

SRUK NEWS



Are you getting the most from each appointment?
Download our new Appointment Planner.

The SRUK Patient Registry Survey:
what we learned from you.

Our Christmas Appeal:
how you can make a difference this winter.

Living with scleroderma:
where are you on the journey?

Thank you to all our amazing supporters!

A night to remember:
SRUK's flagship concert with Matthew Slater.



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.



But we won't be slowing down anytime soon, and we are looking forward to an even busier 2024.

We have many, many more opportunities available over the coming year, so if you or someone you know would like some more information, please contact us.

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

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

Thank You!

2023 has been a great year so far for SRUK and as ever, we are incredibly grateful for your support. We have been truly privileged to meet so many of our community at various events over the course of the year, including London Landmarks and the London Marathon, and more recently at Royal Parks Half and our flagship Concert with Matthew Slater in September.

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			
SRUK Walk	Virtual Walk	Anywhere	Ongoing
Barcelona Half Marathon	Half Marathon	Barcelona	11 February 2024
Barcelona Marathon	Marathon	Barcelona	10 March 2024
Paris Marathon	Marathon	Scotland	7 April 2024
London Landmarks Half	Half Marathon	London	7 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

We have 100s of places in events across the UK and overseas, so if there's something you're interested in that's not listed above, then do get in touch.

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

You can also call us on 020 3893 5993

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

With temperatures falling and the nights drawing in, SRUK remains as committed as ever to raising the profile of how the energy crisis is impacting our community. We will continue to advocate on your behalf, and we are very grateful to everyone who has supported us and shared their own experiences as these really do make a difference. We will of course keep you updated over the coming months.

On a similar note, we have worked with The Disability Law Service to provide an up-to-date picture of the welfare benefits that are most likely to be relevant to our community. You can read more on page 16. We hope that this information will be helpful, and we are very grateful to the DLS for their support.

Another of our recent campaigns is dedicated to ensuring that everyone diagnosed with scleroderma can access the right information at the right time. We partnered with the Patient Information Forum and worked with leading healthcare professionals and members of our community, to develop some new information resources. These are designed to reassure people they are not alone, and that reliable information can be found via SRUK. Please turn to page 7 to find out more.

I would also like to thank everyone who responded to our Patient Registry Survey.

The Patient Registry is an exciting new initiative to develop a secure, reliable dataset of health information on Scleroderma and Raynaud's. It will be created to improve outcomes for people affected by these conditions in the future.

We were delighted to welcome so many of you to our flagship concert in September at St Bride's Church in Central London. We were so grateful to celebrated composer and conductor Matthew Slater, who put together a wonderful concert and even wrote a piece especially for the evening. I would also like to say Thank You once again for your lovely comments and feedback after the event. You can read the full story on page 9.

As the festive season approaches, I would like to take this opportunity to thank you all for everything you do for SRUK. Whether that's support as a member, giving your time or sharing your stories and offering words of support to others we really couldn't do this without you. It may seem early to be saying this now, but I do wish you all the very best for Christmas and the New Year, which will be here before we know it!

With very best wishes,

Sue

Contents

4. Doc Spot: your medical questions answered
7. The Perfect Patient Information Journey in Scleroderma
9. SRUK's Concert with Matthew Slater
11. Research: The SRUK Patient Registry
14. Our Partnerships
16. Welfare Benefits
19. Ashley's story
21. Leaving a Legacy
22. Find Support
24. Christmas Appeal
26. Fundraising Heroes



DOC SPOT

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



Q Are people with systemic sclerosis entitled to free eye tests? Is there an increased risk of issues like glaucoma etc? Or anything else the optician should be made aware of?

A Systemic sclerosis does not usually affect the eyes directly and there is no increase in the risk of glaucoma. Dryness of the eyes is a common symptom and can be especially troublesome if there are also features of Sjogren's syndrome that can occur in overlap with systemic sclerosis. Artificial tears and ointments to hydrate and lubricate the eyelids can be helpful. Some medications such as hydroxychloroquine that can be used in systemic sclerosis and Sjogren's require regular eye monitoring for signs of toxicity and usually an annual optician's examination is recommended. There is no specific entitlement to free eye tests for people with systemic sclerosis.

Q I keep getting tiny blood spots on my fingers, is this linked to scleroderma? They just seem to come up and go down, but they are not painful.

A Red spots can occur on the hands and face in systemic sclerosis, especially in the limited cutaneous subset. These spots are called telangiectasia. They are often persistent and can sometimes be treated with laser or light therapy in a dermatology clinic.

Q I am now suffering from extreme pain in my legs, around both the joints and muscles that is now affecting mobility. Is this part of scleroderma and is there anything I can do?

A In systemic sclerosis it is common to experience pain in and around the joints and tendons, especially in the legs, feet, and ankles. Sometimes this can be due to inflammation in or around the joints and about one-in-five people

with systemic sclerosis can have a form of arthritis. However, the tightening of soft tissues and loss of fat around the feet may also result in mechanical foot and leg pain. Treatment can be helpful including adjustments to footwear and local measures to relieve inflammation. Of course, there are other causes for leg pain including poor circulation in the arteries or veins and so you should discuss your symptoms with your healthcare team.

Q I have heard of a gel called Eroxon, that relaxes the blood vessels in the body. Could this help my Raynaud's?

A There are some reports that Eroxon gel applied to areas affected by Raynaud's can be helpful, but it is not a treatment that we have experience of or recommend. However, it is unlikely to cause any harm and so you could try applying it to affected areas. It has been promoted as a treatment for erectile dysfunction by stimulating the nerve endings in the skin to increase local blood flow. Other drugs that are absorbed and work systemically in the blood, such as sildenafil (Viagra®) are helpful in Raynaud's, but Eroxon works quite differently and is not systemically absorbed.

Q I am wondering if Barrett's oesophagus is a common side condition to scleroderma, or have I just got really unlucky?

A Barrett's oesophagus describes the medical condition in which cells in the lower oesophagus change to resemble lining cells of the stomach. It can lead to cancer formation and so once diagnosed is generally followed up with regular endoscopy and biopsy checks. It can be associated with acid reflux and so is quite commonly found, but there is no specific link to systemic sclerosis, and the treatment and monitoring should be as advised by a gastroenterologist according to expert recommendation.

Q I was diagnosed with scleroderma two years ago while also being diagnosed with breast cancer. Over the last few months, I have noticed slightly increased tightness in my hands and developed rough skin along my fingers. I have also recently developed a sore,

dry area on my right elbow which is tender when touched. I would like to ask about any possible impact this may have on my right arm - given that this was the side of my mastectomy and the lymphedema implications.

