SCLERODERMA & RAYNAUD'S UK

Issue 30
Summer Edition 2023

SRUK NEWS

The TCS London Marathon: A Day Like No Other!

"(SRUK) want to reach everyone affected by Scleroderma and Raynaud's and your support is key to that."
Chadya (pictured)

Scleroderma Awareness Month 2023:

Over 80% of rheumatologists told us they would value further training.

Find out what else we learned as we call for greater investment into scleroderma care.

The Role of Physiotherapy:

How hand exercises can help.

The 2023 British Society of Rheumatology Conference:

All the latest research news.

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 keep on providing vital information and support? There are countless ways to get involved and help raise vital funds to help us continue our work.

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

We have many more opportunities available during 2023 and beyond, so if you or someone you know would like some more information, please contact us.

You can also support us without leaving your home or taking part in an event; simply helping us to spread the word and sharing our social media posts really does 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.

Bucket collections: can you help?

We are now able to do 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!

Here are just a few of the events we are looking forward to over the coming year:

EVENTS CALENDAR 2023			
SRUK Walk	**Virtual Event**	**Anywhere**	**Ongoing**
Peak District Challenge	**10k, 25k, 50k, 75K**	**Peak District**	**15 & 16 September 2023**
Warrington Running Festival	**10k and Half Marathon**	**Warrington**	**24 September 2023**
Great Scottish Run	**10k and Half Marathon**	**Glasgow**	**1 October 2023**
Royal Parks Half Marathon	**Half Marathon**	**London**	**8 October 2023**
Inflatable 5K	**5k, 10k, 15k**	**Stratford upon Avon**	**1 October 2023**
Manchester Half Marathon	**Half Marathon**	**Manchester**	**15 October 2023**
Great South Run	**10 Miles (16K)**	**Portsmouth**	**15 October 2023**
TCS London Marathon	**Full Marathon**	**London**	**21 April 2024**

We have 100s of places available across the UK and beyond, 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 also call us on **020 3893 5993**

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

I hope you're all enjoying the warmer weather and the opportunity to get out and about. I try and take the opportunity to spend some time outside every day to help increase my vitamin D levels, as there is growing evidence to show that it is good for our overall health.

Being active is also important, but that doesn't mean you have to run a marathon or climb a mountain. The simplest of gentle exercises can really help and in this edition, we look at why exercise can help along with other therapies.

During Scleroderma Awareness Month in June and in the run up to World Scleroderma Day, we increase our awareness activity around scleroderma and this year we reached out to general rheumatologists to find out their levels of awareness and understanding about the condition.

Of the **150 rheumatologists** we surveyed, almost two-in-three **(64%)**, said they were unsure about scleroderma's signs and symptoms and more than one-in-five **(21%)**, had either not heard of scleroderma or did not fully understand what it does to the body.

Many thought that scleroderma training and education is underfunded and nearly nine-out-of-ten **(87%)** said they would value further training in scleroderma care.

We know every healthcare professional, every rheumatologist, wants to provide the best care possible to their patients and so SRUK will be calling for greater investment in supporting the rheumatology workforce to make this a reality.

One of the most powerful ways to explain scleroderma and the impact it has is through your stories, and so I would like to say a massive **thank you** to everyone who shared their stories. They have had a great response on social media. My thanks as always to the team, to our volunteers and trustees, but especially to our community. It's only by coming together that we will drive the change that is so much needed to improve equitable access to the best treatment and care.

Very best wishes

Sue

Contents

DOC SPOT

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

Q **For my chilblains, I have been using Balmosa cream with success, but recently found that it is no longer available to buy. Do you have any suggestions or an alternative with the same active ingredients?**

A Balmosa cream contains a variety of ingredients that may help to soothe local skin inflammation including methylsalicylate, menthol, capsicum and also emollients such as white soft paraffin. Chilblains develop when poor circulation in the skin or the extremities leads to inflammation in and around blood vessels. It is often related to cold exposure. Generally, creams or ointments should not be applied if the chilblains ulcerate, or when there is broken skin. There are other topical creams or gels containing these and so you can discuss that with your pharmacist or other healthcare professional.

Q **I have Raynaud's and I am getting ulcers on my fingers. I would like to ask how best to look after these to encourage healing?**

A Ulcers on the fingers can occur in secondary Raynaud's that is associated with diseases such as systemic sclerosis. They are very rare in isolated or primary Raynaud's. Treatment of digital ulcers includes management to reduce Raynaud's symptoms, as well as specific drugs that reduce ulcer formation such as bosentan, sildenafil tablets or iloprost infusion given via a drip. Local dressings and the treatment of any infection is also important to speed up ulcer healing. Trials are ongoing to test whether cutting away dead skin around the ulcer (called debridement) might also help them to heal.

Q **I have been told I have scleroderma, and I am under the local rheumatologist. I feel it is important to be seen at a specialist centre, but what is the best way to get a referral and am I entitled to this as a scleroderma patient?**

A Scleroderma is the medical term covering localised forms of skin thickening or fibrosis, termed morphoea, and those with systemic sclerosis that also causes blood vessel damage and internal organ complications such as lung or gut problems. When the diagnosis is suspected, patients should be referred to a hospital specialist such as a rheumatologist or dermatologist. The most severe cases may also be referred to one of the UK scleroderma centres and current treatment guidelines recommend that all cases of severe systemic sclerosis are seen at least once in a specialised centre. Often an NHS referral can be made by your family doctor (GP) or by another hospital specialist.

> **Systemic sclerosis often leads to scarring or fibrosis in the face and lips that may limit mouth opening.**

Q **Is there any specific information that you should give to your dentist if you have scleroderma that affects the mouth? Or should I see a dentist who specialises or at least understands scleroderma?**

A Systemic sclerosis often leads to scarring or fibrosis in the face and lips that may limit mouth opening. In addition, some patients also develop a dry mouth with reduced saliva production (called "sicca symptoms"). Finally, there can be some loss of gum tissue. All these factors can make dental care more challenging. However, it is very important to maintain oral hygiene and have regular dental check-ups. Exercises of the face and mouth may help improve mouth opening, and a surgical treatment called "fat transfer" has been reported to be beneficial and is given routinely in some centres.

Q **I have very itchy ear canals, could this be linked to scleroderma? I am finding this quite troublesome, so are there any treatments for this?**

A Itching of the outer ear canal is likely due to dermatitis or inflammation of the skin at that site. It is not specifically associated with systemic sclerosis, and you should seek medical advice. You might need to consult a dermatologist or an ear, nose and throat specialist for further diagnosis and treatment.

Q **I have limited scleroderma, Sjogren's Syndrome and Raynaud's. I have been experiencing quite severe pain in my ears whenever I am flying. It is worst when landing and affects my hearing for at least a day afterwards. Is this normal and there anything I can do?**

A The middle ear is normally air-filled and should have the same pressure as atmospheric air outside the body. The usual air pressure changes that occur with flying can lead to middle ear symptoms including pain and loss of hearing. Sometimes that is due to fluid accumulation in the ear.

