

SRUK NEWS

**“A feeling like
no other!”**

Meet the incredible team
of runners who took
on the iconic
TCS London Marathon
for SRUK.

**Can you take HRT if
you have Scleroderma
or Raynaud's?**

Research news:

SRUK-funded research
to facilitate access to
the most effective
treatments in limited SSc.

New hope for easier
and painless treatment
for fibrosis.



**SRUK
Christmas Appeal**

How a small gift
really can make a
big difference.

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.



Join Team SRUK your way!

Are you interested in fundraising for us or taking part in an event to help those affected by Scleroderma and Raynaud's? From an inflatable 5k to a marathon, and from bake sales to golf days, there really is something for everyone. You can also help us by spreading the word of upcoming opportunities and events to your family and friends.

But you do not need to run a marathon to support SRUK and help us continue our work. There are countless ways to get involved; you can even help us raise vital funds without even leaving your home.

Whatever you decide to do, when you join us for some fundraising you'll receive a free fundraising pack, SRUK running vest or T-shirt and ongoing support from a member of the fundraising team.

Check out our calendar below for just a few of the events that we are looking forward to over the coming year:

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

You can also call us on **020 3893 5993**.

EVENTS CALENDAR 2022/23

Inflatable 5k 2022	Obstacle Course/Fun Run	Stafford	1 October 2022
	Obstacle Course/Fun Run	Peterborough	10 December 2022
	Obstacle Course/Fun Run	Varied	TBC
Santa in the City	Fun Run	London	7-8 December 2022
London Landmarks Half Marathon	Half Marathon	London	2 April 2023
TCS London Marathon	Full Marathon	London	23 April 2023
SRUK Walk	Virtual Walk	Anywhere	Ongoing
London Asics 10k	10k Run	London	July 2023 TBC
Leeds 10k	10k Run	Leeds	August 2023
Bath Half Marathon	Half Marathon	Bath	15 October 2023
Cardiff Half Marathon	Half Marathon	Cardiff	October 2023

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters.

As I write we are putting the final touches to our letter to the Chancellor, whoever that might be, to raise awareness of the challenges faced by our community through the cost of living and fuel crisis and ask them not to forget us when it comes to financial support.

Our recent survey showed that more than one-in-three people have suffered a painful Raynaud's attack due to foregoing their heating because of the cost and worryingly, around one-in-five people say they are buying less food so that they can afford to heat their homes. This is unacceptable, and so along with other charities, we will be making the case to Government and the energy industry that much more needs to be done.

We have been working with the media to raise the profile of Raynaud's and how it affects people with scleroderma. Some of you may have seen the programme on Channel 5 featuring Jenni Falconer sharing her story and visiting Dr Voon Ong at the Royal Free Hospital to understand how people are tested and diagnosed with the condition.

And thank goodness there's more conversation taking place about the menopause. Given that scleroderma affects four-times more women than men, we know that many

of you have asked for more information. I'd like to thank Dr Elizabeth Price for the article in this edition and those of you who have very generously shared your stories.

This October I joined staff, family, and friends from our community at the TCS London Marathon to cheer on #Team SRUK. It was a great day and fortunately, the weather was kind, no rain and probably the perfect temperature for running. My thanks to everyone who contributes so much to the charity, be that volunteering or fundraising. All your contributions really do make a significant difference.

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 would like to ask about any help that may be out there as I have been experiencing really low mood since my diagnosis. Can my consultant help? I was diagnosed earlier this year, but I was feeling really ill for a long time before that. It is also very difficult just to trying to come to terms with everything.

A Diagnosis of any potentially serious medical condition will almost inevitably affect emotional state and mood, although sometimes it can also be a relief to have an explanation, and to understand symptoms, and consider new treatment approaches. However, conditions such as scleroderma are long term illnesses that can impact upon many aspects of everyday life. Therefore, low mood is common, and it is important to recognise and address the issue. Sometimes antidepressant medication is appropriate, and it is notable that some antidepressants such as fluoxetine may have additional direct benefit for Raynaud's symptoms. It is important to discuss mood with family, friends, and healthcare professionals. Research studies are helping to understand the psychological impact of systemic sclerosis (for example SPIN: spinsclero.com).

Q I have systemic sclerosis, but I feel that many of my newer symptoms may overlap with those of Sjogren's Syndrome, is this common for people with scleroderma? Are the treatments more-or-less the same, or could anything else be done to help? I wondered if I should push for a proper diagnosis either way as I am concerned about progression in the future.

A Around one-fifth of patients with a diagnosis of systemic sclerosis also have features of an additional rheumatic disease such as lupus, arthritis, or Sjogren's Syndrome; these are termed overlap syndromes. Sjogren's leads to

inflammation and scarring of the salivary and tear glands and causes dry eyes and mouth as well as general features such as fatigue. However, some patients with SSc will have these same symptoms due to direct effects of systemic sclerosis, and this can be clarified by blood tests and other assessments. This is important, because for overlap patients additional therapy targeting non-SSc features may be helpful.

Q Is it possible to take HRT when I am already on mycophenolate for SSc? I want to ask my GP about trying HRT but would like an expert opinion to take along first please.

A There is no reason not to take HRT (hormone replacement therapy) along with mycophenolate; and so you can discuss with your GP whether HRT is right for you, and check whether there are any non-systemic sclerosis aspects to also be considered, such as risk of thrombosis, severe cardiovascular disease or a history of breast cancer.

Q I am having increasing problems with my jaw, and I am now unable to fully open my mouth. This affects cleaning my teeth and I am unable to floss, so as well as all that comes with the scleroderma, I am also very worried about my dental health. I am unsure if there is anything that can be done, or how much worse this could get in the future? Many thanks.

A Systemic sclerosis affects mouth opening through tightening of the skin and soft tissues around the mouth. In addition, some patients develop reduced movement in the temporomandibular joint (TMJ) of the jaw, located just below the ear. This can be painful. Sometimes exercises can improve the situation when skin tightness is the cause, and "fat transfer" from the abdomen or thighs also has been reported to be helpful. If the problem is localised to the TMJ then specialist assessment and imaging can help to consider if surgery or local injection may be advised.

Sometimes antidepressant medication is appropriate, and it is notable that some antidepressants such as fluoxetine may have additional direct benefit for Raynaud's symptoms.

Q I have been diagnosed with scleroderma that only affects my skin. I would like to know what treatments are available, and also will it be safe to have a tattoo done please?

A Scleroderma means "hard skin" and can occur as a localised form that only affects the skin (morphoea) or systemic sclerosis where blood vessels and internal organs can also be involved. However, even in systemic sclerosis some patients only have skin changes. In either situation there are treatments that can be given, including immunosuppressive drugs such as methotrexate or mycophenolate mofetil. You should discuss the options with your clinical team as it is important to balance potential benefit against possible side-effects.

