VASCULITIS UK

NEWSLETTER JOURNAL

Member of
EURORDIS
Rare Diseases Europe

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Chairman's Report

Change of Charitable Status

(Boring – but not for ignoring).

Many readers will be aware that the Board of trustees of Vasculitis UK are working towards changing the status of the charity from being an ordinary charity to that of a "Charitable Incorporated Organisation" or CIO.. This status is more befitting for a charity of the size and influence that Vasculitis UK has now achieved.

The trustees of Vasculitis UK have now approved the final draft of the CIO Governance Document (the constitution) of the "new" organisation. This now requires the endorsement of the voting members of the charity, at the AGM. After that it will be submitted to the Charity Commission for approval.

The new CIO Constitution is now available on the website for all to read. If anyone has any comments or queries, please contact John Mills john.mills@vasculitis.org.uk

Europe – In or Out?

No, this is not about the coming referendum, but about Vasculitis UK's increasing involvement in European vasculitis and rare disease groups. Vasculitis UK now has direct links with vasculitis groups in Finland, France, Holland, Italy and Ireland and is involved with the European Rare Diseases Research Consortium.

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"Together we are stronger" so it makes sense to join forces with other similar groups in Europe. As you will read elsewhere, Vasculitis UK is now part of Eurordis, which is an alliance of over 700 patient groups for people with rare diseases. (see elsewhere in this edition).

We are also working with the very large and active Dutch vasculitis group to create a European vasculitis patient organisation, which will be a federation bringing together all the vasculitis groups in Europe. This is very much a work in progress.

Rare Disease Strategy

In June 2009, the European Commission approved a requirement that all EU Member States should develop and implement a plan or strategy to ensure that patients have access to high quality care, including diagnostics, treatments, support for those living with the disease and, if possible, effective orphan drugs.

The regional departments of the NHS, for England, Wales, Scotland and Northern Ireland have now published their strategies and these were launched at four separate events on Rare Disease Day, 29th February.

New types of vasculitis on the website

We have now added two "new" types of vasculitis to the list of vasculitis diseases on the website.

Relapsing Polychondritis is a very rare type of vasculitis involving inflammation of cartilage and affects the ears, nose, throat and lungs.

IgG4-RD is a very newly recognised type of vasculitis which can affect many organs including the aorta, pancreas, kidneys, lungs, tear and salivary glands, thyroid and testes. links a number of inflammatory diseases that previously were considered unrelated and affecting only one organ.

We are grateful to Dr Alina Casian and Professor David D'Cruz of Guys & St Thomas's Hospital, London for this new website information.

Research Report

One of the core aims of Vasculitis UK is to support research into vasculitis. This is often by offering practical support to researchers but also by offering financial support. This typically takes around two thirds of the charity's total income.

Following last year's major overhaul of the awards process and the introduction of a well defined Research Strategy, the Board of Trustees allocated £150,000 for research and a "call" was made for applications on a strictly controlled competitive basis. This funded five projects which are now all ongoing.

The Board approved a further tranche of £100,000 for the current financial year. Another "call" for applications was made in January, with a closing date of March 31st. These applications are now being evaluated through a formal peer review process by independent reviewers who are experienced in the aspects of vasculitis relevant to each application.

Processing and managing these research applications is a demanding and time consuming job, which last year was undertaken entirely by Mike Patnick. However, for personal and family reasons, Mike is reducing his commitment to Vuk, so we have engaged Lynn Laidlaw (whom many of you will know from the telephone and online support service) to be Mike's assistant, with a view, perhaps, to taking over his role eventually.

John Mills

From the editors

It doesn't seem that long ago since our last edition, Christmas has been and gone and Easter will also have passed by the time this edition goes to print.

I hope you the readers are enjoying your Newsletter/Journal as much as I am, It's been a bit of a learning curve all round but I think we are getting there as each edition passes.

Of course you the readers are our main focus so if you have any ideas you would like included in forthcoming editions please either contact Graham or myself and we will look at them in our edtorial meetings and discuss them. We will soon be gatherering articles for our next Autumn edition so get your thinking caps on!

Its good to see all the different ways that people are raising awareness and fundraising for VUK, Rare Disease day on 29th February was a prime example with all of you getting involved on Twitter and Facebook, we have Vasculitis UK Awareness month in May so I hope everyone will get involved promoting that as well.

Keep up the good work raising awareness and fundraising and remember Together we are Stronger!

Kevin Soper

kevin@vasculitis.org.uk

Being involved with helping to produce this newsletter has exposed me to so much fascinating information about the resilience of the Vasculitis community.
It is a group made up not just of sufferers, but also friends and relatives, fundraisers, doctors and nurses, researchers and many others.

Whilst we all share a common interest in Vasculitis, in this edition we have tried to recognise that each of us may find some parts of the newsletter more relevant than others. With that in mind we've introduced a 'colour-coding' for the pages, which we hope will make it easier for you to target the articles of greatest interest.

Of course we hope you will enjoy the whole newsletter! Please get in touch if you have any suggestions. Kevin and I are always grateful for feedback.

Graham Baker

VASCULITIS UK Needs Trustees & Volunteers.

Most larger charities have a Board of Trustees which has overall responsibility for the "Governance" of the charity – ensuring that the charity works towards achieving its stated aims and objectives, ensuring its financial probity and solvency, ensuring it complies with legal requirements and in general, that the work of the charity is conducted in a proper, responsible and respectable manner.

Trustees concern themselves mainly with policy and strategy, rather than day-day operations. They are expected to be of good character, capable of understanding the operation of the charity and making considered, wise decisions in the best interest of the charity. Trustees are usually elected at the AGM and serve for a set time before needing re-election.

In the case of Vasculitis UK, many of the trustees have vasculitis themselves and are also the volunteers who do the work involved in running the charity, but these are certainly not essential requirements for trusteeship. If you, or anyone you know, has a serious interest in the charity aspects of vasculitis support, has medical or organisational knowledge and/or professional skills and can spare the time, we would very much like to hear from them.

Vasculitis UK is a national charity, so physical, face- face meetings are difficult and expensive to organise. Thus, trustees usually meet physically all together only twice a year, but conduct the charity's business in between meetings using emails and teleconferencing. For more information about being a trustee, visit the Charity Commission website.

We also need eager and enthusiastic volunteers to carry out the everyday work of the charity, such as offering support to people with vasculitis, producing publications, liaising with other groups, Public Relations and social media, website and newsletter support, fundraising and clerical and admin support.

If you think you have something to offer and some spare time and you would like to become more involved, please get in touch. John.mills@vasculitis.org.uk or phone 0300-365-0075.

Front Cover: Some of our fantastic fundraisers at last years London 10k - Stronger Together

Wales Rare Disease Network Launch: October 2015

Attended by Jennifer Fulford Brown, Jennifer's partner Neil and Ryan Davies

A mixture of patients and professionals attended the launch. The stories told by some of the patients rather contradicted the upbeat presentations of the professionals, with so many experiences of failure of various services, and the harm this caused in treatment.

Emma Hughes speaking on behalf of Rare Disease UK

It was emphasised that the different rare disease groups supporting different illnesses, should join together and contact their health boards to galvanise them into action, reminding them that 1 in 17 will have a rare illness, (the politician whom Emma Hughes, from Rare Disease UK spoke to, thought there may be only one person in Wales!).

As the event was sponsored by Genetic Alliance UK/Rare Disease UK, it was not surprising that the benefits of genetic testing were emphasised. There is a sense of frustration by the scientists at the lack of response from doctors in Wales and their failure to ask for such a powerful diagnostic tool.

No doctor representative attended the launch as a speaker, however Prof Maggie Kirk spoke about education for medical professionals by utilising patient experience via "Telling Stories".

Chris Dawson, a policy strategist for the Welsh Government was enthusiastic and said they would be implementing the plan for rare diseases. He asked for a patient representative. I spoke to Emma about the possibility of me being on the committee, but said we would talk about it later. I recognise that others have more experience in being activists, but I have experience of various illnesses, i.e. vasculitis, spina bifida and autism, and UK responses to these problems.

Once again I got the sense that the politics, finances, and forthcoming elections will be engaging the Welsh politicians, and was glad to see that some candidates had signed a document agreeing to promote the Rare Disease plan.

Jennifer Fulford Brown

Web sites www.awmsg.org
Telling stories.nhs.uk

John Mills and Lynn Laidlaw attended the Vasculitis Rare Disease Group Meeting (UKIVAS/Lockwood Club) in Cambridge Autumn 2015.
John and Lynn have also been invited to the UKIVAS/Lockwood Club Spring Meeting, representing patients diagnosed with Vasculitis & Vasculitis UK, on April 22nd 2016, in Leeds.

Vasculitis UK contributed to the Vasculitis Registry and more details about UKIVAS & the Registry can be found by following these links
http://www.vasculitis.org.uk/professionals/ukivas
http://www.vasculitis.org.uk/professionals/registry

European Conference on Rare Diseases 2016

Lynn Laidlaw will also be representing Vasculitis UK at the EURORDIS Conference in Edinburgh on 26 May 2016.

All Ireland Vasculitis two Day Conference 2015

Attended by Susan and John Mills

John and I were invited by Julie Power, Chairman of Vasculitis Ireland Awareness to attend the 4th Annual Conference October 2015. Julie had invited us before but because of our busy schedule working for Vasculitis UK we had always been unavailable, but this year we were finally able to accept her invitation.

After registration, coffee and chatting to others, the Saturday started off with a Question and Answer session lead by Dr Derek Mitchell, CEO of IPPOSI. He was joined by Prof Mark Little, Chair in Nephrology at Trinity College, Dublin, Dr Eamonn Molloy, Consultant Rheumatologist at St Vincents's University Hospital Dublin and Dr Niall Conlon, Consultant Immunologist St James's Hospital Dublin. All the doctors were so very enthusiastic and interactive and answered all the questions put to them with honesty and openness.

After a delicious lunch the afternoon session resumed with a talk and presentation by Mike Kelly, Counsellor with Ireland Kidney Association. His main presentation discussed the personal issues of being diagnosed with a long term chronic illness such as vasculitis, including coping skills and self management but he also covered sensitive issues such as how important it is to give support for carers and how a long term chronic illness can affect the whole family.