Normally the air pressure is balanced in the middle ear, due to the Eustachian tube that connects the ear and the back of the nose. In scleroderma and Sjogren's, the tube can become blocked by thickened secretions of narrowing, and differences in pressure that occur on descent and landing after a flight that can take a while to normalise. In your case this would explain the persistence for a day afterwards. Sipping water, sucking a sugar-free sweet or yawning may all help to open the Eustachian tube and could be beneficial.

Q **I have systemic sclerosis and Raynaud's. I have now been told that I have low bone density, and I would like to use a low intensity vibration plate to help with this. Is this safe with Raynaud's, or are there any other risks to be aware of?**

A I do not expect the power plate would be detrimental to Raynaud's and certainly not cause any long-term issues, so if the GP recommends this I would be happy for you to try it. If it were to impact Raynaud's this should be readily apparent, and you should then discontinue.

Q **Is there a particular kind of diet that is beneficial for those with Scleroderma and Raynaud's? I have tried raw ginger, but it does not seem to have much of an effect. I have been reading about gut bacteria and I wondered if there are any friendly-bacteria foods that are more likely to help with severe reflux?**

A Although there is no specific diet recommended in systemic sclerosis, many patients describe improvement in symptoms with dietary adjustments. Spicy and hot foods may aggravate symptoms of heartburn and all food should be chewed well and consumed with fluids if there are swallowing difficulties. Some patients with bloating, diarrhoea, or constipation report that their symptoms improve from excluding wheat, whereas others may benefit from a reduction in dairy or red meat. However, it is important to maintain a good dietary intake to avoid becoming malnourished. Many scleroderma patients have a reduced appetite and so there is the risk of losing weight. If that is severe then advice from a dietician may be helpful.

Some patients with bloating, diarrhoea, or constipation report that their symptoms improve from excluding wheat, whereas others may benefit from a reduction in dairy or red meat.

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

Team SRUK raised over £42,000!

THE TCS LONDON MARATHON 2023

The iconic TCS London Marathon took place in the capital on Sunday 23 April.

Team SRUK joined over 48,000 participants to take on the world-famous course in near-perfect conditions. They were supported all the way by family and friends, together with the volunteers and SRUK staff gathered at our dedicated cheer point.

We are incredibly grateful to our amazing team, who have now collectively raised over £42,000 with the help of Matched Giving.

About Matched Giving

Also known as Matched Funding, the Matched Giving scheme enables employers and companies to increase your fundraising in support of the causes you care about, by matching or boosting the amount you raise. Matched Giving can also help you raise awareness within the workplace.

TEAM SRUK: YOUR STORIES

Everyone taking on the London Marathon for SRUK had their own, inspiring reason for doing so.

"The fundraising will enable additional research into scleroderma to enable them to establish causes of the conditions, and treatments to prevent the condition going forwards." **Marc Evans**

"Why have I chosen SRUK? Well, (my Mum) Ann suffers with scleroderma and it is sad to see how much it is affecting her life and daily activities. … They want to reach everyone affected … and your support is key to that. This is a cause close to my heart and your donations will give me that extra boost to keep running to the end. They are not one of the well-known charities, so it will be good to raise awareness and support." **Gareth Clifton**

"…Wow, what an incredible experience! I can't put into words how amazing it was to see so many people running for different charities. The positive energy from the crowd was electric, the dedication and passion from the runners! It was such an emotional run, and many times I think I welled up with tears… but yet at the same time running with this big grin on my face. I didn't need any music, the crowd was enough. I was slow and steady and made it around without serious injury! In a way I almost didn't want it to end…" **Jo Walters**

"I made it, nowhere near the time we'd hoped and trained for, thanks to my poorly knee, BUT we crossed that finish line! Your support, both financial and emotional, really did push me on, my knee was painful by Mile 5, but I knew giving up wasn't an option and that I just had to 'Keep on running' (lost count of how many times I heard that song on the course!) Thank you so, so much, it really means the world to me and my family who all turned out for the day to cheer me on, including my brilliant Mamma." **Laura Neaves**

"…Scleroderma is a rare condition. It took years for my Grandma to be diagnosed and sadly she battled with the more complex type which affected her organs. During the later years, you could see the disease affect her quality of life and daily activities. Despite her diagnosis and symptoms, she always showed great fortitude and her strength and constant smile throughout her diagnosis is something I will always admire and cherish. She is dearly missed by all." **Annika Chauhan**

"This is a cause close to my heart as my mum passed away from scleroderma several years ago. Your donations will give me that extra boost to keep running to the end. All support is greatly appreciated, thank you!" **Mark Thomas**

"Diagnosed with this condition, which can deteriorate causing lots of disability and pain. Although this is a rare disease, for those living with the condition it can be life changing. Patients have difficulty moving their hands, some have breathing problems or kidney failure – so we are extremely keen to find a cure." **Jack Whitby**

"I am running to change the lives of people living with Scleroderma and Raynaud's. SRUK fund vital support, information and research. My lovely sister Vicki passed away only aged 49 on 4 December 2020. She had Antisynthetase Syndrome, a rare autoimmune condition which includes Scleroderma and Raynaud's. I am raising money in her memory." **Laura Beagrie**

Matched Giving enables your employer to match the amount you raise in support of the causes that matter to you.

"In 2012, I ran my first London Marathon thanks to and for my Auntie Mags as she got me a place through a charity she became involved with having been diagnosed with the incurable scleroderma. On the day along with family, friends and my Auntie Marmar she cheered me onto the finish line.

Last year the plan was to do it all again 10 years later, but calf injuries got the better of me. Sadly, both Mags and Marmar passed away shortly after.

So, I'll be running this year in their memory, both women supported me unconditionally in everything I did and were a tower of strength and inspiration throughout my life. I know they'll be guiding me on all the way through.

I'll be supporting … (SRUK) … as I did in 2012. Now as then, I'm very fortunate to have such an incredibly supportive family and friends around me." **Alistair Pitfield, in memory of Auntie Mags and Marmar**

"I will be running in memory of our lovely Dad, Michael Joshua ("Josh" to many). In November 2017 he passed away, aged 54, after being diagnosed with scleroderma … I chose to support …(SRUK) … as it is the only UK charity dedicated to improving the lives of people with Scleroderma and Raynaud's. My Dad would think I'm partly mad for running the marathon, but mostly he would be proud – I will be thinking of him every (literal) step of the way!" **Millie Joshua, in memory of Michael Joshua**

Thank You Team SRUK!

Marc Evans
in memory of Lauren Beckett

Gareth Clifton

Jo Walters

Chadya El Karimi

Laura Neaves

Annika Chauhan
in memory of Granny C

Mark Thomas

Jack Whitby

Laura Beagrie
in memory of Vicki Walker

Aliastair Pitfield

Millie Joshua

And finally...

On 21 April 2024, the TCS London Marathon will take place all over again, and we are accepting applications now! For more information, please get in touch, we would love to hear from you!

