

SRUK NEWS

John

(pictured with wife Estelle and their family),
is a true Fundraising
Hero!

Read their
heartwarming
story.



“It’s so important to raise awareness about how being diagnosed with a disease like scleroderma can impact your mental health.”

Living with anxiety
(and how to manage it).

Research news:

Predicting disease progression in ILD.

Does scleroderma or lupus place you at greater risk from COVID-19?



**Thank you for supporting
Scleroderma Awareness
Month 2022**

Find out more on page 24

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.

Fundraising news

We have a limited number of places in next year's **London Landmarks Half Marathon**. Join us for this scenic half with amazing views of London's most famous landmarks. All you need to do is pay a registration fee of £20 and commit to raising £400.

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

Join Team SRUK

Are you interested in fundraising for us or taking part in an event to help those affected by Scleroderma and Raynaud's? From inflatable 5ks to marathons and bake sales to golf days, there's something for everyone.

If you join us for some fundraising you'll receive a free fundraising pack, SRUK running vest or t-shirt and the dedicated support of the SRUK fundraising team every step of the way!

Check out our calendar below for just a few of the events you can get involved in.

Interested? Get in touch on fundraising@sruk.co.uk or

EVENTS CALENDAR 2022	
Leeds Running Festival (Various Distances)	21 August 2022
Inflatable 5K (Various Locations)	Various dates in August
The Peak District Challenge (10-100k)	17 September 2022
Sheffield 10k	25 September 2022
London Marathon (including Virtual)	2 October 2022
Royal Parks Half Marathon	9 October 2022
Manchester Half Marathon	9 October 2022
London Landmarks Half Marathon	2 April 2023

call **020 3893 5993**.

THANK YOU!

We would like to say a big **THANK YOU** to everyone who has donated to our **Summer Appeal!** As ever we have been overwhelmed by your generosity and your support really does make a difference. Your donations enable us to continue making the greatest possible impact in providing information and support to affected people and their loved ones, and to continue funding research to improve treatment and care.

There are so many ways that you can help us; it's never too late and every one of our supporters really does count!

- Spread the word by sharing our content on social media.
- Plant a sunflower to help start a conversation about this little-known condition. Turn to page 24 for a little more inspiration!
- Walking is not just for June - you can still Take Steps for SRUK, to raise awareness of scleroderma. Whether it is 10 steps or one million, we will keep on walking together.

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

Alison

WELCOME TO THE LATEST EDITION OF SRUK NEWS

Dear Supporters

I hope you are enjoying the warm weather we've been experiencing, albeit a tad hot on occasion, and that you've been able to get away and visit friends and family. I'm certainly looking forward to taking some time out and going away with family to Ludlow, where I hope to do some walking and possibly kayaking.

I'm very aware that COVID is still with us and that for many in our community it still presents a threat, which is why we have joined forces with other charities representing patients who remain vulnerable to COVID, even after vaccination, to call on the UK Government to procure and provide prophylactic monoclonal antibody therapies such as AstraZeneca's Evusheld.

COVID has been challenging, but when you put that alongside living with a rare autoimmune condition, such as scleroderma, and the uncertainty about progression, it can be an anxious time for many. In this edition, we have an excellent article by Lucy Reeves, who is an Occupational Therapist and has scleroderma, on some helpful tools and techniques to manage your anxiety.

And I would like to thank Sara Dyson and Avtar Gill for contributing their stories on how they have dealt with anxiety and the steps they took to improve their emotional wellbeing. Your

stories about your experiences are so important and we are very grateful that as a community you are so willing to share your insights.

We also appreciate all the amazing work you do to fundraise for SRUK, whether that's holding a bake sale, walking with friends to conquer a million steps or taking on incredible challenge events. The money you raise through activities and donations helps us continue to provide support and information, to advocate for better healthcare and to fund much needed research.

With very best wishes,

Sue

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DOC SPOT

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



Q I have limited scleroderma and I have been diagnosed with long COVID, but I have since developed Raynaud's of the nipple. It started with breast pain, and then my nipples started changing colour and turning white. It is not related to pregnancy or breastfeeding. I have had many other issues including fatigue and severe chilblains since developing long COVID. I would like to know if there is a connection, and any treatments that would help as this is very painful and not improving?

A Several research studies have shown that COVID-19 infection can result in abnormalities in the blood and blood vessels which lead to chilblains. During the waves of infection abnormal blood clots and circulatory problems were very serious for many patients. Milder cases could aggravate pre-existing Raynaud's, and this can affect any part of the body, including the nipples. In most cases the longer-term effects of COVID-19 do stabilise or improve with time, but it can take many months. Treatment in this context is similar for other patients with vascular problems including avoiding cold exposure and taking supplements or prescription vasodilators. Chilblains can also respond to the application of topical treatment, including steroid-based ointments or creams in some cases.

Q I was wondering if there is a known link between having a low breast milk supply and Raynaud's Phenomenon? I have also become aware of other mothers with low milk supply who also have Raynaud's so is there an established connection, and is there anything that can help?

A 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.

Many women, particularly those with Sjogren's, report struggling to breastfeed. This may be because the breast is a secretory gland, and since Sjogren's 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.

Q I am concerned that my right hand is becoming permanently clawed, are there any exercises or self-help that can prevent this from happening?

A Systemic sclerosis can cause tightening of tissues in the hands and wrists, and in some cases this leads to contractures or bending of the fingers. It is often more marked in the dominant hand (usually right). The explanation for the asymmetry is not known. Treatments for the underlying disease including immunosuppressive drugs such as mycophenolate mofetil or methotrexate may be helpful. Exercises to stretch and straighten the fingers are critical and should be performed every day, and you should discuss these with your clinical team.

Q Before an angiogram and stent insertion my online reading advised against the use of the radial artery because of the increased risk of arterial spasm in someone with Scleroderma and Raynaud's Phenomenon. What is your advice in this situation please?

A In systemic sclerosis, the blood vessels in the extremities can become narrowed or blocked and this can occur in the arm and wrists. There are two main arteries supplying the arm, called the radial and ulnar. The ulnar

artery is narrower and more often becomes blocked in systemic sclerosis. This is not usually a major problem if the radial artery can compensate. In heart bypass surgery the radial artery is sometimes removed to use as a graft. This can leave the hand starved of blood if the ulnar artery is blocked so it is certainly important for surgeons to consider this risk in patients with systemic sclerosis.

Q What is the meaning of 'mechanic's fingers' or 'mechanic's hands' please? Could this be a sign of something wrong?

A Some patients with connective tissue disease and Raynaud's develop thickening and cracking of the skin over the fingers. This especially occurs over the tips and may reflect sensitivity to minor injury and poor healing. This is termed "mechanic's hands". It is more often seen in cases of polymyositis than systemic sclerosis (scleroderma). In the absence of any other features of connective tissue disease it probably relates to dryness of the skin or a more local issue such as dermatitis or eczema.