Whilst I have not seen specific problems from tattoos in scleroderma, and many patients have them without complication, I would not recommend this in severely affected or inflamed skin as there may be a greater risk of infection or local complication.

Q I have systemic sclerosis and I am now having issues with my balance, could there be a connection to my scleroderma please, and if so, is this something that could get worse? I am more and more worried about falling and I feel I need to do something about it before something happens, could a physiotherapist help?

A Systemic sclerosis does not usually have a direct effect on the balance mechanisms of the inner ear that can lead to vertigo and dizziness, although these symptoms can occur for other reasons. Another consideration is that low blood pressure (hypotension) can cause dizziness upon sudden standing up from sitting. It would be advisable to check your blood pressure, especially if taking drugs for Raynaud's, and discuss this with your clinical team or GP.

AROUND ONE-FIFTH OF PATIENTS WITH A DIAGNOSIS OF SYSTEMIC SCLEROSIS ALSO HAVE FEATURES OF AN ADDITIONAL RHEUMATIC DISEASE SUCH AS LUPUS, ARTHRITIS, OR SJOGREN'S SYNDROME.

Q I have been diagnosed with Raynaud's and sticky blood antiphospholipid syndrome. I had blood clots several years ago. I am now taking HRT, but I have noticed that Raynaud's is worsening, and this makes me worry about getting another clot. The doctor said that he thinks that the HRT is making my Raynaud's symptoms worse, however do you know if this sounds right please, and if so, is there a risk of even more complications?

A Antiphospholipid syndrome is a specific medical condition associated with autoantibodies in the blood that can interfere with blood clotting. Sometimes antiphospholipid syndrome is associated with another autoimmune disease including lupus or systemic sclerosis. If it is confirmed, and especially if there is a history of thrombosis (such as a deep vein thrombosis), you should have treatment to reduce the risk of a blood clot. In general, HRT is not recommended in patients with antiphospholipid syndrome because HRT can also increase the risk of blood clots. You should discuss this with your doctor as it may be medically advisable to adjust or discontinue HRT.



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



#TEAMSROK: YOUR STORIES

The TCS London Marathon took place on 2 October, and our incredible team of 10 runners rose to the challenge, all to raise vital funds for SRUK.

Team SRUK joined more than 40,000 people to run the iconic 26.2 mile course in near-perfect conditions, cheered on by their families and friends, along with the volunteers and SRUK staff members who gathered at our cheer point along The Highway, just outside the City of London.

We are incredibly grateful to all our amazing runners for fundraising and raising awareness of Scleroderma and Raynaud's, as well as all the training and dedication that led up to their fantastic efforts on the day.

Meet our runners

Nick Jackson

I've never run before since doing cross country running in PE at school, so doing the London Marathon has been a big deal for me.

I ran for my mum who has scleroderma which has,

in her words, affected her interactions with her grandkids. I see the daily issues this disease causes and wouldn't wish it on anyone.

I'm hoping the money I've raised can help contribute to research.

The highlight of the day was crossing the finish line with my whole family watching.

Sylvia Herring

I've run before but stopped after I got my diagnosis of scleroderma due to joint pain.

Having scleroderma myself, I'm so grateful that four-and-a-half years in I can still do most things I want, albeit much slower and more painfully than before. I wanted to run the London Marathon for those who no longer can.

The start was amazing, I was so excited. I tried to keep it nice and slow though as I hadn't been well for a couple of



days before (just the stress of travel, excitement and typical sclero tummy!).

We joined the other start colours on the course and the noise of the runners swelled as more joined, it was so exciting. Mile 1 was lovely, Miles 2 and 3 ticked by... the course support was immense! Miles 4 and 5 flew by so fast.

But then I started to feel the nausea creep in. I continued to take on my fuel and kept sipping my water as I knew I needed to. By Mile 8 I started vomiting which continued well into Mile 12.

I turned my Garmin off at Mile 14 as I was sure that was it for my London Marathon journey. Anyway, I saw St John's ambulance people, took some anti sickness meds and some Dioralyte and walked the next six miles with hubby on the pavement next to the course.

I re-joined later at around Mile 20 and walked with a friend for a few miles and finished the last two miles run walking on my own.

It got done!





Connie Vallis & Stacey Halford

Myself and my sister Stacey started our running journey in 2016. After both having babies and being on maternity leave, we decided it was the time to get some fitness back. We started with Couch to 5k, and then both bought running buggies for our little ones and the adventure started!

After a fair few Park Runs, 10ks and half marathons over the next few years we sadly lost our lovely, kind, caring and beautiful mother, Sharon, from systemic scleroderma at the young age of 57. My whole world came crashing down

around me, but running with my sister

was the one constant that kept me sane. We ran through tears and laughter, and it really helped with everything going on.

Even as a nurse myself I had never heard of systemic scleroderma. I started to research it and realised very quickly that she was already end stage. She died just a few short weeks later. Losing her to such a life-limiting and aggressive condition made me want to help in some way and raise money in her memory.

Of course, it made sense to combine this with my passion for running. I got a place in the London Marathon 2020 with SRUK. I trained and fundraised and I was so ready to complete that marathon. But sadly, COVID-19 hit and the London Marathon was swiftly cancelled. I couldn't let my supporters down, so I ended up running 26.2 miles completely on my own around Norwich.

Fast-forward a few months and Stacey also got a place with SRUK. We trained together but once again London was not meant to be, and we ended up completing another virtual marathon around Norwich!

Since then, so much has happened. We've joined

a wonderful running group called Norwich Social Joggers and have carried on running regularly. In fact, we ended up running a 53km Ultra Marathon for SRUK in June 2021.

We've definitely been fitter, and we've definitely trained better before (training through the summer is the worst) but it was such an amazing experience! Highlight of the big day was knowing we were going to see people along the route - our husbands and children, family, friends, our running club and of course SRUK - it really kept us going and gave us something to focus on!

It's hard to explain how we felt passing the finish line. Pure raw emotion of relief, happiness and pride, a feeling like no other!

James Burdett

In late summer 2021 I decided it's about time to do some fundraising again and stupidly I thought a good way to do that would be to try and get a place in the London Marathon. Then SRUK gave me a place!

Whilst I've been running for a while, I've never run long distances. I've never run more than a half marathon, and even then, only on one occasion in 2007. So, leading up to the

big day I was thinking 'Cripes, 26.2 miles!'

Why SRUK? Well, Maureen (my wife's mum), suffers from Scleroderma and Raynaud's, and that personal connection gave me inspiration. Also, SRUK are a small charity and it's great to support something less well-known and raise awareness.

On the day itself, Cutty Sark to Tower Bridge seemed to go on forever, but then going over the bridge with all the crowds, turning the corner and then seeing the SRUK cheer point was a real high point.

Crossing the finish line was almost too hard to take in. 30-38kms were so tough, but after that I knew I had it in the bag and enjoyed the last few kms. Slightly bittersweet too in that it was all over, despite being done in!