A Sometimes, autoimmune diseases including systemic sclerosis can develop around the same time as cancer. This is thought to be a result of the immune system developing "self-reactivity," as part of the body's mechanisms to limit a tumour. Sometimes thickening or cracking of the skin on the hands is particularly prominent in cancer associated systemic sclerosis. There are not usually any specific problems with surgery in breast cancer although the diagnosis may alter treatment plans, for example to reduce or avoid radiotherapy in some cases due to risks of local reaction. However, it is important to prioritise treatment of the cancer and discuss any concerns with the relevant scleroderma experts involved in your care. You should discuss the elbow pain and tenderness with your clinical team.

Q I would like some information on lip fillers or similar procedures that can benefit people with SSc with small mouth please.

A One treatment that is proving helpful in systemic sclerosis for fibrosis and tightening of tissues around the mouth is "fat transfer". This is a surgery (termed autologous lipotransfer), performed by a plastic surgeon where fat is removed from the thigh or abdominal wall and injected carefully around the mouth and face. It can improve mouth opening. Cosmetic fillers (e.g., hyaluronic acid) can also be used for appearance, but are less likely to directly benefit fibrosis and can cause local problems in some cases with scar formation.

Q Are infections under the fingernails and the nails falling off a common symptom of Raynaud's?

A The poor blood flow to the nailbed in Raynaud's can result in poor nail growth and increased infections around the nails, especially in association with systemic sclerosis. If the problem is severe or persistent you should seek advice from your medical team.

Sometimes, autoimmune diseases including systemic sclerosis can develop around the same time as cancer.

Q I have scleroderma with fibrotic nodules in both lungs now identified as cancerous. What treatment pathway are available please?

A I am so sorry to hear of your diagnosis of cancer. Scarring and fibrosis in the lungs are quite common in SSc. This may be associated in some cases with the development of cancer and can make the diagnosis of cancer very challenging because scans may not easily distinguish scars and nodules. Treatment should be by an expert team including lung specialists and oncologists, so that the most appropriate treatment can be given.

Q I have diffuse system scleroderma and take immunosuppressants. I recently had a message from my GP surgery, inviting me to make an appointment to have the shingles vaccine. Do you know if it is safe to get this vaccine whilst taking immunosuppressants?

A In general, any live vaccinations must be avoided if you are taking immunosuppressive medication and so the live shingles vaccine cannot be given in this situation. However, a “recombinant subunit - non live” vaccine called Shingrix® is now available and can be safely administered if you are otherwise eligible by age for the vaccination. From 1 September 2023, the UK Health Security Agency (UKHSA) and NHS England has recommended this for those over the age of 50 that are immunosuppressed. Two doses of vaccine are usually given. The need for boosters has not yet been determined.

One treatment that is proving helpful in systemic sclerosis for fibrosis and tightening of tissues around the mouth is a surgical treatment called “fat transfer”.

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

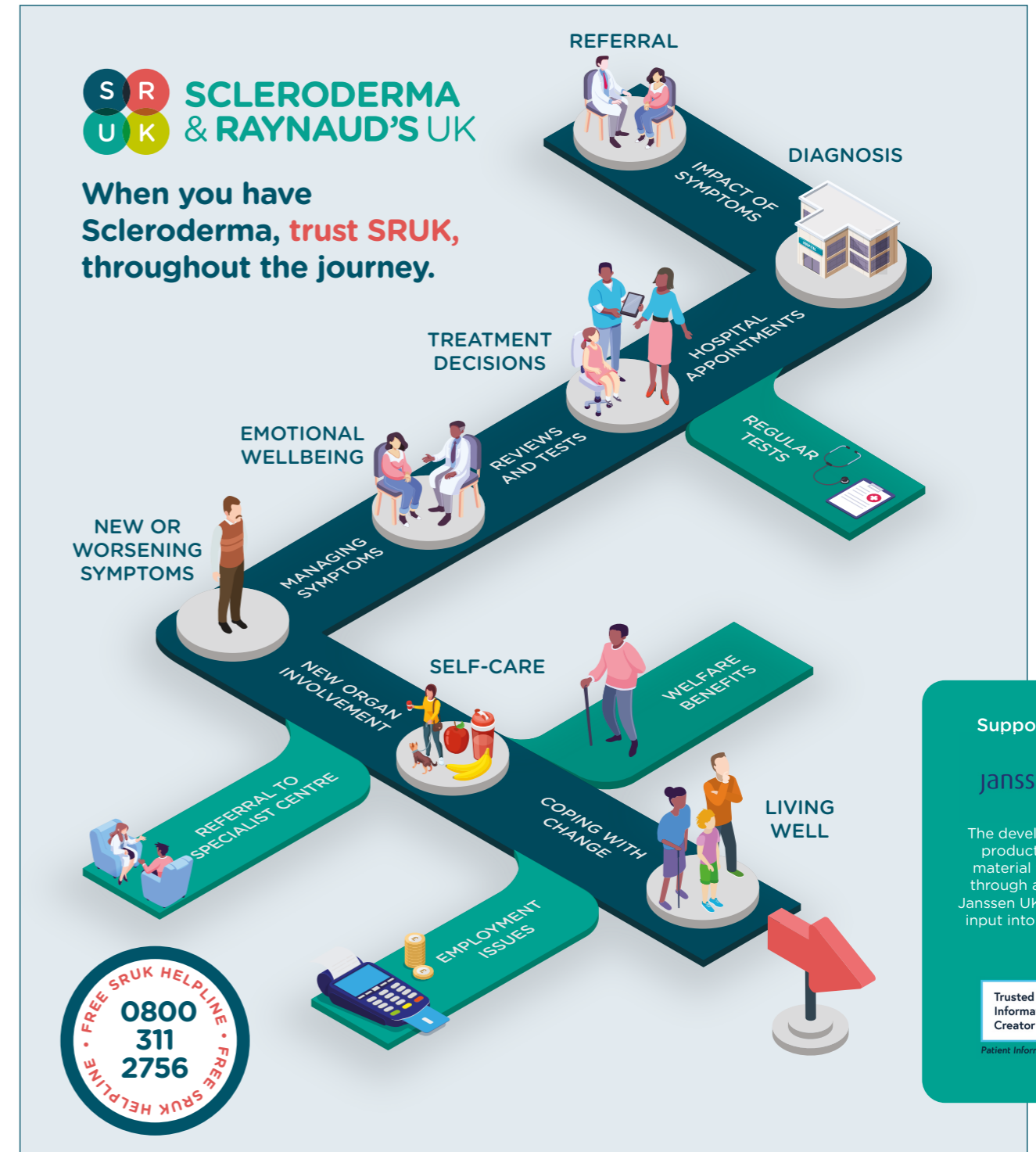
You can also connect with us on Twitter, Instagram and Facebook. /WeAreSRUK



THE PERFECT PATIENT INFORMATION JOURNEY IN SCLERODERMA

Scleroderma can be complex and unpredictable, affecting people in many different ways. But what might the scleroderma journey look like? And why is it important to find out?