Q I would like to ask about Sine Scleroderma please. I have struggled to find any information and I would like to know if this can be treated, and also about prognosis. Are there different antibodies to systemic sclerosis? I feel I need a clear diagnosis of what is wrong, but I don't know what to ask for?

A A small number of patients with systemic sclerosis do not have skin thickening and these can be considered as "systemic sclerosis sine scleroderma" (sine = "without"). Fewer than one-in-100 patients have this form of the disease. Blood tests such as antinuclear antibodies and features such as Raynaud's are generally present and internal organs may also be affected and so it is important to make the diagnosis, even though the condition is very rare.

Q I have calcinosis and I have been told I will need surgery, but I feel that I have not been given a lot of information. What exactly will the surgery involve, and will it be a major procedure with a long recovery time?

A Calcinosis describes the development of chalky material under the skin that leads to lumps and can result in local pain or even ulceration. Sometimes the calcinosis breaks

SYSTEMIC SCLEROSIS CAN CAUSE TIGHTENING OF TISSUES IN THE HANDS AND WRISTS, AND IN SOME CASES THIS LEADS TO CONTRACTURES OR BENDING OF THE FINGERS. IT IS OFTEN MORE MARKED IN THE DOMINANT HAND (USUALLY RIGHT).

through the skin. It can occur at any site but is most often seen on the fingertips or at sites of pressure or trauma. Treatment is difficult and although there are some reports of medical therapies that have been helpful, such as the antibiotic minocycline that can help the body break down the calcified lumps, the most effective way of treating the problem is surgical removal. However, calcinosis may recur, and it can be difficult to remove it completely. Also, when calcinosis develops close to nerves or blood vessels there can be risk of complications. It is important to balance risks and benefit, and this should be discussed with your surgeon to help reach the best decision for you.

Q I have increasing issues with my mouth, including a very dry mouth and persistent ulcers. I feel that things are getting worse, and that the whole area is tightening now. Is there anything that can be done to help?

A Systemic sclerosis can lead to scarring or fibrosis around the mouth as well as loss of fat tissue in the lips. In addition, reduced saliva production leads to a dry mouth. Local measures such as saliva sprays may help, but the tightness may also be reduced using regular facial exercises. For some people, surgical treatment including transfer of fat cells from the abdominal wall or thighs (termed autologous lipotransfer, or Coleman fat transfer), may be very effective at softening the scar tissue, replacing lost fat and diminishing mouth dryness, and this treatment can be offered at some centres. You should discuss this with your clinical team.

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



REDUCING UNCERTAINTY IN THE PROGRESSION OF LUNG FIBROSIS IN SCLERODERMA PATIENTS

Having scleroderma often means living with uncertainty around how the disease will progress over time and the impact of this progression upon quality of life. New research funded by SRUK aims to help address this 'prognostic uncertainty', by using indicators that will predict disease progression and ultimately improve treatment options.



If you have scleroderma, you may often feel unsure about how your condition and all its related symptoms might develop over time. It's also common to worry about how any progression could impact your life in the future, particularly if you've been told that the condition will affect parts of your body like your heart or lungs. This has the potential to create anxiety about the condition, as well as confusion about when certain treatments might be necessary. As a result, this prognostic uncertainty can potentially have a profound effect on your quality of life.

However, by developing indicators that allow us to predict the progression of scleroderma and its symptoms, research can help reduce some of the uncertainty that surrounds the condition. Ultimately, such indicators could be one of the keys to enabling considerable improvements for individuals around both quality of life and treatments.

New SRUK-funded research led by Dr Elisabetta Renzoni at the Royal Brompton Hospital and Imperial College London looks to assist in the development of an indicator that could help predict the progression of lung disease in people diagnosed with scleroderma.

Specifically, the project aims to assess whether it is possible to establish a computer algorithm which would allow early CT scans of the lung to be used as a tool to predict the progression of lung fibrosis in scleroderma patients with interstitial lung disease (ILD). As a result, people living with systemic sclerosis (SSc) and ILD could soon be offered a better understanding of the likely progression of their lung fibrosis.

Lung fibrosis and scleroderma

ILD is an umbrella term for conditions that cause lung fibrosis, meaning the stiffening of the lungs by scar tissue that occurs to some degree in around half of people diagnosed with SSc. However, the extent to which symptoms develop over time varies considerably between patients. Whilst more than half of people living with SSc have some form of lung-involvement, only around one-third will experience increasing lung scarring, breathlessness and reduced survival chances as a result. As such, when someone is told that they have ILD, they often face extreme uncertainty about how the disease will progress and the impact this could have upon their life.

The impact of uncertainty

Naturally, uncertainty about the prognosis of this condition can be a major catalyst to the anxieties that people living with scleroderma so often report that they experience. Worries about how or when the disease could deteriorate, and the health outcomes that this could cause, can seriously

RESEARCH CAN HELP REDUCE SOME OF THE UNCERTAINTY THAT SURROUNDS THE CONDITION

affect the mental wellbeing of patients and their loved ones. In turn, there is the potential for an individual's quality of life to be affected, which can ultimately impact upon their general health, independence and enjoyment of everyday activities.

Furthermore, 'prognostic uncertainty' of this sort can also affect the ability to make effective treatment decisions. If the prognosis of a patient's condition is unclear, this can restrict the doctors' ability to determine which therapies they are likely to require, as well as when these will be needed. This limits the ability of doctors to manage a patient's condition with the correct treatments before their symptoms worsen. As such, prognostic uncertainty does not merely generate concerns regarding mental health and quality of life, but also directly affects the treatment of individuals living with scleroderma.

Reducing uncertainty in lung fibrosis progression

To tackle these issues and reduce the 'prognostic uncertainty', there is an urgent need for better indicators that can accurately predict the likelihood of a patient's ILD getting worse. These indicators can enable doctors to start effective therapies sooner and prevent irreversible scarring to the lungs, whilst also avoiding the use of potentially toxic treatments in patients who don't need them.

As such, Dr Renzoni and her team at the Royal Brompton Hospital have set out to assess the possibility of establishing a computer algorithm that would enable early lung CT scans to predict the progression of ILD in scleroderma patients. During the study, which began in February 2022, they aim to assess archived chest CT scans of 500 patients with ILD, which were taken when they were first diagnosed. The team then plan to analyse long-term follow-up data of these patients and run a pre-existing algorithm that is already used in the treatment of

patients with other types of lung scarring, in order to see whether it can accurately predict the progression of ILD in people with scleroderma.

