

# SRUK NEWS

Meet some of our **Fundraising Heroes** including **Dimple**, who completed a skydive for SRUK!

## **Women's Health and SSC**

A look at some of the more intimate aspects of life, what helps, and what doesn't

## **The Rare Autoimmune Rheumatic Disease Alliance**

Working to achieve equality in care and treatment for all

## **Research News:**

Developing personalised treatments for interstitial lung disease

Improving quality of life



# FUNDRAISING 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 incredibly grateful to everyone that has supported us during these incredibly challenging times: each and every one of you really has made a difference, and we are thrilled that we can now connect in person once again!

## Fundraising News

We are all set for an action-packed 2022, and we are looking forward to meeting many more of our Fundraising Heroes along the way!

Registration for all 2022 events is now open, and we are ready and waiting to welcome you to **#TeamSRUK**.

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

## Raynaud's Awareness Month: February 2022

Every February, we ask our community to **Catch up with a Coffee**. You can arrange your own tea/coffee catch up, either in person or via Zoom, to raise vital funds and help increase awareness of Raynaud's and its impact. It's never too late to get involved, and we can help you to organise the perfect get-together.



## Get your free fundraising pack!

However you choose to fundraise for us, our free fundraising pack has everything you need! Please email [fundraising@sruk.co.uk](mailto:fundraising@sruk.co.uk) or call **020 3893 5993**.

## Here are just some of the events that we are looking forward to in 2022:

EVENTS CALENDAR 2022	
Raynaud's Awareness Month	February 2022
London Landmarks Half Marathon	3 April 2022
Inflatable 5K Chester	22 May 2022
Edinburgh Half Marathon	29 May 2022
Scleroderma Awareness Month	June 2022
Nightrider London	11 June/12 June 2022
Hull Half Marathon	12 June 2022
Goodwood Motor Circuit 10K	3 July 2022 (TBC)
Barry Island 10K	7 August 2022
London Marathon	2 October 2022
Royal Parks Half Marathon	9 October 2022

For more information, please call **020 3893 5998** or email [info@sruk.co.uk](mailto:info@sruk.co.uk)

## Rare Disease Day: 28 February 2022

28 February is Rare Disease Day. We would love to hear your story of what your diagnosis has meant for you, and if you can, please help to spread the word on social media!

# WELCOME TO THE LATEST EDITION OF SRUK NEWS

## Dear Supporters

Well, it certainly has the feeling of *Groundhog Day*, as we enter the New Year. At the beginning of 2021, I recall saying, 'this may not be the start to the year that any of us quite expected,' and here we are again in 2022. However, I am the eternal optimist, so I'm quietly confident that I will not be saying the same thing in January 2023. But rest assured that no matter what happens, the SRUK team will be here for you.

I know that it's not been an easy year for many people, especially those in our community. Throughout 2021, we have worked hard to get answers to your questions about the vaccines, the third dose and more recently the news of antivirals that people in the highest risk category will get access to.

Late last year, we were very pleased that the National Institute for Health and Care Excellence (NICE), approved the use of Nintedanib in treating progressive fibrosing interstitial lung disease. Your views on the realities of living with this condition contributed to the success of the appraisal process, and your input helped SRUK to build a case as to why patients with systemic sclerosis who have interstitial lung disease need access to this life-extending and enhancing treatment.

We were pleased that so many of you were able to attend SRUK's first Virtual Conference. Over 800 people registered,

with 90% of respondents reporting their understanding of their condition and ability to self-manage had improved because of the sessions. Interestingly, 75% said they would prefer an online conference in the future, so we will take this feedback into account when we consider what to do this year. But what I can tell you is that we will have a monthly programme of webinars on various topics, such as communicating with your doctor; mental health and wellbeing and managing your work/life balance.

Thank you all so much for your continued support. I do know from previous conferences how many of you enjoy the opportunity to meet one another face-to-face, and so I am really hoping that we may have the opportunity to see some of you in person this year.

Wishing you all the very best for 2022,

*Sue*



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# DOC SPOT

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



**Q** My Raynaud's attacks always seem to flare up on a monthly basis, just before and during my period. Is this normal and can I do anything to help? I have been told that I have primary Raynaud's but I think I am quite a severe case.

**A** It is quite common for Raynaud's symptoms to vary with the menstrual cycle, and this probably reflects the impact of female hormones like oestrogen on blood vessel function. At certain times in the cycle there may be more symptoms. The effect of hormones might also explain why Raynaud's is more common overall in women.

**Q** I was diagnosed with limited scleroderma three years ago, and I would like to ask if there is a link between scleroderma and breast cancer, as I do have a family history. I have looked into arranging to have a mammogram privately just as a precaution, however this would be extremely expensive.

**A** In a small minority of cases scleroderma can develop in association with a malignant tumour including breast cancer, but this is rare and most often linked to the diffuse form of the disease, and so limited scleroderma probably does not affect cancer risk. However, if you have a family history of breast cancer you should discuss this with your doctor to ensure that you have all the recommended screening procedures, and I hope that these would be available through the NHS.

**Q** I have very sore fingers especially around the nails, which is making it difficult for me to use my hands. I have now also noticed cracking around my fingertips, which is very painful, especially in the colder weather. I have tried various moisturisers, but these do not seem to help. Are there any medications or natural therapies that could help?

**A** In Raynaud's, reduced blood supply to the nailbed can lead to poor nail growth and when there is an associated connective tissue disease such as systemic sclerosis, the blood vessel damage around the nailfolds can lead to soreness and sometimes ulceration of the skin. Cracking of the skin over the fingertips also occurs. Applying moisturisers is useful, but it may be necessary to experiment with different formulations to find one that suits your skin. Treating any associated Raynaud's can be helpful. If infection of the ulcerated skin occurs then a course of antibiotics may be required. If the problem persists and you have not been diagnosed with any associated disease you may require specialist assessment by a dermatologist or rheumatologist.

**Q** I have Raynaud's and erythromelalgia. I have noticed my symptoms getting worse lately, especially the Raynaud's attacks. I would like to be referred to a rheumatologist as I fear there is something else, but my GP said to watch and wait, as apparently it could be hormonal (I am 50). Should I follow his advice or ask for another opinion?

**A** If Raynaud's is worsening and your GP is not able to help, then my recommendation would be to request a referral to a specialist clinic for assessment to confirm the diagnosis and look for any associated medical conditions that may need more investigation or treatment. The combination of Raynaud's and erythromelalgia is not infrequent but can be especially challenging because vasodilator treatment to open the blood vessels for Raynaud's might aggravate the burning and redness of the extremities associated with erythromelalgia.

