

SRUK NEWS

Research news

- Improving dental care in scleroderma

Raynaud's Awareness Month 2024

- Turning up the heat: The Raynaud's Energy Campaign
SRUK are once again calling for the UK government to expand the Cost of Living Payment criteria, for people severely affected by Raynaud's.
- What causes Raynaud's?
- Jo's story

"It's so good to know there are others who understand!"

The new Wales Support Group

Thank you to all our amazing supporters!



This amazing group of 37 people walked the Thames Path for SRUK, in memory of their colleague Danielle Turner.

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.

We are looking forward to a very busy 2024, and we are thrilled that so many of you have already been in touch about getting involved. If you or someone you know would like more information, please get in touch!



Events news

We are very much hoping to meet even more of our fantastic Fundraising Heroes at some of the many events taking place this year, with 100s of opportunities available across the UK and overseas. To find out more, please visit sruk.co.uk/get-involved/events/ or email fundraising@sruk.co.uk You can also call us on **020 3893 5993**.

Whatever you decide to do, we will be by your side every step of the way. When you join **TeamSRUK** you’ll receive a free fundraising pack with an SRUK running vest or T-shirt and some materials to help you spread the word such as banners and wristbands, along with ongoing support from our dedicated fundraising team.

Here are just a few of the events that are coming up in 2024:

Barcelona Half Marathon	Half Marathon	Barcelona	11 February 2024
Barcelona Marathon	Marathon	Barcelona	10 March 2024
Paris Marathon	Marathon	Paris	7 April 2024
London Landmarks Half	Half Marathon	London	7 April 2024
London Marathon	Marathon	London	21 April 2024
Leeds Half Marathon	Half Marathon	Leeds	12 May 2024
Hackney Half Marathon	Half Marathon	London	19 May 2024
Ford Ride London-Essex 60	Cycling	London-Essex	26 May 2024

Other ways you can help

You don’t need to run a marathon to make a difference. We are always very grateful to the wonderful people who can help us out by occasionally giving just a little of their time to help us to continue our work.

Online workshops

Throughout the year, we are holding a series of workshops and focus groups, that are vital in helping us ensure our services are fully tailored to our community. These meetings are usually held online for around an hour, when participants are invited to have their say about our work.

For more information on these opportunities and more, please get in touch.

Please visit sruk.co.uk/get-involved/events or contact us at fundraising@sruk.co.uk

Publication reviews

We are always updating our factsheets and booklets, and we often ask people living with these conditions to help us with these reviews and provide feedback when necessary before they are published. This will sometimes involve just a couple of pages at a time, and the material can be sent via email.

Spread the word!

And finally, you can always support us without even leaving your home. Simply helping us to spread the word and sharing our social media posts really can make a difference.

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

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

Welcome to our Winter edition of the SRUK magazine and may I wish you all the very best for the year ahead.

February is **Raynaud’s Awareness Month**, and we want to ask for your help to build on the success of last year to spread awareness of the condition. Every action helps, whether it’s putting up a poster in a GP surgery, community centre or local pharmacy, or holding your own Catch up with a Cuppa to help fundraise and increase awareness.

At SRUK we believe that no-one’s health should be put at risk because they are too scared or worried to turn on their heating.

This winter, we are once again calling for the UK government to expand the Cost-of-Living Payment criteria, to help people who are severely affected by Raynaud’s. This is more crucial than ever, as our latest research shows that many people still struggle to heat their homes amid the current cost-of-living crisis.

Since last year, our Raynaud’s energy campaign has gained momentum and received cross-party support, but we need your help to reach as many MPs as possible so that they understand the true impact of the energy crisis on people living with Raynaud’s. There’s more about the campaign on page 10.

You can help us by getting in touch with your own MP about our campaign, to let them know why this is so important. You can email, telephone or write to them. There are helpful hints and a template letter on our

website. To find out more, please visit: sruk.co.uk/get-involved/awareness-events/write-your-mp

Although Raynaud’s is so common, there’s still little awareness and understanding of this condition. However, recently there has been some interesting research looking to increase our understanding of the genetic mechanisms linked to Raynaud’s, which could help us develop better, more targeted treatments and identify existing drugs that could also be effective against the symptoms. Turn to page 16 for more information. We would like to thank Jo for sharing her story about living with Raynaud’s, how she manages her symptoms and the impact the fuel crisis has had on her.

Many of you have shared with us the challenges you face when you go to the dentist. In 2021, SRUK funded a project entitled ‘*Scleroderma in the Mouth: Improving Pathways to Care*’, led by Professor Liz Walker from the University of Hull, supported by her co-investigator Dr Liz Price and Professor Francesco Del Galdo and Dr Vishal Aggarwal from the University of Leeds.

Through the insights gathered from their patient surveys and the analysis of previous research regarding barriers to care, the team were able to produce a list of recommendations to foster better oral and dental treatment. The team also developed some materials to increase awareness of the oral manifestations of scleroderma amongst dentists.

It is because of your continued support that

we are able to fund research like this. By uniting as a community, we really can make a difference to the future of everyone affected by Scleroderma and Raynaud’s.

Very best wishes

Sue

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DOC SPOT

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



Q What is burning foot syndrome, and is it possible to have this alongside Raynaud's please?

A Burning foot syndrome is another term describing the uncommon medical condition "erythromelalgia" (EM), a vascular disorder in which there is increased blood flow to the extremities associated with warm temperature. Essentially it is the opposite of a Raynaud's attack and is caused by the blood vessels "overreacting" to warm temperatures. EM can coexist with Raynaud's in some people and the burning symptoms with increased redness at the end of a typical Raynaud's attack may be more prominent than the "white" or "blue" phases. EM is a very difficult condition to treat and is associated with small fibre neuropathy, so it can respond to drugs that modify nerve irritability in some cases.

Q Could there be a connection between having Raynaud's and also an underactive thyroid? Or is it more likely to be a coincidence?

A The thyroid is an important gland in the neck which produces thyroxine, a hormone that regulates metabolic activity. Underactivity of the thyroid function is associated with a lower metabolic rate and body temperature. In people with Raynaud's Phenomenon this can make the attacks more severe or frequent. There is no direct association between Raynaud's and an underactive thyroid, but patients with autoimmune disease including scleroderma are more prone to autoimmune thyroid disease which can cause hypothyroidism. This association is a coincidence rather than being causally linked.

Q I have Raynaud's, especially in my hands, and I have a couple of warts on my fingers. What is the best or the safest way to treat these please?

A Since Raynaud's can be aggravated by low temperature exposure it is sensible to avoid freezing treatments as a therapy for viral warts. It is better to consider treatments using salicylic acid, which is often included in solvent-based treatments that are applied daily with removal of the dead skin around the wart every few days. There may be some slow healing of the skin due to Raynaud's of the fingers, and so it is important not to be too vigorous in the treatment and certainly to seek medical advice if any concerns arise or there is any uncertainty about diagnosis.

Q I've been taking nifedipine for almost a year, and my dentist thinks it is now causing inflammation in my gums. Does this sound right, and should the treatment be stopped?

