care professionals about physical activity (Table 3).

In conclusion, although physical activity has the potential to improve long-term musculoskeletal, cardiovascular and psychological problems in patients with GCA receiving high dose glucocorticoids, only a fifth of patients met national guidance on total duration of physical activity over one week. Around a third of patients recalled receiving exercise advice from their GP or rheumatologist.

Further work is needed to raise awareness of the potential benefits of physical activity for patients with GCA.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>15 (29.4)</td>
<td>19 (37.2)</td>
<td>10 (19.6)</td>
<td>5 (9.8)</td>
</tr>
<tr>
<td>Pain</td>
<td>8 (15.7)</td>
<td>18 (35.3)</td>
<td>17 (33.3)</td>
<td>6 (11.8)</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>12 (23.5)</td>
<td>27 (52.9)</td>
<td>10 (19.6)</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Stiffness</td>
<td>5 (9.8)</td>
<td>24 (47.1)</td>
<td>16 (31.4)</td>
<td>4 (7.8)</td>
</tr>
<tr>
<td>Concern about safety</td>
<td>2 (3.9)</td>
<td>10 (19.6)</td>
<td>25 (49.0)</td>
<td>11 (21.6)</td>
</tr>
</tbody>
</table>

Table 2. Reasons given for not participating in physical activity since diagnosis of GCA, n=51

Table 3. Advice recalled about physical activity since diagnosis, n=51, frequency (%)

VASCULITIS UK TRUSTEES - CHRIS STAIT & LYNNE JACQUES

The Trust is sorry to announce that Chris stood down as a Trustee in October, although his resignation was not unexpected.

Chris was one of the charity’s longest serving Trustees. It was his management skills and his business knowledge which were the essential gifts he brought to the Trust, and these are a sad loss to the Trust.

Lynne had been a Trustee for about two years, but sadly she also decided to tender her resignation in February.

Lynne’s “Yorkshire Nouse”, her efficient management of the shop and her innovative ideas will be sadly missed.

Our best wishes are extended to Chris and to Lynne and also to Lynne’s husband, and assistant/chauffeur, Sam, for their future.
WALK THE WORCESTER WAY - A FEW PERSONAL MEMORIES FROM A LITTLE WALK WITH FRIENDS ON 29TH JUNE 2013

03:45 Worcester - It's Saturday morning. I think. The grey pre-dawn light shows the forecast is right, and after a week of heavy rain, the skies are drying out. It takes an hour to sort out medication, pack a rucksack full of food and gather together any pain relief I might need later. I tape up my lower legs and cover them with compression stockings; it's not really a good look with my shorts! With my partner Hazel, we scoff a quick breakfast, load up the car with other bleary-eyed friends, and take the 30-minute drive north to the start.

06:00 Bewdley – With the group complete, I was joined by Chris Jewson, another vasculitis patient, his daughter and 11 friends and family members. Our support team (including Dilys Powell, another vasculitis patient) 31 miles, £6,500 of sponsorship and 5,000 feet of vertical ascent lay ahead of us. Maps at the ready, it was time to Walk the Worcestershire Way!

07:20 Somewhere just before Heightington – Out of Bewdley town, it wasn’t long before the first hill strung the group out into a 250 metre line. Conversations buzzed and banter bubbled, as we naïvely joked about the walk ahead. As part of the front group of 9, we had settled into a good rhythm together. Then my phone rang. The others had got lost on the golf course. Could we help them? We were already too far up the road to turn round. We tried to give directions, which was fruitless, as we later found out that they had got lost on the wrong golf course! 14 became 8 quite quickly.

10:00 Abberley; 10-mile marker. The walk up Abberley quarry was a shocker, the steep muddy slope never ending, sapping energy and enthusiasm from our legs. Miles 8, 9 and 10 were quite a challenge, with the ridge line providing views across the valley to the abandoned Witley Court and over to Ankerdine Hill. The sky was clearing and the temperature slowly climbing, buzzards floating on the breeze over the valley. We arrived at our first rest stop right on time, hot, sweaty and grateful for the water. Socks were changed, energy tablets taken as we prepared for the next leg. Sadly, 2 of our group retired with injuries and were whisked home by our support team. It would be another 3 hours before the trailing group arrived.

12:10 Martley: Halfway. The next 5 miles passed in a blur. Uphill. Cross a field, Up a hill. Up another hill. And another. We had passed the halfway point as the sun beat down, so we paused at the Admiral Rodney in Martley, where our helper Dilys was found enjoying an alfresco lunch and iced Cider. We munched on sandwiches that had been flattened into pancakes by our backpacks, drank bottled water warmed by the sun, chewed energy tablets. By this stage my legs were grumbling too much and I couldn’t take any more ibuprofen and paracetamol, so emergency rations of tramadol were broken out.

14:05 Knightwick; 20-mile marker. The climb up Ankerdine Hill had me pull on what felt like the last dregs of my reserves, and then we were in free fall, down the steep slope and road, descending 600 feet into Knightwick, our next rest stop. We were now down to 7, with another front runner dropping back to bathe his sore feet in the idyllic River Teme and enjoy his pipe amongst the flitting damsel flies dancing in the sunshine. The last of our rations were devoured, fresh socks were applied to swollen hot feet and water rations topped up. I took a dose of MST at this stage; I had no idea if I was going to make the next mile, let alone the next 11.

18:37 Malvern. After departing from Knightwick, I found from somewhere a second wind, and took up the pace. Knowing we needed to get some miles under our belt, and from a personal perspective, whilst the analgesia was at its strongest, I pushed hard and at the fastest pace of the day for over an hour, under the shade trees that marked the ridge line of the Suckley Hills. We dropped down on to flat land at Longley Green, the Malvern Hills growing ever closer. Passing through farmland and orchards, Chris and his daughter continued to press on whilst the remaining 5 of us collapsed in a huddle under a row of apple trees, North Hill looming over us. It took the last of our water, paracetamol, ibuprofen and determination to get back up. The final 2 hours were agony, but we finished in a fair time of 12 hours 37 minutes. We had done it and beaten the Worcestershire Way!

Martyn Wells
(Finally, fun that it was, I don’t advise you try this yourselves)
RITUXIMAB - IT’S FAB! - HOLLY HAMPSHIRE’S RECENT RITUXIMAB EXPERIENCE

Rituximab is a drug I’d been hearing about for the last few years but I’d also heard it’s very expensive. It costs thousands of pounds per treatment but the results are apparently impressive.

When it was suggested to me, I jumped at the chance to give it a try. The team at Barnsley Hospital have never used Rituximab on a patient with vasculitis before but between us we agreed it was the way forward for me after a flare up. All drugs come with risks and side-effects but after weighing up the options it seemed like the best course of action.

Once the decision had been made consultations with doctors and nurses ensued, followed by tests and checks but within a surprisingly short period of time I was booked in for the first of two infusions. There’s a two week gap between each infusion and then a six month break before the next cycle of treatment.

D-day arrived and with it the expected butterflies but as I walked onto the ward, I was greeted by two other patients, who cheerily introduced themselves to me as Del and Rodney! I kid you not. I knew from that moment that despite a long day ahead, I certainly wouldn’t be bored.

After downing two paracetamol and an anti-histamine a cannula was inserted into my arm and a bag of steroids hooked up. Unfortunately after five minutes it became clear the cannula had missed my vein and the fluid was pumping into my arm which was blowing up into the shape of an egg. The nurses quickly stopped the machine and started the process again, on the other arm. Another missed vein later and we were away.

Half an hour after that the steroids had run dry and the bag of Rituximab was brought out from a back room. It was carried with a great deal of care and it may have been a trick of the light but I could have sworn it had a golden glow about it.

I must have looked pretty nervous because Del lent towards me and with a twinkle in his eye said ‘Your first time is it?’ He went on to rave about what I could expect in the coming weeks ‘You won’t really notice a difference to start with.’ Great I thought ‘But then slowly but surely you’ll start to notice an improvement. It creeps up on you but all of a sudden you’ll feel better than you are now.’

Hours passed with frequent blood pressure and pulse checks as well as jokes and laughter provided by the afore mentioned Del and Rodney. There was no getting away from the fact that it’s a long process that can’t be rushed but after the initial nerves had subsided (thanks to the friendly staff) I decided to take advantage of some time to myself. At home I have an energetic 19 month old who keeps me on my toes so the thought of some peace and quiet was quite attractive. Unfortunately that wasn’t to be. A double act was in full swing for the whole seven hours but at least I was entertained throughout.

During the infusion there were a few side effects to cope with, the most noticeable being a tendency to feel hot and bothered but that was a small price to pay in comparison to the promise of the fantastic results that were to come.

The drug must be discarded by four o’clock whether the bag is finished or not but mine was all done by half past three. I thought I’d be able to make my escape but I had to sit for another hour to make sure I didn’t have a reaction to the treatment.

When I finally got back home I felt pretty drained but whether that was down to the medication or the two-man stand up routine I’d been listening to all day I wasn’t sure. Over the next couple of days I continued to feel fatigued but that slowly lifted and a week after the treatment I noticed my energy levels improve and I started worshipping at the feet of the Rituximab gods – long may that continue.

I’d like to thank the staff at Barnsley Hospital and most especially those in the Rheumatology department and the Planned Investigation Unit. I’ve been going to the hospital for the last five years and feel I’ve always been given excellent care and treatment.

I hope this report helps others contemplating having Rituximab treatment. Take care.
A POTTED HISTORY OF THE VASCULITIDES - 5BC TO 1957

It is thought that Hippocrates first described vasculitis symptoms in the 5th century BC. However, it has only been in the past 160 years that vasculitis has been fully recognised as a distinct group of diseases.

In 1801 Dr William Heberden a London physician described the first case of Henoch-Schönlein purpura. Heberden wrote of a 5-year old boy seized with pains and swelling in various parts, sometimes in his belly with urine tinged with blood. It was in 1837 that Johann Schölein and then in 1874 that Eduard Henoch reported additional cases.

In 1866 Dr Adolf Kussmaul described the first case of Polyarteritis Nodosa and for almost 100 years most forms of vasculitis were thought to be variants of PAN. It was Dr Kussmaul who noted that the disease was associated with inflammation within the walls of the blood vessels and the signs and symptoms he described constituted a new disease.

In 1890 the most common of the systemic vasculitides, Giant Cell (Temporal) Arteritis was described by English surgeon Jonathan Hutchinson in the British Archives of Surgery. It was not until 42 years later that Bayard Horton and colleagues at the Mayo Clinic performed the first temporal artery biopsy.

Takayasu’s Arteritis is also known as “Pulseless disease”. In 1908 Makito Takayasu described the first case of what would become known as Takayasu's Arteritis at the 1908 Japanese Society of Ophthalmology.

