

# SRUK NEWS

**Ex Professional  
Footballer Travis  
Munn Talks about  
His Cutting Edge  
Treatment**

**We Need You!  
Please complete  
our first annual  
patient survey on  
pages 14&15**

**Our New Research Strategy**  
Find out how we'll be  
changing more lives sooner

**Doc Spot**  
Your questions  
answered by  
our medical  
professional

**Scleroderma  
Awareness  
Month 2019**



# Event Calendar 2019

## APRIL

- 7th April - Bedford Support Group Meeting
- 8th April - Asics Manchester Marathon
- 28th April - Virgin Money London Marathon

## MAY

- TBC - SRUK Information Stand, QEUH, Glasgow
- 4th May - Isle of Wight Challenge
- 18th May - Leeds Support Group Meeting
- 19th May - Virgin Sport Hackney Half Marathon
- 25th May - Brighton to London Trek

## JUNE

- Scleroderma Awareness Month
- 29th June - World Scleroderma Day
- TBC - SRUK Information Stand, Salford Royal Hospital
- 27th June - SRUK Information Stand, Royal Free Hospital London
- 29th June - Cotswold Way Trek

## JULY

- 13th July - Race to the Stones
- 27th July - 1st Regional Conference, Cambridge

## AUGUST

- 31st August - South Coast Trek
- TBC - SRUK Information Stand, Alder Hey Children's Hospital, Liverpool

## SEPTEMBER

- 7th September - Thames Bridge Trek
- TBC - 2nd Regional Conference Glasgow

## OCTOBER

- 13th Oct - Royal Parks Half Marathon
- TBC - SRUK Information Stand, Chapel Allerton Hospital, Leeds

We will be visiting hospitals across the country to provide information and support. We are currently working with all the hospitals above to find a suitable date to visit and will be sharing the date on our website, social media and with people in the local area when this has been confirmed.

If you would like us to visit your local area to provide information, support an event or talk about the charity and the conditions then please get in touch with us at [info@sruk.co.uk](mailto:info@sruk.co.uk) or **020 3893 5998**

## Dear Supporters

We've had an amazing response to this year's campaign for Raynaud's Awareness Month. We broke all targets with 10,000 people taking the online test in just one day following the feature on BBC Breakfast, taking us to a total of over 25,000 people during the month of February. Our press and radio coverage reached over 75 million people, helping us to increase awareness of the symptoms of Raynaud's and provide access to information and support.

We'll be building on the awareness of signs and symptoms for Scleroderma Awareness Month in June this year. We're very keen for people to share their experiences, so if you'd like to share your story please get in touch with Hannah at [hannah.stevens@sruk.co.uk](mailto:hannah.stevens@sruk.co.uk).

Thanks to everyone who has renewed their membership, made a donation, been baking, running, or walking to support our work. Let us know about any fundraising you're doing and whether we can help with any press or promotion for your event. Contact [shauna.creamer@sruk.co.uk](mailto:shauna.creamer@sruk.co.uk) who'd love to hear from you.

Best wishes

Sue

## Regional Conferences 2019 Cambridge and Glasgow

Following feedback from Members, this year we will run a couple of smaller regional conferences, rather than one big conference, to allow a better geographical spread/coverage across the country.

The first will take place in Cambridge on the 27th July and the second will be in Glasgow in the Autumn. If this works well and people prefer the shorter day, we'll repeat this approach in 2020.

## Patient Survey

Please help us ensure we're delivering the right services and support to you.

When SRUK was established in 2016 we asked what you wanted SRUK to achieve. There were several key areas which stood out, which included ensuring people with scleroderma and Raynaud's are better informed and more able to manage their condition, to increase awareness of the conditions and for money to be invested into research. But



- 3 **Doc Spot**
- 5 **Our New Research Strategy**
- 7 **Iloprost Treatment Guide**
- 9 **Meet the Scientists**
- 11 **How we're raising awareness in 2019**
- 13 **Hannah's Story of Localised Scleroderma**
- 14 **First Annual Patient Survey**
- 17 **Travis Munn's Cutting Edge Treatment**
- 19 **6 Tips for Self Management**
- 22 **Support Contacts**
- 23 **Step Our for SRUK**
- 24 **Upcoming Challenge Events**
- 25 **Our Fantastic Fundraisers**

there were other aspects that were also important to you, such as not feeling so alone and feeling more confident to talk about your condition.