John Thompson

I ran the marathon back in 2017, which was two years after I started running. Since then, it's fair to say I have the running bug and try to get out running as often as I can.

I'm running for SRUK because my wife



awesome parts of the day was seeing my wife and daughter at the SRUK cheer point which gave me the boost to keep going. The crowds were amazing throughout.

I felt so much jubilation and relief when crossing the finish line and a sense of achievement after months of hard work and at some points worry of not being able to do it.

I'm going to do more challenges this year too, to raise even more for SRUK and on behalf of Estelle. My next challenge is the Coast to Coast, which I'm hoping to do in October too. Even if I just get up one morning and do it, that'll be great!

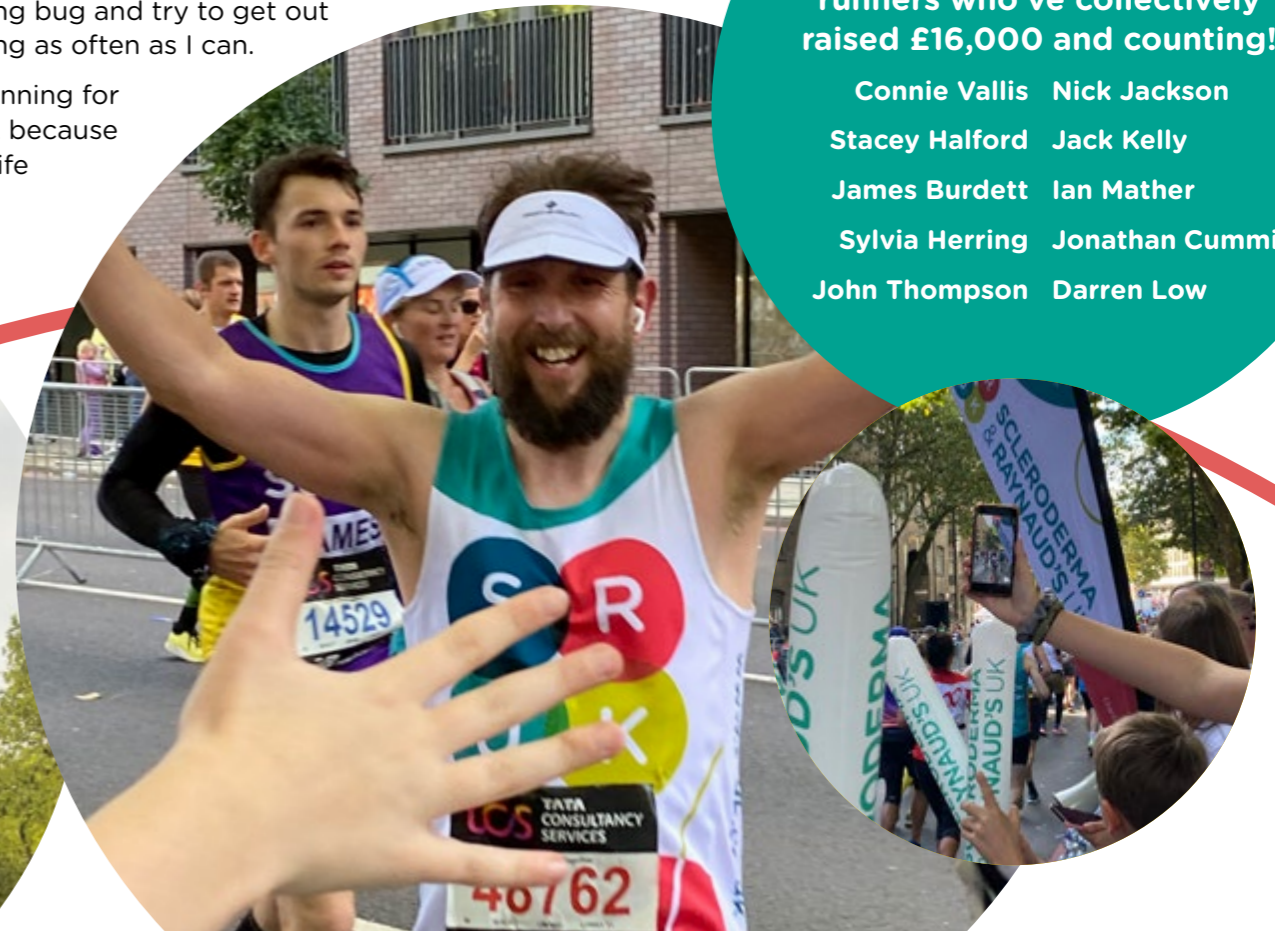
Estelle was diagnosed with scleroderma (systemic sclerosis) back in 2018 and our lives since then have dramatically changed. Estelle wanted to do some personal challenges to raise awareness and money for SRUK. Unfortunately, Estelle then developed severe fatigue and is now unable to start these challenges. I suggested I take up the mantle and run the London Marathon in 2022.

Although I run regularly, I haven't run many marathons since 2017 and am now that little bit older so it was a bit more of a challenge this year.

One of the most

Thank you to all of our amazing London Marathon runners who've collectively raised £16,000 and counting!

- Connie Vallis Nick Jackson
- Stacey Halford Jack Kelly
- James Burdett Ian Mather
- Sylvia Herring Jonathan Cummins
- John Thompson Darren Low





SRUK SHOP

Welcome to the SRUK Shop, where you can find products that have been specially selected for our community.

Snuggle Up Blanket

Relax with a Heat Holders premium fleece blanket – perfect for wrapping up warmly on chilly nights. With a 1.4 tog rating, its generous size and incredible softness make it a must-have item for peaceful days at home. Dimensions: 180cm x 200cm..

Comes in three different colours: Duck Egg Blue (pictured), Antique Silver and Cranberry

£26.99



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.

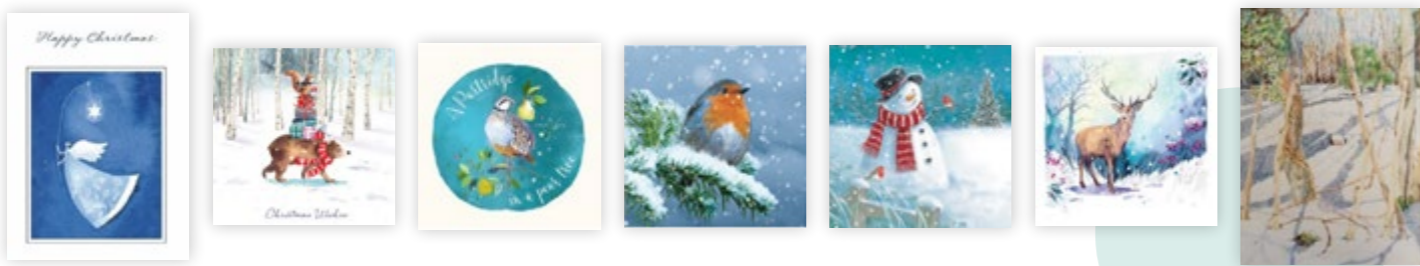
£5.50



Christmas Cards

Buy any four packs of Christmas cards and get one free! Just return the form with the correct payment amount or call us on 020 3893 5998 to complete your order.