Skin itching can occur in scleroderma, and in the early stages of the disease can reflect inflammation in the skin. Later, dryness of the skin can be a major problem. Applying moisturisers can be helpful and avoiding strong soaps.

**Q** Is Ginkgo Biloba an effective natural therapy to help to control Raynaud's symptoms please? Is this considered safe for most people?

**A** Ginkgo Biloba is a natural plant leaf extract containing chemicals called flavonoids, that has been reported to benefit symptoms of Raynaud's as well as having other possible health benefits. Although it is not a licensed medicine it is likely to be safe and some small trials have suggested benefit for Raynaud's symptoms. It is certainly a reasonable supplement to try, and any effects should be apparent within four-to-six weeks based on reports from other patients. Some people have experienced allergic reactions, bruising and other side-effects, and so if any adverse symptoms are noticed the supplement should be discontinued and you should seek medical advice.

**Q** Is there a link between Raynaud's and the AstraZeneca COVID-19 vaccine?

**A** All of the approved COVID-19 vaccines in the UK have gone through rigorous testing and are generally safe and very effective. However, all vaccines stimulate the immune system and can very rarely cause serious side effects. There is no specific association between any of the COVID-19 vaccines and the development of Raynaud's Phenomenon.

**Q** I have scleroderma and currently take hydroxychloroquine, methotrexate, nifedipine, fluoxetine and folic acid. I recently had my third COVID vaccine (Pfizer). Am I entitled to a booster or to a fourth vaccine? If so, how do I get it?

**A** Yes, according to the recent update to the Joint Committee on Vaccination and Immunisation (JCVI) guidelines, since you were eligible for and have received a third dose of a COVID vaccine then you will be entitled to a booster vaccination no earlier than 12 weeks after your third dose. Please use the online booking systems in place for England, Wales, Scotland or Northern Ireland as appropriate.

IF RAYNAUD'S IS WORSENING AND YOUR GP IS NOT ABLE TO HELP, THEN MY RECOMMENDATION WOULD BE TO REQUEST A REFERRAL TO A SPECIALIST CLINIC FOR ASSESSMENT, TO CONFIRM THE DIAGNOSIS AND LOOK FOR ANY ASSOCIATED MEDICAL CONDITIONS THAT MAY NEED MORE INVESTIGATION OR TREATMENT.

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](mailto:info@sruk.co.uk)

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



**Q** Is it important to take proton pump inhibitors (PPIs) first thing before other tablets?

**A** Proton pump inhibitors (e.g. lansoprazole), are very effective drugs that suppress stomach acid production, which can be very helpful in systemic sclerosis to treat reflux oesophagitis, swallowing problems and stomach inflammation (gastritis).

Studies suggest that they may be most effective when taken first thing in the morning, however in systemic sclerosis, higher than normal doses may be needed, and some patients find that taking these drugs in the morning and in the evening is necessary. You should discuss this with your doctor if you have ongoing symptoms despite current treatment.

**Q** I have dreadfully itchy skin despite no soap, prescription antihistamines and emollients. Any tips?

**A** Skin itching can occur in scleroderma and in the early stages of the disease can reflect inflammation in the skin. Later, dryness of the skin can be a major problem. Applying moisturisers can be helpful and avoiding strong soaps. Sometimes medication can help such as antihistamines or other approaches, but it remains one of the most difficult symptoms to deal with, and is an area that is being actively researched to see if some of the drugs being developed for eczema or other diseases might also be helpful.

## COLLABORATING TO DRIVE IMPROVEMENTS IN HEALTHCARE

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

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

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

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

### Raising the profile of rare autoimmune conditions

Over the past few years, RAIRDA has produced several reports based on patient surveys, setting out key challenges faced by our communities and making a series of recommendations to improve services. These reports, which have been downloaded over 1,000 times, have helped to increase our profile and credibility with key decision makers across Government and the NHS; and we are now regularly invited to meet with Ministers and to participate in working groups.

We have continued to build a network of support amongst parliamentarians within the Welsh, Scottish and UK Parliaments. Following contact with Liz Twist MP, she specifically referred to non-genetic rare diseases, such as rare autoimmune conditions, in her speech for the Rare Disease Day debate on the new Rare Disease Framework in Parliament.



SRUK contributed to the NICE Health Technology Appraisal on Nintedanib. We engaged with our community to build a case as to why people with SSc-ILD need access to this treatment. We are pleased that NICE has now approved Nintedanib for this group.

### Shaping patient pathways

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

In June 2021, SRUK's CEO, in her capacity as Co-Chair of RAIRDA, was invited by the Department of Health & Social Care (DHSC) to join the Rare Disease Forum, which will advise the UK Rare Disease Framework Board on the implementation of the Rare Disease Framework in England and the devolved nations. The Framework was published in January 2021 and outlines the Government's priorities for improving the lives of people with these conditions.

### Building an evidence base and policy positions for future work

RAIRDA submitted evidence to the Welsh Government in response to their consultation on guidance for services for people with arthritis and long-term musculoskeletal conditions. We gathered qualitative and quantitative evidence in Wales, supporting our call for systemic change.

In June 2021 we conducted a survey to provide fresh insight to one run previously in 2018, which found that on average, patients in Wales report a lower standard of care than those in the rest of the UK. We informed the Welsh Government of the clear need to improve care for people with rare autoimmune conditions. Although there is some good care and certain clinicians with specific expertise, we believe the lack of a commissioned specialised centre in Wales is a major reason for this difference; and have called for one to be established.

We also contacted key Members of the Senedd and the Senedd's Health and Social Care Committee about the evidence, asking them to look into issues surrounding these often-ignored conditions.

### Contributing to consultations

We have continued to submit evidence to key consultations, one of which was the National Institute for Health and Care Excellence (NICE) consultation on their 'Methods and Process' review. We advocated for measures to make NICE appraisals of new treatments and technologies more supportive of innovations which will benefit people with rare diseases.

SRUK contributed to the NICE Health Technology Appraisal on Nintedanib, a treatment for interstitial lung disease. As part of this work, we engaged with those affected within our community to build a case as to why patients with interstitial lung disease (SSc-ILD) need access to this life-extending and enhancing treatment. We are pleased to report that NICE has approved the use of Nintedanib for this group.

### COVID-19

This year has been dominated once again by COVID-19, and a significant part of our work has been focused on raising matters affecting our community with Government and seeking answers on issues such as safety at work, the third primary dose and access to antivirals.

With a wider group of charities, we signed an open letter to employers, highlighting polling

**Patients in Wales report a lower standard of care than those in the rest of the UK. We informed the Welsh Government of the clear need to improve care. We believe the lack of a commissioned specialised centre in Wales is a major reason for this difference; and have called for one to be established.**

which shows that most people don't realise the risk that COVID-19 poses to those who are immunosuppressed, and asking them to ensure they take every measure possible to keep everyone safe.