MILLIE'S STORY

Millie Joshua is 22 and lives in Essex with her Mum and three sisters. She took on the London Marathon in memory of her Dad. She has raised over £22,000 for SRUK, with help from her employer who boosted her sponsorship with Matched Giving. We talked to Millie about why completing the Marathon was so important to her and her family.

My Dad passed away in 2017 at the age of 54, after being diagnosed with scleroderma. I always remembered him having Raynaud's, his hands would always be cold and blue after working outside, however in winter 2016 he had what seemed to be a cold which then worsened to affect his breathing. In June 2017 he was then diagnosed with scleroderma, his lung capacity had reduced to 30% and he needed help to breathe.

Despite only being given three weeks to live, my family and I had a wonderful five more months together before he passed away in November 2017.

Prior to his passing, my sisters and I completed a skydive in support of SRUK. We were able to raise £2,835 through many generous donations, we wanted to give back to SRUK as we knew it was a small organisation. This ultimately led to me deciding to run the London Marathon in April 2023, I applied via the charity in October and once my place was confirmed I began to train.

I have been able to raise £7,382 for SRUK, which with my company's matching of £2 for every £1 will amount to a final donation of £22,146. I enjoyed the marathon training and feel really grateful to have been able to run the 26.2 miles, even more so knowing it was in support of all of those affected by Scleroderma and Raynaud's.

SRUK PRESENTS

A CONCERT WITH MATTHEW SLATER

13 September 7pm–9pm
St Bride's Church, Fleet Street,
London EC4Y

St Bride's Church

SRUK is delighted to host our first-ever concert, to be held in St Bride's Church in Central London, a stone's throw from the SRUK office!

Join us for an evening of world-class classical music featuring celebrated composer Matthew Slater and the London Metropolitan Orchestra. They will be debuting an original piece especially written for SRUK.

This one-of-a-kind classical concert specially curated for SRUK by Matthew Slater will be a truly unique experience. It will be an evening to remember and will create memories to cherish; to celebrate those living with the conditions and those whom we have lost.

Matthew Slater

Matthew is a highly experienced composer and conductor with many flagship, long running series credits including Endeavour, Grace and Tom Jones. He has also worked in music preparation on major feature films such as Black Panther II. A regular conductor on the London session circuit, Matthew can often be found conducting at Abbey Road and Air Studios among many other international venues.

Matthew's mum has scleroderma – and he is passionate about doing this to raise funds and awareness for a cause close to his heart.

London Metropolitan Orchestra (LMO)

LMO is London's finest multimedia orchestra and has been engaged by all the major Hollywood studios and worldwide record companies since its formation in 1994. The orchestra employs London's best musicians renowned for their virtuosity, combining to give universally acclaimed performances.

LMO has also gained worldwide recognition for numerous television soundtracks and has collaborated in recordings and live performances internationally with many well-known artists including Paul McCartney, U2, Eric Clapton, and Stormzy.

About St Bride's

St Bride's Church is one of the most famous and historic churches in Central London. It was all but destroyed during the Great Fire of London in 1666 and was rebuilt almost a decade later by celebrated architect Sir Christopher Wren.

Located in London's Fleet Street, St Bride's is known as the Journalist's Church, offering a spiritual space to all those who work in the media. The church has amazing acoustics and will be the perfect venue for SRUK's first concert, where people can enjoy and feel close to the music and musicians. There will also be the chance to make connections and start valuable conversations.

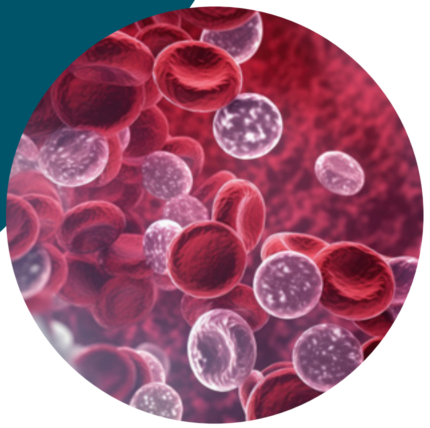
Tickets are available online – scan the QR code

Or go to: sruk.co.uk/get-involved/events

THE BRITISH SOCIETY FOR RHEUMATOLOGY ANNUAL CONFERENCE 2023

A little bit of what we learned...

- **One study showed that people with SSc have an increased risk of developing certain cancers. This highlights the need for early screening for some groups.**
- **Improving our understanding of the small blood vessels (the capillary network), could enhance our understanding of what causes sclerodema.**
- **Precision medicine means tailoring treatment to the individual. An SRUK co-funded study has found that some people with lung involvement respond better when treated with a particular drug.**
- **The latest guidance around heart involvement aims to ensure that people are diagnosed and treated sooner.**
- **Higher levels of a blood protein called CCL24 could be linked to lung disease. Treatments such as therapeutic antibodies against this could lead to a new therapeutic avenue for scleroderma.**
- **Research into rheumatic and musculoskeletal disease has shown that regular aerobic exercise can help in just three months. Could this include scleroderma?**



In April, SRUK attended the British Society for Rheumatology* Annual Conference in Manchester. We joined over 2,300 attendees including leading doctors, nurses, and healthcare professionals.

The conference was a fantastic opportunity to raise awareness of Scleroderma and Raynaud's and the work of the charity. We listened to talks from experts and researchers whose work has been supported by SRUK in the past, and learned of the latest developments aiming to improve our understanding and open new avenues of care.

Understanding the link between systemic sclerosis and cancer

Dr John Pauling from the the University of Bristol showcased a project co-funded by SRUK in 2016 in partnership with the Bath Institute for Rheumatic Diseases.**

The study aimed to investigate the relationship between systemic sclerosis and cancer, another leading cause of death within the scleroderma community.

By analysing anonymised healthcare data held within the Clinical Practice Research Datalink, which holds data on 60 million UK patients, the study found a 32-41% increased risk of cancer in people with systemic sclerosis, who are also twice as likely to die within six months of a cancer diagnosis. Mucocutaneous cancers, as well as breast and lung cancer, were most common.

Crucially, the study identified several high-risk groups who could be candidates for targeted pre-screening. These included people aged 50-65 and those testing positive for certain auto-antibodies. Dr Pauling described the potential to pre-screen these groups for cancers, especially by imaging the chest for signs of breast and lung cancer. The work could pave the way for earlier detection of cancer in SSc, which could greatly improve individual outcomes.

Could capillaries be the key to understanding scleroderma?

Professor Francesco Del Galdo from the University of Leeds often works closely with SRUK. He presented the latest research relating to nailfold capillaroscopy for the early diagnosis of scleroderma, and explored how broader investigation of the capillary network is being used to better understand what causes the condition.

Nailfold capillaroscopy is a non-invasive imaging technique that assesses the capillaries in the nailfold area. Professor Del Galdo discussed the diagnostic value of this in early stage scleroderma, explaining that several studies have demonstrated that finding no abnormalities on a nailfold capillaroscopy is a strong indicator that someone will not progress from Raynaud's to SSc.