All £3.99 except Pack G Winter Woodland which is £4.99



A. Blue Angel B. Present delivery C. Partridge in a Pear Tree D. Robin on a Snowy Fir E. Snowman and Robins F. Winter in the Forest G. Winter Woodland

MyCoal Hand Warmers

Once opened, the disposable heat packs are activated by gently shaking or squeezing and can then be placed in your pocket, mitten, or glove. Stay comfortable with up to seven hours of warmth. These come in a pack of four pairs. Not re-usable.

£4.99

Box of hand warmers: £37.99 (40 pairs)



MyCoal Foot Warmers

Once opened, the disposable foot warmers or heat packs are activated by gently shaking or squeezing and can then be placed at the toe end of your shoe. They are shaped for comfort. The heat pads remain warm for up to seven hours, ideal for anyone who gets cold feet or has Raynaud's. They then must be disposed of as they are not re-usable. They come in a pack of four pairs.

£5.49

Box of foot warmers: £43.99 (40 pairs)



Astec Self-Warming Insoles (cut to size) for cold feet

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.

£24.99



SRUK SHOP ORDER FORM

SRUK shop order form	Cost	Qty	Size	Colour/Item
SRUK Face Mask	£5.50			
Astec Self Warming Insoles (cut to size) for cold feet	£24.99			
MyCoal Hand Warmers	£4.99			
MyCoal Hand Warmers Box	£37.99			
MyCoal Foot Warmers	£5.49			
MyCoal Foot Warmers Box	£43.99			
Snuggle Up Blanket <i>Please specify the colour</i>	£26.99			
Christmas Cards (pack of 10)	£3.99			
Christmas Cards - Winter Woodland Pack G (pack of 10)	£4.99			

Postage & Packing Costs

Postage and packing for single items	£2.99
Postage and packaging for multiple items	£1.00 extra for more than 3 items

Total Order	
Total cost of goods	£
Postage & Packaging	£
To include a donation please add here	£
Total enclosed	£

Name	
Address	
Postcode	
Telephone	
Email	

FOR MORE PRODUCTS AND INFORMATION GO TO WWW.SRUKSHOP.CO.UK OR CALL 020 3893 5998

Please return to: Bride House, 18-20 Bride Lane, London EC4Y 8EE

A PRIMETIME SLOT FOR RAYNAUD'S PHENOMENON

On 12 August 2022, Raynaud's Phenomenon received primetime TV coverage as part of Channel 5's ground-breaking documentary series: **'Women's Health: Breaking the Taboos'**.

Presented by Cherry Healey, the series sought to shine a light on some of the biggest issues surrounding women's health. Since Raynaud's affects many more women than men and is surprisingly common, this has been a truly valuable opportunity to raise awareness.

The series was broadcast as part of a documentary series that aired over four nights at 7pm. The episodes looked in depth at various health conditions, and shared personal testimonies from affected women, including some celebrities who took part and shared their own experiences.

The episode that featured Raynaud's focused on well-known TV and radio presenter Jenni Falconer, who herself lives with Raynaud's Phenomenon. Jenni talked about living with the condition and the impact that it can have upon her life.

Speaking candidly on the programme, Jenni revealed, "I was about 16 years old. I was playing hockey at school. I realised I was getting really weird white tips [on] my fingers, like the blood just stopped flowing. They looked like dead fingers."

"When the blood does start flowing back, the best way to describe it is like extreme pins and needles and burning hot. It's really painful."

The documentary enabled Jenni to learn more about her condition, including the difference between primary and secondary Raynaud's.

Although SRUK was not featured in the programme, we worked closely with the documentary makers for several months, to make sure they had the right



Simi Sokan wearing Snugtoes

Raynaud's is far more common in women than in men, and is thought to affect up to **1-in-6** of the general population



Jenni Falconer/Instagram

We are very grateful to Jenni Falconer and Dr Voon Ong for taking part in this documentary and raising awareness of the impact of Raynaud's.

information and connect them with medical experts and other women with the condition.

Appearing alongside Jenni was Raynaud's specialist and SRUK supporter, Dr Voon Ong of the Royal Free Hospital, London, who provided a full and concise explanation of the condition itself and the symptoms to look out for, as well as the risks associated with secondary Raynaud's that will usually indicate an underlying autoimmune condition such as scleroderma.

"It was a pleasure to meet Jenni and have the opportunity to highlight Raynaud's as a common medical condition with its life-changing effects on those affected," said Dr Ong.

"Recognition of Raynaud's may also uncover the less common but important autoimmune connective tissue disease, scleroderma. By highlighting a common feature of a rare disease in the public arena, we hope that patients with suspected scleroderma can reach out to seek medical advice early."

The episode followed Jenni's own personal journey as she attended a consultation with Dr Ong and his colleague, Dr Kevin Howell, and underwent a nailfold capillaroscopy, to reveal whether she has primary or secondary Raynaud's and what her

prognosis might be. Following the procedure, Dr Ong was able to diagnose Jenni with primary Raynaud's, meaning that her condition exists on its own and is not likely to be linked to any underlying causes.

Later in the programme, following her consultation at the Royal Free Hospital, Jenni said, "What an interesting afternoon it's been...to find out a little bit more about Raynaud's syndrome and the different types. Also, to have some clarification of exactly what I struggle with and how to deal with it and manage how we live our lives."

We also arranged for Jenni to visit one of our supporters, Simi Sokan, who also lives with Raynaud's. They shared their experiences and Simi told Jenni how the condition inspired her business, SnugToes. Unfortunately, Simi wasn't featured in the final programme, but her advice and experience helped to inform the filming.

We would like to thank Jenni Falconer and Dr Ong for taking part in the documentary and Simi Sokan for her valuable contribution to the programme, and for helping us continue raising awareness of Raynaud's Phenomenon.

At the time of writing, the programme is still available to watch online. Please visit [channel5.com/show/women-s-health-breaking-the-taboos](https://www.channel5.com/show/women-s-health-breaking-the-taboos)

THE CRISTAL INDEX: IMPROVING THE ASSESSMENT OF NEW SCLERODERMA TREATMENTS IN CLINICAL TRIALS

SRUK-funded research aims to help ensure that people with limited scleroderma can access the most effective treatments.

One of SRUK's central objectives is to advance research that will lead to the development of new and effective treatments. But how do we make sure that new therapies will be effective? Recently, SRUK has funded a US-based research project to develop the CRISTAL Index, that will help to ensure that potential treatments are effective in ways that are relevant to both patients and clinicians. This could be vital in giving people access to treatments that work for them.