Please complete the pull-out survey in the middle of the magazine and return it to us in an envelope marked Freepost Scleroderma or go to [www.surveymonkey.co.uk/r/SRUKpatientsurvey](http://www.surveymonkey.co.uk/r/SRUKpatientsurvey). Your views and thoughts are important to us and will help us shape what we do over the next few years.



# Doc Spot

Your questions answered by our medical professional, Prof. Denton

useful in scleroderma. As a treatment for skin ulcers, EST has mainly been used for leg ulcers related to poor circulation in the veins. There is certainly a scientific rationale why electrical stimulation might benefit the biology of wound healing. I am not aware of it being used in scleroderma for the more common finger ulcers. At the moment I would consider it as one of the possible treatments for further study.

## Can balance and speech be affected by scleroderma?

Systemic sclerosis (scleroderma) does not usually have a direct effect on balance and speech but there are ways in which problems can occur that are indirectly relate. First, it is common to have muscle weakness and some limitation of the range of joint movement that may give difficulties with balance and walking. Secondly, the changes of scleroderma affecting the mouth (e.g. mouth dryness) and the loss of tissue and tightness around the face and lips can impact on speech and make it slurred.

## Are any of the specialist hospitals using electrical stimulation therapy (EST) to treat digital ulcers and if so, how can patients access this service? I know the NICE has guidance on the use of EST for plantar fasciitis.

I am not aware of any hospitals using this treatment as part of routine care for digital ulcers. Electrical stimulation therapy (“EST”) describes a number of medical procedures that aim to provide stimulation to the nerves to improve symptoms or to improve local medical conditions such as skin ulceration. Some applications are already widely used such as transcutaneous electrical nerve stimulation (“TENS”) for chronic pain.

Other applications are being developed such as posterior tibial nerve stimulation (“PTNS”) for faecal incontinence and are looking potentially

I suffer from Raynaud’s, however things have got a lot better recently. Just before Christmas I came down with a bad cold and my Raynaud’s seems to have disappeared. Previously, for example, holding cold hand tools used to really set off a Raynaud’s attack. However, since recovering from the cold my Raynaud’s seems to be much better however, it’s still early days. Maybe Raynaud’s is also caused by a virus and in my case cured by a virus. I wondered if anyone else had noticed the common cold can stop the Raynaud’s attacks?

Your observation is interesting and one that other patients in my clinic have also occasionally reported. In fact, there are several plausible explanations. For example, when you have a viral infection with fever your blood vessels will generally dilate due to the inflammatory chemicals that the body makes in response to the virus. In particular levels of natural substances such as “prostacyclin” are increased. This is a bit like having an “iloprost” infusion for Raynaud’s (iloprost is a medical form of prostacyclin). Another possibility, in an autoimmune disease like scleroderma, is there are some cases when a viral infection may seem to improve symptoms after recovery, perhaps by altering immune system regulation, although this only may be temporary.

## I have Scleroderma and I suffer with blisters on my fingers. How can they be dealt with?

The poor blood supply to the fingers together with skin changes of scleroderma mean that many patients develop changes over the fingers. This can include painful and itchy lumps (chilblains), cracking of the skin, ulceration or sometimes blister formation. Sometimes the blisters can later develop into digital ulcers. Treatment involves good skin care (with emollients to keep skin soft, supple and hydrated) and Raynaud's therapies – including prescription drugs or iloprost infusions in some cases. high blood pressure.

### Handy Technical Guide:

**Electrical stimulation therapy (EST):** A type of physical therapy used to treat injuries or illnesses that cause pain or limited function mobility. It may be used to provide relief from back pain, post-surgical pain, muscle weakness and tendonitis. Electrodes are applied to parts of the body that need to be treated in order to improve muscular strength or function.

**NICE:** The National Institute for Health and Care Excellence. This is a public body of the Department of Health in the UK and provides guidelines on: the use of health technologies within the NHS; clinical practice; health promotion and ill-health avoidance for public sector workers; social care services and users.

**Plantar fasciitis:** One of the most common causes of heel pain, where there is inflammation of a thick band of tissue that runs across the base of the foot and connects the heel to the toe. It commonly causes a stabbing pain, which is worst with the first few steps are awakening. Age, certain types of exercise, foot mechanics, obesity and occupations that involve a lot standing can increase the risk of developing plantar fasciitis.

**Skin ulceration:** A skin ulcer is a break in the skin that either does not heal or heals very slowly. They usually resemble small, round craters in the skin with rough edges, and can sometimes bleed, ooze or become inflamed. They often occur on the hands, lower legs or feet.

