



VASCULITIS **UK**

NEWSLETTER JOURNAL



AUTUMN 2021 ISSUE 62

It's been another tough time for immune suppressed people. Hopefully, we are all double vaccinated. Although, as we know this doesn't guarantee full protection against Covid 19. The OCTAVE study was published in August indicating those who are immune suppressed would need a booster jab or third jab. The full report can be found in this newsletter.

Some of our members in the Facebook support group have had antibody tests, showing that they have low antibody counts. We have also had a number who have contracted covid, thankfully most have recovered. Its not just the antibodies we need to look at but the T cells. The immune system is very complex. We should soon have the interim report from the Nottingham research into patients having rituximab and their response to the vaccines. Thanks to all our members who have taken part in these studies.

This time the government haven't been so clear on how we should be protected, no shielding. At the time of writing this we are awaiting further information from the JCVI. So, for those members who work they have a difficult decision to make. I still wear a mask when out, though that's not very often, and I continue with the sanitiser. We were thinking of having a face-to-face AGM in October, but again the covid case numbers are rising. The idea of bringing together so many immune suppressed people seemed to be tempting fate. We are therefore, thinking of a zoom meeting in November.

For Vasculitis UK it has been a very strange 6 months. When I wrote the last report, we had 9 trustees and were looking to add to that number. Sadly, we've had some resignations since then.

Martin Makin has suffered a tragic family circumstance and decided to take a step back from the charity.

Gareth Garner, our own virologist, was promoted and asked to be a consultant lecturer at Liverpool University. We wish him every success in his new job, and he will still continue as a volunteer.

Kelly Jefferies has recently added family circumstances plus her Behcets is causing added health issues. So she decided to step down as a trustee, but will continue as a volunteer with the shop and graphic designs.

David Newman will retire as a trustee at the AGM, he has a new role in retirement which isn't compatible with being a trustee.

Ian Kayes, has retired as a trustee but will continue as a volunteer and as our very vigilant treasurer.

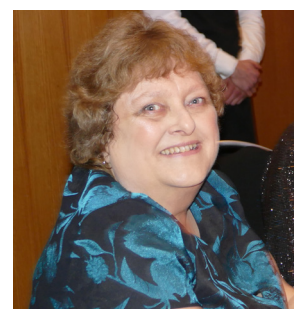
We will miss all of them and their contribution to the charity.

The remaining Trustees are: **Dorothy Ireland** chairman and fundraising co-ordinator. **John Mills**, Vice Chairman and Director of Operations. **Susan Mills** currently our acting secretary. **Zoi Anastasa** deputy Director of Operations.

We did have a response to our first ever "online ad" for new trustees. We would like to welcome **Charlie Harper**, already a star of ITV news and with some great ideas for the younger members. **Jen Harper**, who wrote the booklet "Holly Helps Out" and again has new ideas. **Charlotte Smith** who has a background in a Charity fundraising. Finally, **Peter Rutherford**, who has spoken at our meetings and previously worked for the pharma company involved in Avacopan. Their statements will be on the website soon. These new trustees will continue to move the charity forward and have already suggested changes.

Fundraising has been very quiet during the covid lockdowns. However, people have still be doing some great things, and although our fundraising is down by around 20%, we have been luckier than the big charities, as we have very low running costs. I'm writing this just as we near the Great North Run. We should have 21 runners, but a lot have deferred to 2022. I think that their training has been affected by the restrictions earlier this year and for many in the health service the stresses of work. I want to thank all those who did the run. I will apply for 2022 in November and hopefully, places will be advertised soon after.

Take care everyone!



Chairman's Report

Dorothy Ireland
Chairman

Dear Reader



Welcome to this our 62nd edition of our charity's bi-annual newsletter/journal, in which we also welcome our new trustees Charlotte, Charlie, Peter and Jen, you can read their introductions on page 19.

Creating this Bi-annual newsletter/journal has the benefits of seeing what our fantastic fundraisers, patients and healthcare professionals have been up to before anyone else, along with some very moving personal stories and journeys, for me, the downside is that the months in between seem to go so quickly and before I know it the next edition is due.

Hopefully this edition gives you the reader the same satisfaction as it does me compiling it!

We always welcome you our readers input, and if you have any personal stories or feature suggestions for future editions please let me know, and I will try to accommodate them.

Its good to see us all slowly getting back to the new normal, this will hopefully help many of our fantastic fundraisers to get out and do what they do best. I know that creating this helps me give something back to our fantastic charity, it also helps with our own mental well-being and forms part of the five steps:

1. Connect with other people
2. Be physically active
3. Learn new skills
4. Give to others
5. Pay attention to the present moment

Now in this present moment it's time to pour yourself your favourite brew and enjoy our current edition..... Until the next !

Kevin Soper Editor

This editorial feature is done in loving memory of my dear Sister, Clare Grossman, who was taken from us at the age of 38 due to Wegener's granulomatosis (GPA) back in 2010.

CONTENTS

Cover Page	James Mancini
Pages 2-3	Chairman's Report / From The Editor
Pages 4-5	Covid Booster/UKIVAS
Pages 6-7	PMRGCA (UK)/RAIRDA
Pages 8-9	Our Fantsatic Fundraisers
Pages 10-11	Great North Run / Charlies Story
Pages 12-13	VUK Awareness Month Patients Story / Book Review
Pages 14-17	Research roundup
Pages 18-19	Support Groups New Trustees
Pages 20-21	Double Vaxxed Doctor/ BIOVAS
Pages 22-23	Research Round up two / Trials
Pages 24-25	In Memoriam / Donations & Fundraising
Pages 26-27	Local Support Groups / Events
Back Cover	Officials / Contact Details

Covid Vaccine – Booster Doses/Third Vaccine Explained.

BOOSTER DOSE.

The effectiveness of vaccines tends to wear off with time, especially in older or very young people.

The Booster dose is for those who have had both doses of covid vaccine at least 6 months ago. It will be offered to **all over 50's and 16-49 year olds** with underlying health conditions
Boosters will be given at least 6 months after the second vaccine.

Boosters will be either Pfizer or Moderna (unless there has been an allergic reaction to these vaccines previously, in which case the Astra Zeneca will be given).
The booster dose is half a normal dose.

THIRD VACCINE.

A Third vaccine will be offered to all those who **are immune suppressed** or **Clinically Extremely Vulnerable**. You *should* receive a letter inviting you to have the third vaccine.**

Third vaccines will be a full dose of either Pfizer or Moderna (unless there has previously been an allergic reaction to these vaccines previously then A-Z will be given).

Third vaccines will be given **at least 8 weeks** after the second vaccine.

FLU VACCINE

All people with vasculitis are recommended to have the flu vaccine. The influenza virus can be extremely dangerous for people who are immune suppressed or clinically extremely vulnerable.

Some doctors suggest that it is better to not have the flu vaccine and COVID19 vaccine at the same time - maybe a week or two apart. This is because if an allergic reaction should occur, the reaction will be reported for the vaccine involved.
Delivering the vaccines on different days might be difficult for some GP practices.

** All notification letters should be posted out 27th September.

Some may receive two letters, ie. to receive both the booster and third vaccine especially if they are in either the under 50 group or 19 - 49 group with underlying health conditions.

If this occurs then please check with your own consultant to which vaccine is appropriate for you.

Third vaccines must also be carefully timed for those receiving Rituximab or other biologics. It important please check with your own consultant when/if you should have the vaccine.

This advice was posted on the VasculitisUK website in mid-September. (Susan Mills 9/2021)

Vasculitis in the Media

See Me, Hear Me/ My ANCA Vasculitis

A project funded by VIFOR Pharma aimed at improving understanding of vasculitis & the patient experience involved vasculitis patients from around Europe. This sophisticated project resulted in some amazing graphics and numerous videos of patients narrating their experiences. Vasculitis UK's Shanali Perera contributed exciting graphics. You can view these and see some familiar faces by going to:

www.myancavasculitis.com

Vasculitis Registries, Pathways & Therapeutics

The UKIVAS Autumn 2020 Education Meeting

UKIVAS is the UK & Ireland Vasculitis Society/Study Group. It was formerly known as the “Lockwood Club” in memory of the great pioneer in studying and treating the ANCA types of vasculitis. There is also the UKIVAS” Registry” a vasculitis research database created in the late 1990s by Dr Mark Little & Dr Alan Salama – both now Professors.

UKIVAS is exclusively for medical professionals. It is now developing an educational role for medical professionals with an interest in vasculitis and has teamed up with the Nephrology section of the Royal Society of Medicine to offer educational webinars. The first of these in November 2020 was a 2 full day online event which was viewed live by 570 delegates from 42 countries; with the recorded version attracting a further 212 participants.

The first session on day1 was an introduction to the UKIVAS registry and its work. Inevitably Covid related topics were a recurring theme, reflecting the valuable contribution made by data from the UKIVAS registry to gaining a greater understanding of the impact of Covid on those with vasculitis. This led into a presentation by Prof Mark Little on the EU funded FAIRVASC project which aims to link 7 European vasculitis registries, giving access to data on care & outcomes of over 15,500 patients.

