

SRUK NEWS

Childhood Scleroderma:
symptoms,
treatment and
prognosis

**Growing up
with juvenile
scleroderma:**
Alison's story

COVID-19:
Do you feel safe now?

STAR is here!
All about the
Raynaud's App and
how to use it!



Sunflowers for Scleroderma:
Help us plant the seeds of change

FUNDRAISING UPDATE



JUNE IS SCLERODERMA AWARENESS MONTH!

Scleroderma Awareness Month takes place in June every year. This is SRUK's own initiative to highlight the signs of scleroderma, as well as who may be at risk and how SRUK can help.

This year, we need your support more than ever. If you have a story that you would like to share, please let us know. You can also help us by following us on social media and sharing our posts to spread the message even further.

This year, we are also inviting our community to join us and **Take Steps for SRUK**, to raise awareness of the condition and its impact. For more information, please see page 24

"Scleroderma is incurable at present but with timely and proper support, life quality can be enhanced, and life expectancy significantly extended." Una

For more information, please call 020 3893 5998 or email info@sruk.co.uk



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.

Fundraising news

There are now even more ways to get involved and help us continue our work: you can fundraise from home, host a virtual event or take part in one of the many challenge events taking place across the UK throughout the year.

Registration is now fully open, and we are ready and waiting to welcome you to **#TeamSRUK**.

For more information on all the opportunities available and to secure your place, please visit sruk.co.uk/get-involved/events/

Get your free fundraising pack

If you are interested in fundraising for us or you would just like some more information, our free fundraising pack has everything you need! Please email fundraising@sruk.co.uk or call **020 3893**

5993. Whatever you would like to do, we are here to support you every step of the way.



EVENTS CALENDAR 2022

Edinburgh Half Marathon	29 May 2022
Scleroderma Awareness Month	June 2022
Nightrider London	11 June/12 June 2022
Hull Half Marathon	12 June 2022
Goodwood Motor Circuit 10K	2 July 2022 (TBC)
Inflatable 5K Various Locations	Various dates in July and August
Barry Island 10K	7 August 2022
London Marathon	2 October 2022
Royal Parks Half Marathon	9 October 2022

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

We are delighted that spring has finally arrived, and with our team now returning to our London office, we are very grateful for the opportunity to work together in person once again.

As ever we have had a busy few months, and we are delighted that the new SRUK Children and Families Support Group is now up and running. The Group meets regularly using Zoom and is designed to provide information and support to the parents and carers of affected children and young people. For more information, please turn to page 18.

We are also thrilled to announce the launch of STAR (formerly known as the Raynaud's App), that is now available to download. The App is designed to help you track your symptoms and identify any triggers whilst contributing to further research into Raynaud's Phenomenon. The App was released in time for Raynaud's Awareness Month in February, and you can read more about the story so far on page 7.

With the rules relating to the spread of COVID-19 now relaxed, we know that many of our community remain at an increased risk of serious complications from the virus. Antivirals are now being offered to those most at risk, and subject to certain criteria, lateral flow tests are still available free of charge to some vulnerable groups.

Many of you will by now have received your spring booster dose of the COVID-19 vaccine, and we will continue to provide the most up-to-date information as the situation moves forward. If you do have any queries or difficulties surrounding testing or the vaccine, do please let us know.

With gardening season now well and truly upon us, we are asking our community and their families to help us sow the seeds of change and plant a **Sunflower for Scleroderma**, with the aim of increasing awareness of this condition and its impact. We would love to see your photos during the coming months and will share the team's efforts via our social media platforms.

Thank you all so much for your continued support. We are looking forward to a busy summer with a number of challenge events in the pipeline, and our wonderful network of Support Groups are as active as ever. If you would like more information on the many ways that you can get involved with SRUK and be a part of what we do, please contact us. I am very much hoping that we will have the opportunity to meet some of you in person again in the not-too-distant-future.

With very best wishes,

Sue

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DOC SPOT

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



Q Is there a recommended way to manage the pain of a Raynaud's attack for a child (aged 10)? Ideally something that could be given or done in advance, before being exposed to the cold?

A Raynaud's can develop at any age, but fortunately most cases are "primary Raynaud's," without any associated serious medical condition. In children, there is often a family history. Prevention of symptoms is the best approach – so it is important to keep warm, especially by wearing layers. Symptoms are often triggered when the body's core temperature falls, rather than from simply having the hands exposed to the cold. I generally try to avoid prescribing medication in children and would explore vitamins and supplements as with all patients – vitamin C, or fish oil supplements for example are safe and have been reported to help.

Q I have increasing breathlessness, and my consultant wants me to start cyclophosphamide which would be given intravenously. I understand this is a cancer drug so I am nervous about trying it, could there be an alternative?

A There are many causes for breathlessness in systemic sclerosis. These may include lung fibrosis, pulmonary hypertension, heart involvement, or anemia. I am sure that your consultant has investigated the cause and if cyclophosphamide is being recommended it may be that you have lung fibrosis that has progressed. Cyclophosphamide is a very effective approach for some cases and although it is given in high doses to treat some cancers, the doses used in rheumatology and systemic sclerosis are much lower. There are other treatments available, but they may have been considered and found not to be suitable.

Nintedanib is a new tablet therapy for progressive lung fibrosis in systemic sclerosis and can be given in addition to immunosuppressive drugs. You may wish to discuss this with your clinical team.

Q I have a pelvic prolapse and the specialist nurse thinks that it could be part of my scleroderma. Does this sound correct, and if so, am I at risk of more problems in the future? I had two natural deliveries and then no real issues until now.

A Although systemic sclerosis is generally associated with thickening or scarring of connective tissue in the skin and some internal organs, it may also lead to weakening of connective tissue at the later stages of the disease. One consequence can be an increased risk of pelvic prolapse although this is probably not actually caused by scleroderma. When this occurs it is important to consider treatment options including surgery, but this is a very specialised area and can be complicated by the slow healing and increased risk of post-operative complications that is reported for some people living with systemic sclerosis.

Q I have patches of redness appearing on my arms and legs, which seem to be worsening. I think this may be part of the condition, but can anything be done to help?

A Skin changes are common in systemic sclerosis and can include alteration in the superficial blood vessels. Red spots can be caused by dilated blood vessels (telangiectasia) and the rashes could reflect associated blood vessel or circulatory changes. Some patients have overlap with other connective tissue disease such as dermatomyositis, lupus (SLE), or antiphospholipid syndrome.

I suggest discussing with your family doctor or hospital team, as a dermatology opinion might be required.

Q I am a 53-year-old female and I have a urethral stricture. I have Raynaud's and I have now been referred to the rheumatologist as I have many other symptoms. I would like more information on the bladder issues please: is there a connection to autoimmune disease, and can anything be done to help in the longer term?

A Raynaud's is a common symptom, that affects up to one-in-ten otherwise healthy people, so it could be a coincidence and not related to the urethral stricture. However, if you have other symptoms, it is sensible to look for any associated rheumatic disease, as Raynaud's can sometimes be an early symptom of connective tissue disease and it is important to diagnose this early so that treatment can be considered.