A Your dentist is correct that some patients do develop overgrowth or inflammation of the gums when they take nifedipine and related drugs that are used to treat Raynaud's. The mechanism is unclear, but it may relate to increase in blood flow in the gum tissue. If it is a significant problem, then generally nifedipine is discontinued and an alternative treatment could be considered. Drugs such as losartan or other vasodilator treatments can be tried and may not cause the same issue.

Q I have been diagnosed with Raynaud's and am very sensitive to the cold, but I really can't regulate my body temperature. It's like the colder it gets, the lower it goes. Is this a normal part of having Raynaud's?

A There are many causes for Raynaud's Phenomenon, but a general feature is that attacks are triggered when body temperature lowers. Patients with primary Raynaud's particularly illustrate the sensitivity to temperature, and it is often core temperature that triggers attacks, rather than exposure to cold temperatures in the hands and feet. In this case it may be that oversensitivity to low temperatures or body temperature is a key mechanism. When Raynaud's is secondary to a connective tissue disease such as systemic sclerosis, there may be other factors that trigger Raynaud's attacks or complications.

There are many causes for Raynaud's Phenomenon, but a general feature is that attacks are triggered when body temperature lowers.

Q Will using an infrared sauna help with Raynaud's, or could it make things worse?

A Infrared saunas use infrared light energy, rather than the hot steam of a regular sauna, to warm the skin, and there are various types of saunas and infrared blankets. There is no strong medical evidence to support their use for Raynaud's Phenomenon, but it is unlikely they would cause any harm, and so this is an approach that some people may find helpful, although it is not proven based on strong medical evidence. In the future, research studies may better define the benefit of this.

Q Is it possible to get an elbow ulcer? I think I am developing something like this, and I would appreciate any advice you may be able to offer.

A Skin ulcers can develop in connective tissue disease associated with blood vessel damage or other mechanisms such as calcinosis cutis, when chalky calcium containing material is deposited under the skin. This can occur at areas of pressure or trauma, including the elbows. For some patients with systemic sclerosis or dermatomyositis this can develop over the elbows and may be painful and troublesome. Calcinosis with ulceration may become infected and require antibiotic treatment. If ulcers develop you should seek medical advice, as specialist assessment and treatment might be needed together with dressings.

Q I have been in remission from Non-Hodgkin's lymphoma for many years, but now it seems to be active again. Is there a link between autoimmune disease and Non-Hodgkin's please, and is it common to have both together?

A I am sorry that your lymphoma seems to be active again. Lymphoma is a malignant condition of the immune cells or lymphocytes. Although it is uncommon, some patients with lymphoma do develop autoimmune disease such as dermatomyositis. In addition, there are some specialised forms of lymphoma that can associate with Sjogren's syndrome.

There are many forms of cellular therapy, including treatments that use stem cells. Stem cells are the cell type important in growth and development that can produce different types of specialised cell. The best example relevant to systemic sclerosis is autologous hemopoietic stem cell transplant.

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 Can you please provide some information on stem cell therapy? Is this available as a treatment for scleroderma now?

A There are many forms of cellular therapy, including treatments that use stem cells. Stem cells are the cell type important in growth and development that can produce different types of specialised cell. The best example relevant to systemic sclerosis is autologous hemopoietic stem cell transplant. This is now an established treatment for severe cases of systemic sclerosis but involves intensive immunosuppression followed by an infusion of harvested stem cells. It has been shown in clinical trials to be superior to some other forms of immunosuppression in systemic sclerosis. It is not a treatment that is suitable for all patients, particularly because there are severe complications in some cases.

Another stem cell-based treatment is autologous lipotransfer, when fat stem cells are taken from one part of the body such as the abdomen or thighs and injected to an area affected by scleroderma such as the face. This is a promising approach, but more research is needed to fully define its potential and mechanisms. Other forms of “experimental” stem cell treatment that you may come across are used for neurological or other diseases. These are not well characterised or advised and some of these are potentially dangerous.

In summary, whilst some approaches look promising, stem cell treatment is something that should only be delivered in reputable specialist medical facilities with knowledge of systemic sclerosis.

SCLERODERMA AND THE MOUTH IMPROVING PATHWAYS TO CARE

SRUK-funded research aims to improve access to effective dental care for people living with scleroderma.

Scleroderma can affect the mouth in different ways. These oral manifestations can lead to further health complications, as well as difficulty in being able to access effective dental care. New SRUK-funded research has explored these barriers in detail, and developed new guidelines for dentists and healthcare professionals that are available to download and designed to improve oral and dental care for people with scleroderma.

Research suggests that 80% of people diagnosed with scleroderma will experience oral and dental complications as a result of their conditionⁱ. These symptoms can affect an individual physically, emotionally and even socially, and have a significant impact on quality of life.

Despite these complications being so common in scleroderma, people living with the condition often face a number of barriers, including:

- Accessing appropriate oral and dental care, and,
- Obtaining timely referral when necessary to specialist dental services.

ⁱ Mills, T.J., Price, E., Aggarwal, V.R. orcid.org/0000-0003-0838-9682 et al. (2 more authors) (2023) Clinician and Patient Experiences of Managing and Living with Oral and Dental Manifestations of Scleroderma: A Scoping Review. *Journal of Scleroderma and Related Disorders*.



This means there has been an unmet need for research around the oral and dental aspects of scleroderma, to improve overall understanding of these issues, as well as to develop awareness and specialist guidance for dentists and rheumatologists.

SRUK's 'Improving Quality of Life' Grant Call

In 2021, SRUK launched the 'Improving Quality of Life' grant call. Through this, we have funded an exciting project: **'Scleroderma in the Mouth: Improving Pathways to Care'**, that aims to improve quality of life for people with scleroderma by focussing on oral and dental care.

The project is led by Professor Liz Walker from the University of Hull, supported by Dr Liz Price, with Professor Francesco Del Galdo and Dr Vishal Aggarwal from the University of Leeds, where Professor Del Galdo is undertaking the STRIKE study.ⁱⁱ

ⁱⁱ Stratification for Risk of Progression in Scleroderma (STRIKE) is a five-year study led by Professor Francesco Del Galdo in Leeds. It aims to develop a screening tool to identify people at risk from severe disease in scleroderma, provide therapies for those at higher risk and avoid unnecessary interventions for people who do not need them.

'Scleroderma in the Mouth' about the project

The project is underway, and aims to improve oral and dental care for people with scleroderma in the following ways:

- Understanding patient and clinical perspectives of the problems,
- Identifying barriers to good care, and,
- Raising awareness and developing guidance for dentists and rheumatologists to improve the referral pathway to specialist dental services.

Once the project commenced, the team set out to undertake certain key exercises:

- Firstly, surveys of patients involved in the STRIKE study in Leeds, along with rheumatologists, and dental professionals were carried out. The surveys aimed to assess people's experiences of scleroderma-related dental problems, clinical awareness of the condition and its oral manifestations, as well as current strategies for referral to specialist dentistry.
- Secondly, the team set out to analyse the existing literature on oral and dental problems in scleroderma by performing a 'scoping review' of previous research, to gain further insight on how these problems are experienced by patients, and how they are being identified and managed by healthcare professionals.
- The team were also interested in identifying current barriers to receiving good oral and dental healthcare for people living with scleroderma, which could inform a set of recommendations for healthcare professionals.