Speakers from the UK, US & Europe took part. In the “Patient Perspective” session, Vasculitis UK patient representatives John Mills & Zoi Anastasia took part in discussions on doctors being in “silos” & not communicating, patients having to take part in the departmental carousel as they search for a diagnosis, Zoi highlighted problems with access to care for those living in more remote areas. Julie Power and Patricia Ryan from Vasculitis Ireland talked about the advantages of Telemedicine (as experienced during the pandemic) for people with rare diseases and the value of Art in representing vasculitis as represented in the “Sear Me, Hear Me” & “My ANCA Vasculitis” social media campaign.

So many excellent speakers covered so many relevant subjects on small and large vessel vasculitis, with different chairs for different sessions. Speakers included Prof David Jayne, Sarah Mackie, Maria Cid (from Barcelona), Maria King, Rachel Jones & Rona Smith, with Peter Lanyon talking about the GIRFT (Getting it Right First Time) NHS Improvement initiative. Rosemary Hollick and Allyson Egan talked about the VOICES project, looking at service delivery and Louise Oni spoke about standardising care in paediatric IgA cases.

Feedback from delegates was very positive. The success of the event was largely down to Drs Alysson Egan & Steve McAdoo of the Hammersmith Hospital Lupus & Vasculitis Clinic and the Royal Society of Medicine. The meeting was sponsored by Vifor Pharma.

A further session is planned for 17/18 November this year.

ABOUT PMRGCA(UK)

PMRGCAuk is not the snappiest of titles for a charity, but effectively, it does what it says on the tin. Our overall aim is to support our members, who have either polymyalgia rheumatica or giant cell arteritis, or indeed not uncommonly both these conditions. And by supporting our members, we also support many non-members both nationally and internationally.

The charity was founded about 15 years ago by a small group of people with polymyalgia and/or giant cell arteritis who found that there was no patient support group to help them. When one considers that the lifetime incidence of these two conditions in the UK population exceeds 2%, that their causes are unknown, and that symptoms or potentially debilitating treatments may last for several years or more, the need for the charity is clearly apparent.

From those modest beginnings we have grown considerably, now with a membership exceeding 1,400 and an online community of 12,000.

I volunteered to act as Chair of the Trustee Board a couple of years ago, and have found PMRGCAuk to be an extraordinarily worthwhile and exciting organisation.

Our activities extend over four domains:

Support – to people with these conditions, their relatives and their carers

- 1) **Education** – not only for those affected, but for health care professionals
- 2) **Advocacy** – for improved services
- 3) **Research** – not only by supporting and encouraging research, but by helping to define the research agenda.

In each of these areas we have expanded our activities recently, in part as a response to the circumstances of the pandemic, and in part as real increases in knowledge, and disease management, have come on stream. To summarise these:-

Support - our activities range from group meetings up and down the country (we partner with PMRGCA Scotland), meeting in halls, libraries, and so on, sometimes with outside speakers, sometimes just for a talk (these have obviously moved to an online medium throughout the pandemic; but slowly our groups are returning to being face to face). More formally we have a series of webinars for our members, with nationally known speakers such as Jenni Murray of Woman's Hour fame and Dr Michael Mosley, as well as leading UK clinicians.

We run a telephone helpline manned by volunteers where anyone – most generally the newly diagnosed – can call for a chat. On a larger scale we publish information on our website <https://pmrgca.org.uk>, and publish a regular magazine NewsWire. Finally we moderate our PMRGCAuk forum on the HealthUnlocked internet site <https://healthunlocked.com/pmrgcauk> - this is devoted to PMR and GCA, and used both nationally and internationally.

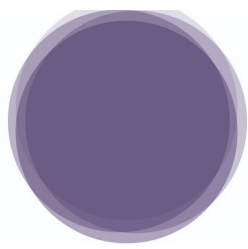
Education – our website carries concise information on both conditions and their treatments; and we seek ways to educate the medical profession. Whilst this sounds an arrogant comment, we persistently hear stories of people with both conditions undiagnosed over weeks or months – and even more distressingly of GCA patients, when diagnosis and treatment has been delayed, developing irreversible sight loss.

Advocacy - we held discussions with the Medical Director of the NHS and the Czar for musculoskeletal diseases about improving referral pathways to optimise treatment; sadly the first meeting on this was held just as Covid struck, but the dialogue has now resumed. A particular area that we push is the implementation of fast track referrals for suspected giant cell arteritis – which have been demonstrated to improve diagnosis and prevent visual loss. Achieving this requires education along with provision of fast track ultrasound scanning to avoid the need for temporal artery biopsy to establish the diagnosis of GCA.

Research – as a patient group, we have a unique perspective on research, and a particular ability to define the priorities that we think will help people with the conditions. Increasingly we work with academics and clinicians in planning research. Excitingly we received a major donation from one of our members, and are in the process of awarding a £50,000 grant for research into those aspects of polymyalgia which were highlighted as research priorities by a survey of opinion amongst patients with the condition.

Our strength as a charity comes from our position as the only UK charity concentrating on these two conditions. I would encourage everyone who is affected by them to join; I am very confident you will find something of personal interest or help, and you would contribute to our work for others.

Humphrey Hodgson (chair- PMRGCA-UK)



RAIRDA UPDATE

Rare Autoimmune Rheumatic Disease Alliance

Vasculitis UK is a member of and contributes to support the work of RAIRDA. RAIRDA is a coalition of charities and doctors working together to improve care for people with rare autoimmune rheumatic diseases.

RAIRDA - Situation in Wales

RAIRDA recently submitted evidence to the Welsh Government in response to their consultation on guidance for services for people with arthritis and long-term musculoskeletal conditions.

On August 24th 2021 RAIRDA told the Welsh Government that there is a clear need to improve care for people with RAIRDs in Wales. Evidence from RAIRDA surveys indicates that patients in Wales, on average, have more problems with their care than those in the rest of the UK. Whilst there is some good care in Wales and some clinicians with specific expertise in RAIRDs.

We believe the lack of a commissioned specialised centre in Wales is a major reason for this difference.

<https://rairda.org/updates-and-news/>

Impact of COVID-19 pandemic on access to care

In June 2021 RAIRDA's survey asked patients what impact the pandemic had on the care they received:

41% said it had a major negative impact

29% said it had a minor negative impact

There were clear variations in how responsive services had been able to be, and some services had delivered good care despite the pressures of the pandemic. However, some very ill patients reported issues getting care.

COVID19 Infection, Admission & Death Amongst People with Rare Autoimmune Rheumatic Diseases in England

Research published in August 2021 indicated that the 170,000 people in England with rare autoimmune rheumatic diseases like lupus, scleroderma, and vasculitis were more likely to be infected with, and die from, COVID-19 compared to the general population during March-July 2020.

<https://www.medrxiv.org/content/10.1101/2021.08.17.21260846v1>

As a result of this research, RAIRDA are calling for further steps to protect people with these diseases from COVID-19. Including actions to: protect people receiving treatments in hospitals through testing; ensure everyone with these diseases receives a booster jab; and for employers to act to protect people. As a result of this research, RAIRDA are calling for further steps to protect people with these diseases from COVID-19. Including actions to: protect people receiving treatments in hospitals through testing; ensure everyone with these diseases receives a booster jab; and for employers to act to protect people.



James Mancini cycled 114 miles and 11500 ft elevation, raising £940 for VUK.



Martine Ross's wing walk, raised an amazing £2990. Martine has been fundraising for VUK in memory of her mum, who very sadly lost her life, in February of this year to ANCA Vasculitis.



Candice Ursell hair shaving for Vasculitis UK in memory of her mum, Catherine who very sadly lost her life to Vasculitis 2 years ago.



Evan Robinson and medal



Thank you to Katie Tyson-Phillips and Liam's Blue and White Army for raising an amazing £4240 taking part in the 5 Peak Challenge in August of this year. Liam, Katie's husband was diagnosed with Vasculitis (EGPA) in March 2020 during the COVID19 pandemic - showing many symptoms of Coronavirus.



Annie Barton hosted a charity lunch on The Lady of Lee Valley barge and raised £155 for Vasculitis UK. This is their 5th year for different charities and Annie thought it only fair to raise money for VUK as she was diagnosed with Anca Positive Vasculitis 2 years ago!

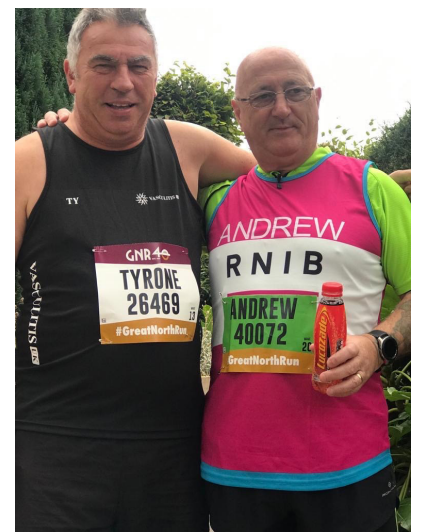


Rajesh Shah Lockdown hair cut fundraising for 5 charities including Vasculitis UK

So in August this year Ryan Ahern pictured right managed to complete his first Triathlon on behalf of his mum Lynne, who has Vasculitis. Ryan has raised over £1k for VUK.