Working with the Patient information Forum, SRUK has now identified the patient journey and created some new information resources for everyone affected by scleroderma. These materials are designed to reassure people they are not alone, and that reliable information is available from SRUK, wherever you are on the journey.



Many people have never heard of scleroderma before being diagnosed. This means it is vital that everyone can access clear and reliable information whenever they need it: such as at diagnosis, or if symptoms suddenly change.

In 2021, SRUK partnered with the Patient Information Forum to map and identify the patient journey. We held workshops with leading doctors and nurses alongside people living with scleroderma, to find out more about peoples' experiences and where information has been lacking.

These sessions revealed a patient journey that can be complex and uncertain for many people. Some of the key findings included:

- If you have never been in this situation before, early appointments can be quite daunting, therefore some appointment information may be helpful.
- There might sometimes be an assumption that people already have all the information they need.
- There can be considerable variations in individual experiences of accessing information, depending on location.
- The need for psychological support is very real. Some people could not recall ever being asked how they are coping emotionally during an appointment.
- More information is needed on self-care.

Everyone agreed that wherever you are on the scleroderma journey, it is vital to have reliable information. This should be:

- From a trustworthy source, i.e., SRUK,
- Easy to understand,
- Accessible to everyone.

The groups identified the following key points upon the scleroderma journey when reliable information is needed:

- Diagnosis,
- Treatment and making treatment decisions,
- Preparing for an appointment,
- General information about the patient journey.

'At diagnosis, it would be useful for someone to explain what the condition means, how it affects you, how it might develop. I found the lack of information quite frightening.'
Anonymous

Our new resources

Taking what we learned, we then worked together to produce some new information materials. It was agreed that the best way to meet the needs identified was by introducing some information posters into scleroderma care centres, with SRUK's contact details. Participants also discussed the need for a new resource to help people make the most of an appointment with a scleroderma specialist.

With support from Janssen, we have developed a series of posters, that will be displayed initially within the specialist centres at the Royal Free Hospital in London and at Chapel Allerton in Leeds. Each poster has a key theme:

- Diagnosis,
- Treatment,
- The patient information journey.

We have also developed an appointment guide to help people get the most from an appointment with their scleroderma specialist. You can download your copy by visiting bit.ly/SRUKplanner or scan the QR code.



This project is currently in its pilot phase, and we are hoping that the materials can be displayed in more centres soon.

We would love to know what you think of these new resources! Please complete our short survey here: bit.ly/SRUKsurvey or scan the QR code.



We are very grateful to The Royal Free Hospital in London and the Leeds University Teaching Hospital for their support in this project, and to Janssen for their kind support. We would also like to thank the healthcare professionals and members of the SRUK community who took part, without whose support this would not have been possible.

A NIGHT TO REMEMBER: a concert with Matthew Slater



On 13 September, SRUK hosted our first-ever live music event at St Bride's Church in Central London. The concert was an evening of world-class live music featuring celebrated composer Matthew Slater and the London Metropolitan Orchestra.

Matthew took the audience on a journey of music that has helped influence his career as well as pieces that he has written for the hugely popular TV series 'Endeavour'. Matthew also debuted "Concertino for the Cello," a beautiful piece that he composed especially for the evening, inspired by his mum's experience of living with scleroderma and associated conditions.

On the night our speakers were Martha Grekos - The City of London Alderwoman, Dame Professor Carol Black, and our CEO Sue Farrington.

Matthew Slater is a celebrated composer and conductor with many TV and film credits including Hollywood blockbusters. His experience in the industry of film and television spans over two decades across a huge variety of styles and genres. ITV, BBC, Channel 4, PBS plus numerous other international stations have all



"I was honoured to be asked to host this event - there was no way I could refuse. My mum is a sufferer, and I wanted to help SRUK who have given her so much support."
Matthew Slater

broadcast Matthew's work across the world on a regular basis. Matthew's recent *Endeavour Variations* album has also been featured on Classic FM.

Matthew put together a varied programme of music from Vivaldi's "Four Seasons - Autumn" to Debussy's "Serenade for Strings" and finishing with the Theme from 'Inspector Morse'. Performed by the world-class London Metropolitan Orchestra in the beautiful surroundings of St Bride's Church, it truly was a special night to raise funds and awareness for SRUK.

Everyone left feeling truly uplifted and we can't thank Matthew, the orchestra and everyone else enough for making it such a wonderful event.

**Thank you to our sponsors
Fleet Street Quarter BID and Sushil Saluja.**

The concert raised over **£12,800!**

Some of your feedback from the night!

Just wanted to say what a very special evening it was last night. Everything was amazing - the music, orchestra, soloists and Matthew Slater and for it all to happen in such a beautiful church.

Congratulations on the concert last night - what a splendid event and so good for awareness raising too!

A most wonderful concert with @Matt_Slater & LonMetOrchestra in @stbrideschurch

for the benefit of the marvellous @WeAreSRUK. My sincere thanks to everyone who worked so hard to make tonight such a success!



SHARING DATA TO IMPROVE LIVES: The SRUK Patient Registry Survey

SRUK is developing a Patient Registry, with the aim of improving outcomes for people diagnosed with Scleroderma or Raynaud's. Our Registry will be a secure, anonymous database, containing health information about people living with the conditions. It will be used to improve our understanding of Scleroderma and Raynaud's and how different people are affected over time, to help accelerate research into new and better treatments designed to improve quality of life.

As part of our research strategy, SRUK aspires to advance research into the areas of early diagnosis and detection, precision medicine, quality of life, and the causes of Scleroderma and Raynaud's.

Scleroderma experts have suggested that developing an **SRUK Patient Registry** would be a powerful resource to gather data for research and provide real-world evidence on the conditions. This data could enable SRUK and other organisations to better advocate for improved care and access to treatments.

Our ambitions to develop this Registry can only succeed if people living with Scleroderma and Raynaud's are willing to take part. In April, we reached out to our community through the SRUK Patient Registry Survey, to find out your views.