Q I have had secondary Raynaud's for 21 years along with systemic sclerosis. My index finger has been extremely painful for some time and three months ago my rheumatologist prescribed sildenafil (150mg per day), which doesn't appear to have stemmed the pain. I was also offered at the same time an MRI of my hands if things didn't improve. This finger is now useless, and I am trying to function without it. Lately, the throbbing and additional pain increases when laying down. Would you be able to confirm if this is normal or would you be able to advise?

A Finger and hand problems are very frequent in systemic sclerosis. This includes poor circulation due to Raynaud's that can lead to skin breakdown and tissue damage. Associated infection or inflammation may occur. Sildenafil is an excellent treatment for secondary Raynaud's and can help treat digital ulcers but does not directly treat pain. Other drugs for the circulation or to help with pain may be necessary and you should discuss this with your specialist. In addition, other causes for the pain such as infection or arthritis can be assessed and treated. An MRI scan can help to find the cause of the pain and diagnose inflammation or infection.

Q From approximately 2001 until two or three years ago, I had annual tests and subsequent consultations with the rheumatologist at my local hospital, due to a diagnosis of CREST/limited scleroderma. On my last visit, I was informed my blood test had come back negative and I was discharged. However, I still had – and still have – the symptoms (luckily mild – Raynaud's and reflux), and I continue to take medication for these. What I've been confused about is, does being discharged mean I no longer have the disease, even though I still have the symptoms? Also, can a single blood test determine if the condition has gone for good?

SKIN CHANGES ARE COMMON IN SYSTEMIC SCLEROSIS AND CAN INCLUDE ALTERATION IN THE SUPERFICIAL BLOOD VESSELS. RED SPOTS CAN BE CAUSED BY DILATED BLOOD VESSELS (TELANGIECTASIA) AND THE RASHES COULD REFLECT ASSOCIATED BLOOD VESSEL OR CIRCULATORY CHANGES.

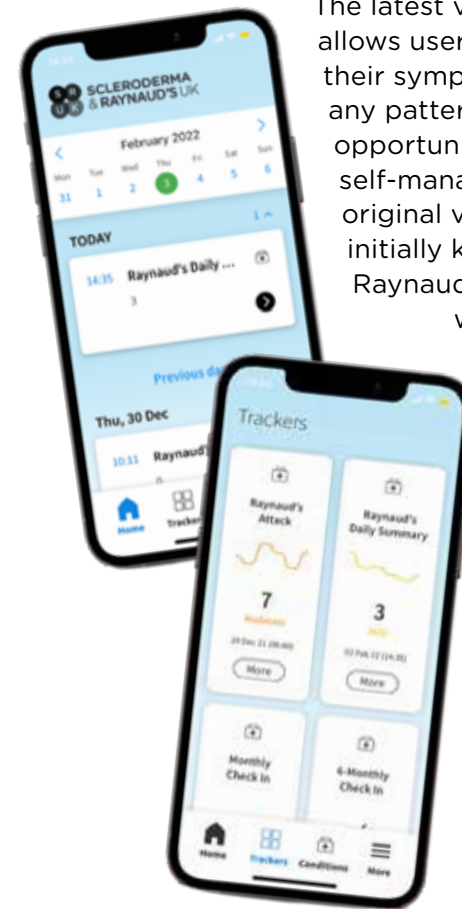
A Fortunately, many cases of limited cutaneous systemic sclerosis (also called CREST in some countries as an abbreviation for some key features of calcinosis, Raynaud's, oesophageal dysmotility, sclerodactyly and telangiectasia), are mild, but it is still recommended to have regular reviews and monitoring of lung and heart function in case more treatment is needed. Sometimes blood tests change over time, but it is unusual for a diagnostic blood test such as antinuclear antibody to become completely negative and even if that was the case, it does not mean that a connective tissue disease is resolved. I suggest discussing with your GP and perhaps ask for referral back to rheumatology if appropriate.

Q I have been diagnosed with CREST syndrome and am trying to find out whether it is safe to take a bovine-based collagen supplement to help with joint issues. I have been unable to find any guidance and wondered whether you might be able to point me in the right direction?

A There is no evidence that bovine collagen supplement is harmful in systemic sclerosis and so you could try this, although I am not aware of convincing evidence that this supplement would be beneficial in any way for your medical condition. If patients wish to try supplements that are otherwise safe, I generally suggest taking them for at least six weeks and if benefit is not obvious then perhaps discontinue and monitor symptoms. You should make sure you inform your clinical team about any supplements you take, as some can interfere with prescription medicines.

FREEZING FEBRUARY: THE LAUNCH OF STAR

This January, SRUK launched the Symptom Tracking App for Raynaud's - STAR for short! The app is designed to track a person's Raynaud's attacks and symptoms. It has the dual purpose of helping to increase an individual's awareness of their Raynaud's by linking triggers to attacks, whilst also contributing to academic research focused on Raynaud's.



The latest version of STAR allows users to track their symptoms, identify any patterns and create opportunities for better self-management. The original version that was initially known as the Raynaud's ResearchApp was significantly more limited, containing only six trackers that focused on the severity and duration of a person's Raynaud's attacks. This version was tested by a small cohort of people living with Raynaud's, and, based on their feedback, a new specification was developed to revamp it!

Leading the updates and upgrades of the original app were members of the SRUK community, alongside clinical rheumatologists researching Raynaud's. Over a six-month period, they worked closely with us to prioritise the data that should be recorded by the app, in order to help form a deeper understanding of Raynaud's on both a personal and population level.

If you would like to try using STAR to track your own Raynaud's symptoms, please visit sruk.co.uk/research

STAR now houses over 20 trackers, to enable a user to track not just the severity of their Raynaud's attacks, but additional

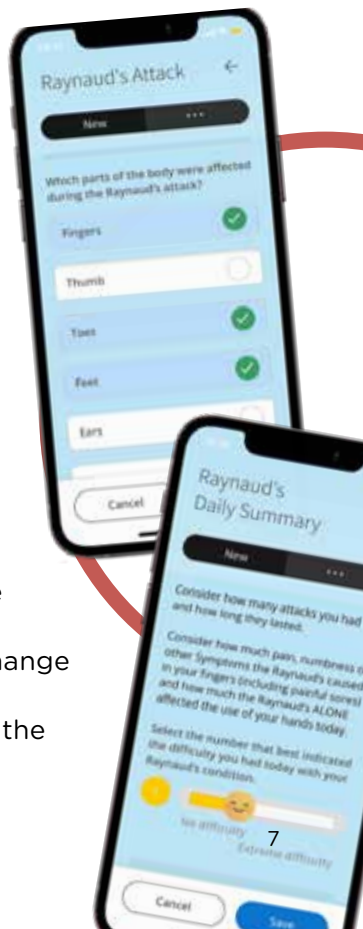
details such as colour change experienced in the affected areas, contributing factors such as exercise, caffeine intake or smoking, and any related conditions and medications that may be relevant. Collecting more granular information allows each user to better identify events that may be triggering their Raynaud's and will also facilitate more in-depth research on Raynaud's by clinicians and scientists in the field.