He then talked about his current investigation around whether damage to the capillary network may be a cause, rather than an effect, of scleroderma. Capillary network alterations throughout the body are a hallmark of SSc, and could be a cause of early physical changes as the condition develops. This ongoing study offers the potential to learn more about what drives the development of scleroderma – a crucial gap in our current understanding.

Precision medicine: improving treatment outcomes in SSc-associated lung disease (SSc-ILD)

The conference also hosted a session on the management of lung and heart disease in SSc. The first talk was given by Dr Voon Ong from the Royal Free Hospital and supervisor of Dr Nina Goldman, whose PhD research (co-funded by SRUK in partnership with the Medical Research Council***), is investigating the role of B-cells in SSc-ILD.

Dr Ong discussed the evidence for the effectiveness two drugs – tocilizumab and rituximab. Focusing on the results of some recent clinical trials and the findings from a study at the Royal Free, he outlined the effects of these drugs on lung function, and highlighted that the data shows both treatments can be effective in patients with lung involvement.

The team also wanted to understand whether some patients will respond better to one drug or the other. They looked at how people respond to these treatments based on their auto-antibody profile, and found that those testing positive for the ATA auto-antoantibody were more likely to improve when given toculizumab.

Cardiac involvement in systemic sclerosis

This was followed by a talk from Professor Maya Buch of the University of Manchester. SRUK have previously supported their research relating to heart involvement in SSc.

Professor Buch's talk focussed on recent work by an international consortium of doctors, researchers, and organisations to improve understanding and management of cardiac involvement in scleroderma. She described how they developed a consensus definition of SSc-related heart involvement, to assist with diagnosis and detection, monitoring, risk stratification, and treatment.

Professor Buch also shared the consortium's guidance relating to the screening, diagnosis, and follow-up for people with cardiac involvement. This aims to ensure individuals at high-risk are identified and effectively treated, and could lead to improvements in the detection and management of heart involvement in SSc.

The session was concluded by Dr Daniel Knight from the Royal Free, who detailed the use of cardiac MRI in assessing heart involvement. This can provide key information about the size and function of the heart, as well as the presence of disease. A study carried out at the Royal Free used cardiac MRI and machine-learning to analyse 260 patients with SSc and assess their prognosis. It showed that features captured by the MRI, (such as cardiac size and function), were prognostically important and related to poorer survival outcomes. This technique could provide useful insight into cardiac health and help identify people needing treatment.

Combating the causes of inflammation and fibrosis

A team from the University of Leeds working alongside Professor Del Galdo have identified a potential biomarker and therapeutic target for treating systemic sclerosis, particularly in people with lung involvement.

They found that high levels of a protein called CCL24, which regulates inflammation and fibrosis, are present in the blood of 25% of SSc patients. Their research using blood samples showed that patients with high circulating levels of CCL24 in their blood were more likely to experience complications such as digital ulcers, calcinosis, and crucially, interstitial lung disease. This means that higher levels of CCL24 may mean a higher chance of disease progression and even mortality (particularly as a result of lung disease).

These findings suggest that CCL24 could be a therapeutic target to prevent some of these complications. The team are working with an industrial partner who have developed an antibody capable of neutralising CCL24 that could soon be assessed in clinical trials.

Looking beyond medications: – The anti-inflammatory effects of exercise

The conference also hosted a series of talks on alternative, non-pharmacological approaches to managing rheumatic conditions that can be used alongside medical treatments.

Professor George Metsios from the University of Wolverhampton presented on the anti-inflammatory effects of exercise. He outlined the potential benefits of aerobic and strength training over time for individuals with rheumatic and musculoskeletal diseases, using the recommended physical activity guidelines published by EULAR in 2018.

He noted that aerobic exercise performed three-to-five times a week for 20-45 minutes, at 60-85% of an individual's maximum heart rate could potentially reduce fat mass (a factor linked to inflammation) and cardiovascular disease risk, while increasing cardio-respiratory fitness, even within just three months. Exercise can also improve quality of life and functional ability in the longer-term, when exercise load increases progressively over time to avoid injury.

Highlighting the lack of studies around the effect of exercise in rheumatic and musculoskeletal disease, Professor Metsios stressed the need for further research. We hope that this could ultimately lead to the development of exercise guidelines and prescribable training protocols to improve health and quality of life.

*The British Society for Rheumatology is the leading UK specialist medical society for rheumatology and musculoskeletal care professionals. Their vision is for people with rheumatic conditions to receive the highest quality outcomes and live well. The Society exists to champion the speciality, influence change, and build a thriving community of best practice.

The Society supports members to deliver the best care at all stages of the care pathway, improving the lives of children and adults with rheumatic and musculoskeletal disease.

**The Bath Institute for Rheumatic Diseases (BIRD), a registered charity, exists to support arthritis research, education and patient engagement so that we can improve treatment for patients with rheumatic diseases.

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

SRUK SHOP UPDATE

We are very sorry to announce that the SRUK shop will close later this year.

SRUK remains committed to helping our community source products designed to help with the day-to-day management of Scleroderma and Raynaud's. We would like to sincerely thank you for your support over the years.

The decision to close the shop is mainly due to the fact that we can no longer stock key items such as Silver Socks and Gloves, as a result of ongoing supply issues with our European partners.

As we move forwards, we will be working directly with suppliers to offer discounts on certain products, with some companies offering a donation to SRUK for purchases made within our community.

We are very grateful to the following companies for their kind support.

Fibreheat

Fibreheat offers a range of self-heating accessories including **hats**, **gloves**, and **socks**. They are equipped with laboratory-tested heat-storing fabrics, with no batteries or wires required. The products are designed to use naturally occurring body moisture by converting it to heat when worn.

Fibreheat will give SRUK customers 15% off products purchased from their webpage. Please visit fibreheat.com and enter code SRUK15 when prompted.

Fibreheat have also kindly offered a generous donation to SRUK, of 20% of the product price every time such a purchase is made.

We would like to thank **Fibreheat** for their kind support.

ASTECtherm Self-Warming Insoles

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** or the following QR code:

You can also get free shipping with code **RAY23**.

We would like to thank **ASTECtherm** for their kind support.

Feel the Warmth Infrared Kidney Warmer and Heat Pad

These products work by using an infrared heat technology. **The kidney belt** works on the idea of maintaining the "core body temperature", heating the blood vessels around the kidneys to allow the distribution of warm blood around the body.

The **heat pads** are designed to penetrate heat deep into the muscles, nerves and bones and can be slipped into any regular cushion. The products are intended to be affordable to use.

Feel the Warmth have kindly offered SRUK two free products for every ten sold, to help us to continue supporting our community.

The goods can be purchased via **ftwscotland.com**

Please enter (SRUK) after your name when purchasing, to ensure SRUK benefit from the referral.

We are very grateful to **Feel the Warmth** for their support.