The SRUK Patient Registry

A Patient Registry is an organised system that collects uniform data on people with a particular medical condition. A rich dataset will be collected over time and used to:

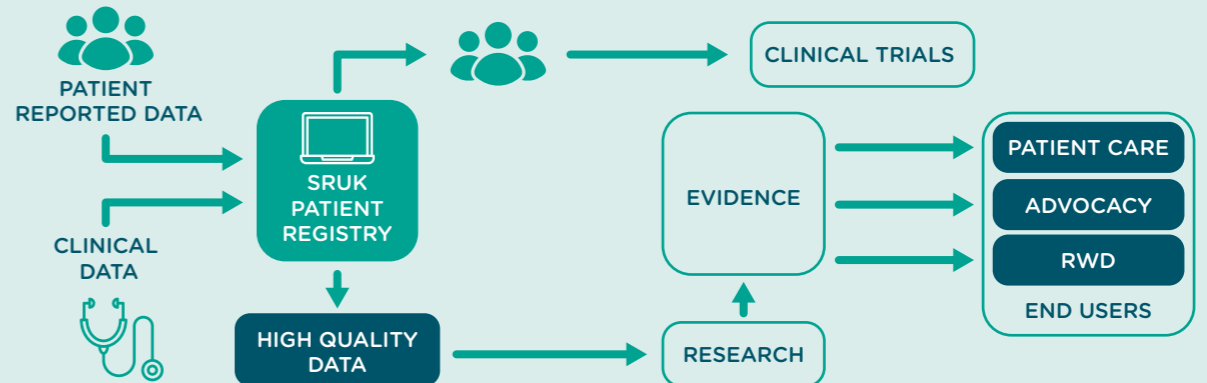
- Advance research into Scleroderma and Raynaud's,
- Identify appropriate patients for clinical trials of new treatments, and
- Develop real-world evidence of how different groups respond to certain treatments and care. This Real World Data (RWD), is important in developing our understanding of how people are doing in everyday life as opposed to controlled clinical trial environments. It will enable SRUK and others to advocate for better care for patients.

The Registry will be developed as a secure database that holds anonymised health data on people diagnosed with Scleroderma and Raynaud's. As a patient organisation, we aspire to put those living with the conditions at the forefront and offer everyone the opportunity to participate, regardless of where they are treated. This will provide a comprehensive picture of how patients are doing across the country, and not just within specialist centres.

The Survey

The Registry Survey was launched in April and promoted through our social media and e-news. It was open to participants aged 16+, including the carers of children and adults living with the conditions. The survey explored our community's attitude to reporting and sharing data, the use of anonymised data in research, internet literacy, and overall motivation to participate in the Registry.

The Patient Registry



Who Responded?

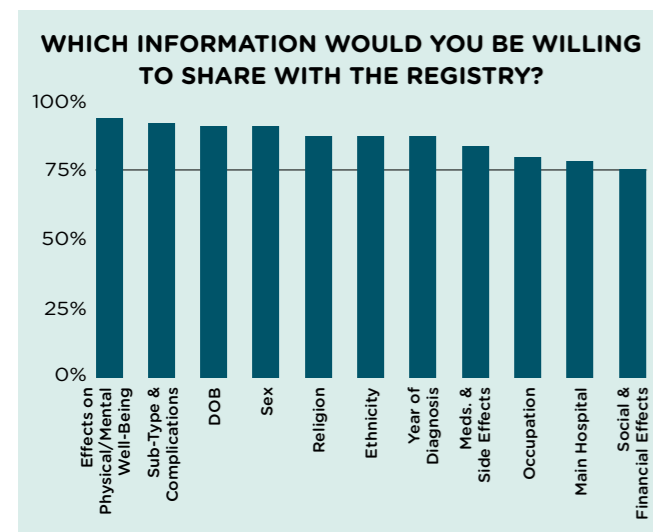
530 people completed our survey.

- 51.6% had either diffuse, limited systemic, or sine scleroderma.
- 36% had Raynaud's only.
- 8.44% had mixed connective tissue disease.
- 1.88% reported localised scleroderma.
- A small number were carers of affected children.

The majority were UK-based and treated at a range of specialist and non-specialist centres. Nineteen people reported living overseas.

The majority of responses came from white females, aged 45-74 years old, so we are working on ways we can gather more insight from men, people of non-white backgrounds and different age groups, and from carers of affected children.

What type of data are people willing to share?



We first asked whether people would be willing to share information related to their symptoms and their effects upon day-to-day life. Everyone was either willing (82.18%) or maybe willing (17.82%) to share this information.

Over 90% of respondents reported a willingness to share information on:

- Effects of Scleroderma and Raynaud's on physical and mental wellbeing,
- Disease sub-type,
- Organ complications.

This can provide insight into the impact of the conditions and help enable SRUK, healthcare professionals and researchers to identify those requiring new treatments and methods of care.

Lifestyle information

Over 80% would share information regarding:

- Their region,
- Ethnic background,
- Year of diagnosis,
- Medications and side-effects,
- Occupation/previous occupations.

Knowing where patients are based will allow us to see how people with Scleroderma and Raynaud's fare across the country and help address disparities in care. Similarly, understanding differences in the effects of the conditions within different ethnic groups could help us better understand the risk of progression among different ethnicities, and advocate for better screening for those at highest risk of developing complications and severe disease. Likewise, knowing when patients were diagnosed would also assist our understanding of disease progression.

Knowing past and present occupations has the potential to give insight into environmental factors that could trigger Scleroderma and Raynaud's. It is also useful to understand whether people have been forced to step back from work, to show the wider effects of the disease.

Over 75% would share information regarding:

- The main hospital where they receive care.
- The social/financial effects of their condition on them and their family.

Knowing where people are treated and how this is linked to their outcomes could help further highlight disparities in care.

Scleroderma often strikes people in the prime of life when they may have dependent children or family members. The social and financial effects upon the individual and their extended family are currently poorly understood. Having access to data on these impacts would be a powerful tool in understanding the extent to which people are able to continue working and would help us advocate for change to help you stay in employment for longer.

Sharing the data

Because scleroderma is a rare disease, we can make more of an impact by giving other parties access to the data to carry out research, and combining SRUK Registry data with other international datasets.

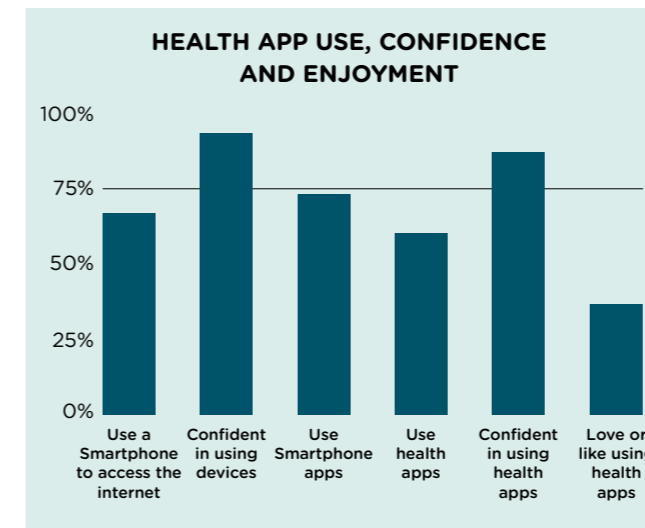
Therefore, we would need to provide access to anonymised participant data (so individuals cannot be identified) to some external parties via a secure environment, such as:

- Researchers,
- Healthcare professionals (for research and to identify those suitable for clinical trials),
- Certain companies, such as pharmaceuticals, who might be interested in using the data to plan therapeutics or see how their drugs are performing or to gain insight into the patient experience.