The patient experience of oral and dental problems

People affected by the oral and dental complications of scleroderma frequently report a variety of physical, psychological, and social issues, arising from problems affecting the mouth and teeth. However, up until now, these aspects (especially the related psychological and social impacts), have been understudied, with an unmet need for more research into how these problems impact upon everyday life.

Through their patient survey, the team were able to assess the patient-reported experiences of

160 respondents affected by oral and dental issues. Reported physical symptoms included:

- mouth dryness,
- microstomia (reduction in the size of the mouth),
- crumbling/breaking/loosened teeth,
- bleeding and receding gums,
- tooth decay,
- mouth ulcers,
- altered facial features.

Moreover, some patients reported an inability to eat and weight loss as a result of their symptoms.

The team found that patients felt a lack of understanding, knowledge, and awareness of the condition amongst dental professionals meant that the care they received was often inappropriate.

People also reported that the physical symptoms led to a variety of connected psychological and social impacts. Through the surveys and face-to-face patient interviews, the team heard that people frequently experienced pain, fear, social exclusion, a loss of self-confidence, and also feelings of embarrassment, anxiety, and depression, as well as restriction from social interaction/events, and a reluctance to be in public settings.

Barriers to good oral and dental care

Given the severity of symptoms and their effects on everyday life, high-quality care is essential. However, we know that many patients do not receive appropriate care or timely referral to specialist dental services. Understanding the current barriers to good oral and dental care is therefore key to improving the quality of treatment that patients receive.

Lack of awareness

Through the patient survey, Professor Walker's team found that patients felt a lack of understanding, knowledge, and awareness of the condition amongst dental professionals meant that the care they received was often inappropriate, did not take their condition into account, and reduced their chances of being referred to specialist services. The importance of this lack of understanding was echoed in the team's scoping review, which highlights that previous research has also suggested that a central barrier to high-quality care is the lack of awareness among dental professionals of scleroderma and its oral, facial, and physical effects.

Psychological effects and physical aspects

The review also identified that psychological symptoms including depression and anxiety as a result of previous negative dental experiences, pain, or stigma can also act as barriers. Similarly, physical restrictions (like restriction in opening the mouth), can prevent the daily maintenance of dental hygiene and limit oral access for dentists, restricting the care that people can receive. Beyond this, the team found that the financial burden of regular dental appointments and specialist tools to maintain dental hygiene can also limit a person's access to dental services.

New guidance for dentists and healthcare professionals

Through the insights gathered from their patient surveys and the analysis of previous research regarding barriers to care, the team have produced a list of recommendations to foster high-quality oral and dental treatment in their review paper:

Recommendations for dentists:

- Seek personalised information from patients and their healthcare team.
- Provide accommodations in appointments and plan for limitations (e.g., smaller instruments, longer appointment times).

Recommendations for rheumatologists:

- Routinely inquire into oral and dental health at the point of diagnosis.
- Refer to specialist dental services to facilitate early intervention.

For all dental and healthcare professionals:

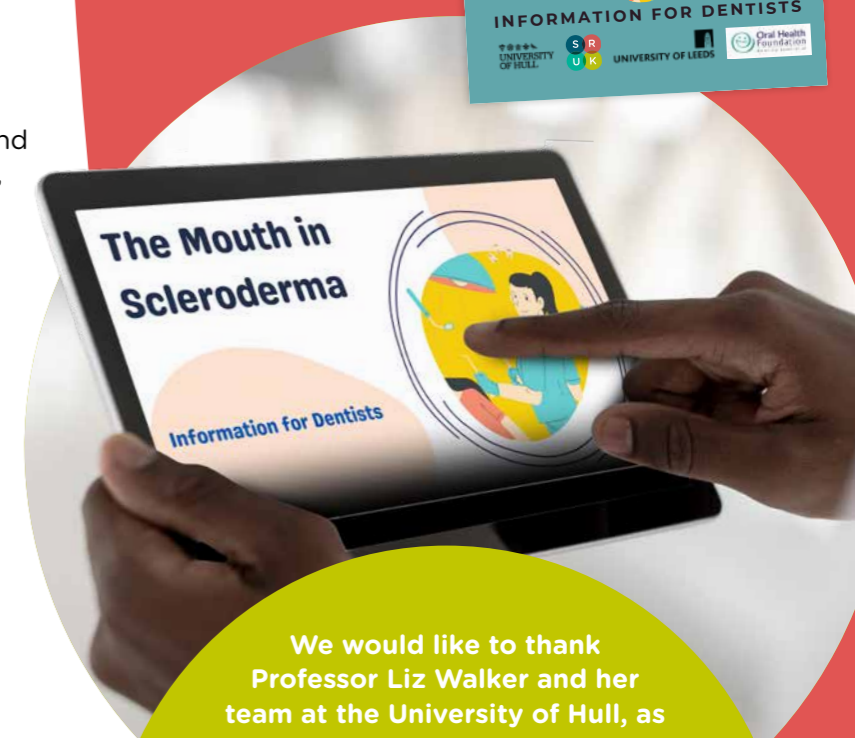
- Increase awareness of the oral and dental manifestations of scleroderma, the related negative psychosocial impacts, and barriers to care (e.g., stigma, functional limitations, mental health).
- Communicate and collaborate with other healthcare professionals (requests for advice and guidance, co-created treatment plans, sharing knowledge and information).
- Consider referral to physical therapy, occupational health, and psychological services for assisting patients in maintaining dental hygiene.
- Treat patients with empathy, patience, flexibility, and a willingness to learn more about the condition.

Tools for patients and dentists

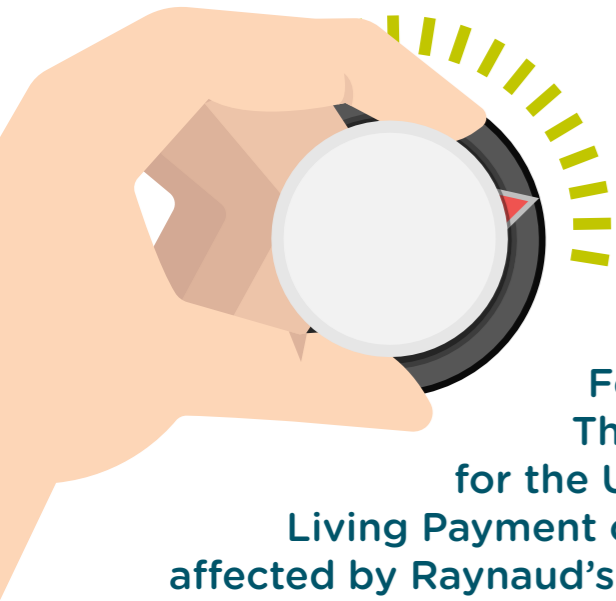
Beyond providing recommendations for healthcare professionals, the team also developed some materials to foster greater awareness of the oral manifestations of scleroderma amongst dentists.