Sharon Hopkins - raised £400 at the Great North Run 2021



Ty Buckley and his friend Andrew - Great North Run September 2021

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



Henry King ran the Iron man Bolton in memory of his dad, Gary, who sadly lost his life to vasculitis in 1999. Henry was only 3 years old. The Iron man is a 2.4 miles swim, 112 miles bike ride and 26.2 miles run. Henry has raised an amazing £3,285.



Thank you to Jess Randle & Rachael who completed the Three Peaks Challenge 2021. Raising £670 so far for VUK.



In February of this year, Raju & Craig lost a much loved family member to Vasculitis. Valerie didn't receive the diagnosis until it was too late. Raju & Craig ran the Thetford Trials in memory of Valerie and have raised over £1100.

The Dey Vasculitis Family Challenge

In late 2020 Andy, started feeling unlike his usual self. He is a very fit person but was struggling to run short distances. This progressed to an inability to do everyday activities such as walking around the block and up/down stairs. Things came to a head in February 2021 when one weekend Andy found he couldn't walk properly and was coughing up blood.

He was rushed in to hospital where he stayed for around 2 weeks including 10 days in the high dependency unit. After countless blood tests, scans and biopsies we were given the diagnosis of vasculitis. While we were relieved to have a diagnosis we had never heard of vasculitis so didn't know what to expect.

Andy has now been out of hospital for several months and is making a steady recovery. It has been a challenging time for the family as they have got used to Andy's new normal.

In the past month he has gone from being unable to walk from the living room to the bedroom by himself to initially taking short walks around the block to longer 5 mile hikes. The outlook is very positive hopeful thanks to the early detection of vasculitis.

As a family we wanted to do something positive to raise money for Vasculitis UK. May is World Vasculitis Awareness month. On the 22nd May it was 66 days since Andy was discharged from hospital. So the Dey family collectively planned to run/cycle/walk 66 miles to raise as much money as we could for Vasculitis UK. In the end, we managed to run/cycle/walk a total of 164 miles and were delighted to raise £6,355 for Vasculitis UK.





In 2015, at the age of 42, I was diagnosed with Vasculitis, probably HSP. It was a frightening time and I was very poorly. I know that I'm very lucky as I made a recovery, have remained in remission and haven't had any flares since then although I now have an irregular heartbeat and will need a pacemaker.

It wasn't until a bit later that I found out about Vasculitis UK and the fantastic work the charity and its volunteers does in supporting people with Vasculitis and their families. I'm now taking on two running challenges: the Great North Run

and the London Marathon. Not only do I get to run in two races I've wanted to complete for a long time but I'm also raising money for Vasculitis UK too.

I was first offered a Vasculitis UK place on the Great North Run in 2020 but as we all know nearly everything got postponed or cancelled due to the pandemic. Fast forward into 2021 and I now have two great events to train for and look forward to in the space of three weeks.

I've always loved exercising and being physically fit through daily cycling helped when I had to fight Vasculitis initially. I've had to take a step back from cycling for health reasons but this has meant I've been able to start running again which I really enjoy.



My training has been going well and I'm as confident as I can be that I'm going to be able to complete the events and raise much needed funds for VUK. My long runs are up to 20 miles and weekly mileage approaching 50. I took a week off when I caught my first chest infection since the one that triggered vasculitis in 2015 and Covid is potentially my next hurdle as my wife and children have caught it one by one but somehow I'm managing to stay healthy.

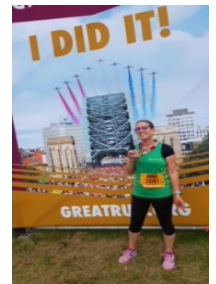
Many of your stories inspired me in the early days when I didn't really know what I was battling with my illness, so I hope that myself and the other VUK runners can give others hope too and I wish you all well.

Graham Mully



William Larmour (left) ran the Great North Run 2021 for VUK on behalf of his mum who has Vasculitis. Will has raised an amazing £800.

Anna Mayhew (right), Specialist Nurse at Addenbrookes Hospital ran the Great North Run for VUK. Anna has raised over £683 to date.



Father & Daughter, Martin & Suzy, Ran Together for Vasculitis UK in the Great North Run and have raised over £1000

We are so grateful to Vasculitis UK for giving us the chance to take part in the world's biggest half-marathon, the Great North Run – it was a terrific experience.

The weather conditions were ideal, cool and dry, with a gentle breeze. The wonderful Geordie crowds were out to cheer us on. We finished together in just one second under two hours.

It was awe-inspiring to see so many people running to raise money for so many charities and we were very happy to be a small part of something so much bigger. Would we do it again? You bet!



How to navigate life with a subglottic stenosis.

By Charlie Harper



It is easy to forget that we are always breathing, the gentle flow of air in and out of the lungs has inspired numerous types of meditation and relaxation practices. But for GPA patients living with a subglottic stenosis, every breath can be a struggle.

My name is Charlie, I am 28 and live in Oxford. I want to tell my story and what I have learnt through living with a subglottic stenosis. I hope my experiences and "top tips" can help others navigate life with such a debilitating and scary condition.

First, what is a subglottic stenosis? A subglottic stenosis refers to the narrowing of the windpipe just below the vocal cords. It starts with inflammation of small blood vessels in the windpipe, with inflammatory tissue building up and eventually turning into thick scar tissue. Around one in ten people with GPA develop a subglottic stenosis. With treatment usually a combination of increasing steroids/immunosuppressants and/or surgical dilations of the throat. The symptoms for patients are often scary and debilitating, with many describing feelings of being "strangled" and "always trying to catch their breath". Unfortunately, this manifestation of GPA is not often talked about, and I would like to share my story so others are more aware of this disease.

My story starts back in the summer of 2019, I had been diagnosed (with GPA) in March of that year and was tapering off my steroids as the disease was believed to be under control. Slowly over many weeks my breathing started to get noisier and felt like a lump was stuck in my throat. After this got worse, I ended up in A&E with breathing difficulties. ENT diagnosed the subglottic stenosis quickly and Rheumatology were able to act quickly to up my steroids and start me on cyclophosphamide (as previously as I was on Rituximab only). Soon after this I went into surgery, with ENT dilating (stretching) my windpipe and providing some small laser cuts around the area. The surgery really helped short-term and allowed me to breathe normally again.

Here are my tips on managing life with a stenosis:

Have a direct email/telephone number of your local ENT team. If your breathing worsens, you don't want to be stuck in A&E for hours trying to explain to the receptionist/nurse why you are there and who you need to see.

Invest in a good nebulizer. Using a nebulizer with saline solution helped me manage my symptoms at home.

Find your most comfortable position. It is important you find a place/position at home you feel most comfortable breathing (for example I found I could breathe easiest on my side lying down).

It's normal to be noisy. When my stenosis was particularly bad, my breathing sounded like a hiss and was most noticeable around others less familiar with my health. But it is important to remember this is okay and normal: if it is something you feel self-conscious about then spend time with those you feel most comfortable around.

Rest your voice. Speaking can become exhausting, as you are trying to push air out of a very small hole in your throat. Try to talk in short bursts (15-20 mins) then have quiet times in the day to rest it.

Unfortunately, my story does not stop there.

Over several months my stenosis continued to get worse, and surgical treatment was only effective for a few weeks. After some very difficult days, I ended up in A&E again in November 2019 with little ability to breathe. I was given adrenaline and then taken into the operating theatre to undergo an insertion of a tube in my throat (called a tracheostomy). Fortunately, this was not a surprise for me as my surgeon had already warned me this would be the last resort.

After the surgery, the experience of waking up is quite scary. I was not able to speak as they had blocked my upper airway, I could not move my neck, I had a feeding tube, and lost all independence for a short period. Without doubt, one of the worst moments that I have experienced with GPA. But I was able to recover quickly, and within a few weeks I was swallowing and speaking again, with nurses teaching me how to manage my own tracheostomy at home.

Here are my tips on managing life with a tracheostomy:

Get in contact straight away with the private medical supplier who will send you tracheostomy supplies free of charge (mine is called Atos Medical).

Learn as much as you can while in hospital about cleaning and looking after the device. Nurses are a great place to start, and they are happy to go over things as many times as you need.

It does get better. When you leave hospital, it will be challenging to look after, and the stoma will take a while to heal. A few months later and all the inflammation will have died down and living with the tracheostomy is far easier.

Keep an eye on the weather. Breathing can be challenging on days where the temperature is particularly cold or wet. The summers tend to be far easier than the winter months.

Build confidence in leaving the house. With a whole new addition to your day-to-day life, practice with a loved one leaving the house, over time gaining confidence to do it by yourself.

Soon after having the tracheostomy in place, I lost my voice completely due to the airway fully closing. Me and my wife had to negotiate communicating, often mouthing words, or using hand gestures.

Throughout this period my daughter Heidi was born, and the new parent experience had to go hand in hand with managing without a voice. After further rounds of cyclophosphamide and further dilations, I was finally able to gain my voice again and smell my daughter for the first time. We recorded the first time I was able to speak to her, a magical moment for us all. We were worried that she would grab and damage the device, but after lots of repetition she learnt it to be normal (like someone might wear glasses).