Data access requests would be considered by an independent committee with patient representation. We could also enrich patient reported data by linking with other data sources like NHS data.

Over 90% of respondents suggested that they would or may be willing to share or link their data with the NHS, researchers, clinicians, and companies (i.e., pharmaceuticals), and 95% indicated they'd like to be contacted if eligible for a clinical trial.

How do people want to provide their data?



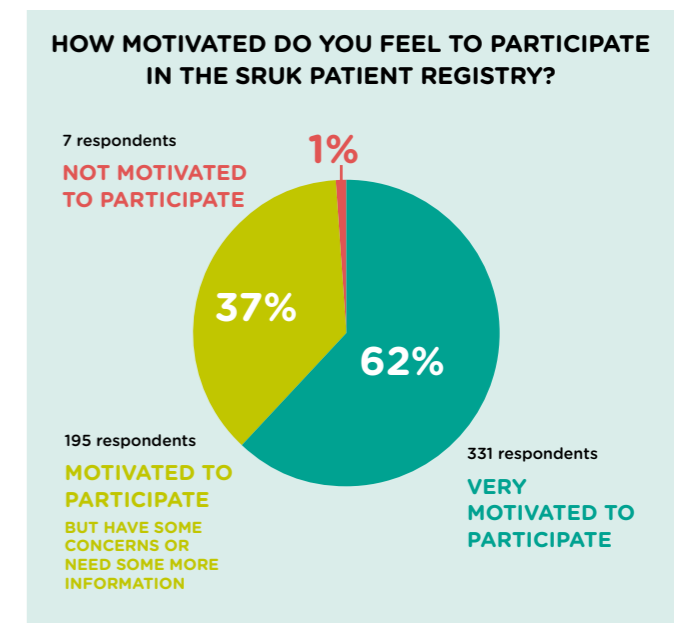
Individuals can contribute information through an online patient portal, such as an app or secure website. We therefore need to understand our community's attitudes to the internet and apps, and how you feel about using these platforms.

Our survey revealed high levels of smartphone use, internet access, and use of health apps. More than 60% of respondents regularly or sometimes use health apps, reporting high confidence in using them. 37% indicated they

love or like using such apps, and only 13% of respondents indicated they do not enjoy using them.

This is a topic that we will explore further to ensure a solution that is accessible for all of our community.

How motivated are patients to participate in the Registry?



Our last question was undoubtedly the most important: to understand how motivated our community is by this project. 99% of all those who responded said that they were very motivated or motivated to participate in the Registry! There was a strong desire to participate across all condition subtypes.

Thank you to everyone who participated in this vital piece of work to help plan the Registry. By continuing to shape the direction of the Registry with the perspectives of our community at the forefront, we hope to create a powerful resource that will benefit everyone living with Scleroderma and Raynaud's.

We are still keen to hear our community's perspectives, and are especially interested to hear from men, people who identify as BAME, and carers of children with scleroderma. If you would like to participate, please visit the research section of our website or scan the QR code to access the survey and share your views!



OUR PARTNERSHIPS

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

ASTECtherm have kindly offered a donation of £5 to SRUK for each pair of their self-warming insoles, that are purchased via warminginsoles.myshopify.com or 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/

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.

Christmas Cards (pack of 10)

All £3.99 except Winter Woodland which is £4.99

Buy any four packs of Christmas cards and get one free!

Please call us on **020 3893 5998** for us to complete your order.



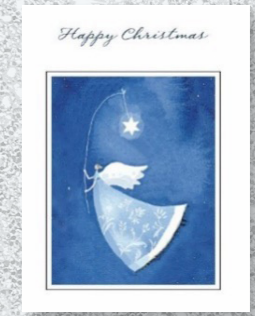
A: Robin on a Snowy Fir



B: Present Delivery



C: Snowman and Robins



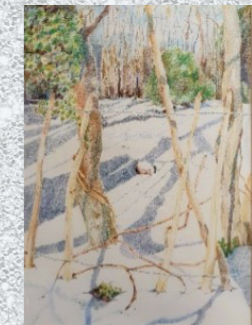
D: Blue Angel



E: Partridge in a Pear Tree



F: Winter in the Forest



G: Winter Woodland

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.

The following insurance intermediaries can often provide cover to people with diagnoses such as 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.



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

WELFARE BENEFITS

Could you be entitled to some extra help? If you have Scleroderma and Raynaud's, you may be entitled to support from the UK welfare benefits system. Even if you have never claimed in the past, it is important to know if you could be eligible, and how SRUK can help.

Welfare benefits and the SRUK community

We have worked with the Disability Law Service (DLS) to develop this article, which is intended for information purposes only. The following benefits are mentioned because they might be relevant to some members of our community. We recommend contacting the DLS if you would like more information.

• Means tested benefits

Your (or your partner's) assets and savings will be considered. If you have between £6,000 – £16,000, this will either reduce or stop your entitlement to means-tested benefits.

- Universal Credit (UC)

• Contribution-based benefits

These are purely based on your previous National Insurance contributions.

- 'New Style' Employment and Support Allowance (NSESA)

- 'New Style' Jobseekers Allowance (NSJSA)

• Non-means tested benefits

Your saving and capital will not be taken into account.

- Statutory Sick Pay (SSP)

- Personal Independence Payment (PIP)

- Child Disability Living Allowance

- Attendance Allowance (AA)

- Carers Allowance (CA) (this is earnings-based)

Applications and assessments

When you make an application, the best supporting evidence will be medical evidence from your GP, detailing:

- All aspects of your diagnosis,
- How your condition affects your life.

You can also use evidence from anyone involved in your day-to-day care. Always send everything via Royal Mail Recorded Delivery.

For an assessment or appeal, you can ask for reasonable adjustments to be made, and there is a duty to provide these to avoid disadvantage. If you do not feel safe travelling to the interview location, you can ask for a home-based assessment instead.

Means tested benefits

Universal Credit (UC)

UC is designed to supplement income and help with rent and childcare costs. It is generally open to all working-age claimants in the UK aged over 18. UC is paid monthly, and you must generally be on a low income or out of work to be eligible.

Because this is an income-related benefit, earnings and savings are considered. If you have between £6,000 and £16,000 the award will be reduced accordingly.

Contribution-based benefits

New Style Employment and Support Allowance (NSESA)

NSESA is available if you are unable to work due to illness, disease, disability or impairment.

It is based on your previous Class 1 or 2 National Insurance contributions over the past two – three years, so you must have paid (or been credited) sufficiently to be eligible. Savings and assets are not relevant.

You cannot apply if you are already eligible for SSP. However, as soon as SSP comes to an end, you can apply for NSESA.

