

SRUK NEWS

Research News:

The Oasis Project:
a major step towards
better skin monitoring.

The Microbiome:

The secret to
self-management?

Raynaud's & Self-Management:

Your questions answered.

London Landmarks Half Marathon:

Thank You TeamSRUK!
Full coverage inside!

**Get ready for Scleroderma
Awareness Month!**



**Meet some of
our amazing
supporters
like Caroline
and Sue!**

(pictured, with Sox
and Blue Eyes!)

EVENTS UPDATE

Scleroderma & Raynaud's UK is the only charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's. We exist to improve awareness and understanding of these conditions, to support those affected, and ultimately to find a cure.

Team SRUK needs you!

Could you help us continue supporting our community? There are countless ways to get involved and raise vital funds to help us continue our work.

We now have many opportunities available over the coming months, from the **SRUK Walk** to a 10k run, all the way to a full marathon.

If you or someone you know would like some more information, please contact us.

With so many opportunities to choose from, you can also support us without even leaving your home. You can get involved

without having to go to an event, as simply helping us to spread the word and sharing our social media posts really can make a difference.

Whatever you decide to do, we will be by your side every step of the way. When you join **TeamSRUK**, you'll receive a free fundraising pack, SRUK running vest or T-shirt and ongoing support from our dedicated fundraising team.

Turn to page 7 to read about the London Landmarks Half Marathon that took place during April, and the amazing team who took on the event to raise awareness and support our work.



Bucket collections: can you help?

We are now able to start doing some public fundraising, that will also help us to increase awareness of the impact of Scleroderma and Raynaud's. If you can spare a few hours and you would like some more information, please get in touch!

Check out our calendar for just a few upcoming events over the coming year:

| EVENTS CALENDAR 2023 | | | |
|---------------------------|-----------------------|---------------------|------------------------|
| Hackney Half Marathon | Half Marathon | London | 21 May 2023 |
| SRUK Walk | Virtual Walk | Anywhere | Ongoing |
| London Asics 10k | 10k Run | London | 9 July 2023 |
| Peak District Challenge | 10k, 25k, 50k, 75K | Peak District | 15 & 16 September 2023 |
| Great Scottish Run | 10k and Half Marathon | Anywhere | 1 October 2023 |
| Royal Parks Half Marathon | Half Marathon | London | 8 October 2023 |
| Inflatable 5K | 5k, 10k, 15k | Stratford upon Avon | 1 October 2023 |
| Bath Half Marathon | Half Marathon | Bath | 15 October 2023 |

We have 100s of places in events across the UK and overseas, so if there's something you're interested in that's not listed above, then do get in touch.

For more information and to secure your place, please visit sruk.co.uk/get-involved/events or contact us at fundraising@sruk.co.uk

You can call us on 020 3893 5993

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

Welcome to the Spring edition of *SRUK News*. While the sun has been shining and the blossoms and spring flowers are looking beautiful, it is still a little chilly. And for many of you, that means no respite from your Raynaud's.

In this edition of the magazine there's a great article from Dr Michael Hughes on managing your Raynaud's as well as answers to some questions from our community, covering a wide range of topics, including medications. You can also access our recent webinar which gives more information on self-management. Please turn to page 8.

Our webinar series is proving very popular, featuring different topics every month. We're keen to know what you would like to hear more about, so please do get in touch if there are any issues you think we should be covering. Nutrition and the GI tract are popular topics, and you may well have noticed an increased focus on the gut microbiome.

Dr Elizabeth Volkmann pioneered the first study to investigate the gut microbiome in patients with systemic sclerosis. On page 19 you can read more about an international consortium of investigators she is leading, dedicated to understanding how the microbiome contributes to inflammation and clinical symptoms. As a result of the research, they hope to learn more about this link and to be

able to offer more targeted therapies in the future.

At SRUK we continue to fund groundbreaking research, thanks to your generous donations, and we are pleased to report the outcome of research we began funding in 2020, which has demonstrated the potential for the use of a new, non-invasive tool that could improve skin assessment in the diagnosis and monitoring of scleroderma. For more information, please see page 12.

Thank you for your continued support. It is only by working together that we will get one step closer to our vision of a world where no-one has their life limited by Scleroderma and Raynaud's.

With very best wishes

Sue



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DOC SPOT

YOUR MEDICAL
QUESTIONS ANSWERED
BY PROF. DENTON
OF THE ROYAL FREE
HOSPITAL, LONDON



Q I have scleroderma and have developed difficulties swallowing. What causes this and what can be done to alleviate it?

A Systemic sclerosis frequently leads to swallowing problems with a feeling that food sticks “on the way down”. In addition, there can be reflux of stomach acid that can lead to inflammation of the oesophagus. All these issues are the result of a “slowing” of normal contraction of the oesophagus that results from damage to the small nerves and blood vessels in the gut. Treatments can reduce acid reflux or “heartburn”. If the symptoms are new or worsening, you may need to have investigations such as an endoscopy to advise on further treatment.

Q I have Raynaud’s and have recently started getting leg cramps at night. Is this normal with Raynaud’s?

A Leg cramps are very common, and unlikely to be directly linked to Raynaud’s. However connective tissue diseases such as systemic sclerosis or myositis can affect muscles and cause cramps. The commonest cause for cramps is a local increase in salt concentration in the muscles, and avoiding dehydration is important. Increasing the amount of water you drink each day, especially in the evening, can be helpful.

Q My daughter who is just under a year old has just been diagnosed with Raynaud’s, and I’m at a loss on how to keep her warm. Even with multiple layers and several pairs of socks her feet are still like blocks of ice. What would you advise for babies and toddlers in this situation please?

A Whilst Raynaud’s can develop at any age, it is uncommon in young babies and infants. At that age medical treatment is not appropriate, and so measures to keep her warm are probably the best approach. Raynaud’s is an exaggeration of normal mechanisms of the body to conserve temperature and may improve as your daughter grows up. If she develops more symptoms or problems with the circulation, you should see a specialist paediatrician for advice.

Q In addition to Raynaud’s I now have poor nail health, that seems to have started along with the other Raynaud’s symptoms. My nails are now brittle, discoloured in places (white) and sore around some of the cuticles. As the winter goes on, they tend to break off with new growth eventually appearing during warmer weather. Could this be another symptom of the Raynaud’s vasoconstriction, or could it be caused by an unrelated issue?

A The fingernails require a good blood supply to grow normally and so it is quite common to have brittle nails if you have Raynaud’s. This can improve with treatments such as drugs to dilate blood vessels (such as nifedipine and others), and with vitamins and supplements that are recommended for Raynaud’s. However, other medical conditions can also affect the nails and cuticles, and so you should discuss this with your doctor. Blood tests and investigations such as capillaroscopy will determine if there are any associated medical conditions.