A year on from these life changing events and I still live with a tracheostomy; it is so normal now that I forget I have it. Life remains challenging with it but is far sweeter for me with a wonderful daughter and wife. Soon I will be undergoing a full resection (reconstruction) of my throat in London, and we hope that this may be my final airway procedure, with the tracheostomy tube also being removed.

There is no doubt that this whole journey has been incredibly hard, with many points where I lost hope. But the value of community (family/friends/nurses/doctors) cannot be understated, I would not be where I am today without each one of these individuals. So, I want to say THANK YOU.



Vasculitis UK Awareness Month

Shanali Perera a contemporary artist, educator, retired Rheumatologist, and a person living with Vasculitis, based in Manchester, UK. Shanali is also a LENS (Lived Experience Network) champion for the Northwest region.

Shanali designed the Moving Forward Vasculitis Awareness T shirt for Vasculitis Awareness Day 2021, she also organised a 5k walking challenge to fundraise for Vasculitis UK to support the Vasculitis community. As well as raising awareness of Vasculitis, globally, for International Vasculitis Awareness Day. The walk took place on World Vasculitis Day, 15th May 2021 at Manchester Athletics Arena. Shanali raised an amazing £3270



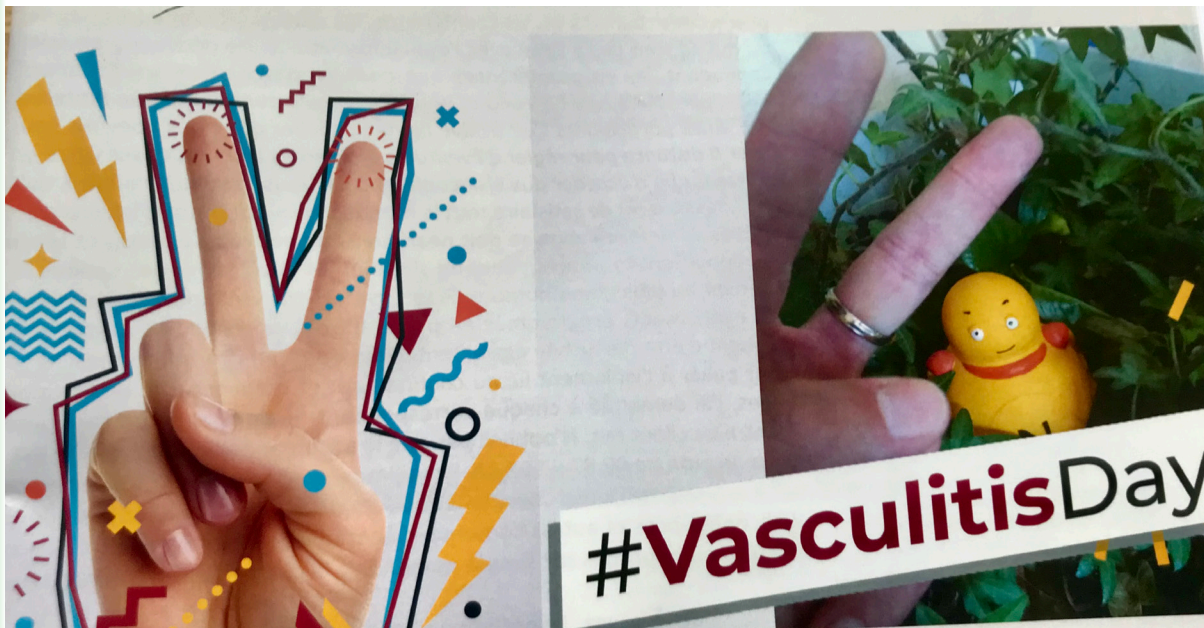
Shanali crosses the finishing line



John and Shanali walk one lap together



Moving Forward - with the lucky mascots - Susan & Shanali



Shanali receiving her flowers to say thank you



Vasculitis Anthem - May 2021

The first ever song specifically written about a disease. It is a shanty style song written about Vasculitis, a rare autoimmune disease. Written and performed by Keith, John and Sylvia. Acknowledgments to Prof Alan Salama for the idea. <https://www.youtube.com/watch?v=mJ0P5RpgTTY>

Vasculitis Patient Interviews for the ITV News and the Daily Mirror Online



Vasculitis patient Hannah Burden has secured valuable media coverage to help the public understand the challenges for those for whom vaccines don't offer the same benefits as for most. Hannah explains on the Daily Mirror website how her vasculitis drugs are likely to render Covid vaccines ineffective for her.

<https://www.mirror.co.uk/news/uk-news/wonder-drug-keeps-alive-never-24953610>

Vasculitis patient Charlie Harper is featured in an ITV News item on how Covid vaccines affect immunosuppressed people.

<https://www.vasculitis.org.uk/news/itv-news-on-vasculitis-and-covid>



Jane Edwards & Susan Mills, Trustee for VUK, have secured high-profile coverage for VUK's message that 'Freedom Day' poses serious challenges for those whose medical condition may preclude vaccination, or make it less effective.

<https://www.mirror.co.uk/news/uk-news/please-carry-wearing-masks-after-24533374>

Book Review

MIND The GAP (by Terry McCormick)

Although Terry McCormick comes from a Welsh farming family with roots in the c19th, he is an academic, an expert on the works of Wordsworth, having gained his PhD at Cambridge in 1976 on the poetry of the great Lakeland poet. This resulted in a job as curator of the "Wordsworth Trust" at Dove Cottage, Grasmere for 15 years.

With his wife Julia, they bought a 6 acre smallholding, above Grasmere, in 1989. They also acquired 40+ gaps in the drystone walls on the small farm – gaps that needed rebuilding – hence the title of this book. This was in addition to running a research & training consultancy – small farms only yield small profits.

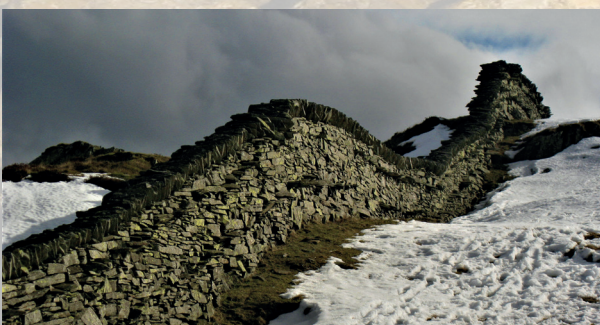
Terry learned the ancient craft of drystone walling with a 3-day course, working with a master craftsman, but subsequently refined his skills by working as a shepherd/stone waller for a large upland sheep farm, Forest Hill Farm.

This is not a textbook on the techniques of drystone walling; more of a semi-autobiographical series of short essays, reflecting on the hard life of the shepherd on the fells. As you sink into the rhythm of Terry's gentle prose, you can almost hear the bleat of the lambs, and feel the icy sting of an early Spring shower on your face.

This Cumbrian idyll was interrupted by an unexpected Gap in a different form in 2006 - stamina-draining MPA vasculitis. Then a further relapse in 2013. Fortunately Terry's vasculitis was "superbly taken care of" by the teams at Addenbrookes Vasculitis Clinic and the Royal Preston Hospital – aided & abetted by lashings of "Unicorn Juice" –ie rituximab!

Also by Terry McCormick are "Wordsworth & The Shepherds" and "Lake District Fell Farming; 1750-2017". Now officially retired, he is writing a sequel to Mind the Gap, entitled "Completing the Sheepfold".

"Mind the Gap", illustrated by an ample gallery of beautiful photos of the Cumbrian Fells, is a delightfully evocative read for both lazy summer days and cosy winter afternoons by the fireside; and an excellent Christmas gift! A limited edition, it is only available from the author .at £13.50 per copy inc p&p. terry.mccormick@cantab.net. To learn more about Wordsworth & the Lake District visit: <https://wordsworth.org.uk>.



Vasculitis UK 2021-22 Research Programme

The Trustees of Vasculitis UK have launched a "call" for applications for grants to fund research into topics related to systemic vasculitis. These grants are up to £50k – not much in research terms, but enough for a pilot study which might then lead to a more ambitious project. The closing date for applications is mid-October. All applications are then peer-reviewed by a panel of experts before the final decision by a Vasculitis UK committee, including the Scientific Advisory Board, next Spring.

Over the course of 2021, Vasculitis UK has contributed joint funding to three other covid-related research studies.

Research Roundup

The Octave Trial

This study looked at the immune response to the covid vaccines in various groups with impaired or suppressed immune systems funded by the Medical Research Council and led by Prof Iain McInnes of Glasgow University. It is a national collaborative project involving the Universities of Glasgow, Birmingham, Oxford, Liverpool, London & Leeds and Imperial College and supported by Versus Arthritis. The study investigated the effectiveness of various covid-19 vaccines in people with a variety of conditions including liver & kidney disease, cancer & leukaemia and those taking immune suppressing drugs to control various auto-immune diseases, including vasculitis.