PHYSIOTHERAPY FOR SCLERODERMA

Will Gregory is a physiotherapist working at consultant level for the rheumatology team at Salford Royal Hospital. He has led on rehabilitation for many people living with scleroderma, and has undertaken research in this area. He has also spoken nationally and internationally on scleroderma rehabilitation. We would like to thank Will Gregory for his help and support in producing this article.

Physiotherapy is a person-centred approach that uses a variety of techniques designed to restore movement and function in the body.

Physiotherapy is an umbrella term encompassing both treatment and preventative measures. It will be tailored to each individual, and may include:

- Education and advice,
- Movement and exercise,
- Manual therapy.

Physiotherapy and scleroderma

Around 90% of people living with scleroderma will experience musculoskeletal problems at some time. Skin changes are also common and can have a significant effect upon everyday life. Physiotherapy can often help with these aspects and reduce their impact.

The smallest amount of daily exercise can make a difference when you are living with Scleroderma and Raynaud's. Whilst it may not ultimately prevent disability and the many physical changes that can occur, physiotherapy aims to limit the extent and impact of these complications to help people retain movement, fitness, and function for as long as possible. It has been observed to help in minimising skin contracture, optimising strength, maintaining skin movements around joints, and preserving overall suppleness.

Because of these potential benefits, physiotherapy exercises have now become a key part of scleroderma management, so a referral at some stage is not uncommon. The role of physiotherapy features within guidelines issued by both the British Society of Rheumatology[i] from 2016 and the European League Against Rheumatism[ii] in 2017, with reference to the efficacy of non-pharmacological treatments in scleroderma, alongside research evaluating the benefits of various physiotherapy treatments. In recent years, researchers have explored the possible benefits of different interventions including cardiovascular fitness work, mouth stretches, wax bath therapy and hand exercises.

One study found the majority of participants showed improvements from hand exercises, re-enforcing the view that then do help those with scleroderma.

Physiotherapy and hand mobility

A Swedish study by Sanqvist et al.[iii] observed significant clinical improvements in hand mobility in scleroderma (HAMIS), as well as greater finger flexion and increased grip strength. These findings were used to adapt certain hand exercises according to an individual's needs, with improvements observed in many cases.

SRUK also funded a research project led by Will Gregory, to compare the effects of daily hand exercises with or without daily home wax bath hand treatments in people with scleroderma.[iv] Thirty-six participants affected by hand skin tightening were randomised into two groups: either with or without the wax bath intervention. Both groups continued to perform regular hand exercises as part of their treatment.

Most participants showed some form of improvement over the study period, with some improvements quite significant. This re-enforced the view that hand exercises do help those living with scleroderma. Between the two groups the differences were not significant, meaning that a full recommendation of wax bath therapy for all could not be made. However, these findings could not exclude the possibility that individuals may still benefit from this treatment approach.

Wax bath therapy

Wax baths have been used since the early 1900s, and are thought to help increase pain threshold, reduce joint stiffness and swelling, and even improve mobilisation. They can help relieve certain symptoms by moisturising and softening skin, improving circulation and muscle movement and even reducing joint pain. A wax bath uses paraffin wax that melts at a lower temperature than normal and should not burn the skin.

The use of wax baths is not appropriate for everyone living with scleroderma and must not be used if there is any skin breakdown, including digital ulcers.

A wax bath is not suitable for everyone. Do not try this if you have any breakdown of the skin, e.g., digital ulcers.

The following information is intended for information only. As ever, always talk to your doctor before trying something new.

You will need:

- A wax bath with a thermostat
- A pair of mittens
- Around 1kg paraffin wax, which is reusable
- Plastic liner or tinfoil.

Method:

- Melt the wax and allow to cool a little.
- Wash your hands or feet thoroughly.
- Test a small area on the inside of your wrist to check the temperature.
- Dip your hands or feet into the wax and then remove them. Allow the wax to begin solidifying. Rapidly re-dip for another few seconds and remove again. Separate the fingers or toes before dipping to allow the wax to coat all around.
- Repeat until you have built up four or five layers. Then wrap quickly with the plastic liner or tinfoil.
- Put your hand or foot inside the mitten or wrap in a towel for 20–30 minutes.
- Peel off the wax and make it into a ball, exercising the fingers by gripping and un-gripping the wax before returning it to the pan for future use.
- Moisturise using emollients or moisturisers.
- Continue to exercise the joints for at least ten minutes afterwards.

Hand exercises

The following hand exercises are intended as examples only as they may not be suitable for everyone. Always start slowly and stop if things become uncomfortable. Breathing deeply throughout each exercise will help.

Opening the thumb joint:

- Starting with your hand flat on the table, pull your thumb away from your index finger using your other hand. Hold it as far as possible for 10-20 seconds. Up to five repetitions should be done with each hand.
- Starting with your thumb on the table, lower your other fingers towards the floor. Continue for up to five repetitions on each hand.
- Spread your thumb as far as possible from your index finger. Place a round object (e.g., a glass) in the gap to hold the fingers as far apart as possible. This position should be held for 10-20 seconds or longer if tolerated.

Position for extending the wrists:

- Starting with your hands flat on the table, position your shoulders over your hands with your elbows stretched. Keep them stretched as much as possible for 10–20 seconds.
- Whilst standing, grip the edge of the table with your hands. Then position your shoulders above your hands with your elbows stretched. Hold this position for 10–20 seconds and repeat this up to five times.

Will has created a video on hand exercises for SRUK that you can watch on our YouTube channel. Please visit youtube.com/WeAreSRUK

Have you seen a physiotherapist as part of your care? We would love to hear about your experiences! Please call us or email **info@sruk.co.uk**

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[i] https://www.rheumatology.org.uk/guidelines

[ii] https://www.eular.org/

[iii] Sandqvist G, Eklund M. Validity of HAMIS: a test of hand mobility in scleroderma. *Arthritis Care Res*. 2000 Dec;13(6):382-7. PMID: 14635314.

[iv] Gregory WJ, Wilkinson J, Herrick AL. A randomised controlled trial of wax baths as an additive therapy to hand exercises in patients with systemic sclerosis. *Physiotherapy*. 2019 Sep;105(3):370-377.

PAULA'S STORY

Paula Manning is a mental health physiotherapist, CEO of Healthy Chats CIC and has specialised in physical activity promotion. Paula is living with connective tissue disease and has been working to build and maintain her strength and fitness.


Paula

I was diagnosed with mixed connective tissue disease around five years ago, which completely changed how I lived my life at that time. Once I was diagnosed and prescribed medication to ease my symptoms of muscle weakening and pain, I decided to also help myself by moving around more at home, stretching my body in the places that were tight and then congratulating myself on tiny successes I had made that day.

There were so many things that had become difficult, but I was sure that I could help myself. There is something helpful about taking some charge of your body when it is doing things that you don't understand. The tightness in my hands, mouth, knees, and feet were the worst bits for me, as these meant that everyday life had suddenly got harder, and I was frightened of falling over.