By following the link or scanning the QR code, you can access a video and information card, which you can show to your dentist to help them learn more about your condition, how it affects your oral health, and how they can best help someone living with scleroderma.

Please visit: bit.ly/SRUKDentistinfo



We would like to thank Professor Liz Walker and her team at the University of Hull, as well as collaborators at the University of Leeds, for undertaking this important project which aims to address a major cause of diminished quality of life for people living with scleroderma. We hope that this research will enable those living with the condition to receive better oral and dental care, and ensure there is a clear pathway for referral to specialist dental services. We look forward to sharing further insights from the project after completion!



TURNING UP THE HEAT FOR CHANGE: THE SRUK RAYNAUD'S ENERGY CAMPAIGN

February is **Raynaud's Awareness Month**. This winter, SRUK are once again calling for the UK government to expand the Cost-of-Living Payment criteria, to help people who are severely affected by Raynaud's. This is more crucial than ever, as our latest research shows that many people are still struggling to heat their homes amidst the current cost-of-living crisis.

We ran our first energy prices campaign last year, and quickly gained invaluable support from Members of Parliament. Two MPs raised the matter within The House of Commons, and many of our community wrote to their own MPs requesting their support. However, with prices remaining high and even less available support than last year, our campaign continues this winter.

"No-one's health should be put at risk because they are too scared or worried to turn on their heating."
Sue Farrington

When you are living with severe Raynaud's, your wellbeing could depend on keeping warm. It remains as vital as ever that everyone can heat their homes, without having to sacrifice food or other basic essentials.

Since last year, our Raynaud's energy campaign has gained momentum and received cross-party support. Last March, our initiative was publicly backed by the then Shadow Business Minister (now Shadow Minister for Skills) and MP for Feltham and Heston, Seema Malhotra. She said at the time: *"The government and energy companies must work to keep heating affordable for people with Raynaud's, where hands or feet can suddenly turn white and be very painful. Those living*

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

Our latest survey shows that for many households within our community, navigating the energy crisis has become more difficult than ever, with people still having to risk a painful attack rather than turn the heating on. Our survey has revealed that over half of respondents are finding it even harder to pay their energy bills, compared to last year. However, many still do not qualify for government support in the form of the Cost-of-Living Paymentⁱ.

These results are alarming, given that the often-debilitating symptoms of Raynaud's are usually triggered by cold conditions and emotional stress.

The survey

Our online survey was promoted across our social media channels and Enews. In total, 1,162 people living with Raynaud's responded to the survey, and you told us:

The Cost-of-Living Payment is a welfare benefit that may be available to people who were entitled to receive certain other benefits during the qualifying period.

#KNOWRAYNAUD'S

Throughout Raynaud's Awareness Month, SRUK campaigns to raise awareness and help more people to:

- **know** the symptoms,
- **know** how to manage them, and,
- **know** and understand the risks.

- **51%** of people living with Raynaud's are finding it more difficult to pay their energy bills compared to this time last year.
- Almost **one-third** reported things are still just as hard as in 2023.
- **68%** of people living with Raynaud's would like to see the £400 Cost-of-Living Payment return this year.
- **52%** do not believe that Ofgem's lower energy price cap will result in less expensive energy bills.
- **57%** do not trust the government to act in the best interests of the public when it comes to tackling the cost-of-living crisis.

Some people have also had to make changes and even sacrifices as they attempt to manage rising heating costs:

- **Over 10%** of our respondents reported buying less food than they need, in order to pay their energy bills.
- **57%** said they had not received any Cost-of-Living payments this year to help with rising energy costs.
- To keep their energy bills affordable, **41%** of people said they are finding other ways to keep warm at home, such as wearing thick jumpers and gloves.
- Almost one-in-four (**23%**) are cutting back on leisure activities.
- **20%** are consciously choosing budget food options, and,
- More than one-in-10 (**13%**) are buying less food overall to prioritise their energy bills.

Sue Farrington said in response to these findings: *"There is no cure for Raynaud's but one of the best treatments is a warm home. No-one's health should be put at risk because they are too scared or worried to turn on their heating. If the government is serious about improving health outcomes for patients, they must step up their support for people with Raynaud's. This must start with some financial support to ease the immediate crisis, alongside other solutions to ensure people with this often-debilitating condition can have a pain-free winter and Christmas."*

In addition to an expansion of the Cost-of-Living Payment criteria, SRUK is also urging the government to explore practical solutions to help people living with Raynaud's through the winter, such as a national roll-out of the Warm Home Prescriptionⁱⁱ.

We are arguing that this support could be funded by using a proportion of the money raised by the ongoing Energy Profits Levy as well as other options such as the Household Support Fund.

We are very grateful to everyone who responded to our survey. Your support helps us steer our campaign to best reflect the needs of our community.

ⁱ gov.uk

ⁱⁱ Es.catapult.org.uk

Energy suppliers

We have written to the six major energy suppliers and asked them if they could offer support to people with Raynaud's. EDF were the only supplier to let us know that they do list Raynaud's as a condition that would be eligible for more support.

In December we wrote to the other companies to ask them if they would follow EDF's example. At the time of writing we were still waiting for replies.

About the Cost-of-Living Paymentⁱⁱⁱ

Cost-of-Living Payments are designed for people struggling with living expenses. To be eligible, individuals must have been entitled to receive certain benefits during specific timeframes. This means that many people living with severe Raynaud's who may be struggling with energy costs during winter may not be able to claim.

To be eligible for Cost-of-Living Payments, you must have been entitled to receive any of the following benefits during the qualifying period:

- Income-based Jobseeker's Allowance (JSA)
- Income-related Employment and Support Allowance (ESA)
- Income Support
- Pension Credit
- Universal Credit (UC)
- Child Tax Credit
- Working Tax Credit

Many people are having to risk a painful Raynaud's attack rather than turn on the heating.

Getting support with energy costs

If you are having serious difficulties with energy costs or if you need urgent advice, you can contact Citizens Advice Consumer Service on **0808 223 1133**, or visit **citizensadvice.org.uk**

If you are having difficulty paying your energy bills, your supplier must work with you to reach an affordable plan under the rules of the Energy Regulator of Great Britain (Ofgem). There could be several solutions available, such as more time to pay, breaks from payments or access to hardship funds.^{iv}

iii gov.uk/guidance/cost-of-living-payment
iv Ofgem.gov.uk

You may be entitled to some support from the government to help with rising costs this winter. The following is intended for information only, it remains as important as ever to seek individual advice based on your own situation.

Winter Fuel Payment^v

This is one-off payment to help older people with the cost of living. It is generally payable to people in receipt of the State Pension, and is usually paid automatically.

Warm Home Discount^{vi}

The Warm Home Discount is a one-off discount on your electricity bill. It may be available to people with high energy costs who receive the Guarantee Credit element of Pension Credit, or certain means-tested benefits. However, not all energy companies are participating in the scheme. For more information, please visit **gov.uk/winter-fuel-payment**

Cold Weather Payment^{vii}

This is payable to people in England, Wales or Northern Ireland, who are in receipt of Pension Credit or income-related benefits. It is paid automatically if temperatures fall 0°C/32°F for seven days in a row.