Also in 1908 Leo Buerger of Mount Sinai Hospital in New York evaluated a series of leg amputations. He recognised that what he saw was a new disease which he called “thromboangiitis obliterans” Eventually this became known as “Buerger’s Diseases” Unfortunately Buerger did not link the disease with the main risk factor of cigarette smoking.

In 1931 Heinz Klinger reported, in his thesis, on two patients who had died from an overwhelming systemic disease. He believed that infection was the cause, and his thesis was entitled “Variants of Periarteritis Nodosa”.

It was not until 1936 that Alfred Wegener described three patients in their 30s who presented with innocuous symptoms but quickly progressed and the patients died from kidney failure within months. He recognised that this was a new disease and distinct from Polyarteritis Nodosa. The disease was named Wegener’s Granulomatosis (now renamed Granulomatosis with Polyangiitis).

It was in 1937 that Turkish physician, Dr Hulusi Behçet (Professor of Dermatology) described three patients with what was to become known as Behçet’s Disease (sometimes referred to as the Silk Road Disease). He had first recognised the disease in 1924.

In 1939 an autopsy was conducted on a 5 year old girl who was admitted with a sore throat, high fever and red rash over her body. Her tongue resembled a ripe strawberry. The disease was referred to as “infantile periarteritis nodosa”. Then in 1961 Dr Tomisaku Kawasak i recognised these symptoms in one of his patients. He undertook an epidemiological study and identified 50 patients with a disorder he called “mucocutaneous lymph node syndrome”, which by the mid 1970s became known as “Kawasaki’s Disease”.

Until 1948 Microscopic Polyangiitis was considered to be a form of PAN. It was English physician Charles Davson and his colleagues who distinguished MPA from classical PAN as their findings showed that MPA tended to involve the smallest blood vessels within the kidney.

In 1951 Dr. J. Churg and Lottie Strauss identified another branch of the “Periarteritis nodosa family’. Thirteen patients with asthma, fever, elevated eosinophils and inflammation of the blood vessels were described. It was the striking number of eosinophils that Churg and Strauss recognised as distinguishing this condition from patients with PAN. Churg Strauss Syndrome was recently re-named Eosinophilic Granulomatosis with Polyangiitis.

Polymyalgia Rheumatica was first described in 1957 and the name polymyalgia rheumatica was given to the disease by Stuart Barber. Prior to 1957 many patients were misdiagnosed as having rheumatism.

This information only highlights the more common of the vasculitides. It has been compiled from internet articles, particularly “From Kussmaul to Kawasaki - Thumbnail sketches in the history of vasculitis” - Parts 1 and 2 (2002) (http://vasculitis.med.jhu.edu)
The Large Vessel Vasculitis Masterclass was held at Birchwood Park, Warrington on Wednesday 20th November 2013. The Masterclass was attended by Richard Eastoe, John and Susan Mills.

In November last year we were invited back to another Vasculitis Masterclass organised by ReMEC (the Renal Multidisciplinary Education Committee). This year’s event was chaired by Mr Mark Field, a Cardiothoracic Surgeon at the Liverpool Heart & Chest Hospital (LHCH) and Dr Devesh Mewar, a Rheumatologist at the Royal Liverpool.

The Masterclass was well attended by about 50 clinicians, all there to hear the talks about large vessel vasculitis. As usual we had a small stand and did a brisk trade in routemaps, leaflets and newsletters. The stand was a good place to catch the attention of the visiting clinicians and we chatted to Professor Justin Mason from Imperial College London who was there to talk about Takayasu’s Arteritis, Dr Sarah Mackie who was over from Leeds and Dr Mike Venning from Manchester Royal.

Dr Janice Harper - First to speak was Dr Janice Harper from the Royal Liverpool. She spoke about ANCA Associated Vasculitis affecting the aorta, the large artery that takes blood from the heart to all parts of the body.

She told us that she has changed her approach to clinical practise as aortic problems are not as rare as once thought. She challenged vascular surgeons to think differently about cardiovascular problems and to consider vasculitis.

Dr Amira Stylianides, a medical ophthalmologist from the Royal Liverpool, then spoke about Giant Cell Arteritis (GCA). He said that early diagnosis was essential to prevent loss of vision and that clinicians should screen for the disease. Pulsed intravenous steroids are the standard treatment but he reported that there have been some promising results from using the new biologic drug Tocilizumab.

Prof Justin Mason from Imperial College then spoke about Takayasu’s Arteritis. Prof Mason again talked about problems with the aorta and agreed that Takayasu’s is probably not as rare as once thought. Early treatment with biologics such as Adalimumab and Tocilizumab is best although there are issues with funding this off license drug due to a lack of clinical trials. Prof Mason is a big fan of Magnetic Resonance Angiography (MRA) to detect the disease before it causes narrowing of arteries. He concluded that research is required into creating a scoring system for MRA screening as the traditional BVAS scoring is not sensitive enough for large vessel vasculitis.

Mr Aung Oo - After lunch Mr Aung Oo, a Cardiothoracic Surgeon at LHCH, talked about the timing of surgery in vasculitis. Mr Oo showed us some beautiful pictures of his home country, Burma by way of some light relief from the incredible but rather graphic pictures of his aortic surgery! But Dr Oo confirmed that inflammation from vasculitis should be treated where possible before surgical intervention. He also agreed that a multidisciplinary approach to treatment was essential.

Dr Manos Panagiotidis - Finally Dr Manos Panagiotidis from University College London talked about Positron Emission Tomography (PET) and Computerised Tomography (CT) scans in testing for vasculitis. Dr Panagiotidis said that whilst PET scanning is useful in diagnosing large vessel vasculitis, it is unreliable for assessing inflammation in GCA. He thought there was a need for further research and studies.

At the end of the day there was a fascinating group discussion about imaging techniques and screening for aneurysms and underlying disease activity. The group agreed that up to two years ago cardiologists knew very little about vasculitis and there is still no screening for cardiac issues (such as regular Troponin blood tests or taking the “6 minute walk” test). The group also wondered whether they were missing Central Nervous System Vasculitis where currently a brain biopsy is essential in diagnosis.

So it was another fascinating day in Manchester. We saw clinicians from very different disciplines all coming together to discuss large vessel vasculitis. I think all the clinicians present benefited from the exposure to such a wide range of disciplines and ideas on the diagnosis, monitoring and treatment of these diseases. I continue to be impressed by the enthusiasm and interest these clinicians take in their work. Days like these can only be of benefit to all vasculitis patients such as ourselves.

Richard Eastoe
LITTLE T’S HOLIDAY COTTAGE
HOLT, NORFOLK

Tracy Martin has raised awareness of vasculitis and several thousand pounds for V-UK with her themed balls. Tracy also raised funds for the Trust through the kind donations made by those who stay at her holiday cottage.

If you would like to hire the cottage, sample the fish and chips and visit this lovely part of the country, please contact Tracy: 01359 233343 (answer machine).

You will find full details and photographs at:
www.littletscottage.co.uk
e-mail: littlet@lineone.net
or write to: Tracy Martin, 10 St Mary’s View, Pakenham, Suffolk, IP31 2ND

V-UK FUNDS AN IMPORTANT RESEARCH PILOT STUDY

V-UK is part funding a pilot study to be carried out by Dr Nina Brown, of Manchester University Hospital. Nine hopes to establish whether “micro-RNA” particles can be found in blood plasma in different levels according to whether the disease was active or in remission and if these particles can also be detected in the urine.

If there is found to be a correlation and the particles are also found in urine, it might be the key to a new biomarker for disease activity, thus aiding diagnosis and monitoring of maintenance. In addition it might lead to new drug therapies that would reset the immune system.

If the theory proves correct, it would lead to a much larger clinical trial to produce some hard clinical evidence in statistically significant numbers.

The majority of the funding for this pilot study is being met by the Manchester Renal Research Fund.

DONATING TO VASCULITIS UK

Thank you to everyone who has donated to the work of Vasculitis UK.

Whether your donation was £5 or £5000, a one-off or an ongoing standing order, the charity is so very grateful that you thought of us, and we send our heartfelt thanks. Our work is only possible thanks entirely to voluntary donations. Without your financial support we could not meet our aims of supporting patients, raising awareness and helping to fund vasculitis research here in the UK.

As you know, we do not have an annual donation or a joining fee. However, if you don’t already make a voluntary donation, please consider donating at least £6 a year towards the cost of your two biannual Newsletter Journals. Each Newsletter costs V-UK £3 with printing and postage costs. Donating just £6 a year will cover these costs and enable us to use our finances for the benefit of all vasculitis patients.

Unlike many charities we have a Board of unpaid Trustees and we have no paid staff or fancy offices.

You will find a Donation Form enclosed with this Newsletter, or you can pay by card at: www.justgiving.com/Vasculitis/donate or you can donate via PayPal.

If you pay UK tax please Gift Aid your donation. For every £5 donated we are able to claim an additional £1.25 from HMRC. Thank you.
V-UK’S ROVING REPORTER INTERVIEWS DR RICHARD WATTS

Dr Richard Watts is a consultant rheumatologist in Ipswich and senior lecturer at Norwich Medical School and Visiting Professor of Rheumatology at University Campus Suffolk. However, there is even more to Richard. Along with Professor David GI Scott, Dr Watts was co-editor of the excellent reference book “Vasculitis in Clinical Practice”. He has also been the author and co-author of numerous publications on vasculitis and is heavily involved in vasculitis research.

During the Autumn of 2013 Richard joined Professor Lorraine Harper as a medical advisor to Vasculitis UK.

First of all, Richard, welcome to Vasculitis UK. Can I start by asking you to tell us if you have always wanted to be a doctor, and what made you decide on rheumatology and in particular vasculitis?

My parents were both doctors and it is fair to say that if they had not been then I probably would not have become a doctor. I decided to become a rheumatologist whilst working in London as a registrar for an especially good teacher who made rheumatology an exciting and interesting speciality. This was just at the time when modern immunosuppressive therapy was just beginning to make a difference to patients with arthritis. My interest in vasculitis was sparked by Professor Scott, when I was working for him in Norwich in the early 1990s.

You work with a team at Ipswich, are they part of the key to the success of the clinic?

Team working is key to running a successful rheumatology clinic, particularly one with a focus on conditions such as vasculitis which require the input of specialists from different disciplines together with nurses, physiotherapists and occupational therapists.

Is yours a multi-disciplinary clinic, and do you think this is the future for the treatment of vasculitis?

We have access to most of the different specialists that we need either in the clinic or through close collaboration. The future pattern of care for patients with vasculitis will be through clinics linked through regional networks to specialist centres. The specialist clinics will be multi-disciplinary but those in more peripheral units may not be, but even so they should have ready access to all required specialists. The challenge is to provide high quality care to all no matter where they live. In rural areas such as Suffolk where I practise this is a challenge because of the distances involved with relatively poor roads and public transport. The recent completed British Society for Rheumatology guidelines on the management of vasculitis, together with work from NHS England, are providing considerable impetus to development of this model of care.