**Transcutaneous electrical nerve stimulation (TENS):** This is a method of pain relief, involving the use of a mild electrical current. Equipment tends to be a small device that is connected to electrodes on sticky pads, which can be attached to the body. When turned on, small electrical impulses are delivered to the area of pain. The impulses may reduce the pain signals going to the nervous system, which result in less pain and relaxed muscles. Incontinence: the unintentional passing of urine or faeces due to lack of voluntary control.

**Posterior tibial nerve stimulation:** Non-surgical treatment that works by providing electrical stimulation to the nerves that enable bladder and pelvic floor function. During treatment, an electrode is placed near the nerve at the ankle to send small electrical pulses to the tibial nerve. This treatment is for people experiencing overactive bladder symptoms, causing urinary urgency and/or urge incontinence.

**Inflammatory chemicals:** These are chemicals released by cells to mediate inflammation. An example is histamine, which triggers vasodilation, which is the widening of blood vessels.

**Prostacyclin:** This is a prostaglandin molecule that is produced in the body and is a natural vasodilator. This means that it relaxes the walls of blood vessels, making it is easier for blood to flow through. Iloprost is a synthetic (man-made) version of prostacyclin.

**Iloprost:** This is a drug that comes under the prostaglandins group of treatments. It is used to treat a range of conditions, such as scleroderma, Raynaud's phenomenon, pulmonary hypertension and other diseases where blood vessels are constricted, and so blood cannot flow to the tissues in affected areas. It is important that issues like these are treated otherwise the tissues can become damaged and lead to high blood pressure.

**Emollients:** These are non-cosmetic moisturisers, in the form of creams, ointments, lotions and gels. Alongside keeping skin soft and flexible, it can also help reduce itching and prevent cracks. Finding the right emollient is down to trial and error, so it is up to the person to decide what they prefer the most. GPs, nurses and pharmacists should be able to provide advice on the different products available.

If you have a question you would like to ask Professor Denton, or have a comment on some of the answers given, please email [info@sruk.co.uk](mailto:info@sruk.co.uk)



Or you can connect with us on Twitter, Instagram and Facebook.

[/WeAreSRUK](#)

# At Scleroderma and Raynaud's UK, we firmly believe that research saves lives.

**Over the last 30 years, research has made huge inroads into extending and improving the quality of life for a person diagnosed with scleroderma. For example, if you were diagnosed with systemic scleroderma in 1985 and had subsequent kidney involvement, you would not be expected to live more than a year. Now, more than 30 years later, that has significantly changed. The advent of ACE inhibitors, and the research that brought them into play, means that people with kidney involvement live for much longer and can lead relatively normal lives.**

SRUK's two parent organisations, the Raynaud's & Scleroderma Association and the Scleroderma Society, were instrumental in funding a significant number of the high-quality research that took place in the UK over the last 30 years.

Now, the torch has passed onto SRUK. We are committed to carrying through the incredible legacy of accelerating research so that people living with the conditions see benefits sooner not later.

As part of this commitment, last year we embarked on a year-long process to develop the first SRUK 5-year Research Strategy. This strategy has taken a big picture look at the research that is currently carried out in the UK and seeks to accelerate and support those areas where people with the conditions will see the most benefit.

To ensure we adhered to our core values of collaboration, trust, compassion and drive, we created a development process to include the voices of our community, create consensus amongst industry and academic experts and support our key researcher clinicians, with a view to delivering tangible change.

As part of this process, we convened two key groups. The first group was our Community Research Panel, which comprised of a spectrum

of people with scleroderma and Raynaud's. This panel was critical to helping us identify the community's priorities for research. The second group was our Strategy Advisory Group. This group included our Research Sub Committee, who oversee our grant funding process, as well as other experienced and respected external senior experts who helped to ensure that the research strategy truly has the potential to accelerate the rate of progress.

The first 5-Year SRUK Research Strategy will focus on accelerating research in the following areas:

- Precision Medicine
- Early Detection
- Quality of Life
- Cause of Scleroderma and Raynaud's

## Precision Medicine:

Precision medicine refers to the tailoring of medical treatment to each individual person based on their own unique data. The reason why this is important for scleroderma is because the condition is considered to be heterogenous, which means that no two people will present with the exact same set of symptoms.