Priority Services^{viii}

Each energy supplier will have a Priority Services Register, for customers who may be in a vulnerable situation or require additional support, such as older people or those living with a long-term condition or disability. You can sign up to this register for additional support, for example in the event of a power cut. Remember to join all available registers if you have multiple suppliers.

The Warm Home Prescription^{ix}

The Warm Home Prescription has been trialled within England and Scotland. It aims to help people struggling to afford their energy bills who are also living with severe health conditions that are aggravated by the cold. The scheme is looking at providing a low carbon warm home, and if this could help improve the health and wellbeing of individuals so that overall use of health services would naturally reduce. This could result in cost savings to the NHS, and also reduce some of the pressure upon the service and its staff.

v gov.uk/winter-fuel-payment
vi gov.uk/winter-fuel-payment
vii Ofgem.gov.uk
viii Ofgem.gov.uk
ix bbc.co.uk/news

Energy Profits Levy

This is a temporary levy that is applied to the profits of oil and gas companies operating within the UK or the UK continental shelf^x.

Household Support Fund

This is designed to help vulnerable households afford basic essentials over the winter period.^{xi} The funding is available to local authorities for those who need it most.

Turning up the heat: how you can get involved

We will keep on campaigning for vital change to support people with severe Raynaud's, during Raynaud's Awareness Month this February and throughout the winter. We now need your help more than ever, to make sure that our voice continues to be heard. There are many ways that you can get involved and be part of the campaign so if you would like some more information, please get in touch.

Contact your MP

We need to help as many MPs as possible understand the true impact of the energy crisis on people living with Raynaud's.

You can help us by getting in touch with your own MP about the campaign, and telling them why this is so important. You can email, telephone or write to them. There are helpful hints and a template letter on our website. To find out more, please visit: **sruk.co.uk/get-involved/awareness-events/write-your-mp**

Contact your energy provider

Get in touch with your own energy supplier to encourage them to recognise severe Raynaud's as a criterion for extra support.

Let them know about Raynaud's, how it affects you and why it is crucial that you are able to heat your home without sacrifice.

Take the online test

You can take our easy, online Raynaud's test by visiting **sruk.co.uk/testme**

You can also share the link with friends and family; they might be affected and not even know it!

x gov.uk
xi gov.uk

Spread the word

Helping to raise awareness about the impact of Raynaud's and how the energy crisis is affecting many of our community really will make a difference. You can support us by sharing our posts across your own social media to keep on spreading the word.

Share your views

It's not too late to get involved in the campaign and share your views and experiences! For more information, please contact us.

About Raynaud's Awareness Month

Every February is SRUK's Raynaud's Awareness Month, when we encourage people to **know the symptoms, know how you can manage them and know what the risks are**. Our aim is to spread awareness and encourage people to take our online test to find out whether they could have Raynaud's.

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. There may also be many more people out there who are struggling due to the energy crisis. We are working tirelessly to change that and offer information and support to help.

For more information or to get involved, please contact us.

Catch up with a Cuppa for Raynaud's Awareness

We're encouraging everyone to Catch Up with a Cuppa this February.

Get together with friends, colleagues or neighbours and help raise awareness as well as vital funds for SRUK.

Register today to receive a FREE SRUK T-shirt and fundraising pack. We also have banners, posters and more to help make your event a success.

We would love to hear all about your Catch Up, so do please get in touch.

To say thank you, everyone who raises £250 will receive one of our bespoke SRUK mugs!



There should be more available for those who have no choice but to stay warm.

I am dreading the cold this winter.

Help should be provided by the government to help those with Raynaud's.

Health really matters.

WE DON'T PUT THE HEATING ON

I am really struggling...

Costs are high and have a serious impact on ... quality of life.

I have no help And it's very difficult to keep warm.

Dreading moving further into winter. At the moment having 5-6 Raynaud's attacks daily and that is with medications. Only turning heating on as a last resort as we can't afford things as it is.

Keeping warm this winter

It is clear that for many of our community, the cold weather has brought stress around health as well as household finances. Keeping warm is not always as simple as turning up the heating, especially during times like these. We have put together some helpful tips designed to help you to keep warm – and hopefully keep well, this year.

"We are now turning off the radiators during the day in the rooms we are not using. We get up in the morning and go rushing around to make coffee and we turn the heating up to 20 degrees. Once we are up, the heating goes off in the bedrooms. During the day, we mostly have the heating on in the kitchen, where we spend most of our time."

Barrie

Keeping warm at home

- The UK government website suggests heating your home to a temperature that is comfortable for you, and the recommended temperature is a **minimum of 18 degrees** for the rooms you spend the most time in.¹
- Other government suggestions include fitting draught excluders to retain warmth, and keeping windows closed at night. Please see gov.uk for more information. You could try using old towels, blankets, or pillows as a temporary measure, to help stop draughts coming in through window frames or under doorways.
- To save money, choose only a few rooms to keep heated, with timings that work for you. Try to heat your home when it is coldest, such as early mornings and in the evening.
- Close the curtains or blinds when it starts to get dark, as this will help keep the warmth inside your home.

The recommended home temperature is 18 degrees for the rooms you occupy most.

Going outside

- If you are walking or exercising outdoors, stretching beforehand can help circulation.
- Always try to keep your body's core warm. As soon as core temperature begins to drop, blood flow starts to reduce towards exposed areas like the hands and feet, and this can exacerbate Raynaud's.
- Dress in layers rather than in one single garment, because the air trapped in-between will help to insulate your body. Ensure that clothing is not too tight, as this can restrict blood flow.
- Try to avoid getting hot very quickly and then suddenly cooling down.
- Prepare in advance by warming up gloves and socks on the radiator. Always have extra pairs ready in case you need them.
- Put on as many warm clothes as you can before you go out in the cold. It is better to retain your temperature as much as possible, rather than having to warm up after getting too cold.
- Breathing and stretching before exercise can help improve circulation.

- When you are spending longer periods outside, take a thermos with a hot drink that you can also use to warm your hands.
- Try using heat packs in your gloves and socks when spending time outside.
- Breathe in through your nose and out through your mouth when outdoors – this stops cold air being sucked in through your mouth and sent straight to your lungs. The nose acts as a filter.

And finally, remember to check whether there is any extra help you could be entitled to. Visit gov.uk for the latest information and how to apply.

Download our leaflet for more information: bit.ly/SRUKkeepingwarm

"I work from home ... and we cannot afford to put the heating on every day. I remember last winter I was suffering 3 to 4 Raynaud's attacks per day which affected my face, hands and feet. The pain and numbness affected my ability to concentrate, type and answer the telephone. I tried my best to keep warm with hot water bottles, gloves, warm drinks etc, but was still very ill and remember many occasions crying with pain and frustration because I felt so cold. All year, I have been dreading this winter because I know I will experience the same again."