Q My doctor has suggested me taking nifedipine for my Raynaud’s. Is there any research looking at the effectiveness of this medication compared to side-effects for Raynaud’s in women outside of pregnancy and breastfeeding?

A Nifedipine is a drug developed to treat high blood pressure. It works by dilating blood vessels. It has been shown in careful analysis in a number of clinical trials to reduce Raynaud’s symptoms and is often the first drug prescribed by doctors for Raynaud’s.

Unfortunately, it does have side effects, such as headaches from lowering blood pressure, or swollen ankles due to fluid retention. It is also one of the few potential treatments for Raynaud’s that is safe to take in pregnancy or when breastfeeding.

Q I have had an ultrasound of my hands which showed ‘flexor tendon calcification at MCPJs’. Is this the same as calcinosis or is that something completely different?

A Calcinosis occurs in some cases of systemic sclerosis and is the result of deposits of chalky material developing in the soft connective tissue. It often occurs at sites of minor injury or pressure such as the elbows or fingertips but can sometimes build up around tendons. It may also occur without an associated disease such as systemic sclerosis. Ultrasound is the best test to determine tendon inflammation that can sometimes benefit from local steroid injections.

Q I have systemic sclerosis and have been reading about the health benefits of drinking lemon water. I was wondering whether it is considered safe, as I also read that it may boost collagen production?

A It is unlikely that lemon water will do any harm, although specific benefits have not been shown. Vitamin C, in all citrus fruits, does stimulate collagen production in the laboratory and deficiency causes problems such as scurvy, but there is no evidence of harm in systemic sclerosis. Through its natural “antioxidant” properties, high dose Vitamin C may help the symptoms of Raynaud’s.

Systemic sclerosis frequently leads to swallowing problems with a feeling that food sticks “on the way down”. In addition, there can be reflux of stomach acid that can lead to inflammation of the oesophagus.

Adenbach syndrome is the name given to a condition where small blood vessels in the skin of the palms or fingers are fragile, and so small bruises develop in response to minor trauma or pressure. It is not associated with Raynaud's, but the two conditions could co-exist.

Q I have Raynaud's and have started getting bruising around my fingertips. I read that this might be a symptom of Adenbach syndrome - is this linked to Raynaud's? I find the bruising worsens at times when my Raynaud's is worse.

A Bruising without any injury can develop when blood vessels are damaged or inflamed but can also occur without any serious associated medical problems. Adenbach syndrome is the name given to a condition where small blood vessels in the skin of the palms or fingers are fragile, and so small bruises develop in response to minor trauma or pressure. It is not associated with Raynaud's, but the two conditions could co-exist. It is important to seek medical advice if the symptoms become more severe or the bruises are increasing.

Q Since being diagnosed with Raynaud's, I have been getting brown marks on my skin including my hands, it looks like pigmentation. Could this be connected to the Raynaud's, or could it be something else?

A Raynaud's does not usually cause any permanent colour changes in the skin and so this is unlikely to be related. If there is an associated medical condition such as a connective tissue disease like systemic sclerosis, lupus or dermatomyositis then there can be inflammation in the skin that leads to increased pigmentation and so you should seek medical advice if the brown marks are troublesome in case further investigation is needed.

If you have a question you would like to ask Professor Denton, or you would like to comment on any of the answers given, please email info@sruk.co.uk

You can also connect with us on Twitter, Instagram and Facebook. /WeAreSRUK



LONDON LANDMARKS HALF MARATHON 2023



Emily Harber

SRUK's team of seven runners have raised over £5,900!

THE LONDON LANDMARKS HALF MARATHON TOOK PLACE ON 2 APRIL. THIS ICONIC EVENT IS THE ONLY RUN THAT COVERS BOTH THE CITY OF LONDON AND THE CITY OF WESTMINSTER.

The event offers participants an unrivalled experience of running through the capital whilst raising vital funds for the causes that matter to them. Since the event started in 2018, over £30m has been collectively raised for many good causes. The run is also a great day out for the runners and the families and friends who come along to support them.

This year, the course started at Pall Mall, taking participants through the sights of London including Soho, Chinatown, Westminster Bridge, Somerset House, St Paul's, Big Ben, and the Houses of Parliament, before eventually finishing at Downing Street.

A team of seven runners took on London Landmarks for SRUK. They have raised over £5,200 so far.

One of those runners was **Emily Harber**. Emily ran in memory of her Mum who sadly died in 2019. This is her story:

Have you run before?

"I've run many half marathons and marathons in the past!"

Why are you supporting SRUK?

"In memory of my wonderful Mum who passed away in 2019 and lived with scleroderma for over half her life. She was the bravest and wisest person I've ever known."

What are you most looking forward to?

"Race day and running in central London alongside so many other people fundraising for great causes."



Thank You to everyone who ran the London Landmarks Half Marathon for SRUK:

- Emily Harber
- Helen Alford
- Leigh Cunningham
- Jan Cunningham
- Michaela van der Linde
- Joseph Barker
- William Needham

RAYNAUD'S & SELF-MANAGEMENT WITH DR MICHAEL HUGHES

As part of Raynaud's Awareness Month, we were delighted to welcome Dr Michael Hughes as the expert speaker for SRUK's webinar entitled 'Raynaud's & Self-Management'.

Dr Hughes is a Consultant Rheumatologist at Salford Royal Hospital and Honorary Senior Clinical Lecturer at the University of Manchester. He is a leading international investigator into both systemic sclerosis and Raynaud's Phenomenon.

We would like to thank Dr Hughes for his expertise and support with this webinar, and for answering our viewers' questions so comprehensively.

Summary

Raynaud's is a complex experience that is not just about the physical symptoms. There is often a significant emotional impact as well, with the need for constant vigilance and self-management. Many people find they have to adapt over time to manage their condition.

The first step in managing Raynaud's is effective diagnosis to rule out any other causes. Early diagnosis is important because secondary Raynaud's is often an early sign of scleroderma. Individual experiences can be relevant as well. For example, if the thumb is involved, this could be a sign of secondary Raynaud's.

When you are living with Raynaud's, self-management is key, including practical measures such as keeping warm and trying to avoid sudden temperature changes. Drug treatment may also be considered when necessary, especially if there is a risk of developing ulcers.

Your Questions

Do COVID vaccinations make Raynaud's worse?

We do not really know the answer, but some patients have reported that their conditions worsened or developed around the time of vaccinations. However, there is no evidence of a direct risk, and the benefits of the vaccines still outweigh any potential risks.

I have connective tissue disease (CTD) and Raynaud's. A nailfold capillaroscopy was normal two years ago, so does this mean that it is primary Raynaud's?