A great deal of your involvement in vasculitis is research, can you tell us about your latest project?

My main research interest remains the occurrence of vasculitis in different populations. We are in the process of trying to establish a new study to look at the occurrence of giant cell arteritis in the communities of Norfolk. We are particularly interested to look at the occurrence of visual impairment in of giant cell arteritis and whether we can identify any risk factors. Another ongoing study is looking at the occurrence of vasculitis in people of different ethnic origins as there are suggestions that vasculitis is not evenly distributed across the world. Establishing whether there are differences may provide important clues about the causes of vasculitis, which by and large are unknown at present.

How important is patient participation in your research work?

Patient participation is key to successful research, not only as participants in studies, for example by taking part in clinical trials of new medications or donating blood samples for genetic studies. They are also very important in determining topics and areas that require research and thereby helping develop research studies that will help answer questions of importance to patients. It is only too easy for the academic researchers to study areas, which impact relatively little on patients.

You are involved with EUVAS and UKIVAS how important are these organisations in raising awareness and treatment of vasculitis?

Both these organisations are important in raising the awareness of vasculitis amongst clinicians. EUVAS in particular has been instrumental in successful conducting several international clinical studies, which have laid the foundations on which much of present treatment strategies are based.

Your professional life is so busy, but which part do you enjoy most?

I particularly enjoy caring for patients over many years. Most patients with vasculitis require treatment lasting months to years and therefore over this period of time one builds up a long term relationship with them.

The prestigious ANCA Vasculitis Conference will be held in London in 2015. Will you be involved?

I very much hope to be actively involved in whatever the organisers’ wish.

Thank you so much for taking the time to participate in this interview. Perhaps I could finally ask - you lead a very busy life, but does Dr Richard Watts get time to relax, and if so, how?

My main relaxation is walking in the Alps high above the Rhone valley with my family, otherwise it is growing fruit and vegetables in my garden in Suffolk.
ANOTHER MAY ANOTHER VASCULITIS AWARENESS MONTH

It doesn’t seem like nearly twelve months since the last Vasculitis Awareness Month, but it is.

The month isn’t about raising money for the Trust (but we won’t turn it away) it’s about raising awareness of vasculitis diseases.

Here are a few ideas:

- why not contact your local newspaper to tell your story,
- hand out vasculitis leaflets at your office or school,
- Speak to your local WI,
- hold a coffee morning or have a tea party for friends and tell them about vasculitis,
- run a cake stall - this is everyone’s “cup of tea”,
- hold a quiz night,
- have a book stall.

Whatever you do, Vasculitis UK can provide you with leaflets and balloons. If you have an event and hold a raffle, to raise money for the Trust, then we can provide a Winston Bear or a Victor the White Rabbit as a prize.

We also have some goodies for sale in the shop, like our smashing new cotton shopper, which will help you to raise awareness wherever you shop.

For further details contact Jann Landles (Vasculitis UK Hon Secretary). (see page 28 for contact details).

EAST ANGLIAN LUPUS UK INFORMATION DAY - RICHARD EASTOE

Back in October last year, my partner Suze and I went along to a Lupus Information Day at the Welcome Trust Conference Centre near Cambridge. We had kindly been invited to take an information stand by Shelagh Cheesman of the East Anglian branch of Lupus UK.

For those not familiar with it, lupus or systemic lupus erythematosus (SLE) is another autoimmune disease, like vasculitis. In fact some lupus patients have vasculitis as a secondary condition. So the event was an excellent opportunity to meet and offer help and information to people who might not have otherwise heard of Vasculitis UK.

We set up our table in the foyer of the conference centre alongside the local branch of the PMR-GCA UK charity. Charlotte and Peggy explained how they supported people with polymyalgia rheumatica and giant cell (or temporal) arteritis. So we had a lot to share and chat about before everyone started arriving.

The event was fully subscribed with around 300 people attending. Not surprising given the calibre of some of the speakers!

Known better by us for his work in vasculitis, Dr David Jayne was there and talked about “Current and future treatments for lupus”.

Dr Frances Hall, a consultant Rheumatologist, talked about associated conditions such as Raynaud’s and Sjögren’s.

Julie Burkin, an occupational therapist, gave a very interesting talk about coping with stress and fatigue, a problem which we share with lupus patients.

Jane Hollis also talked about her role as a lupus specialist nurse. Jane told me afterwards that she works closely with Stella Burns who some of you will know as the vasculitis specialist nurse at Addenbrookes.

During the breaks we had a brisk trade in routemaps and information leaflets. Hopefully we made some new friends and it was nice to put faces to VUK Facebook group members who said hello too!

At the end of a very interesting day, I think I’d learned a lot about Lupus. It was fascinating to hear how similar some of the problems and treatments that lupus patients have to live with are to those of vasculitis patients.

If you’re interested in Lupus or any of the associated talks (I’d particularly recommend the energy and stress one by Julie Burkin) they are all available online at: www.northantslupusgroup.org.uk/videos-and-recordings.

CONGRATULATIONS TO MR & MRS ANDY BONE

Andy has been a member of the Trust for many years and he was the previous V-UK Treasurer. It was Andy’s stewardship of the finances which ensured that the charity continued when it was feared that the then Stuart Strange Trust would be wound up.

It was with great pleasure that we received news, in October, that Andy and his partner Lorna had finally tied-the-knot. We wish Lorna and Andy every happiness in their life together as man and wife.
It started with a cough - a "nasty cough" as someone commented - which lasted for eight months. It didn’t respond to over-the-counter medicines or the antibiotics or nasal/throat sprays prescribed by my GP. Chest x-rays, a CT scan and lung function tests were all normal.

As time went by appointments at respiratory medicine clinics resulted in no definite diagnosis. Various conditions were considered - TB, bronchiectasis, lupus, even malignancy. It was then that the vasculitis diagnosis was finally agreed on, and a "kick-start" dose of 60mg Prednisolone was administered intravenously. What joy to be told within a couple of days that the very high inflammatory markers in the blood had plummeted to near-normal levels. "This is magic stuff!" It appeared I did have temporal arteritis after all; the consultant rheumatologist saying it was very unusual for it to go to the legs. There I was with cellulitis which necessitated a lengthy regime.

Meanwhile I began to feel extremely ill and suffered the most excruciating headaches. I remember, but not fondly, many days spent laying on the sofa waiting for the painkillers to take effect. I lost two stones in weight - not a slow weight loss but a rapid and alarming loss.

Then a strange thing happened. Eating and chewing became difficult due to acute pain in the jaws. Had I known it (if I had that magic science hindsight) these were classical symptoms of temporal arteritis, aka giant cell arteritis. A couple of doctors did feel my temporal arteries, but apparently there was no hardness or enlargement, so that possibility was discounted.

Then another strange thing. Walking became painful because of cramp-like sensation in the calf muscles, and I couldn’t walk more than about twenty yards without stopping. "What now?" Gradually the left leg became colder and colder and the foot turned an increasingly darker shade of blue. It got so painful that I couldn’t put it to the ground let alone bear any weight on it. Observe me, if you can, hopping around, hanging onto furniture, afraid to venture outside!

In February 2010, six months after the troubles began, I was admitted to hospital with critical ischaemia (lack of blood supply) to the foot. There I underwent by-pass surgery - veins being taken from both arms to provide a supply of blood to the offending foot. This was a particularly interesting experience as I am a retired radiographer and had spent many years "on the other side", dealing with and caring for sick patients. An interesting observation from my small granddaughter “Grandma, why have you got those scars all down your arms?” Strangely enough she was not impressed by my brief explanation of the operation!

It then was that the vasculitis diagnosis was finally agreed on, and a "kick-start" dose of 60mg Prednisolone was administered intravenously. What joy to be told within a couple of days that the very high inflammatory markers in the blood had plummeted to near-normal levels. "This is magic stuff!" It appeared I did have temporal arteritis after all; the consultant rheumatologist saying it was very unusual for it to go to the legs. I then "entertained" a succession of medical students who came to investigate "this interesting case".

Following three weeks in a nursing home, I was deemed strong enough to go home. I was living alone (thankfully in a bungalow) as my dear husband had died, after a short illness, just after my symptoms began. A definite connection there, I think, but some medics may not think it’s obvious.

The leg graft served me well for six months and I gradually got used to walking again - just short distances with a Zimmer frame. Then, more leg pain - the blood supply had coagulated. No more veins were available, so a second operation has given me a polythene tube to act as an artery. However, I developed cellulites which necessitated a lengthy course of intravenous antibiotics. My hospital stay was extended by six weeks. What upset me greatly was that one poor little cat spent a total of three months in the cattery.

Gradually decreasing doses of steroids have kept the vasculitis at bay, but I have had two blood clots and have added Warfarin (for life) to my medication regime.

The last four years have been a learning curve, adapting to living alone and being disabled, having other people to do jobs for me - housework, gardening, window cleaning., shopping and driving me to hospital appointments.

Obvious physical disability evokes different reactions. "Can't that lady walk?" asked a little girl when seeing me on my disability scooter, or the waitress who ignored me in my chair and asked my two companions "table for two?"

Contemplating an outing or a job is like being an army general working out the logistics of preparing for a battle. I rather enjoy the challenge but not the reason for it. I have, however, experienced great kindness from friends, neighbours and complete strangers. I also have a very supportive family, although none of them live near. I am happy to say I have no cause for complaint about my health professionals.

More recently heart failure has been diagnosed (family genes are responsible). This condition affects the lungs - so it's back to coughing again!
Hi to everyone in Britain. I’m pleased to be sending you my second Letter from America.

So much has been happening, so where do I start?

Thanksgiving

As you know, we celebrate Thanksgiving in November. Perhaps you didn’t know that each Thanksgiving, the President “pardons” a hand-selected turkey, sparing the gobbler from someone’s dinner table and ensuring the rest of its days are spent roaming on a farm, doing whatever it is turkeys love to do. Twenty-three turkeys had been pardoned, and in 2013 President Obama pardoned “Apple” No. 24.

You can read about the Presidential pardon and the history behind it at:


‘American football player goes to the Super Bowl’

America football is a big deal here and the biggest game of all, the Super Bowl, has just been played (2nd February).

Amongst the thousands in the crowd was teenager Nate Carter. He nearly died after being diagnosed with WG and even after surviving, doctors told him he’d never play American football again.

But he defied those odds and as part of his fight to get back out on the field NFL Films made a documentary featuring Nate’s story. That programme was shown on American tv prior to the Super Bowl.

Nate and his parents were given tickets to the game after getting a personal message from former president Bill Clinton

Son of Rituximab

So your NICE have approved Rituximab for the treatment of WG and MPA. That’s great news.

In January we received this exciting news: Gazyva (obinutuzumab), Genentech’s successor to its own long-time blockbuster drug Rituxan (rituximab), gained US approval — the first under the Food and Drug Administration (FDA)’s breakthrough therapy designation.