They also plan to build on existing work in order to refine predictive algorithms specific to scleroderma, which they believe could have the capacity to predict the progression of lung fibrosis with even greater precision. The study will resultantly provide the basis for further research involving the UK's other scleroderma centres, which will aim to ensure that the results of the study are applicable to all scleroderma patients with ILD and evaluate whether providing accurate prognostic information can increase the quality of life of individuals in practice.

As a result of this project and the research that could stem from it, people living with scleroderma and ILD could soon have a much more definite understanding of the prognosis of their condition and may therefore benefit from multiple improvements to their quality of life and treatment. What is certain is that research of this sort - which enables earlier diagnosis, more precise treatment, and improvements to quality of life - is integral to tackling the condition and will be one of the keys to ensuring that nobody living with scleroderma has their life limited by the disease in the future.

Reference: Acorn A., Joachim G., Wachs J.E; Scleroderma: living with unpredictability; AAOHN J 2003 Aug;51(8):353-7; quiz 358-9.

DOES HAVING SCLERODERMA PLACE YOU AT GREATER RISK FROM COVID-19?

SRUK and LUPUS UK are co-funding a new study on the effects of COVID-19 on people living with scleroderma or lupus.

Since the COVID-19 pandemic began, many people living with rare diseases such as scleroderma and lupus have faced uncertainty about the level of risk that the virus poses to them as a result of their condition. Whilst many of those with rare autoimmune conditions have been considered at-risk and categorised as high priority for vaccination, the actual threat that COVID-19 is likely to pose if you have scleroderma or lupus is still not entirely clear. This can be a source of anxiety for those living with these conditions and can also cause apprehension about the safety of everyday activities like going to public venues or travelling into work.

However, new SRUK and LUPUS UK co-funded research is now seeking to address this. The project, led by Dr Megan Rutter from the University of Nottingham, aims to clarify the risk of COVID-19 infection and death in people living with either of the two conditions, and looks to examine the effect that factors such as shielding and immunosuppression may have upon such outcomes. This has the potential to assist in planning for new waves of COVID-19; and may even give insight into how we respond to any new disease outbreaks in the future to better protect people living with rare autoimmune conditions.

The new research is based on previous findings from the RECORDER (Registration of Complex Rare Diseases - Exemplars in Rheumatology) project, which found that in a cohort of 168,691 people living with rare autoimmune rheumatic diseases, there was a larger increase in deaths from all causes during the first two months of the COVID-19 pandemic than in the general population. This cohort included 41,261 people living with lupus and 11,578 people living with scleroderma, suggesting that people diagnosed with one of these conditions may be at higher risk of mortality from COVID-19.

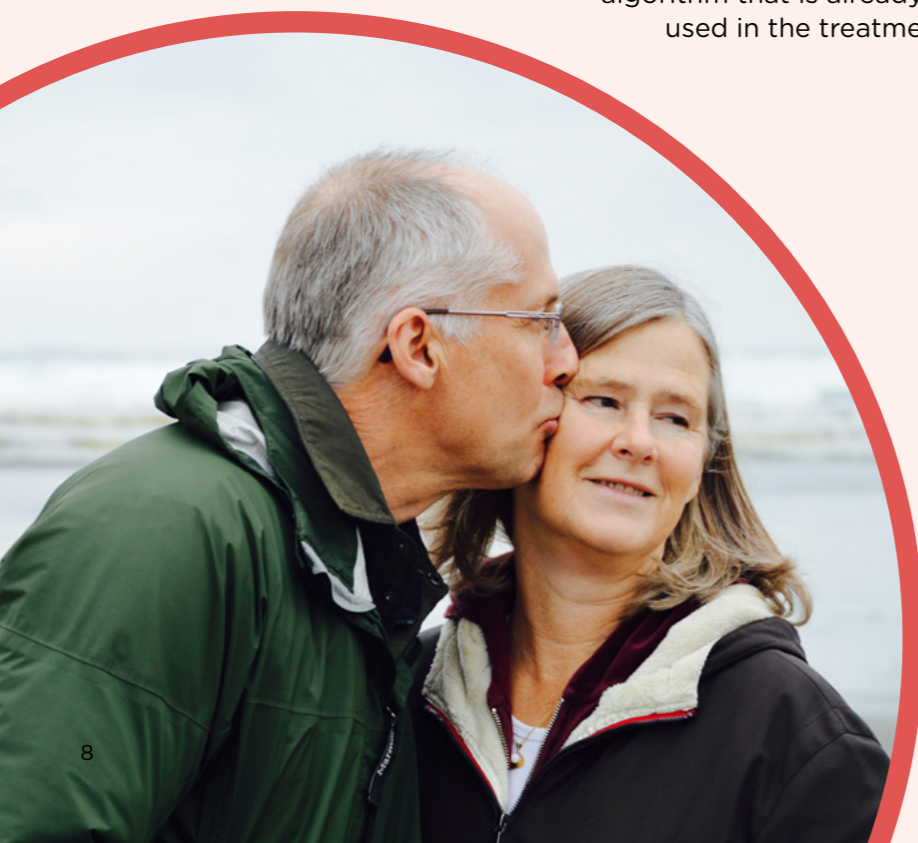
Dr Rutter will now further investigate the incidence of COVID-19 infections and risk of death during the first and second waves of the pandemic among people with lupus, scleroderma

and other rare autoimmune rheumatic diseases. This will give further insight into whether people with the conditions are more likely to contract or even die from the virus; and could provide information on whether the risk from COVID-19 changed during the second wave of the pandemic, for example due to the use of new treatments. In turn, this could shed light on how the risk to people with lupus and scleroderma has changed over time, and which treatments have been most effective in influencing these outcomes.

Dr Rutter and her team will also look at the influence of shielding, and of immunosuppressive treatments such as cyclophosphamide and corticosteroids, which have the potential to influence the risk of developing a severe COVID-19 infection. This data could potentially inform clinical guidelines, treatment pathways, and shared decision-making about treatment choices.

This research offers the potential to help develop a better understanding of whom is most at risk from COVID-19, and how this risk has changed throughout the pandemic in response to different treatments and preventative measures. It could also help to reduce the uncertainty and associated anxiety faced by many people with scleroderma around the risk level they may face due to COVID-19, which could assist in improving quality of life. Equally, the research could also enable a more developed understanding of which treatments are most effective in reducing the incidence of COVID-19 infections and related deaths amongst those who have scleroderma and lupus. As such, the research could ultimately be key to enabling more effective treatment of COVID-19 within the rare disease community moving forward.

Previous findings have suggested that people affected by SSc or lupus may be at a greater risk of mortality from COVID-19.