February findings

Now that STAR is up and running, we wanted to tell you a little bit about what we learnt from our users this February!

Across the month, 272 Raynaud's attacks were recorded by 87 of our active users. These are people who may have primary Raynaud's, secondary Raynaud's, or scleroderma, therefore the average experience of each user varies significantly. Within STAR, as well as asking individuals to report whether they have experienced a Raynaud's attack or not, we also collect additional details to give these experiences some context.

Firstly, we examined what was causing people to experience Raynaud's attacks. STAR lists a range of triggers, and individuals can select one or more for each attack that they have. The five factors listed below were the most-reported during February, as being either the full or partial trigger for an attack. For many people, their Raynaud's symptoms could be caused by multiple triggers, an example of which is how change in temperature was frequently reported alongside cold air as the cause of an attack.

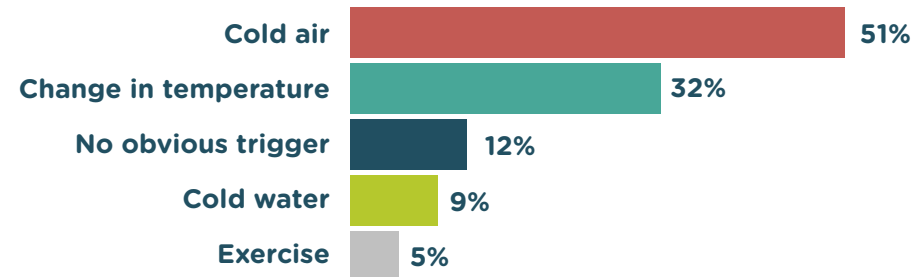


If you have a question you would like to ask Professor Denton, or you would like to comment on any of the answers given, please email info@sruk.co.uk

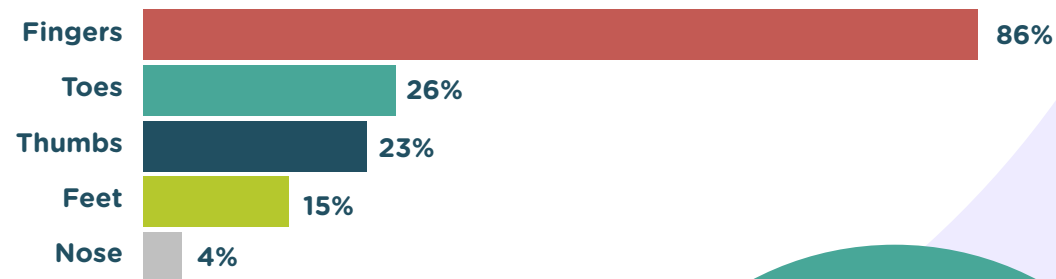
You can also connect with us on Twitter, Instagram and Facebook. /WeAreSRUK



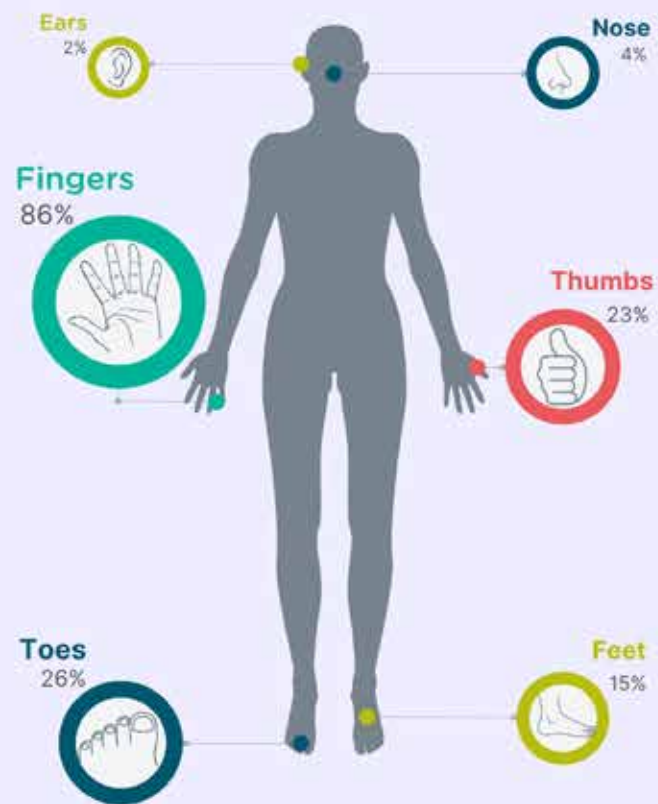
February's biggest triggers



Body parts most affected



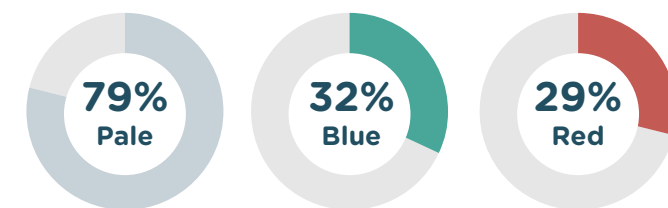
STAR has been designed in conversation with people with Raynaud's, for people with Raynaud's.



When asked about the body parts affected when a Raynaud's attack occurs, it was not a surprise that over 80% of STAR users reported attacks that included the fingers. Thumbs were included in just under one-quarter of the attacks affecting the hand; and were not seen to be impacted without the fingers also being involved. Experiencing Raynaud's in the feet and toes was less common when compared to the hand, however over one-quarter of the attacks reported did involve the toes.

When we explored this a little bit further, we found that out of all the Raynaud's attacks reported in February, 11% of these affected only the feet and/or the toes, with no involvement of the fingers, the hands, or the rest of the body.

Lastly, we examined the colour changes to the skin that STAR users reported during their Raynaud's attacks. By far the most common change was to 'pale', which nearly 80% of people experienced. This discolouration is almost always the first symptom of a Raynaud's attack. It occurs due to a lack of blood in the capillary network of the affected area and will last for the duration of the attack. Where changes to blue or red skin were experienced, they were often in combination with pale, however some individuals did experience these colour changes in isolation. When the skin changes to blue, this is the result of deoxygenation of that tissue, with red skin occurring in the 'rewarming' stage of a Raynaud's attack, as the blood vessels widen and blood flow returns.



If you are living with Raynaud's, these findings have probably not surprised you. STAR is designed to collect typical, day-to-day data from members of our community, both for personal use, and also to test out the app's capacity to support research.

To best understand STAR's utility in a research setting, SRUK are working alongside Professor Francesco Del Galdo from the University of Leeds, who will be using STAR within his existing

research study: STRIKE (stratification for risk of progression in scleroderma). As a study, STRIKE is aiming over the course of five years to develop a screening tool which will allow patients at risk of developing severe scleroderma to be identified, and their disease progression more accurately predicted. The participants within STRIKE who are using STAR either have risk factors associated with the development of scleroderma or have already been diagnosed with the condition.