Gazyva’s dual mechanism of action: the antibody binds directly killing B cells, and through antibody dependent cytotoxicity it recruits the immune system to attack B cells.

So it’s the US first and hopefully the UK soon.

Ghostbuster and Groundhog Day actor/writer - Harold Ramis

Sadly, I end this letter with the news that on 24th February actor/writer Harold Ramis (above right) died due to the complications of vasculitis. Harold was 69 and was diagnosed in 2010.

That’s it from me for this time. Keep well, keep positive and keep happy.

Ji

VASCULITIS WEB DISCUSSION GROUPS

HealthUnlocked - A private group where you can set your own levels regarding who can see your posts. All posts are relevant to vasculitis. Join at: healthunlocked.com/vasculitis-uk

Facebook There are now four Facebook groups. Three of the groups are Closed groups**. Your posts can only be read by members of the group:

Vasculitis UK (SSVT)** Join the original group at: www.facebook.com/groups/16351007695/

Young Vasculitis** For patients aged 16 to 30ish. Join at: www.facebook.com/groups/5052015

Bereavement Support** For those who have lost loved ones because of vasculitis. Join at: www.facebook.com/groups/18400764835810/

Timeline (Cause) information Up to date information, news, photographs and much more. View at: https://www.facebook.com/VasculitisUk

Twitter - Join at: https://twitter.com/vascuk
MARTYN WELL’S INTERNATIONAL COOKERY -
FRAGRANT THAI CHICKEN CURRY WITH JASMINE RICE

This is a great recipe for spring, for a quick and unctuous supper that will warm you up after a late afternoon walk, or as a reward for some pottering in the garden as the nights start to draw out. Your kitchen will fill with the delightful aromas of Thailand as you cook it, and is packed full of healthy anti-oxidants from the spices. If you prefer a lower fat version, you could use half full coconut milk, or substitute 200ml of the coconut milk for chicken stock. As this dish uses chillies, garlic and ginger, do remember to wear gloves if they irritate your skin.

Ingredients: (serves 2 extremely hungry/high dose prednisolone or 4 normal appetites)

4 chicken breasts
1 packet of fine beans
3 sticks of lemongrass
Thick sized piece of ginger or galangal (if you can get the latter)
4 plump cloves of garlic
3 shallots (or 1 big eschalion shallot if you prefer)
Bunch of coriander
3 shallots (or 1 big eschalion shallot if you prefer)
Bunch of basil (even better if your supermarket does Thai basil, but not important)
4 kaffir lime leaves (if you cannot get these, use the juice of 1 fresh lime)
2 green chillies
2 tablespoons of Fish sauce (Nam Pla)
2 tablespoons of Palm sugar (you could use Jaggery if you have any, or even granulated. Just not icing sugar please)
½ teaspoon caraway seeds (if you don’t have these, omit them)
400ml can of coconut milk
1 mug of Jasmine rice
6 tablespoons vegetable oil
Salt to season

Method:

1. Smash the lemongrass stalks on a board with a rolling pin, discard the outer couple layers, trim off the hard bit from the root, and the fibrous bits at the top. Roughly chop and throw in a hand blender
2. Peel the ginger or galangal, roughly slice, and whack in the blender, along with the peeled garlic, peeled and roughly chopped shallot, the stalks from the bunch of coriander (reserve leaves for later), half of the basil, the kaffir lime leaves or lime juice, the green chillies roughly chopped (remove seeds if you only want flavour and not heat too), caraway seeds and about 2 tablespoons of oil
3. Whizz the hand blender until you have a thick and fragrant green paste, keep scraping the sides of the blender and add a little more oil if required. This is the curry paste we will use as the base of sauce
4. Chop the chicken into bite sized chunks. Add 2 tablespoons of the vegetable oil to a wok and heat until smoking. Stir fry the chicken until sealed on all sides, then drain and reserve on kitchen paper
5. If you’ve got an extractor fan, put it on now! Add the last 2 tablespoons of oil to the wok. Heat again full pelt until smoking, then add all of the blended curry paste. Stir fry rapidly for 2 minutes ensuring it does not stick to the pan and burn. The paste will naturally darken and give off very strong aromas. Keep stirring!
6. Now add a quarter of the coconut milk, and stir in well to incorporate the cooked paste. This will help to ensure that the sauce will not split when you add the rest of the coconut milk
7. Turn the heat down to medium and add the Fish sauce and sugar. Stir well again to incorporate both
8. Add the remaining coconut milk and stir until you have a wet and sweetly fragrant sauce. Bring the sauce to the gentlest of simmers, with just a few bubbles at the side of the pan. Add the reserved chicken back into the sauce, and throw in the trimmed fine beans. Stir, and check the taste. It should balance heat, sweet, sour and salty. Adjust now with more fish sauce and sugar to suit your taste. Don’t worry too much about chilli heat at this point, which will tame slightly before serving. Stir occasionally for the rest of the cooking period and scrape any thickened sauce from the sides of the wok back into the sauce
9. With your curry gently cooking, put the Jasmine rice into a pan. Add a generous pinch of salt, then pour in cold water, just enough to cover your finger to the first joint above the level of dry rice (about 2cm above). Bring the rice to the boil, stir the pan once then cover with a tight fitting lid and reduce the heat to a gentle simmer. Boil gently for 8 minutes. All of water will become absorbed in the rice, leaving little steam tunnels. Do not remove the lid during this time
10. After 8 minutes, turn off the heat under the pan. Leave the pan alone, with the lid still on for a further 8 minutes
11. Meanwhile, remove any stalks from the remaining basil and coriander leaves. Finely chop the herbs, then add them all to the curry sauce when there are about 2 minutes left for the rice
12. Remove the lid from the rice after the second 8 minutes have passed and fluff it up nicely with a fork. Spoon the rice into warmed serving bowls. Add some chicken and beans from the curry to each bowl on top of the rice, then pour the coconut curry sauce over and serve with a slice of lime or a sprig of coriander if you are being posh.

Enjoy. Martyn
HOW TO HELP OURSELVES THROUGH DIET

A report on the talk given at the Cambridge Vasculitis Support Group in December 2013 by Jacky Davis, Dip.ION, MBANT, Nutritionist

While Jacky has not worked specifically with vasculitis, she had a wealth of information on areas that might aid vasculitis patients. She covered healthy eating; foods that might reduce inflammation; how to combat weight gain and water retention that steroids often cause; and how to put on weight for those weakened by illness.

Jacky emphasised that nutrients are essential for our biochemical processes. First and foremost, we all need a varied and balanced diet. She covered all the food types, but especially emphasised the need to eat at least 5 different fruits and vegetables every day - preferably more. And to help vary our diet, rotating 2 or 3 different breakfasts, instead of the same one every day would make a big difference!

Fats and oils are an essential part of our diet and she recommended choosing anti-inflammatory oils over those which promote inflammation. Particularly harmful "bad fats" are trans fats, which our bodies have no mechanism to cope with. These are created in some manufacturing processes and may be in shop-bought cakes, biscuits and margarine and butter-like spreads (a vagary of food labelling means that the presence of trans fats is often not listed). Saturated fats, found in meat and dairy products, are best eaten in small amounts only, as they contribute to inflammation. One suggestion was to make your own spread by blending butter 50/50 with olive oil - a much healthier option than manufactured spreads.

Particularly harmful "bad fats" are trans fats, which our bodies have no mechanism to cope with.

A number of oils have a beneficial anti-inflammatory effect. Omega 3 oils are 'healthy fats' found in oily fish such as mackerel, salmon and sardines and also walnuts, flax seeds, chia seeds and pumpkin seeds. (Fish oil has a blood thinning effect, so is not advised for anyone on blood thinning medication). Omega 9 oils, which include avocado and olive, also have an anti-inflammatory effect.

Omega 6 oils - sunflower, canola, rape seed and rice bran oils are generally healthy when consumed unheated, eg in salad dressings. They are, however, readily damaged by heating, so when cooking, keep the temperature as low as possible and heat for the least possible time.

Jacky mentioned other helpful anti-inflammatory foods such as ginger, turmeric, chilli, onions, garlic apples, carrots and sweet potatoes. Some inflammatory responses are driven by damaging free radicals. Foods containing flavonoids - the brightly coloured pigments in many fruits and vegetables - may be helpful in combating these. Purples and blues are especially potent, so blackberries and blackcurrants would be healthy choices. Shiitake mushrooms may also help to reduce inflammation associated with autoimmune disease.

Pineapple, papaya, mango and kiwi all contain protein-digesting enzymes and, if eaten between meals, may be useful in clearing metabolic waste. Celery and celeriac also help to clear waste and also act as diuretics, so may be useful against fluid retention. Other natural diuretics include parsley, dandelion, fennel and watermelon.

For those who need to gain weight - ginger was recommended to soothe stomach irritation and stimulate appetite. Grate a teaspoon of fresh root and make a tea by adding boiling water and drink before meals. Choose foods high in calories such as tinned or fresh oily fish, nut butters, avocados, oils in salad dressings and full fat dairy products.

For those who need to lose weight following a low G.I. diet was recommended. The glycaemic index (G.I.) measures how quickly a carbohydrate food is absorbed and converted to glucose in the blood. Fast releasing carbs - sugar, white bread, refined cereals, potatoes and starchy vegetables - release sugars quickly and lead to weight gain. Conversely, slow-releasing carbs - whole grains and cereals , pulses, berry fruits and green and leafy vegetables - keep us feeling fuller for longer and aid gradual weight loss. Eating protein and fibre with carbohydrates also slows down sugar release. Green tea, fennel and chia seeds are also useful as part of a weight loss programme.

When asked how to obtain calcium if dairy products were being reduced, Jacky gave values for other calcium-rich foods (mgs. per 100 g of food): kale 249, almonds 234, wheat bran 119, watercress 151, sunflower seeds 120 and tofu 128. (milk has 118mg, per 100g.) Other important nutrients which aid the absorption of calcium are vitamin D (sunlight, oily fish, full fat milk, fortified foods, and egg yolks), magnesium (seaweed products, wholewheat, green leafy vegetables, chocolate, buckwheat and nuts), vitamin K (broccoli, kale and spinach) and boron which comes mainly from plant sources, especially berries.

A quote from one of the patients in the audience shows just how well Jacky’s talk was received: “a huge amount of information to which I thought that all people sick or well should have been listening.”

One-to-one consultation - Jacky is available for consultation - email: jdadis793@btinternet.com telephone 01767 677534

References:
"Fats that Heal, Fats that Kill,” Udo Erasmus
"The Inflammation Syndrome” by Jack Challen also:
"The everything anti-inflammation diet book” by Karlyn Grimes, recommended on Vasculitis UK web page on diet.

*Editor’s note: You should always discuss major changes in your diet with your medical team.
OUR FANTASTIC FUNDRAISERS

V-UK would like to thank all those who fundraised for the Trust during the late summer, autumn and winter. Also many thanks to those who sponsored their gallant efforts.