Following reports from our Helplines of people struggling to access their third primary vaccination, which is an additional dose to the booster for people who are severely immunosuppressed, we ran a rapid survey to help us understand the extent of this problem. We shared these findings with NHSE&I, showing that nearly one-quarter (22%) could not get a third primary COVID-19 vaccine dose and that two-in-five respondents (41%), believed they received a booster jab instead of a primary dose. This raised concerns that some primary doses are being misclassified as boosters, which could prevent patients from accessing a recommended booster later. We were then pleased to see that NHS England updated the COVID-19 vaccination booking system on their website, to include a category for third primary doses.

### Next steps

In 2022, we will build on the work undertaken to date and continue to lobby for improved standards of care for people with rare autoimmune conditions. Next year we want to involve you in our campaigning work, helping to get the message out that everyone, no matter where they live and what their circumstances, should get the responsive and person-centred support they need.

**For more information on the work of RAIRDA, please visit [rairda.org](http://rairda.org)**

# PERSONALISED TREATMENT FOR INTERSTITIAL LUNG DISEASE

**We are delighted to announce that Dr Nina Goldman is about to embark upon a groundbreaking research project, that will focus on developing personalised treatment approaches for interstitial lung disease (ILD).**

Nina has recently been awarded a prestigious Clinical Research Training Fellowship from The Medical Research Council that is co-funded by SRUK. This funding enables clinicians to train in research, thus building clinician research capacity within their specific field.

Fascinated by rheumatology and respiratory medicine, Nina has found a way to

study both. Whilst working in the Middle East with Médecins Sans Frontières, she successfully applied for a very competitive Medical Research Council Fellowship, co-funded by SRUK.

Almost having to complete her interview from a hotel in the Middle East due to pandemic-related travel restrictions, Nina eventually made it to the Royal Free Hospital in London in early 2021 and succeeded in her application: securing funding to research and train in the intersection of her interests; scleroderma associated interstitial lung disease (SSc-ILD).

### Personalised medicine

This research, entitled **"Defining pathogenic B cell regulation and its role in scleroderma associated interstitial lung disease,"** focuses on identifying biomarkers (molecules found in blood or tissue samples). These indicate how well someone will respond to two selected therapies to treat SSc-ILD, therefore showing which one will work best for each individual. The ability to divide patients into subgroups based on their biomarkers and then identify the most effective medication will enable more targeted treatment plans for SSc-ILD patients in the future.

In studying SSc, we will also build a better understanding of the mechanisms surrounding lung fibrosis, which is associated with many other conditions. This could have wide-reaching effects across the medical community.

**"[Scleroderma is] such a debilitating illness. I think it's key that we try to improve treatments, and keep researching it... There has been an improvement in treatment options over recent years, but there's more we could do!"**

Dr Nina Goldman

“I want to say a huge thank you to the SRUK community who are co-funding my fellowship; researching the role of the immune system and the precise mechanisms of action of different treatments in scleroderma associated interstitial lung disease in order to increase our understanding and allow for more effective and personalised treatment for people with this condition. I’m really grateful for the support you give to SRUK which allows me to do my work.”

Dr Nina Goldman

clearly about SSc-ILD and my research. Alongside this as a clinical researcher, I still get to see patients in the clinic. I love knowing that I’m making an active difference: you can see treatments working, and I get to work out how!”

### Your support helps make it happen!

Talking to Nina has provided an insight into the importance of fellowships, which are essential in developing laboratory science skills and furthering medical training, in order to specialise in a research area such as respiratory medicine or rheumatology.

Enabling clinicians to develop these skills can translate into clinical trials towards future treatments that could benefit many patients. Your continued support allows SRUK to fund such projects and further our understanding and ability to treat scleroderma.

### What does this mean for people with scleroderma?

Interstitial lung disease is the biggest cause of mortality in scleroderma: contributing to around 50% of deaths. Since the current treatments available for SSc-ILD are hugely limited, Nina hopes to gain a better understanding of the issues surrounding B cells and the immune system

in SSc-ILD; and to utilise this to improve targeted therapies.

Nina also spoke about the importance of the SRUK co-funded fellowship in allowing her to dedicate time and resources to this research. “The grants and fellowships from MRC and SRUK allow doctors like me to develop our research skills so we can run more clinical trials in the future. I’ve been given the space to think

“Fibrosis is a huge topic in medicine at the moment: it’s a universal pathway in many diseases, and scleroderma offers a way of potentially understanding it better”.

To keep up-to-date with the latest research news, please visit [sruk.co.uk/](http://sruk.co.uk/) research

## SRUK FUNDS NEW RESEARCH TO IMPROVE QUALITY OF LIFE

### How does living with Scleroderma and/or Raynaud’s impact upon your life?

Living with Scleroderma or Raynaud’s can have a significant impact upon quality of life; and this is something that SRUK are well aware of. Ongoing research towards developing new treatments and therapies has a cumulative effect in improving quality of life, but can the problem be addressed more directly?

### Improving Quality of Life

In 2020, SRUK launched a grant call, entitled: “Improving Quality of Life in Raynaud’s and Systemic Sclerosis.” Applicants were encouraged to focus on areas relating to SRUK’s research strategy, and to consider how their proposals would drive improvements to quality of life.

Five applications reached the second stage of the application process, and following a thorough peer review, the following proposals were granted full funding to bring them to fruition:

#### 1. Scleroderma in the Mouth: Improving Pathways to Care

- **Lead Investigator:** Professor Liz Walker
- **Co-Investigators:** Dr Elizabeth Price, Dr Vishal Aggarwal, Professor Francesco Del Galdo
- **Lead Institution:** University of Hull

Professor Walker and her team will develop a care pathway to improve oral and dental outcomes for people with scleroderma. Currently, there is a critical gap of knowledge, awareness and coordination between rheumatology clinicians and dentists. The oral manifestations of scleroderma include a dry mouth, ulcers and disorders of the salivary glands. However, because not many dentists are fully aware of the condition, these complications may often go untreated, or end up being managed less effectively. This is something that Professor Walker hopes to improve.

The care pathway will be achieved by developing a set of clinical guidelines that will increase awareness among primary care dentists and promote early referral from rheumatology to special care dentistry. In developing these guidelines, individuals with scleroderma will be engaged in interviews, as part of an advisory group, to better understand their experiences of dental problems.