Sharon

RAYNAUD'S PHENOMENON

Raynaud's Phenomenon is a relatively common condition with around 10 million people thought to be affected within the UK alone. Whilst this can be a debilitating condition for one person, it may be quite manageable in another. In severe cases, it can have a huge impact on daily life.

What causes Raynaud's?

Raynaud's attacks are often caused by changes in temperature or emotional triggers like stress or anxiety. However, this does not explain why some people develop Raynaud's when others do not, or why certain individuals are more susceptible to particular triggers. What happens to cause the extreme narrowing of the blood vessels that is a Raynaud's attack, or, in other words, **what causes Raynaud's?**

The simple answer is that we still do not fully understand why Raynaud's develops. However, because of the potential impact, and because secondary Raynaud's indicates an underlying condition such as scleroderma, it remains critical that the research continues. This is the only way to develop our understanding and ultimately improve treatment outcomes across our community.

Is Raynaud's an inherited condition?

Although Raynaud's sometimes appears to run in families, there have not been sufficient investigations to define a clear inheritance pattern. However, there is evidence that variations in certain genes may contribute to a person's risk of developing the condition.

Research conducted during 2018 in London associated a variant within the **NOS1** gene with Raynaud's.ⁱ More recent research, carried out by UK and German-based scientists and published in October 2023, identified two further genetic variants associated with Raynaud's. The research

ⁱ Munir S, Freidin MB, Brain S, Williams FMK. Association of Raynaud's phenomenon with a polymorphism in the NOS1 gene. PLoS One. 2018 Apr 26;13(4):e0196279. doi: 10.1371/journal.pone.0196279. PMID: 29698501; PMCID: PMC5919461.

team analysed the electronic health records of more than half a million people participating in UK Biobank, a biomedical research resource capturing biosamples (blood and tissue samples, genetic data) and health information on participants, discovering 5,000 people with Raynaud's. By comparing the genetic information of these people with over 400,000 controls, they discovered variations in two genes which may play a role in the development of Raynaud's:

- the **alpha-2A-adrenergic receptor for adrenaline, ADRA2A**, a classic stress receptor that causes the small blood vessels to contract,
- The **IRX1** gene, thought to regulate the ability of blood vessels to contract.

Increasing our understanding of the genetic mechanisms linked to Raynaud's could help us develop better, more targeted treatments, and identify existing drugs that could also be effective against the symptoms. Future research focussed on distinguishing specific gene variations and assessing which of these variants have been passed on in families could help in establishing inheritance patterns.

The female factor

Raynaud's is around four-times more common in women and girls than in men, and this is probably connected to female hormones.

There is a known association between Raynaud's and the female hormone oestrogen.

Symptoms are often first noticed around the time of the menarche, when periods start, and oestrogen levels rise.

Hormone changes are also significant, and attacks may be worse at mid-cycle, when oestrogen levels peak.

In pregnancy, oestrogen levels will naturally rise, although (surprisingly), Raynaud's symptoms sometimes improve, because circulation is increasing at the same time.



Common triggers include:

- Cold temperatures or changes in temperature.
- Emotional distress (like stress or anxiety).
- Certain lifestyle aspects, such as smoking.

The SRUK STAR App

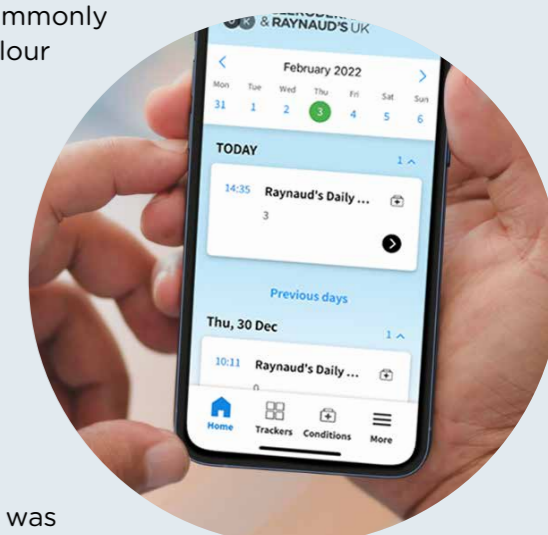
The SRUK STAR (Symptom Tracking App for Raynaud's) App is designed to help users to understand their Raynaud's symptoms, frequency, and potential triggers.



Since January 2022, almost 300 people have signed up to the App, which collects user-reported data. You can also track lifestyle factors that could be relevant, like caffeine intake, alcohol consumption, and mood.

What we learned from STAR so far:

- Attacks were most frequent during winter.
- Some people were affected all year round.
- Cold air was the most frequently reported trigger, followed by temperature change.
- Attack severity and duration did not dramatically differ between seasons.
- Stress was also reported as a cause.
- Some attacks had no obvious trigger.
- The fingers were involved in the majority of cases, followed by the thumbs, toes and feet.
- Paleness to the skin was the most commonly reported colour change, however:
- Fourteen percent of attacks involved a colour change from red, to white, to blue, often when the severity was more extreme.



The link between oestrogen and Raynaud's also needs to be considered when it comes to hormone-based medical treatments, such as the contraceptive Pill. Some people may be advised to avoid those containing oestrogen, although the progesterone-only Pill, if suitable, will usually be considered safe.

There are some known cases of women with no previous history of Raynaud's who suddenly developed symptoms after taking the oestrogen-containing Pill or hormone replacement therapy. However, topical treatments including pessaries are often suitable for women with Raynaud's and associated autoimmune conditions, although it is essential to obtain medical advice.

Possible triggers

To identify the best approaches to management and treatment, it is important to understand what is triggering symptoms and causing attacks. This is made harder by the fact there are various known, potential triggers, although some attacks appear to have no obvious cause at all.

Chemical triggers

There are certain drugs that can sometimes make the narrowing of the blood vessels (vasospasm) worse. These include:

- Over-the-counter nasal decongestants (e.g., phenylephrine, pseudoephedrine).
- Amphetamines, diet pills, and herbal preparations containing ephedra.
- Agents used to treat attention deficit hyperactivity disorder (ADHD), such as (methylphenidate and dextroamphetamine).
- Some medications used to treat migraine, including serotonin agonists (e.g, sumatriptan) or ergotamine.

Lifestyle triggers

Smoking is known to compromise circulation and could make symptoms worse.ⁱⁱ

Repeated trauma to the hands or fingers, caused by repetitive actions or vibration, could increase the risk of developing Raynaud's. Possible examples include typing, playing the piano or doing similar movements for long periods of time.

Vibration white finger occurs when Raynaud's has been caused by vibration. This typically happens to people who regularly use certain types of vibrating tools, including jackhammers, sanders, grinders, and powered lawn mowers.

COVID-19

More recently, a couple of very small studies have linked COVID-19 to developing Raynaud's Phenomenon.^{iii iv} However, more research is needed into this area to fully establish the existence or the extent of any connection.

In the meantime, we would love to know what you think about this: **did your Raynaud's symptoms change following COVID?**

Could there be a link between COVID-19 and Raynaud's?