Nailfold capillaroscopy examines the capillaries and their structure. If you have a diagnosis of CTD you would normally expect the capillaries to be abnormal, although



Dr Michael Hughes BSc (Hons) MSc MBBS MRCP (UK) (Rheumatology) PhD

this is not always the case. Repeating the capillaroscopy at certain intervals may be helpful.

I don't get blue deoxygenation, just white and red skin colour changes. Does this mean it is Raynaud's and could it be milder?

Raynaud's a cold sensitivity, that can also be caused by stress. In scleroderma, we tend to see the blue colour change rather than the white and the red.

Most clinical trials have reported a white colour change and then a second colour change, but what this tells us is not fully understood. In clinic, cold sensitivity and colour change is the way to make a diagnosis of Raynaud's, so there is a difference between clinical practice and the clinical trials.

Is it ok to sometimes vary the dosage of Raynaud's medication in response to ambient temperatures, e.g., during a heatwave?

Yes absolutely. These drugs are preventers. It is ok to increase the dose if symptoms are especially bad, or to decrease it in the warmer months. However, the effects will not change immediately, so this cannot be done on a day-to-day basis. This is something that needs to be done over a period of weeks and months.

Raynaud's a cold sensitivity, that can also be caused by stress. In scleroderma, we tend to see the blue colour change rather than white and red.

Raynaud's is more common in women, and we see symptoms changing during the menopause. Hormone replacement therapy has potential side effects, but if you are taking this anyway, it could benefit Raynaud's as well.

My Raynaud's improved during the menopause. Could this be influenced by hormone changes, and could hormone therapy be of any use?

We know that Raynaud's is more common in women, and we do see symptoms changing during the menopause. Hormone replacement therapy has potential side effects, so we wouldn't recommend it specifically for Raynaud's. However, if you are taking this anyway, then there could be some benefit for Raynaud's as well.

Can frequent Raynaud's attacks cause permanent damage to the blood vessels of the hands and feet?

The answer is that we do not really know. The current opinion is probably not. Raynaud's is seen as a problem that comes and goes, but eventually the blood flow comes back. In scleroderma, if you are having frequent Raynaud's attacks, this is a sign that we need to treat the disease.

What is the link (if any), between blood pressure and Raynaud's?

I am not aware of any link between blood pressure and Raynaud's.

Low blood pressure can be a problem because the treatments we tend to use are usually given for high blood pressure, and other drugs can also reduce blood pressure, such as Iloprost. On the other hand, people being treated for high blood pressure may benefit, because many treatments are also used for Raynaud's. It is important we talk to GPs and select the best drug that covers all the bases.

If you have Raynaud's but no other problems, is it still important to get a clinical diagnosis?

Raynaud's is very common, but if in doubt, get it checked out. You can go to your GP or visit [SRUK.co.uk](https://www.sruk.co.uk) to take the online test. If it is severe and causing problems on a day-to-day basis, or if there are other symptoms or things suddenly get worse, you should ask the GP for an antinuclear antibody test or for a referral to a rheumatologist.

Can taking beta blockers exacerbate Raynaud's?

Beta blockers are used for heart problems. The answer is not clear, however if beta blockers are taken for a major problem like heart failure, this should take priority. If there is an option of another drug, or if Raynaud's gets worse after treatment, there should be a conversation between the cardiologist and the rheumatologist on the best way forward.

Could there be a link between having coeliac disease and Raynaud's?

There may not be a direct link, however coeliac disease is an autoimmune disease that affects the bowel, and if you have one autoimmune disease, you are probably more likely to develop another. With coeliac disease, you could be more likely to have an underlying autoimmune disease, so it might be an indication there is something else causing the Raynaud's.

Is Botox an option, and is it better than sildenafil?

Surgery is sometimes an option in Raynaud's, so we work closely with hand surgeons. There are a number of reasons, e.g., in cases of ulcers or gangrene.

Botox can help to open up circulation; it lasts for around three months. It can be helpful, but this is variable. Other treatments may be needed as well.

You can watch this webinar with Dr Hughes, as well as the rest of our back catalogue including our past webinars, at [youtube.com/@WeAreSRUK](https://www.youtube.com/@WeAreSRUK)



SRUK SHOP

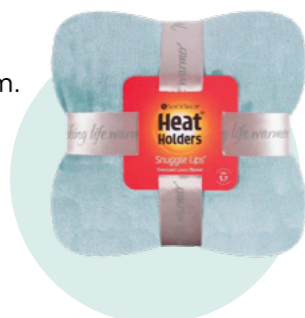
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SRUK Face Mask

Our re-usable face masks are machine washable. The covering is double-layered and made with a soft cotton lining for comfort and features elasticated ear loops. The outer layer is 95% polyester/5% spandex and the inner layer is 95% cotton/5% spandex. They are washable up to 30 degrees Celsius.

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Gently lever the Jarkey against the rim of a lid to release the vacuum inside the jam jar, making it easier to open. Helps people with hand conditions.

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We would like to thank ASTECtherm for their kind support.

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These insulating insoles help keep your feet warm. You can add them to the insides of your shoes to insulate your feet from cold ground. They are thin and unobtrusive, incredibly lightweight, robust, and durable.

ASTECtherm have kindly offered a donation of £5 to SRUK for each pair of their self-warming insoles, that are purchased via warminginsoles.myshopify.com/

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| Snuggle Up Blanket <i>Please specify the colour</i> | £21.60 | | | |

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THE OASIS PROJECT

SRUK-funded research builds evidence for new methods of skin assessment.

SRUK-funded research has revealed the potential for a new, painless and less invasive method of monitoring skin thickness in scleroderma. This could help facilitate new avenues in managing the condition, including enabling people to self-monitor and even helping doctors prevent or limit certain complications.

These findings provide strong, evidential backing for the use of a new, non-invasive tool that could improve skin assessment in the diagnosis and monitoring of scleroderma.

The 'OASIS Project', was funded by SRUK and led by Dr Peter Worsley at the University of Southampton. The study has built evidence for the use of new, non-invasive tools to accurately measure skin health in scleroderma. Its findings could help accelerate the use of such methods, using tools already employed in the assessment of other conditions affecting the skin. Because of the importance of skin assessments in scleroderma care, this project could be an important step towards improving the diagnosis and monitoring of the condition.

The findings will also form part of the basis of a further three-year research project, led by Dr Worsley and funded by the Medical Research Council*. This will continue to investigate the use of new tools and technologies to monitor skin health and has the potential to bring further benefits in the future, by improving both routine

clinical monitoring and self-management. This could be an important step in advancing the care and monitoring of scleroderma

Skin assessment and 'The Hackathon'

Because one of the characteristic symptoms of scleroderma is thickening and tightening of the skin, the ability to accurately assess and measure skin health is crucial for effective diagnosis and monitoring.