#### 2. Self-Assessment of Skin Thickness in Systemic Sclerosis – Improving Quality of Life and Value of Telemedicine for Scleroderma by Empowering Patients

- **Lead Investigator:** Professor Christopher Denton
- **Co-Investigators:** Dr Julia Spierings, Dr Voon Ong, Professor Ariane Herrick, Professor Francesco Del Galdo, Dr John Pauling
- **Lead Institution:** University College London

Evaluating skin involvement in scleroderma is central to patient care. Understanding how scleroderma will progress or how a person is responding to treatments relies on taking accurate and reliable skin measurements. Pre-COVID, the modified Rodnan Skin Score was used routinely, however the focus on remote medicine during the pandemic has led to the creation of the PASTUL Questionnaire (Patient Self-Assessment of Skin Thickness in Upper Limb), that allows patients to grade their own skin.

This research project seeks to refine the questionnaire, thus increasing its potential for use within future clinical trials. In addition, the impact of skin involvement on a person’s quality of life will be measured, using the PASTUL questionnaire as a measure of skin severity.

These projects form part of our ever-evolving research programme and ultimately, each one will have a positive impact on quality of life for people affected by these conditions.



## SRUK SHOP

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

### Snuggle Up Blanket

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

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

**£26.99**



### SRUK Face Mask

Our re-usable face masks are machine washable. The covering is double-layered and made with a soft cotton lining for comfort and features elasticated ear loops. The outer layer is 95% polyester/5% spandex and the inner layer is 95% cotton/5% spandex. They are washable up to 30 degrees Celsius.

**£5.50**



### Silver Gloves

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

Available in 12%, black.

**Available in XS, S/M, L/XL**

**12% = £23.50**



### MyCoal Hand Warmers

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

**£4.99**

**Box of hand warmers: £37.99 (40 pairs)**



### MyCoal Foot Warmers

Once opened, the disposable foot warmers or heat packs are activated by gently shaking or squeezing and can then be placed at the toe end of your shoe. They are shaped for comfort. The heat pads remain warm for up to seven hours, ideal for anyone who gets cold feet or has Raynaud's. They then must be disposed of as they are not re-usable. They come in a pack of four pairs. Warm up your toes and feet with these warmers designed especially for those wintery days or cold nights, or if you are standing on cold ground for a long time.

**£5.49**

**Box of foot warmers: £43.99 (40 pairs)**



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

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

**£24.99**



## SRUK SHOP ORDER FORM

SRUK shop order form	Cost	Qty	Size	Colour
12% Gloves (XS or S-M or L/XL)	£23.50			Black
Other Products	Cost	Qty	Size	Colour
SRUK Face Mask	£5.50			
Astec Self Warming Insoles (Cut to size) for cold feet	£24.99			
MyCoal Hand Warmers	£4.99			
MyCoal Hand Warmers Box	£37.99			
MyCoal Foot Warmers	£5.49			
MyCoal Foot Warmers Box	£43.99			
Snuggle Up Blanket <i>Please specify the colour</i>	£26.99			

### Postage & Packing Costs

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

### Total Order

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

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FOR MORE PRODUCTS  
AND INFORMATION GO TO  
[WWW.SRUKSHOP.CO.UK](http://WWW.SRUKSHOP.CO.UK)  
OR CALL 020 3893 5998

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

# WOMEN'S HEALTH AND SYSTEMIC SCLEROSIS

In Autumn 2021, SRUK hosted a webinar entitled *Women's Health and Systemic Sclerosis*, presented by Dr Elizabeth Price.

Dr Price is a Consultant Rheumatologist at Great Western Hospital in Swindon. She has a specialist interest in Sjogren's Syndrome and runs a multi-disciplinary Sjogren's clinic. Dr Price is also Medical President of the British Sjogren's Syndrome Association.



Dr Elizabeth Price

Autoimmune disease occurs far more commonly in women than in men. This is probably due to a combination of factors, however one reason may be that the female immune system is more complex, as the body is designed to cope with pregnancy so that the baby is not rejected.

The female hormone oestrogen has been shown to affect the immune system, although the mechanisms are not fully understood and research is ongoing.

## Raynaud's Phenomenon

Raynaud's is a very common condition that affects up to one-in-six of the general population. It is probably an exaggeration of a normal physiological response to very cold temperatures, however a Raynaud's attack may be triggered by very slight temperature

changes, emotional stress and sometimes vibrations. Primary Raynaud's is the most common form, and secondary Raynaud's occurs with another autoimmune condition.

Raynaud's is also far more likely to affect women, and there is a positive association between Raynaud's and oestrogen, with symptoms often starting around the menarche, when periods start and oestrogen levels rise. Hormone changes

**Raynaud's is far more likely to affect women, and there is a positive association between Raynaud's and oestrogen**

are also significant, and attacks may be worse at mid-cycle, when oestrogen is at its peak.

In pregnancy, oestrogen levels will naturally rise, however, (and rather surprisingly), Raynaud's symptoms may sometimes improve, due to an increase in circulation that occurs at the same time.

The link between oestrogen and Raynaud's also needs to be considered when it comes to the contraceptive Pill. In some cases, it may be recommended to avoid those that contain 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.

## Vaginal dryness

Vaginal dryness following the menopause is very common in the general population, affecting up to 75% of women in this group. Living with SSc or Sjogren's may also be a factor, especially when vaginal dryness occurs at a younger age. Whenever this issue arises, it can be extremely uncomfortable, and you may become more prone to thrush and other vaginal infections.

**Avoid all conventional soaps;** use a soap substitute instead. These may be available on prescription, although many can be bought over the counter, including Oilatum or Aveeno.

**Moisturing** is essential. This should be done regularly and it is important to persevere. There are many products available, and you may need to try more than one to find the most suitable. If you do not tolerate paraffin-based moisturisers, try an oat-based lotion instead.

It is vital to note that any product used in the intimate area must be acid-based, because the vagina, unlike most other areas of the body, is an acidic zone. If this acidity is lost you may become prone to thrush or to bacterial vaginosis, meaning bacterial overgrowth within the vagina which can be unpleasant and uncomfortable.

If you are affected by dryness and discomfort in the intimate area, you may also benefit from a product that contains oestrogen. The skin around the vagina naturally becomes thinner following the menopause, and when thinner skin is affected by dryness, it may also be prone to tearing and cracking. In these cases, an oestrogen-based cream

or pessary can make a big difference and may be used alongside an acid-based moisturiser.

**Always wear cotton underwear,** as other fabrics can cause or exacerbate irritation. It is also a good idea to stick to white or light-coloured items, since some of the dyes that are commonly used can also cause problems.

**Avoid perfumed products** around the intimate area. These could also include certain brands of pads and pantyliners, which may be fragranced.