Rita Allen - On a lovely summer afternoon in Clacton-on-Sea, Rita held a garden party which was attended by her friends and neighbours. They had a wonderful time and raised £160 for V-UK.

Elizabeth Attfield - Elizabeth held a coffee morning in November and was most generously supported by friends and neighbours. The morning raised £300 for the Trust.

Ballochmyle Ladies Golf Club, Mauchlins, Ayrshire - The ladies of Ballochmyle Golf Club and the entrants of their 2013 Tri-am match raised a wonderful £475 for V-UK. The Trust was the nominated charity of the Captain.

Bawtry Amateur Dramatic Society held a raffle during their evening performances during November. They kindly raised £173 for the charity.

Daniel Bean - In February 2014 Daniel, whose mum has vasculitis, organised a Concert in Croydon to raise funds for V-UK. Daniel’s Dad and his Sister make up the duo “Generation Gap” who entertained the audience with their lively singing act. The concert raised £2,860 for V-UK.

Helen Beatham - Helen’s father has CSS and she ran in the Robin Hood Marathon on 29 September for her dad and raised £555 for V-UK.

Brenda and George Bennett recently celebrated their Golden Wedding. Instead of presents donations to V-UK were requested. The kind donations totalled £1,000. Our best wishes are extended to the happy couple.

David Bingham - On 8.9.13 David entered the “Ironman”. David’s dad has vasculitis and this was for him. As David said “As midlife crises go, doing an ironman triathlon may not be as bad as buying a fast car or running after a younger woman, but it is pretty stupid.” However, he did it and raised a wonderful £2,170.

John Bramall - Over 4 days in October John cycled from Nice to Carcassonne in France in memory of Debbie Gregson who passed away in early 2013 from the complications of vasculitis. This was a journey of over 250 miles (403 km) over varying terrain. John’s gallant efforts raised £625

Janine Emma Brown and Team Clare - Janine and Team Clare have been fundraising during 2013 (in memory of Clare Grossman). In September they entered the Ashford 10K and in October Janine entered the Amsterdam Marathon to finish off her marathon year. During the year Janine and Team Clare have raised nearly £3,000 for V-UK.

Katie Brown - Katie ran in the BUPA Great North Run in September. Katie’s sister Sophie was diagnosed with vasculitis 2 years ago. They raised £540 for the Trust.

Buckingham Charity Cup Competition - Vasculitis UK are once again grateful to the Charity Cup Competition for nominating our charity to receive £75 from the money they raise for charity.

Debbie’s Delicious Desserts, Cake & Bake Book - Vasculitis UK is indebted to Sam Cunningham and her friends for producing the wonderful Cake & Bake Book in memory of Debbie Gregson who passed away in early 2013 from the complications of vasculitis. The Trust would also like to thank the sponsors who ensured that the cost of producing the book were met to enable all the profits to be donated to the Trust, and to everyone who bought a copy of the book. The total amount raised from the sale of the book was a staggering £6,700.

Dersingham Methodist Church, Norfolk - A Coffee Morning was held at the Church during November where the proceeds were for Vasculitis UK. The Trust were pleased to received £125 from Dersingham Church.

Patrick Dixon - in September Patrick entered the GNR. He did this because he said “I am an idiot”. We at V-UK don’t think he was an idiot and Patrick raised £200 for the Trust.

Jane Edwards decided to stay silent for 24 hours for Rare Diseases Day. We don’t know yet if she succeeded but so far she has raised £370.

continued
Our fantastic fundraisers - continued

Cory Fairhurst - 5th October saw Cory enter the “Tough Mudder” for his colleague and friend who has vasculitis. The event is a 12 mile marathon with 20+ obstacles and “a chance to be electrocuted”. Luckily that fate didn’t befall Cory. He raised £274 for V-UK and got thoroughly muddy.

Cath and Wayne Fisher – Cath and Wayne cycled the 50 miles from Glasgow to Edinburgh in the “Pedal for Scotland” event in September. Then in October Wayne entered the Great Scottish Run. Both events were in memory of Cath’s mum, Mary Hughes, who died from vasculitis in 2010. The events raised £380.

Philippa Fortesque’s Scottish Country Dance Evening - Scottish country dancing fans travelled from far and wide to join in the fun and dance reels and jigs and have a wonderful evening at the dance organised by V-UK member Philippa at Lyme Regis in October. The event raised £425 for V-UK.

Grendon Rangers FC - Grendon Rangers kindly donated £70 from the Buckingham Charity Cup towards Andy Bone’s “Sports Shots”. Andy in turn donated this to V-UK.

Paul “Hammy” Hammond - Paul was a keen runner until WG struck. Now he takes photos and raises funds for V-UK. [http://hammy8241.smugmug.com] So far Paul has raised £1,475.

Holly Hampshire’s friends do the Leeds Abbey Dash - Holly’s friends turned out in force to enter the “Dash” in November. Holly and V-UK are grateful to the team who helped Holly through the worst of her early vasculitis days. The total amount raised for V-UK was £476.

The Family Hart - Giles and family had a little “doo” at the Grypton Harvester near Enfield in December. They sold old cuddly toys, Irish music, Christmas jumpers and held a raffle for V-UK and NAPAC. They raised £450 V-UK.

Emma Hayward - Emma “Ran to the Beat” in London in September. Emma’s mum has WG and was diagnosed just before Christmas 2012. Emma has raised £252 for the Trust.

Martin Hill - Martin entered the Great Scottish Run Half Marathon on 6th October in memory of James Maitland. In total Martin has raised £255 for the charity.

Hopton CE Primary School & Rachel Marsh - £180 was raised at the school Christmas concert and by staff in lieu of Christmas cards.

Monica Hughes and Catherine Fisher - Took to their bikes for the 47 mile ride from Glasgow to Edinburgh in the Pedal for Scotland event on 8th September. They did the event in memory of their mother Mary Hughes who lost her fight with CSS in 2010. Monica and Catherine have raised £143.

Ann and Melville Jackson - In the late summer Ann and Melville undertook a rigorous challenge - a 148 mile coast-to-coast bike ride. They kindly donated their fundraising donation amount (£150) to Vasculitis UK.

Kendall-Jane Knox - Kendall is only 3 years old but she entered the Great Scottish Mini Run on 6.10.13. Kendall’s big brother has vasculitis. Mum, brother and V-UK are very proud of Kendall who raised £405. Shortly after taking part in the event mum (Claire) was rather busy having a wee sister for Kendal.

John Lacey recently celebrated his 70th birthday. Instead of presents he kindly requested donations to V-UK. His family and friends donated a wonderful £595.

Lathkill Hotel, Peak District - Christmas Food and Craft Fair - Every year the Food and Craft Fair is organised to raise money for charity. For Christmas 2013 the Fair was held on 17 November on behalf of Vasculitis UK and Weston Park Hospital in Sheffield. There was a chance to meet Father (John Mills) Christmas in his Grotto. The amount donated to Vasculitis UK was £187.

Leicester Terrace Healthcare Centre patients and staff raised £1161 for the charity by holding three different cake stalls and having a Christmas raffle.

Ian MacInness of Oban 365 (charity fundraisers) held a Hogmanay Family Party on New Years Eve in memory of James Maitland. John and Susan Mills attended the Party and were pleased to meet, James’ wife, Catriona and his daughter Marie Muir and their family. A wonderful evening was had by all and a fantastic £3950 was raised for four charities. V-UK received £658.

continued
Mackinlay & Suttie Solicitors of Barrhead, Glasgow, have kindly sent a charitable donation of £225 to the Trust.

John Mahoney celebrated his 60th birthday in 2013 and asked for donations to V-UK instead of presents. John’s friends donated £95.

Martley Coffee Morning - In November the Ladies of Martley held a coffee morning for Vasculitis UK. Martyn Wells spoke to them about the Worcester Way Walk, and Diliys Powell was also on hand. We believe that Martyn and Diliys helped to ensure all the cakes were eaten or found a good home. The morning resulted in £275 being raised.

Natalie Mouldsdales - On 28.10.13 Natalie organised a Halloween Party at Blackbrook Rugby Club in St Helens. The evening was a tremendous success. The Party was held in memory of Natalie’s late father Neale Mouldsdale who passed away from complications with vasculitis. So far Natalie has helped raise £3,200 for V-UK.

New Unity (Newington Green Unitarian Church & Unity Unitarian Church - Islington) - The Trust is grateful to the congregation of both churches and to the Rev Andy Pakula for donating £282 to the Trust from collections held during September 2013.

Valerie Pask - £115 was kindly raised by Valerie’s neighbours who joined her in November for an afternoon tea party. Lots of catching up on gossip and for Valerie a personal achievement. She says this was the first positive thing she had done since being diagnosed with vasculitis in 2013.

The Pines Medical Surgery in Kingsthorpe, Northampton held a Christmas hamper raffle and held a Coffee and Cake morning to raise funds for V-UK in memory of Debbie Gregson who was a well loved member of staff at the surgery. £1,153 as raised for V-UK.

The Possee Western Linedancers of Sheffield have again kindly donated to the charity. On this occasion they have donated £60.

Potters Leisure Resort, Norfolk and Jill O’Loughlin donated £74 from their book sale and from money raised by not sending Christmas cards.

Lucy Reveiros again made and sold her wonderful Christmas cards to friends and family for V-UK. Lucy raised £170 for the charity.

Margaret Robinson - Margaret held a Beetle Drive and a Jewellery and Candle party at her home in September and raised £103 for V-UK.

Claire Roumph, Rebecca Ledger & Joanna Hargreaves entered the Stroud Half Marathon in October. Claire’s mum has been battling WG for the past few years. The friends raised £1,500.

Amy Rowley & Craig took part in the Bridgewater Half Marathon in September. Amy was diagnosed with HSP in January 2013 so this was a major event for her. Amy and Craig raised £60 for the Trust.

St Margaret’s Church, Hopton-on-Sea

The congregation of St Margaret’s kindly donated £87 in lieu of giving Christmas cards.

Paul Smith of Studley always requests family and friends to donate money to good causes instead of presenting Christmas presents. Paul has WG and this year named Vasculitis UK to receive £300.

Ian Surplice celebrated his 60th birthday and requested donations to V-UK. Ian’s late mother, Joyce, had vasculitis.

Rachel Thornton entered the McCain Yorkshire 10K in November. Rachel’s 13 year old son Tom has PAN. She has raised £1,300, £500 which was kindly matched by Lloyds Bank.

William Tunncliffe - William entered the BUPA Great Yorkshire Run on 29th September. He decided to take part and raise money for V-UK because of the courage and determination of a vasculitis patient. Will raised £405.

Universal Components of Sheffield held a Christmas raffle and donated £130 to the Trust.