SRUK SHOP

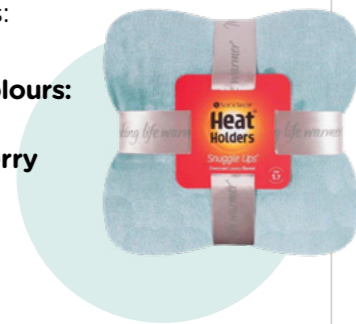
Welcome to the SRUK Shop, where you can find products that have been specially selected for our community. We are experiencing some product shortages at the present time, however please contact us if you have any queries and we will do our best to help.

Snuggle Up Blanket

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

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

£26.99



SRUK Face Mask

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

£5.50



Silver Gloves

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

Available in 12%, black.

Available in XS, S/M, L/XL

£23.50



MyCoal Hand Warmers

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

£4.99

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



MyCoal Foot Warmers

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

£5.49

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



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

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

£24.99



SRUK SHOP ORDER FORM

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

Postage & Packing Costs

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

Total Order

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

Name	
Address	
Postcode	
Telephone	
Email	

FOR MORE PRODUCTS
AND INFORMATION GO TO
WWW.SRUKSHOP.CO.UK
OR CALL **020 3893 5998**

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

ESTELLE AND JOHN'S STORY

After Estelle's diagnosis of scleroderma, she and husband John have made a number of changes. John has also taken on an incredible four challenge events in aid of SRUK, with Estelle supporting him every step of the way. This is their incredible story.



"This has made us want to take advantage of every opportunity, and we try not to put things off as we might have before. You have got one life, and we are living it."

Estelle and John Thompson live in Lancashire with their two children. John works in technical sales and Estelle is a teaching assistant. Estelle, aged 43, was diagnosed with systemic sclerosis in 2018, and has had to adapt her life considerably due to the impact of her condition. Since her diagnosis John has been taking part in multiple physically gruelling challenges, to raise awareness of scleroderma and raise vital funds for SRUK. Taking part in these challenges is the closest he can get to 'walking a day in Estelle's shoes'.

Estelle's story

I was diagnosed with systemic sclerosis during 2018, although the signs had been there long before that. In 2010 I developed Raynaud's Phenomenon, initially only in the winter, so I started wearing gloves more often. Then, during 2017, the symptoms began to get progressively worse, to the extent that I had to stop going swimming with my daughter; I would have to get out because I was actually turning blue! I then began to experience increasing pain, especially in my hands that affected my grip. I was also getting a rash on my face, although we did not think anything of it at the time.

Someone eventually suggested that I visit the GP to ask about trying some medication for the Raynaud's. At the time I had no idea about this, I think you sometimes just learn to put up with it, and I just had gloves everywhere.

The doctor said that it was strange to have had symptoms for so long before it suddenly started having such a dramatic impact. It was summer at the time, and I always had a hat and gloves. They ordered a blood test but told me not to worry. I was then called back as something had shown up, and it was then that I was referred to the hospital and was first told about limited systemic sclerosis.

I feel that I was really lucky, because we have always been so active. We did a lot of running

and cycling; and we always did things together. I have been told that all this has helped, because I was fit to begin with. Although our lives have been changed completely by this diagnosis, it could have been a lot worse, and the positives of a healthy lifestyle have really been a bonus.

We got through the COVID-19 pandemic, but I wasn't this bad before. In 2020, I had a chest infection, and I think this was the catalyst for everything changing, and I am now living with breathlessness and fatigue. Before that I could still cope with some cycling and running, as long as I kept warm and took it fairly easy, but not anymore.

Since then, it has been a case of reducing working hours, but you just have to adapt. For example, we wrap foam around pens so that they have a soft touch, and I use a bigger knife and fork to help with my hands.

My children are very good as well. My son is 17 and understands all this, and my daughter has also made changes. I struggle to carry heavy wash baskets or shopping bags, so they jump in and help with things like that.

It is now very much a team effort, and everybody chips in, which is hard sometimes. I went from being the person who did most of the cooking and cleaning as John worked more hours than I did, but all this had to change. I can vacuum in small amounts, but it is very tiring.

I can now work around 20 hours a week comfortably, but I do have to listen to my body, and stop when I know I am tired. I was going to train to become a teacher and have already completed a first-class honours degree in teaching and learning with a view to attaining Qualified Teacher Status, but this is more difficult now. So, we are looking at different routes and different avenues to where we want to be. There might be a different way to become a teacher, and I will never say never.

John is now taking part in challenge events to raise funds for SRUK, and knowing that I can't do it anymore is soul destroying in one way, but on the other hand, I see it as John picking up my bit, and doing what I can no longer do. For my part, I have participated in clinical trials of drugs

to treat Raynaud's. If I can't do fundraising in the same way as John, I will do my bit in this way instead. If I can take part in medical trials, then this is my way of contributing. I have found the staff are amazing, and it can be quite intense, but as an overall experience it is worth it; it gives me the sense that I am doing something useful that could help people in the future as well.

Living with a chronic condition has definitely changed my perspective on life. As a couple we have been together for 24 years, and the future we are facing now is not the one that we planned. However, the future we are going to have will be just as good. This has made us want to take advantage of every opportunity, and we try not to put things off as we might have before. You have got one life, and we are living it.

John's story

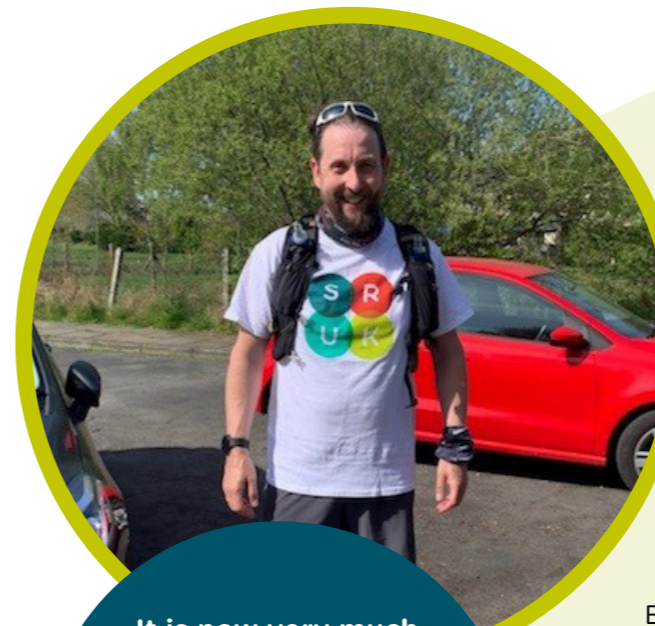
John has taken on the incredible challenge of completing four events to raise vital funds for SRUK to help us continue supporting our community. We are very grateful to John and to the family for all their support, and we couldn't resist the opportunity to chat to him and find out a little bit more.