Within four weeks of your first payment, you should receive an ESA50 questionnaire. This is a

work capability questionnaire. It is important to submit as much medical evidence as possible. You will then be invited to a Work Capability Assessment (WCA), to discuss your conditions and how these affect certain activities. Remember that reasonable adjustments can be requested.

You will be assessed on certain work-related activities under two specific categories:

1. **Physical disabilities** include mobility, standing and sitting, manual dexterity, communication and understanding, bladder and bowel evacuation and safety of consciousness during waking hours.
2. **Mental, cognitive and intellectual function**, including learning and retaining information, awareness of hazards, getting around without support, social engagement and behaviour.

If you score a total of 15 points or more you will be placed into the Work Related Activity Group (Limited Capability for Work). If you meet one of the additional activities (Limited Capability for Work Related Activities) you will be placed in the Support Group and you'll also receive an additional, regular payment.

NSESA can only be claimed for 356-days unless you are placed into the Support Group.

'New Style' Jobseekers Allowance ('New Style' JSA)

'New Style' JSA is for working-age claimants based upon previous Class 1 or 2 National Insurance contributions. You can only receive 'New Style' JSA for a maximum of 182 days, then you must switch to Universal Credit.

You must be fit and able to seek work for each week you are paid 'New Style' JSA (the 'jobseeking period'). You should not have a Limited Capability for Work (LCW), because you need a current jobseeking agreement, that satisfies the following:

- You are available for work each week.
- You are actively seeking work each week.

Non-means tested benefits

For these benefits, your earnings and savings will not be taken into account. When you make an application, always call the claims line first, because your claim will be backdated to the day that you first requested the form, regardless of processing time.

Statutory Sick Pay (SSP)

If you are off work due to illness for more than four days, you can apply for SSP from your employer for a maximum of 28 weeks. You will need a fit note from your GP.

Personal Independence Payment (PIP)

PIP is for people with daily living and/or mobility needs, to help with extra costs. PIP is available to claimants below state pension age; and you may be able to claim even if you are working or studying. You will be invited to an assessment, and reasonable adjustments can be requested.

PIP has two components:

- The **Daily Living component**: to cover extra costs if you need help doing everyday activities.
- The **Mobility component**: if you have difficulties in getting around.

Each component can be paid at either the standard or enhanced rate, depending upon whether you can carry out certain activities.

Daily living

- Preparing food
- Taking nutrition
- Managing therapies or taking medications
- Washing and dressing
- Toiletry issues
- Communicating verbally
- Reading and understanding signs and symbols
- Engaging with people face-to-face
- Making budgeting decisions

Mobility

- Planning and following journeys
- Standing and then moving around

Attendance Allowance (AA)

Attendance Allowance (AA) is for people of state pension age who need attention or supervision with their personal care, regardless of income, savings, or National Insurance contribution.

To be eligible you will need to show:

- You have reached state pension age,
- You have a physical or mental disability,
- Your disability warrants attention or supervision for your care or safety,
- Your conditions have been present for six months.

AA is awarded based on the level of care you need, and whether you meet a daytime or a night-time condition.



Daytime conditions

You must show that you require either:

- frequent attention throughout the day in connection bodily functions, or
- continual supervision throughout the day to avoid danger.

Night-time conditions

You must show that you require either:

- prolonged or repeated attention throughout the night in connection with bodily functions; or
- another person to be awake during the night for prolonged periods or at frequent intervals to avoid substantial danger.

If you have an existing claim for Personal Independence Payment (PIP) or Adult Disability Living Allowance (DLA), you cannot make a new claim for AA.

Carers Allowance (CA)

CA is for those with 'regular and substantial' caring duties for a 'severely disabled' person, for at least 35 hours per week. It is taxable but not means tested and can be backdated for up to three months.

If the person you are caring for receives one of the following, it is likely that you will be eligible.

- PIP Daily Living Component,
- Child DLA at Middle of Higher Rate Component,
- Attendance Allowance.

To be eligible for Carers Allowance, you must be:

- Aged over 16.
- Not in full-time education.
- Earning less than £139 per week (after tax, National Insurance and expenses).
- Resident in the UK and not subject to immigration control.

Appeals

Remember that if your application is turned down, you do have some options. Usually, it is best to get legal advice.

The appeals process has three stages:

- **Mandatory reconsideration.** This is essentially asking the DWP to look again and reconsider. You can submit further evidence at this stage.
- Appealing to the **First-Tier of His Majesty's Courts and Tribunals Service (HMCTS)**. You can also submit further evidence at this stage.
- Appealing to **Upper-Tier HMCTS**. This is the final stage, where you can only appeal on

grounds of an error of law, e.g., an error in considering your claim.

There is a general time limit of one calendar month for each stage, although there is provision to extend this for up to 13-months (excluding Upper-Tier).

Cost of Living (COL) payments 2023/24

COL payments are for people struggling with living expenses who were entitled to a payment of certain benefits in the period between 18 August - 17 September 2023.

To be eligible for COL payments, you must have been entitled to the payment any of the following benefits during the period stated above:

- 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

The second low income cost of living payment for 2023/2024 will be made between 31 October and 19 November 2023. For Tax Credit claimants it will be 10 November and 19 November 2023. The Spring 2024 dates have not been released yet.

You do not need to apply for the COL payments. If you're eligible, you will be paid automatically in the same way you usually receive your benefit or tax credits.

For further information on the Disability Cost of Living Payment and the Pensioner Cost of Living Payment see www.gov.uk/guidance/cost-of-living-payment

How SRUK can help

SRUK can help you with your claim or appeal by writing a letter about the condition to help support your application. For more information, please contact us.

This article is intended for general information purposes only. For advice that is tailored to your own personal circumstances, please contact the Disability Law Service by calling **0207 791 9800** (option 5) or by emailing benefits@dls.org.uk

We would like to thank Jo Mitchell and Dami Owobamirin of the DLS for their support with this article.

ASHLEY'S STORY

Ashley lives in South Yorkshire with her family. Her six-year-old daughter Luna has Raynaud's, which has a significant impact on her life. She has recently been awarded Disability Living Allowance. We talked to Ashley about how Luna's condition affects her, and her experiences of navigating the benefits system for the first time.

My daughter Luna was diagnosed with Raynaud's at 18 months, but I first noticed the symptoms much earlier, when she was only around four months old.

Luna was an early talker, so by the time she was 10 months she had started to communicate. She would get upset and flap her hands and say 'hurt'. I just felt that something wasn't right.

I went to the GP and asked for a referral. We saw the rheumatologist who asked lots of questions and ran some tests to rule out underlying conditions. Her diagnosis is primary Raynaud's.