Vasculitis Ireland Awareness
Annual Conference 2015
Q&A's with Professor Mark Little, Dr Derick Mitchel, Dr Eamon Malloy & Dr Nial Conlon

Dr Neil Basu, Consultant Rheumatologist Aberdeen University Hospital, gave the final presentation of the day called "Unravelling Vasculitis Related Fatigue". He discussed the impact of quality of life vasculitis can have on those diagnosed with vasculitis. He said that it was important to understand the "biology" of fatigue. He also discussed the successful research programme for fatigue and vasculitis carried out at the hospital in Aberdeen over a 7 week period, which included an exercise programme.

On the Sunday , after the VIA AGM the second day of the conference began. The first speaker was Rachel Lynch, Accredited Counsellor MIACP. She is also a support group facilitator for Fibro Ireland.
Rachel gave her an over view of her own experience of living with a long term illness and how it affected her life. She also discussed the definition of stress , the pain cycle and how to manage a "contract of self care".

The last speaker of the conference was Eva Currid, Accredited Psychotherapist MIAP and a group facilitator for Fibro Ireland. Eva spoke about living mindfully with illness, finding ways of relaxing, dealing with loss, adjusting to the new and moving forward with your life. Eva also gave a practical interactive demonstration of relaxation techniques.

A vote of thanks was given to Julie and husband Mike for all their hard work in organising the conference. By the end of the second day John and I felt as though we had found a new family, everyone had made us feel so welcome.

Susan Mills

The 2016 Vasculitis UK AGM
will be held at the Derby University Conference Centre on Sunday15th May.

See the insert with this Newsletter for more details. Please note that numbers are limited so booking is essential.

TRAVEL INSURANCE

Vasculitis UK have a comprehensive list of companies who provide travel insurance for patients with pre-existing conditions.

Details are available on the VUK website: www.vasculitis.org.uk/living-with-vasculitis/insurance or contact John or Susan Mills details on page 28

Keeping the fun in Fundraising

Work colleagues of Emma Smith ran the Leeds Abby Dash 2014 and raised over £480 for Vasculitis UK. Emma’s personal story was covered in the Autumn/Winter 2015 Newsletter and is on the website http://www.vasculitis.org.uk/living-with-vasculitis/emmas-story

John and June Clark recently celebrated their 50th wedding anniversary and instead of people giving presents they put money in a donation box and £500 was raised for Vasculitus UK, Their son, James who has Vasculitis says “Both my parents have been a great support to me through the difficult times when the Wegeners Granulomatosis (GPA) was making life difficult for me”.

Emma Clyn organised a Ceilidh in support of Vasculitis UK and over £1400 was raised. The Bank of Scotland matched this figure with a further donation of £1000.

Will, Benjamin, Jake, Matt, Tom and Ben from the Sports Lab, Long Road Sixth Form College raised over £550 for Vasculitis UK by cycling, collectively, 375 miles over a period of 3 days. (The equivalent distance from LRSFC to Amsterdam). Special congratulations and thanks to Ben Eames who has Vasculitis, who also took part in the cycling challenge.

Jill Tuck ran the Gower 50 mile Ultra in memory of her mum, who recently lost a 15 year battle with Vasculitis.
Jill raised over £600

Erica skydiving for brother Martin Makin raising over £800 for Vasculitis UK

Kelly and Greg Swift after taking part in the North West Triathlon, September 2015, Kelly raised over £850

Congratulations

Vasculitis UK’s very own Santa (John Mills) with Ruby, William and Phoebe
Lathkil Christmas Craft and Food Fair 2015
raising over £400 for VUK

Lisa Hetherington pictured above completed the 10k Loggerheads trail run and has raised awareness of vasculitis and raised £800 for Vasculitis UK . Here she is with her inspiration Finn, who has been diagnosed with a rare form of vasculitis

Jon and Gill Jones
Maldon half Marathon raised over £1000 matched by the Royal Bank of Scotland

Some of Our Fantastic Fundraisers

Derek Wheatland plus his Ski Group in Italy, held a Quiz night and raised £300 for VUK.

Donation 0f £50 given to VUK by Darwin Forest Derbyshire. Father Christmas (John Mills) with Elf Becky - Christmas party time for the children.

Congratulations to Jen Winnard and Holly-Beth Mansfield who raised £558 for Vasculitis UK and for the MS Society at their quiz night! "Thank you to everybody that attended or donated, we have smashed our targets and all expectations have been exceeded" said Jen.

Steve and grand daughter Bethany walking 8 miles fundraising for VUK

Kane pictured above with his VUK collection box from Engayne Primary School Upminster Essex, donated £332 which was raised from collections from parents, in the Christmas Assembly, Nativity and year 2/3 play.

Mini dfwf (Dance Fit with Faye) fundraising and raising awareness at the Newcastle Film and Comic Convention. Thank you Faye Bell, for all the support she has given Vasculitis UK for 2014/2015 and we wish Faye and her family all the best for the future.

Claire and Colin Douglas Autumn 2015 Great North Run. Special congratulations to Colin who has Vasculitis.

Winslow Utd v Buckingham Athletic Fundraiser
Grand total raised -
£945.52

Professional Profile

Prof Caroline Savage is presently Vice President and Head of the Experimental Medicine Unit in the ImmunoInflammation Therapy area, GSK, Stevenage. She is still an honorary Professor of Nephrology at University of Birmingham. She is a fellow of the Academy of Medical Sciences and a past Academic Vice President of the Renal Association. She has been author and co-author of many publications on vasculitis and renal disease. Here Prof Savage talks about her professional life and how her interest in vasculitis was sparked.

Can you give us a glimpse of your early life? Was medicine "in the family"?
As a child I grew up in Gold Coast (now Ghana) and Nigeria. I didn't attend real school until I was around 9 years old – how cool was that!! We had veterinary surgeons in the family (a tradition that continues) but no doctors for human beings. However, I think I was influenced by the gross pathologies that I saw all around me while living in Africa. Also, I was very aware that medicine had saved my life on more than one occasion after contacting malaria. On another, I was flown back to Great Ormond Street Hospital as an emergency after a capillary haemangioma on my arm broke down.

How did your special interest in vasculitis develop?
My interest in vasculitis was tweaked by three events early in my career. I first heard about Wegener's granulomatosis when I was on a postgraduate course studying for MRCP exams at Whipps Cross hospital. An old style physician described this illness in graphic detail and I recall being surprised that I had not heard about it before as a medical student. I then encountered a patient with acute microscopic polyangiits in the A&E department at Ealing Hospital – transfer to Hammersmith Hospital for urgent renal biopsy followed by cyclophosphamide and prednisolone had a dramatic effect in turning the course of the disease around. That really increased my interest in what caused vasculitis and how it could be treated. The third defining moment was when I looked down the microscope in Martin Lockwood's lab at some neutrophils and saw that they were 'lit up' by ANCA!! I was then hooked!

How would you describe your time at Birmingham?
My seventeen years in Birmingham were very exciting. I was part of the hugely busy Renal Unit, Paul Bacon and rheumatology was nearby. I hope our laboratory work on how vasculitis develops contributed in a small way to the evolution in our understanding of these disorders. Of course, the Birmingham Vasculitis Activity Score (BVAS) and the Vasculitis Damage Index (VDI) emerged during this time. And in 2002 we had the opportunity to set up the specialist, multidisciplinary Vasculitis Clinic in the Wellcome Trust Clinical Research Facility, which helped to align care and treatment for patients with vasculitis.

At what stage did you become involved with the Stuart Strange Trust?
I was involved with the Stuart Strange Trust very early in its inception. In fact David Jayne and I were invited to talk about vasculitis on Thames Television, along with Rachel Strange. As I now work at the GSK site in Stevenage, it is a strange twist of fate that an early meeting (the first?) of the Stuart Strange Trust was hosted at the site.

What prompted your move from the academic and clinical world into the more commercial world of GSK?
I was invited to undertake a secondment at GSK for a year. While I was there, I was bowled over by the science and the opportunity to bring medicines forward for patients in a manner that was not so possible, at least then, from the clinical and academic world. So the secondment turned into a permanent position where I now head up the Experimental Medicine Unit in medicine early development.

What has been the most fulfilling aspect of this career change?
Having a new challenge and working with amazing people who are really dedicated to developing new medicines.

You have had a very busy life. How do you turn off?

I love spending time with my husband and two daughters – one is now a doctor and got married last year, the other is a vet! I like running, especially with my two dogs Ozzie and Barney. As a family we do a lot of sailing. Right now I'm transitioning back to coastal sailing after spending many years racing dinghies on inland lakes while the kids were growing up!

That's me in red in the white boat (22619) in the middle!!

Caroline Savage

Online Support

The internet and social media can be a mixed blessing, but the internet can also offer a wonderful way for people meet and talk to others who share the same interest, whether they live in the same street or half way round the world. For people suffering from a rare disease, this can be such a huge benefit.

Most readers will know that Vasculitis UK has two online discussion groups, one on Facebook and one operating through HealthUnlocked. The Facebook group has over 2000 members and the HU group over 3000, most of whom have vasculitis or are family members of someone with vasculitis and are from the UK. These groups can offer an invaluable source of information, advice and mutual support, especially for those who are newly diagnosed, feeling bewildered, scared and isolated.

If you have access to a personal computer and have moderate ability to use the internet you can very easily join either or both of these groups. The Facebook group tends to be more chatty and the HealthUnlocked group is more seriously focused on vasculitis.

To find these groups, go to the Vasculitis UK website **www.vasculitis.org.uk**

Look in the top right corner of any page and you will find three "bubbles", a dark blue one marked F (Facebook) and a green one marked HU (HealthUnlocked). A click on each bubble will take you to the relevant group. You need to be a member of Facebook to join that group. For HealthUnlocked you need to apply to join, as this is a closed group.

facebook

HU health unlocked

Both groups are monitored by Vasculitis UK administrators and have rules about posting material that is of a commercial or religious nature or may be misleading or offensive to others.

If you do join either group, use a pseudonym to protect your identity, never disclose your home or email address or 'phone number or anything that you might later regret.

There is a "private messaging" facility so that you can exchange messages with another member of the group without it being seen by every member of the group.

Website notes

The Vasculitis UK website www.vasculitis.org.uk is an increasingly important part of the charity's operations and has become the Vasculitis UK showcase for the world. It has now been running since September 2012 and is becoming increasingly recognised globally as a valuable and reliable source of information about all aspects of vasculitis. Each year we now get almost a third of a million "visitors" a year, viewing almost a million website pages.