Precision medicine means that we would be able to give people treatment packages that are designed to be 'bespoke' and appropriate to the symptoms that they are presenting with. In order to get to this model of healthcare, we need to be able to analyse large amounts of data from individual people. This includes gathering data such as which condition specific biological molecules are present in people's bodies, lifestyle data, data on heart rates etc.

Recent advances in Artificial Intelligence (AI) technology over the last 5 years have meant that we are now able to analyse all of this data and produce patient profiles for precision medicine approaches.

Precision medicine has been shown to work in cancer, of which there are more than 100 different types and requires a targeted treatment approach.

This means that we are now much closer to being able to apply precision medicine approaches to rare conditions like scleroderma. As part of SRUK's drive to move this area forward in the treatment of scleroderma and Raynaud's, we will be investing in areas that will allow us to create a strong data foundation across the UK. Having a strong data foundation will enable the clinician researcher community to accelerate developments in precision medicine for scleroderma and Raynaud's.

### Early Detection:

One of the key factors in combating scleroderma and Raynaud's lies in being able to detect and diagnose the conditions earlier. This does not come without challenges, one of which is being able to identify what the key markers of the conditions at early stages are. Being able to identify the conditions earlier means that potentially life-saving treatments can be administered sooner.

As part of our commitment to furthering research into early detection, SRUK has already invested in a research study that will track people with secondary Raynaud's over a period of time to determine what the earliest indicators of scleroderma are. We have also partnered with a technology company so that more information can be collected from the people taking part in the study. This partnership allows us to collect data such as lifestyle data, biometric data (e.g. heart and pulse rate) and how often someone will report a Raynaud's attack. This means that we can then take all of this data and analyse it to understand whether there are specific circumstances that can lead to somebody developing scleroderma. Crucially, we will be able to pinpoint what some of the earliest symptoms may be.

As part of the 5 year Research Strategy, SRUK will be investing more funds into research studies like these that will enable us to be able to detect the conditions sooner.

### Quality of Life:

The last 30 years of research has meant that life expectancy for people diagnosed with scleroderma has significantly increased. Although people are now living for longer, the quality of their lives has not significantly improved. We are seeking to change that through investing in research that addresses key issues such as mental health provision and non toxic treatments.

Our community have said that mental health is of growing importance to them. Many of our community members have reported feeling depressed and/or anxious due to their diagnosis. Currently, there is little evidence to show a

physiological link between the conditions and depression/anxiety. However, recent advances in understanding the causes of various mental health illnesses means that there is now opportunity to conduct research into mental health and rare conditions like scleroderma.

In addition to mental health, another key 'quality of life' factor for many community members is the lack of treatments without toxic side effects. Members of our Community Research Panel report having to take large numbers of medication to treat their condition, as well as another set of medication to treat the side effects of the first set of treatment.

As an example of our commitment to ensuring better treatments, we will be looking at already existing drugs with fewer side effects that can be re-purposed to treat symptoms of both scleroderma and Raynaud's.

### Cause of the conditions:

Fundamental to understanding what it would take to cure scleroderma and Raynaud's is knowing what causes these conditions.

There is already a substantial body of work that has taken place over the last 30 years that has enabled us to understand the underlying biological processes in more detail. For example, there is currently a vast body of literature that focuses on understanding the various factors involved in fibrosis and the autoimmune response in scleroderma.

However, despite these significant advances, we still do not understand what the 'triggers' for developing scleroderma and Raynaud's are. Nor do we understand why some people will develop scleroderma and why others will not – despite often being from the same family and living in the same areas. In addition, we still do not understand why women are more at risk of developing the conditions. Women are up to 5 times more likely to develop both (or either) scleroderma and Raynaud's than men are.

SRUK will seek to invest in research that builds on the already substantial body of work that has taken place to understand once and for all why scleroderma happens.

SRUK will be launching our first 5 year Research Strategy in full later this year, and we'll be sharing with you the various ways in which we will be working with the research community to develop these four areas further. We rely very heavily on your support and together we can accelerate the pace of research so that more people feel the benefits sooner rather than later.

# Iloprost Treatment

**If you've been diagnosed with severe Raynaud's and receive Iloprost, here's some helpful information**

## What is it?

Iloprost is a drug that comes under the prostaglandins group of treatments. It is used to treat a range of conditions, such as scleroderma, Raynaud's phenomenon, pulmonary hypertension and other diseases where blood vessels are constricted, and so blood cannot flow to the tissues in affected areas. It is important that issues like these are treated otherwise the tissues can become damaged and lead to high blood pressure. Iloprost is prescribed if a person is suffering from ulcers of the fingers, if there is gangrene, or if a person has severe Raynaud's Phenomenon, and if other drugs such as nifedipine have not been successful in relieving symptoms.