Assessing treatments for limited cutaneous scleroderma

During 2020, SRUK, in partnership with The World Scleroderma Foundation, funded the CRISTAL Project led by Professor Dinesh Khanna of the University of Michigan (USA), and Dr Alain Lescoat of the University of Rennes (France).

This project was funded as part of a grant call on 'outcome measures'. These are measurable changes in a patient that are monitored during clinical trials to allow clinicians to determine whether the treatment being tested is effective. The CRISTAL project set out to develop a set of

outcome measures which could be used to assess the efficacy of treatments for the most common type of systemic sclerosis - 'limited cutaneous scleroderma' (lcSSc). This is an unmet area of need within systemic sclerosis research.

Why are new outcome measures needed for limited SSc?

Limited systemic sclerosis is a debilitating condition affecting the skin on the lower limbs, hands, feet, neck and face, along with the internal organs. It is the most common form of systemic sclerosis, accounting for around 70% of all cases. Despite this, there are fewer treatments being tested in patients with limited SSc than in those with diffuse SSc. This is because one of the most common outcome measures used to test the effectiveness of treatments in clinical trials is the modified Rodnan Skin Score (mRSS). Since those with ISSc have a lesser degree of skin involvement, the use of the mRSS is less effective in assessing whether a treatment is of clinical benefit in these patients.

This means that there is a pressing need for outcome measures that can be used to adequately assess the efficacy of treatments for lcSSc. To work in practice, outcome measures can be grouped together to give an 'index', which is a collection of multiple relevant measures that can

all be assessed to indicate how effective a prospective treatment is. The CRISS index, which has had an impact in testing treatments for the diffuse form of the disease, is an example of this type of index.

The team in Michigan therefore aspire to create a similar index for lcSSc, by identifying and validating outcome measures that can be grouped together to effectively and comprehensively assess potential treatments.

The CRISTAL Project: What did the team identify?

Clinicians and patients can have very different views on an individual's condition and what constitutes both an improvement or the worsening of symptoms. Because of this, the team wished to work in partnership with those living with lcSSc, as well as the clinical community, to establish a set of outcome measures which included measures that are important to patients.

As such, Professor Khanna and Dr Lescoat sought to add to the areas they had identified through review of the scientific literature, by identifying measures that are of particular importance to patients. To this end, they carried out focus groups with people based in the United States. From these sessions, 15 symptoms were identified as being

particularly troublesome for patients and were highlighted as potential candidate areas for outcome measures. Ten of these areas were systemic sclerosis specific, and included gastrointestinal involvement, calcinosis and Raynaud's. The remaining five were more general domains, including symptoms such as fatigue and pain. This gave the team a list of 15 initial candidate areas for outcome measures for lcSSc.

They then put this list along with the techniques that would be used to measure them, to a team of international experts who were invited to rate these measures in terms of various factors including feasibility, reliability and validity.

Finally, the team held a two-day consensus meeting involving 11 clinical experts on lcSSc and three patient partners. Through this meeting, 18 potential outcome measures were endorsed to be included in a future study into their validity and reliability, based on

the real-life longitudinal data collected from lcSSc patients.

Potential outcomes

Dr Khanna and Dr Lescoat are now ready to validate the utility of the candidate outcome measures through an observational study. This will take significant strides towards the development of the CRISTAL index, which could generate considerable benefits for lcSSc patients in the coming years.

Firstly, the selection of patient-informed, consensus-based and data-driven outcome measures has the potential to lead to the design of trials with strong potential for achieving regulatory approval. This means that the development of the index could propel the advancement of effective drug treatments for lcSSc in the not-too-distant future, which might grant lcSSc patients better access to effective therapies that can manage their symptoms, thereby improving their health and quality of life.

Furthermore, because the proposed candidate outcome measures have been selected through a consensus process which heavily involves patients as well as clinicians, individuals may also be more likely to receive access to treatments targeted at the symptoms of lcSSc that are particularly troublesome from the patient perspective. As a result, symptoms which may not be adequately alleviated by current treatment options might be better dealt with, and the experience of the patient is central from the earliest stages of the drug development process.

SRUK hopes that this research will lead to the successful development of the CRISTAL index in the coming years, and we are very excited to see how this might propel the development of effective treatments for people living with lcSSc in the near future.



TREATING FIBROSIS IN SCLERODERMA

New SRUK-funded study lays groundwork for potential new treatment for scleroderma-related skin fibrosis.

SRUK has recently supported a new study that aims to help enable effective and painless treatment for fibrosis in people living with scleroderma.

Fibrosis, which leads to excessive thickening or scarring of the body's tissues, is a characteristic symptom

of systemic sclerosis which can affect multiple organs in the body including the skin, lungs, gastrointestinal tract, heart, blood vessels, and kidneys. This can lead to an array of debilitating complications and potentially a high level of physical disability, which together can have

a considerable impact on everyday life.

Findings from an exciting and recently completed research project, led by Dr Richard Stratton and funded by SRUK in 2018, may open a new therapeutic avenue for the treatment of skin fibrosis.

About fibrosis

We are all familiar with what happens to our skin following an injury, like a cut or a graze. As part of the wound healing process, a scar is formed over the damaged area. The scar is formed as the result of specialised cells called fibroblasts depositing collagen over the damaged area. This usually allows the correct amount of scar tissue to form: enough to patch over the wound but not so much to over-stiffen the tissue. However, in scleroderma these processes do not function as normal, with excessive fibroblast activity leading to the overproduction of collagen and the stiffening of the tissues which make up the skin and internal organs.

The reason why fibroblasts are active in people with scleroderma when there is an absence of actual 'damage' to the skin is still not fully understood. However, evidence suggests that the immune system is the culprit – with one type of cell, the macrophage (the 'pac-man' of the immune system responsible for gobbling up debris such as dying cells and bacteria), being implicated as a driver of the excessive fibrotic response.

SRUK hopes that this research will lead to an effective, pain-free therapy with lower side effects for those with scleroderma.

What did the team do?

The current project, led by Dr Stratton's team, set out to investigate whether a small and relatively simple protein molecule known as a 'peptide', which was developed by a US based biotechnology company called Riptide Bioscience, has potential as a therapeutic in treating fibrosis. Dr Stratton's team has collaborated with Riptide before, and this current project builds upon the findings of previous research also supported by SRUK which studied these peptides. Previous work by the team showed that some peptides could block fibrosis by preventing pro-fibrotic macrophages from communicating with fibroblasts. Furthermore, these peptides can also prevent the growth and development of new pro-fibrotic macrophages.