Georgia Upjohn, Kathleen Macnee & Chloe Hopgood are undertaking three events for V-UK in 2014. They have already completed a half marathon. Still to come, climbing Ben Nevis and cycling from John O’Groats to Lands End. So far the girls have raised £153.

Ella Wells (Martyn’s daughter) raised £25.80 with her cake sale.

Russ Wingfield - Russ ran in the Stevenage Half Marathon in November. His dad has CSS. Russ beat his pre-race time by 2 minutes. Will he do another half marathon? “Not for some time”, but he raised £625 for V-UK.

Lucy and Phoebe Woodbridge entered the Reading Half Marathon on 2nd March because their dear Godfather Richard has vasculitis. The sisters have raised £930.

Jennifer Wormald continues to make her exquisite jewellery which she sells for V-UK. This year she has raised £200.

Wyn’s Tor Pack, Winster, Derbyshire - V-UK are grateful to Korky and the Wyn’s Tor Pack for the kind donation of £50.
VASCULITIS SUPPORT GROUP MEETING REPORTS

London (North), Swiss Cottage - October 2013
David spoke about the NICE 3rd Appraisal for the biologic drug Rituximab being used to treat ANCA related vasculitis. In order to increase awareness of vasculitis it was agreed that it would be useful to invite trainee doctors or GPs to the meetings.
Dr Ruth Tarzi gave a presentation about ANCA related vasculitis, the development of treatments since the 1950’s to the present day use of biologic drugs. Dr Tarzi’s points were illustrated in an excellent animated slide show. A lively Q&A session followed.
An informal session with refreshments followed where discussions centred on having drop in sessions to be held every month, to start in 2014, and the possibility of having the Group’s own Facebook page.
During November, Waitrose (John Barnes) in Swiss Cottage, Hampstead, London raised £1000 for three local good causes. Dave was thrilled to receive £298 for the London VS Group.

York N&E Ridings VSG - October 2013
A dozen people attended and enjoyed a hearty Sunday lunch at the Blacksmith’s Arms in Huntington, York. The lunch was personally cooked by Anna (hostess and chef) and there was plenty of opportunity for everyone to chat together as everyone was within earshot of each other.
Jennifer will be organising a meeting with a speaker after Easter.

East Midlands VSG - October 2013
The second meeting of the group was held at the Clock Warehouse, Shardlow. Over 22 people attended, mainly from Derbyshire and Leicestershire.
"Coping with" strategies were discussed as were problems with sleeping and fatigue. Alice Muir from QMC talked the group through tai chi moves. Great fun for everyone.
At Christmas there was a lunch at Shardlow with 18 attending for an enjoyable meal.

West Yorkshire VSG - October 2013
The Autumn Meeting of the group was held on the 20th October 2013 at the Gomersal Park Hotel.
Dr Sultan gave an extremely good talk on Vasculitis in general.

Cambridge VSG - December 2013
A “jam-packed” audience attended the meeting to listen to two excellent speakers. First Jacky Davis, who is a practising nutritionist in Cambridgeshire, emphasised that diet is fundamental in fighting disease, dealing with the side effects of the drugs we take and keeping as healthy as possible.
An extended report on Jacky’s presentation can be found on page 18.
Dr Federico Alberici, from Addenbrooke’s, gave an in depth review of the drugs that are used to treat vasculitis, the side effects that go with these, and the way that the medical teams work to mitigate these side effects.

South Wales VSG - January 2014
On 4th January 18 members met for the S. Wales VSG meeting. They had a jolly time with afternoon tea and homemade cakes.
Emma Hughes of Genetic Alliance UK explained her research and actions to improve co-ordinated medical services in Wales for those with rare diseases. The next meeting will be held on 12th July.

West Country VSG - January 2014
Wonderful food and wonderful company - the largest gathering so far with 20 attending the informal VSG lunch in January. The team can’t wait for the next one which will be held on 27th April. Please come and join them.

Bed's, Bucks & Herts VSG Lunch - March 2014
The group met and had a super lunch and chat at the Magic Mushroom in Billerica. Their fame is spreading as they again had their own private room !!. Many thanks to Jack & Carol Mcmenamin for organising the lunch.

Our fantastic fundraisers - continued

Donations via JustGiving for Anniversaries and Birthdays
For Colin and Lesley £50 for their Golden Wedding Anniversary. For John Mahoney’s birthday £90.
Thank you to everyone else who made donations via JustGiving.
Many of the fundraisers mentioned in the Autumn Newsletter have increased the amounts donated by their friends and family.
Finally our thanks are extended to all the wonderful people who have donated to those fundraising for Vasculitis UK.

Tea, coffee and biscuits were served and there was a raffle to boost the group funds. Emma brought cupcakes which she sold for Vasculitis UK - decorated in Vasculitis UK colours of course.
There were a wide range of ages and vasculitides and so there was plenty note comparing. Lynne and Sam hope to see more new members in the future.

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There were a wide range of ages and vasculitides and so there was plenty note comparing. Lynne and Sam hope to see more new members in the future.
IN MEMORIAM

The charity often receives donations or funeral collections which are made in memory of a family member or friend many of whom had vasculitis. Many of us with vasculitis are past the first flush of youth and may have been living with the disease for many years. It is very 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.

Mrs Teresa Aney of Lancashire
Mrs Aney sadly passed away on 2nd January 2014 aged 84. Her daughter (Mrs E Getty), family and friends kindly donated £250 to the charity in memory of Mrs Aney.

Mr Bernard Armitage of Leeds
Mr Armstrong passed away during 2013. He had battled varicose ulcers successfully for four years, but relapsed and suffered further complication. Bernard’s son Mark and family and friends have kindly donated £600 to V-UK in Bernard’s memory.

Christine Bekiroglu of Lincolnshire
The Trust is grateful for the donation of £50 made in lieu of flowers at the funeral of the late Christine.

Mrs Mary Bolwell of Bradford on Avon, Wiltshire
Mrs Bolwell passed away in the Autumn. She had been born in London but was evacuated during the war to Wiltshire, leaving her parents behind. Mary’s granddaughter, Laura Kate Noel, has Takayasu’s being diagnosed 12 years ago aged 49. Sadly Mary passed away before she could see Laura marry in February 2014. Daughter Sue Blagden and family and friends kindly donated £180 in Mary’s memory.

Albina Burke of Tiford
Vasculitis UK wish to acknowledge the kind donations of £65 made in memory of Albina (Bina) from Mervyn and Christina Eyett and from an anonymous donor via Just Giving.

Mrs Patricia Anne Chamberlain of High Legh, Knutsford
A funeral collection of £270 was kindly made to the Trust by Mrs Chamberlain’s husband Gordon and by their family and friends. Patricia passed away in Autumn 2013.

Mrs Margaret Davies of Oldbury, West Midlands
Margaret passed away in September 2013 having been diagnosed with vasculitis for many years. Sadly Margaret had a serious fall from which she never really recovered. She leaves behind a son Rob, and close family and friends. A funeral collection in Margaret’s memory was made to V-UK of £650.

Mr Hans Engstrom
A kind donation of £20 was received from Mrs Ann Stead in memory of Mr Engstrom who passed away in 2013.

Mrs Dorothy Evans of Kings Norton, Birmingham
In the summer of 2013 Mrs Evans sadly passed away. Dorothy’s family and friends kindly donated £200 to the charity in her memory.

Mr Roy William Fellows of West Midlands
Mr Fellows passed away in the late summer. His daughter, Mrs Debbie Large, and family and friends kindly donated £170 to the charity in memory of Mr Fellows.

Mr Frank Flynn of Dundee
In November, a kind, but anonymous donation of £100 was received via JustGiving in memory of Mr Flynn.

Mr Paul Garratt of Alvaston, Derbyshire
Vasculitis UK would like to thank Mr Garratt’s next-of-kin, Thea, and his family and friends for the kind donation of £586 made in memory of Paul who passed away in the summer of 2013.

Mr Clive Gould of Fikkins, Oxfordshire
Mr Clive Gould passed away suddenly on 18th July 2013 aged 76. He had been treated for vasculitis for the previous 8 years. A congregation of more than 300 attended the funeral. Mr Gould lives his wife Sheila, daughter Christine, son Stephen, eight grandchildren and a great grandson. Among the mourners was Mr Gould’s mother who is aged 102. Donations in Clive’s memory were £458.

Mr William Henshaw
A kind donation of £60 was received from Mrs Sarah Henshaw in memory of Mr Henshaw who passed away in December 2012.

Mr Robert Ashley Hobson of Chinley, High Peak
Robert was diagnosed with WG in December 2013. Unfortunately because of complication he had to undergo emergency surgery, but sadly passed away on 24th January. Robert’s wife, Glenys, and family and friends kindly donated £402 in his memory to help raise awareness of vasculitis and to fund vasculitis research.

Mrs Audrey Stafford Hughes of West Midlands
Mrs Hughes passed away in the Autumn of 2013. Audrey had Wegener’s Granulomatosis and was a member of the West Midlands Support Group. Her son, family and friends kindly donated £93 in Audrey’s memory.

Mr Ronald John Hughes of Compton, Wolverhampton
John sadly passed away in May 2011 from the complications of vasculitis. We are most grateful to Mrs Janet Hughes, Ronald’s widow, for her kind donation of £100 made in remembrance of her dear husband.

Mr Donald McElvilly of Liverpool
Mr McElvilly passed away in late 2013. His friends and colleagues at the Bakery at Costco in Liverpool kindly donated £60 to the Trust in Mr McElvilly’s memory.

Mrs Marcella Moran of Olton, Solihull
Mrs Moran sadly passed away on 1st August 2013 - the same year as her beloved grandson Liam who was diagnosed with Wegener’s. Marcella’s daughter, Mrs Pauline O’Keeffe and her family and friends kindly donated £370 to V-UK. Their wish is that Marcella rests in peace.

In Memoriam continued ➔
In Memoriam - continued

Mr Sydney Norris
Vasculitis UK has received a donation in memory of Mr Norris in the sum of £5,000. This was made anonymously via JustGiving. The Trust extends its condolences to the family of Mr Norris on his passing, and to the person(s) making this very generous donation.

Mrs Joan Rook of Benfleet
Mrs Rook was the mother of the late Mrs Mary Coulson who was a Vasculitis UK member for several years. Mrs Rook sadly passed away in 2013. Joan’s family and friends have kindly donated £520 to the Trust in her memory.

Mrs Dorothy Shrimpton of Knowle, Solihull
It was with sadness that the Trustees learned of the passing of one of our members Mrs Shrimpton. Dorothy had vasculitis and passed away in November 2013. Her nephew, David Hodgson, has kindly made a bequest to the Trust of £500 adding that his aunt was very appreciative of the work the Trust.

Mrs Ellen Margaret Smith of Great Baddow, Chelmsford
Mrs Smith passed away on 14th October. She was 72 years old. Mrs Smith’s husband Peter and her family and friends kindly donated £92 in Ellen’s memory.