The modified Rodnan Skin Score (mRSS) involves a doctor 'pinching' a patient's skin to measure its thickness. This method is used in clinic to measure the activity of a person's scleroderma and how well treatments may be working. Although it requires extensive training, this test is so subjective that results can vary between different doctors.

The 'Hackathon' in 2020

SRUK therefore identified the need for new methods for use in both diagnostic and routine assessments, to effectively monitor changes in a patient's scleroderma and the extent to which the skin is tightening or thickening.

In February 2020, SRUK and the Engineering and Physical Sciences Research Council (EPSRC)** partnered to co-host a three-day event entitled 'The SRUK / EPSRC Hackathon'. You might remember reading about this in the Spring 2021 edition of *SRUK News*.

The event brought together clinicians, bioengineers, data scientists and bioscientists from universities and industry to produce ideas for new devices which could easily and objectively measure the skin, to improve the diagnosis and monitoring of the effects of scleroderma. Teams could apply for funding to develop these projects, with a total of £418,000 available to the right candidates.

Four of the projects created during the Hackathon event submitted funding applications. Out of these, two teams were selected - one of which was co-funded by SRUK and the EPSRC (Team SCIDEX), whilst the other (Team OASIS), was solely funded by SRUK. This was led by Dr Peter Worsley, an Associate Professor of Health Sciences at the University of Southampton, who specialises in skin and soft tissue health, as well as healthcare technologies.

Dr Peter Worsley, speaking in 2020, said: "We were able to meet fellow academic researchers, clinicians and industrialists interested in skin health research. Of particular interest were the talks provided by individuals with scleroderma, and hearing their experiences of current clinical assessment and treatment. I was personally interested in how skin is assessed and what improvements could be made through technologies".

The OASIS Project

Dr Worsley brought together Professor Francesco Del Galdo, (Leeds); Dr Ashleigh Boyd, (University College London); Dr David Childs, (University of Glasgow) and Dr Rodney Gush, (Moor Instruments***). They formed a team, to create the 'Objective Assessment of Scleroderma Skin Tissues (OASIS)' project.

OASIS aimed to assess whether existing, non-invasive tools developed for skin assessment in other medical and scientific fields that can measure factors such as water loss, hydration, and stiffness of skin, could be repurposed to monitor the skin in scleroderma. This could then enable patients to self-monitor changes in skin health.

The first task was to determine which skin factors could give clinically useful information on a person's scleroderma, and how these could best be measured. The factors could then be used to assess the effectiveness and reliability of the potential skin measurement tools for scleroderma-affected skin.

The next step was to measure the performance of the existing tools in identifying differences between skin types of varying thicknesses.

Testing took place at the University of Southampton with healthy volunteers, to assess how reliably the tools could differentiate between the skin on various parts of the body with different thickness (such as the sole of the foot and the forearm).

After the most reliable of the candidate tools were identified, the OASIS team then collaborated with the clinical team in Leeds, led by Dr Francesco Del Galdo, to assess their clinical utility. This involved a cohort of individuals with SSC, who are all part of the ongoing 'STRIKE' study. By assessing factors such as the clinical characteristics of the skin, as well as the presence of inflammatory biomarkers, the team could evaluate how accurately the range of candidate tools could measure skin in these individuals with scleroderma.

What did the team find?

The findings of the OASIS project provide strong, evidential backing for the use of a new, non-invasive tool that could improve skin assessment in the diagnosis and monitoring of scleroderma. Describing these findings, Dr Worsley outlined that the OASIS team *“successfully evaluated a range of non-invasive tools to monitor skin health both in the lab (Southampton) and clinical setting (Leeds), and demonstrated that these skin measurements could be used reliably, and that the corresponding information was highly related to clinical tests of skin.”*

In particular, one of the tools called the **MyotonPRO** demonstrated strong reliability, sensitivity to detect different skin sites, and a high correlation with the modified Rodnan scale score. This suggests that it can accurately measure the skin in individuals with scleroderma. It involves a non-invasive, hand-held device that measures the stiffness of tissue and is easy and painless to use.

This has the potential for routine clinical assessments to become less painful and less invasive. In addition, given the reliability of the device in the study, it could even help doctors to recognise the signs of scleroderma earlier, with more accuracy and reliability.

Equally, tools and technologies that are non-invasive and easy to use could enable the use of home-based, wearable, monitoring equipment for scleroderma. Devices which can be easily used by the individual to self-monitor their skin health could help patients and doctors to predict and prevent events that would otherwise lead to the worsening of symptoms or even a hospital admission (for example, due to skin ulceration).

Continuing the introduction of new tools and technology to enable improved monitoring of the condition could therefore represent a key strategy for advancing both care and quality of life of people living with scleroderma.



The MyotonPRO

The OASIS Project was funded entirely by SRUK.

In addition, this SRUK-funded study has now enabled the next step in this field. With support from the Medical Research Council, Dr Worsley will now undertake a further three-year research project entitled 'Temperature modulation of skin tolerance to applied mechanical loading and shear'.

This project will investigate therapeutic cooling and heating to support skin health - the results of which could be applied to a number of conditions, including Scleroderma and Raynaud's, to support the design of garments and devices to maintain skin health.

Dr Worsley told SRUK *“We hope that our ongoing work will result in benefit to individuals with scleroderma, to support routine clinical monitoring and self-management.”*

*The Medical Research Council funds research at the forefront of science to prevent illness, develop therapies and improve human health.

**The Engineering and Physical Sciences Research Council (EPSRC) is the main funding body for engineering and physical sciences research in the UK. It seeks to address the scientific and technological challenges facing the nation through investing in research and scientific training.

***Moor Instruments specialise in the design, manufacture and distribution of medical monitoring and imaging systems.

RAYNAUD'S AWARENESS MONTH

“There must be something the government can do to give people with Raynaud's a little extra help to get through the winter. (My son) Thomas is a wonderful little boy who loves to be on the go and when he gets a Raynaud's attack it's so sad to see him in pain.”

Rebecca

Our Raynaud's Awareness Month was busy as we continued our Energy Campaign - asking for support for people with Raynaud's struggling with their energy bills. We asked you to write to your local MP and you did! Thanks to everyone that has let us know, including Liz Smith, who wrote to her MP Olivia Blake in Sheffield Hallam, and received the following response:

Thank you for writing about the affordability of heating for people with Raynaud's.

I am seriously concerned about the rising cost of energy and the lack of government support for people across our society, including for those affected by conditions exacerbated by cold temperatures.

I certainly support calls for the government to keep heating affordable and to provide the support that people with Raynaud's need.

I have written to the Chancellor and the Health Secretary to ask that they consider this.

It's good to know that there is support out there. This includes Seema Malhotra, MP for Feltham and Heston and Labour's Shadow Business Minister.