Being a physiotherapist was both a help and a hindrance to my rehabilitation. Knowing what I ought to do compared to the pain that I was in was an internal battle ground which I'm glad to say the physio and exercise part of me won, although I often didn't feel like doing anything.

I'm not saying that any of this was easy but wow, what a difference it has made! Strengthening my muscles, practicing my balance, and keeping the range of movement in all my joints has been so important.

Mentally (and with the occasional jig of excitement) over the years I have celebrated lots of small successes such as being able to hang my washing outside, putting the shower curtain back up after washing it, being able to carry all my shopping to my car without using a trolley and most importantly, getting back onto the dancefloor at my beloved northern soul and Motown gigs.

So let me recommend using the exercises that physiotherapists give you.

If you've noticed that you've become weaker or less able to do activities that you normally do around your house, then a physiotherapist or occupational therapist will definitely be able to help you.

Please don't think that just because you can't do it now, you won't do it in the future. Watch out for your balance and practice the six strength and balance exercises recommended. I created a video for SRUK that you can watch on Youtube via **https://bit.ly/44Q2GFj**

My top tip is to smile, even when you don't feel like it. Kid your body into thinking everything is okay. It may not be, but it helps to stop the occasional panic we can feel. Pace yourself, book in rest periods as well as activities as these are equally as important.

I do find swearing can be very helpful when it just gets too much, and it's okay to have a cry and share with your friends and family your successes and frustrations.
Most importantly look at what you can do, rather than what you can't do, and don't look too far ahead.

To find out about physiotherapy, please visit our website. For more examples of hand exercises and to watch Will Gregory speaking in more detail, **please visit youtube.co.uk/wearesruk**

SARA'S STORY

Sara lives in Derbyshire, and was diagnosed with scleroderma in 2021, after living with Raynaud's for many years. Since her diagnosis, Sara has become a tireless campaigner to raise awareness of scleroderma and its impact. She shared her story with *Take a Break Monthly* magazine in 2022, and more recently she was interviewed on BBC Radio Sheffield to talk about her personal experience.

Sara

On 14 March 2023, I was interviewed live on BBC Radio Sheffield to talk about my scleroderma. I was very nervous obviously, but it went very well!

The interview came about because I heard that they had broadcast a segment on scleroderma last year, and I contacted them to ask if I could listen to it. They said that unfortunately it was no longer available, however I could come in myself, to talk about my own experience on the morning show hosted by Paulette Edwards.

Paulette already followed my Instagram, and then one day she messaged me to say: *'when are you coming in?'* So, I did!

It was all quite straightforward on the day. I was just asked to come to the studio, and I was told that the interview would be broadcast live at midday.

I arrived at 11.30 with my husband. They made us a drink and we could hear the radio while we waited. At about 12.10 I wondered what was happening, but then they took me into the studio.

They began by playing a clip from another member of the SRUK community who had been on air last year, and whose daughter has scleroderma. Then the interview started, with Paulette doing an introduction and asking me some questions. In preparation, I had taken a sheet with some information bullet points, but I didn't even look at it in the end! They also talked to Sue Farrington, SRUK's Chief Executive, about the condition and the work of the charity.

I really enjoyed the whole experience, and it was really nice to meet Paulette.

I want to raise awareness of scleroderma and its impact. I shared my story in *Take A Break* magazine last year, and I will continue with my dedicated Instagram that follows my scleroderma journey.

Since the interview was broadcast, other scleroderma warriors have contacted me on Instagram, just to say thank you for doing this. To do something that you find so nerve wracking is actually a real confidence boost in the end. I am really glad that I have done it! Now I think to myself: *'I have done that, what else can I do?'*

You can follow Sara's journey on Instagram at **sclerodermawarriorsara**.

STORIES SPEAK LOUDER THAN STATISTICS!

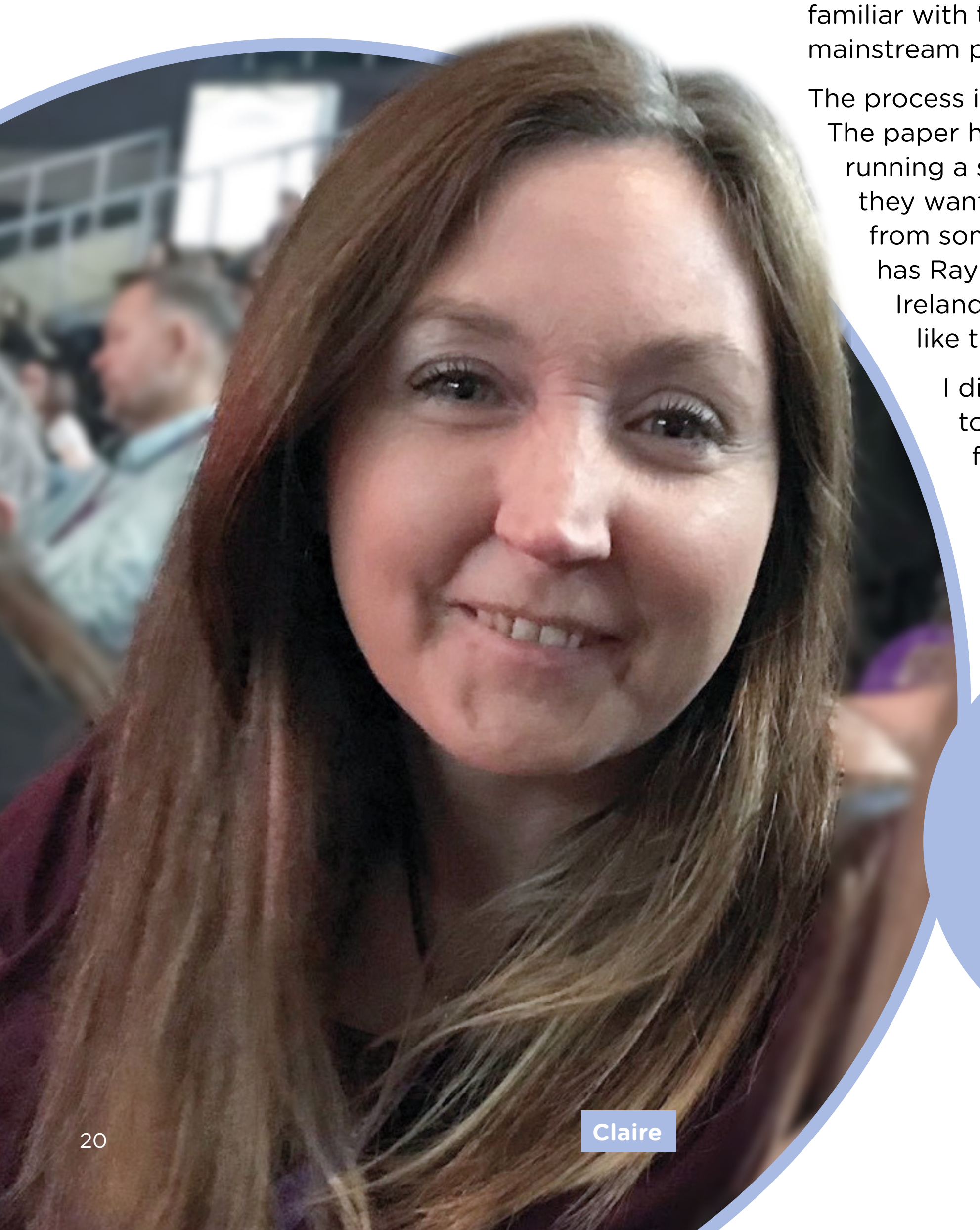
Claire, 43, is a music teacher who lives with her family in Bangor, Northern Ireland. She first noticed the symptoms of Raynaud's in 2018 and was diagnosed with diffuse scleroderma two years later.