It is known that immune-suppressing drugs, especially drugs like rituximab, can reduce the effectiveness of some vaccines. Alarmingly, initial results from the study showed that after two doses of vaccine, those patients with ANCA vasculitis, on rituximab, showed little evidence that they had produced any significant amount of anti-covid antibodies.

However, the immune system is very complex, with many different systems working together. Current antibody blood tests only tell us about only one aspect of the immune response to the vaccine, so the true full picture is probably not as bleak as it might seem.

The Octave study covered many conditions beside vasculitis but not all types of vasculitis and did not evaluate immune suppressing treatment other than rituximab, so further work is needed.

A follow-up study, OCTAVE –DUO, will investigate the effects of a third dose of vaccine on the immune status of heavily immune suppressed patients.

The MELODY Study

(Full title: - **Mass Evaluation of Lateral flow ImmunOassays to Detect SARS-Cov-2 antibodyY responses in immunocompromised populations**).

This study, initiated by a team at Imperial College, will investigate the proportion of immunocompromised patients who are not adequately protected from coronavirus after a third vaccine dose. The patients involved will be from across the spectrum of those with an organ transplant or diagnosed with an auto-immune disease or with cancer.

The study will involve many thousands of patients with different conditions; in the case of immune-suppression, patients on a variety of drugs besides rituximab will be assessed.

The study, led by nephrologist Dr Steve McAdoo, is a collaborative project between Ipsos MORI and Imperial College, on behalf of the Department of Health & Social Care & supported by various charities, including Vasculitis UK, who will also be providing some financial support for this important study.

Appropriate patients will be selected randomly from NHS databases. They will be contacted directly by post and invited to take part – you cannot apply to take part.

If you do know of anybody who has been invited to take part in the **MELODY** study, please do encourage them to sign up for it.

RONAPREVE for Treatment of covid-19

This new drug is a mixture of 2 monoclonal antibodies (casirivimab & imdevimab) which target the SARS-Cov2 spike protein to reduce the severity of covid infection. In trials it has proved to be effective and has received provisional marketing authorisation. Casual or indiscriminate use could trigger covid mutations, so it will **only** be used on those patients who are:-

- 1) age 50+ or 12-49 and formally deemed to be immunocompromised **and**
- 2) hospitalised specifically due to confirmed acute covid **and**
- 3) negative for baseline serum anti-spike antibodies against covid

This might offer some reassurance to those on rituximab who believe their response to the covid vaccine is possibly restricted by their immune suppression.

The PROTECT V Trial

(**PRO**phylaxis for pa**T**ients at risk of COVID-19 inf**ECT**ions)

This new exciting trial, led by Dr Rona Smith at Addenbrookes, looks at how patients who are at particularly high risk of Covid-19, might be protected using a variety of drugs. The trial will enrol patients with kidney disease or autoimmune diseases

This trial is funded by the UK Government and others including KRUK and Addenbrookes Charitable Trust.

The first drug to be tried out as a prophylactic (preventative) treatment is niclosamide. This is currently used to treat tapeworm infections, but laboratory experiments with niclosamide have shown it to be effective against the SARS-Cov2 virus, maybe by stopping it multiplying & penetrating cells. In this trial, the drug will be taken as a nasal spray – to maximise its effect in the nasal tissues, where the virus mainly replicates itself. Volunteers will be given either niclosamide or placebo in a “blind” trial.

Other promising drugs will be trialled – possibly including new drugs that have already been shown to be effective against coronavirus.

This trial has been awarded “Urgent Public Health Prioritisation” and will be rolled out across the UK in coming weeks.

For a list of participating centres. See the Vasculitis UK website. www.vasculitis.org.uk

Humoral & T-Cell Responses to Covid Vaccination in Patients Receiving Immunosuppression

There is an urgent need to assess the impact of immunosuppressive therapies on the effectiveness of the covid vaccines. In this trial, carried out by a team comprising mainly researchers from Imperial College & several other London hospitals, led by Maria Prendecki, sophisticated immune assays were carried out on 140 participants receiving immunosuppression for autoimmune rheumatic & kidney diseases.

The trial showed that after 1 dose of vaccine about 25% of this group responded to the vaccine & had a detectable T-cell response; this rose to over 80% after a second vaccine. Those patients with evidence of prior covid infection all showed a very good response to the vaccine.

Only 8.7% of those with no prior covid infection failed to show an antibody or T-cell response. B-cell depletion due to rituximab does impair antibody production but T-cell responses are preserved.

Research Roundup

TRIAL OF Benefits of “CONVALESCENT PLASMA”

A new trial is taking place at Addenbrooke’s Hospital to test whether COVID-19 patients with weak immune systems have a better chance of survival if they are injected with plasma from people who have successfully recovered from the virus.

The trial will examine whether antibody-rich plasma, known as ‘convalescent plasma’ can be given to people who are struggling to develop an immune response to the illness. Scientists want to discover whether this treatment would improve a COVID-19 patient’s speed of recovery and chances of survival.

The clinical trial is being run nationally by NHS Blood and Transplant (NHSBT). Although there is some evidence of patient benefit, it will seek to confirm the safety and effectiveness of convalescent plasma transfusions.

Convalescent plasma is a promising treatment which could help patients whose immune systems aren’t producing enough antibodies. It is given to patients with Covid-19 via a transfusion if they are receiving treatment, or likely to receive treatment, in the intensive care unit.

“By taking part in this national trial, we are helping understand whether convalescent plasma should be widely used to treat serious Covid” - said Prof David

Menon, from Cambridge University Hospitals NHS Foundation Trust, who is one of the principal investigators for the trial).

If successful, the plasma has the added benefit of being freezable, so donations can be stockpiled ahead of a potential second wave. Plasma is

being collected from people who have recovered from Covid-19 by NHS Blood and Transplant at its blood donor centres nationwide. It is then being distributed to hospitals around the country.

Anyone who has received a positive test result or had symptoms of Covid-19 can register to donate using a form on the NHSBT website www.nhsbt.nhs.uk, or visit their local blood donor centre. (In Cambridge this is located on Long Road).

NHSBT particularly wants to hear from recovered patients who needed hospital treatment, or who are male, or who are aged over 35, as people in one of these three groups are more likely to have high antibody levels.

Donating plasma takes about 45 minutes, during which time volunteers can sit back and relax. Afterwards they can get on with their normal day. The body usually replaces the plasma donated in 24-48 hours and the immune system will quickly replace any antibodies. This means people can donate plasma as often as every two weeks.

An NHS Blood and Transplant spokesperson said: “We thank everyone who is donating convalescent plasma and we hope this treatment proves to be of benefit to patients at Cambridge University Hospitals NHS Foundation Trust.

Plasma donation is safe and easy and you could save lives. You’ll also be playing a part in world-leading research and treatment. If you get the call, please donate.

Results of the trial are expected in late 2021.



national-cancer-institute-uVnRa6mOLOM-unsplash.jpg

Research Roundup

Vasculitis UK newsletter report - GCA PRO Study Apr 2021

The GCA PRO Study, led by a team from the University of the West of England Bristol and University of Leeds (including two patient partners who have GCA), is developing a Patient Reported Outcome Measure (PROM) for Giant Cell Arteritis (GCA). This is a questionnaire which measures how GCA and its treatment impacts patients' health-related quality of life. A snap-shot of the start of the questionnaire is shown in Figure 1. The questionnaire has been designed to be used in clinical trials and clinical practice to measure aspects of greatest importance to patients with GCA, and aid communication between patients and their clinicians.

Firstly, we interviewed patients with GCA from the UK and Australia about their experiences of GCA. We took care to include people with a range of different GCA presentations (e.g. those with and without cranial disease, visual involvement and large vessel vasculitis). All patients had a confirmatory test (either temporal artery biopsy or imaging). The analysis of this interview data identified a range of important topics related to GCA itself, and how it impacted on daily life. This work was published in the journal Rheumatology in January 2021 and has also been the basis of questions for the PROM, based on the topics identified. We performed further patient interviews to pilot the questionnaire through a method called cognitive testing to refine format and wording. The wording of the questionnaire was also assessed for its future translatability into different languages. This resulted in a questionnaire with 40 questions related to the patient perception of GCA and its treatment.

In the last year and a half, we have worked with clinicians and research teams from 38 NHS sites in England and Scotland to perform a large-scale patient testing of the GCA PRO. Patients were recruited via a mixture of rheumatology and ophthalmology departments, either face to face, remotely or via post. We have now received 427 completed sets of questionnaires from patients, which exceeded our target figure of 400. This was due to the tremendous efforts and hard work of site teams, who continued to recruit patients in the midst of very challenging circumstances in the last year. Data analysis is currently being completed. This involves refining the questionnaire by removing unnecessary questions, to ensure it is a consistent and reliable measure for use in clinical trials and practice. The overall length has also been reduced to 30 items to make it more feasible to use.

For the final phase of the study, 10-20 pairs of patients and clinicians will be recruited in Bristol/Weston-Super-Mare and Leeds. Each patient will be supported to complete the questionnaire before their clinical appointment so that it can be used as a communication tool between the patient and the clinician during the consultation. We will get feedback from both patients and clinicians after the appointment.