Before these peptides can be tested in humans they must first be tested for toxicity and efficacy in pre-clinical models of scleroderma, so the team set about initiating testing in mouse and human tissue models. They were particularly interested in preventing the progressive and disabling effects on the skin that the condition causes. They decided to test whether the peptide could be targeted locally to the skin (as opposed to being taken as a tablet or an infusion into a vein), using a new method of drug delivery to the skin known as microneedles, to

directly deliver the peptide to the skin of mice. A more targeted approach to drug delivery could reduce any potential side effects and the use of microneedles, which are applied via skin patches like in modern blood glucose measuring devices, could facilitate easy treatment at home.

Conclusions

Dr Stratton's team found that the peptide, administered via microneedles, may effectively inhibit scleroderma-like fibrosis in human-tissue models, and in mice. This offers up new hope of a potential therapeutic avenue and an effective and pain-free way of delivering this to people living with scleroderma.

Of course, more research is required if this therapeutic is to enter the clinic. More extensive pre-clinical work such as further toxicity testing will be required, along with the need to secure funding to support clinical trials in a small number of targeted patients. The microneedle patches used are already FDA-approved and CE marked for use in humans, which means that if the therapy is found to be safe and effective in humans by any eventual clinical trial then it's delivery via microneedles could become a reality.

SRUK hopes that this research will lead to an effective, pain-free therapy with lower side effects for those with scleroderma, helping to combat the debilitating effects of widespread skin fibrosis.

HORMONE REPLACEMENT THERAPY AND SSC: IS IT SAFE?

Whilst a diagnosis of SSc may not rule out HRT, it is important to know the facts. We talked to Dr Elizabeth Price about why an autoimmune disease may mean considering the options a little more carefully.



Dr Elizabeth Price

Hormone replacement therapy (HRT) is a treatment designed to relieve common symptoms of the menopause. It has recently received considerable media coverage, with much emphasis on its potential benefits.

When you are living with an autoimmune condition, the decision around whether to try HRT could be more complex, and you may need to consider the risks and benefits more carefully. This article is intended for information only; it is essential to talk to your doctor for tailored advice based on your own situation.

Hormone replacement therapy helps to replenish levels of the hormones that naturally fall as a woman approaches the menopause. As well as helping to reduce the impact of symptoms such as hot flushes and mood swings, taking HRT can also provide some protection against developing osteoporosis, which is more common after the menopause due to the decline in the body's hormone levels.

Although everyone will have a different experience, the menopausal years can typically last for around a decade. The average age is 45-55, however this can also vary considerably.

Women living with a connective tissue disease such as scleroderma may be more likely to experience an earlier menopause as well as early ovarian failure, especially if they were relatively young when symptoms first began. Certain treatments including cyclophosphamide are also associated with early menopause. Regardless of age and medical history, when a woman has gone for twelve months without having a period, she will be considered post-menopausal.

About HRT

HRT works by replacing the hormones that naturally decline during the menopausal years. There are various types of treatment available, and the first step is usually to contact your GP. When you are living with an autoimmune condition, it is important to be as informed as possible and to

For some women living with SSc, HRT may be considered safe. It is important to talk to your rheumatologist about whether or not you may be a candidate for HRT, and if so, the safest way you can take it.

talk to your rheumatologist if you are considering whether this could be right for you. You can also ask to be referred to a specialist menopause clinic, so do not be afraid to ask if you feel this would be helpful.

Types of HRT

HRT comes in different forms and as ever, the most appropriate treatment will always depend on your individual situation.¹

- Many women are treated with two hormones: **oestrogen** and **progesterone**.
- The progesterone element can sometimes be delivered via a uterine device rather than oral tablets.
- If you have had a hysterectomy, you may be able to take oestrogen on its own.
- There are various ways that HRT can be taken, including tablets, skin patches and gels or vaginal creams and pessaries.

Treatment often begins at a low dose that may be increased. You may not feel the benefits immediately,

although there may be some side effects.

Over-the-counter therapy

From autumn 2022 and for the first time ever, women will have the opportunity to purchase certain treatments from pharmacies without a prescription from their GP. At the time of writing, these services will be available to those who are over the age of 50 and who have not had a period in over a year.

Following a consultation with a pharmacist, people can now buy a localised treatment designed to relieve symptoms such as vaginal atrophy, meaning the thinning and drying of the vaginal wall that leads to symptoms such as dryness and itching. Because the treatment is delivered topically it is not considered high risk amongst the general population. However, as with any over-the-counter therapy, always talk to your doctor before trying something new, in case they have any concerns or alternative suggestions.

Risks of HRTⁱⁱ

Broadly speaking and within the general population, the benefits of HRT are considered to outweigh the risks, by helping to bring menopausal symptoms under control.

Living with an autoimmune disease may mean having to consider the potential risks of HRT more carefully. It is important to be as informed as possible to make the best decision for you.

- There is a small, increased risk of **breast cancer** in women taking HRT. This applies to combined therapy involving progesterone and oestrogen; there is little

or no increase in the risk to women using oestrogen-only treatment following a hysterectomy.ⁱⁱⁱ If you have a family history of breast cancer or other women's cancers, it is important to tell your doctor before starting treatment.

- HRT taken in tablet form is associated with an increased risk of developing **blood clots**, although this is also considered small. There is no evidence of this when treatment is given via the skin as a patch or a gel.
- HRT is not thought to significantly increase the risk of **cardiovascular disease** such as heart disease or strokes when treatment starts before the age of 60, in fact it may even be slightly reduced. However, there could be a slightly higher risk of a stroke in women over 60.

The relationship between hormones and connective tissue disease

The fact that scleroderma is four-times more common in women than men does seem to suggest that female hormones are a factor. This relationship is not unique to scleroderma; for example, many women living with lupus find that their disease settles considerably during and after

You may be advised to avoid certain treatments containing oestrogen, as this may make symptoms worse. However, oestrogen-based creams and pessaries for use in the genital area are considered safe in SSc.

the menopause, as monthly hormone surges naturally reduce. On the other hand, if HRT is being considered for someone with lupus, it is normally recommended that this is given for the shortest possible timeframe, to reduce the risk of an associated flare.^{iv}

Female hormones are also significant in Raynaud's Phenomenon, which also occurs far more commonly in women. There is a known, positive association between oestrogen levels and Raynaud's, with the initial onset of Raynaud's often arising around the time of the menarche, when periods start and oestrogen levels rise. Hormone changes are also significant; since symptoms may become worse around the middle of the menstrual cycle when oestrogen is at its peak.

You may be advised to avoid the oestrogen-containing contraceptive pill and some forms of HRT, because the oestrogen content could make symptoms worse. There is also some anecdotal evidence of women with no previous history of Raynaud's who have developed the condition after starting HRT.^v

A study from 1998 suggested an associated between oestrogen-only therapy and Raynaud's in postmenopausal women, although this did not affect those receiving combined treatment.^{vi} Similarly, a study from Japan reported that when mice had higher levels of oestrogen circulating through their systems, there was an increased sensitivity to cold temperatures in their extremities.^{vii}

HRT and SSc

If you are living with systemic sclerosis, you may be advised against trying HRT, so it is essential to talk to your rheumatologist about whether you may be a candidate and if so, the safest way you for you to take it.