Prevention and treatment

With Raynaud's, prevention is key. A Raynaud's attack can limit daily activities and take time to subside, so taking steps to reduce the number of attacks or symptom severity is a significant part of managing the condition.

ii Suter LG, Murabito JM, Felson DT, Fraenkel L. Smoking, alcohol consumption, and Raynaud's phenomenon in middle age. *Am J Med* 2007;120:264-71.

iii COVID-19 Infection Induced Raynaud's Syndrome | Proceedings (ucla.edu)

iv Bansal CJ, Kamel K. Worsening of Primary Raynaud's Phenomenon During Episodes of Pyrexia and Rigors in SARS-CoV-2 Infection. *Cureus*. 2023 Jan 14;15(1):e33781. doi: 10.7759/cureus.33781. PMID: 36819449; PMCID: PMC9928217.

Keeping warm in colder environments can help prevent and manage Raynaud's attacks, and dressing in layers helps increase and maintain the body's core temperature to retain warmth. There are lots of tips on our website.

Relaxation techniques are beneficial when Raynaud's is triggered by stress or anxiety. Stress is known to narrow the blood vessels (vasoconstriction) which compromises circulation, especially to the extremities like the fingers. By practicing stress management and relaxation strategies, Raynaud's attacks may improve.

Exercise can help to lift our mood and improve circulation. Incorporating regular exercise such as walking, at a level that is comfortable and manageable, may help Raynaud's symptoms.^v

Medical treatments

Drug treatment may be given when Raynaud's is having a significant impact or there is a risk of developing ulcers. This is given to alleviate symptoms; however, it does not provide a cure.

- **Calcium channel blockers** are a group of medicines that relax and open the small blood vessels in your hands and feet, decreasing the frequency and severity of attacks for many people. They can also help heal digital ulcers. Nifedipine is a drug in this group that is licensed for Raynaud's, and others are also commonly prescribed.
- **Iloprost** is a type of prostaglandin, a medicine used to treat high blood pressure (hypertension) and other diseases where blood vessels are constricted. Iloprost is a type of prostaglandin, that works by relaxing your artery wall muscles. It is usually given via a drip over several days.
- **Phosphodiesterase 5 (PDE5) inhibitors** including sildenafil (or Viagra), work by preventing an enzyme called phosphodiesterase type-5 from working too quickly and relaxing the blood vessels.

v 1. Non-drug approaches to treating Raynaud's phenomenon (2015), Kwakkenbos, L. & Thombs, B.D. Springer.

- **Fluoxetine** is an antidepressant that works by increasing the amount of serotonin within the brain. Altering this balance can also help the symptoms of Raynaud's.

Surgical treatments

There has been growing interest in the potential of Botox surgery for Raynaud's. Doctors can inject chemicals such as local anesthetics or onabotulinumtoxin type A (Botox) to block sympathetic nerves in the hands or feet. The sympathetic nervous system is activated in times of stress or danger.

The procedure may be repeated if symptoms return or persist.

Another surgical procedure, called a cervical sympathectomy, can sometimes be performed by laser in severe cases. A similar procedure has also been shown to relieve severe pain and to heal finger ulcers. Lumbar sympathectomies for the feet can produce good results and can be carried out by injection rather than surgery.

For all the latest information about Raynaud's, please visit [sruk.co.uk/raynauds](https://www.sruk.co.uk/raynauds)

To find out more about SRUK-funded research in the field of Scleroderma and Raynaud's, visit [sruk.co.uk/research](https://www.sruk.co.uk/research)

There has been growing interest in the potential of Botox surgery for Raynaud's.

YOU CAN'T POUR FROM AN EMPTY CUP...

Jo Walters is 37 and lives in Hampshire with her partner and her son. She was diagnosed with Raynaud's after first noticing the signs in her late teens. Her mother is living with systemic sclerosis, and Jo is also under the care of a rheumatologist.

Jo is a personal trainer and Pilates instructor. In 2023, she ran the London Marathon in honour of her Mum, to raise funds for SRUK.

My official diagnosis is Raynaud's Phenomenon. My Mum has systemic sclerosis and I have secondary Raynaud's, so for now the plan is to watch and wait. I have been told that it could possibly be lupus.

I think I was always fairly aware, just because of my Mum. I was playing sports outside from a young age, and I was aware of the signs even then. I think I went to the GP when I was 17 or 18. Things got much worse post-childbirth after I had my son, with lots of autoimmune-type symptoms, including aches and pains, rashes, and fatigue. I saw the rheumatologist for the first time, however they were not very knowledgeable and I am now under Basingstoke Hospital.

Today, I always have to make sure I have clothing that is warm enough. If I am just going for walk then I can't just wear normal socks, I need two pairs of gloves and I have to be sure that I have enough layers. I sometimes need painkillers for the Raynaud's.



"It's important for people with severe Raynaud's to be given more help from the government, because it can be truly debilitating."

When the weather is cold and wet, I find this makes things worse. My own experience of autoimmune conditions is that things tend to come in flares, so I have to try and find ways to help manage this.

Sometimes, I do need to take a step back and rest, and just try to let everything settle. It's important to understand what your body needs, but this can be quite hard.

I work as a personal trainer, and I run my own Pilates studio. I also go out running, normally five times a week. I feel that being active really is the best thing for my circulation, but the downside is the cold temperatures. I also have to go out early; before my son wakes up and I have to get ready for work. I sometimes feel like the Michelin woman, wrapped up in millions of thick gloves and socks! I also play netball outside, but sometimes it can be hard even to catch the ball.

As a Pilates teacher, my studio has to be kept warm as well. We try to heat the studio with the sauna, but it does take a bit of time to warm up.

I sometimes have to make some adjustments when I am working with clients, as I do need to use my hands. It can also be hard when I am teaching, especially if my joints are inflamed. When I was fundraising for The London Marathon, I did let people know about all of this and some of them were really surprised.

It's really important to keep on raising awareness, because often people tend to just dismiss Raynaud's. But it could be linked to another, serious autoimmune condition in the future. But when I was diagnosed, there was never any suggestion of looking into it further. If more awareness was raised within the younger generation, this could really make an impact in the future.

When I first got together with my partner, he had no idea about what it's like to have Raynaud's, he just thought it was bad circulation. I had to explain that it is really painful, and I can't just sort it out with extra socks. But there are still many people who don't understand about these conditions, so education and raising awareness are really important. People tend to think you are just cold.

I feel I have definitely been affected by the energy crisis, 100%. I need to have the heating on all the time as I am always cold, but putting on an extra jumper just doesn't help. Winter is the hardest time for me. My hands are really affected now, and the Raynaud's has been horrific in last few weeks with the cold weather.

You have to be prepared, and working can be uncomfortable, especially if you have to put on a brave face because you are in pain but you can't let it show, and you can be exhausted by the end of the day. I find that I am now having to work harder to pay for everything, because prices have gone up. I need to earn more money just to cover the basic necessities.

I do think it's important for people with severe Raynaud's to be given more help from the government, because it can be truly debilitating. My mum has an open fire, but sometimes her hands are so bad that she can't make the fire, so the only option would be to use the heating.