As expected, most visitors are from the UK, US and other parts of the English speaking world, but many are from less obvious places like India, or unlikely places such as Iran, or Kyrgyzstan on China's northern frontier.

The website information is regularly added to and updated. There is a news column and an events column which advertises forthcoming events. There is a new gallery of fundraisers photos. A newly introduced feature is that local vasculitis support groups can now have their own website included within the Vasculitis UK website. If the organisers of local groups wish, we can help them in creating their own webpages. If they choose to create their own website we will add the link to the list of local support groups.

So far there is an East Midlands webpage (covering Derbyshire, Leicestershire and Nottinghamshire), an All-Ireland website, a West Country website and an All Yorkshire website. You can find these here: http://www.vasculitis.org.uk/about/find-a-local-group

Managing, maintaining and updating the website and its content is demanding and time consuming. The trustees are considering a major overhaul of the website to make it more attractive, easier to use and much easier to maintain and update.

Wegener’s Granulomatosis (GPA)
and the Nose (Part1)

Problems with nose and sinuses are frequently associated with ANCA vasculitis (Wegener’s, Microscopic Polyangiitis, Churg Strauss Syndrome) and Relapsing Polychondritis, but only in GPA and Polychondritis do we see the severe destructive effects that lead to saddle nose deformity or perforations. If the vasculitis is not effectively treated, in extreme cases it can result in total destruction of the nose.

Disfigurement of the nose can be particularly distressing. It is not just a minor cosmetic issue. When looking at someone’s face, the eyes and the nose are the main features that you automatically focus on.

Here we are featuring two quite different personal accounts of this particularly disfiguring aspect of GPA, by Avril and Sarah, describing how they have coped with it.

Vasculitis is not the only cause of destruction of nasal tissues. Facial cancer is another very distressing cause. Part 2 of this feature will be in the Autumn edition of the newsletter. We will be showing how seriously damaged noses can be repaired surgically and how nose reconstruction is dealt with by Dr Callum Faris, a Consultant ENT Facial Plastic Surgeon of the Centre for Nose Reconstruction at Poole Hospital NHS Trust, who has made a speciality of this subject.

Avril’s story

I had suffered with sinus problems for a long time, then a painful lump on my nose appeared and gradually got worse, so in March of 2012 I visited the GP. I was given antibiotics, but these were not effective so I was referred to ENT at the local hospital.

By September 2012, the lump had developed into a hole at the side of my nose. After a biopsy I was finally diagnosed with Wegeners Granulomatosis (GPA) in October 2012. An ANCA blood test earlier in the summer had been negative. A CT scan done at this time showed sinus blockage and damage to the bone.

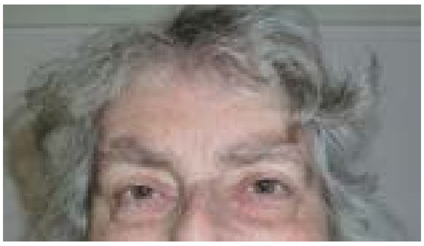
Following diagnosis, I was referred to Addenbrookes Hospital in Cambridge where I was promptly given cyclophosphamide infusions and high dose steroids. This was followed by maintenance therapy of azathioprine, which adversely affected my liver so I was then given rituximab, gradually reducing the prednisolone to 5mg a day, by September 2013.

I was given dressings to place across the hole in my nose so I could wear glasses. I was very self conscious about the dressings and if the hole was showing. In July of 2013 I went to see a plastic surgeon and prosthesis technicians. A mould was made for a prosthesis and it was fitted August 2013.

I was pleased with the results and the outcome was much better than I had anticipated. The new prosthesis certainly made me feel happier about facing the public.

Both the consultant and I have now agreed that it’s best I do not have any re-constructive surgery on my nose, for the time being at least, as the prosthesis has been so effective and as I was told that the result would not look cosmetically any better than the prosthesis. It would have involved several operations, and the inconvenience of being without my glasses for several weeks was also something I did not welcome! I may have thought differently if I’d been younger!

A second prosthesis was made in July 2014, but it made my nose sore. This was partly due to a small lump on the side of the bridge, which was then removed in Aug 2014. However, I still found the original prosthesis more comfortable, and the colour was better! I’m still using this one now, but as they are supposed to last for about three years, I may be due for a new one this year.



I’ve now had two years on Rituximab and I am not sure at present, if and when I will need more. I’ve also been steroid free since the end of Feb 2014, apart from a short course to treat gout.

Avril Smith

Sarah's story

I was diagnosed with Wegener's Granulomatosis in June 2003, just before my 22nd birthday. I had my tonsils removed in the February and never really recovered from the operation.
I became really poorly. I was coughing up blood, had copious nosebleeds, joint pain, had no appetite and lost a lot of weight. A couple of days before being diagnosed I noticed something wrong with my nose - it seemed to have sunk in the middle.

I was later told this was called "saddle nose". At the time I was so ill that it didn't really hit me what had happened. Within a year of being diagnosed I had to have surgery to fit a tracheotomy and was told at one point that it could be permanent! The tracheotomy stayed in place for a year but, happily, my consultant agreed to remove it just before my wedding in 2006.

Unfortunately, I wasn't so lucky with my nose. I was told I could eventually have a reconstruction but that this could not happen until the WG was in remission as, in my case, it was all upper respiratory and sitting in my nose and throat and there was every chance it could collapse again. I found this very hard to deal with. I looked and felt different. My social life suffered as going out and meeting new people was stressful in case they stared at me.

I hated having my photo taken, preferring to be the one behind the camera. It didn't matter how many times family and close friends told me "you can hardly notice" or "it looks fine" - to me it was horrible. I couldn't even put moisturiser or foundation on my face because that meant looking in a mirror. Smiling was particularly hard, it seemed to make my sunken nose even more defined. I used to call myself "Skeletor"! Over the next 7-8 years I had numerous relapses.
It became a standard joke at my ENT appointments that the first thing I would ask was "When can I have my nose done?" In 2010 he finally agreed to do a reconstruction and said he would take some cartilage from my ear to build up my nose. I don't know how I felt at this point - excited, thrilled, apprehensive - but mostly scared. What if it didn't work! Luckily, it did work and, for a time, I did feel a little better. I was slightly happier about my appearance, but I still wasn't me!

I was warned before the operation that it might not last and, unfortunately, after a few months it did start to slowly collapse again. Shortly after this, around the time of my 30th birthday, I started to relapse again.

In 2014 I was feeling well enough and went to see my ENT consultant to discuss other options for me. I asked him about collagen fillers. He said he didn't do fillers himself but suggested that I go to see a colleague of his who did maxillofacial work. I wasn't sure what this would entail but agreed to the appointment. I am so glad I did. When I met the consultant he said that he had never treated anyone with WG before and was quite interested/excited in the condition.

I explained to him that I wasn't just there for vanity, that it was affecting my whole life. He totally understood and really put me at ease. He suggested a treatment, which would involve injecting Hyaluronic Acid into my nose. He said normally it would involve two sessions close together with follow-ups every six months or so. However, because of my condition, he literally had no idea what the result would be! He therefore said that in my case he would rather build the nose up slowly to see how the fillers would take. He went through the whole procedure with me, explaining the possible downsides one of which was that it could kill the skin on my nose, more so in my case because I have thin skin.

On the day of the first treatment I was really nervous. Because my nose was so sunken, the procedure involved numerous injections. When I left the clinic he gave me his mobile number, asking me to ring him that night if I had any concerns and also to send him a photo of my nose. It was quite painful to start with and very red and swollen. However, after a couple of days, when the swelling had gone down, I was quite pleased with the result. I was nearly back to me again!
When I went for my second appointment we were both impressed by how well it had taken. Since then I have had a couple of "top-ups" and when I went to the clinic in August this year I was told to come back for a review in November. I am now very happy with the shape of my nose - I finally have a profile again! The only, small, downside for me is the redness, but this could simply be down to my thin skin. I feel more confident and relaxed and find myself able to smile more.
I have been told that this is not a permanent fix and I've no idea how long it will last, but at least I still have the option of a full reconstruction at some point in the future if needed. As everyone with WG knows, we are all different and there is no guarantee it will work for everyone, but there are always options out there if we ask.

Sarah Skinner

Hey Mr Robertson

Andrew has Vasculitis and Cares for others too, a Mother's Story

My son Andrew was diagnosed in 2008 with a rare life threatening illness called Granulomatosis with Polyangitis formely known as Wegener's Granulomatosis.

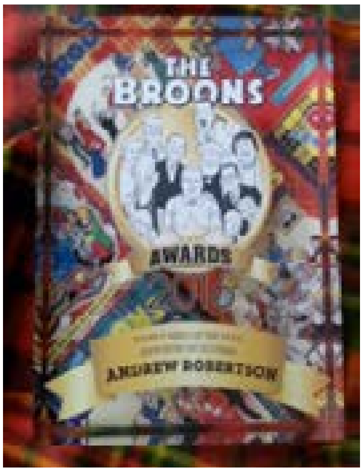
He had six months of chemotherapy, still continued working and two months afterwards he entered and finished the Great North Run. He continued running, competing in half and full marathons and progressing to participating in triathlons. He encouraged his work colleagues to take up the sport and with the help of his family and friends has raised over £11,500 for various charities. He now has a Just Giving page https://www.justgiving.com/Andrew-Robertson2 because he is planning to compete in 10 triathlons in 2016 (health permitting) to raise funds for Vasculitis UK and also hopes to raise awareness of this life threatening illness: the earlier it is diagnosed the less damage is done to the organs.

In May last year two weeks after doing the Alnwick Triathlon he discovered his illness had returned and was threatening his eyesight -even though he was on toxic drugs to suppress his immune system and had been for over 6 years. Whilst in hospital they did a scan of his head & discovered what they thought was a growth in his jugular vein. Further investigation showed it was a thrombosis . He had a further seven months of chemotherapy and treatment to blitz the thrombosis and thin his blood. Andrew just accepts whatever life throws at him, never complains and is truly amazing. Andrew has very little time off work, is very determined and a true inspiration to all who suffer from this life threatening illness.

Andrew was only out of hospital 2 months when his mother-in-law became seriously ill, spending eight months in hospital – three months in intensive care. Three times they were told she wouldn't survive the night. Although undergoing chemotherapy for the vasculitis, Andrew supported his wife, Alyson, visiting her Mam in hospital almost everyday and being a shoulder for her to cry on. Alyson's Mam is now in a wheelchair and Andrew & Alyson stay with her at weekends looking after her and cheering her up.