STAR will be used to facilitate the daily monitoring of each STRIKE participant's Raynaud's symptoms, in order to compare them with related values measured in clinic as part of the study.

On a more individual note, SRUK are delighted to see that STAR is being used by our community to enable conversations with their healthcare professionals and GPs about their experience with Raynaud's. One STAR user emailed in to tell us:

"Once again, thank you for allowing me on to the study. My GP has never prescribed me any medication for my Raynaud's, stating that previous patients had reported unpleasant side effects so that he won't prescribe any for me (and presumably other patients). This is sad and I don't know enough to challenge him. However, with the help of this app, at least I will have the evidence to one day go to him and show how Raynaud's is affecting me on a daily basis - perhaps persuading him to look for a medication to help."

STAR has been designed in conversation with people with Raynaud's, for people with Raynaud's. SRUK are pleased to see it improving people's own ability to self-manage their Raynaud's and support their self-advocacy within a healthcare setting.

If you have been inspired to use STAR to track your Raynaud's symptoms, please visit sruk.co.uk/research/ to complete the form on the STAR Research App page. Once you have submitted your name and email address, we will contact you with your log in details and you can get started supporting the latest research into Raynaud's!



SRUK SHOP

The SRUK Shop is always open, so please visit us at srukshop.co.uk to see our complete range. Our products have been specially selected to help keep you warm and comfortable through the winter and all year round.

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



Silver Gloves

These gloves are seam free, flexible and will allow you to operate your mobile device and visit a cash point without having to remove them. Made using 12% silver thread woven on the inside, they have light stretch for improved fit and have been designed to accommodate swollen fingers.

Available in 12%, black.

Available in XS, S/M, L/XL

12% = £23.50



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. Warm up your toes and feet with these warmers designed especially for those chilly days or evenings, or if you are standing on cold ground for a long time.

£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
12% Gloves (XS or S-M or L/XL)	£23.50			Black
Other Products	Cost	Qty	Size	Colour
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			

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

COVID-19: DO YOU FEEL SAFE NOW?

In February the rules relating to COVID-19 changed in England, and at the time of publication, most of the restrictions, such as self-isolation and the use of face masks, have been removed.

Rules and behaviour may have changed but the virus is still out there, with new cases continuing to emerge and the prospect of new variants rarely out of the news. So, what do these changes mean for the many people within our community and beyond, who may be at a greater risk of serious illness from COVID-19? Can life really get back to normal?

According to data from the Office for National Statistics, there were 3.7 million clinically extremely vulnerable people (CEVs) in England in May 2021. Of these, around 2.2 million were on the shielded patient list. After shielding was paused on 1 April 2021, ONS data suggests that over 40% of the CEV community effectively continued to do so.*

Today, the advice for CEVs is the same as for the rest of the population, with no separate guidance currently in place. The rationale is that many people who were previously considered CEV are now well-protected from the virus, thanks to the vaccine programme. It is still acknowledged however that there are some people who are still at risk of serious illness from

COVID-19, for example, due to having certain conditions or because they are immunosuppressed. We are aware that many members of our own community are within this group.

“I do not come under the immunocompromised ... but I have always been mentally compromised by COVID. I can see it is very worrying for the ones who are.”

The vaccination programme

The evidence continues to indicate that vaccination provides the best protection against serious illness from COVID-19. In England, people over 75 as well as anyone over the age of 12 who are immunosuppressed can now book a spring booster jab for maximum protection. For the most vulnerable, this is likely to be the fifth dose.

Last year, we became concerned that some vaccines were not being properly classified, after hearing reports that some members of our own community may have struggled to access their third primary vaccination, with some believing that they were actually given a booster jab instead of the third dose that they were entitled to.

Whatever your situation, if something does not feel quite right, or if you have any concerns surrounding accessing the vaccine, do not be afraid to speak up.

Staying safe

As society's behaviour changes to try and 'get back to normal', there is concern that the continued risk to certain vulnerable groups could be forgotten. SRUK recently came together with a group of charities in signing an open letter to evidence that many people do not appreciate the risk that COVID-19 still poses to many vulnerable people. We also highlighted the need to take necessary measures to protect vulnerable employees as people return to work. If you are returning to the workplace, talk to your employer about your working arrangements and any adjustments that would help you stay safe.

Although free COVID-19 tests are no longer available to the general public, this is not necessarily the case for those at higher risk. At the time of writing, lateral flow test kits are still being provided free of charge to eligible groups who are at an increased risk from this virus.

Many people originally classed as CEV have now received a priority PCR test kit, to be used as soon as symptoms develop, with the aim of enabling faster access to antiviral treatments when indicated. These are targeted treatments being offered to the people who are most at risk from severe illness or death from COVID-19 infection. If you test positive, call 111 and ask for advice. When indicated, an assessment can be arranged. Please visit [gov.uk/order-coronavirus-rapid-lateral-flow-tests](https://www.gov.uk/order-coronavirus-rapid-lateral-flow-tests) for more information.

Lageviro (or Molunpiravir), is an oral antiviral given in tablet form twice daily. It works by introducing mistakes into the virus's genetic code which ultimately kill it. Lageviro reduces the risk of hospitalisation or mortality in at-risk adults by at least 30%.

Ronapreve is another drug that can be given to people most at risk via intravenous drip in hospitals, and can reduce the risk of hospitalisation or death by 70%. It uses monoclonal antibodies to target the COVID-19 virus, preventing it from entering body cells and therefore minimising the damage it can cause.

Everyone is different, and your individual comfort level will be unique, and dependent on many different factors, including your diagnosis and the effects of treatment. If you would still prefer to take extra precautions to

help you stay as safe as possible, the following may be helpful as a starting point:

- Consider whether you and those you are meeting have been vaccinated – you might want to wait until 14 days after everyone's most recent dose of a COVID-19 vaccine before being in close contact.
- Do not be afraid to ask if the people you are meeting have had their vaccines.
- Continue to practice social distancing if this feels comfortable for you.
- You can ask people from outside your household to take a rapid lateral flow test before coming into contact with you. These are still available free of charge if certain eligibility criteria are met.
- Continue to wear a face covering in enclosed spaces, if this feels more comfortable.
- You may feel safer if you avoid indoor, crowded spaces. Consider also visiting at quieter times, the venue should be able to advise you of when they are usually less busy. In addition, Google often gives the busiest and quieter times of shops and other venues.

*Source: ons.gov.uk

“I'm advised by my rheumatology team to maintain quite strict restrictions ... Try to only meet people outside, don't meet anyone who hasn't been vaccinated, don't go into crowded public places...”

“I am immunosuppressed and have spent the last two years being extremely careful.”

JUVENILE SCLERODERMA

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

Dr Pain is a paediatric rheumatologist at Alder Hey Children's NHS Trust. She is also an NHS researcher who has led multi-centre and international work into rare conditions including scleroderma, with the aim of improving care and outcomes for affected children.