We would like to extend our sincere thanks to all the patients who have participated and sites who supported the study throughout 2019 - 2020. The final GCA PRO will be completed by the end of 2021. Ms Celia Almeida and Dr Jo Robson on behalf of the GCA PRO Study Team.

Figure 1. Snap - shot of the start of the new GCA PRO questionnaire.

the GCA-PRO

SYMPTOMS

the following questions ask about symptoms and problems sometimes reported by people with GCA. Please indicate the extent to which you have experienced these symptoms or problems during the past 7 days. For each question please tick the box under the answer that best applies to you.

During the past 7 days, due to your GCA or its treatment, how would you rate your experience of the following.....

	None	Mild	Moderate	Severe
1 Headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Pain, discomfort or stiffness in and around your jaw or teeth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do people with vasculitis and other autoimmune rheumatic diseases mount an effective response to COVID-19 vaccination, and for how long does it last?

Dr Lucy Fairclough; Dept of Immunology, Nottingham University.

This study has been under-way since early Spring 2021, and we are very grateful to the 52 people who are participating (37 with vasculitis and 15 with related conditions on similar treatments).

We are now at a very exciting stage of this study. We are writing up the initial results of how well people have responded to vaccination by measuring their SARS-CoV2 specific-antibody levels following their 1st and 2nd COVID-19 vaccinations. We hope to submit this for publication by the end of the month.

The complementary expertise of the clinical team (Dr Lanyon and Dr Pearce) and the immunology team (Dr Fairclough and Dr Tighe) are continuing to work together to rapidly assess whether factors such as type of vaccine, treatment - including length of time since Rituximab - influence the response to vaccination, as well as the influence of things that can't be changed (such as a person's age and diagnosis).

We look forward to sharing this data as a pre-print very soon.

This study by the team at Nottingham has been jointly funded by Vasculitis UK and the National Institute for Health Research (NIHR)

SUPPORT GROUP NEWS

Vasculitis in general is a rare disease and some types are extremely rare. People with vasculitis often feel very alone and isolated because few people properly understand their problems and they know nobody else with vasculitis.

Local groups provide an opportunity for people to meet and share knowledge and experiences.

You will find details of support groups throughout England and Wales on page 27. Some groups are large, holding formal meetings with invited speakers, others are very small, perhaps meeting for coffee in someone's house, or at a cafe or pub. The most important part of any meeting is the sharing of experience.

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

We, at Vasculitis UK, do our best to ensure that support group meetings are well attended by advertising them in the "Dear Diary" section in the Newsletter, the e-News, on our Facebook and Health Unlocked discussion groups, and here on our website.

For new groups the charity will advertise your endeavours by checking our main database for all members in your area and writing to them with details of the meeting. We can supply you with posters for your local hospitals/GP clinics etc, and send loads of "goodies" – balloons, pens, stick-it notes, car stickers etc. We also have a leaflet available to give you ideas about how to set up a Group.

We do not believe that anyone setting up a group should be out-of-pocket if they are willing to organise and run support group meetings. The charity can offer some financial assistance towards funding at least the initial meeting.

Why not check the Support Groups? If there isn't a group in your area then email John Mills to discuss setting up a group.



First London Vasculitis Support Group Zoom Coffee Morning

Just wanted to thank Mirela for organising this zoom support group meeting in September.

There were 6 of us joined the coffee morning.

We all introduced ourselves and enjoyed a general chat.

We then moved on to discuss the problems of having

to return to work from working from home. We also discussed

the risks and benefits of going on holiday.

We discussed fatigue and coping strategies for managing

fatigue.

We also discussed referrals and the importance of getting

a second opinion if a patient is not totally happy with the

care they are receiving.

We finally finished with a short discussion about the OCTAVE report and what impact it would have on all those who have Vasculitis.

Next meeting is planned for the beginning of November. An invitation and date will be posted by Mirela in the VUK Fb support group and in the VUK HU group in October.

Anyone wanting further information regarding the new London Group please contact Susan Mills - susan@vasculitis.org.uk



NEW TRUSTEES

Fundraising Coordinator



Hi I'm Charlotte and I was diagnosed with GPA in my early teens in 2009. I never let it hold me back and try to live life to the fullest. I currently work for Ronald McDonald House Charities who support families with children in hospital and have been formally involved in fundraising for 5 years. It's a real passion of mine and I'm excited to see how I can support Vasculitis UK so that we can fund research and support to better outcomes for those with the condition. If you've got a fundraising idea, I want to hear about it! In my spare time, I'm a volunteer dog walker and I play on my local touch rugby team.



Peter Rutherford is a Geordie in exile in North Wales but still supporting a losing football team of course - as well as the Wrexham movie stars. He is a nephrologist who had a 25 year career in the NHS including as a consultant nephrologist and hospital Medical Director. He then has had a career in the Pharma Industry and is currently Vice President, Head of Global Renal Medical Affairs at Baxter Healthcare.

Peter's interest in vasculitis began as a junior doctor and was cemented by the very first person he saw on his first day as a Consultant in North Wales. The need to improve care and get new effective therapy options is critical for patients with rare diseases such as vasculitis and Peter remains passionate to support in all ways he can. Peter is married to a nurse and has 2 grown up children. He enjoys walking, running, reading, sport and loud music.



Charlie Harper - Young Adult Support Co-ordinator

I'm Charlie and I was diagnosed with granulomatosis with polyangiitis (GPA) in 2019 at the age of 27. As well as the common ear, nose, and lung involvement from GPA, I also developed a subglottic stenosis (narrowing of my airway below my voice box) and inflammation of my pituitary gland. For 18 months I lived with a tracheostomy and only recently had this removed after a full tracheal reconstruction. I live in Oxford with my wife Jen (also a trustee) and daughter Heidi. Currently I work as a Statistician at the University of Oxford and am studying part-time for a PhD in population health. Outside of work I enjoy days out with my wife and daughter, playing the ukulele, swimming (well trying to at least), and reading plenty of fiction during periods of downtime.

After my diagnosis I was initially wanting to distance myself from anything related to vasculitis. Only recently have I stated reaching out to others and found the benefits to be extraordinary! I am delighted to have been appointed as a trustee for Vasculitis UK and excited to contribute my skills and experience to the charity. As a trustee, I'm keen to establish a supportive community for young adults with vasculitis.

Jen Harper - Vasculitis Patient, Information and Education Coordinator



I'm Jen and I'm the wife and advocate of vasculitis patient and fellow trustee, Charlie. My professional background is in education and science communication and, as a trustee, I'd like to support patients and their families to understand their health and to access accurate and reliable information. I currently manage my role as a trustee alongside raising my young daughter and working in communications for a local craft shop. When I'm not running around after a rambunctious toddler, you can find me behind my sewing machine or working my way through endless crochet projects.

Although I don't have vasculitis myself, I feel my insight into the world of chronic illness as a wife and advocate will enable me to offer support to families and friends of those on their vasculitis journeys.

Double vaxxed Doctor gets Covid!!



Dr Fiona Pearce, Consultant Rheumatologist, was delighted in December 2020 to be vaccinated at the same time as other healthcare workers and those in their 70s to protect herself, her family, and more importantly her patients from COVID-19.

She had her second dose of the Pfizer vaccine in February 2021. However, there is now evidence that the more transmissible delta variant can cause breakthrough infections even in the double vaccinated.

Fiona found this out the hard way when she felt unwell on 4 September and tested positive for COVID-19 on 5th September. She is recovering, but says "COVID-19 is a very nasty virus – I can say that based on the data, and now also personal experience. In particular, the delta variant, which now accounts for nearly 100% of cases in the UK, is changing the way we look at things".

"Please be aware that people who are double vaccinated can still catch and pass on the COVID-19 virus. For most people, the COVID-19 vaccine reduces the severity of your illness if you catch COVID-19, and reduces the length of time that you are at risk of spreading the virus to others".

So please do get vaccinated and urge others to do so. However, the vaccines are not perfect.

How ill you become if you catch COVID-19 depends also on the amount of virus you are exposed to – so other strategies such as wearing a mask, meeting others outside where possible, and ventilating indoor spaces if you do meet others indoors can be very important too.

Dr Fiona Pearce; Consultant Rheumatologist.

Diagnosed with **VASCULITIS?**

Living in the **UK?**

Aged **18 to 39?**

Vasculitis UK Young Adult Group is a new community aimed at supporting young people living with vasculitis

Join the community:

<https://www.facebook.com/groups/vasculitisukyoungadult>



Vasculitis UK Christmas Cards

Pack of 12 (4 of each of the 3 designs as below): £5

To order visit the Vasculitis UK's Online Shop:
<https://www.vasculitis.org.uk/shop>
or call 0300 345 0075

Are you living with Vasculitis?

Do you have one of these types of non-ANCA associated vasculitides?

- Giant cell arteritis
- Takayasu's arteritis
- Polyarteritis nodosa
- Cerebral vasculitis
- Cogan's syndrome
- Relapsing polychondritis
- IgA vasculitis (Henoch-Schönlein Purpura)
- Non-infective cryoglobulinaemic vasculitis



Researchers are seeking **adults and children aged 5 years and older** to participate in a **2 year** clinical trial called BIOVAS.