Two years ago, two of Alyson's young uncles died. This was a very traumatic time for the family and last year Alyson's mother's marriage broke down. Andrews's dad has had two accidents and six operations for basal cell carcinoma in the last three years, and Andrew supports him even though he is coping with his own illness. Andrew never moans or grumbles. He always takes time to help and inspire others, is very funny and likes to make people laugh.

Margaret Robertson
(Andrew's Mum)



Andrew was nominated by his mum for the Broon's Awards http://www.broonsawards.co.uk/ in Scotland and was selected as one of the ten finalists. Andrew attended the Broon's Award Evening in Glasgow with his extended family on March 10th 2016.

Margaret, Andrew's mother is a member of the Toastmasters International and gave a presentation about Andrew and his life since being diagnosed with GPA (WG) to the Elvesthad Speakers and has been asked to do a follow up presentation. Margaret is hoping to develop her presentation about Andrew so she can talk to other groups in the future.

Mapping new territory:

Southend Symposium on GCA, PMR and LVV

The Third International Symposium and Imaging Workshop on Giant Cell Arteritis (GCA), Polymyalgia Rheumatica (PMR) and Large Vessel Vasculitis (LVV), was held in Southend. It was preceded by a meeting of the GCA guideline development panel. Comprehensive reviews of the literature were presented and their implications for patient care discussed. The evidence base in GCA is undoubtedly not as extensive as we would wish it to be. What the limited, patchy evidence means in practice is that our clinical decisions are beset by genuine uncertainty. In the meantime, patients still need treatment, and treatment decisions have to be made. Hopefully the guidelines will help doctors to do this.

The symposium was a stimulating mixture of eminent academics and clinicians presenting personal overviews of the field; breaking news from the clinical trials world; and presentations from some of the best and brightest young researchers in basic and clinical science. The buzz this year was all about the GiACTA trial, currently in progress. Nobody knows yet what the results will be – or if they do, they're not saying.

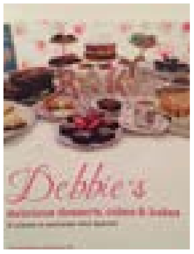
I felt as if we were a group of explorers meeting at base-camp, full of stories about the wildernesses we'd encountered and trying to collectively construct a map setting out all the things each of us have seen. But each of us have seen different things in the same landscape, and everyone is pushing the boundaries of their own particular research frontier, whether in the laboratory or in the clinic. Occasionally we reach the crest of a hill and feel we can see a bit more of the view. But they are only foothills; the mountain of discovery still remains to climb.

I really enjoyed the meeting and I hope that the exchange of data and ideas will further promote fruitful collaborations and ultimately help improve outcomes for patients with GCA, PMR and LVV.

Dr Sarah Mackie
(Associate Clinical Professor and Honorary Consultant Rheumatologist - Leeds)

VASCULITIS UK ON-LINE SHOP

We are so very pleased to announce that there is to be a reprint of Debbie's Delicious Cakes and Bakes recipe book and will be available from the 1st February 2016. Price will be £5.00 plus p&p.



THE LUCY RIVEIROS "V" RANGE OF JEWELLERY EXCLUSIVE TO VASCULITIS UK - A PERFECT GIFT FOR A BIRTHDAY OR ANNIVERSARY

Lucy is an up and coming jewellery designer and she has designed and made this limited edition range of beautiful jewellery exclusively for Vasculitis UK. As Lucy buys the raw materials herself, and donates the jewellery free to the charity, all income comes to V-UK. Price on request from Lucy.






All profits from the shop sales are used to meet the aims of the Trust - to support patients, raise awareness, and help fund vasculitis research here in the UK.

You can browse and view the goods we have for sale on the link below.
http://www.vasculitis.org.uk/shop

RARE DISEAS

Rare Disease UK Receptions were held in Cardiff, Edinburgh, Belfast & London

to raise awareness of all rare diseases for Rare Disease Day Feb 2016

Rare Disease Day Reception House of Commons 2nd March 2016

I attended the above in the Terrace/Marquee of the House of Commons, organised by Rare Disease UK. There were plenty of people from many rare disease organisations, MP's and even a couple Lords from the House or Lords.

The event was opened by Alastair Kent OBE, Chair of Rare Disease UK and Director of Genetic Alliance UK Pictured left with Northern Irelands Health Minister Simon Hamilton, He told us that theme for the year is 'Listening to the Patients' Voice' and that further improvement is needed and more attention paid to ensure that awareness of rare diseases passes to every corner of our health service.

Lord Walton of Detchant spoke, saying he teaches medical undergraduate and postgraduate students in Newcastle, ensuring that rare diseases are an important part of his lectures.

Dr Gina Radford, Deputy Chief Medical Officer, told us how she once delivered a baby boy who was very poorly, but did not have a diagnosis for a long while. That was her first experience of a rare disease.

George Freeman MP, Minister for Life Sciences, informed us that he is the National Champion for Rare Diseases and Ben Howlett MP, Chair of the All Party Parliamentary Group for Rare Disease, urged us to contact our respective MPs to ask if they would be willing to be involved in the APPG as the more we can get involved, the better.

Fiona Marley from NHS England was also there and showed us a video of a patient explaining how important it is to raise awareness about rare diseases.

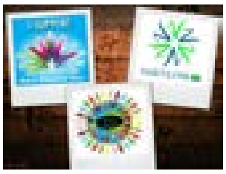
I had a really interesting day and was glad I went along.

Jacqui Moran

Liz Kendall MP was speaking at the Rare Disease Day Reception in Westminster, London."3.5 million people have a rare disease, must reform services to put them at the centre"

Julie Power (Northern Ireland Awareness) and VIA members attending Rare Disease Day event NI.

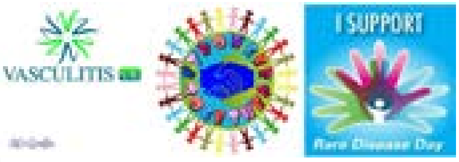
A big thank you to Kelly Jefferies who has been busy once again creating various images for Rare Disease Day on behalf of VUK.



Many of you were using these designs on social media to help raise awareness.

Emma Hughes of (RARE Disease UK) was speaking at the Welsh Assembly Rare Disease Day Reception in Cardiff

Jamie Hepburn MSP holding the Rare Disease Pledge for Paitents Scottish National Parliament, Scotland.



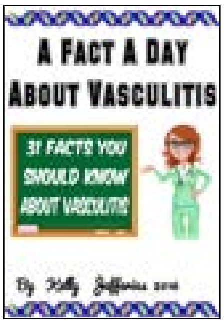
The designs used on both these pages top left and right were used along with the central

SE DAY 2016

Stonger Together design and the two in this column.

Kelly is currently in the process of designing a book pictured below for VUK Awareness Month in May.

It will be available in the VUK shop from mid April



Birmingham Children's Hospital Open Day Event for Rare DiseaseDay February 2016

John and I attended a special fun day on Saturday 27th February at Birmingham Children's Hospital, an event to mark International Rare Disease Day 2016. The hospital treats more than 9,000 children with rare diseases, from across the UK every year and around 500 different rare diseases, including vasculitis.

150 young people and their families attended the fun day along with Felicity Dahl, widow of the late children's author Roald Dahl. Roald Dahl's "Marvellous Children's Charity" exists to help seriously ill children and their families. They focus on supporting those with rare, undiagnosed or low profile conditions. There are over 6,000 rare conditions. Some affect as many as 5,000 children in the UK, while others affect just 1 or 2.

The event also celebrated the recruitment of two new specialist nurses for rare diseases and was a fundraiser for the planned new Rare Disease Centre at the hospital.

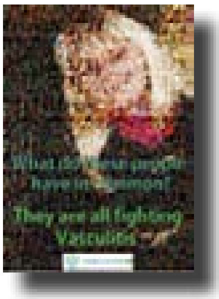
To find out more about supporting Birmingham Children's Hospital Charity's Star Appeal visit: www.bch.org.uk/starappeal. and for more information about the Roald Dahl Charity, visit www.roalddahlcharity.org.

Susan Mills

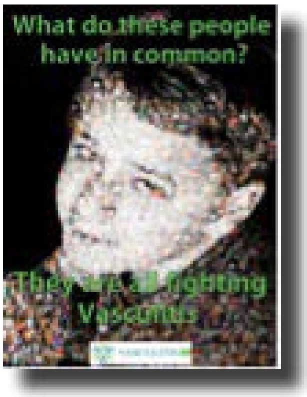
Vasculitis Awareness Month 2016

Last year we made a bit of a splash during Awareness Month. We would like to make a bigger splash this year. Can you help?

During May 2016, we would like to put your stories on social networks such as Facebook and Twitter as part of the initiative to make more people aware of the impact of Vasculitis.

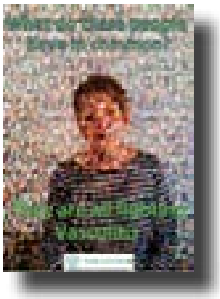


Therefore, can you tell us briefly, how any area of your life has been impacted by Vasculitis as a patient, carer or family member. Remember Twitter is just 160 words so please keep it brief.



Send a photo if you do not mind us using it. Alternatively, perhaps you would rather send a short video, which you are happy for us to put it on social media.

Please send your contributions to jann@vasculitis.org.uk
Together we can tell others about our condition.



Signposting and Advice

Hello, I'm Vicky Taylor and I was diagnosed with Granulomatosis with Polyangiitis (GPA) in November 2013. It was a shocking diagnosis, as my youngest child was only 9 months old and my symptoms, up to that point, had been blamed on my pregnancy and readjustment to becoming a mum again.

Urged by my husband, I gave up my job and concentrated on my health and my family.

Fast forward 2 years (and ten rounds of Cyclophosphamide, 2 lots of Rituximab, a bit of Methotrexate, a bit of Azathioprine, far too many steroids, plus some other stuff to hush my rumbling disease), I was finally fit and ready to give a bit back to the people who'd helped me in my early and darkest days.

When I made contact with VUK to offer my help it became apparent they had a suitable gap I could fill; Benefits Advice.