As a family we don't tend to stop, and so I have decided to complete a series of four challenges to raise money for SRUK. Between the training, helping at home and doing my job, there's not much time now for anything else.

Estelle goes to bed early, so I sometimes go to the gym at night for some training. It's all about time management and knowing what we can do and when we can do it.

I first did the London Marathon for charity in 2017. It was enjoyable but I did not think I would do it again. Then this came along, and I thought that if I can help raise money and awareness, then I am very willing to do it. But rather than just doing the marathon I wanted to add to it, so I took on the four challenges. I completed the Ultramarathon during February and the Leeds 2 Liverpool Charity Bike Ride in May. Next is the Coast to Coast Cycle Challenge, which is 135 miles from Whitehaven to Sunderland, and then finally the London Marathon this October.

During the Leeds 2 Liverpool I cycled 129 miles. Afterwards I was happy that I had done it, but I did feel fatigued, so I can understand how Estelle feels after a day at work. Although I didn't feel unwell, I was physically drained. We have been thrown a curveball, but we just have to deal with that now. When things change, we can change with them.



It is now very much a team effort, and everybody chips in, which is hard sometimes. I went from being the person who did most of the cooking and cleaning, but all this had to change.

LIVING WITH ANXIETY

Lucy Reeve is a Clinical Specialist Occupational Therapist who has worked within the NHS for 26 years in Rheumatology and Pain Management. She is also living with scleroderma herself, so she fully understands what it's like to have this condition and its impact upon daily life. We would like to thank Lucy for her help and support in producing this article.



Lucy Reeve

Anxiety is very common.

In fact, most people are affected by anxiety to some degree at certain times, because this is a normal response of the body when we are faced with difficult or worrying situations. Anxiety can be triggered by various aspects of our lives, including our health.

Having a long-term condition such as scleroderma may therefore lead to some level of anxiety and it is crucial to acknowledge this; because for many people, the anxiety in itself may be a significant part of living with this condition. Just like other symptoms, it can also have a considerable impact upon daily life.

Anxiety is a feeling that is familiar to many of us. It is a perfectly natural response of the body and mind, often when faced with stressful or challenging situations. For example, many people can relate to feeling anxious before important events such as exams or medical appointments.

Every year, one-in-four people will experience some kind of mental health problem.¹ Because mental and physical wellbeing are so closely linked, when you have a chronic condition like Scleroderma or Raynaud's it is normal to encounter some anxiety around the diagnosis, symptoms or prognosis, as well as the physical manifestations of the disease itself.

If anxiety is presenting as a frequent or even constant

aspect of life, it may be helpful to approach this in the same way as the other symptoms of your condition, because when it comes to the many different manifestations of scleroderma, there are often effective treatments and self-help strategies that really can make a difference.

What is anxiety?

Anxiety means a feeling of unease, worry or fear, that exists on a very broad spectrum and can range from mild to severe. It is experienced through thoughts, feelings and physical symptoms and is associated with several conditions including panic disorder, post-traumatic stress disorder, phobias and generalised anxiety disorder.

Anticipatory anxiety refers to anxiety surrounding future events that are not actually

happening right now. It involves thinking about a lot of 'what ifs?', although the situation or event that is triggering this response has not yet taken place. Anxiety will be considered a problem when it is having such an impact on everyday life that it stops you from doing the things you want to.

Although experiencing some anxiety is perfectly normal, for many people it may be more frequent and sometimes continuous. Many people with a long-term condition will experience a psychological impact to some degree, although this may often become a significant aspect. If you are naturally a worrier, then any health issue could act as a trigger because it represents another thing to worry about. Feelings of fear, uncertainty, and the

loss of the life once taken for granted can all exacerbate the health anxiety that so many people experience. During recent times, aspects of life such as socialising and living as independently as possible have become much harder, and this could also be significant for many of our community; because anxiety may naturally be exacerbated when we feel isolated, for example during times of shielding.

A study from Denmark in 2013 found that the likelihood of anxiety or depression increased by 45% in people with an autoimmune condition.² A diagnosis such as scleroderma is likely to mean having to manage symptoms, medications and appointments, as well as navigating the impact of the condition upon everyday life.

Fight or flight

The body's response: stress chemicals

Our minds are naturally negative, because this is simply the way that humans have evolved. Our imagination can work against us and we can produce our own horror movies and scary stories that fire up our stress levels. When we have anxiety, we experience the 'fight or flight' response that is triggered by the body's sympathetic nervous system, and is a normal physical response to events or situations that the brain sees as stressful or frightening.

When we are faced with fear or distress, the brain alerts the nervous system. This response is designed to help the body prepare to fight the threat or to flee; and can trigger intense emotion and the need to escape. Within the body, the adrenal glands respond by pumping adrenaline into the bloodstream.

If the stress is chronic or prolonged, the adrenal glands release the hormone cortisol, so that the body remains in a state of anxiety.

A study from Denmark in 2013 found that the likelihood of anxiety or depression increased by 45% in people with an autoimmune condition.

Symptoms of anxiety

Physical symptoms

- A sensation of butterflies or churning in your stomach
- A faster heartbeat
- Rapid breathing
- Lightheadedness
- Restlessness
- Difficulty sleeping
- Nausea
- Sweating and feeling hot
- Needing the toilet more frequently
- Changes to your sex drive
- Panic attacks

Emotional symptoms

- A feeling of dread
- Feeling depressed
- Needing reassurance from others
- Feeling that you cannot stop worrying
- Feeling disconnected from your mind, body, or the world around you
- Worrying about how others see you or feel about you
- Worrying that anxiety is about to strike or that something terrible may happen

Rest and digest

It is unpleasant to be in a state of anxiety and it is physically and emotionally exhausting. Therefore, it is useful to recognise how to break this pattern and return to a state of calm. If you can calm down, the body turns on the parasympathetic nervous system, switching off the **'fight and flight'** response and turning on the **'rest and digest'** response. When this happens, the hormone levels can get back to normal and symptoms will pass. **'Rest and digest'** means the natural response of the body that occurs as the brain communicates that we are safe, so that hormone levels fall, blood pressure drops and breathing returns to normal.

It is important to try to develop some self-awareness. The human brain naturally looks out for problems to solve. Therefore, practise recognising when anxiety strikes, and then acknowledge **'I am stuck in my head and I am worried.'** There are a number of techniques that many people find helpful in alleviating anxiety symptoms to help the body return to a calmer state.



Grounding techniques

Different techniques work for different people, and some may be easier at certain times, or in particular situations. Whilst it is important to consider and acknowledge what works best for you, the following ideas are a good starting point.