Luna is affected by changes in temperature, so she can't be outside for long or even go in a paddling pool. Her condition limits her playing with her friends, and she can't play in the snow. She doesn't always understand why other kids can do things that she can't, it's just heartbreaking. She has a two-year-old brother so if there is something she can't do, then he can't do it either.

There is not much information out there on Raynaud's for Luna's age. Her two-year-old brother is also being

investigated for Raynaud's as he seems to react with changes in temperature. But Luna also reacts with her mood: if she is anxious, then her hands will be freezing. Her symptoms are also triggered by her emotions and even illness. I couldn't find any information for Luna's age on keeping them warm. Things are written generically, as if every child has the same symptoms. But with Luna it's not just the weather, it's also if she's anxious or upset or unwell.

Luna is now being assessed for ADHD and high functioning autism, and this is impacted by the Raynaud's because she has sensory issues. She often struggles with clothing, because she doesn't like the feel of certain things, which is a massive challenge because it makes it even harder to keep her warm. I buy thermal vests with long sleeves, but if it feels strange under the school shirt, she will have a meltdown. When her hands are really bad

and she gets upset, she often struggles to express what is wrong.

I don't think the doctors are used to seeing children with Raynaud's at this level. Luna's condition isn't typical, it's as if she can't control her body temperature. She will seem really hot but still say she feels freezing.

Luna does not take medications for the Raynaud's. The doctor said she had never given it to a child so young, and so they didn't know how she would react. She said: "It might do good, but I'm very against it."

Luna does not take medications for the Raynaud's. The doctor said she had never given it to a child so young.

I can't get silver gloves in infant or child sizes. My mum is amazing at sewing, so I buy adult gloves designed for Raynaud's and she has made them into mittens. Nothing seems to be available that she could put on and take off herself. So, my mum has made everything with the sewing machine. It's hard as a parent and if my mum didn't sew, I don't know what I would have done."



We have now been awarded Disability Living Allowance for Luna, but our initial application was turned down, so I did have to appeal.

When I first filled in the application, I didn't really go into a lot of depth. I think I was expecting to have to appeal it and to argue, I'm good at that now!

The application form didn't really allow me to fully express how Raynaud's affects Luna. It's quite generic, and I felt that the questions did not really relate to the effects of Raynaud's.

When the application was turned down, we went to Mandatory Reconsideration, and I found that I could go into a lot more depth. I wrote an additional statement about Luna's condition and we had a letter from SRUK, as well as support from Luna's school.

I asked to speak to the person who had assessed and turned down our application. She called one morning whilst I was walking to school in the rain, but I took the call. I asked about her medical background as I wanted to know her experience of Raynaud's. She was a physiotherapist who had not dealt with Raynaud's as a whole.

When we applied, I had sent information from SRUK and highlighted the key points. I asked where the assessors had got their information from when they decided to turn us down. She said it was their in-house medical team who used information from the NHS. I had to bite my tongue a bit during the call! I would say it's important to remain calm and try not to get angry. As

soon as I got to school, I ran into the office to make notes.

My statement for the appeal probably comes across as argumentative, but I feel that it needed to be. The letter of support from SRUK was amazing, it expressed exactly how Luna's condition affects her, based on the information that we gave them.

The appeal was successful, and we were awarded higher rate Care Component and lower rate Mobility Component. The award is for two years, so we will have to renew it. I will resend all the evidence with a letter to direct them to SRUK for accurate information on the condition.

You just have to advocate for yourself or your child. It may be uncommon, but children can get Raynaud's, and it can affect them in different ways. If you are making a claim or if you need to appeal, try to think outside the box. What does your condition stop you from doing that other people can? Or what do other children do that your child isn't able to? My child can't play in the pool or walk long distances.

"Always think carefully about how your condition affects you."

I don't want other people to miss out on something that could be a massive help, especially with the current cost of living crisis.

An amazing doctor once said to me: "when a child has an illness, no one will know more about their situation than the parents." So, I would say, always think carefully about how your diagnosis affects you. We are not generic."

Top Tips for your benefits application

- Always send everything by recorded delivery
- SRUK can supply a letter for the DWP with relevant information about Scleroderma and Raynaud's.
- If you speak to anyone in connection with your application, make notes including the date, time and their name.
- Remember that this is something you could be entitled to, so if you do not agree with the decision, do not be afraid to appeal!
- When preparing an appeal, always include how you are affected by your condition.



HOW WILL YOU BE REMEMBERED?

Create a lasting legacy this Autumn



Our Free Wills initiative in partnership with Bequeathed can help you ensure your estate is distributed exactly how you want, as well as remember the causes you care about.

October is Free Wills Month. This is a time when we encourage our supporters to think about their future and their legacy, as well as the future of the charities that matter to them. If you decide to make a will, we would be extremely grateful if you would consider leaving a gift to SRUK.

A gift in your will can help us to continue supporting everyone affected by Scleroderma and Raynaud's. You can also have peace of mind by completing your will through our new Free Will initiative.

SRUK has partnered with Bequeathed to help you with these decisions and make a lasting impact. Bequeathed is a trusted organisation that will guide you through the process of creating your will, exactly the way you want.

Joan's Legacy: Joan kindly left SRUK a gift in her will. Her daughter, Diane, told us of her mother's legacy and her wish; 'Hopefully, her gift can help SRUK to continue providing this kind of information and support to others affected by this condition.'

Through our Free Will initiative with Bequeathed, you too can assign SRUK a portion of your estate or assets to help ensure we can continue our vital work and positive impact.

Download our new guide to leaving a gift in your Will



Simply visit bequeathed.org/sruk to leave SRUK a gift in your will once your friends and family are taken care of. In just three easy steps, you can create your Will For Good:

1. **Take the online will interview.** Bequeathed will support and guide you through the process and create your will based on your answers.
2. **Attend a 30-minute appointment with a legal professional** found by Bequeathed, to discuss your situation and requirements and ensure the will fully caters for all your needs.
3. **Receive your free will in the post,** sign it and have it witnessed. Return it to the legal firm who will check it has been executed correctly.

FIND SUPPORT

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

Our online community

You can also find help and support 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

The SRUK webinar programme

We have an exciting series of webinars this year, featuring leading clinicians and experts in the field of Scleroderma and Raynaud's.

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

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

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

Our publications

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



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.

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](https://www.youtube.com/wearesruk)

Social media

Join the conversation and find support through social media. You can ask a question, share tips and read advice from others on our [Facebook](#), [X](#) (formerly Twitter) and [Instagram](#) pages.

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

“It's hard to find anyone who understands the challenges of living with these chronic conditions.”



Lyn

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**.

Lyn, who lives in Bedfordshire was diagnosed with limited cutaneous systemic sclerosis in 2014. This Autumn, Lyn started the new SRUK Support Group in Bedfordshire that is currently meeting online via Zoom. We talked to Lyn about the Group, and the importance of connecting with others who understand your situation.