Luckily, I used to work face to face with clients on a daily basis in a very busy 'One Stop Shop' contact point for a Local Authority. I would give very specific advice on: welfare benefits, council tax arrears, accessing social services, blue badges, housing issues, consumer advice and much more. I have a good working knowledge of the benefits system and would frequently help with appeals and applications. So naturally, I was only too happy to commit myself to VUK and repay them for the invaluable advice which I had taken from them and from their members of the online support groups.

These days, I am happy to say I have been lucky with my treatment and as such I have no need to claim any sickness or disability benefits but I am more than aware of the importance of these benefits for those of us whose lives have been badly affected and those whose lives have been badly affected and those who's ability to work has been abruptly halted.

I can help you if you need guidance or signposting to access the benefits system. I can provide you with the information you need to apply for DWP benefits such as Personal Independence Payments or Employment Support Allowance and also help you identify if you qualify for any further assistance; practical and financial.

I can also share guidelines from the brilliant Benefits and Work website, to help strengthen your application or appeal, and recently I have been very pleased to share links to new and excellent online benefit checkers provided by www.seap.org.uk.

Please don't hesitate to get in touch to ask for my help, even if I don't know the answer I will certainly find out and get back to you.

For more info contact:
vicky@vasculitis.org.uk

Donating To VASCULITIS UK

*The charity is **entirely** dependent on voluntary donations*
Just £8 a year will pay for the printing and posting of both your Spring and Autumn Newsletters

Without your financial support we could not meet our aims of supporting patients, raising awareness and funding Vasculitis research here in the UK.

There are easy ways to make a voluntary donation by cheque, standing order (donation forms enclosed with this Newsletter) or by card via donations at JustGiving.com, VirginMoneyGiving or by PayPal.

Please remember that ***Gift Aid*** can increase your donation by 25 per cent at no extra cost to you.

For Further details about donating to Vasculitis UK, please contact the Treasurer, contact details on page 28

Donate with JustGiving

Support Group Meetings

West Country Support Group
Christmas lunch

Lincoln Spring Vasculitis Support group lunch organised by Sandra and Caroline and held at The Fox Inn , Kelham.

Carol Gillespie Holistic Therapist gave a demonstration of reflexology and massage.
http://www.vasculitis.org.uk/about/local-support-groups

Yorkshire Vasculitis Support Meeting with Lynn and Suze.

First Meeting of the Northumberland and Cumbria Support Group September 2015 attended by Dr Jim Lordan,
Dr Bridget Griffiths and John Mills

Support Group Leaders

The first-ever Vasculitis Group Leader Meeting was held in Birmingham on Saturday October 24th.

This was a one day event organised by and for vasculitis support group leaders and designed to give us - and those thinking of setting up a group - the chance to get to know each other, exchange ideas and experiences and maybe pick up tips and hints to improve and expand how we manage our own group.

The day was a great success with representatives from 14 separate groups attending. Discussions ranged from group management, promotion and administration to organisation and content of the actual meetings themselves. All those who attended felt the day was well worthwhile and that it should be repeated on an annual basis.

If you are involved in running a group or are thinking of setting one up and would like to receive more information about this year's meeting, please let me have your details and I will add you to the emailing list: Charlotte Stoner (West Country Vasculitis Support Group) the.stoners@talktalk.net.

Charlotte Stoner

To find a local support group in your area , or to find out what is available to start a support group or to view the support group photo gallery, please go to:- http://www.vasculitis.org.uk/about/local-support-groups

Wales Vasculitis Support Group

Professor Caroline Savage, Lindsey Chapman and David Sambrook
West Midlands Annual Support Group Meeting October 2015

Merseyside Cheshire & North Wales Winter 2015 Vasculitis Support Meeting. Speakers were Dr Janice Harper and Specialist Nurse Sarah Hardy

East Midlands Vasculitis Support Christmas Party - Max, William, Ruby and William are pictured here with Father Christmas.

British Society for Rheumatology Spring Annual Conference 2016

Each Spring the British Society for Rheumatology hold their Annual Conference. This year it will be held in Glasgow on the 26th/27th/28th April

The BSR conference is attended by about 2,000 Doctors, Nurses and other Medical Professionals with an interest in Rheumatology.

Once again Vasculitis UK members, John Mills, James Walker, Lynn Laidlaw and Susan Mills will be representing patients diagnosed with vasculitis at the conference, to raise a greater interest and awareness in vasculitis.

On the 29th February (Rare Disease Day) the BSR launched the two-year update report on implementation of the UK Strategy for Rare Diseases. The British Society for Rheumatology (BSR) has outlined its priorities to help improve outcomes for people with rare rheumatic and musculoskeletal conditions.

Please follow this link for more details.

http://www.rheumatology.org.uk/about_bsr/press_releases/bsr_sets_out_priorities_to_improve_outcomes_for_people_with_rare_rheumatic_diseases.aspx

For more details visit:
https://www.eiseverywhere.com/ehome/rheumatology2016/340165/

This one day workshop for patients runs alongside the world class BSR Rheumatology conference and gives you, the patient, an opportunity to hear from world class experts in sessions tailored to the patient experience.

If anyone would like to meet for lunch in Edinburgh on Saturday April 30th please contact Susan or Lynn. susan@vasculitis.org.uk lynn@vasculitis.org.uk

Feedback from the BSR

Rheumatology 2016
26-28 April 2016 | SECC Glasgow, UK

The BSR Rheumatology Conference in April 2016 now includes a patient programme.

Conference will be covered in the Autumn Newsletter later this year.

Eurordis Membership

Member of EURORDIS Rare Diseases Europe

VASCULITIS UK

Vasculitis UK are proud to announce that we became a member of EURORDIS in February 2016

EURORDIS is the voice for rare disease patients in Europe, a non-governmental patient-driven alliance of patient organisations representing 705 rare disease patient organisations in 63 countries.

They are the voice of 30 million people affected by rare diseases throughout Europe.

EURORDIS' mission is to build a strong European community of patient organisations and people living with rare diseases, to be their voice at the European level.

http://www.eurordis.org/

Trustee News

The Charity is sorry to announce that Jacqui Moran has decided to stand down as a trustee of VUK. Jacqui has been a trustee for three years and has been so very supportive to both Vasculitis UK and the Chairman John Mills. Jacqui has been unwell just recently and has decided to reduce her responsibilities. She has acquired a little dog, a miniature daschund, called Lottie, who needs and gives lots of love. But Jacqui along with Karen St Ledger will still carry on running the South East London/North West Kent Vasculitis Support Group http://www.vasculitis.org.uk/about/find-a-local-group and will still be organising the Bi-Annual Thames River Walk for Vasculitis UK.

We wish Jacqui and Lottie all the best for the future and we are sure some of the trustees and VUK members will be seeing her again at the 2017 Thames Riverside Walk.

Young Vasculitis - weekend break in the beautiful Peak District

Being a young person myself and suffering from Vasculitis I know all too well how isolating and lonely it can feel at times.

For a long while now I have wished that I had friends who were going through the same thing as me. After over 5 years of living with vasculitis the loneliness is still very much there. It got me thinking that there are so many other people suffering and will feel exactly as I do, is there anything I could do to help us all? I attend the Vasculitis Support groups and although they are very informative and a huge help I struggled to make a real connection with anybody as I seemed to be at a different stage in my life to everybody else which meant I have different worries and struggles.

Upon discussing this with Susan Mills she agreed that it would be a great idea to put something in place that will benefit the Young Vasculitis suffers. We quickly decided we didn't think a support meeting would be the best option so we had a think out of the box and this is what we have come up with….

A Friday and Saturday night away with the option of coming for one night or both, it will be very relaxed and will give everybody the opportunity to talk about their Vasculitis but more importantly it gives us the chance to make friends which will then help give us the ongoing support.

Rather than going full steam ahead and booking different places all over the country we have decided to put one weekend in place to start off with as a trial and take it from there.

Weekend break details

- November 25th, 26th and 27th 2016 – staying over the Friday and Saturday nights
- Hathersage YHA House – in the beautiful Peak District http://www.peakdistrict.gov.uk/
- Sleeps a maximum of 42 people (the whole house is ours for the weekend)
- 5 minute walk from the train station – trains from Sheffield and Manchester
- 30 minute drive from the M1, Junction 29
- Nearby – 4 pubs, 4 cafes, 2 restaurants, take away, a bank and lots of shops
- Coming along for the weekend will be a young doctor who is a research and clinical doctor for Vasculitis. She cannot wait to be part of it!!
- Spouses/ partners/close friend welcome
- Cost – 20 people - £18 per night, 25 people - £15 per night, 30 people - £12.50 per night, so the more take part the less expensive it will be.

Anybody who is interested in coming along or would like any further information please email me on emma@vascultis.org.uk

Well-being

Some great tips for being well

Complementary medicine uses therapies that work alongside conventional medicine. Alternative medicine includes treatments not currently considered part of evidence-based Western medicine.

Generally speaking, complementary and alternative medicine is relatively safe, although you should always talk to your doctor before you start treatment. There are some risks associated with specific therapies, for example some herbal therapies may have significant side-effects or may interact with prescribed medication.

In many cases the risks associated with complementary and alternative medicine are more to do with the therapist than the therapy. This is why it's important for you to go to a legally registered therapist or one who has a set ethical code and is fully insured.

Some of the most well known are:
Acupuncture involves inserting fine needles at particular points in your skin. The therapist may stimulate the needles manually, by heat (with a dried herb called moxa) or by a small electrical current (electro-acupuncture). The needles are very fine, so having them inserted is rarely painful. Acupuncture seems to relieve pain by diverting or changing the painful sensations that are sent to your brain from damaged tissues and by stimulating your body's own pain-relieving hormones (endorphins and encephalins). This pain relief may only last a short time when you begin treatment, but repeated treatment (usually weekly for six or eight sessions) can bring long-term benefit, often for several months.

Relaxation, hypnosis and cognitive therapies are psychological therapies. They can be divided into those which focus on relaxation and those which focus on patterns of thinking and feeling (cognitive therapies).
The purpose of **relaxation** is to cancel out the effects of stress and fatigue. Relaxation can help control pain. Learning how to relax your muscles and get the tension out of your body can be very helpful for many painful conditions.
Hypnosis is a deeply relaxed state, induced by a practitioner, in which you're given therapeutic suggestions to encourage changes in your behaviour or relief of your symptoms. Hypnosis might include a suggestion that the pain can be turned down like the volume of a radio.
Cognitive therapies involve talking and aim to change negative patterns of thinking, feeling and behaving.
The most widely used cognitive therapy is cognitive behavioural therapy (CBT). It cannot resolve your problems, but can help you manage them in a more positive way by breaking them down into smaller parts. It encourages you to examine how your actions affect the way you think and feel. CBT is often helpful in long-term health conditions. CBT may be done on a one-to-one basis, in a group or with a computer program.
There's quite good evidence that these techniques can help with pain and symptoms such as anxiety.