Seema Malhotra has supported our Energy Campaign with a press release and said:

“The government, and energy companies must work to keep heating affordable for people with Raynaud's, where hands or feet can suddenly turn white and be very painful. Those living with this condition rely

on staying warm to keep it under control. This is why I'm backing SRUK's fight to make sure people with Raynaud's are heard and given the support they need to live well.”

We have also written to the CEOs of the top six energy suppliers and asked them to give extra support for people living with Raynaud's. We are still waiting for responses at the time of writing.



Raynaud's in the news:

We had coverage on radio stations throughout the month as well as in the lead up:

BBC Radio Solent ran a feature with one of their presenters and SRUK community member Les Fry. They talked about the impact of Raynaud's on their everyday lives, followed by an interview with our CEO Sue Farrington to explain more about Raynaud's, the signs and symptoms and general tips.

BBC Radio Three Counties spoke to our Head of Fundraising & Communications, Gemma Cornwell about Raynaud's in general.

Black Country Radio spoke to Sue Farrington about Scleroderma and Raynaud's and gave us a lot of time to really explain what they are and hopefully help others to find the support they need.



GB News featured a piece with Jodie Jones, who lives with Raynaud's, as well as an interview with Gemma Cornwell.

We also had stories and features online across various different media, including: *Daily Express Online*, *Twinkl* and *The Belfast News Letter*.

There is still lots of interest out there, and we are expecting some follow up pieces in the near future.

The month in numbers:

3,000
new monthly email subscribers

1,325
new social media followers

OVER 2,730
messages received on social media

192,285
engagements on social media

68,279
visits to website - 38% increase on last year

Webinars

We had two very popular webinars in February.

The first one was Dr Michael Hughes' discussion on Raynaud's and Self-Management (**details on page 8**) 424 people registered.

Later in the month Dr Ariane Herrick discussed Calcinosis - another popular webinar with 171 people registered.

You can watch these on our YouTube channel [@WeareSRUK](#)

The stories we featured

Caroline Colborne-Baber, 40, is a veterinary surgeon from Milton Keynes. She has had Raynaud's since she was a child, and she shared how it affects her and particularly the impact on her work:

"There have been times at work where my fingers have been too numb to perform injections and I have to ask a veterinary nurse to do it for me."

Karen Raney-Marr, 33, is a play specialist for a local hospice in Hertfordshire. She told us about life with Raynaud's and the challenges she faces keeping warm in winter to prevent painful attacks:

"The cost of heating my home has been an issue, but I don't have a choice - I need to stay warm if I'm going to stay well."

Jodie Jones, 36, has been living with Raynaud's since she was a teenager and last year put together a video of some of the daily challenges that her Raynaud's causes. This year, she shared her story with GB News, and highlighted how even everyday tasks can be challenging when you have Raynaud's.

Thanks to everyone that shared their own stories, shared our stories and generally helped us to spread the word.

REBECCA'S STORY

Rebecca has two young children. Her son Thomas has symptoms of Raynaud's that began during 2021 when he was just two years old.

Because Thomas is so young, he is unable to take any medication to help manage his symptoms, so keeping warm is vital to preventing flare-ups.

Before Thomas's diagnosis, Rebecca says she had no idea that someone so young could be affected. He can often experience painful attacks quickly and without warning, which can sometimes be difficult to manage. Speaking about the recent harsh winter, Rebecca says it's been 'a nightmare' to keep her home heated in order to stop Thomas from having painful attacks in his hands.

We are very grateful to Rebecca for supporting SRUK's call for the government to provide extra support to people with Raynaud's to keep their heating affordable. This is her story:

"Thomas was two when I first noticed it. We were in a shop, and I noticed that the tips of his fingers were blue. I just thought it was because they were cold, so I warmed his fingers up and didn't think too much of it.

"But it started to keep happening and then his fingers started going completely white. In the end it was happening all the time, so that's when I contacted the doctor.

"I'd heard of Raynaud's and seen it before in older people, but I didn't know it could happen to someone so young. I was worried seeing it in Thomas; worried that something was causing it.

"I spoke to the practice clinician who referred me to a paediatrician, and we went from there. I printed out some photos of Thomas's hands and she agreed that it looked like typical Raynaud's.

"Thomas was also referred to a rheumatologist for testing to see if his symptoms were being caused by another condition. Thankfully, it isn't. Because of this, and the fact that he's so young, doctors think there's a possibility he might even grow out of the condition as he gets older. It's hard for them to know for sure.

"Thomas copes okay, but he does struggle. We really have to think about the cold. I see other children walking around outside with no gloves on, but for us it's like a military operation before we can even leave the house. I have to plan half an hour before and make sure everything is ready.

"I will make sure he has one or two pairs of gloves on, two pairs of socks and his hat. When it's really cold, I might put two coats on him to help keep him warm. He can't just get up and leave the house like a lot of children can.

"It can happen in warmer weather too, not just when it's cold. We've been at the beach before and the water will make his hands go red, and then turn his fingers and toes white.

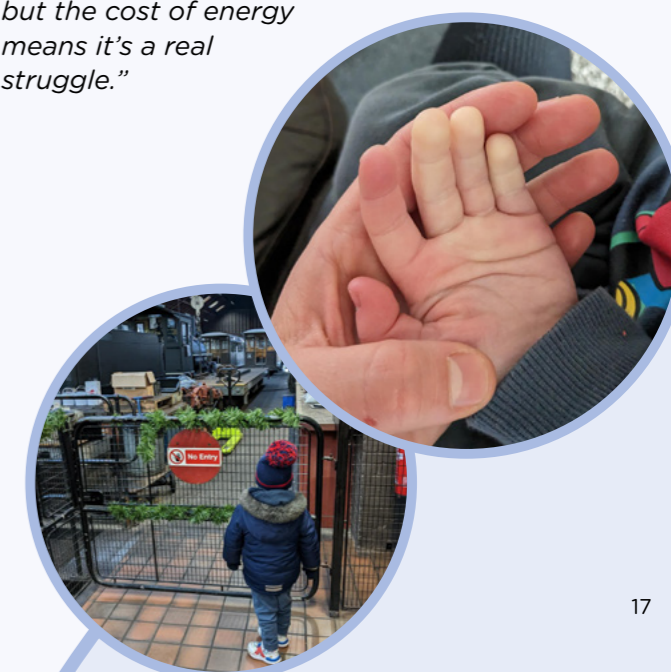
"And it's not just when we're outdoors either. We can be in the house and his fingers will go white. He used to do gymnastics and he took his socks off one day and his poor little toes were white. It affects everything and I think it is quite painful for him.

"This winter has been playing havoc with Thomas's hands and feet. He doesn't take any treatments for Raynaud's because he's so young, so keeping him warm is the main thing that helps him. Last winter, I'd have the heating on all the time, but that's unrealistic now.