Acceptance

It is vital to keep in mind that feeling anxious is perfectly normal, so always try to be self-compassionate. Expressing your feelings is an outlet for these emotions and is necessary in helping us to identify what is at the root of the anxiety.

Relaxation

Relaxation and a good sleep routine will help to regulate hormones in the body, reducing excess adrenaline from anxiety and increasing positive endorphins.

Relaxation is important and a very personal choice: some people find mindfulness to be effective, whereas others find that distractions such as music or reading are more helpful. Try different strategies and incorporate one or two relaxing periods per day - you will reap the benefits quickly. The more enjoyable activities we do, the better we feel and the more we are inclined to do; and this cycle is extremely positive for healthy emotional wellbeing.

Physical activity

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

Avoiding avoidance

When we are feeling anxious or depressed we may be inclined to retreat and avoid

some situations and even other people, and this can lead to a negative spiral that can be hard to escape. Avoidance often forms part of a negative cycle that can contribute to feelings of anxiety and low mood in the long run, despite providing us with short-term relief at the time. It is important to be aware of this and to acknowledge the desire to retreat; but try to maintain your daily routine as much as possible.

Social support

Keeping connected is vital to maintain positive mental health and combat feelings of isolation. The evidence shows that it is the depth rather than the frequency of contact with others that is important, so keep reaching out and deepening the connections you already have, because it is these relationships that will persist and help you maintain a sense of stability when things feel out of control.

Managing anxiety in real life

- **Remember that anxiety** is not all in your head. Understanding helps us to take back control, so learn about what anxiety is, and what is happening inside the body when symptoms arise.
- **Stay in the present moment;** and try not to let your mind wander into worrying territory. Mindfulness is all about focusing on the present, on your own thoughts and feelings and the world around you. Anxiety is often about the past or the future, so living in the present moment often helps us to manage stress levels more effectively. Put your hand on your heart and acknowledge what is happening for you in this moment.

- **Avoid doomscrolling.**

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

- **Identify your own coping mechanisms.**

These are things you can do every day that help to break the pattern and maintain a calmer state. Think about what works for you.

- **Writing down our thoughts and feelings**

gets it out of our heads and on to paper. Consider whether the issues are solvable or not. There are some things we cannot do anything about. Rather than letting it churn round in your mind, write it down.

- **Think about your caffeine intake,**

as this can often alert anxiety and induce its impact. Over time the alerting component reduces but the anxiety is still produced, so be aware that this could be contributing to your anxiety and impacting on your sleep.

Quick and easy calming techniques

Do a regular check in - How am I?

Think to yourself: **"I feel..."** What do you need right now?

Hug someone, or yourself, or a pet, or a teddy bear!

Say to yourself in a calm voice: **"I am safe in this moment."**

To be at your best you need to rest, so take regular time outs to be as efficient as possible.

Look for the good - write down or talk about three good things that are happening in your life.

Plan happy things in your diary - it helps to have something to look forward to.

Relaxation - learn some easy breathing techniques, or find a relaxation practice that you love, then do it regularly!

Learn to say no - if your resources are limited, don't waste them.

Go slow - monotasking and doing things calming and slowly signals to the brain that everything is ok.

- **Always remember that you are not alone.** You can use social media to connect with other people living with Scleroderma and Raynaud's, and to chat with others who may be in a similar situation. Visit our Facebook page or our online forum hosted on HealthUnlocked.
- **Consider also connecting with your local support group.** Many of SRUK's network of support groups are meeting online or have adopted a hybrid approach, making it easier to keep in touch during times like these.

Scleroderma is a highly complex condition, with the psychological impact often representing a significant aspect that is probably not talked about nearly enough. Always talk to your doctor if anxiety is affecting your everyday life, because they can offer help with managing symptoms and make a referral if necessary. Whatever works for you, always try to remember that the emotional element is a very normal part of living with an autoimmune condition, so try to be kind to yourself. You can call our free Helpline seven days a week to talk to one of our volunteers and as ever, there is lots more information on our website. Please visit sruk.co.uk

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

Helpline:
0800
311 2756

Sources:

1 mind.org.uk

2 JAMA Psychiatry. 2013;70(8):812-820. doi:10.1001/jamapsychiatry.2013.1111 <https://www.health.harvard.edu/staying-healthy/understanding-the-stress-response>

SARA'S STORY

Sara Dyson is 33 and lives in Hull with her husband. She was diagnosed with systemic sclerosis during early 2020, just before the onset of the COVID-19 pandemic. Here, Sara shares the story of her diagnosis, the impact that this had upon her emotional wellbeing and her journey to find support.



After several years of being constantly severely ill, with conditions that should be mild in most people, I was diagnosed with limited systemic scleroderma in February 2020.

I had been getting severe infections for several years, as well as symptoms of Raynaud's Phenomenon, and suspected an autoimmune condition due to already having a family history.

In January 2020, I visited the GP, as I was concerned that my constant illnesses were getting worse. They sent off blood tests, which came back positive for one of the autoantibodies linked with scleroderma and I saw a rheumatologist a week later. Unfortunately, the rheumatologist I was able to see at that time knew nothing about the condition, the screening tests that may be needed to definitively confirm the diagnosis, nor the available treatment options, so I left the appointment no more informed than I did when I went in, and feeling, honestly, quite unsupported.

My diagnosis came at a very difficult time; a few weeks after my appointment with the rheumatologist, lockdown happened and all access to doctors and specialists was cut off, I was signed off work for nine weeks with severe fatigue, chronic insomnia and anxiety, my grandmother had been recently diagnosed with terminal cancer and I had suspected COVID-19.

It was a really overwhelming experience, as I'd been given news that I may have a condition that could significantly impact my quality of life, as well as

everything else that was going on, and my mental health took a massive hit, especially with the pandemic, lockdown and shielding happening at the same time. The anxiety also led to an exacerbation of my physical symptoms – the Raynaud's got worse, I had an increase in acid reflux, the insomnia was torture, and the fatigue that came with it all was severely debilitating.

I recovered relatively quickly from the COVID-19 infection itself, but unfortunately developed 'long COVID', which included a partially collapsed lung, and long-term loss of taste and smell. This was followed by parosmia (a distortion in taste and smell), which was in itself very distressing. It is thought that the scleroderma also significantly delayed my recovery, and it's taken a lot longer to 'get back to normal' than my partner, who contracted suspected COVID-19 at the same time as me.

My treatments and specialist appointments were also delayed, and since this was so early in my scleroderma journey, it was daunting to have to self-manage without much information.