Meditation, t'ai chi and yoga
Most of the traditional meditative therapies have ancient roots in Asia. They combine meditation, special movements or postures and breathing exercises. They are usually done in a group, and the social contact with like-minded people can itself be helpful.
Yoga originated in India about 5,000 years ago. It uses breathing exercises and postures – movements designed to increase strength, balance and flexibility – to boost physical and mental wellbeing. It can be helpful for low back pain, depression and stress.
T'ai chi and qigong originated in China and are increasingly practised around the world. They can both help with stress, balance and mobility and increase muscle strength.
Meditation involves concentration on breathing or a sound (called a mantra) which you repeat to yourself. Mindfulness-based stress reduction (MBSR) is a modern therapy with roots in Buddhist meditation. It helps you pay more attention to the present moment – to your own thoughts and feelings and the world around you. It can help with pain, anxiety and sleep problems. There are now MBSR apps for mobile devices which some people find helpful.
Are they safe?
There's quite good evidence that these techniques can help with pain and associated symptoms such as anxiety. Some may also help with movement and flexibility. They are safe, although you should take care when attempting some of the more extreme yoga positions.

With grateful thanks to Arthritis Research UK

Vegan Coconut and Raspberry Scones

This adapted scone recipe can be made with butter or margarine and cows milk instead of coconut oil and almond milk. They can be eaten by themselves or with butter and raspberry jam! They are very light in texture and not too calorific.

- 7 oz Self Raising flour
- 1 oz dessicated coconut
- 1 1/2 oz coconut oil
- 1 tbsp caster sugar
- 5 fl oz almond milk (or coconut or soya milk)
- Handful of frozen raspberries (fresh go all squidgy)

a little extra flour
Pre heat oven to gas mark 7, 425 f, 220 c

Line a baking sheet with grease-proof paper or baking parchment

Sift flour into a bowl, and rub the coconut oil into it. Stir in sugar and dessicated coconut, and use a knife to mix in the almond milk little by little.

Flour your hands and knead the mixture to a soft dough, add a drop more milk if it seems dry. Poke the frozen raspberries into the dough.

Turn out onto a floured pastry board, you can roll the dough out but I just pat it into a big, thick circle of at least 2cm depth.

Use a circle cutter or break off balls of dough, roll them in your hands and put on the baking sheet. You will get around 8 good sized scones.

Bake near the top of the oven for 12 to 15 mins, until pale brown on top. Turn onto a wire rack and eat straight away or allow to cool. Freezing - wrap them singly in cling film or freezer bag. Try different flavour combinations (apple and cinamon, chocolate and raspberry or banana, peach and ginger etc)

Lynn Laidlaw

We've Got the Runs

Great North - Birmingham - London

This year we have been very fortunate to secure places in 3 races. One is among the most prestigious in the country, the Great North Run.
For the first time we have 5 runners for whom we have bought the places: Caroline Leck, Mick Rochford, Martin Makin, Rebecca Wass and Roger Clarke.
We also have 2 more that paid for their own entry Philip Mayor and Tracey Denham-Watson.

Please look out for them on the 11th September and support them with fundraising on our behalf. We will try to apply for more next year as the places were taken within 2 hours of the posting on Facebook. We also have places and runners for the Great Birmingham 10K on the 1st May. This is the first time we've had places or runners for this event, so we hope they do well and we can repeat it next year.

Martin Makin with runners from last years London 10k

This was the first time I've used the "Great" entry system and it's been quite a learning experience as its set up for big charities

Finally we have 12 places for the Vitality London 10K on the 10th July 2016. This is the 4th year that we have had places for this event and we've done very well with it in the past and we have high hopes for it this year.

We have many runners who pay for their own entry to events this includes the London Marathon (Martin Makin), the Great Manchester 10K (Victoria Gorton and Laura Heaton) and runs in Putney, Basingstoke, North Wales, South Coast and numerous others in the UK and abroad.

I'm always amazed at what people are willing to put themselves through (not just running) to raise money for Vasculitis, they are remarkable. I hope you will support them.

Dorothy Ireland
(Fundraising co-ordinator)

All fundraising photos can be found on the website http://www.vasculitis.org.uk/about/fundraisers-photo-gallery

World Kidney Day March 10th 2016

Some types of Vasculitis affect the kidneys and if the damage is too severe dialysis is needed which can lead to a transplant. .

This is Ryan's Story, Ryan has Granulomatosis with Polyangiitis (Wegeners Granulomatosis)

In May 2013 I had a kidney transplant from my fantastic uncle, David Starling. Without his donation, my wife, Ellen, would have been next in line. If she had given me her kidney, or if I hadn't had a transplant, at least one of us would have been too ill to have our daughter, Alice.

Because David and Ellen are not blood relatives, my transplant wouldn't have been possible just a few years ago. It's only possible now thanks to the hard work of people like Kidney Wales, Kidney Research UK, and of course, the amazing staff in the renal and transplant units at UHW.

It's worth remembering too, that I was very lucky to have so many amazing family and friends who volunteered to donate a kidney. There are lots of people who are on a waiting list for various organs, who don't have someone to donate, so have to wait for an organ for a long time, and they don't always have a happy ending because of the shortage of donors.

Please encourage friends and relatives to register as an organ donor, and help organisations like these so that other people get a chance to have a happy ending like I have.

To read more about Ryan's and David's story please follow this link http://www.walesonline.co.uk/news/local-news/real-life-hero-urges-more-people-4923008

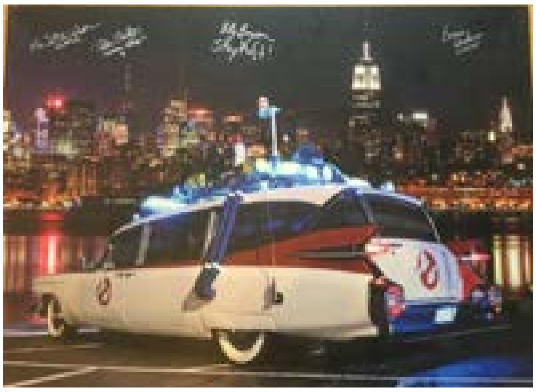
Ryan Davies Wales

More of Our Fantastic Fundraisers

Thank you GHOSTBUSTERS

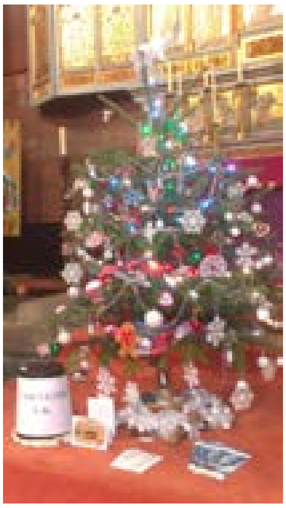
Sadly on February 25th 2014, Harold Ramis, director, writer and actor lost his life to complications to Vasculitis. In 1984 Harold Ramis collaborated with Dan Aykroyd on the screenplay for the film, "The Ghostbusters", which he also starred as Dr Egon Spengler. The film became one of the biggest comedies of all time. VUK would like to thank the "UK Ghostbusters" a fantastic group of Ghostbusters fans who have been fundraising and raising awareness for Vasculitis and Vasculitis UK for the last two years, through appearances in film and comic conventions, digicons and holding auctions.

To find out more about the UK Ghostbusters follow this link to their website http://theukghostbustersgroup.weebly.com/charities.html



The UK Ghostbusters auction of a signed print of Ecto-1 for Vasculitis UK.

Vasculitis UK took part in the annual Christmas Tree Festival in Bakewell Church December 2015. Almost 100 trees were displayed from local businesses, organisations and charities. http://www.bakewellchurch.co.uk/activities/christmas-tree-festival/



St Faith's Waterloo Merseyside Christmas Tree Festival - raising awareness &fundraising for VUK with Vicky Taylor. http://www.waterloopartnership.co.uk/christmas-tree-festival-at-st-faiths/

Martin Richardson ran in the Harwood House 10k on behalf of his sister-in-law, Holly Hampshire, who was diagnosed with Wegener's Granulomatosis in 2008. The team were fundraising for VUK and Age UK

Little T's Holiday Cottage

Tracy Martin has been a supporter and fundraiser for Vasculitis UK since her partner, Gordon Mott, sadly died in 2006 after fighting vasculitis for several years. She has a holiday cottage in the picturesque town of Holt in Norfolk. Visitors to the cottage make contributions to Vasculitis UK in return for borrowing books from the cottage's library. If you would like to take a holiday in Tracy's charming character cottage, visit the website www.littletscottage.co.uk. Or 'phone Tracy 01359-233343

NIHR / Wellcome Trust
Clinica Research Facility

CANVAS UPDATE

This article was written by Dr Dimitrios Chanouzas
(School of Immunity and Infection)

The CANVAS (CMV Modulation of the Immune System in ANCA Associated Vasculitis) study is jointly funded by the Wellcome Trust and Vasculitis UK. Led by Professor Lorraine Harper at the University of Birmingham the study commenced in 2012. CANVAS is run through the NIHR / Wellcome Trust Clinical Research Facility at University Hospital Birmingham and is due to be completed later this year.

The CANVAS team is interested in finding out whether a common virus called Cytomegalovirus (CMV), which most people contract at some point in their lives, affects the immune system in a negative way in people with ANCA vasculitis.
The CMV virus lives in cells of the immune system and undergoes periods of reactivation without necessarily causing any clinical symptoms. In many people it profoundly affects the composition of the immune system as the immune system is pre-occupied with keeping it 'in-check'.

Previous work by Professor Harper's research group has suggested that people with ANCA vasculitis are more at risk of infection partly because of the way the virus alters their immune system. The CANVAS study aims to carefully tease out the details of the ways in which CMV affects the immune system in people with ANCA vasculitis.
It also aims to test whether taking an anti-CMV tablet for 6 months can halt or reverse the negative effects of CMV on the immune system.