In December 2022, Claire shared her story of living with Scleroderma and Raynaud's with *The Belfast News Letter*. We talked to Claire about her experience and the power of personal stories.

My story appeared in *The Belfast News Letter* in December 2022.

I initially had fairly mixed feelings about putting my story out there, as I was apprehensive about compromising my public image as a music freelancer. I wondered if it was a good idea to have such a different slant on my persona. But I feel that I personally have benefitted from reading other people's stories of living with Scleroderma and Raynaud's, and I felt it was important to give something back. I was already familiar with this publication as it is a fairly mainstream paper here in Northen Ireland.

The process itself was fairly straightforward. The paper had contacted SRUK, as they were running a story about the cold weather, and they wanted to include a personal story from someone from Northern Ireland who has Raynaud's. SRUK asked the Northern Ireland Support Group if anyone might like to take part, and I responded!



Claire

> My story was published ... and I was really happy with it!

I didn't have to talk to a journalist or to anyone from the paper. Helena from SRUK called me and we just talked about my experiences. There was no pressure, and I was always free to change my mind at any time. SRUK showed me the story before sending it back to *The Belfast News Letter* to make sure that I was happy with it. It was great to have had the opportunity to read and approve it before it came out.

> "It's never a bad thing to put your own story down into words."

My story was published quite soon afterwards, and I was really happy with it!

I would say that if you have been helped by reading about someone else's experiences, it's never a bad thing to put your own story down into words. I had never really done an interview before, so this was the first time.

> I didn't have to talk to a journalist or to anyone from the paper. Helena from SRUK called me and we just talked about my experiences.

I do know several other people who have primary Raynaud's, and it has taken me a while to adjust to the fact that with me it is something more. My mum has had Raynaud's for years, but my experience is very different, and I can have an attack at any time, including during the warm summer months. If I was going to talk about anything publicly, it would usually be about my work, so it was really nice to be approached for something like this.

Although I have scleroderma, I still look fairly healthy and well. I have no obvious visual signs of illness or disease. I don't really like to make myself vulnerable in front of other people, so it was great that I could put my story into print without having to answer any questions. It felt a bit like a journaling exercise. I think that these stories can also give you some hope and be helpful to you in dealing with your own situation. Stories speak louder than statistics!

I am so glad that I did this, and I would definitely encourage others to do the same if you get the opportunity.

You can sometimes feel as if you are in a bit of a wilderness with all the symptoms and wondering where to go for guidance and help. It is good to get different perspectives on living with something like this. Reading about others' experiences can offer a sense of direction.

Could you share your story?

There are so many ways that you can help us keep the conversation going and continue to raise awareness about these conditions and their impact.

If you would like to find out more, please let us know!

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 this year, featuring leading clinicians and experts in the field of Scleroderma and Raynaud's.

A webinar is an interactive, online presentation that 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 our social media for all the latest updates. You can register online and then simply click on the joining link when the webinar is about to start.

Let us know any topics you would like us to cover by emailing **info@sruk.co.uk**

Our publications

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

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.

Please visit **youtube/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.

Our local Support Groups

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

If you'd like to find out about upcoming meetings, please email **info@sruk.co.uk** or give us a call on **020 3893 5998.**

Helpline:
0800 311 2756

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.

NEW SUPPORT GROUPS

We are thrilled to announce the launch of two new Support Groups, to cover Bedfordshire and Wales.

Both groups will start out by meeting online over Zoom. To find out more or to join a group, please email us at **info@sruk.co.uk**

Could you help make a difference to our community?

- **Have you ever thought about bringing people with Scleroderma & Raynaud's together to find support and lasting friendships?**
- **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 help ensure no one has to face these conditions alone.

At the moment, we are especially keen to find volunteers in the following areas:

- Scotland
- The South West
- Anywhere: to help facilitate 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.

For more information or an informal chat, please email us at **info@sruk.co.uk** or call us on **020 3893 5998**

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."*

SCLERODERMA AWARENESS MONTH UPDATE

This June for Scleroderma Awareness Month, we shared the results of our survey of 150 rheumatologists in the UK.

SRUK is calling for greater investment into scleroderma care.

Our survey revealed that many rheumatologists lack confidence in scleroderma symptoms, and would welcome more training around the condition.

Our survey *found that many rheumatologists are not confident about the condition's signs and symptoms, believe scleroderma services are underfunded and would welcome more training and education.*

- Of the 150 rheumatologists we surveyed, **almost two-in-three (64%)** said they were unsure about scleroderma's signs and symptoms.
- **More than one-in-five (21%)** had either not heard of scleroderma or did not fully understand what it does to the body.
- **2%** said they had not heard of scleroderma.
- **65%** thought scleroderma services and training and education are underfunded.
- **Nearly nine-in-10 (87%)** said they would value further training in scleroderma care.
- **Six-in-10 (60%)** said that their overall workload does not always enable them to stay up to date with best practice guidance on the treatment and care of people with scleroderma.
- **Half of all respondents (50%)** reported using SRUK as an information source to inform patient care, the highest of all the sources mentioned.

We are calling for greater investment into scleroderma care to support rheumatologists in providing the best possible care. We are also investigating the possibility of developing our own specialist training programme for rheumatologists and other healthcare professionals, such as nurses and GPs, to help raise awareness of the condition and ultimately support the NHS in speeding up the diagnosis and treatment of people with scleroderma.

Throughout the month we continued to share useful information, start conversations and highlight your stories on our social media channels. We are really grateful to everyone that shared their own stories or shared our posts, and to our community for keeping these important conversations going.

It doesn't stop at the end of June – we still have a lot more to say and do!

People's Friend featured an article on scleroderma in June:

UNDERSTANDING SCLERODERMA

Our health writer, Jackie Mitchell, finds out more about this autoimmune condition.

IT'S Scleroderma Awareness Month, highlighting this rare autoimmune condition that causes the hardening and thickening of the skin, and in some cases the internal organs.

The condition usually develops in middle age, although it can affect people of all ages. Women are four times more likely to develop it.

There are two types: localised (also known as morphea) and systemic sclerosis.

The localised condition only affects the skin, causing patches of hardened skin to develop on the body.