The relationship between oestrogen and autoimmune disease may mean that you need to consider oestrogen-based therapies more carefully, because there have been cases where absorption of oestrogen into the body have caused scleroderma to flare up. A literature review on hormone-based contraception and autoimmune disease published in 2017 acknowledged that these treatments do have an effect on the immune system, and may even increase the chances of developing an autoimmune condition, although the study made no direct reference to scleroderma.^{viii} Other medications already prescribed could also be relevant, for example, HRT can slightly increase the risk of blood clots, therefore if this is a known side effect of one of your existing medications then HRT might not be a suitable option.

On a more positive note, oestrogen-based creams and pessaries for use in the genital area are normally considered safe in SSc, because the hormone element is only used topically to relieve symptoms. Depending on your situation, you may be advised to receive progesterone via an intra-uterine device rather than orally, however your doctor can advise further depending on your individual level of risk.

Other benefits of HRT

As well as the potential to relieve menopausal symptoms, there are some other positive aspects that are associated with HRT for some women.

HRT is known to help prevent osteoporosis, because bones become thinner as oestrogen levels fall. Although the effect is only thought to last for as long as you continue treatment this is useful to know, especially if you have taken steroids in the past or you already have a diagnosis of osteoporosis or osteopaenia.^{ix}

Another study has suggested that some forms of HRT may offer some protection against pulmonary hypertension in women with SSc. This can be a very serious complication of SSc, when high blood pressure builds in the pulmonary arteries. Sixty-one patients with limited scleroderma took part, and the results suggest that HRT could be effective in helping to prevent isolated pulmonary hypertension in post-menopausal women.^x However, these studies used relatively small samples and should not be considered conclusive. More research is needed to ascertain whether there are any forms of HRT that could lead to tangible benefits within our community, and if so, the limits and warnings that may well apply.

In the meantime, the question of whether to consider trying HRT remains a personal decision, that may require more time and care when you have an autoimmune condition. However you approach life during the menopausal years and beyond, help and support is always available within our community, and many people have told us they have

found mutual support to be especially helpful.

You can call our free Helpline on **0800 311 2756** to talk to one of our volunteers. SRUK also runs a network of Support Groups designed to provide a friendly space to find friendship and support around all aspects of living with Scleroderma and Raynaud's. For more information, please contact us.

We would like to thank Dr Elizabeth Price for her help and support in producing this article.

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Your stories: Hormone Replacement Therapy

Daphne's story

Daphne is 76 and lives in Swansea with her husband John. Her working life was secretarial and she also worked for British Airways on Jumbo 747s as long haul cabin crew in the 1970s. She retired at the age of 50 in 1996. Daphne was diagnosed with Raynaud's Phenomenon in 1984 and limited scleroderma in 2001. We talked to Daphne about her diagnosis and her experiences of hormone replacement therapy.

In 1992 at the age of 47, I started to have hot flushes, night sweats and mood swings. I was prescribed hormone replacement therapy in 1993 by my female doctor and when I started taking it my menopausal symptoms stopped almost immediately and I felt very fit and well. I have never had any children and was put on the appropriate combination HRT tablet, but I cannot remember the drug name.

I continued to take HRT until 2002, when the same doctor said that I should stop taking it, because there was a scare around possible links to breast cancer at the time. Despite my

saying that I wanted to continue, she said the risk was too high, and that no more prescriptions would be issued.

My menopausal symptoms returned very strongly and have continued. Stress gives me hot flushes, facial sweats and irrational short temper outbursts. I also had speech problems. I often could not complete a sentence; halfway through I would forget what I was going to say. Perhaps brain fog is the right word. I loved being on HRT, it made me feel so well and energetic. I felt very disappointed and depressed at not being able to continue on this treatment, and I always wonder how things might have been if I had carried on.

In October 1999 my brother died suddenly and in September 2000 I gave up smoking. I think that smoking attributed to my Raynaud's diagnosis. I was offered a strong cessation drug to help. This worked and I have not smoked for 22 years.

I became aware of the early symptoms of scleroderma in May 2001. We were in Spain, and one morning I was not able to lift my head off the pillow. All my joints were aching. When we were back home, I saw my doctor and asked for a rheumatology blood test. My mother had rheumatoid arthritis severely for most of her adult life, and so I thought there may be a connection. It was confirmed that I had limited scleroderma in February 2002, and I joined Scleroderma & Raynaud's UK after seeing an advert in a magazine during one of my earlier hospital appointments.



Daphne and John

I do have joint pain that is helped by medication and thickening skin, particularly on my hands which feel tight and swollen and it also affects my nail cuticles. I have a morphea area on my back which at times is extremely itchy. I still have hot flushes regularly, that occur especially if I feel stressed or frustrated by even minor things.

Acid reflux has been a big problem during the last few years despite taking Lansoprazole and in 2019 I was diagnosed with Schatzki's Ring. It was good to have this diagnosis because I thought my swallowing problems and acid reflux were perhaps linked to stress.

Raynaud's and limited scleroderma have been part of my life for over 20 years now. I feel that if I had stayed on HRT, well who knows if I would feel any different? I do feel aggrieved that I was denied the right to continue when I had to stop, but I also feel lucky that my scleroderma symptoms are mild.

Raynaud's now causes me more problems with increased cold finger spasms and loss of feeling in my feet plus leg neuropathy pain. I am not currently on medication for Raynaud's, but I need to consider it. Nifedipine gave me flushes, so I feel it's a full circle!

Daphne

"I loved being on HRT, it made me feel so well and energetic. I felt very disappointed and depressed at not being able to continue.... and I always wonder how things might have been if I had carried on."

Daphne



"I started taking the HRT in 2014. At the time, the doctors did not seem too concerned about my diagnosis of systemic sclerosis.

I had heard many people say that they had found HRT to be brilliant, so I did a lot of research myself and I found that a lot of positives came up, e.g., HRT is known to help protect against osteoporosis. I was just asked some general questions, for example, if there was a history of breast cancer in the family. I don't remember them specifically discussing systemic sclerosis.

I am not aware that the HRT has caused any negative effects at all, although I suppose you don't know what things would have been like without it."

Alison

"I was struggling through the menopause, and I initially wasn't going to try HRT.

My periods stopped but I was still feeling dreadful and emotional so I wondered if HRT would help. I have been on it for a year now and it has been fantastic. It seems to be working fine now, I am much more even-keeled emotionally.