Preliminary results from the study suggest that the immune response to the CMV virus may increase the stiffness of blood vessels thereby increasing the risk of heart disease and stroke.

The results of the clinical trial will be valuable in determining whether controlling the CMV virus can reduce such risks in people with ANCA vasculitis.

Chronic pain- What can I do to help myself?

The following is an extract from the booklet "Managing Chronic Pain" produced by the Scottish Intercollegiate Guidance Network (SIGN).

The booklet covers many topics to help you understand your pain, covering issues such as how it is assessed and how to manage your pain, including complementary medicines.

You can view the booklet at:www.vasculitis.org.uk/living-with-vasculitis/dealing-with-pain

Nobody else can understand your experience of pain or what it feels like to live with it every day. You are the best person to understand your pain and the best to manage it.

You can try to "self-manage" your pain. This could include:
- Formal self-management programmes (group-based, individual or online); or
- Informal self-management (for example, learning about pain management by reading about it).

Learning about your pain and understanding it can help you manage it well.
Healthcare professionals can help you find a self-management programme that suits you.

Take medication regularly: To achieve good pain control, it is usually important that you take your medication every day, as guided by your healthcare professional, even if your pain doesn't feel as bad. You should not change the dose of the medication or when you take it until you have discussed this with your healthcare professional.

Exercise: Staying active can help to improve your pain in the long term. If you are not sure what exercise is best to do with your pain, discuss this with a doctor or physiotherapist.

It is important that if you are experiencing pain you should discuss this with your GP or consultant and follow the regime suggested by your healthcare professional.

IN MEMORIAM

Vasculitis UK receives donations from bequests and funeral collections in memory of particular individuals who have suffered from vasculitis, or where vasculitis affects a family member. Our sympathies are extended to the families and friends of those mentioned below.

The Trust is extremely grateful for families remembering us in this kind and generous manner.

All donations received will be used to fund activities of the Trust, especially our research projects.

Funeral donations of £335 were made in memory of Mr Barry Lunn of West Bay, Dorset; formerly of Calow, near Chesterfield, Derbyshire. He was 71.

Donations totalling £230 were made in memory of Mr Peter Sabine.

A donation of £500 was made in memory of Tracey Jackson by her husband, Ian.. She was 49 and suffered from HSP.

Somerfield Ltd sponsored Bryan Benjamin in the Bath & Bristol Marathon for £500. Bryan donated this to Vasculitis UK in memory of Rachel Dring.

The family of James Waterhouse kindly donated £2000 to Vasculitis UK in his memory.

Donations totalling almost £2000 were made in memory of Mrs Miriam Richards, of Esher, Surrey.

A funeral collection in memory of Mr Reginald Blunden of Arundel, Sussex resulted in donations totalling £225.

Donations totalling £543 were made in memory of Trevor Gale of Chichester.

A collection of donations in lieu of flowers in memory of Paul Coates resulted in a total of £186 being donated to Vasculitis UK.

Donations totalling £90 were received in memory of Mrs Anne Plant of Middleton, Manchester, who passed away in November 2015

Donations totalling £100 were received in memory of Mrs Anne O'Connor of Sale, Cheshire.

£200 was donated in memory of John Wallace Gardner, who passed away in November 2012.

Funeral donations totalling £112 were made in memory of Mrs Lucy Diana Meekings of Ovington, Essex.

Funeral donations in lieu of flowers totalling £337 and donations from the staff of Moore Stephens totalling £165 were received in memory of Mark Williams.

Vasculitis UK received funeral donations totalling £183 in memory of Peter Turnbull of Altrincham, Cheshire.

Lorraine May kindly donated £300 in memory of her husband, John, who had vasculitis for 12 years.

Donations of £275 were received in memory of the late Mary Coulson of Benfleet, Essex, who died due to vasculitis, following the funeral of her father Albert Rook.

Ruth Shail donated £25 in memory of her dear friend Bunty Cameron

Funeral donations totalling £411 were received in memory of Mrs Margaret Georgeson of Gateshead.

The sum of £500 was donated by those attending the funeral of Mr A.G.Ramsay of Carnoustie, near Dundee.

Funeral donations of £130 were received in memory of Richard Roy Thompson of Wimborne, Dorset.

The members of Slimming World Group, Whitchurch, near Cardiff, donated £100 in memory of Ian Shellard.

The family and friends of Mr Ian Griffin of Stevenage donated £250 in his memory.

Donations & Fundraising

The charity has a simple and sensitive JustGiving page for those who may wish to raise funds for Vasculitis UK by celebrating the life of a loved one. If you would like to remember a loved one in this way to help raise funds for the charity please visit: **www.justgiving.com/VasculitisUK/Remember**

Kelly Swift raised £294 for Vasculitis UK by taking part in the North West Triathlon.

Manda Taylor and her sister Emma raised £1535 for Vasculitis UK by organising a family party and a disco.

JLT Management gave £350 in matched funding for their staff member, Dee Elias's participation in the Vasculitis UK 2015 Thames Walk.

Ruth Shail gives her friends lifts and they give her mileage money which she kindly donates to Vasculitis UK , totalling £90 last autumn.

**See Spring 2014 edition for Tracy Martin's cottage – small advt

The team at Swithland Spring Water Ltd of Charnwood, Leicestershire kindly donated £850 to Vasculitis UK in lieu of sending Christmas Cards to their customers.

Engayne Primary School in Upminster, Essex, very kindly donated £332 which was raised from collections at the parents' Christmas Assembly and the reception Nativity play and Year 2/3 School play.

Vicky Taylor entered a Vasculitis UK tree in the Christmas tree festival at her local church and sold goods in aid of Vasculitis UK. This raised a total of £146

The "Spire Club" at Newark once again donated £100 to Vasculitis UK

Andrew McMellon is a postman who has vasculitis. He is the regular postman at Wooton Hall Residential Caravan Park, where the Tea Club holds a monthly raffle for good causes. Andrew and Vasculitis UK were nominated, resulting in a donation of £200.

May Willavoys of Cheltenham donated £1250, the proceeds from her catering and sales of greeting cards at craft fairs throughout 2015.

Staff of Bristow Helicopters Ltd in Redhill, Surrey, held a charity day and raised £110 for Vasculitis UK. This donation was matched by the company

Will, Benjamin, Jake, Matt, Tom and Ben, students at Long Road Sixth Form College in Cambridge, raised £556 for Vasculitis UK by collectively cycling to Amsterdam; or to be more precise, over 3 days, between them they cycled 376 miles in the College Sports Lab, the equivalent of pedalling from Cambridge to Amsterdam.

The Bank of Scotland donate £1000 in matched funding for Lorraine Reilly and Caroline Richards, who raised funds for Vasculitis UK.

Vasculitis sufferer Paul Smith, his friends and family very kindly donated £310 to Vasculitis UK in lieu of exchanging Christmas presents.

Natalie Hewitt and her family kindly donated £200 to Vasculitis UK

Gail Coughlan kindly donated £50 in sponsorship money for her "Dry January".

The Shaw family of Burntwood, Staffordshire, passed on a donation of £150 for Vasculitis UK, which was raised at their local Masonic lodge.

Joyce Blackwell of Sidmouth kindly donated £100 to Vasculitis UK

Malcom Harwood of Thirsk, near York, kindly donated £120 to Vasculitis UK.

Beverley Hey's mum recently celebrated her 80th birthday and she requested donations to Vasculitis UK in lieu of presents, thereby raising £230 for Vuk. Beverley's son suffers from vasculitis.

Jean Gibson of Sheffield kindly donated £96 to Vasculitis UK

Jenny Fulford-Brown kindly donated £180 to Vuk

Mr & Mrs Harwood of Rainton, near Thirsk, N.Yorkshire donated £120 to Vasculitis UK.

Mrs Mary Jones of Hengoed, near Cardiff, donated £150.

Brenda Potter of Horsham donated £250

The members of the Warden Lodge (No.794) kindly donated £150 to Vasculitis UK.

Margaret Meech of Littlehampton kindly donated £50

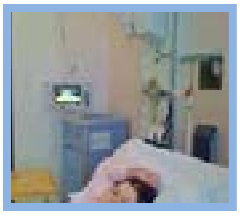
The pupils of Hopton Primary School, near Great Yarmouth, donated £11.60.

We received many other donations from members and supporters, for which we are most grateful.

There are easy ways to make a voluntary donation by cheque, standing order (donation forms enclosed with this Newsletter) or by card via donations at JustGiving.com, VirginMoneyGiving or by PayPal.

Donate with JustGiving

Me, HSP and Tillypops



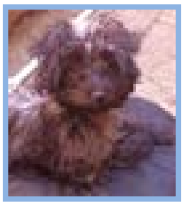
My name is Kyri, I am 29yrs old, I've been ill almost all my life.

I was first taken ill when I was about 18 months old, I was admitted into hospital in December 1988, I was in hospital for 11 days and my mum was told I had chronic juvenile arthritis, I was so very weak and had so much pain in my joints and had a rash all over me.

I missed out on a lot of school because of illness and I attended lots of hospital appointments and hospital stays. I had to have fluid drained from my knee and had to learn how to walk again because my muscles had collapsed in my upper legs, my pain had got so much worse and finally in 2010 I was told I had vasculitis, a type called Henoch-Schonlein Purpura and IgA Nephropathy, as well. My body burned all over with a horrible rash for over 8 months and the vasculitis started to affect other parts of my body, I had chronic renal failure, and was admitted to Birmingham hospital.

About a year later I was critically ill for 2 nights with a infection from my kidneys, ever since then, I have been having many hospital stays for months at a time. Over the last few years I've become more reliant on my wheelchair as my arms hurt too much to use my crutches anymore. I see a psychiatrist for my depression and I've now been told I have fibromyalgia as well. I have gall stones which cause me pain, but the operation to remove the gall bladder is not easy to do because of my medication and other illnesses.

My psychiatrist said when I'm not in as much pain maybe I could do something for charity, because I love helping others, so I decided to make pet toys, because last year my Mum and Dad brought me a little tiny Shihpoo called Tillypop. She helps me with most things from taking my socks off to opening me doors or even covering me up in bed, She's like my second carer and helps me by giving me the confidence to go out with her by my side, so I wanted to make her a few toys.



Tillypop

It was then I thought of making them to sell and donate the money to Vasculitis UK.