Systemic sclerosis is the more serious form of the condition, as it can involve the heart, lungs, liver, kidneys and digestive system.

"For those with systemic sclerosis, their condition may be 'limited' or 'diffuse'," Dr Emma Blamont from charity Scleroderma & Raynaud's UK (SRUK) explains.

"Limited is the most common form. It affects smaller areas of skin, but can still affect internal organs, particularly the digestive tract.

"Diffuse systemic sclerosis is rarer and affects larger areas of skin.

"It is seen as a faster progressing form of the condition and can lead to organ complications.

"Systemic sclerosis can be a debilitating and life-limiting condition, which is why it is important to be aware of the symptoms and know when to seek professional advice."

The most common first symptom of systemic sclerosis is Raynaud's, a condition that affects blood supply to the extremities, such as fingers, toes, ears, nipples and nose.

It can cause painful "attacks" in response to cold temperatures and stress.

"During a Raynaud's attack, blood flow to these parts of the body is restricted, leading to them becoming noticeably paler and sometimes taking on a bluish tinge," Dr Blamont says. "This leads to numbness and pain when the blood flow is restored."

Hardening and tightening of the skin is another symptom of scleroderma.

When the body produces too much collagen, it causes scarring and stops the affected body parts from functioning normally. Other signs include fatigue, hard lumps under the skin (called calcinosis) and joint pain.

"Do consult your GP if you think you have Raynaud's," Dr Blamont says.

"For the majority, it's not linked to another condition, but for some it can be a sign of a more serious underlying condition, such as scleroderma.

"There is no cure for systemic sclerosis, but there are treatments to help slow and manage the condition."

Topical skin creams can help with hard, tight skin. Medical treatments include drugs that suppress the immune system and painkillers.

You might also be prescribed blood pressure medications and treatments to relieve symptoms of acid reflux.

Physical and/or occupational therapy can help to manage pain and improve strength and mobility.

For more information, visit www.sruk.co.uk or call the helpline on 0800 311 2756. ■

Shutterstock.

Webinar

Our June webinar hosted by Dr. Andrea Murray was a fascinating look at imaging techniques and the skin. Dr Murray talked about non-invasive imaging and new technologies, and over 70 people registered.

You can watch it on our YouTube Channel: www.youtube.com/WeAreSRUK

Appeal

Thank you to everyone that was able to support our appeal – so far you have donated over £7,000 which is fantastic. Thank you also to **Sara**, **Claire** and **Matthew** for sharing their stories for the appeal.

Walkers

We've had 50 people sign up so far and over £6,100 has already been raised. You can read more on the next page. People are still doing their walks or planning them, and we are very grateful to everyone that has raised money or supported others that are walking.

World Scleroderma Day 29 June 2023

We continued to support the FESCA (Federation of European Scleroderma Associations) campaign ***"Find the Light to Bloom"***, to shine a light on the unmet needs of people living with scleroderma and urge policy-makers to prioritise improved diagnosis, treatment and quality of life.

"Find the Light to Bloom" intends to empower the scleroderma patient population and showcase that they can thrive, despite living with such a disabling disease. This year they produced a beautiful video that represented through dance, the journey of a person living with scleroderma. You can watch it on our YouTube channel.

FUNDRAISING HEROES

SHINING THE SPOTLIGHT ON SOME OF OUR FANTASTIC SUPPORTERS!

Philip Beckett teamed up with **Great Yarmouth Pleasure Beach** to fundraise for SRUK on 18 June, in memory of his daughter, Lauren. Huge thanks to the Pleasure Beach who kindly made a donation for every wristband or fun card purchased. With the money collected on the day by Philip and his team, the grand total raised was **£625**.

Marian Kyle completed the **Mourne Way Marathon** on 10 June, one of the hottest days of the year so far, because her sister Claire has scleroderma. She has raised over **£758**, with donations still coming in.

Charlotte Sweeney took on **The Great Birmingham Half** on 7 May in memory of her Mum Gail who passed away in 2020 after living with Raynaud's and Scleroderma for 20 years. She has raised a staggering **£1,102** for SRUK!

Thank you to **Bronwen Ford**, who completed **The Great Manchester Half Marathon** on 21 May, in memory of her Nanny Sunnyside. She has already raised **£522**, and the donations are still coming in!

Huge thanks to **Emma Reynolds**, who completed her third **Leeds Half Marathon** on 14 May!

Emma raised **£330** for SRUK, in memory of her Nana who sadly died of scleroderma over 27 years ago. Once again, Emma wore her SRUK running vest personalised with her Nana's name as she took on the challenge!

James, Shaun, Tom and Dan ran the **Helsinki Marathon** on 12 May for James's mother-in-law who has scleroderma. They have raised over **£445** so far.

Pat de Gier is taking on another **skydive** to mark a milestone birthday on 15 July. She's raised **£465** so far!

Cheryl Iddion is also taking on a **skydive** with her friend, she's already raised over **£1,500!**

THANKS TO OUR SRUK WALKERS

So far, we have **50 people** registered to take on a **Walk for SRUK**. Some of you have finished your walks and some are happening soon. We will update you in the next edition with the grand total, but so far over **£6,100** has been raised.

Sara's story

Having been recently diagnosed with a rare form of localised scleroderma, **Sara** recently participated in the **SRUK Walk**.

She told us: "I'm urging everyone to start conversations about scleroderma with those in their networks and communities. By increasing awareness about scleroderma, the hope is that people will recognise the signs and symptoms more quickly and easily, which in turn could lead to earlier diagnosis and less harm to people living with scleroderma."

Victoria's story


Victoria

Victoria was given her diagnosis of systemic sclerosis during 2019. She developed interstitial lung disease and was treated with cyclophosphamide which has stabilised her condition. This year, Victoria also took part in the **SRUK Walk**.

"After this treatment I was told this year my lungs are finally stable at 52% capacity, I have decided that now I am stable it's time to give back to help those who may be in a similar situation to me. So, this summer, I am walking for SRUK. My aim is to walk 19 miles over the summer for the 19,000 people diagnosed with scleroderma in the UK, but even if I reach this target I am going to keep going to see how far I can go!"

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**

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.

If you would like further information on the sources we use on a particular publication, please contact the Information and Support Services team at **info@sruk.co.uk**

Your magazine, your way
Your feedback is really important to us. If you have a comment or suggestion on how we can improve the magazine, please call our team on **020 3893 5998** or email: **info@sruk.co.uk**

Your Stories
We want to hear from you if you have a story that you would like to add to the magazine.

Pay your Membership by Direct Debit
You are now able to pay your membership by annual direct debit. This means it's a lot easier for you as you won't have to remember to renew each year.

A Direct Debit is easy to set up; please call us on **020 3893 5998** or visit **sruk.co.uk/donate/direct-debit**

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We hope you enjoyed your edition of the SRUK magazine. If you have finished with your copy then please do pass it on to a friend or your local GP surgery. Alternatively, all the inner pages can be recycled locally to help look after our planet.

@WeAreSRUK /WeAreSRUK