Dr Clare Pain

Scleroderma is an autoimmune condition, meaning that the immune system is overactive, causing it to attack healthy tissues within the body. Although scleroderma occurs more commonly in adults it can affect anyone at any age; and will sometimes present during childhood.

There are two types of scleroderma:

- **Localised scleroderma (also known as morphoea)**
Localised scleroderma primarily affects the skin, but can also affect soft tissue, muscle, and bone. In children, it may affect the growth and shape of limbs and the face. In rare cases it may affect the joints, the eyes, or, more rarely, the brain. Localised scleroderma is by far the most common form of scleroderma in children, accounting for over 90% of all juvenile cases. It is not thought to overlap with systemic sclerosis (SSc).

- **Systemic scleroderma, (SSc), also known as systemic sclerosis**

Juvenile systemic sclerosis (SSc) is a serious and extremely rare condition. It is the more severe form of scleroderma that can affect other parts of the body as well as the skin.

SSc is usually characterised by Raynaud's (explained below), and thickened skin; and it may also affect the internal organs such as the lungs, the digestive system or the heart. The disease may progress over several years and requires careful monitoring to identify any changes.

As with many autoimmune conditions, scleroderma is more prevalent in girls and although the initial onset may occur at any age, it rarely presents in children under the age of two.

Causes

The cause of scleroderma remains unknown. No clear inheritance pattern has been identified, although we do know of multiple cases occurring within the same family, and some people report a family history of other autoimmune conditions. This suggests that whilst no specific 'scleroderma gene' has been identified, there may sometimes be a genetic predisposition. In many cases however there is probably no single cause, but rather a combination of circumstances that could help to 'trigger' the condition in some people with a genetic predisposition, such as a viral infection, an injury, or certain environmental factors.

What we do know is that more research is needed to determine the true extent of the relationship between genetics and developing scleroderma.

Living with localised scleroderma

Localised scleroderma affects the skin, leading to patches of thick, hardened skin developing upon the face and body that may become discoloured and feel tight, itchy and uncomfortable. In some cases, the condition may spread to the tissues beneath the skin, such as fat, muscle and bone. This can affect a child's growth in that area, for example an affected limb may not develop properly, leading to asymmetry. When thickened skin develops over a joint such as the fingers, wrists, or knees, it may become fixed and 'stuck down.' This can restrict movement and affect the child's motor skills.

The condition may also affect the head and the neck, altering skin texture or leading to a groove developing in a vertical line, rising up the forehead into the hairline. It may also involve the cheek, the chin, or the side of the neck. When this occurs, it may change the shape of the face and cause other complications including hair loss, eye and dental problems and even neurological complications such as migraine and epilepsy, although this is very rare.

Living with systemic sclerosis

SSc is considered a broad-spectrum condition, that affects different people in different ways, with no two cases ever identical. An affected child may therefore experience some of following, although for many children, the disease will be mild.

Skin tightness and digital ulcers

In systemic sclerosis the skin is also likely to be affected, leading to skin tightness and

discomfort. This often occurs around the fingers and toes, where it may eventually cause a break in the skin, called a digital ulcer. If an ulcer does develop, it is vital to see a health professional for advice and care, because ulcers can easily become infected and will require treatment with antibiotics. Digital ulcers can take a long time to heal and are known for being painful. They may therefore have a considerable impact upon hand function and what the young person is able to do.

Raynaud's Phenomenon

Most people who are living with SSc will be affected by Raynaud's. In children, this may be one of the first symptoms that parents or the child will notice.

Localised scleroderma accounts for over 90% of cases of childhood scleroderma. Systemic sclerosis in children is extremely rare.

Raynaud's is usually an exaggerated response to changes in temperature and exposure to the cold. The small blood vessels in the extremities such as the fingers and toes suddenly become narrower as blood is redirected to the body's core and the vital organs. This may lead to numbness as the extremities have reduced blood flow, turning to pain as circulation returns. There may also be a noticeable colour change in the hands and feet, from white to

blue as blood flow is restricted and the area loses oxygen, and then to red as the circulation eventually resumes.

There are two types of Raynaud's Phenomenon: primary and secondary. Primary Raynaud's is actually very common, and in its milder forms is thought to affect around 10 million people in the UK alone. Primary Raynaud's occurs on its own, meaning there is no underlying condition that causes it to develop.

Secondary Raynaud's accounts for only 10% of all cases, and is considered more serious, because it is usually part of an underlying autoimmune condition, such as SSc. It is thought that secondary Raynaud's is caused by damage to the blood vessels that occurs because of this associated condition.

Raynaud's can be painful and debilitating and may have a considerable impact upon everyday activities. Pain and numbness from an attack can affect the motor skills, that may in turn impact upon aspects such as handwriting and PE at school, as well as mobility and simply getting around. Everyone is different, and so it is important that schools work alongside families to put in place appropriate solutions so that the child can participate as fully as possible.

Pain

Pain may be a part of living with SSc that affects both school and home life. Always talk to your medical team because chronic pain can have a considerable impact upon a young person, and they can help to work out what is causing the pain and how best to manage it.

Heart and lung involvement

If the condition is affecting the child's heart or lungs, they may experience breathlessness and palpitations, and they may also feel tired easily. Organ involvement may progress over time, however treatment can be given to slow down, halt or in some cases improve this process.

Gastrointestinal (GI) tract involvement

SSc can affect any part of the gastrointestinal tract, from the mouth to the anus. GI tract involvement is thought to affect up to 90% of people with SSc at some point in their lives. Early signs include reflux and heartburn, bloating and changes in bowel habit; however people may also experience difficulty swallowing, constipation, pain, diarrhoea and even incontinence, depending on which part of the GI tract is involved.

Fatigue

Because the immune system is overactive, children may experience extreme tiredness (fatigue).

Managing juvenile scleroderma

Following a diagnosis of scleroderma, a child or young person will be seen regularly by a specialist team that will include their consultant and possibly specialist nurses, physiotherapists, occupational therapists and/or psychologists, depending on how they are affected. There is no cure, but treatment can be given to control the symptoms, and will be tailored to the child according to how their condition affects them. For some children with localised scleroderma the disease will eventually go into remission.

It is vital to monitor disease progression, because early detection and treatment often lead to better outcomes. In systemic sclerosis, regular testing should form part of the management plan, to assess the body's internal organs. The results can be compared to previous tests to identify any changes, since a decline could indicate that the condition is progressing, and that treatment should be increased.

Medication side effects

All medicines can have side effects, and children may be dealing with these in addition to their symptoms. Common medications could lead to a range of side effects including tiredness and nausea, and it is important to mention any changes to your medical team.

Weakened immune system

Some treatments work by reducing the activity of the immune system, so that in some cases, children may become more susceptible to infections as a result. Your medical team will provide you with information about the medications, and whether your child requires COVID-19 and flu vaccines.

Emotional wellbeing

Scleroderma is a complex condition that affects everyone differently. There is no one-size-fits-all approach to scleroderma care, and the needs of an individual child will depend on how their condition affects them, and to what extent.

Living with a long-term condition may cause a child to experience anxiety for many different reasons. They may worry about getting worse and their future, or they may be anxious and distressed if

they feel they look different. Sometimes children may feel worried before their treatment is due: if they are worried about taking it or the side effects.

It is therefore crucial that children have the right level of care and support for their mental wellbeing, alongside the medical management of the disease itself. Psychological support may be needed for some children, and it is important to discuss this with your medical team.

School and college life

Every school or educational setting should have a policy that outlines its approach to students with medical needs. This should be accessible to staff, parents and carers.

By law, schools are required to ensure that having a condition such as scleroderma does not put a child at a disadvantage when it comes to their education. Therefore, if there are any reasonable adjustments that would make it easier for your child to fulfil their potential at school, you have the right to ask for them.

Every child with Scleroderma and/or Raynaud's is affected differently, so the needs of the individual will vary greatly. If you do need to speak to the school or college about making some adjustments to accommodate a chronic condition, it may be useful to think about the following as a starting point:

Individual Healthcare Plans

You can request an Individual Healthcare Plan for your child at school. This should include details of their diagnosis, how it affects them and any reasonable adjustments the school should make.

Writing and other fine motor skills

If writing and drawing are difficult, having a laptop in class or being allowed to use a special pen or pencil grips may help. An occupational therapist will be able to give tailored advice.

Toilet pass

If a child or young person has gastrointestinal involvement, they may need to use the toilet more often, and may benefit from a toilet pass that allows them to leave class when necessary.

Time out card

Some schools and colleges will issue a 'time out card', to allow students to leave class if needed. If the child is affected by fatigue or by anxiety around their condition or their symptoms, it may be worth exploring this.

Additional or extended breaks

If a child with Raynaud's is coming in from the cold, it may take a little time for their fine motor skills to warm up

in class. For some children, fatigue or treatment side effects may also mean that they need rest times during the school day.

Keeping warm

When it comes to Raynaud's, prevention is better than cure. Allowing a child or young person to wear base layers or to keep their coat on, and seating them away from draughts and near to a radiator can help keep symptoms under control.

Uniform rules

As well as keeping warm, a relaxation of uniform rules may help a child's confidence if they want to cover up affected areas of skin.

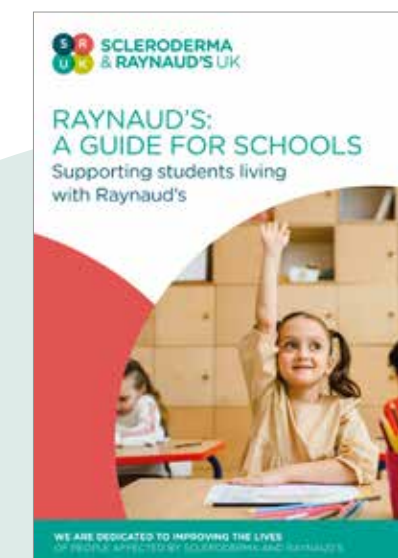
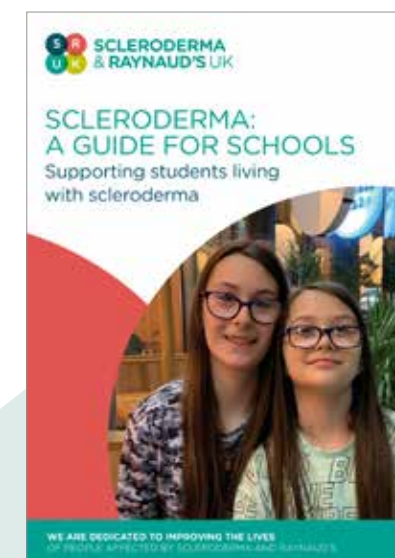
Hair and makeup

Any condition that affects their appearance can have a dramatic effect upon a young person's self-confidence. If they would benefit from a relaxation of the usual rules surrounding hairstyles and makeup at school, do not be afraid to ask.

Parenting and caring

When a child is diagnosed with scleroderma, this is likely to affect the whole family. For parents and carers this impact is often considerable and multi-layered, as you have to digest the information, navigate education, deal with appointments and make treatment decisions. It is therefore crucial to acknowledge these aspects and the inevitable impact upon your own life, your other relationships and responsibilities, and to ensure that you have support when you need it.

Many parents and families have reported peer support to be very helpful. SRUK has recently launched a new Children and Families Support Group, that meets regularly over Zoom to enable all parents and carers to find support and share information with one another. The group is led by Alison, who has two daughters who are living with localised scleroderma. You can read Alison's story on page 18.



We have recently produced two new information booklets for schools, to help them understand the impact of Scleroderma and Raynaud's and offer support to affected children and families. For a free copy, please call us or visit sruk.co.uk/publications/



Eliza has what I would class as generalised morphea, with multiple patches of discoloured, thickened skin around her body. When she was first diagnosed, she had to miss quite a few school days to attend appointments and because of treatment side effects, but now she typically misses just one day every three months to see her consultant. Eliza also initially struggled with her medication, as she was given methotrexate which made her feel really unwell and tired. Now she has changed to a drug that agrees with her more.

We do still have some issues with Eleanor, who often refuses her medication and misbehaves in the lead up to taking it. Her patches are much smaller and mainly appear on her ankles, legs, torso and arms. Eleanor was diagnosed with autism in 2021, and she also has sensory processing disorder. She has been attending the medical day care ward at the hospital for her blood tests, following a recommendation from a psychologist at Sheffield Children's Hospital and this has made things better.

“(Scleroderma) is so rare that not many families have experience of it, but there are other people out there who understand what you are going through. I feel it is crucial to know that you are not alone in this journey, and I want to help provide that support.”

Compared to many other cases of childhood scleroderma, the girls haven't really been too badly affected. They often feel tired because it is an autoimmune disease, and Eliza has started to complain more about pain travelling from her hips, down her thighs and into her knees. But for both the girls, the condition itself rarely stops them from doing anything.

It has been aspects like the medication and travelling to hospital appointments that have caused the main issues.

As their mother and their main carer, it has usually always been me that has taken the girls to their appointments. For us, I feel that this works well; I know them, I know their skin and their symptoms; and I have come to

know the doctors as well. It has given us some consistency: I can be confident that I have given all the information that we needed to share, and I also feel that I have taken back some control, which I think helps with the associated anxiety as well. I have also had to arrange for an Individual Healthcare Plan for Eleanor, which has been another challenge. I had to keep fighting to get this put in place, and I did need to appeal.

I am thrilled that the SRUK Children and Families Support Group is now up and running. I decided to volunteer as group leader because I truly understand how overwhelming and lonely it can be when your child is diagnosed with scleroderma. The condition is so rare that not many families have experience of it, but there are other people out there who understand what you are going through. I feel it is crucial to know that you are not alone in this journey, and I want to help provide that support, particularly to families of newly diagnosed children who may have many worries and questions.

Our first Support Group meeting went very well; we met over Zoom, and it was wonderful to connect with other affected families. Dr Clare Pain joined us to answer some questions, and then we chatted together about our various experiences. It was all quite emotional in a way, as many of us have felt so alone in facing this. I feel that I have come through that phase

ALISON'S STORY

Alison Grunwell lives in Doncaster with her husband and three children. Two of her daughters, Eliza aged 12 and Eleanor aged 9, both have localised scleroderma which is also known as morphea.

Alison is a long-term supporter of SRUK and has recently helped us to launch the SRUK Children and Families Support Group, in the role of Group Leader. The group is a safe and friendly space that aims to offer information and support to parents, carers and families of children and young people affected by Scleroderma and Raynaud's. The group meets virtually using Zoom and is designed to be fully accessible in helping parents, carers and families to find friendship and support. This is Alison's story.

My daughter Eliza was diagnosed with localised scleroderma at the age of four-and-a-half, but it had taken 14 months to reach the diagnosis. Eleanor was diagnosed at the age of five, and this happened much more quickly. The first signs of the condition were similar in both Eliza had Eleanor. Eliza had bruise-like marks under her arm and on both hips, that were pinkish-purple in colour. Eleanor had similar, bruise-like marks appearing on both her ankles.



now, but when Eliza was first diagnosed, I felt completely out of my depth, and it was such a scary time with all the medications. For a couple of years, my life revolved around the hospital, the methotrexate and folic acid. If I can draw on this experience to help someone else on this journey, then it will be worth it.

The group is open to all affected families whatever your story, and you can just listen if you want to, or chat to others if you are comfortable doing so: there is no pressure. The purpose is to share experiences, provide ongoing support and help people to feel less isolated. We are not professionals, but we are experts in our own way around the lived experience, and we can share our insight and signpost people to find the help that they need. It is all about sharing our experiences, and it can make a big difference just to know that other people understand what is going on and to know that you are not alone, as this can be so lonely and worrying. Every child different, but there is still some commonality among us all, for example in having the treatment.

As a parent, it is important to gather the information you feel you need, and I have found that social media and support groups can be very useful. Always remember however that this is not medical advice so do not take it as fact; always consult a healthcare professional for any medical queries you may have. The information from SRUK is always a good starting point.

However, it can be very helpful to get other people's perspectives on your own situation. When Eliza was first diagnosed, we were not given a lot of literature from the hospital; I think that I was given information for adults on one occasion, when she was four-and-a-half. My advice to other families who may be starting on the journey following a diagnosis of childhood scleroderma would be to always make sure you are as informed as possible, and don't be afraid to speak up.

“Our first Support Group meeting went very well, and it was wonderful to connect with other affected families. If I can draw on (my) experience to help someone else on this journey, then it will be worth it.”



“The group is open to all affected families whatever your story. The purpose is to share experiences, provide ongoing support and help people to feel less isolated. It is all about sharing our experiences, and it can make a big difference just to know that other people understand what is going on and to know that you are not alone.”



The Children and Families Support Group aims to provide support to families affected by Scleroderma and Raynaud's. The Group meets regularly over Zoom and everyone is welcome. For more information, please call 020 3893 5998, or email info@sruk.co.uk

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.



New SRUK Publications

Our latest information booklets are designed to inform both **schools** and **employers** about Scleroderma and Raynaud's, to help them better understand these conditions and hopefully provide the right level of support.

We would also like to say thank you once again to the clinicians and members of our community who helped to make them possible.

To get your copies, please contact us or visit sruk.co.uk/publications

The SRUK 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.

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.

Keep in Touch Support Service

This is a telephone-based service that offers a little extra support during times like these. You can receive a regular phone call from one of our volunteers for a friendly chat about anything you like.

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

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.



Helpline:
**0800
311 2756**

The SRUK webinar programme

We have an exciting webinar series taking place throughout 2022, covering a wide range of topics and delivered by leading clinicians and experts in the field of Scleroderma and Raynaud's.

What is a webinar?

A webinar is an interactive presentation that is delivered online and allows viewers to ask questions in real time. Each SRUK webinar lasts for one hour and will focus on a specific aspect of living with Scleroderma and/or Raynaud's, such as GI tract involvement or living with pain and fatigue.

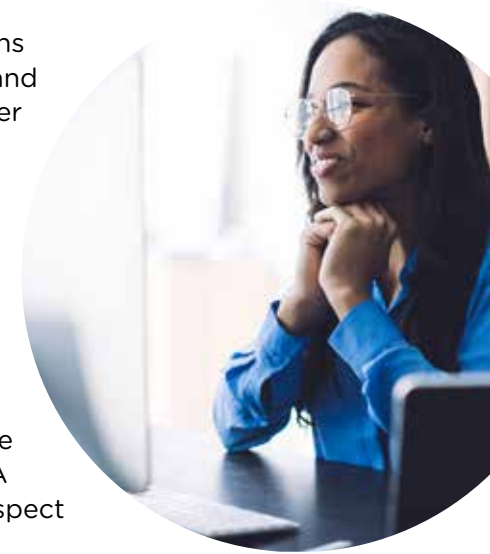
To join the next webinar, simply register in advance and then join the webinar at the appropriate time by clicking the joining link.

Each webinar is hosted by a member of the SRUK team, accompanied by the expert speaker who will deliver a detailed presentation on the relevant topic. Participants can submit questions online and anonymously if they wish, for the host to put to the speaker on their behalf. There is no obligation to send a question, you can just log on and listen if you prefer.

Getting the most from a webinar

- Register beforehand using the registration link that will be available from SRUK and via our social media. You will then receive a separate link to join the webinar.
- Ensure that you have Zoom already installed on your device.
- Log in a couple of minutes before the webinar is due to start so that you do not miss anything. You can do this simply by clicking on the joining link.
- SRUK webinars are usually recorded, and we will share the video after the event. We will also use the content on our Youtube channel and our social media.
- Participants can only see the host and the expert speaker on screen; no one else appears on camera during the session.
- Do not worry about background noise, this will not be heard during the webinar.
- You can submit questions to the expert speaker via the Q&A function at the base of the screen at any time during the webinar. The host will ask the questions following the presentation, so you will not need to say anything.

- Try to keep questions short and concise, and stick to one topic per query. Remember that you can submit as many questions as you like during the webinar.
- If you would prefer to ask a question anonymously, please note this in the Q&A and the host will respect your wishes.
- You will receive a feedback form via email shortly after the webinar, and we would be very grateful if you would take a couple of minutes to complete this. We value your feedback in helping us improve our services to better meet the needs of our community.



Local Support Groups

Our local Support Groups are still as active as ever and working hard to keep people connected. We have also recently launched the SRUK Children and Families Support Group, that meets regularly over Zoom to be accessible to everyone. To find out more, please contact us.

Local Support Contacts	
Amersham	Marilyn York
Bedfordshire	Rita Boulton
Midlands	Avtar Gill
Lothian and Borders	Anne Hogan
Exeter	Mike Corbett
Yorkshire	Chris O'Hora
Merseyside	Pam Neagle
Norfolk	Lucy Reeve
Scottish Highlands	Lorraine Jack
South London	Celia Bhinda
South West Midlands and Cotswolds	Shirley Lynch
Northern Ireland	Una Gillespie
Wales	Enid Connick
Children and Families	Alison Grunwell



TAKING STEPS WITH SRUK

During lockdown and beyond, many people have found solace in walking round their gardens or discovering new local areas and parks. Over the last two years our community has stepped up and raised vital funds for SRUK, and whether they have walked 10 steps, 10 miles or 100km – they have all shared the common purpose of helping people with Scleroderma and Raynaud’s.

As well as raising vital funds for SRUK, there are also many health benefits linked to walking. These include:

- Maintaining a healthy weight and reducing body fat
- Improving cardiovascular fitness
- Strengthening your bones and muscles
- Improving muscle endurance
- Increasing energy levels
- Improving your mood, cognition, memory, and sleep
- Improving your balance and coordination
- Reducing stress and tension*

Preparing for your walk

We asked our community for their top tips when going out walking:

- Wear layers and try to maintain a steady core temperature – avoid getting too hot and then suddenly cooling down.
- Have your gloves and extra socks ready just in case.
- If you are going for a brisk walk, make sure to do some light stretching before you start.
- Know your limits and take plenty of breaks.
- Walk with friends – it’s much more fun!

*Source www.mayoclinic.org/

OUR SRUK WALKERS

Everyone has their own challenges and every year our community has stepped up for SRUK, from walking in the garden to walking from Land’s End to John O’Groats. We have featured them in previous magazines and here is a snapshot of their stories to inspire you:



Sara has scleroderma, and she took on SRUK’s Virtual Relay Walk with her partner. They walked 10km in June 2020 and raised **£420!**

Did you know?
 There are two million annual searches in the UK for “Walks Near Me”.
 Women walk more than men, searching for “Women’s Walking Boots” 109,000 times per month on average.
 Source: oursportinglife.co.uk/walking-statistics-uk/

Not sure where to walk? How about these top 10 places to walk in the UK, as voted for by the British public:

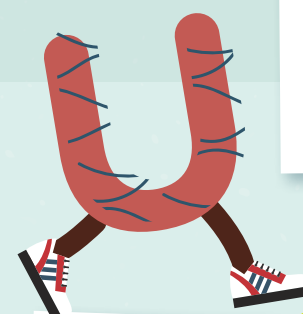
- | | |
|--------------------------------------|---------------------------------|
| 1. Hellvelyn Cumbria | 6. Tryfan, Gwynedd |
| 2. Snowdon, Gwynedd | 7. Buttermere, Lake District |
| 3. Malham Tarn Estate, Lake District | 8. Coniston, Cumbria |
| 4. Cat Bells, Cumbria | 9. Dunstanburgh, Northumberland |
| 5. Scafell Pike, Cumbria | 10. Mam Tor, Peak District |

Source: nationaltrust.org.uk/features/celebrating-britains-100-favourite-walks



Karen walked 10km in 2020 with her sister **Catherine** and again in 2021 with her son **Dan**, she has raised **£695** and is already looking forward to walking in 2022!

Jai Barber clocked up 175 miles in series of walks and raised **£1,000!**



Zoe and her Mum **Caz** raised over **£150** walking 10,000 steps every day in June.

Una walked 10km around the perimeter of her house every Saturday for four weeks. She has diffuse scleroderma which affects her skin and internal organs including her lungs – so this really was a challenge for Una. She smashed her original **£250** target and raised over **£5,850!**

Friends **Emily** and **Zoe** walked Hangers Way in Hampshire, inspired by Zoe’s mother and Emily’s younger sister who both have scleroderma. They raised over **£2,738!**



Xandro Rinaldi walked the 1,200 miles between Land’s End and John O’Groats, and raised over **£1,550** as his mum has scleroderma.



Sue and her nephew **Lee** walked Wainwright’s Coast to Coast path; a distance of around 200 miles.

They raised over **£3,000** for SRUK, inspired by Caroline, Lee’s mum and Sue’s sister, who has scleroderma.



Claire O’Farrell and her dog **Ivy** walked 105 miles in June 2021 and raised over **£280**.



Follow in their footsteps this June for Scleroderma Awareness Month

Every year we ask you to help us raise awareness in June for **Scleroderma Awareness Month**. Join thousands of people across the world who are taking steps to raise funds and change lives.

Together we can reach the **£19,000** goal – small steps to make a huge difference.

Find out more and get your info pack to get you started at: sruk.co.uk/walk/ or contact the team at fundraising@sruk.co.uk or call **020 3893 5998**

£ **FUNDRAISING HEROES**

SHINING THE SPOTLIGHT ON SOME OF OUR FANTASTIC SUPPORTERS!

4X4X48 CHALLENGE

Chris Palmer completed the 4x4x48 challenge – running four miles every four hours for 48 hours!

Chris has limited scleroderma and his hands are painful most days. He wears big mittens or gloves when running, even in the summer.

He has raised **£453** for SRUK – Thank you and well done Chris!

LONDON LANDMARKS

We would like to say a big **Thank You** to our London Landmarks Half Marathon runners – **Gina and Millie Morris** and **Shahinara Craveiro** (pictured). They have raised over **£1,000!**



“I started running at the end of 2019. I was not very fast at all! I don’t think I’ve ever overtaken someone! As far as the 4x4x48 goes, it was a fun two days. I like the discipline of the challenge. I have run further in 48 hours, but this was more difficult because of the structure of it.”

Thanks to **Turtle Doves**, who supported us during February and March by making a donation of **£5.00 for each jumper** they were able to recycle into gloves and other garments.

Good luck to everyone taking on challenges this Spring. **Antonia Fella** is taking on her first half marathon in Edinburgh in May. Inspired by her mum who has scleroderma, she is hoping to raise **£750**.

Good luck to **Helen Jevons, Anita, Jules and Sally** who have set themselves the challenge of walking 250,000 steps each to reach **One Million Steps** in total! They will be doing a series of walks from 9 April to 6 August, in memory of Helen’s wife Alice. They have a target of **£2,500** and we will let you know how they got on in the next edition of *SRUK News!*

SUNFLOWERS FOR SCLERODERMA:

Help us to sow the seeds of change

This year we are launching an initiative to encourage as many people as possible to plant and grow sunflowers – the worldwide symbol of scleroderma organisations. The sunflower has become synonymous with scleroderma, because people usually feel more comfortable in warmer weather, just like the way that sunflowers naturally turn towards the sun.

Whether you grow a plant to honour the memory of a loved one or to raise awareness of scleroderma, this beautiful flower could start a conversation that could change someone’s life. You could also encourage your family, friends and neighbours to join in and give awards for the best, the tallest, or even the smallest sunflower!

Make this a real talking point and sow the seeds of change.

For more details, please contact us.



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.

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

Scleroderma & Raynaud's UK

Bride House, 18-20 Bride Lane,
London, EC4Y 8EE

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.

www.sruk.co.uk

Helpline: 0800 311 2756

Office 020 3893 5998

 @WeAreSRUK

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