## Pregnancy

Planning is vital if you are considering trying for a baby. Pregnancy outcomes are also likely to be influenced by how well you are when you conceive. It is therefore essential to talk to your doctor before becoming pregnant, and to take as many steps as possible to optimise your health and hopefully stay as well as possible, to maximise your chances of a successful pregnancy.

Most women living with systemic sclerosis will have normal fertility, although just like within the general population, this will depend on individual circumstances. There are many factors that could have an impact, including your specific diagnosis and medical history; and previous treatment with cyclophosphamide may have an adverse effect.

There may be an increased risk of miscarriage among women with connective tissue disease, although the actual incidence is difficult to measure, partly because it is not consistently

recorded within the general population either; as some early miscarriages are never reported. A study\* published in 2020 did suggest a slightly higher rate of miscarriage in women with systemic sclerosis.

Early deliveries and low birth weight babies are both more common in women with SSc and other connective tissue diseases than within the general population. Specifically, if you are living with SSc you are around twice as likely to have an early baby, and around three-times more likely to have a baby with a low birth weight.

Your connective tissue disease is not likely to get worse in pregnancy and providing it is well-controlled, your doctor may be happy for you to go ahead and try for a baby. However, you may be advised against pregnancy if you have pulmonary arterial hypertension (PAH). This is a condition where you develop high pressure in the small arteries of the lungs that leads to additional strain being placed on the heart. If you do have SSc-associated PAH this will make pregnancy more risky, and your consultant will be able to offer advice based on your own individual circumstances.

**If you are living with SSc you are around twice as likely to have an early baby, and around three-times more likely to have a baby with a low birth weight.**



Careful monitoring is essential throughout pregnancy, and it is likely you will be referred to a specialist obstetrician with a plan in place for a hospital birth. Pregnancy increases circulation and can raise blood pressure as well as affect kidney function, so you should be offered regular tests along with extra scans to monitor your baby.

### Breastfeeding

Breastfeeding is safe for women with SSc and other connective tissue diseases. Almost all the medications that are commonly prescribed are also considered safe for breastfeeding mothers, with a few exceptions including methotrexate and cyclophosphamide. It is vital that you do not stop taking any medication without speaking to your doctor, as this may lead to a sudden disease flare.

Many women, particularly those with Sjogrens, report struggling to breastfeed. This may be because the breast is a secretory gland, and since Sjogrens affects the secretory glands the amount of breastmilk may be reduced. Whatever happens, stress will make things worse. If things are very difficult, remember that formula milk is a perfectly suitable substitute for your baby.

### Raynaud's nipple

Raynaud's can affect any extremity, including the nipple, and this can make breastfeeding very painful. It may be precipitated by the cold, although the stress that

often accompanies trying to establish breastfeeding so soon after birth may also be a factor. Raynaud's nipple may sometimes be misdiagnosed and treated as thrush or an infection, when in fact what is needed is treatment for Raynaud's. It is vital to keep warm, and this means maintaining core temperature with warm, thermal clothing and layers, as this will help to ensure that blood is not redirected away from the extremities. It may be useful to note this in your birth plan prior to a hospital delivery, and do not be afraid to remind those around you if necessary. There is some evidence that taking Omega 3 and fish oils may be helpful, although in some cases medication will be needed to control symptoms.

### The menopause

The menopause is the natural process in which oestrogen levels decline and periods eventually stop.

Many women with connective tissue disease may have an early menopause, as well as early ovarian failure. In the general population, women often follow a similar pattern to their mother, and certain treatments, e.g. cyclophosphamide, may also be relevant. Age at diagnosis can be a factor, as women diagnosed at a younger age may experience the menopause earlier. However, it is not all bad news, as symptoms such as migraines tend to improve following the menopause, as do period problems.

### Hormone replacement therapy

Hormone replacement therapy (HRT) is a treatment designed to relieve the symptoms of the menopause. It works by replacing the hormones that naturally reduce during the menopausal years.

If you are considering trying HRT, it is important to be informed and to talk to your rheumatologist.

The link between oestrogen and the immune system may be relevant, and in some cases you may be advised to avoid treatment containing oestrogen as this may make symptoms worse. However, oestrogen-based creams and pessaries for use in the genital area are considered safe for women with SSc.

### Looking after your wellbeing

In general, all the evidence shows that keeping as fit as possible helps to preserve bone health, muscle mass and general wellbeing in later life, so whether or not you start HRT, taking other steps to preserve your health should be a vital part of self-management through the menopausal years and beyond. Whatever your age, always remember to take care of you, and that it is never too late to try something new.

\*Blagjevic et. Al 2020.

You can view Dr. Price's presentation on women's health here: [bit.ly/3t7yLZx](https://bit.ly/3t7yLZx)

You can also watch our webinars to date as well as many other useful videos via our Youtube channel: [youtube.com/WeAreSRUK](https://youtube.com/WeAreSRUK)

# YOUR STORIES

## HEALTH, WELLBEING, AND HOW A LITTLE SUPPORT MAKES A BIG DIFFERENCE

**The gender we are born with determines many of our health needs for the rest of our lives. Around 80% of people diagnosed with scleroderma are female, so women's health will be a part of life for many people in our community.**

Each individual experiences a unique journey through their reproductive years, the menopause and beyond; with no single approach that is guaranteed to help. However, because health and wellbeing are closely linked, it is often helpful to take a holistic view, especially with an underlying autoimmune condition.

**Paula Manning is a mental health physiotherapist, CEO of Healthy Chats CIC and has specialised in physical activity promotion. She was diagnosed with mixed connective tissue disease over three years ago, and has been working to build and maintain her strength and fitness after her acute illness. We asked Paula for some tips to help preserve strength, fitness and wellbeing, for women of any age.**

During lockdown, The SRUK Support Group Midlands began an online exercise group, led by community member Paula. Within this safe space, the conversation shifted to some more intimate issues, and as people began to share their experiences, some common themes began to emerge.

### The pelvic floor

The pelvic floor muscles surround the bladder and the urethra and control urine flow. If they are weak or damaged this may contribute to incontinence, so it is vital to keep these muscles strong. Obstetric history may often be relevant, especially if you have had a vaginal delivery. Age can also be a factor, and even some medications.

Exercising the pelvic floor muscles regularly can strengthen them so they give the right level of support to help maintain continence in the longer term; and could even help you enjoy sex more. Your doctor can refer you to a women's health physiotherapist if necessary.



Paula Manning

For some useful resources, please visit The Chartered Society of Physiotherapy, at: [csp.org.uk/conditions/incontinence/exercise-advice-incontinence](https://csp.org.uk/conditions/incontinence/exercise-advice-incontinence)

### Relationships

Living with SSc may impact upon the more intimate aspects of life. This effectively creates another layer of self-management, so it is important to acknowledge this. Talking really helps, as the Midlands Support Group has found.