But she is aware of the costs and probably doesn't use the heating as much as she should. At home, I have to keep the heating on all the time, just to try and stay warm.

"I sometimes need to take painkillers for the Raynaud's."

When you are living with an autoimmune disease, I would say it can be hard to make sure you are not stressed and to look after yourself. You have to say: 'am I ok?' before you can give to other people. You have to manage it and live your life, but you also have to be aware of how you feel, and taking a step back is also important.

Ask yourself, 'what do I need?' In my job I look after others, but you also have to look after yourself. You can't pour from an empty cup!



SHOPPING PARTNERSHIPS

SRUK is committed to helping our community to source products designed to help with the day-to-day management of Scleroderma and Raynaud's. We are now working directly with suppliers to offer various discounts on certain products, with some companies offering a donation to SRUK for purchases made within our community.

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



Fibreheat

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

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

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

We would like to thank Fibreheat for their kind support.

ASTECtherm Self-Warming Insoles

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

ASTECtherm have kindly offered a donation of £5 to SRUK for each pair of their self-warming insoles, that are purchased via warmingsoles.myshopify.com or scan the following QR code:



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

We would like to thank ASTECtherm for their kind support.

Feel the Warmth Infrared Kidney Warmer and Heat Pad

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

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

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

The goods can be purchased via ftwscotland.com/

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

We are grateful to Feel the Warmth for their support.



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

8% off at Heat Holders

Heat Holders offer a range of products designed for warmth, comfort, and protection. They will offer 8% to our community across their entire range with code: **SRUK8**

Thank you, Heat Holders!

Please visit heatholders.co.uk

Have you thought about making your will?

SRUK has partnered with **Bequeathed.org**, an organisation that works with many charities to help individuals make a will the way that they want it. Bequeathed is a trusted organisation that will guide you through the process of making your will.

Please visit bequeathed.org/sruk for more information.

Travel Insurance

Insurance is essential whenever you travel abroad, to avoid liability for the costs of any medical treatment needed overseas.

When you have a pre-existing health condition it is vital to ensure that this will be covered by your policy, and it may take longer to find a provider that offers the right level of cover at an affordable price. If you are advised that insurance is included when you book your trip, remember that this may not include pre-existing conditions.

When you obtain a quote, remember to include details of all diagnoses and prescribed medications, and answer all questions as fully as you can. If anything is omitted, even accidentally, this could invalidate your insurance if you need to make a 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.

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.

Could you partner with SRUK?

Would you or someone you know like to partner with us? We are always keen to explore new possibilities, especially with providers of goods or services that could benefit our community.

As well as promoting your business or brand, a partnership can provide ongoing support to the work of SRUK. For more information or an informal chat, please get in touch.

We are especially keen to talk to someone who could assist our community with life insurance. If you may be able to help, we would love to hear from you!



Just Travel Cover
justtravelcover.com
0800 294 2969



Freedom Insurance Services
freedominsure.co.uk
01223 446 914



OK To Travel
oktotravelinsurance.co.uk
01223 446 920

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.

Our Online Community

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

Our Publications

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

SRUK is on Youtube!

Our Youtube channel holds our full back catalogue of video content including past webinars, presentations by expert clinicians and video diaries from real people across our community.

To join with nearly 1,900 people already subscribing, please visit youtube/wearesruk



**Helpline:
0800 311 2756**

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

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](#), [X](#) (formerly Twitter) and [Instagram](#) pages.

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, wherever you are on this journey.

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

**SRUK
Needs You!**

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

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



The SRUK Wales Support Group
Liz lives in between Bridgend and Cardiff in Wales with her husband Mark and their Jack Chi Dilys.

Following her scleroderma diagnosis, Liz found online support groups very helpful and last year she set up the SRUK Wales Support Group. The Group currently

meets via Zoom, and offers friendship and support across Wales to everyone affected by these conditions.

We talked to Liz about SRUK's latest Support Group.

I'm Liz and I was finally and officially diagnosed with systemic sclerosis sine scleroderma in May 2023. On my journey I have found SRUK and Facebook support groups an invaluable resource, and I asked SRUK if there were any groups near me. As there were no active ones, we decided to set up the Wales-wide online group with a view to supporting and encouraging each other.

I am hoping that in time we'll be able to hold in-person groups across Wales, as we find pockets of people who live close enough to one another to be able to meet up. At the same time, we can keep the online group for Wales-wide support, discussing relevant issues (maybe with a speaker), and for those who can't travel.

It's so good to know there are others who understand some of what you're going through and to be able to share tips that have helped us. To remind each other that we are not alone and make the best of every day.

So why not come along to our next Zoom meeting? It would be lovely to meet you!

Could you help make a difference to our community?

We are always looking to expand our Support Group network and we need your help to facilitate bringing people together.

We offer a fantastic once-in-a-lifetime training day and ongoing support, by continuing to work with you to help ensure that no one has to face these conditions alone.

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

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

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



FUNDRAISING HEROES

THE SRUK WALK: A RECORD-BREAKING YEAR!



THANKS TO OUR SRUK WALKERS

The SRUK walk raised over **£33,000**; the highest total that this event has ever achieved. We would like to thank all our SRUK walkers; you all deserve your medals so please wear them with pride!



Hari Takhar – has scleroderma and ran the Dorney Lake event. Hari was part of a team of over 30 runners including friends and family who raised over **£1,200** – as well as generating lots of awareness on social media.



Walk for Danielle

A fantastic group of 37 people from Insightful Environments have walked in memory of their much-loved friend and colleague, Danielle Turner. Danielle had Scleroderma and Raynaud's and she herself was an SRUK Fundraising Hero!

Danielle sadly died from scleroderma in 2023, and her incredible colleagues were keen to carry raising vital funds for SRUK in her memory.

They have now reached an incredible **£8,744**, by walking 15 miles along the Thames Path in London. This amount will also be matched by their company, bringing their total to an astonishing **£17,488**.

Thank you!



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 joining #TeamSRUK, or know someone who might be, we still have places available for different events throughout 2024!

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



THE SRUK CHRISTMAS QUIZ

Chris O'Hora is one of SRUK's amazing support group leaders. Last December he organised The SRUK Christmas Quiz, a fun and interactive event that was attended by other support group members, plus SRUK staff, volunteers, and supporters. Chris has raised over **£520** so far, with donations still coming in!



Christmas Appeal: Thank You!

We are extremely grateful to all of you for supporting our Christmas Appeal yet again. We know times are tough, but you've all shown such generosity, and this really will make a difference.

We have raised over **£14,600**

Special thanks to Barrie, Scott, Charlotte, Tamikea, Philip and Avtar for being a part of our campaign and helping us raise awareness by letting us share your stories.

David Kavanagh ran the Athens Marathon in aid of SRUK in November, raising a fantastic **£640**.

Ollie Ross – completed the Lisbon Marathon in loving memory of his fun, incredible and kind Aunt Nicky. Ollie has raised over **£2,300**.



WAYS TO SUPPORT US

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