Mrs Renee Thomas of Walton-on-Dale
Renee was diagnosed with WG in 1996 and was a long standing member of Vasculitis UK. We were saddened to hear of her passing in November. It was a long and difficult journey with vasculitis for Renee but she was a very courageous, strong and positive lady. Her family are convinced it was this fortitude which kept her going and allowed her to keep bouncing back until the latter stages of her life. Rene’s family and friends kindly donated £430 in her memory.

Mrs Margaret Townsend of Lancashire
Mrs Townsend was 75 when she sadly passed away in January 2014. Her daughter, Kath, and family and friends have kindly donated £295 to V-UK in Margaret’s memory.

Mrs Jan Waissen of Basingstoke
Jan was diagnosed with WG in 1991. Her health started to deteriorate in 2008 and towards the end she was wheel-chair bound. Jan was a determined lady who loved sport and travelling. Although she struggled with the disease for many years she lived to see both sons, Jack and Matt, graduate in the US in Dec 2012 and May 2013 respectively. However, she suffered a pneumothorax whilst in the USA and never really recovered. She passed away in her sleep, at home, on 15th September, aged 51. Jan’s husband Peter, their sons, family and friends have kindly donated £700 in Jan’s memory.

Mrs Margaret Townsend of Lancashire
Mrs Townsend was 75 when she sadly passed away in January 2014. Her daughter, Kath, and family and friends have kindly donated £295 to V-UK in Margaret’s memory.

Mr Andrew Willows of Annesley Woodhouse
Andrew was a wonderful and loving husband to Debbie and father to Emily. Andrew had Wegener’s and sadly passed away on 18th December. His family and friends have kindly donated £1000 in Andrew’s memory. His passing has left his family totally devastated and heartbroken and their hope is that their donation will help towards funding future research into vasculitis.

A tribute to Miss Kathleen Rawlinson, founder of the West Country Vasculitis Support Group
It was with great sadness that the Trustees heard of the passing of Kathleen in October 2013. Kathleen was in her 84th year and she had lived a full and active life.

In the 1980’s Kathleen was diagnosed with Churg Strauss (EPGA), and she started the West Country Group about ten years ago. Those who were members in the early days speak of their gratitude for the time and energy Kathleen put into setting up and running the Group. Failing health meant that Kathleen stood down from leading the Group two years ago.

Kathleen was a lovely lady, she had many friends, and a career spanning nearly 40 years. She worked as a nurse both in hospitals and, later, undertook further training to work in the community, with a particular interest in the care of families with children. Kathleen had an extremely strong faith and after being diagnosed with CSS she retired to Exminster where she worked tirelessly for the good of St Martin’s Church. Kathleen’s friends from the West Country Support Group have kindly donated £85 to the Trust in her memory. She will be sadly missed by all her friends and by all the vasculitis patients she has helped over the years.
THE EDITOR SAYS “ADIEU”

Hi Everyone. I’ve been the Editor of the Newsletter/Journal since 2010. I took over at a time when it was published in black and white and was in dire need of some TLC, and I’ve enjoyed making it into what I hope has been an informative and interesting read for V-UK members.

However, times change. This is my seventh issue as Editor and it is my swan-song. I am handing over my red editor’s pen and green eye-shade to let others take over. This is the final time I shall utter those immortal words “stop press”.

I believe the new editorial team will offer innovative ideas regarding content and a more professional looking layout than my talents and publishing skills permit. They may even consider a completely new approach to producing the Newsletter. So watch this space!

I do hope you have enjoyed the Newsletter/Journals that I have had the privilege of producing for you.

I would like to say thank you to everyone who contributed to the Newsletter over the past few years whether it has been a one off article or ongoing input. My very special thanks go to Maya Anaokar, Holly Hampshire and Pamela Todd for their help, support and input.

Pat

VASCULITIS UK JOINS ARMA

Vasculitis UK is now a member of Arthritis and Musculoskeletal Alliance (or ARMA). ARMA is a charitable umbrella organisation providing a voice for the arthritis and musculoskeletal community in the UK. Their vision is of an effective, unified musculoskeletal community working together to improve the lives of people with musculoskeletal disorders (MSDs)

ARMA’s aim is to transform the quality of life of people with musculoskeletal disorders by shaping policy and best practice in partnership with its member organisations. This objective sits comfortably with our efforts at Vasculitis UK.

ARMA have 40 member organisations, ranging from specialised support groups for rare diseases to major research charities and national professional bodies.

We are delighted to be a member of ARMA and will be looking for opportunities to promote the welfare of vasculitis patients.

TRAVEL INSURANCE

Freedom Insurance Services Ltd Richmond House, 16-20 Regent Street, Cambridge, CB2 1DS. information@freedominsure.co.uk or ring 01223 454 290. www.freedominsure.co.uk

Goodtogo Insurance - ring 0844 334 0160 www.goodtogoinsurance.com

JustTravelcover - Cover for pre-existing medical conditions or for clients over 65. www.justtravelcover.com/ or ring 0800 294 2969

Medici Travel - customer.services@medicitravel.com, phone: 0845 8800168. www.medicitravel.com

The Post Office - Details are available from any Post Office or phone 0844 888 3900

Virgin Insurance - Cover for pre-existing medical conditions or for clients over 65. Phone: 0844 888 3900. www.uk.virginmoney.com/virgin/travel-insurance/

More travel insurers can be found on the V-UK www.vasculitis.org.uk/living-with-vasculitis/insurance

The Trust would be pleased to hear of your experiences - good or bad - when using any of these travel insurance providers. When booking please mention Vasculitis UK as some of these companies pay a small commission to the charity.

Please stay in touch

If you move home or change your e-mail details please let us know.

e-News and Newsletter/Journal

Contact John Mills to:

1. receive the e-News or update your e-mail address.
2. update your home address or other details on the database.

john.mills@vasculitis.org.uk or write to John Mills - Contact details on page 28.
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Lincolnshire
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London - SE London/NW Kent
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patvernalls@btinternet.com

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lynne@vasculitis.org.uk

Yorkshire - South **
Pat Fearnside 01709 583722
pat@vasculitis.org.uk

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

** Vasculitis patients offering support — not a Support Group

Possible new Support Group in the Portsmouth area. If you are interested in becoming a member of the group please contact John Mills - contact details on page 28
Winston the V-UK Bear invites you to view the goods available from the charity. We have a wide range of quality goods which we are selling to raise awareness of vasculitis and to boost the Trust’s funds. All profits will go towards meeting our Aims.

Below are some of the items we have for sale in the shop. You can find further details and special offers on the V-UK website.

Did you know that you can still pay by cheque or you can now pay by PayPal. To order and pay using PayPal please visit our on-line shop: www.vasculitis.org.uk/shop

**Prices INCLUDE Postage & Packing except for special offers**

**Clothing**
- t-shirts & v necks £13.25
- Sweatshirts * £17.50
- Hoodies* £23.00
- Waterproof hooded coat** £24.00

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

Colours: green, royal blue or black except for * = grey or black, and ** = black only

**Other items**
- Route Map for Vasculitis £11.50
- New Wristbands ** £2.00
- Beaded bracelet £4.00
- “Winston” V-UK Bear £15.75
- “Winston” baseball hat - white or black £3.50

“Victor” V-UK White Rabbit £15.75
Enamel V-UK lapel badge £2.00
Waterproof backpack £8.95
V-UK 4 pen pack £3.00

**For Vasculitis Awareness Month (May)**

For members who might not be able to engage actively in VA Month, there will be a special Awareness Pack for sale, which will include a quality cotton shopper. This will raise awareness whether you shop at your local farmers’ market or the local supermarket. Details will be available on the website in late March/early April.

To order by post please send a note of your order, including the item name, size, colour, and number required. Don’t forget your name and address + a phone number in case of query. Your cheque should be made payable to: Vasculitis UK. Please forward to:

Vasculitis UK Shop, c/o 37 Pinfold Close, Swinton, South Yorkshire, S64 9JE

If you are not satisfied with your purchase, just return it unused and we will refund your money, less the cost of p&p.

V-UK Shop Manager

---

“There are no shortcuts to any place worth going” - Beverly Sills, American opera singer.

Suitable for steroid reduction?

“Ever forward, but slowly” - Gebhard von Blucher, 19th-century Prussian officer
LIFE PRESIDENT — LILLIAN STRANGE

Officers and Trustees

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Matlock, Derbyshire, DE4 1DQ
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john.mills@vasculitis.org.uk

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PROF LORRAINE HARPER
DR RICHARD WATTS

Trustees:
Danni Brunwin
Dorothy Ireland
(Fundraising coordinator)
Jacqui Moran
Anita Parekh
(Assistant Treasurer)
Lisa Ranyell

Have you visited the Vasculitis UK website?
www.vasculitis.org.uk

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

The main aims of the Trust are:

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

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

Vasculitis UK is formerly known as: Stuart Strange Vasculitis Trust

Registered Charity No. 1019983
Since 1992
STANDING ORDER DONATION TO

I wish to make a **REGULAR STANDING ORDER PAYMENT** to Vasculitis UK. Please complete the “Instructions to your Bank or Building Society” section below. If you are a UK tax payer please also complete the Gift Aid section. This will enable the Trust to claim an extra 25% on your donations from HMRC. The complete form should be sent to:

Patricia Fearnside, Vasculitis UK Treasurer, 37 Pinfold Close, Swinton, South Yorkshire, S64 8JE

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

To: The Manager  
(Bank or Building Society)

Name(s) of Account Holder(s)

Address

Branch Sort Code

Your Bank/ Building Society Account No.

Please make the following payments to the account of Vasculitis UK as shown below

Please pay

<table>
<thead>
<tr>
<th>TSB Bank</th>
<th>Long Causeway, Peterborough</th>
<th>30 - 96 - 60</th>
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For credit of

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<tr>
<th>Vasculitis UK</th>
<th>A/c No. 0 0 4 0 4 9 9 9</th>
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Ref:

The sum of

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Date of First Payment

Commencing and thereafter each

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

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

Please print clearly:

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

Home address ....................................................................................................................................

....................................................................................................................................................... Postcode ..........................................................

**Gift Aid : Vasculitis UK** (Registered Charity No, 1019983)

I am a UK taxpayer and would like to claim Gift Aid tax relief on my donation to: Vasculitis UK. Please see conditions below.

[ ] Treat ALL gifts of money that I make today and in the future as Gift Aid donations.

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

Please notify the Trust if you (a) want to cancel this declaration (b) change your name or address (c) no longer pay sufficient tax on your income and/or capital gains. **If you pay income tax at Higher Rate**, you must include all your Gift Aid donations on your Self Assessment tax return if you want to receive the additional tax relief due to you.
DONATION TO

Vasculitis UK

I wish to make a DONATION to Vasculitis UK and enclose a cheque in the sum of £.............

Please make cheques payable to: Vasculitis UK.