Gently stretching the muscles and soft tissue around the inner thighs, hips, knees and lower back will help to maintain and improve your ability to achieve any position you may want to. Feeling comfortable is key to enjoyment and can play an important part in relationships, whatever you choose to do. If you are affected by vaginal dryness and tightness your doctor can help, however drinking plenty of fluids will benefit this area as well.

**Physical activity** can boost self-esteem and effect chemical changes in the brain that have a positive effect upon mood; and doing things that make you feel good will help your sense of wellbeing. Being active does not need to involve anything strenuous: taking the time to simply walk in a green space really can make a difference.

- Walking slowly and mindfully helps us to observe nature and calm the mind.
- Walking and talking with a friend can be a bit faster and helps us get active with some social interaction.
- Walking for health means walking faster and getting a bit hot and red in the face as the heart rate speeds up. This helps to strengthen muscles and powers up both physical and mental health.

**Bone strength:** Women begin losing bone density from the age of 30, however there are steps you can take that can help. These include taking vitamin D and calcium supplements and doing bone loading activities such as walking faster, climbing stairs, gardening or attending the gym or exercise classes. If you have osteoporosis, always take the medications exactly as directed, as this may affect how well they work.

**Pace yourself by starting low and build up over time. It may be a bit uncomfortable; but getting stronger is vital in helping you continue your life as you want to live it, and in easing pain.**

**Muscle strength:** Women lose 10% of muscle bulk every decade after the age of 30: unless we do something about it. Strength training exercises can help improve wellbeing, physical health and balance; reducing the risk of falling as we get older.

- Try lifting a bottle of laundry detergent above your head and repeat ten times: you may need to work up!
- Practice changing your position from sit-to-stand, straighten those knees out in front of you, tapping your feet.
- Try walking up and down the stairs, two-three times more than usual.
- If you can access a gym or have equipment at home, strength or resistance training twice a week using progressively heavier weights or stronger resistance bands is recommended. If you can, eight repetitions of a strength exercise, with the last one being a challenge, will help develop muscle. Everyone is different, so sometimes starting with just three repetitions is best.

Pace yourself by starting low and build up over time. It may be a bit uncomfortable; but getting stronger is vital in helping you continue your life as you want to live it, and in easing pain.

### Mindfulness

Mindfulness is about staying focused on the present moment: on your own thoughts and feelings and the world around you. This can improve mental wellbeing, by helping us to enjoy life more and understand ourselves better.

- Think about your breathing. Close your eyes and breathe in slowly.
- Still focusing on breathing, allow the breath to fill your lungs.
- Do not criticise your mind for wandering, as this is perfectly normal. Simply acknowledge this and then return to the present.

### Have fun

Taking the time to look after ourselves mentally and physically will bring multiple benefits, but whatever you are doing, from walking a bit further, dancing or taking part in a fitness programme, enjoyment is key.



Jyoti

## JYOTI'S STORY

**Jyoti is 49 and lives in Birmingham with her family. She is living with systemic sclerosis and myositis and is also involved in the SRUK Support Group Midlands. We asked Jyoti about her experiences of diagnosis and the importance of mutual support in dealing with some of the more intimate aspects of living with these conditions.**

I felt that my diagnosis may well have been hormone-related, but I do not know. I was diagnosed in February 2020 at the age of 47. When I first approached my GP, she said that my symptoms were probably due to changes I was going through around the menopause. She suggested HRT, so I said I would think about it and then come back. A few months later I was diagnosed with systemic sclerosis and myositis.

I had been back and forth to the GP a few times, probably for about five months. Then by chance I saw a locum who had previously come across a patient with systemic sclerosis. He asked if my Raynaud's was primary or secondary, and since I had not had a blood test he arranged this straight away - which led to my diagnosis. I was also having serious issues with muscle strength, and I was diagnosed with the overlapping condition myositis, which was extremely debilitating at the time.

Luckily, my GP pushed through the referral, and I was seen urgently at the hospital in March 2020. I went straight onto medication, and by now the myositis was affecting my whole body. I was very active before my diagnosis. I went to the gym four times a week and I had a very healthy lifestyle, so it was such a shock to be hit by something like this.

The conversation around women's health all started within our Support Group, when we began to discuss the similarities between the symptoms of systemic sclerosis and the menopause. When I joined the Group, I built up friendships and we became more confident talking about more intimate issues. The group was also proactive in asking SRUK to cover these aspects, otherwise it may not have happened.

Peer support has been vital in understanding this condition and especially the issues around women's health. The online exercise sessions hosted by Paula during lockdown were an absolute Godsend. She was really encouraging, and there is so much more I can do now.

**The conversation around women's health all started within our Support Group, when we began to discuss the similarities between the symptoms of systemic sclerosis and the menopause.**

Often, someone will say something or raise an issue that others can relate to, and we can share tips that might be helpful. I know that I have come out of these meetings with useful ideas that have helped. There is no pressure, and some people prefer just to listen, whereas others contribute more. Some days you just don't want to be reminded of what you are going through and some days you want to chat more. Because peer support can be so valuable, I have suggested that callers to the SRUK Helpline contact their local Support Group, as this has really helped me.

My mum has osteoporosis, so I am trying to do as much as I can to preserve my bone health. I recently had a telephone consultation with the GP about hormone replacement therapy. I had watched SRUK's webinar on systemic sclerosis and women's health, and I told her what I had learned. I have now been referred to another GP within the practice who is more experienced in the menopause, but I may end up going back to the rheumatology team.

I think that the main challenges in relation to women's health when you have SSc are the symptoms you deal with and finding the expertise within the medical profession to help you to manage the condition; alongside coping with the hormonal changes of the menopause. Recently, there has been a huge amount of media coverage, but there seems to be limited information out there for people with chronic conditions such as this, and where to find additional support during this already challenging period.

# FINDING SUPPORT

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

For more information on any of the services listed here, please contact us.

Helpline:  
**0800  
311 2756**

## Our Latest Publications

We are delighted to announce the launch of three new information booklets for people affected by scleroderma and their families.

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



To get your copies, please contact us or visit [sruk.co.uk/publications](http://sruk.co.uk/publications)



“Volunteering on the Helpline was about giving something back to the community that had been so supportive to me when I was first diagnosed with diffuse scleroderma.”

Amelia

### SRUK Helpline

Our free Helpline enables anyone affected by Scleroderma and Raynaud's to receive support whenever they need it. This service is available from 9am-7pm, 365 days a year and our amazing Helpline volunteers all have some personal experience of life with these conditions. The Helpline does get busy, so if the call goes to voicemail, please leave a message and we will aim to call you back within 24 hours. As an accredited member of the Helplines Partnership, we always conform to their standards of excellence.