"I'm on a pay-as-you-go meter and I've noticed that even just having the heating on for a few hours will make it go down by £10 or more, and that's not even a full day. Some days I have to give my children hot water bottles instead of leaving the heating on, because I just can't afford it. Energy bills are such a huge issue.

Thomas needs to be kept warm in order to be comfortable and out of pain, but the cost of energy means it's a real struggle."

"Energy bills are such a huge issue. Thomas needs to be kept warm in order to be comfortable and out of pain, but the cost of energy means it's a real struggle."



BARRIE'S STORY

Barrie is 71 and lives in North Yorkshire with his wife Irene. He is living with severe Raynaud's and limited scleroderma, as well as osteoarthritis. Barrie first noticed symptoms around 1999 at the age of 48, that initially affected his hands. He was diagnosed by a GP, who looked at his hands and immediately said that he thought it was scleroderma.

"I used to be a master butcher, but I sold the business aged around 40. I was getting up at 2.45am and getting home at 6pm. I would be at Smithfield Market at 4am, but I just got used to it. I built up a good business and I could run around for 14-15 hours a day, I could just keep on going.

"Since this diagnosis, life has changed a lot. I'm just exhausted all the time. I have always told the rheumatologists this and they always say the same thing: 'you just have to plan your life around it.'

"My main issues now are severe Raynaud's, and the pain and exhaustion. I have to sleep for an hour every day by around 4pm and I now have to wear ski gloves all the time. The pain in my hands is also an issue due to osteoarthritis. I always have the ski gloves, but the cold just goes through them...I always say that when you go to

the supermarket, avoid the cold aisles in winter and the whole supermarket in summer because of the air conditioning.

"I have never had a bad experience at any hospital, they have always been very kind to me. There's a lot to be said for that. When I go in, I always look around to see if any windows are open and I have to close them if they are, and the nurses chuckle and say: 'We forgot Barrie's in this week!'

"Friends and family know that I have scleroderma, but no one can work out you are always going to have it. People say out of kindness: 'let's hope it will be the last time', and suggest different over-the-counter medications. They don't understand that it is ongoing.

"Irene, my wife of 49 years, is an absolute star. She understands everything. We sold our house and we moved to a bungalow because the stairs were becoming a problem. But we are so happy here.

"We don't know what caused my condition to develop. My wife thinks that the stress of trying to sell my business might have caused it. After the business was sold, I retired at around 48-49."

Barrie and Irene have also been affected by the current cost of living crisis, as they attempt to balance rising costs against the need to heat their home to help manage the impact of this condition.

"We are now turning off the radiators during the day in the rooms we are not using. Our heating bills have gone up from £100 a month to over £300 a month. We received the £67 government grant, and we get up in the morning and go rushing around to make coffee and we turn the heating up to 20 degrees. Once we are up, the heating goes off in the bedrooms. During the day, we mostly have the heating on in the kitchen, where we spend most of our time. When we lose the government grant, we will have to rethink what happens then."



Barrie

GUT FEELINGS: IS THE MICROBIOME THE SECRET TO SELF-CARE?

We would like to thank Dr Elizabeth Volkmann MD, MS. (Assistant Professor of Medicine, Director, UCLA Scleroderma Program, Co-Director, CTD-ILD Program, Division of Rheumatology, Department of Medicine, University of California, Los Angeles); for her help and support in producing this article.

Dr Volkmann pioneered the first study to investigate the gut microbiome in patients with systemic sclerosis. Today, she is leading an international consortium of investigators dedicated to understanding how the microbiome contributes to inflammation and clinical symptoms.¹

Studies have shown that people with certain autoimmune conditions including systemic sclerosis (SSc) may be more likely to have imbalances within the gut microbiome. If we can learn more about this relationship and what it means, it could enable more targeted therapies in the future.

The **human microbiota** refers to the trillions of live microorganisms, including the bacteria and fungi, that naturally live within the human body throughout our lifetimes. They can outnumber our body cells more than twice over. Microbiota are found on the skin and the mucosal surfaces like the mouth, nasal cavities, reproductive tract and the intestines.

The **human microbiome** refers to the collections of genes that are harboured within all the microorganisms making up the microbiota. Research interest in this area has increased significantly in recent years, with the microbiome now linked to many aspects of our wellbeing, from digestive to mental health.

The gut microbiome

The gut microbiome represents the dense colony of bacteria and other microorganisms that live within the human digestive system. It has many functions, from the absorption of nutrients to the development of immunity and prevention of disease. It is even thought to affect human behaviour.

Good vs. bad: the right balance

Although the individual gut microbiome is likely to comprise countless types of bacteria, these can be split into two broad groups: the 'good' and the 'bad'.

- The **'good bacteria'** have a positive impact on our wellbeing. They help us to stay healthy and reduce inflammation.
- The **'bad bacteria'** on the other hand do not have this positive effect. This group can work against us, by promoting inflammation within and even outside of the bowel.



Dr Elizabeth Volkmann MD

To help promote wellbeing, good and bad gut bacteria must be effectively balanced within the microbiome. When there is an imbalance and the bad bacteria have increased abundance, this is called dysbiosis.

Dysbiosis can cause digestive discomfort and may have a negative impact across various aspects of our health. It could also be an aggravating factor in autoimmune disease, including SSc.

The microbiome and autoimmunity

There are probably many factors that could combine and cause someone to develop an autoimmune condition. Some of these are unique to the individual, like genetic makeup and immune response. However, there could be many others as well, including environmental aspects such as a person's diet, and exposure to certain chemicals or even medications. It is the responsiveness of autoimmune conditions to these

In one study, the group affected by SSc were found to have decreased levels of commensal or 'good' bacteria, and increased levels of 'bad' bacteria

factors that seems to suggest that the microbiome could play a role in autoimmunity.

Research into this topic began with autoimmune conditions affecting the gut, such as Crohn's disease and ulcerative colitis.ⁱⁱ People affected by these conditions have reduced microbial diversity and increased levels of certain bacteria in their intestines, in comparison to 'healthy' controls. Since then, the gut microbiome has also been studied around lupusⁱⁱⁱ, rheumatoid arthritis^{iv} and multiple sclerosis.^v

The microbiome and systemic sclerosis

Researchers have now begun to explore the significance of the gut microbiome in SSc.^{vi} In one study, scientists performed colonoscopies on patients with and without scleroderma. During the colonoscopy, washings were taken from two different regions of the colon, and they measured the abundance of different bacteria in these areas. The group affected by SSc were found to have decreased levels of commensal or 'good' bacteria, and increased levels of 'bad' bacteria, compared to the control group. In addition, patients who were experiencing

moderate to severe gastrointestinal symptoms were shown to have increased levels of two other types of 'bad' bacteria, in comparison to those with mild or no symptoms.^{vii} Another recent study also demonstrated that patients with increased GI symptoms had increased dysbiosis compared with those affected to a lesser degree.^{viii}

More recently, research into the gut microbiome has evolved to investigate its association with other manifestations of scleroderma, such as interstitial lung disease (ILD), with differences already observed in patients with and without ILD.^{ix}

Although these findings are encouraging, we do not yet fully understand what they mean. This is because we cannot be sure that these changes occurring within the gut microbiome are what causes an autoimmune condition to develop or worsen. Instead, it may be that these microbial changes are happening in response to the inflammation that occurs with SSc. The studies thus far have also been relatively small. Larger research projects are needed to help us truly understand the significance of the microbiome in SSc.