The completed form and your cheque should be sent to: Patricia Fearnside, Vasculitis UK Treasurer, 37 Pinfold Close, Swinton, South Yorkshire, S64 8JE

First name .............................................. Surname ..............................................................
Home address ...................................................................................................................................
................................................................................ Postcode .............................................

Would you like an acknowledgement? We are, of course, happy to send an acknowledgement but please consider requesting an e-mail acknowledgement (if you have e-mail). This will help V-UK to save the cost of postage. Many thanks.

No thank you ☐ Yes please by post ☐ Yes please by e-mail ☐

Please Gift Aid your donation if you are a UK Tax Payer. By completing the Gift Aid section below Vasculitis UK will be able to claim an extra 25% on your donation from HMRC — and it is completely free.

Gift Aid : Vasculitis UK (Registered Charity No, 1019983)

I am a UK taxpayer and would like to claim Gift Aid tax relief on my donation to: Vasculitis UK. Please see conditions below. Please tick the following boxes as appropriate:

☐ Treat the enclosed donation of £ as a one-off Gift Aid donation, or
☐ Treat ALL gifts of money that I make today and in the future as Gift Aid donations.

Signature ................................................................. Date ......................................................

If you pay income tax at Higher Rate, you must include all your Gift Aid donations on your Self Assessment tax return if you want to receive the additional tax relief due to you.
Programme & Agenda

11.45  Registration: “Meet & Mingle” over coffee and a bite.
       A light finger buffet lunch will be provided for those attending the meeting (**)

1.00  Annual General Meeting

       AGENDA

       1) Welcome & Apologies
       2) Minutes of Previous Meeting
       3) Matters Arising
       4) Chairman’s Report, Treasurer’s Report
       5) Election of Trustees and Officers
       6) Any Other Business
       7) Close of formal meeting

2.00  Guest Speaker:

       Dr. Nina Brown BSc. (Hons) Healthcare Law & Ethics. MBChB.,MRCP (UK)

       Nina is a Clinical Research Fellow, currently taking time out from specialist nephrology training
       to undertake a PhD entitled "Improving outcomes for patients with ANCA Associated
       Vasculitis". The title of her presentation will be:-

       "Research in Vasculitis: From Bench to Bedside"

       Nina will give an overview of the vasculitis research currently carried out in her
       unit, which is centred at Manchester Royal Infirmary. She will focus on the
       developments of a new web-based “Vasculitis Care Optimisation Tool” as well as
       her research study investigating the microRNA (genetic regulators) signature of
       ANCA Associated Vasculitis. This project is currently supported by Vasculitis UK.

3.00  Coffee and Biscuits: Open Discussion

4.00  Meeting Closes

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** Please note ** there is no charge for attending the meeting or for the refreshments.
However, to ensure that the Trust's expenditure is kept to a minimum, a contribution
the cost of the buffet and coffee would be greatly appreciated. Envelopes for this
purpose will be on the seats so you can, if you choose, increase the value of your donation
by 20% by claiming Gift Aid relief.

Very Important Notice.

If you are planning to attend the meeting, for catering purposes, please let us know before
Tuesday 6th May if possible. By email: john.mills@vasculitis.org.uk or by phone: 01629-
650549 or by post John Mills, West Bank House, Winster, Matlock. DE4 2DQ
We Need Your Help.

Vasculitis UK has no paid staff and no offices, so no "overheads". It is run almost entirely by people with vasculitis for people with vasculitis and we are very proud of this fact. Unfortunately, the downside of this is that we, like you, sometimes have to battle with that dreadful disease that never quite goes away. Consequently those running the charity sometimes have to step back and concentrate on their own health and welfare rather than the work of the charity.

We do periodically have vacancies for new trustees for the Vasculitis UK Board. The role of the Board of Trustees is about overseeing the policies and strategy of the charity and ensuring that Vasculitis UK operates in a proper manner in accordance with the law, the requirements of the Charity Commission and the charity’s own constitution. So whilst being a trustee does involve serious legal responsibilities and duties that are not to everyone’s taste, it is an essential part of running the charity.

Trustees do not need to have vasculitis, but can also be friends or family members of people with vasculitis. We welcome those who can bring a particular skill or knowledge to the Board.

Trustees are elected to the Board. If you wish to stand for election to this position, please notify the secretary, Jann Landles, giving your details, the names of a proposer & seconder, and a short statement (max 120 words) stating the reasons you wish to be a trustee and what skills or knowledge you can contribute to the Board. Applications in writing please to: Jann Landles, 18 Mill Lane, Holtom, Lancaster. LA2 6ND. Closing date 15th April 2014.

We know there is a lot of talent and experience amongst our members. There are also vacancies for volunteers who want to be hands on, with or without the additional responsibilities of trusteeship. This might be just on a regular or an occasional basis or in a particular area of interest. Examples of this are:-

- Helping the new editor with the Newsletter
- Fundraising – experience in corporate fundraising & sponsorship.
- Experience with media/PR/advertising.
- Medical/healthcare or legal skills
- IT skills & graphics skills. Design of leaflets and posters etc.
- Sourcing publications and papers relevant to vasculitis and summarising them.
- Helping with the telephone advice and support line (only for those with the necessary knowledge & skills).
- Offering advice on benefits (only for those who understand the system)

Volunteers can include anyone – friends, family or anyone who feels they would like to be involved in supporting the aims and objectives of Vasculitis UK)

If you feel you would like to help in the valuable work of Vasculitis UK, as a trustee or volunteer and you want to know more, please contact:-
John Mills, WestBank House, Winster, Matlock. DE4 2DQ.
Tel 01629-650549 Or john.mills@vasculitis.org.uk
A potential new drug to prevent flares in ANCA vasculitis
(David Jayne, Vasculitis Clinic, Addenbrooke’s Hospital, Cambridge).

Once patients have been diagnosed and treated for ANCA vasculitis, the attention turns to stopping the disease returning, a flare or relapse. Most patients are advised to take a drug such as azathioprine or methotrexate for several years, often combined with a low dose of prednisolone. This treatment is not always effective and 30% of patients relapse within three years, with over half having a relapse over a longer time period.

An international clinical trial has recently started to see whether a drug called belimumab can prevent flares or relapses in ANCA vasculitis. Belimumab, also known as Benlysta, has been extensively tested and is now licensed for the treatment of systemic lupus erythematosus, a related autoimmune disease to ANCA vasculitis.

Belimumab is an antibody based drug given once a month by intravenous infusion which has been designed to block a chemical messenger in the blood called BLYS (also know as BAFF). BLYS levels are high when vasculitis is active and BLYS stimulates B cells, a type of white blood cell, to promote vasculitis and produce ANCA. We know B cells are important because they are eliminated by rituximab, and rituximab is an effective treatment for ANCA vasculitis.

The clinical trial is called BREVAS and is sponsored by the drug company GSK. Patients with AAV will be eligible if they have recently been treated for active disease, either new disease or disease relapse, and the vasculitis is now controlled. If they agree to enter they will receive the standard relapse prevention drug azathioprine, and in addition will receive either belimumab or a dummy, placebo. The trial aims to recruit at least 300 patients and see whether belimumab will be effective in stopping flares of disease occurring. BREVAS will also assess how safe belimumab is for vasculitis patients.

BREVAS is now actively recruiting at several vasculitis centres in the UK.

For a list of the centres and for further information please see overleaf.
BREVAS Centres in the UK

Addenbrookes Hospital, Cambridge
Prof. David Jayne
Please contact Research Nurse James Perry at Telephone Number 01223 217827

Royal Berkshire Hospital, Reading
Dr Oliver Flossmann
Please contact Research Nurse Julie Foxton or Linda Jones at Telephone Number 0118 322 8593

St Thomas’s Hospital, London
Dr David D’Cruz
Please contact Research Nurse Louise Nel at Telephone Number 0207 188 7188 Ext 83575

Nuffield Orthopaedic Hospital, Oxford
Prof. Raashid Luqmani
Please contact Research Nurse Pam Lovegrove, Jennifer O’Donoghue or Alice Harin at Telephone Number 01865 737537

Aberdeen Royal Infirmary, Aberdeen
Prof. Lars Erwig
Please contact Dr Neil Basu or Research Nurse Vera Herd at Telephone number: 01224 554332 or 554499

Please note that it will be necessary to visit the chosen centre on a monthly basis if you take part in this trial.
The trial will probably last for a year, possibly longer in some cases. Travel expenses will be re-imbursed.
Taking Part in Vasculitis Research

Vasculitis in general is considered a rare disease, but “vasculitis” actually comprises fifteen different varied diseases and some types of vasculitis are very rare. Some research is carried out in the laboratory and patients are not involved, but for the purposes of clinical research and clinical trials, those carrying out the research need people with vasculitis to take part in clinical research and in trials of new drugs.

Modern medicine has to be “evidence based”. To get sufficient evidence for a piece of clinical research to be convincing it needs numbers. A piece of research involving only ten people would be worthless, with a hundred it might be significant and if it involved a thousand it might be convincing evidence.

With rare diseases, it is very difficult to get anything like these numbers in one place, so rare disease research tends to involve research at many centres or hospitals around the UK. Many pieces of clinical research are now collaborative projects involving many centres in Europe or even worldwide. Only this way can the data from enough patients be collected to produce reliable and trusted “evidence”.

As a vasculitis patient, you may be able to help in clinical research. This could be just a matter of giving permission for your anonymised clinical record to be entered on a research database, or giving a blood sample, or trying out a new procedure or drug. This research may or may not benefit you personally, but it may help others in the future.

No matter how much money is poured into vasculitis research, there will be no advances without patients being involved. The rarer your type of vasculitis, the more valuable is your participation in vasculitis research.

Most trials do involve travelling to participating hospitals, although in some cases, travel expenses may be re-imbursed.

On the Vasculitis UK website www.vasculitis.org.uk there are several research projects that are currently “recruiting” volunteers. These are as follows:-

1) A study looking for a “Biomarker” that will show disease activity in ANCA vasculitis. At present this is only for patients with MPO ANCA (mainly people with microscopic polyangiitis)

2) A trial of a new drug for treating Giant Cell Arteritis (GCA) cases where conventional high dose steroid treatment is not working of the disease keeps relapsing. (See also this newsletter)

3) A trial of a new drug for preventing relapse (flares) in ANCA vasculitis. (See also enclosed letter from Professor David Jayne).

4) A trial of mepoluzimab, a new drug for the treatment of EGPA - Churg Strauss Syndrome (See also this newsletter).

Please, if you are able, do your bit to support advances in vasculitis diagnosis and treatment by taking part in clinical research and trials.
Get creative and produce a winning design!

If you enter our competition, your design could be on our 2014 Christmas card. All you need to do is send your entry in JPG format to danni@vasculitis.org.uk by Monday 30th June. You can use any medium you wish be it photography, painting or graphic; we will leave the creativity up to you!