### Medical Enquiries

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

### Keep in Touch Support Service

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

Our volunteer will arrange to call you on a regular basis at a time that suits you. If you or someone you care for would like some more information, please let us know.

### Our Online Community

Help and support is also provided via our online forum hosted on **Health Unlocked**. This is a friendly space where you can exchange advice, information and support with others, 24-hours-a-day, seven days a week. Many of our community members are living with these conditions themselves, although friends, family and partners are also very welcome. Please visit [healthunlocked.com/sruk](http://healthunlocked.com/sruk)

### Social Media

Join together and support each other through social media. Start a discussion, share tips and read advice from others on our Facebook, Twitter and Instagram pages.



### Local Support Groups

Our local Support Groups are still as active as ever and working hard to keep people connected. If you are interested in joining a group or you would like to find out more, please call us or send us an email and we will be happy to put you in touch with your local support contact.

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

# RAYNAUD'S AWARENESS MONTH

## Help us to Educate, Empower, Engage

February is our Raynaud's Awareness Month. Our key messages are always consistent: **know your 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. We want to change that and offer information.

Thank you to everyone that has already shared their story with us; this is a really powerful way to show the reality of living with Raynaud's.

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

### Catch up with a Coffee

Host a **Catch up with a Coffee** event – whether virtually or in-person, with your friends or with your colleagues. Ten million people in the UK have Raynaud's and one of them may be at your event. Perhaps they've always had cold hands and feet and didn't know why. By talking about Raynaud's and raising money for SRUK you will be helping us reach more people.

### Your Mugshot



The **SRUK Support Group Midlands** with their favourite mugs for Raynaud's Awareness Month 2021

As part of the campaign, we are asking people to take a picture with their favourite

mug, share it with us and this will help us raise awareness.

**Find out more, visit:** [sruk.co.uk/get-involved/fundraising/raynauds-awareness-month-2021/](https://sruk.co.uk/get-involved/fundraising/raynauds-awareness-month-2021/)

### Our online test: pass it on!

Take our online test and encourage others to do the same. You could use social media to challenge your friends and family to take the test by telling them that you did. Get them pass it on to their contacts.

**Visit:** [sruk.co.uk/takethetest](https://sruk.co.uk/takethetest)

### Challenge yourself

Take on a challenge – we have lots of tips to help you manage your Raynaud's whilst exercising, whether your passion is running or a gentle stroll with friends, make sure people know



**Dannii Levi**, who has Raynaud's, challenged herself and many others to run 28 miles during 28 days in February 2021. They raised over £400.

**Know your symptoms**  
**Know how you can manage them**  
**Know what the risks are**

the extra challenges you face and ask them to support you and SRUK.

### Share your story

Telling your story always helps; this year we have asked people to record their own video diaries of their Raynaud's – you could do the same. Give people a real sense of what it's like to live with Raynaud's every day.

**Find us on Facebook, Instagram, Twitter and YouTube @WeareSRUK**

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

**Find out more:** [sruk.co.uk/ram](https://sruk.co.uk/ram)

**Contact us; email** [PR@sruk.co.uk](mailto:PR@sruk.co.uk); **or call** **020 3893 5998** to **find out more or to get involved.**

# Leaving a gift in your Will

**A legacy gift is a very special and unique donation, that will help us continue to advance care, treatment and support for people affected by Scleroderma and Raynaud's, for many years to come.**

Many adults in the UK still do not have a valid Will. Whilst many of us might prefer not to think about it, getting your affairs in order is actually very important, to ensure that your final wishes are respected when the time comes.

Making a Will enables you to take care of your loved ones, and to remember any charitable causes that you care about if you wish to do so. A legacy gift to a named charity ensures that your priorities will be looked after by people who understand and share your values. It is thought that overall, people give an average of three charity bequests when making their Wills.

When you pledge a legacy gift to SRUK, you help us continue to fund ground-breaking research and develop our information and support services for people living with Scleroderma and Raynaud's. Our community has been incredibly generous with their legacy gifts over the years, and we truly value every gift at any level; each and every one really has made a difference.

## The true value of a legacy gift

Legacy giving represents the largest single source of support across the charity sector. Over the years, legacy gifts have been vital to SRUK, accounting for over half our income. Without this support we would not have been able to fund ground-breaking research, given support to as many families or helped as many people manage their conditions. Of course, it is important that your family and loved ones are taken care of in any eventuality before your donation is committed, and there are several ways to frame a legacy gift to ensure this.

## How do legacy gifts work?

There are three types of legacy gift. Each one works differently, so the best option to consider will depend on your own individual circumstances, and the way that you would like your estate to be distributed at the relevant time.

**A residuary gift** means giving a percentage of your estate, but only after specified gifts have been made to friends and family. The value of a residuary gift will depend upon the value of your estate at the

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

Anonymous

time, rather than setting a specified amount when a Will is drafted. This means that you can decide what you would like to leave to your loved ones before any money is given to charity.

**A pecuniary gift** does involve a set amount of money, however the effects of inflation may mean that your gift loses value over time.

**A specific gift** refers to leaving a specified item or asset, such as land, property or shares.



**Olive Ayoub** chose to bequeath a very generous gift to SRUK in her Will, after seeing first-hand the impact that living with scleroderma had upon her close friend Helen. After Olive's passing at the age of 97, we talked to her friend Chris about her life and her legacy:

“Olive was befriended and supported by her neighbour Helen. They became firm friends, and Olive used to say that she had found her sister. Helen has scleroderma, and as she became increasingly debilitated by her illness resulting in the amputation of one of her legs, Olive was determined to do what she could to help Helen and the wider scleroderma community. This desire to help resulted in her decision to leave a legacy, which she endowed to SRUK. She was a remarkable lady, and it is fitting that her name will be attached to the Research Fellowship that her legacy will support.” **Chris**

**If you would like some more information, we are here to help. Alternatively, please visit:** [sruk.co.uk/get-involved/leave-gift-your-will](https://sruk.co.uk/get-involved/leave-gift-your-will)



# THE LEGACY OF JOAN CHAPPELL



Joan with her daughter Diane

**We are incredibly grateful to the late Joan Chappell, who has left a very generous gift to SRUK in her Will. Joan had systemic sclerosis, and she very sadly passed away in May 2021. Joan's daughter Diane told us all about her beloved Mum, her scleroderma journey and her motivation to help others. It was this that inspired her to leave a legacy gift to help us continue to provide information and support, fund new research and raise awareness. We would like to thank Diane for sharing the story of her wonderful Mum.**

Mum was born in 1947 and she married my Dad in 1968. They had three children: my two older brothers and then me. Mum worked in the school kitchens when we were young, and she later joined the local council as a benefits assessor. She obtained her qualifications, and she really enjoyed her job. She was able to keep working until the age of 62 as her employers supported her really well. Mum and Dad were always very happy together until he passed away in 2014 after developing lung cancer, and Mum was left on her own.