The only treatment I was able to access was some basic pain relief. On top of all that, in August 2020, I also developed horrific pain in my abdomen, and was diagnosed with severe acute cholecystitis, where my gallbladder had collapsed and was not functioning properly, and gallstones were causing repeated damage. Unfortunately, because of the pandemic, the surgery that I should have had within a few weeks turned into a wait of almost six months; where I had to live with excruciating pain, restricted diet and even more fatigue. Then to finish off a truly horrendous year, my grandmother passed away just before Christmas and I had to deal with some challenges at work, which just increased my stress after everything that had happened.

During all of this, I've also had to try and carry on as normal at work. It's been quite difficult to try not to let my condition impact me at

work, especially with the pain, anxiety and fatigue that are a constant battle. As well as that, because I'm quite young and 'look OK and well', a lot of people struggle to really understand the challenges I'm having to face every day, especially if I'm having a bad day and my mood is different to my usual 'happy go lucky' personality. I've also had some people make comments like 'Oh you're ill again' or 'are you ever not ill?' or 'you always seem to be having time off work'. Although these are normally only meant in jest, and I know it's not meant maliciously, sometimes it's really difficult to hear and upsets me I already have anxiety about how my condition is impacting me in my daily life and work, as well as guilt for how my absences are impacting upon the wider team.

Also, because illness and disabilities are still quite a taboo subject, especially in the workplace, it's often quite difficult to get support and have discussions with people about the impact it's having on you, which really increases your anxiety about the topic.

I've tried really hard to be open with my team though, not just so I can share how I'm feeling, but also so they also feel like they have a safe space to share any concerns or challenges they may be facing as well.

The lack of control that has come with my diagnosis scares me, but I try not to let it get on top of me. This is easier said than done for some people though, and I think unfortunately, the emotional impact of a diagnosis like scleroderma is vastly under-appreciated. I really struggled to get access to any sort of psychological support to begin with – there was no real discussion about any support that might be available from a mental health perspective from my primary care providers or the rheumatologist that I saw. I eventually saw a psychologist privately for several months, which has really helped my mental wellbeing, and helped me come to terms with my condition. It was only after several sessions with my psychologist that I started to come to terms with everything, and also to

“It's so important to raise awareness about how being diagnosed with a disease like scleroderma can impact your mental health.”



“I really struggled to get access to any sort of psychological support to begin with – there was no real discussion about any support that might be available from a mental health perspective from my primary care providers or the rheumatologist that I saw.”

realise that it was okay to be feeling emotions like grief, anger and sadness.

It's a really important process to be able to work through the myriad of feelings that you feel when you have a massive life-changing event, and I think sometimes, we try so hard to squash it and pretend we're okay, that it just makes it ten times worse. It was only after I'd started to have these sessions that some of my physical symptoms started to improve, because of some of the techniques that I learned from the psychologist. My sleep improved, as my mind wasn't racing at all hours, my fatigue improved as I learned about pacing, and not doing too much if I'm having a bad day and my general mood improved as well. I also learned about acceptance and to be kinder to myself, which can make such a massive difference when you're not feeling great to begin with. It's so important that people recognise how important mental health is, and not be afraid to reach out for help when they need it – be it formally, or just with your friends, colleagues or families.

Unfortunately, not everyone has the luxury of going private for their care, and I think there is a massive gap in support for mental health in the NHS because of the enormous pressures they are put under already (never mind with the pandemic on top). I understand there is only so much the NHS can do due to their resource constraints, but I do think there is more they can do to signpost patients to resources that they can access outside a clinical setting to

help support their mental wellbeing. There are so many apps out there now, as well as many charities and helplines that people can call if they're in need. These aren't always going to be the solution to everyone's problems, but I do think they are an excellent tool to help fill the gap until you can access more formal support.

Luckily, I was able to find some great support when I discovered SRUK's website. It was an absolute lifeline, and it was so great to know that I wasn't alone. I have been watching their various webinars and reading the myriad of information they have on their website and social media pages, which has helped enormously. In a lot of cases, this was the only source of information I had, and I don't know what I would have done without their support. It certainly helped me feel like I had some control over my situation.

Whilst I have started to feel more in control of my condition, there are still a lot of unknowns, which in a society that tends to avoid talking about illness, and where disabilities aren't always normalised in the media, can be quite difficult. I think this also leads to increased anxiety, especially if someone can't get support through official channels, as it means they literally have no one to talk these sorts of things through with. Therefore, I think it's so important to raise awareness about how being diagnosed with a disease like scleroderma can impact your mental health. I think it's crucial that people are given access to more mental health support and resources to help them navigate what can be quite a terrifying time in your life. So many are left to suffer in silence, which can have significant consequences to your wellbeing, mentally and physically. Things are improving and moving in the right direction, but I hope more improvements can be made regarding supporting patients with their emotional wellbeing during diagnosis and treatments of chronic health conditions going forward.



AVTAR'S STORY

Avtar Gill is 49 and lives in Birmingham with his partner. He set up the SRUK Support Group Midlands following a diagnosis of systemic sclerosis. Avtar talked to us about the often-unseen impact that living with a long-term condition can have upon emotional wellbeing.

I developed this condition, and then I was laid off work for reasons of health and safety. Since then, I feel that it has been one disaster after another. I used to enjoy my job, it was varied and interesting, now I feel like things have been turned upside down; it feels quite surreal.

I experienced my first panic attack when we were getting ready for a trip to London the following day. I just started to panic, I got very breathless, and I could not eat. Despite all this I did not really think too much of it, and I went to bed as normal.

But the next morning, my partner found me gasping for breath. She called 111, they then sent a responder unit before the call had even ended. I was extremely anxious, and they needed to slow my heart rate down; they said it was not a heart attack but that I was borderline, so we went to the hospital. Ever since then, I have been anxious and panicky, and I feel it can be about the silliest of things.

The hospital has been quite good. I need to have a procedure and I was getting jittery about it, but they have been reassuring and understanding. But if someone tells you not to get anxious, this can just make it harder. I find that the nurses have got to know me, so that now when I go in for infusions, they will ask me how I am. But the consultants never ask me, and so I feel that this aspect is not always catered for as it is not a physical problem. But the nurses here are very good.

When I was first diagnosed, I was told by the doctor not to look at any websites. This was a valuable lesson. However, a lady has recently connected with me who is much more recently diagnosed. She was not given the same advice, so she googled the condition, and this was extremely anxiety provoking. If you do not have the right information, this can exacerbate the anxiety you are naturally feeling. So that is important as well.

FINDING SUPPORT

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

Our publications

Did you know that you can download our full range of publications from our website, completely free of charge? Please visit sruk.co.uk/publications and simply scroll down to the booklet or factsheet of your choice. You can download as many as you want!



Helpline

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



Helpline:
0800
311 2756

Medical enquiries

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

Our online community

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

Social media

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

The SRUK webinar programme

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

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

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

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



SRUK is on Youtube!