My Mum has become my full time carer and helps me with things Tillypop doesn't. My Mum has been there with me, through it all, every test, every scan, and every visit to and in Hospital. With my mum's support and help from Tillypop, I'm where I am today with my "Tillypops". I am doing so well with selling the toys and raising awareness of vasculitis.

I can't do many toys at a time, but I rest my hands and do a few more when I can, my family help as well, as I don't want to let people down, I just want to do what I can for Vasculitis UK

"Tillypops"

This illness is a very depressing, painful illness, it hurts me so much that there are not enough people understand it, my life isn't my own I have to rely on so many people to help me, I don't leave the house, unless it's to go to hospital, it's a lonely life, I can't even make a cup of tea for myself, as I lose the use of my hands and legs without warning, I'm not doing any of this for myself it's for vasculitis awareness, there are so many people out there that need help and they have nowhere to go. John and Susan have always been a brilliant help and support all the way too.

Before the vasculitis I did manage to work even with the everyday pain of arthritis, and also went out with friends and visited family, but now it's all been taken away, by this horrible illness, called Vasculitis. But I'm slowing getting my life back I will not let this illness beat me!

Kyri Roebuck
Nottinghamshire

https://www.facebook.com/groups/tillypopscharitypettoys/
@tillypopstoys

VASCULITIS UK

Helpline

for information and advice about vasculitis by telephone or email. If you prefer you can write to us.

Helpline Telephone:
0300 365 0075

E-mail
john.mills@vasculitis.org.uk
lynn@vasculitis.org.uk
Post: John Mills
West Bank House,Winster, Matlock
DE4 2DQ

The Informational Needs of Carers for People Diagnosed with ANCA Associated Vasculitis

Vasculitis UK is supporting the study being carried out by Dr Richard Watts, Dr Janice Mooney and Karly Graham at the University of East Anglia into "The Informational Needs for Carers"

Karly is Research Assistant and is based at UEA – if you have any participant queries, about the study please do contact Karly.
Karly.Graham@uea.ac.uk
Karly has previously worked with Professor David GI Scott, Dr Richard Watts and Dr Chetan Mukhtyar on various vasculitis and general rheumatology studies and also supports research for the charity BRITSpA (British Society for Spondyloarthritis).
There will be a questionnaire, for both carers and vasculitis patients accompanying the Autumn Newsletter 2016.

Get in touch with your local Vasculitis Support Groups

ENGLAND

Beds, Bucks & Herts Group
Janine Davies - 01525 372733 - family.davies@btinternet.com
Christine Lee - 01480 869162 - chrislee0307@btinternet.com

Cambridge Group
Lesley Noblett - 0776 5897780 - cambsvsg@gmail.com

Canterbury area (Contact Person)
Margaret McGrath - 01227 638469 - margaretmcgrathfmsj@yahoo.com

East Kent (Contact Person)
Brian Hart - 01227 369774

East Midlands
East Midlands Website Group https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home
Dorothy Ireland - 01332 601303 – Dorothy@vasculitis.org.uk
Lisa Ranyell - 01664 857532 - lisa.ranyell@ntlworld.com
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

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

Lancashire/North West Group
Jann Landles - 07979 180145 – nwvasculitis@hotmail.com
Anita Parekh - 07921 682232 – nwvasculitis@hotmail.com

Leicestershire
Leicestershire Group Website https://sites.google.com/a/vasculitis.org.uk/vasculitis-east-midlands-support-group/home
Tricia Cornforth – lvsg@btinternet.com

Lincolnshire Group
Sandra Lee - 0754 514 4777 - sandralee_506@famail.net
Caroline Meyrick - 01780 460354 - cmmyerick@gmail.com

London
North London Group
Dave Newman - 07429137670 - david.newman@londonvsg.org.uk

South East London & North West Kent Group/
Bi-Ennial Thames Riverside Walk
Jacqui Moran - 07792 412768 – jacqui.moran1@ntlworld.com

Merseyside, Cheshire and North Wales Group
Susan Chance - 01244 381680 - susanchance53@icloud.com
Dave Birch - 0151 7229049 or 07968226230 - davebirch@talktalk.net

Northumberland and Cumbria
Rebecca Winlo – rebecca.winnlo@gmail.com
Martin Thomas - 07765 888987 – nwukvsg@gmail.com

Oxfordshire Group
Sue Ashdown - 01295 816841 – oxfordvsg@gmail.com

Solent/Portsmouth Group
Julie Ingall - Julie.ingall@porthosp.nhs.uk

Surrey Group
Group under discussion

West Midlands Group
David Sambrook – davsamuk@yahoo.co.uk
Margaret Gentle - 0121-243-5621 - mgvsgwm@blueyonder.co.uk

West Country Group
Website https://vasculitiswest.wordpress.com/
Charlotte Stoner - 01626 872420 - the.stoners@talktalk.net

West Sussex Group
John Bailey - 07752 122926 – johnbee4@googlemail.com

Yorkshire
Website www.yorkshirevasculitis.org.uk

North Yorkshire Group
Richard Eastoe - 01423 520 599 – Richard@yorkshirevasculitis.org.uk
Lynne Jacques - 01274 412378 - lynne@yorkshirevasculitis.org.uk

York, North & East Ridings Group
Richard Eastoe - 01423 520 599 - richard@yorkshirevasculitis.org.uk
Jennifer Wormald - 01937 586734 – Jennifer@yorkshirevasculitis.org.uk

Yorkshire (North/West) Group
Lynne Jacques - 01274 412378 - lynne@yorkshirevasculitis.org.uk

WALES

North Wales - (Contact Person)
Pat Vernalls - 01766 770546 - patvernalls@btinternet.com

North Wales Group (group also covers Merseyside and Cheshire)
Susan Chance - 01244 381680 - susanchance@53@icloud.com

South Wales Group
Jenny Fulford-Brown - 029-2021-8795 - jenny.swvas@gmail.com
Ryan Davies – ryan@wegeners-uk.co.uk

SCOTLAND

(Contact Person)
Lynn Laidlaw VUK Helpline 0300 365 0075 – lynn@vasculitis.org.uk

Edinburgh and Lothian - Contact Person
Jimmy Walker - 07725 770103 - james-walker@outlook.com

Glasgow - Contact Person
Patricia Henderson - 0141 581 1711

Republic of IRELAND

(Contact Person)
Joe O'Dowd - 00353 (086) 2345705 – dwodo@iol.ie

Ireland - Vasculitis Awareness Ireland
Vasculitis Awareness Ireland Website http://vasculitis-ia.org/
Julie Power - 028 44 842889 - vasculitisireland10@gmail.org.uk

EVENTS CALENDAR

British Society of Rheumatology
26th/27th/28th April – Glasgow
Rheumatology 2016 will be a world-class conference held at the Scottish Exhibition and Conference Centre (SECC), Glasgow and run for all health professionals in the field of Rheumatology.
https://eiseverywhere.com/ehome/121743

EURORDIS Membership Meeting 2016
Edinburgh (EMM 2016 Edinburgh)

The 2016 EURORDIS General Assembly and Membership meeting will take place in conjunction with ECRD 2016 in Edinburgh on 26 May 2016.
http://www.eurordis.org/content/eurordis-events

Vasculitis UK AGM
The 2016 AGM will be held at a new venue this year at Derby University.
Speaker on this occasion is Dr Dimitrios Chanouzas (School of Immunity and Infection Birmingham QE Hospital) (CANVAS study led by Prof Lorraine Harper)
http://www.vasculitis.org.uk/news/vasculitis-uk-agm

UKIVAS/Lockwood Club Spring Meeting
representing patients diagnosed with Vasculitis & Vasculitis UK, on April 22nd 2016, in Leeds

These Vasculitis UK laminated posters are available to share with the hospitial where you receive your treatment please contact Susan for more details.

susan@vasculitis.org.uk

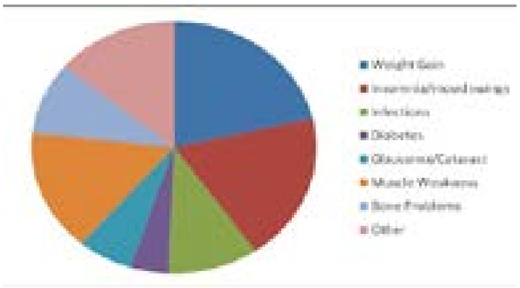
HealthUnlocked Online Surveys

Those readers who use the Vasculitis UK HealthUnlocked online discussion group will be familiar with the polls or surveys that take place at regular intervals. These are usually about what people think about their illness & how it has affected them and cannot be considered in any way as "research".

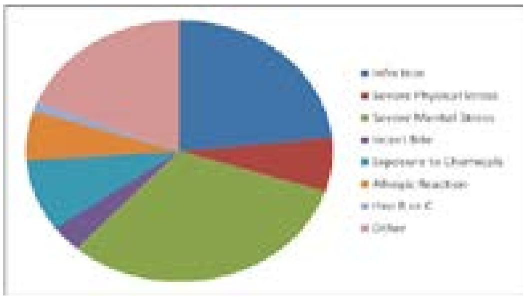
However, the results can be very interesting and may sometimes be used to guide those wanting to undertake formal research. The format is very limiting as you can only ask one question with up to eight choices of answers, but respondents are also able to add comments.

Examples of surveys undertaken over the past year are:-

1. What side effects experienced due to steroids?
2. What do you think triggered your vasculitis?
3. Time from first symptoms to diagnosis?
4. Seasonal patter to vasculitis symptoms?
5. Experience of pain & fatigue?



"Side effects of steroids" attracted the highest ever number of responses and comments



"Vasculitis triggers" was popular and started a very animated discussion.

To see all the polls, you need to join the HealthUnlocked group.
https://healthunlocked.com/vasculitis-uk?tab=polls

LIFE PRESIDENT - LILLIAN STRANGE

Vasculitis UK is the UK's No 1 Vasculitis charity, established in 1992. We are an independent organisation funded entirely 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.
Formerly known as the Stuart Strange Vasculitis Trust
Registered Charity No. 1019983

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john.mills@vasculitis.org.uk

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Mike Patnick

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Jann Landles
secretary@vasculitis.org.uk

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Prof David G.I. Scott
Dr Richard Watts

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Jane Elsom
Dorothy Ireland
Susan Mills
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Volunteers:

Anita Parekh
Lucy Riveiros
Julie Scott
Graham Baker
Kevin Soper
Tali Hewitt
Lynn Laidlaw
Vicky Taylor

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