My mother was always a really loving mum who wanted to provide good food and make us all feel safe at home. She was a keen cook and baker; and Mum and Dad took up ballroom dancing as Mum had always wanted them to be able to dance, but this had to stop because of Mum's illness.

My Mum was diagnosed with systemic sclerosis at the age of 50. She had been ill for a couple of years, and by her 50th birthday she had become very poorly. She was originally investigated for heart problems, and a local cardiologist was luckily very persistent in helping her to get the diagnosis, initially thinking that she possibly had lupus.

At the time, she was given a prognosis of 10 years, however she made it to 73 years of age, so she did amazingly well. She always said that she felt lucky to have stayed as well as she did. After her diagnosis, she was referred to the Royal Free Hospital in London where she was seen every year, initially under the care of Professor Black, and eventually Professor Denton. She also attended the Royal Brompton Hospital for lung function tests and echocardiogram testing.

My parents always really enjoyed the Scleroderma Open Days held at the Royal Free Hospital and attended every year until my Dad's passing in 2014. Mum was always keen to find out the latest news and hear about possible new treatments, which helped her remain optimistic that medicine was always advancing to hopefully help her to live longer.

She was always good at being her own advocate with local medical professionals, who did not always seem to know very much about scleroderma. SRUK's membership magazine kept her up to date with all the latest information in many ways, and even more so when she stopped going to the open days at the Royal Free after Dad passed away. She was a stoic and determined lady, who was always good at

speaking up for herself and letting people know what was behind her symptoms.

Mum took part in one of the medical trials:- she called it the 'Goat Trial!' She had to stop however, because she had to reduce her medication to participate but then her symptoms worsened, so it had to be increased again. She had to take a cocktail of many different medications every day, but she was always grateful that they kept her well enough to keep living fairly well; even though the lung fibrosis was debilitating and did limit what she was able to do. Mum was very good at managing her medicines and always kept on top of things. She developed pneumonia a couple of times, so she was also prescribed prophylactic antibiotics.

During her last two years, she needed ambulatory oxygen and used a wheelchair to get about out of the house. With a little bit of help, she was able to stay in her own home for as long as she possibly could, and this gave her a lot of strength. I visited her on a daily basis and helped her as much as I could since COVID came along, as I had stopped working. I feel lucky, because although COVID was such a horrible time, I was still able to see Mum every day. Sadly, at the age of 73, Mum developed a chest infection and became very poorly. She passed away on 15 May 2021. I miss her very much.

## Mum's legacy

My Mum wanted to leave a gift to SRUK in her Will, so that this could be put to good use to help others. For example, by helping SRUK keep on raising awareness, so that more health professionals can become familiar with this disease. Mum regularly encountered a lack of

**Hopefully, her gift can help SRUK to continue providing ... information and support to others affected by this condition.**

knowledge of scleroderma from healthcare professionals at a local level.

Or perhaps, by helping to fund new research; with the ultimate goal of making this condition easier to live with for future generations.

For my Mum, she always looked forward to receiving the membership magazine, and she always read it from cover to cover. I think it helped her to feel that she was not alone in her illness, by keeping her informed and giving her a kind of a sense of belonging. I'm sure she would have heeded all the advice, such as keeping the hands warm. She often wore gloves in the house and I'm sure your magazine would have told her about that! Hopefully, her gift can help SRUK to continue providing this kind of information and support to others affected by this condition. All these little things really can make a big difference.

*It is wonderful to be able to share Joan's story to honour her memory and to express our gratitude for her legacy gift to SRUK. It is also lovely to know that she found our membership magazine so helpful, and how she looked forward to receiving it.*

*We cannot emphasise enough the significance of legacy giving, which has proved to be so vital to us over the years. We would like to say thank you once again to Diane, for enabling us to remember her Mum and for all her support; this really will make a difference and we are very grateful.*

**Sue Farrington**

# FUNDRAISING HEROES

SHINING THE SPOTLIGHT ON SOME OF OUR FANTASTIC SUPPORTERS!



## HALLOWEEN HOUSE FUNDRAISING

**Kirstie** decorated her house for Halloween in memory of her neighbour **Wendy**, who had scleroderma and absolutely loved Halloween! They raised over **£500** for SRUK – a spooktacular effort!



Thank you to **Dimple**, who amazingly completed a skydive for SRUK and raised a total of **£3,642** so far!

## CHRISTMAS FUNDRAISING

**JudgeService Research** raised **£200** from their Christmas Dress down day, in memory of one of their colleague's friends. They all donned their very best Christmas jumpers and dug deep to support SRUK!

## 12 BAKES OF CHRISTMAS

Hot off the heels of the Great British Bake Off, we launched our **12 Bakes of Christmas** fundraiser and we have some very talented bakers in our community. Thank you to everyone that took part.

You can put your baking talents to work in February and organise a **Catch up with a Coffee** fundraiser. Visit: [sruk.co.uk/get-involved](http://sruk.co.uk/get-involved) to find out more.

Perhaps you'll be inspired by intrepid baker **Lucy Husbands** and set yourself a longer baking challenge? Lucy has challenged herself to bake the alphabet and is off to a flying start with **Almond** croissants and **Belgian** buns!



## SRUK CHRISTMAS APPEAL: THANK YOU!

We are really grateful to everyone that contributed to our Christmas Appeal – you raised over **£12,000**. A very special thank you to all those that helped by sharing their stories – we really can't do any of this without your support.

## LOOKING FORWARD TO 2022

New Year, New Challenge! Do you know someone whose New Year's resolution was to get fit, or is it yours? Then our brand new programme of events for 2022 will keep you on track and motivated! There's something for everyone from seasoned runners to first time cyclists. Check out page 2 to find your challenge!



## COULD YOU BE A FUNDRAISING HERO?

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

### #TeamSRUK Needs You!

If you are interested in running for **#TeamSRUK**, or know someone who might be, we still have places available for different events throughout 2022!

For more information, please email [fundraising@sruk.co.uk](mailto:fundraising@sruk.co.uk) call **020 3893 5993** or visit [sruk.co.uk/get-involved](http://sruk.co.uk/get-involved)

# WAYS TO SUPPORT US

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

**Donate to us through our website at [sruk.co.uk](http://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](mailto: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](mailto: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](http://sruk.co.uk/donate/direct-debit)

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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.

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