With the HRT, I said that 'by the way I have scleroderma, is that ok?' Now that I am on the HRT (some symptoms are) better. Reflux is about the same. I do think that hormone fluctuations seem to trigger the bowel problems. Now that this is stable it seems to be better. The bowel issues were really bad during the perimenopause. I also had a DEXA bone density scan at the start of this year and was diagnosed with osteopenia, but I was told the best treatment is HRT, so I'm glad I've started it. I'd be really interested to know more about HRT and scleroderma though."

Megan

FINDING SUPPORT

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 support services that are tailored to the needs of our community. For more information on any of the services listed here, please contact us.



Helpline:
**0800
311 2756**

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.

Our publications

Did you know that you can download our full range of 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. You can download as many as you want!



Could you become a Support Group leader?

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

Our local Support Groups enable people to come together, find friendship and connect with others who are affected by Scleroderma and Raynaud's. We are always looking for new Support Group leaders to help us keep building this valuable network.

We are currently hoping to recruit someone to lead our Support Group in the **Exeter** area, as well as a leader for the **Children and Families Group** that meets over Zoom.

Wherever you are in the UK, if there is currently no Support Group close to where you live and you are interested in starting one, please contact info@sruk.co.uk for some more information. We can send you a role description and application form following your enquiry.

Medical enquiries

If you have a medical question, we can help you find the answer. Please contact info@sruk.co.uk or call us on **020 3893 5998**. We will forward your query on to a Scleroderma and Raynaud's nurse specialist and get back to you as soon as we can.

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

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.

The SRUK webinar programme

We have an exciting series of webinars taking place throughout the year, 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. Each SRUK webinar focuses on a specific aspect of living with Scleroderma and/or Raynaud's, such as GI tract involvement or living with pain and fatigue.

Each event is hosted by a member of the SRUK team. An expert speaker will deliver a detailed presentation on the relevant topic, then

participants can submit questions online and anonymously if they wish, for the host to ask the speaker on their behalf. There is no obligation to send a question, 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.

Local Support Groups

Our local Support Groups are still as active as ever and working hard to keep people connected.

Local Support Contacts	
Amersham	Marilyn York
Bedfordshire	Rita Boulton
Leicester and Leicestershire	Nicola Kelham
Lothian and Borders	Anne Hogan
Midlands	Avtar Gill
Norfolk	Lucy Reeve
Northern Ireland	Una Gillespie and Roisin Bradley
Scottish Highlands	Lorraine Jack
South London	Celia Bhinda
South West Midlands and Cotswolds	Shirley Lynch
Sussex	Linda Melton-Brooks
Wales	Enid Connick
Yorkshire	Chris O'Hora

SRUK CHRISTMAS APPEAL

By making a gift to SRUK this winter, you can help us keep on working to improve care and treatment for people living with Scleroderma and Raynaud's.

For many people with Scleroderma and Raynaud's, the winter months will bring further discomfort and difficulties to everyday life.

That's why it is so important that SRUK is here to help everyone affected by these conditions all year round. We can achieve this together; and your donations are vital to ensure we can continue our work.

SRUK are working hard to achieve real change through the information and support we offer, and the research we are funding. Over our 30-year history we have invested more than £12 million into research for new treatments and therapies.



Georgina's story

Georgina, 37, first noticed the early symptoms of scleroderma aged 25. Despite visiting her GP on several occasions, she was eventually diagnosed with systemic sclerosis and interstitial lung disease (SSc-ILD) during a trip to Poland in 2012.

"Scleroderma is an incredibly complicated condition, and I can honestly say it has affected every part of my life. I went from being a healthy young woman, to suddenly being surrounded by doctors and given lifesaving treatment as my lungs were taken over by fibrosis.

I was asked if I'd be willing to take part in a research trial, and I didn't think twice about saying yes. I've always been extremely passionate about the importance of research and if quality of life could be improved through more research projects, then it's definitely vital!"

Dr Nina Goldman's story

Last year Dr Nina Goldman was awarded a Clinical Research Training Fellowship that is co-funded by SRUK. Her research aims to provide doctors with the most effective treatment for individual patients with lung fibrosis (scarring of the lung), secondary to scleroderma. This is vital following a diagnosis of lung fibrosis, to help improve prognosis for patients and help maintain quality of life.



"Quality of life in cases of SSc-ILD is often compromised, and my research means that we can try to improve this moving forwards.

I love knowing that I'm making an active difference: you can see treatments working, and I get to work out how! We have already had participants feeling better whilst on the trial, which is exactly what we are aiming for - working to make outcomes better.

I want to say a huge thank you to the SRUK community who are co-funding my fellowship. I'm extremely grateful for the support you give to SRUK which allows me to do my work."

Research projects we currently fund include:

- The development of a new peptide treatment to tackle fibrosis.
- The development of an oral care pathway to improve oral and dental outcomes.
- Using micro-needle skin patches to monitor how secondary Raynaud's progresses to scleroderma, decreasing time taken for a diagnosis.

Please would you consider making a gift this Christmas and help us continue to fund vital and ground-breaking research.

How your gift can help:

£15

could provide a lifeline to someone in need by making sure our trained helpline volunteers are there to answer their call.

£30

enables us to host six users on our Raynaud's symptom's tracking app for a month, feeding directly into essential scientific research.

£50

could fund a PHD student for a day on one of our research projects.

Donate online: sruk.co.uk/donate, call **020 3893 5998** or send a cheque using the Donation Form and return to the Freepost address provided.

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FUNDRAISING HEROES

SHINING THE SPOTLIGHT
ON SOME OF OUR FANTASTIC
SUPPORTERS!

THANK YOU!

We're so lucky to have had so many amazing people take on runs and challenges across the UK over the last few months. We're very grateful to everyone for putting in all those training hours, as well as for your incredible fundraising for SRUK!



Nimesh and Loveleen, took on the Inflatable 5k in Warwickshire with two of their children and two other family members, to raise money in memory of Jasbir Kainth. They smashed their target and have raised **£2,002!**



A huge
Congratulations to
Philip Beckett - whom we've featured in this magazine several times. He's reached his **£50,000** fundraising target in memory of his daughter Lauren. Philip has worked tirelessly to raise vital funds and awareness through cycling, running, holding quizzes and even masquerade balls! He hasn't stopped though and we can't thank him enough for his incredible efforts!



Alexander Patrick bravely let his supporters decide on how to cut and style his long hair to raise funds for us, and rainbow mohawk it was! He's raised **£1,140** too.

Mike Whiting completed his 125th half marathon by running The Great North Run, in memory of his twin brother Stephen, who he's run many events with over the years. He's raised an amazing **£1,897** and also managed to achieve some local publicity to help raise awareness.



Katie Cray ran her first ever half marathon in memory of her Mum, Leigh. She's raised **£710** so far - and is still fundraising!

Mike Faulkner has been taking on cycling challenges in memory of his sister Lynne Geddis. He completed the off-road London to Brighton Cycle in September and has raised **£1,470** so far.

£

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 2022!

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.

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.

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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.

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