If you experience a **relapse** you may be eligible to participate.

3 trial drugs and 1 placebo:

- Infliximab
- Rituximab
- Tocilizumab
- Placebo

For further information please discuss the BIOVAS trial with your doctor or contact your local team:

Contact Name: Viola Ricci (research nurse) Contact Details: 01223 349350

www.biovas.med.cam.ac.uk

FUNDED BY
NIHR | National Institute
for Health Research

Cambridge University Hospitals **NHS**
NHS Foundation Trust

**UNIVERSITY OF
CAMBRIDGE**

Funded by NIHR HTA (award 17/83/01). The views expressed are those of the authors and not necessarily those of NIHR or Department of Health & Social Care
BIOVAS Version: 1.1 20 APRIL 2021 EUDRACT 2019-003964-30 IRAS 269769

Research Roundup

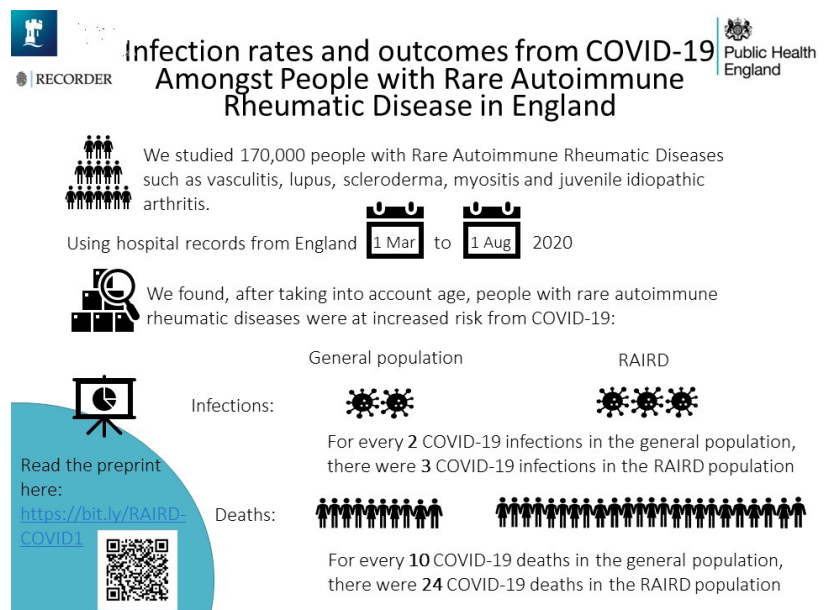
The RECORDER Study.

Covid Research – Megan Rutter/Fiona Pearce

Using data from the whole population of England, the team from the Registration of Complex Rare Diseases Exemplars in Rheumatology (RECORDER) project, working in collaboration with the National Disease Registration Service at Public Health England, published a study looking at COVID-19 outcomes in people with rare autoimmune rheumatic diseases. This research was funded by a grant from Vasculitis UK.

The study found that between March and July 2020, during the first wave of the COVID-19 pandemic in England, people with rare autoimmune rheumatic diseases (RAIRDs) were :

- 1.5x more likely be infected by COVID-19. This means that for every 2 people in the general population infected by COVID-19, 3 people with rare autoimmune rheumatic diseases were infected by it.
- 2.4x more likely die as a result of COVID-19. This means that for every 10 people in the general population who died from COVID-19, 24 people with rare autoimmune rheumatic diseases died from it.



The results highlight the urgent need to understand the real-world effectiveness of vaccination among people with rare autoimmune rheumatic diseases, as there are concerns that they may respond less well to vaccination than the general population. The impact of immunosuppression, and of shielding, is a focus of ongoing research.



Megan Rutter (left) is a Clinical Research Fellow in Epidemiology at The University of Nottingham

Fiona Pearce (right) is a Consultant Rheumatologist & Clinical Academic with Research interests; Fiona is an Associate Professor at Nottingham University.



NICE, Avacopan & the ADVOCATE Trial

Steroids, usually in the form of prednisolone, have saved the lives of many people with vasculitis. But when used long term and/or in high doses, they can cause numerous side effects – serious weight gain, diabetes & cataracts – to name but a few. So most doctors these days try to wean patients off steroids as quickly as possible.

The National Institute for Clinical Excellence (NICE) is currently carrying out a “Single Technology Appraisal” of Avacopan, the new alternative to steroids for treating ANCA vasculitis. Vasculitis UK will be making a submission to NICE of course.

Approval by NICE is a prerequisite for general use in the NHS and would probably only be authorised in specified situations. Cost to the NHS usually plays an important role in NICE decisions.

In the recent ADVOCATE trial prednisolone or Avacopan were used alongside usual immune suppressing medication such as cyclophosphamide or rituximab. The results showed that Avacopan is as effective as prednisolone for inducing remission in AAV and seems to offer a more sustained remission. The drug is safe to use, but so far we do not know of any long-term downside to use of Avacopan or any rare side effects as the study only lasted a year & involved 330 patients – half having avacopan & half the standard prednisolone treatment.

Whereas prednisolone has a very broad effect on various bodily functions as well as being an immune-suppressing agent (hence the numerous side effects) Avacopan only affects the complement part of the immune system, thereby, we hope, avoiding most of the undesirable side effects of steroid use.

Sadly, so far, there is no reason to expect Avacopan to be of use in treating other types of vasculitis which are currently treated by using prednisolone. At present we know all too well of the undesirable side effects of prednisolone – many thanks to those who recently shared their negative experiences of steroids.

Whilst Avacopan seems to be very promising, we really need to see it rolled out more widely to see how it performs “in the field” – on a larger scale. However, if the manufacturers set the price too high, access to this new drug in the NHS might be limited.

John Mills October 2021

First ever clinical trial for children with polyarteritis nodosa published The MYPAN trial.

The team at Great Ormond Street Hospital have published the 1st ever clinical trial exploring the treatment of childhood polyarteritis nodosa (cPAN). This disease affects only a few children but its effect can be devastating. The usual treatment with cyclophosphamide can have equally devastating long term effects. In medical research, numbers of patients matter; as childhood polyarteritis nodosa is so rare, patients were recruited from centres around Europe & beyond.

cPAN is a severe and potentially fatal illness if not recognised and treated properly. It is very rare which explains why a clinical trial has never been performed. The trial explored the relative effectiveness and safety of mycophenolate mofetil (MMF) vs cyclophosphamide (CYC) for the induction of remission. The basic hypothesis was that MMF may be just as effective, but much less toxic in the longer term.

Using state-of-the-art rare disease trial methodology called Bayesian statistics, the team were able to demonstrate that MMF was probably just as good as CYC and had the advantage of sparing from any future risk of cyclophosphamide toxicity such as bladder problems or even infertility.

The advantage of this type of rare disease trial is that very small patient numbers can be used to obtain clinically useful results. Thus, in this trial, 11 children took part: 7 from the UK, 3 from Turkey, and 1 from Spain.

The primary “Bayesian” remission endpoint was 71% for MMF; and 75% for CYC. Time to remission was shorter in the MMF group (7.4 weeks versus 17.5 weeks for CYC). No relapses occurred in either group within 18-months. Physical and psychosocial quality-of-life scores were superior in the MMF group compared to CYC at 6- and 18-months.

The trial concluded that it is possible to do clinical trials in very rare diseases of the young, and specifically that effectiveness of MMF and CYC are similar, and MMF might be associated with better health related quality-of-life.

The MYPAN trial did not have any industry funding. It was funded jointly by Versus Arthritis, Vasculitis UK, and the Lauren Currie Twilight foundation. The University of Liverpool clinical trials unit coordinated and helped deliver the trial, with non-UK support from the paediatric rheumatology international trials organisation (PRINTO).

The full study report can be found as an open access article at: <https://onlinelibrary.wiley.com/doi/10.1002/art.41730>

Professors Paul Brogan and Despina Eleftheriou led the trial (UCL Great Ormond Street Inst. of Child Health)



Bequests - In Memoriam



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

Bequests

A bequest of £1000 was received from the estate of the late Brian George Ridalls of Torquay.

In Memoriam

Caroline Flockton battled with vasculitis for many years and “shielded” through the pandemic but fell victim to Covid in spring 2021 after being hospitalised following a stroke. She was aged 60.

Her close friend and neighbour, Deanna Rossindale donated £30 in Caroline’s memory.

Michael Reed who was born in Hull in 1956 passed away this spring. Friends & relatives donate £373 in his memory. Michael was a keen traveller, participating in walking, skiing and other outdoor pursuits.

Donations totalling £388 were received in memory of Neil Stanford of Wellesbourne, Warwick, who passed away in the Spring of this year.

A donation of £100 was received in memory of Christopher Brooks of Broadstairs, Kent who sadly passed away this spring.

Donations totalling £100 were received in memory of Noel Hickson of Bournemouth, who sadly passed away early this year. A further £298 was received via online donations.

Following the funeral Alan Houlden, of Taunton, donations to Vasculitis UK totalling £876

were received.