The microbiome: the future of managing SSc?

If gut microbial changes can be shown to contribute to inflammation and other symptoms in scleroderma, this could potentially lead to new avenues of treatment in the future. For example, doctors may one day be able to offer targeted treatments to address imbalances in the gut microbiome, such as a specialised blend of probiotics designed to help restore the balance. If treatment is effective, it would have the potential to reduce inflammation or even prevent certain complications from developing in the first place.

Maintaining the balance: the role of diet

The gut bacteria are largely sustained by the food we eat, with the 'good' bacteria maintained by prebiotic fibres.^x Different kinds of prebiotics are naturally found in many plant foods, meaning that diet has an impact on the microbiota and what we eat could be affecting how we feel.^{xi} In theory, a diet rich in prebiotics is more likely to encourage the healthy bacteria to flourish, ideally at the expense of their 'bad' counterparts.

Many plant foods contain prebiotic fibres, including:

- Artichokes,
- Bananas,
- Tomatoes,
- Garlic,
- Legumes,
- Green, leafy vegetables,
- Wholegrains.

To help maintain a healthy balance of 'good bacteria', think about what you eat. If you can



tolerate them, include a wide range of plant-based foods including fruits, vegetables and wholegrains, to help boost your intake of the prebiotic fibres that nourish healthy gut bacteria. On the other hand, try to avoid foods that are overly processed, such as some meat products and ready meals. These contain high levels of artificial additives that are thought to suppress the good bacteria and even encourage their unfriendly counterparts, which in turn may lead to inflammation and feeling worse. An American study from 2018 found that certain additives had a negative effect on microbiota balance, leading to issues including inflammation in study participants.^{xii} As ever, always talk to your doctor before making any changes.

Probiotic food supplements

There are now many probiotic products on the market, that are generally sold as health supplements. They contain various types of live bacteria and yeast, designed to help restore the natural balance of bacteria within the gut. Some also have added prebiotics, that aim to encourage the 'good' bacteria. There is a certain amount evidence that probiotics can sometimes be helpful, for example to someone affected by irritable bowel syndrome.^{xiii}

Probiotic supplements are classified as foods rather than medicines, so they do not face the same level of safety testing.

There are many different types available at varying strengths, so always check what a product contains before taking it. Remember

that these supplements might not be the same grade as pharmaceutical strength interventions that may have featured in some of the studies.^{xiv}

For the time being, investigations into the true nature of the relationship between the microbiome and SSc remain ongoing. This is now a research area with growing interest, with the potential to help us increase our understanding of autoimmune disease itself, not just how to treat it. If the gut microbiota can be shown to play a role, then we will have

discovered what is essentially a natural product that could have the potential to transform how we approach conditions like systemic sclerosis in the future.

Gut bacteria are sustained by our food, with the 'good' bacteria maintained by prebiotic fibres. This means that what we eat could affect how we feel.

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If you would like more information about gastrointestinal involvement in scleroderma, please visit srुक.co.uk

SUPPORT CONTACTS

As the only charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's, we are committed to providing a complete range of high-quality and reliable information and support services that are tailored to the needs of our community.

SRUK Needs You!

We are always looking for volunteers to help us continue supporting our community.

For more information, please contact info@sruk.co.uk

The SRUK webinar programme

We have an exciting series of webinars taking place throughout 2023, covering a wide range of topics and delivered by leading clinicians and experts in the field of Scleroderma and Raynaud's.

A webinar is an interactive presentation that is delivered online and allows viewers to ask questions in real time. There is no obligation to submit a query; you can just log on and listen if you prefer.

Contact us or follow us on social media for all the latest information. You can register online and then simply click on the joining link when the webinar is about to start.

Our publications

You can download the full range of SRUK publications from our website, completely free of charge. Please visit sruk.co.uk/publications and simply scroll down to the booklet or factsheet of your choice. We would also like to say thank you once again to the clinicians and members of our community who have helped to make them possible.

Our Online Community

Help and support is also provided via our online forum hosted on Health Unlocked. This is a friendly space where you can exchange advice, information and support with others. Please visit healthunlocked.com/sruk

Our Helpline

Our free Helpline offers support to anyone affected by Scleroderma and Raynaud's whenever they need it. This service is available from 9am-7pm, 365 days a year and our amazing volunteers all have some personal experience of life with these conditions.

SRUK is on Youtube!

Did you know that SRUK has a dedicated Youtube channel?

You can access our full back catalogue of video content including past webinars, presentations by expert clinicians and video diaries from real people across our community.

Join with nearly 1,900 people already subscribing to our channel, to catch up on any webinars you may have missed or to watch all over again. If you can, please help us keep on raising awareness by sharing our content even further! Please visit youtube.com/wearesruk

Social Media

Join the conversation and find support through social media. You can ask a question, share tips and read advice from others on our [Facebook](#), [Twitter](#) and [Instagram](#) pages.

Helpline:
0800
311 2756



SRUK Local Support Groups

Our local Support Groups enable people to come together, find friendship and connect with others who are affected by Scleroderma and Raynaud's.

Now that COVID restrictions have been lifted, some of our Support Groups are beginning to meet in person once again. If you'd like to be contacted about upcoming meetings, please email info@sruk.co.uk or give us a call on **020 3893 5998**.

Become a Support Group volunteer

Have you ever wanted to make a difference in your community?

- Have you ever thought about bringing people with Scleroderma & Raynaud's together so no one has to face these conditions alone?
- Are you interested in uplifting others and yourself?
- Have you ever wanted to harness and develop your peer support skills?
- Maybe you should think about becoming an SRUK Support Group Volunteer!

We are always looking to expand our Support Group network and we need your help to facilitate bringing people together with good chats, proper support and sometimes cake!

We offer a fantastic once-in-a-lifetime training day to anyone who wants to help facilitate support groups. You'll be supported throughout the process and work closely with SRUK to ensure no one with Scleroderma & Raynaud's feels alone.

At the moment, we are especially keen to find volunteers for the following Support Groups:

- Scotland
- The South West
- Online Zoom meetings to support families of affected children and young people.