“So, you get diagnosed with Scleroderma or Raynaud's and then what next?” Lyn told us, “It's hard to find anyone who understands the challenges of living with these chronic conditions and that's where Bedfordshire Support Group can help.

It's a place to share your journey, listen to others and unload if you want to. There is comfort in being able to meet up, to share ideas and positive experiences or just have a moan!

With the help of SRUK we will also have speakers to talk more in-depth about various aspects of Scleroderma and Raynards as required.

We are also planning to do a 10-minute time out each meeting for a quiz or challenge, but nothing serious!

Although meetings are currently on Zoom, we would hope to also meet up face to face occasionally for a cuppa and cake! Join the group and let's support each other.”

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: by meeting online and sometimes even in-person.

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**

SRUK CHRISTMAS APPEAL

Could you give a gift to help people living with Scleroderma and Raynaud's this Christmas?

As Christmas and the winter months approach once again, those with Scleroderma and Raynaud's often experience the negative effects more than most. With your help, we will continue to conduct vital research into these conditions, raise awareness to advocate for change, and offer ongoing support to our community.

With your support, this year SRUK has been lobbying the government to provide more support for our community impacted by the rising energy costs. Ministers raised questions at parliament, you wrote to your local MPs, and we will continue to raise questions and advocate for change.

Our survey of rheumatologists in the UK showed that there is lack of knowledge on scleroderma and treatments - so we will work together with them to bridge those gaps.

Throughout the year, in *SRUK News* and across all our platforms, we have shared updates on our research projects, and we will continue to invest where you have told us it is needed most.

Scott & Charlotte's story: "It's very hard, I can't lie."

Your scleroderma journey is unique to you. For Scott, being diagnosed with diffuse systemic sclerosis and Raynaud's has affected his ability to do many things that were easy for him before, including spending quality time with his family. His wife Charlotte tells us how this has changed their lives:

"We have three kids, and it upsets Scott that he can't do what he used to with them. We can no longer do activities in the cold, go on long walks, ride our bikes and sometimes it's hard to even go out for a meal or to the cinema if he is having a bad day."

Christmas is often a busy time which can make symptoms worse and make it hard to spend quality time with family.

"It's very hard, I can't lie, to see a very active and fit 40-year-old suddenly become so ill and unable to do things we all take for granted. His hands give him lots of trouble, so he can't do little things like taking out the washing or the dishes...He can't work and was a landscape gardener, so that has hit him very hard and meant that he has had to adapt his life significantly, as he doesn't earn money."

Through this process, Charlotte and Scott have noticed the lack of awareness and knowledge about scleroderma.

"What it is for a start - even paramedics didn't know what it was. How bad it is and how debilitating it is for a person, who on the outside can look healthy and well. It is a disease that can cause huge amounts of physical, emotional and mental pain. It's awful."

"Look at what support you can get from organisations like SRUK. It's good to get support."

Together we can keep raising awareness among the public and health professionals. We can offer support to help people carry on with their everyday lives and we can fund vital research.

Together we have made progress, but there is still so much more to do.

- £80** covers a day's cost of research equipment needed to enable vital breakthroughs.
- £50** enables us to host 10 users on our Raynaud's Symptoms Tracking app, for one month.
- £30** could help train our volunteers to become peer support group leaders.

Donate online sruk.co.uk/donate, call **020 3893 5998** or send a cheque using the **Donation Form**.

DONATION FORM

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

Title (Mr, Mrs, Miss, Ms, Other) Full Name (first and last name)

Home Address

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Email

Tel/Mobile

I enclose my donation of £

I enclose my cheque payable to Scleroderma and Raynaud's UK

Please debit my credit/debit card (Maestro, Visa or Mastercard)

Card number: Expiry date:

Signature/date:

Gift Aid Declaration
Increase the value of your gift by 25%

I confirm I would like all my donations, past, present, and future made to SRUK (registered charity number 1161828) to be treated as Gift Aid Donations. I am a UK taxpayer and I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations to all charities in that tax year, it is my responsibility to pay any difference. I understand that SRUK will reclaim 25p of tax on every £1 that I have given. I will advise SRUK if my circumstances change.

We would like to write to acknowledge and thank you for your generous gift; however, if you do not require an acknowledgement please tick here.

giftaid it

£ **FUNDRAISING HEROES**

SHINING THE SPOTLIGHT ON SOME OF OUR FANTASTIC SUPPORTERS!

Jordan McEnerney and Chelsea Travers took on the York 10K in August, as Chelsea's Mum Janine has Scleroderma and Raynaud's. They have raised **£175!**

Jordan said: "I will be completing a charity run in order to raise awareness for this disease and help families like mine learn how to cope with the difficulties they will have to face."

Thank you to our amazing team of nine who took on **Royal Parks Half Marathon** in October! It was lovely to meet some of you at our cheer station and we are incredibly grateful for your support!

Nathan Chan is completing a number of running events in memory of his Dad **Kenneth**. The latest was Race to the Stones, which is a 100k run. He has now raised over **£1.5K!**

"I'll be running in many events to fundraise for SRUK because my father suffered greatly with the condition.

I want to honour his memory and raise some funds for the ... charity in a hope to do something positive in the aftermath of such a sad time.

It seems there is little awareness of scleroderma and perhaps not as much fundraising as other better known and understood conditions. Scleroderma is a horrible disease that can affect the whole body ... It can be truly debilitating and is an utterly horrific disease!!"



Nathan

Clare Morris is swimming the length of the channel in memory of her Mum **Joan** during October. She has beaten her original fundraising target of **£500!**

"(My Mum) sadly passed away very recently from systemic sclerosis. Over eight weeks until Mum's funeral in October 2023, I will be swimming the distance of the English Channel, that's 21 miles (or 1,352 lengths of the pool), to raise money for SRUK ... Please help me to spread the message about scleroderma so that we can help other beautiful people like my Mum who are suffering from this awful condition, and that one day we can hopefully find a cure."

Cheryl Iddon took on a skydive with her best friend during September, as well as hosting an entertainment evening with live music. Cheryl is living with scleroderma, and she has raised over **£3,200!**



Cheryl and her friend!

"I am jumping with my best friend (she is mad too and I love her to bits) ... (to) raise money for this amazing charity that will fund research into finding a cure for this debilitating autoimmune disease that I have. Maybe not me, but if it helps someone else and raises awareness, I will be so happy."

Chris Rogers held a golf day in aid of SRUK in June and raised **£3,460!** Chris runs a golf society and chose to support SRUK on their annual charity day this year!

BEDANKT!

(Thank you!)

We are very grateful to our latest international fundraisers, **Saskia, Jeffrey and Genevieve**, who are taking part in this year's Amsterdam Half Marathon!



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
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Office: 020 3893 5998



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