Andrew Steven Riordan of Halifax sadly died in May this year aged seventy four. Donations to Vasculitis UK were received in lieu of flowers. These totalled £314.

A donation was received from Rosemary Hudson, in memory of her friend, Mabel Blacklaws, who was very kind and helpful and is very much missed.

Donations totalling £770 were received in memory of the late Mrs Trudy Moore of Stanford le Hope in Essex, who passed away recently. Bereaved is her husband, Mr C Moore.

Several donations, totalling £565, were received in memory of Mr Terence Hugh Quigley of Carrickfergus, Northern Ireland who sadly passed away in May, age 75. Terry was the eldest of six, married to Margaret for 53 years, with 3 children He was a former member of the Irish Guard and served in the Royal Ulster Constabulary.

Donations totalling £465 were received in memory of Mr Ronald Langthorne of Northamptonshire.

Funeral donations totalling £515 were received in Memory of Mr David Harris of Lossiemouth, Scotland.

A donation of £40 was received in memory of long-standing Vasculitis UK member and vasculi-

tis sufferer, Pamela Ann Tansy of Sandy in Bedfordshire who died recently.

Donations totalling £1413 were received in memory of Brendan Herlihy of Brighton who passed away last July at age 56.

Philip Sealey of Bridgewater, Somerset sadly passed away in May, age 84. Philip left a loving wife, Sally, son Tobias & four grandchildren and is terribly missed. A former rugby player, he played an active and influential role in the local community. Donations to Vasculitis UK in Philip’s memory totalled £593.

A donation of £500 was received in memory of Jennifer Smith of Chalfont St Giles.

Funeral Donations totalling £1220 were received in memory of Susan Charlotte Deakin, of Mexborough, who sadly passed away on 9th September this year. Bereaved is her husband, Brian.





Donations & Fundraising



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.

Mrs M Foley of Brough, near Hull was diagnosed last year with vasculitis. She donated £100 to Vasculitis UK to show her appreciation of the nurses and doctors at Hull Royal Infirmary, where she was cared for. Rachel Marsh, of Hopton on Sea, Norfolk recently celebrated her birthday. In lieu of gifts she very generously asked family & friends for donations to Vasculitis UK. This resulted in a total of £226.75 for Vasculitis UK.

Martin Makin, is a former VUK trustee. His dad very kindly raised £25 for Vasculitis UK by making/growing and selling bird feeders and plants. Christine Tarpey of Abersoch has IgA vasculitis. She and her husband, John make regular donations to Vasculitis UK, including a donation of £500 to mark World Vasculitis Day, May 15th, this year.

James Apps works for South-east Coast Ambulance Service. On his retirement, in lieu of a retirement luncheon, James chose the option of a donation of £75 to Vasculitis UK. The Rotary Club of Poole donated £400 to Vasculitis UK.

An anonymous donation of £10,000 to Vasculitis UK was received in May.

Mrs Carol Lorraine Buxton of Bournemouth kindly donated £1500 to Vasculitis UK in memory of her son Daniel Newman, who died in April 2007 after suffering with GPA (Wegener's) for 10 years. Daniel was very artistic & musical.

Elizabeth Longton raised £330 running in the Asda Foundation Leeds 10k in September. She ran on behalf of her Aunty Tracey who has vasculitis.

Sandra Rochfort ran the Yorkshireman Off Road Marathon "In memory of my wonderful Dad, Terence Quigley, who passed away in May this year, due to vasculitis". She raised £697 for Vasculitis UK

Mr Mike Kurjakovski of Long Bucky, Northants, kindly set up a standing order for £20/month



Donations totalling £1106.87 were received in memory of Malcolm Longsdon of Keighley, West Yorkshire, who sadly passed away earlier this year.

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



**For all the latest information and news,
visit the Vasculitis UK website <http://www.vasculitis.org.uk/>**

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 Noble - 0776 5897780 - cambsvsg@gmail.com

Canterbury area (Contact Person)

Margaret McGrath - 01227 638469 - margaretmcgrathfmsj@yahoo.com

East Midlands Group

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
Susan Mills - 01629 650549 - susan@vasculitis.org.uk

Lincolnshire Group

Sandra Lee - 0754 514 4777 - sandylee777@hotmail.co.uk
Caroline Meyrick - 01780 460354 - cmmeyrick@gmail.com

London

North London Group
susan@vasculitis.org.uk

Merseyside, Cheshire and North Wales Group

Susan Chance - 01244 381680 - susan.chance53@icloud.com
Dave Birch - 0151 7229049 or 07968226230 - davebirch@talktalk.net

North East Group

Margaret Robertson - 07443016665 - mgtrob@talktalk.net
susan@vasculitis.org.uk

Norfolk Vasculitis Support Group

Mark Sayer - m-sayer@hotmail.co.uk

The North West Group

Jann Landles - Anita Parekh nwvasculitis@outlook.com

Oxfordshire Group

Sue Ashdown - 01295 816841 - vsgoxford@gmail.com

Plymouth Group

elaine203@live.com

Scarborough Group

ruth.newton@york.nhs.uk

Solent/Portsmouth Group

Julie Ingall - Julie.ingall@porthosp.nhs.uk

Surrey Group

Peter.surreyvs@gmail.com

Sussex by the Sea Vasculitis Support Group

Antony Hart - Antonyghart@outlook.com

Swindon Support

Wendy and Lisa swindonvsg@mail.com

West Midlands Group

David Sambrook - davsamuk@yahoo.co.uk
Margaret Gentle - 0121-243-5621 - mgentle128@gmail.com

West Country Group

Website <https://vasculitiswest.wordpress.com/>
Charlotte Stoner - 01626 872420 - westcountryvasculitisgroup@outlook.com

West Sussex Group

John Bailey - 07752 122926 - johnbee4@googlemail.com

North and West Yorkshire Groups :

Richard Eastoe - 01423 520 599 email richard@yorkshirevasculitis.org.uk

East Yorkshire Group :

Rachel Weeks - 07968 959 850 email rachel@yorkshirevasculitis.org.uk

North East Yorkshire Support Contact :

Richard Eastoe - 01423 520 599 email richard@yorkshirevasculitis.org.uk

South Yorkshire Social Group Contact :

Jenny Gosling - email jenny@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 - susan.chance@53@icloud.com

South Wales Group

Jenny Fulford-Brown - 029-2021-8795 - jenny.fulford-brown@ntlworld.com
Ryan Davies - ryan@wegeners-uk.co.uk
Angharad Jones - Angharadjones.vas@gmail.com

SCOTLAND

Edinburgh and Lothian (Contact Person)

Jimmy Walker - 07725 770103 - jamzywalker@gmail.com

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



<http://www.vasculitis.org.uk/about/about/find-a-local-group>

EVENTS



VASCULITIS2022.ORG

INTERNATIONAL
VASCULITIS AND ANCA WORKSHOP
3-6 APRIL 2022 • DUBLIN, IRELAND

DUBLIN • IRELAND • 3-6 APRIL 2022

The poster features a large red stylized 'C' logo, a silhouette of a city skyline, and a background of red blood cells.



United Kingdom & all Ireland Vasculitis Study Group Board Meeting and Working Group
December 7th 2021 - Medical Professionals Only



Royal Society of Medicine & UKIVAS joint two day Vasculitis Webinar - 17th - 18th November 2022 - Medical Professionals Only



*Vasculitis UK
Christmas Cards*

Pack of 12 (4 of each of the 3 designs as below): £5

To order visit the Vasculitis UK's Online Shop:
<https://www.vasculitis.org.uk/shop>
or call 0300 345 0075



The advertisement shows three Christmas card designs: a green tree with white snowflakes, a yellow card with a red border and a wreath, and a grey card with a green pine branch and a snowflake ornament.

HONORARY 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. 1180473**

Officers, Trustees and Volunteers

Chair:

Dorothy Ireland

Vice Chair & Director of Operations

John Mills

john.mills@vasculitis.org.uk

Secretary:

Treasurer:

Ian Kayes

Fundraising Co-Ordinator's:

Dorothy Ireland

Dorothy@vasculitis.org.uk

Charlotte Smith

Charlotte@vasculitis.org.uk

Independent Advisor:

Duncan Cochrane-Dyat

Medical Advisors & Scientific Advisory Board

Prof David Scott

Prof David Jayne

Prof Richard Watts

Prof Charles Pusey

Research Awards Co-Ordinator:

Laura Whitty

Trustees:

Dorothy Ireland

Susan Mills

Zoi Anastasa

Charlotte Smith

Charlie Harper

Jennifer Harper

Peter Rutherford

Volunteers:

Kelly Jefferies

Kevin Soper

Vivienne Dunstan

Janice Mather

Kath Macintosh

Jayne Hardman

Gareth Garner

The VUK Shop Manager:

shop@vasculitis.org.uk

Web Admin:

Susan Mills

CONTACT US

Helpline:

0300 365 0075

Website:

www.vasculitis.org.uk

Address:

West Bank House

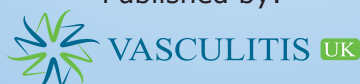
Winsters

Matlock

DE4 2DQ

Phone:

01629 650549



Published by:

