

SRUK NEWS

Thank you for your continued support;
we are looking forward to a very busy 2023!

Taking on the cost of living crisis: what SRUK is doing to help.

"Before this crisis, I didn't have to worry too much about putting the heating on, but now, I've had to rethink everything."

Voices from our community

SRUK research sheds new light on the impact of calcinosis.

Raynaud's Awareness Month:

This February, help us to raise awareness of symptoms, management and risks.

Travelling abroad with SSc:

We have all you need to know!



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!

This New Year, could you help us keep on providing vital information and support? We are looking forward to a packed 2023 with countless opportunities to choose from, and you can get involved without even leaving your home. You do not even have to take part in an event, simply helping us to spread the word and sharing our social media posts really can make a difference.

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 our dedicated fundraising team.

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

EVENTS CALENDAR 2023			
Raynaud's Awareness Month	Do your own fundraising	Anywhere	February 2023
London Landmarks Half Marathon	Half Marathon	London	2 April 2023
TCS London Marathon	Full Marathon	London	23 April 2023
SRUK Walk	Your Own Walk	Anywhere	Ongoing
London Asics 10k	10k Run	London	9 July 2023
Leeds 10k	10k Run	Leeds	20 August 2023
Bath Half Marathon	Half Marathon	Bath	15 October 2023
Cardiff Half Marathon	Half Marathon	Cardiff	1 October 2023

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

You can call us on 020 3893 5993

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

I trust you had the opportunity to meet up with family and friends over the festive season, which for many of us is possibly the first time, in a couple of years, we've been able to do so. While COVID lingers in the background, last year brought with it a whole different set of challenges, in the form of the fuel and cost of living crisis.

This is an issue that has affected all of us, but particularly people in our community. We all know that keeping warm in the winter is vital to prevent an increase in the number of Raynaud's attacks. Having to choose between heating or food is not something anyone should have to be doing, which is why we have been campaigning for Scleroderma and Raynaud's to be included in the Energy Price Guarantee for vulnerable people. You can read more about the campaign on page 14.

Over the last couple of years, we have increased our advocacy work, collaborating with other charities to raise the issues that matter most to you. The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) is a key partnership, seeking to transform care and treatment and ensure equity of access, no matter where you live in the UK. We have started to build strong, effective relationships with key players in the healthcare system and governments in all nations. In 2023 we will continue to build on this work, and we already

have meetings in the diary with MPs and senior civil servants.

This year we will continue to deliver our programme of webinars. We would love to hear from you if there are any topics you think we should be covering, so please do get in touch. Our support group network continues to grow, and I would like to thank all our amazing volunteers, who are always on hand. We are very keen to involve more people across all of our work, be that our communications, information, support or research, and we'll be sharing these opportunities over the coming months.

Thank you all so much for your continued support. It has been a tough time but it's only by working together with yourselves and other organisations that we have been able to pull through.

Wishing you all the very best for 2023,

Sue



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DOC SPOT

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



Q I am having increasing issues with swollen hands, to the point where my wedding ring has had to be cut off. I have been looking into using compression gloves when using my hands and when driving etc.

Is this something you would recommend, and are they safe to use?

A Swelling can occur in systemic sclerosis due to fluid retention in the fingers, inflammation of the joints or skin thickening. Compression gloves could be helpful in some cases but will only benefit some of these mechanisms and you should avoid using them if Raynaud's or joint pain is worsened significantly after treatment.

Q I do not want to stop taking nifedipine as I feel I need it, especially as the weather changes. However, I would like to ask the best time to take it, as I am experiencing side effects afterwards, including anxiety and lightheadness; it can make me feel quite unwell. Should I take it with or after food, and how long should the side effects last for please?

A Nifedipine is generally a safe and well-tolerated treatment, and probably the most frequently prescribed medication for Raynaud's Phenomenon.

Taking this with food and in the evening can reduce issues with low blood pressure that can lead to dizziness. If the side effects are not tolerable or worsen you should discuss this with your doctor or specialist nurse, as alternative drugs may be available.

Q What is the difference between chilblains and chilblain lupus erythematosus (CLE)? How is CLE diagnosed and how is it distinguished from normal chilblains please? Also, how common is it, and when does

it tend to occur? There's so little information available about it.

A Chilblains are painful, itchy, red lumps that develop on the toes or fingers that typically last for a few days and can sometimes ulcerate. They are very common and are caused when the blood supply to the hands or feet (most often) is reduced due to the cold, to the extent that blood vessels become leaky and inflamed. Chilblains can be associated with severe Raynaud's attacks, but also occur without Raynaud's in some cases.

Chilblain lupus describes a form of autoimmune connective tissue disease when blood vessels are more prone to inflammation and where blood tests for lupus (SLE). Chilblains can be more severe or frequent and require treatment with drugs such as hydroxychloroquine or other immunosuppressants which can be used to treat lupus.

Q I have systemic sclerosis, and over the past year I have suffered increasingly from a streaming nose and a constant cough as I am having to clear my throat all the time. Could this be another part of scleroderma?

A A cough is a frequent symptom in systemic sclerosis, and there are several potential factors that can cause a troublesome cough. It may result from gastro-oesophageal reflux with irritation of the throat or sometimes due to inflammation in the lungs or lung fibrosis, and so you should always discuss this with your clinical team.

In addition, some patients have sinus inflammation or nasal problems with a postnasal drip causing a cough. These symptoms should be discussed with your clinical team, as further tests or an ENT referral may be needed.

Q I am having issues with my fingernails, that I think could be linked to scleroderma. How exactly can this condition affect the nails, and what can we do about it?

A Fingernails are an extension of the skin and so can be affected in scleroderma. Typically, they may be brittle or thickened and sometimes prone to infection. This is due to the skin changes around the nail bed and the reduced blood supply and blood vessel damage around the nails that we can see in the

Therapeutic plasma exchange (TPE), is a specialised treatment that removes proteins from the blood and replaces it using donated plasma, a blood product. This is a little like a dialysis machine used for treating kidney failure, but rather than clearing waste products from the blood, it is used when harmful proteins in the blood may be causing disease.

clinic with tests such as the capillaroscopy. Treatment of infection with antibiotics or antifungal ointments or tablets may be needed, and treatments to improve Raynaud's can be very helpful including those used for digital ulcers, such as sildenafil and bosentan tablets, or iloprost infusion in very severe cases.

Q I was told by a private dermatologist that it is likely I have systemic scleroderma. My GP did the referral to a general rheumatologist, but the earliest appointment is in mid-2023.

I don't really know what to do now, I'm worried about waiting for so long; should I go private to get a diagnosis?

A Unfortunately, some NHS services are struggling to cope with the number of new referrals after COVID, and because of the well-publicised challenges in staffing and other capacity within the system. We are all hoping that the situation will soon improve. My advice would be to discuss with your GP whether there is concern about any severe complications in which case a more urgent opinion, either in NHS or if you prefer, as a private patient, may be advisable.



Chilblains are painful, itchy, red lumps that develop on the toes or fingers that typically last for a few days and can sometimes ulcerate. They are very common and are caused when the blood supply to the hands or feet (most often) is reduced due to the cold, to the extent that blood vessels become leaky and inflamed.

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



Q Is therapeutic plasma exchange treatment offered and available to patients in the UK please?

A Therapeutic plasma exchange (TPE), is a specialised treatment that removes proteins from the blood and replaces it using donated plasma, a blood product. This is a little like a dialysis machine used for treating kidney failure, but rather than clearing waste products from the blood, it is used when harmful proteins in the blood may be causing disease. It is available and used in NHS within specialised centres to treat some forms of severe kidney damage, and severe inflammatory nerve damage. Although a few published reports suggest benefit for systemic sclerosis there is not yet sufficient evidence to offer this as a treatment. This is because clear benefit over standard management has not been shown, and the safety and feasibility of plasma exchange in systemic sclerosis has not been confirmed. Future research studies may explore this but, in my opinion, more evidence is essential before this approach could be recommended within the NHS.



COLLABORATING TO DRIVE IMPROVEMENTS IN HEALTHCARE

SRUK IS A PROUD, FOUNDING MEMBER OF THE RARE AUTOIMMUNE RHEUMATIC DISEASE ALLIANCE (RAIRDA).

RAIRDA brings together patient organisations and clinicians to build a strong voice in campaigning for improved care, raising the profile of rare autoimmune conditions, influencing policy and guiding future research.

At SRUK we want everyone with Scleroderma and Raynaud's, wherever they live and whatever their circumstances, to get the responsive and person-centred support they need. A key outcome is to ensure there is equity of access to treatments, with care that is properly co-ordinated in line with best practice guidelines.

We recognised we would have more impact if we joined forces with other patient organisations supporting people with rare autoimmune conditions (RAIRDs), such as lupus, vasculitis and Sjogren's syndrome. This led to the creation of RAIRDA, chaired by SRUK's Chief Executive Sue Farrington and Dr Peter Lanyon, Consultant Rheumatologist at Nottingham University Hospitals NHS Trust.

Raising the profile of rare autoimmune conditions

Over the past few years, RAIRDA has produced several reports based on patient surveys, setting out key challenges faced by our communities and making a series of recommendations to improve services. Most recently, in November 2022, we published '*Resetting the Balance*' which sets out a roadmap of recommendations to improve outcomes and experiences for people living with RAIRDs. The report received coverage in the *Daily Mirror*, the *Daily Express*, the *Daily Record* and *Personnel Today*.

This work has helped to increase our profile and credibility with key decision makers across government and the NHS, and we are now regularly invited to meet with ministers and to participate in working groups.



RAIRDA has been working to build the case for a rare disease quality standard that sets out best practice in key areas of care, to help ensure consistent standards across the UK.

We are also beginning to build support among parliamentarians and recently met with Baroness Ritchie, a Labour peer from Northern Ireland who is a strong rare disease advocate. We will be meeting with Liz Twist MP in the New Year, who also has a particular interest in rare diseases. We hope that these relationships, along with others, will enable us to ensure that the voice of people with RAIRDs is heard clearly in Parliament.

Shaping patient pathways

One of the working groups we were invited to join over the last year is the Rheumatology Optimisation and Restoration workstream, #BestMSK Health Programme, NHS England & NHS Improvement, where we have had direct input in shaping ideal patient pathways for rare connective tissue diseases. Having an ideal pathway for these areas agreed by NHS England, setting out a standard for waiting times, times to treatment, the availability of advice for flares and ongoing monitoring, is a move towards the consistent standards of care we want to see. The pathway also takes on a key recommendation from the RAIRDA report: that patients seeing multiple specialists should have a named person responsible for coordinating their care.

Quality standard for rare diseases

One of the other significant things that RAIRDA has been doing this year is building the case for a rare disease quality standard, to ensure consistent standards of care across the UK. A quality standard sets out what best practice is in key areas of care; and can be audited against to encourage improvements.

A post on the online forum for the Rare Diseases Framework by Sue Farrington led to the bringing together of a group of clinicians and patient representatives, with the shared goal of pushing for this standard to be created. Sue has chaired this group and the work has been supported by the RAIRDA secretariat. It has now been afforded status as the first Independent Advisory Group of the Rare Disease Forum, with Sue continuing as Chair. The group is having ongoing productive discussions with the Department of Health and Rare Disease Framework delivery partners about how to take forward this goal.

Building relationships with the nations

RAIRDA has made good progress in building relationships with key decision makers across the nations over the past year.

In June 2022 we met with the clinical leads for musculoskeletal services in Wales and were able to share concerns about services there, and potential solutions to improve them. There are plans to continue these discussions in early 2023, to discuss in more detail the specific recommendations in our newest report.

Our work on the quality standard has also opened doors to working with Scottish policy makers, who are keen to explore how RAIRDA can feed into future policy developments.

In 2023 we will also be looking to build links with Northern Ireland and to undertake research to understand the gaps in services for RAIRDs there.



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COVID-19

This year, our work around COVID-19 has continued to take up a significant part of RAIRDA's time, as we raised matters affecting our community with government and sought answers on issues such as access to vaccines and antivirals.

To support this work, we undertook surveys of people with RAIRDs in relation to access to vaccines and new treatments for COVID-19. This identified that there were ongoing issues in correctly identifying the eligibility of this group, with large numbers still receiving no proactive contact from the NHS to inform them of their right to access a fourth dose of the vaccine or COVID-19 treatments.

We shared these findings with NHS England and are involved in an ongoing dialogue about how to ensure that people with RAIRDs who are immunocompromised continue to be protected from severe illness caused by COVID-19.

Next steps

In 2023, we will build on the work undertaken to date and continue to call for improved standards of care for people with rare autoimmune conditions, based on the recommendations from our report. This year we want to involve you in our campaigning work, helping to get the message out so that everyone, no matter where they live and what their circumstances, should get the responsive and person-centred support they need.

For more information on the work of RAIRDA, please visit rairda.org

SRUK RESEARCH SHEDS LIGHT ON THE EFFECT OF CALCINOSIS ON PATIENTS

Calcinosis is often a debilitating and painful symptom of systemic sclerosis, that is thought to affect as many as 40% of people diagnosed.

Calcinosis often causes physical impairment that in turn can have a considerable effect upon emotional wellbeing. Last winter, SRUK led a piece of research in partnership with Professor Ariane Herrick from the University of Manchester, which aimed to build our understanding of the effect of calcinosis on people with scleroderma. We are thrilled to announce that our findings from this research, which our community contributed to, were recently published in the journal *'Rheumatology.'*¹ Read on to find out more about what we learned from the research!

What is calcinosis?

Calcinosis cutis, or calcinosis for short, is a condition where insoluble calcium salts are deposited beneath the skin, which appear as chalky white or yellowish lumps. Calcinosis most commonly affects the fingertips, but can also occur on the knees, elbows, and face.

Calcinotic lumps are often painful, especially when they occur at pressure points. They can eventually break through the skin and cause ulcers, which may then become infected and require antibiotic treatment.

Although calcinosis is considered rare, it can affect between 20-40% of those living with systemic sclerosis and is more common in patients with the limited form of scleroderma. It is a neglected aspect of the condition as there is a lack of effective treatment options as well as limited documented evidence on how it affects the physical and mental wellbeing of those who experience it. Improving our understanding of these areas therefore has the potential to drive and inform more effective and tolerable treatments for people who are dealing with calcinosis as another part of their condition.



Professor Ariane Herrick

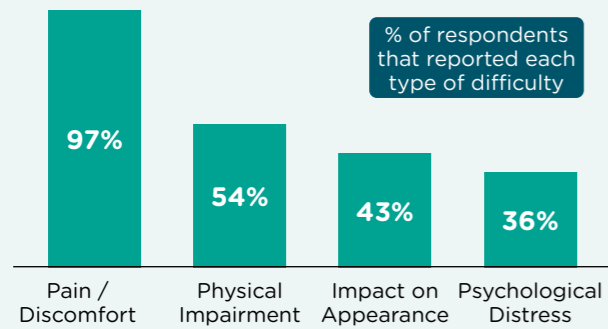
138 people took part in The SRUK Calcinosis Survey!

The hands were the most affected area, according to 89% of our respondents.

97% experienced pain and discomfort from calcinosis.

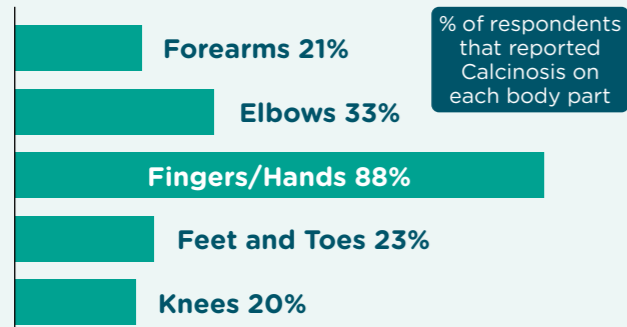
¹Pearson, Emma & Blamont, Emma & Wilkinson, Sarah & Herrick, Ariane. (2022). The clinical impact of systemic sclerosis-related calcinosis-results of a patient survey. *Rheumatology* (Oxford, England). 10.1093/rheumatology/keac538

How does Calcinosis affect our community?



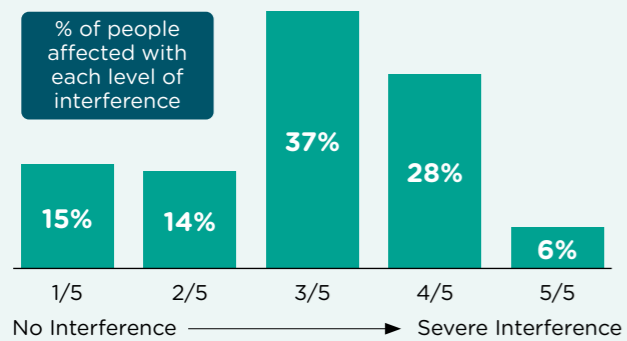
% of respondents that reported each type of difficulty

Which body parts does Calcinosis affect?



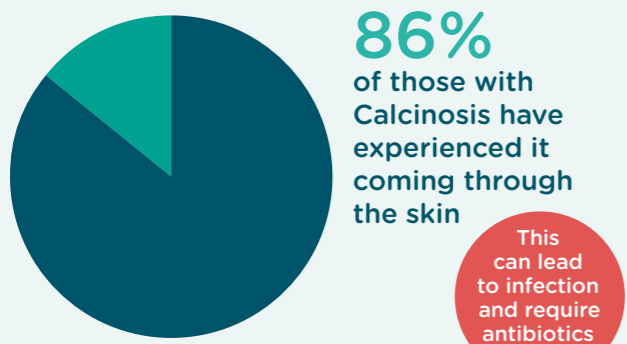
% of respondents that reported Calcinosis on each body part

How does Calcinosis interfere with daily activities?



% of people affected with each level of interference

How often does Calcinosis break the skin?



86% of those with Calcinosis have experienced it coming through the skin

This can lead to infection and require antibiotics

Our research and its findings: The SRUK Calcinosis Survey

The SRUK Calcinosis Survey was promoted through our social media channels. We invited our community to take part in this survey, covering various aspects including the areas of the body affected by calcinosis, the impact of calcinosis on day-to-day life, the treatments people have been prescribed and their levels of effectiveness.

Who responded?

138 people with scleroderma responded to our survey, with **129 people** saying that they had calcinosis. As anticipated, most reported that they had limited systemic sclerosis (68%), followed by diffuse (22%), with the remainder either having localised scleroderma (4%) or being uncertain of their disease subtype (6%).

Which sites of the body are affected?

106 people completed all the survey questions, and their responses were included in the analysis of survey data. Our survey confirmed that **the hands and the fingers were the areas most affected by calcinosis**, with 89% of our 106 respondents all reporting calcinosis at these sites. However, the data provided also showed that other areas were commonly affected as well, including the elbows (33% of people), the feet and toes (24%), the forearms (21%), and the knees (20%). Our survey also demonstrated that calcinosis may affect more than one part of the body, with 64% of people saying they experienced calcinosis at more than one site.

The impact of calcinosis on daily life

Seventy-one percent of those who responded said that calcinosis had a moderate-to-high negative impact on their daily life. The majority of respondents said that the calcinosis caused them pain and discomfort (97%) along with physical impairment (54%). This is perhaps linked to the high percentage of people (86%) who said that their calcinosis had 'come out' or broken through the skin causing ulceration that requires treatment with antibiotics.

Just under half of those affected (43%) said that calcinosis impacted upon their appearance. Given the wide range of effects mentioned above, it is perhaps unsurprising that just over one-third (36%) said that their experience of calcinosis had negatively affected their mental wellbeing and had caused them psychological distress.

Is treatment for Calcinosis effective?



Treatments and their effectiveness

Over half our respondents had not received any treatment for their calcinosis. Of those who did have treatment, a diverse range of medications had been prescribed including antibiotics that were presumably given for ulcerations that became infected. One-fifth of those who participated had received surgery to treat calcinosis. It was widely accepted among participants that the medication(s) they were prescribed were ineffective (90%).

How can this data help inform new treatments or better care?

The publication of the survey results in *'Rheumatology'*, a leading specialist medical journal, form a source of evidence which provides insight into the physical and mental burden of calcinosis on those with scleroderma, along with the need for more effective treatments. Clinicians, researchers and patient organisations like SRUK can point others towards this evidence, to show the burden that calcinosis places on individual patients and the healthcare system, to leverage funding for more research into calcinosis including new treatments, and to advocate for better care for these patients.

Where next?

Professor Ariane Herrick has a clinical interest in calcinosis, and in 2014 was awarded £111,268 by SRUK's legacy charity the Raynaud's and Scleroderma Association (RSA), for a three-year research project entitled 'Novel Therapies for Systemic Sclerosis-related Calcinosis'. This funding enabled Professor Herrick to research the molecular aspects of calcinosis and identify compounds which could form the basis of a new topical treatment (something that could be applied directly to the skin of the affected area).

After completing the RSA/SRUK funded project Professor Herrick obtained another award from Versus Arthritis, to further test the compounds identified through the earlier project and how they should be formulated (i.e., as an ointment, gel, cream, or patch etc), to be applied to the skin.

Professor Herrick has identified a promising compound which she would like to study in a preliminary clinical trial, to test its safety and effectiveness in a small number of patients with calcinosis. Clinical trials are very expensive, requiring the input of the wider healthcare ecosystem, but Professor Herrick and Dr Mike Hughes are currently in the process of applying for funding from a large funder that can support studies of this kind. SRUK are also working with the team in our capacity as a patient organisation. We are delighted to play a role in the continuation of this story to a potential clinical trial, following on from the RSA's initial seed funding which allowed the foundational elements of this research to take place. We hope that work like this, along with the findings of our survey, will lead to greater activity and better treatments for calcinosis in the future.

To keep up-to-date with the latest research news, please visit sruk.co.uk/research



SRUK SHOP

The SRUK Shop offers a range of products that have been specially selected to help manage some of the most common symptoms of Scleroderma and Raynaud's.

As a charitable retailer, all profits from the SRUK Shop will go to the charity to help us support vital research. Please contact us if you have any queries, and we will be very happy to help you.

If you would like to place an order, please use the form below and address cheques to 'RSA Trading Ltd' or visit us at sruk.co.uk

20%
off all
products

(New prices
shown below)

Snuggle Up Blanket

Relax with a Heat Holders premium fleece blanket - perfect for wrapping up warmly on those cold winter 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 two different colours: Duck Egg Blue (pictured), Antique Silver.

£21.59



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.

£4.40



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.

£3.99



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 wintry days or cold nights, or if you are standing on cold ground for a long time.

£4.39



Ladies' slippers for cold feet

Warm up freezing cold and painful feet with a cosy pair of SnugToes, the super snuggly slippers with handy removable heat pads. Pop the heat pads in the microwave, slip them in the slipper tops and enjoy that warm feeling. You'll have toasty toes in no time at all.

Colour: Wine
Available in a UK size 5 or 6

£21.60



SRUK SHOP ORDER FORM

Products	Cost	Qty	Size	Colour
SRUK Face Mask	£4.40			
Snugtoes Ladies' Slippers	£21.60			
MyCoal Hand Warmers	£3.99			
MyCoal Foot Warmers	£4.39			
Snuggle Up Blanket <i>Please specify the colour</i>	£21.59			

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

Please address
cheques to
'RSA Trading'

THE SRUK RAYNAUD'S ENERGY CAMPAIGN

With energy prices soaring this winter, SRUK is calling on the government to take action to help people living with Scleroderma & Raynaud's whose health could depend on access to affordable heating.

In October, we launched the SRUK Raynaud's Energy Campaign. This is the story so far.

Government must act on cost of living to protect health of millions with Raynaud's, says SRUK



The cost of living crisis continues to impact upon households throughout the UK. This winter has already proved more challenging than ever, as many of us still struggle to navigate rising costs across the board, with consumer goods, household energy and petrol prices all affected to some extent.²

When you are living with Raynaud's, heating your home to a constant, comfortable temperature can be an essential part of managing your condition. We know that for many people, maintaining the body's core temperature is crucial in helping to prevent painful and sometimes debilitating attacks. However, due to the increase in energy prices this has now become a challenge for many of our community.

In October last year, we reached out to ask people how they felt about the rising energy prices and how they would cope. We received over 1,932 responses to our survey, and of those, 1,647 people said they are living with Raynaud's.

What you told us

Our survey revealed how big an impact the rise in energy prices is having on people living with Raynaud's, including:

- 83% of our respondents said they rely on their heating to prevent painful Raynaud's attacks but 76% are not turning their heating on.
- More than four-in-five (82%), are worried about the cost of their energy bills, despite the government's current package of support.
- More than three-in-four people with Raynaud's (76%), say it has become more difficult to pay their energy bills.

Our survey respondents also reported having taken certain steps in an attempt to make their energy bills more affordable:

- One-in-four of our respondents (25%), are buying budget food items more often to prioritise spending on energy bills, whilst almost one-in-five (19%), are buying less food overall.
- 23% of people said they are cutting back on leisure activities to be able to afford their energy bills, and 17% said they are now socialising less.

² <https://commonslibrary.parliament.uk/>

We have written to the Chancellor of the Exchequer, asking specifically for support for our community.

Our survey revealed a number of key points:

More than three-in-four of our respondents are experiencing more Raynaud's attacks due to the stress caused by the current cost of living crisis:

76%

have suffered a painful Raynaud's attack because they have been too worried about their energy bills to turn their heating on.



The number of people with Raynaud's paying over

£700 PER MONTH

for their energy has almost doubled.



77%

of our survey respondents believe their condition has worsened because of stress caused by the cost-of-living crisis.



The Raynaud's Energy Campaign

Using the compelling evidence revealed by our survey, we launched our Raynaud's Energy Campaign.

We wrote a letter to the Chancellor of the Exchequer, Jeremy Hunt, urging him to consider:

- extending the Energy Price Guarantee for vulnerable groups, to include people with Raynaud's,
- increasing the Energy Profits Levy with a particular focus on the biggest oil and gas companies, such as Shell and BP who have recently posted record multi-billion-pound profits, and using a proportion of the extra money raised to provide financial assistance to those with conditions like Raynaud's whose health depends on affordable heating,
- including Raynaud's as a criterion for the annual Warm Homes Discount,

In lieu of the Chancellor's Autumn statement we welcomed the increase in the Energy Profits Levy and urged the government to:

- use a proportion of the money raised by the Energy Profits Levy on oil and gas companies to provide financial assistance to those with conditions like Raynaud's whose health depends on affordable heating.

Raising awareness

Although around one-in-six people live with Raynaud's, awareness is still sadly lacking. For example, over half of UK adults do not know the signs and symptoms, with millions likely to dismiss their symptoms rather than visit their GP. We therefore also targeted the national media, to help us raise awareness of these issues.

We secured online coverage on various news sites including; *The Independent*, *MSN.com*, *The Belfast Telegraph* and *Yahoo News*.

We followed this up with regionally specific stats and tips on staying warm - this was picked up with online coverage in *The North Edinburgh News*, *Just Beverley* and *London TV*.

In December, the BBC Morning Live show did a general piece on Raynaud's - having seen our campaign.

We have been continuing this campaign and recently we contacted regional media sources to ensure as much coverage as possible. We also covered this issue across all of our social media channels. We know from all your comments that this is an important issue for you all, and we will continue to campaign and raise awareness of this.

Read more about our plans for Raynaud's Awareness Month 2023 on page 24.



We have already secured media coverage to highlight the impact of rising energy costs on people living with Raynaud's, and the campaign continues.

Our *Handy Hints for Keeping Warm* factsheet has lots of practical tips for this winter and beyond. For a free download, please sruk.co.uk/publications



NEGATIVE ENERGY:

Coping with the stress of rising household bills

Our survey has revealed the very real and dramatic impact of rising energy costs upon the wellbeing of many of our community, with the vast majority reporting they are worried about increasing costs and paying their bills.

If you are experiencing stress and anxiety due to the rising cost of living, our data has shown that you are not alone. However, there are a number of approaches that can be effective and really can make a difference to our wellbeing, which is more important than ever during times like these.

The following suggestions were developed with the help of Lucy Reeve, a Clinical Specialist Occupational Therapist who is also living with scleroderma, so she fully understands what it means to live with this condition. Different techniques work for different people, and it is important to identify your own coping mechanisms: the little things you can do every day that work for you.

Acceptance

Anxiety is not all in your head. Understanding helps us to take back control, so learn about what anxiety is, and what happens inside the body when the feeling strikes. Remember that anxiety is a perfectly normal response of the body to stressful situations, so always try to be self-compassionate.

Relaxation

Relaxation and a good sleep routine will help. This is a very personal choice: some people find mindfulness to be effective, whereas others find that distractions such as music or reading are more helpful. Set aside some time each day to try different strategies and you will reap the benefits quickly. The more enjoyable activities we do, the better we feel and the more we are inclined to do; a cycle that is extremely positive for healthy emotional wellbeing.

Physical activity

Keeping active helps anxiety and can boost our mood, so try to do a little exercise every day, in a way that is comfortable for you. Being active does not need to involve anything strenuous: taking the time to simply walk in a green space can make all the difference.

Remember that you are not alone

Keeping connected is vital to maintaining positive mental health and combat feelings of isolation. The evidence shows that it is the depth rather than the frequency of contact with others that is important, so keep reaching out and deepening the connections you already have, because it is these relationships that will persist and help you maintain a sense of stability when things feel out of control. You can use social media to connect with others who may be in a similar situation, by visiting our Facebook page or our online forum hosted on HealthUnlocked.

Consider also connecting with your local support group. Many of SRUK's network of support groups are still meeting online or using a hybrid approach, making it easier to keep in touch and make connections with others.

Avoid doomscrolling

'Doomscrolling' refers to the tendency to keep reading or scrolling through bad or worrying news, usually on a mobile device when we could be doing something else. If you are concerned about your screen habit, consider how much time you are spending on your devices and ask yourself: Does this really help? Control what you engage with and consider what you spend your time focusing on.

Write it down

Writing down our thoughts and feelings gets it all out of our heads and on to paper and helps us to process them, reducing stress and anxiety. It also helps in gaining perspective. There will always be some things we cannot do anything about, so rather than letting it churn round in your mind, try putting it onto paper instead.

If you are concerned about the cost of living and the increase in household bills, please be assured that you are not alone, and SRUK is here to help.

If you would like to find out more about the Raynaud's Energy Campaign or you would like to know how to get involved, please contact us and we will be very happy to help you. You can also call our Helpline to talk to one of our volunteers if you would like some support: **0800 311 2756**.

We would like to thank Lucy Reeve for her support in producing this article.

LEFT IN THE COLD

The rising cost of living has meant that most of us are feeling the impact to some extent.

We talked to members of our community about how they are coping with rising energy prices whilst still needing to keep warm this winter.

HELEN'S STORY

Helen is an associate university professor from South Wales. She was diagnosed with Raynaud's Phenomenon in 2017. Following subsequent tests, it was confirmed that she has secondary Raynaud's alongside scleroderma.

Helen has been supporting SRUK's Raynaud's Energy Campaign by sharing her story to help us raise awareness. She says that despite earning a good income she is concerned about the cost of heating, and has been actively trying to reduce the amount she uses.

"My Raynaud's has definitely gotten worse this year. I used to have an attack a couple of times a week, particularly if I was outside in the cold, but now it happens every day, even in my own house. We haven't even had any very cold weather yet.

"Although I earn a good income, I'm still worried about the cost of heating. Last winter, I'd have put the heating on from September and have it on quite regularly, but right now, I try not to put it on, and if I do I only have it on for an hour or so a day at the most.

"My Raynaud's has definitely gotten worse this year. I used to have an attack a couple of times a week, particularly if I was outside in the cold, but now it happens every day, even in my own house."

Helen



Helen

"I work from home several days a week, so I've made sure my computer is in the sunniest spot in the house. Other days, I'll compare the cost of travelling to work to the cost of heating my home, and if I know the weather is going to be particularly cold, I might decide to travel to the office that day.

"I've also started to close off rooms, use an electric blanket and go to bed earlier, but it's really difficult because when you've got a Raynaud's attack coming, it doesn't matter what you do to try to stay warm, it's going to happen regardless.

"If I have a particularly bad Raynaud's attack and my fingers and toes go completely numb, I can't manage simple household tasks like making a hot drink, opening a door or using the computer. There are lots of things I can't do until my hands have warmed up.

"I know I'm in a privileged position with my regular income, but I do think there's a squeeze on middle-income earners, particularly people like me with underlying health conditions, who aren't eligible for lots of cold weather benefits and things like that, it means the energy hikes are unaffordable."

"I'm supposed to have my house heated to at least 18 degrees, but I've not had the heating on at all. I'm worried about putting it on, and using energy in general, because of the cost."

Lynn

LYNN'S STORY

Lynn is 67 and lives in St Helen's. She is living with Scleroderma and Raynaud's and talked to us about the impact of rising energy costs on her wellbeing. Lynn says she is so worried about the high cost of energy she is focusing on ways to keep her body warm rather than heating her house.

"Before this crisis, I didn't have to worry too much about putting the heating on, but now, I've had to rethink everything.

"I'm on a fixed deal at the moment, but that ends in February, and I don't know what's going to happen. I'm paying double compared with last year as it is, and I can't afford to pay huge amounts. I had to retire in October due to my health, so I only have a state pension to rely on.

"The cold not only affects my Raynaud's, but I suffer with my scleroderma too. When the temperature gets too low, I get problems with my hands and feet, and I also get muscle and tendon spasms and feel really stiff. A bad flare-up will put me in bed.

"I've made the decision to warm myself rather than my home, so I'm knitting hand warmers, fingerless gloves, leg warmers and a blanket. I've also got hot water bottles, scarves, extra jumpers, thermal t-shirts, silver-lined gloves and a foot heating device for when I really need it.

"I'm supposed to have my house heated to at least 18 degrees, but I've not had the heating on at all. I'm worried about putting it on, and using energy in general, because of the cost."

* Name has been changed.

JOY'S STORY

Joy* is 66 and lives in Greater London. She was diagnosed with Raynaud's around four years ago. She also has scleroderma, as well as psoriatic arthritis and morphea.

Joy is unable to take any medication for her Raynaud's due to the side effects, so keeping her body warm during the winter is vital in helping her to manage her condition and prevent painful attacks. She told us that the prospect of a cold winter worries her enormously.

"I'm terrified of the weather getting colder as anything below 20 degrees in the house triggers a Raynaud's attack and I feel very unwell with it.

"Even the smallest exposure to the cold can trigger an attack; there have been times when I've been in a car park when it's cold and gotten a Raynaud's attack because all I did was take my gloves off to get my money or bank card out to pay for parking. It can be excruciatingly painful.

"I've had horrendous attacks before, and people don't seem to realise how bad they can be. It's awful because you just feel like you want to chop your hand off rather than go through the agony that an attack causes.

"I can't take any medication for my Raynaud's as it made me feel very unwell, so I have to focus on preventing these Raynaud's attacks from happening, which is why staying warm is so important.

"I have lots of gadgets like heated pillows, blankets, hand warmers, Raynaud's socks and gloves, fleece-lined slippers - everything to try to prevent an attack from happening. If I go out, it's with three pairs of layers on my feet, three on my hands and goodness knows what else to stop myself from getting cold in the first place."

"I'm terrified of the weather getting colder as anything below 20 degrees in the house triggers a Raynaud's attack and I feel very unwell with it."

Joy

TRAVELLING ABROAD

With post-pandemic restrictions now being lifted, holidays can happen again. We may be a little out of practice at getting away from it all but with a little preparation, your dream destination could be closer than you think.

Living with a long-term condition often means there is more to consider when travelling abroad. But holidays can be very precious times in our lives when memories are made, and travel might even be essential if loved ones are based overseas. For many people with Scleroderma and Raynaud's, travelling abroad is safe from a medical point of view, although planning will be key in ensuring that your trip goes as smoothly as possible and to address important practical considerations.

Talk to your doctor

Always discuss any significant travel plans with your expert clinical team, if possible. It is best to go away when your condition is fairly stable; however, this may not be easy to predict. After booking, always seek advice again if you develop any new or worsening symptoms, and remember to take all contact details with you, just in case.

Know before you go

Research the area you will be visiting, including the distance from your accommodation to the nearest hospital, the local healthcare system and whether any language barrier could be an issue. If you are staying at a resort, there may be English-speaking staff on site who can be contacted if you need help in an emergency.

Some people with scleroderma may have difficulty providing their "fingerprints". This is more of an issue for countries where fingerprints are scanned at border control such as the USA, and may be due to Raynaud's, ulcers or loss of finger soft tissue or contractures. If this is the case, then a letter from your doctor could be helpful.



Carry all medication in your hand luggage to keep it safe.

Vaccinations for travel

You may need vaccinations to protect you from certain diseases found overseas, including typhoid and yellow fever. Some vaccinations should be given well in advance of travel, so it is important to contact a travel clinic at least eight weeks before your departure date.

Always discuss any vaccine requirements with your doctor, as some vaccinations are unsuitable for certain people, including those with weakened immune systems. For example, the yellow fever vaccine is a live vaccine containing a weakened version of the virus itself, that should not be given to certain groups, including people with a long-term health condition such as scleroderma, those aged over 65 and women who are pregnant, as well as people with weaker immune systems and anyone taking the following drug treatments:

Prednisolone (steroid tablets)	Infliximab
Azathioprine	Mycophenolate mofetil
Mercaptopurine	Rituximab
Methotrexate	Abatacept
Leflunomide	Certolizumab pegol
Cyclophosphamide	Tocilizumab
Etanercept	Golimuma
Adalimumab	

Live vaccines cannot be given to people with weakened immune systems.

As a general rule, if you are taking any disease modifying anti-rheumatic drugs, immunosuppressants or biological therapies, you will not be able to have live vaccines. Usually, such a vaccine will only be offered if the drugs are stopped for at least three months.

In addition, live vaccinations cannot be given if you have been taking moderate or high-dose steroids for more than two weeks; these must have been stopped for at least three months.

If you cannot have the vaccine, then you will not be able to travel safely and this may also invalidate your travel insurance, so it is essential to check before you book.

Sometimes live vaccines can be given before immunosuppressive drugs are started, which should then not be for at least two weeks, but preferably four weeks, after you receive the vaccine.

Medications

Contact your doctor well in advance of your departure date, to ensure that your prescription can be processed in time. Ask for a doctor's note that includes details of your diagnoses, care plan and prescribed medications, which could be useful at the airport as well as whilst you are abroad.

Always carry your medication in your hand luggage within a clear, ziplock bag, along with a copy of your prescription, to make things easier at security checkpoints. It is best to keep everything with you rather than in the hold of the aircraft, just in case something gets lost. However, always contact the airline in advance to clarify their requirements and if possible, try to include a spare supply within your hold luggage as well, especially if you will be away for a long time. A letter from the hospital that confirms the medications and states that these must remain in the hand luggage may be useful - especially in relation to creams or liquids. This should use the generic name of the drug, just in case you need prescription abroad where the brand names may be different.

Travel insurance

It is essential to arrange comprehensive insurance whenever you travel abroad. Without suitable insurance, you or your family will be liable for the costs of any treatment received.

When you have any pre-existing health conditions it is essential to ensure that these are covered by your policy, and it may take longer to find a provider that can offer the level of cover you need at an affordable price. If you are advised that insurance is included when you book your trip, remember that this is unlikely to cover pre-existing conditions so additional cover will still be required.

If you are living with a long-term condition the insurance is likely to cost more, so always shop around to avoid paying more than you need to.

When obtaining a quote, remember to include details of all diagnoses and medications, for yourself and the rest of your party and answer all questions as fully as you can. If anything is omitted, even accidentally, this could invalidate your insurance if you need to claim. Remember to inform your insurance company if your health circumstances change in any way after you have purchased insurance, even if this is unrelated to scleroderma.

The following insurance intermediaries can often provide cover to people who have pre-existing conditions, including Scleroderma and Raynaud's. Please note that SRUK does not endorse any providers, and it remains as important as ever to obtain several quotes and seek the best deal for your own situation.

However, each of the companies listed below will kindly make a donation to SRUK for every policy purchased within our community. If you decide to contact them, please quote 'SRUK' when you ask for a quote.

 **OK To Travel**
 oktotravelinsurance.co.uk
 01223 446 920

 **Just Travel Cover**
 justtravelcover.com
 0800 294 2969

 **Freedom Insurance Services**
 freedominsure.co.uk
 01223 446 914

SUPPORT CONTACTS

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

SRUK Needs You!

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

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

New: SRUK support for affected families

This year, we are developing some online support sessions for the parents, carers and families of children and young people affected by Scleroderma and Raynaud's. We will be hosting meetings with talks from expert guests, with the opportunity to put questions to experienced rheumatology nurses outside of an appointment setting. Most valuably, these sessions will offer the opportunity to connect with other families in a similar situation.

If the sessions sound like something you might be interested in, please email info@sruk.co.uk

Keep an eye out for more information on our social media too!

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



Our 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.

Helpline:
0800
311 2756

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](https://www.facebook.com/sruk), [Twitter](https://twitter.com/sruk) and [Instagram](https://www.instagram.com/sruk) pages.

Could you be a Support Group Leader?

We are now recruiting new Support Group leaders for Wales, the South West and our Children and Families Groups. As a Support Group Leader, you will work closely with SRUK to organise and facilitate meetings. As well as a great training programme, you will receive ongoing support within a caring community with regular volunteer meetings. For more information, please email nina.southworth@sruk.co.uk

SRUK Local Support Groups

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

Now that COVID restrictions have been lifted, some of our Support Groups are beginning to meet in person once again. Amongst these is the SRUK Support Group Midlands, who are planning to get together again this year. The group was started by Avtar Gill, after he was diagnosed with secondary Raynaud's in 2016, followed by systemic sclerosis two years later.

"It was during the process of my diagnosis that I first reached out online to try to find others who may be in a similar situation, as I found it very difficult to make connections locally. I eventually suggested that we all try to meet in person," Avtar told us.



Avtar Gill

"It was enlightening to talk to other people who were also living with Scleroderma and Raynaud's, and since everyone felt the same way, we quickly agreed that our meetings should continue. These conditions can cause a great deal of stress and anxiety, so all-round support remains incredibly important. Many people have now made real, lasting friendships, so setting up this amazing group has definitely been worth it." Avtar Gill.

The SRUK webinar programme

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

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

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

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](https://www.healthunlocked.com/sruk). This is a friendly space where you can exchange advice, information and support with others. Please visit [healthunlocked.com/sruk](https://www.healthunlocked.com/sruk)

SRUK is on Youtube!

Did you know that SRUK has a dedicated Youtube channel?

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

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

Local Support Contacts

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

RAYNAUD'S AWARENESS MONTH 2023

Help us to Educate, Empower, Engage

February is our Raynaud's Awareness Month, and this year we will be building on our recent Energy Campaign as well as promoting our general key messages that are the same every year: **know your symptoms, know how you can manage them and know what the risks are.**

There are 10 million people in the UK living with Raynaud's, and our call to action for those who are not yet diagnosed is to take our online test, a quick and easy step that could help them find out whether they may have Raynaud's.

We know that many people just live with Raynaud's and don't know they have it, and others may not realise there are ways to manage the pain of the symptoms. We want to change that, by offering information and support to help. We do this by sharing stories to bring to life the reality of living with Raynaud's. We hope that when people see these stories they will think *"That sounds like me, I've got that,"* and then begin their journey to get support and information and receive a diagnosis.

This year, we will be continuing with our **Raynaud's Energy Campaign** and calling on the government and the energy companies to give people with Raynaud's more support. We have the support of Labour MP Seema Malhotra, and we will be asking our community to write to their local MPs to highlight the challenges you are facing. We will have a template letter to help, but of course you can write about your story too.

Here are just a few ideas for how you can get involved this February:

Catch up with a Coffee

Host a Catch up with a Coffee event, at home with your friends and family, or in the office with your colleagues. One-in-six people in the UK have Raynaud's, and that could include someone at your event. Perhaps they've always had cold hands and feet and didn't know why. By talking about Raynaud's and raising money for SRUK you will be helping us reach more people.

Our online test: pass it on!

Tell people about our **online test**. This could be via social media, in conversation or a work email. Encourage people to find out if they could have Raynaud's and then ask them to tell their networks too. Visit: sruk.co.uk/takethetest

Challenge yourself

Take on a challenge - we have lots of tips to help you manage your Raynaud's whilst exercising. Whether your passion is running or a gentle stroll with friends, make sure people know the extra challenge you face and ask them to support you and SRUK.

Share your story

Telling your story always helps people understand what it means to have Raynaud's. This year we are asking our community to record their own video diaries of their Raynaud's, and we would love for you to do the same. A video message is a brilliant way to give people a real sense of what it's like to live with Raynaud's every day.

Find us on  Facebook,  Twitter  Instagram and  YouTube [@WeareSRUK](https://www.youtube.com/@WeareSRUK)

Know your symptoms

Know how you can manage them

Know what the risks are

Share our posts

Simply by sharing our social media posts, you can help us keep the conversation going and reach as many people as possible.

Contact us: email PR@sruk.co.uk; or call **020 3893 5998** to get involved.



Scan the QR code to find out more



Shape the future with a legacy gift

A gift in your Will to SRUK is a very special way of helping us continue to make a significant difference to the lives of people affected by Scleroderma and Raynaud's.

Over half of all adults in the UK do not have a valid Will and, whilst many people may prefer not to think about writing one, it is the best way of ensuring your loved ones and the causes you care about are looked after when the time comes.

"I decided to leave a gift to the charity a few years after I was diagnosed with scleroderma.

The reason for my decision was when I realised that research projects sponsored by the charity were carefully monitored and reported to the community. As a small charity, funds are limited and it relies entirely on donations, fundraising and legacies.

By leaving a gift I know that my money will go towards continued research and support for individuals diagnosed with Scleroderma and Raynaud's.

If you suffer from Scleroderma and/or Raynaud's or know someone who does, it makes sense to leave a gift in your Will, which will be tax free, to help provide funding for essential research and support."

Lorna

When you pledge a legacy gift to SRUK, you and your family can take comfort knowing that we value gifts at any level and will ensure that your priorities will be looked after by people who understand and share your commitment to our community.

For Brian, it was very important to honour his wife Brenda's legacy when she died. Her gift was special to them both: *"Brenda was a great supporter of the charity and found your services and support extremely beneficial over the years and this was her way of saying Thank You."*

There are several ways to frame a legacy gift, so that you can support SRUK through your Will whilst also ensuring that your loved ones are taken care of. Each one works differently, so it is important to consider which option is best for you.

"For me, leaving a legacy gift is another way to support a cause that is important to you, especially when you are no longer able to help by fundraising in other ways."

Anonymous

A residuary gift

After your loved ones have been provided for and any outstanding debts or bills paid, you can choose to leave the remainder, or a portion, of your estate to your chosen charity or charities.

A pecuniary gift

This is a cash donation of a specified amount. However, inflation may mean your gift loses value over time.

A specific gift

This is a gift of a specified item or asset, such as a property, shares or jewellery.

If you would like to learn more about leaving a gift in your Will to SRUK, please do get in touch, we would love to hear from you.

You can call us on **020 3893 5998**, email supporter.care@sruk.co.uk or visit our website sruk.co.uk/legacy for more information and download our legacy brochure.



FUNDRAISING HEROES

SHINING THE SPOTLIGHT ON SOME OF OUR FANTASTIC SUPPORTERS!

FAMILY FUNDRAISERS

Karen Doherty and her sister **Angie** organised a coffee morning which raised over **£2,183!** Karen and Angie live with Scleroderma and Raynaud's, and they got all their friends and family involved in this fantastic event.



Roy Dudley was diagnosed with scleroderma in **January 2022**, and he decided to organise his own walk in Liverpool for SRUK to raise funds and vital awareness. He was joined by friends and family, and he has raised over **£3,063**.



Tracey and Jess have raised over **£3,020** in memory of their Mum Christine. It's been a real family effort and they've organised various events, from bake sales to a drag night. Over the festive season they organised a Christmas quiz and a bingo night. They are planning even more events in 2023.



Wayne Walton organised a charity football evening and auction event in memory of his father-in-law, Steve, who was diagnosed with Scleroderma and Raynaud's. Wayne, alongside Hartlepool FC and the Under 8's Blacks Football Team, has raised a fantastic **£1,337.90** for SRUK. He has plans to do more events in 2023.



TAKING ON THE CHALLENGE

Nicola Bowie completed the Vietnam to Cambodia Cycle ride - an epic course of over 380km! She planned to raise £250 but has beaten her original target by raising **£333!**

Natalie Law ran the Stroud Half Marathon in memory of her Dad Colin. She has raised **£595** - completely smashing her original target of £300!

Thank you to our **Royal Parks Half Marathon Runners, Ian, Francesca, Leila and Benjamin**, who altogether have raised over **£2,843** for SRUK.



SRUK CHRISTMAS APPEAL: THANK YOU!

We are so grateful to everyone that has donated to our Christmas Appeal, particularly when times are so tough. The appeal has raised **£11,500**, and this will make a huge difference. **Georgina Pantano** shared her story in support of our appeal, and she has sent a personal message of thanks to everyone:

"Scleroderma has changed my life, and so many others', unequivocally. The reality of living with this debilitating condition is that every day is incredibly challenging. Small daily tasks that we used to take for granted, take every ounce of energy. Despite this, we still want to enjoy and thrive in our lives, so we push through with a smile, even though underneath we are facing a constant battle.

I hope that through continued research, future trials into new treatments and earlier diagnoses, people receiving a diagnosis of scleroderma will no longer face the daily struggles I and so many others have.

I would like to give my sincere thanks for your donations, which will help bring this dream one step closer. Your support is priceless."



COULD YOU BE A FUNDRAISING HERO?

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

#TeamSRUK Needs You!

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

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

WAYS TO SUPPORT US

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

How to support us

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

Sources used

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

All our information is in line with accepted national or international clinical guidelines where possible. Where no guidelines exist, we rely on systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals, and government publications.

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



Your magazine, your way

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

Your Stories

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

Pay your Membership by Direct Debit

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

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

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 /WeAreSRUK

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