/WeareSRUK

Did you know that SRUK has a dedicated Youtube channel?

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

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

Local Support Groups

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

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

PLANT A SUNFLOWER, SPREAD THE WORD...

The sunflower is a symbol that has become synonymous with scleroderma all over the world, but this beautiful flower has a story all of its own. With so many of us planting and growing sunflowers to help raise awareness of the condition and its impact, we decided to find out more about this beautiful, historic, and even record-breaking flower.

Fun facts

1. Each sunflower is actually made up of many tiny flowers

A sunflower may look like a single bloom, but in fact the trademark petals and fuzzy centres are all individual flowers in themselves, with up to 2,000 coming together in each sunflower.

2. The French word for sunflower is 'tournesol'

It means 'turns with the sun.' This is the reason that the sunflower is a symbol associated with scleroderma all over the world: because people often feel more comfortable in warmer weather, just like the sunflower naturally turns towards the sun.

3. There are around 70 species of sunflower

Historically, sunflowers are native to America. With so many different types, they come in many shapes and sizes.

4. Harvest your sunflowers in the morning

When your sunflowers are ready to display in a vase, always pick them in the morning. If you wait until later, they may not last as long.

5. The world's tallest sunflower was over 30ft tall

The record-breaking flower was grown in Germany in 2014. Records have also been set for the largest sunflower leaf, the heaviest head and even the world's smallest sunflower.

6. Your dried sunflower head makes a sustainable bird feeder

Once your flowers have dried out you can repurpose the heads to feed the birds. Simply cut and hang with string (you can use some of the stalk to make this easier), and your birdfeeder is ready.

7. Your sunflower may be holding over 1000 seeds

There will be plenty for the birds to enjoy in the autumn, but don't forget to save a few so that you can do it all again next year.



Sources: guinnessworldrecords.com/world-records/tallest-sunflower
goodhousekeeping.com/home/gardening

Image: Che Conteh

SCLERODERMA AWARENESS MONTH UPDATE

Scleroderma Awareness Month takes place every year in June, when we aim to raise awareness by sharing your stories and highlighting the realities of living with this complex condition.

This year, we shared your stories across all our social media channels and aimed to get local and national media coverage.

We are really grateful to everyone who was willing to share their story. We put together a series of press releases featuring stories from our community and pitched these to national and broadcast media. Unfortunately, we were not able to secure any national media during this busy news month. However, BBC Radio Sheffield interviewed **Alison Grunwell** about her involvement with the *Scleroderma Guide for Schools* and she gave an excellent interview, talking about her daughters and why she wanted to be involved. They also interviewed **Dr Emma Blamont**, SRUK's Head of Research about scleroderma in general, and gave us a good amount of time to discuss the condition properly.

Alison also appeared in regional press, and the *Employers' Guide to Scleroderma* was featured in *Personnel Today*, which we hope will prompt more employers to contact us to support their staff.

SRUK's June Webinar: The Perfect Patient Information Journey in Scleroderma

Thank you to everyone who took part in our very special June webinar, on the topic of identifying the Perfect Patient Information Journey in Scleroderma.

This is a project undertaken in partnership with the Patient Information Forum, that aims to ultimately ensure that patients receive the right information at the right time.

SRUK WALK

Thank you to everyone who has taken on the **SRUK Walk** in June; you can keep on walking throughout the year. In the next edition we will update you on how our walkers have got on, including **Helen, Anita, Jules** and **Sally** who are walking one million steps.

In fact, the SRUK staff team were so inspired by their efforts that we set a challenge to walk 2.5

million steps collectively throughout June, to raise awareness of the 2.5 million people worldwide living with scleroderma. We proudly wore our t-shirts on our walks to start conversations about the cause.

World Scleroderma Day - 29 June

Renowned artist **Paul Klee** died of scleroderma on 29 June 1940, and each year we join with the worldwide scleroderma community to promote **World Scleroderma Day**.

Georgina Foster, a member of our community and an art historian, wrote a fascinating piece for SRUK on Paul Klee, whom she admires very much. You can read the article on our website: sruk.co.uk/about-us/news/creativity-through-scleroderma/

On World Scleroderma Day this year, FESCA (Federation of European Scleroderma Associations) launched their new campaign "**Find the Light**

to Bloom", to shine a light on the unmet needs of people living with scleroderma and urge policy-makers to prioritise improved diagnosis, treatment and quality of life. "Find the Light to Bloom" intends to empower the scleroderma patient

population and showcase that they can thrive, despite living with such a disabling disease. This new campaign also highlights some of the unmet needs of people living with scleroderma; recognising that it can take time to be diagnosed or get access to an appropriate treatment plan. But once the patients receive this treatment, they can feel more at ease, and find the light to bloom.

FESCA would like to encourage everyone to get involved in this campaign and learn more about scleroderma: healthcare professionals, patients, families and policy-makers, but also each and every one of those who come across the campaign.

Find out more at:

www.fesca-scleroderma.eu/wsd2022/





FUNDRAISING HEROES

SHINING THE SPOTLIGHT
ON SOME OF OUR FANTASTIC
SUPPORTERS!

SUMMER APPEAL 2022

Thanks to everyone who very kindly supported our new **Summer Appeal**. We are so grateful for the generosity of our community; each and every one of you really does make a difference. We are thrilled to say that we have so far raised over **£7,000!**

Congratulations to **Antonia Fella** who completed the Edinburgh Half Marathon, despite having an injury and having to hobble the last few miles. She smashed her target and has raised over **£1,200!**



Lucy Husbands – finished her A-Z baking challenge with a Zucchini cake and has raised over **£720**.

Big thanks to the team at **Paul Hubbard Estate Agents** who raised **£1,814** through various activities in support of Philip Beckett's fundraising efforts – getting him closer to his £50,000 target.

Thank you to **Elliott and Dylan** who set themselves a cycling challenge in June in memory of their Gran who actually created the challenge a couple of years before. They raised a fantastic **£1,178** – their Gran would have been very proud.

Big thanks to **Ryan Pilkington and Jennifer Ruffell** who took on the new Great North 10k in memory of Sue – Ryan's Nana and Jennifer's Mum.

They have raised **£479** so far – completely beating their original targets.



GOOD LUCK TO EVERYONE WHO IS FUNDRAISING FOR SRUK

We are very lucky to have so many wonderful swimmers, walkers, cyclists and fundraisers taking part in various challenges in support of SRUK over the coming months. We are incredibly grateful for your support, and we wish you all the very best!

Find out how our London Marathon team got on in the next issue of *SRUK News!*



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!

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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.

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Your stories

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

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Scleroderma & Raynaud's UK

Bride House, 18-20 Bride Lane,
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Helpline: 0800 311 2756

Office 020 3893 5998

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