If you would like to get involved, enquiries from anywhere in the UK are more than welcome as well. As a valued Support Group Volunteer, SRUK can offer everything you need, including:

- a great training programme
- a supportive community
- regular volunteer meetings
- working closely with SRUK to facilitate meetings.



Avtar

'Like penguins, when we are alone, we struggle and find it incredibly difficult to find a way forward, but again like penguins, if we form groups and huddle together, we can ride the storm as one. Like penguins, the inner circle moves out so the outer penguins can gain warmth from by moving into the middle. That's like us. If we stick together, we can warm each other up - in our case - try and keep everyone content without the fear of being left outside alone in the cold.' - Avtar

If this sounds like something you would like to find out more about, please email info@sruk.co.uk or call us on **020 3893 5998**

SCLERODERMA AWARENESS MONTH 2023

We are busy getting ready for Scleroderma Awareness Month this June.

As always, we are aiming to **Educate, Empower** and **Engage** and we need your help.

You are the experts on scleroderma, and you can take action to make more people aware of how this complex and little-understood condition impacts on life every day.

Here are five ways that you can get involved and help us make a huge difference this June:



Involve friends and family

They also have a story to tell about how scleroderma has impacted them – we need to add their voices to the conversation.



Social media

Share one of our posts, post comments and let your friends and followers know that June is Scleroderma Awareness Month and why this is so important to you.

Take steps

Every June our community **Walk for SRUK**; whether it's 10 steps or 10,000 – they all make a difference.



Campaign for change

Energy prices are still an issue, and we need your help to keep campaigning for more support for our community. You can get involved by writing to your MP and to your energy supplier. We need to keep asking and to keep reminding them that our community still needs their support.

Share your story

You can share your story through your networks or with us. Whether it's in the media or just a chat with friends, you are raising awareness by starting the conversation. Tell people about your own experience of living with scleroderma, and how it has changed your life.



WALK FOR SRUK

Every year we ask our community to take steps to help raise funds and awareness, and every year so many of you have taken on your own challenges, from climbing Everest at home to walking in your local park. Our community is walking all over the UK, and your steps really do make a difference.

Here are just some of the people that are planning to Walk for SRUK this year:

Kim Doshanj is taking on a **Virtual Everest Challenge** in 2023.

Kim's son has scleroderma, and she previously completed her own Virtual Everest Challenge by walking up and down her stairs during lockdown. It took her 10 weeks and one day. She raised over **£1,500** and is looking forward to doing it all again in 2023! This time she is taking up the challenge with her niece Rajveer.



Graham and Zoe are taking on the 24 hours **Three Peaks Challenge** starting on 12 April in memory of Graham's Dad Robert, who passed away from scleroderma in 2011. They will start at Ben Nevis, and then move on to Scafell Pike before finishing at Snowden. They are hoping to raise **£500**.



Megan Nelson will be walking the **Cotswold Way** on 24-25 June over two days. She is walking the total distance of 100km in memory of her Dad Dennis. Megan has been raising money for SRUK for four years and has already raised over **£2,000**.

Pamela Campbell and Emily Campbell are taking on the **Glasgow Kiltwalk** on 30 April – they will be walking as part of a team called the Dental Divas!

Take Steps this June for Scleroderma Awareness Month

If you would like to join the thousands of people across the world who are taking steps to raise funds and change lives. Contact us to find out more, get top tips and support along the way.
sruk.co.uk/walk
 Email: fundraising@sruk.co.uk
 Call: 020 3893 5993

You will receive a medal when you raise £50 or more!

Good luck to them and all our SRUK Walkers!



FUNDRAISING HEROES

SHINING THE SPOTLIGHT ON SOME OF OUR FANTASTIC SUPPORTERS!

For the third year in a row, **Matthew Wilson**, has completed his 24-hour Miniatures Paintathon challenge, bringing his total raised to over **£2,500** in memory of his Dad who lived with Scleroderma and Raynaud's for over 12 years. This is his story:

"Whilst battling the condition we managed to find a joint interest in (a) miniature war game hobby, this is known as Warhammer. Thanks to this hobby we spent many late nights and early mornings painting and talking together. My fondest memories are of these times we had together painting."



Caroline Bailey and her friend **Sue** rode their horses, **Sox** and **Blue Eyes**, through the Wessex Ridgeway across Dorset. They covered just over 70 miles in four days, from Royal Tollard to Lyme Regis. They raised over **£1,700** in memory of Caroline's mum, Belinda. The final day of their ride would have been her 65th birthday.



Savannah Turner raised awareness and funds at her workplace on Rare Disease Day on 28 February, she raised **£441**, which will be doubled with her company's matched funding!



COULD YOU BE A FUNDRAISING HERO?

If you have an idea or if you would like any more information on ways to get involved, please get in touch and we can support you every step of the way!

#TeamSRUK Needs You!

If you are interested in running for **#TeamSRUK**, or know someone who might be, we still have places available for different events throughout 2023!

For more information, please email fundraising@sruk.co.uk call **020 3893 5993** or visit sruk.co.uk/get-involved



Martin Lee's wife, Chrisey, passed away in September 2022. She was part of the Scotland support group and a valued member of the SRUK community. Martin organised a fundraiser at his CrossFit gym in Chrisey's memory. This combined with his tribute page and support from his sister means he's raised over **£4,500** for SRUK.

THANKS TO OUR FACEBOOK FUNDRAISERS

People raise money in so many different ways and one of those is through Facebook - so many of you have asked for donations for your birthdays and in just one year, **124 people** have raised **£8,990!**

Giving in memory

This is such a special way to remember your friends and loved ones. In the last year you have given over **£93,000** in memory and we wanted to give our heartfelt thanks to you all.

Thanks to everyone that donated during **Raynaud's Awareness Month** - we received over **£20,300** in February, and over 3,000 new email subscribers joined our community!

FUTURE FUNDRAISING HEROES

Good luck to all our fundraisers taking on various events over the next few months, from marathons to cake sales and more! You can find out how they got on in upcoming editions of *SRUK News!*

WAYS TO SUPPORT US

Firstly, we would like to say Thank You. By receiving this magazine, you are helping us to continue our vital work to make a difference to the lives of people affected by Scleroderma and Raynaud's. We could not achieve as much as we do without you, and we are always striving to achieve more. If you have an idea as to how SRUK can further support the community then we would love to hear from you.

How to support us

Donate to us through our website at sruk.co.uk by clicking the donate button or by phoning our friendly team on 020 3893 5998 using your debit/credit card.

Sources used

We rely on several sources to gather evidence for our information.

All our information is in line with accepted national or international clinical guidelines where possible.

Where no guidelines exist, we rely on systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals, and government publications.

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