## How does it work? How does it help?

Iloprost is a synthetic (man-made) version of prostacyclin. This is a molecule that is produced in the body and is a natural vasodilator. This means that it relaxes the walls of blood vessels, making it easier for blood to flow through.

Iloprost is helpful as:

- It widens/dilates the blood vessels, helping them to transport more blood to all areas of the body. This increases warmth in affected areas such as the hands and feet.
- It reduces the tendency of the blood to clot.
- It helps to prevent and repair damage to the blood vessels.
- It usually starts to come into force and show benefits immediately after administration, but it can sometimes take up to 6 weeks. Cold hands and feet may warm up straight away, and ulcers may begin to improve and heal within a few days. The positive effects of iloprost may carry on for weeks and sometimes even months after treatment.



## How is it administered? Infusion

Iloprost may be given through an infusion (drip) into your arm. This is usually continuous for ~6 hours a day for 3-5 days in a row in a hospital or in a clinic. It can sometimes be given continuously over 24 hours.

In some hospitals, you will stay on the ward for 3-5 days, whereas in others you will attend the day-case unit during the day, and then return home in the evenings. The frequency of iloprost infusions is normally every 6 months, but this can be adjusted depending on the person's needs.

## Inhalation

Iloprost can also be administered through inhalers.

Initially, the process of iloprost inhalation will be started for the patient in hospital, where they will be shown how to inhale the solution, using a nebuliser. A nebuliser is a device that turns the iloprost solution into a fine mist so that it can be inhaled into the lungs.



An individual may have to stay in hospital for up to 3 days to allow for training and for monitoring their response. After this, the person can return and continue taking the medicine independently.

### What are the side-effects?

When receiving treatment in hospital or in a clinic, medical professionals will observe you for potential side effects and how you respond to the treatment, through monitoring of blood pressure and electrocardiograms (test done to check heart's rhythm and electrical activity). If not under observation, such as if inhaling iloprost at home, it is important for the person to be alert to any sudden side-effects. All side-effects disappear very quickly once iloprost treatment is stopped.

Common adverse reactions include facial flushing, cough and a fall in blood pressure. Others are headache, flu syndrome, nausea and insomnia. It is crucial to get emergency medical help if any signs of allergic reactions are noticed, such as hives, difficulty breathing and swelling of the face, lips, tongue or throat. Paracetamol and anti-sickness drugs can be taken if side-effects are noticed, but it is important to check with your doctor first.

If any these serious side effects are noticed, call your doctor at once:

- feeling faint;
- pounding heartbeats or fluttering in your chest;
- coughing up blood;
- unusual bleeding (nosebleeds, bleeding gums);
- fever, chills, cough with yellow or green mucus;
- chest tightness, stabbing chest pain, wheezing;
- anxiety, sweating, pale skin.

### Restrictions

There are some circumstances where iloprost cannot be taken. These include if you suffer from:

- unstable angina;
- a heart condition such as heart valve defects;
- any problems with liver function;
- breathing problems such as asthma or chronic obstructive pulmonary disease;
- a peptic ulcer (open sores in the lining of your stomach or the upper part of the small intestine);
- a recent stroke or heart attack;
- Your doctor will be able to inform you if you are unable to have iloprost treatment and the reasoning behind this.

### Additional medications

Pending your doctor's advice, usual medications can still be taken before and after a course of iloprost treatment. Your doctor will advise you on whether or not to continue taking medications during a course of treatment, as certain drugs can also act to widen blood vessels or lower blood pressure. SRUK recommends individuals to take a list of their medications with them when going to their first day of treatment.

Iloprost should not be taken with the following medicines except upon the advice of your doctor:

- Antihypertensives (blood pressure medicine)
- Anticoagulants and antiplatelets (blood thinning medicine)
- Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen

Iloprost does not affect vaccinations, so these can be had before and after a course of treatment. In the small chance that a vaccination is being administered during treatment, your doctor will provide guidance.

### Fertility

There have been no conclusive results on whether or not iloprost affects fertility. The guidelines currently are that iloprost should only be prescribed to a pregnant woman in extenuating circumstances where the disease is severe. If pregnant or if a person is planning on starting a family, the patient should tell their doctor prior to treatment. Likewise, there has been no research on the drug's activity and influence in breastfeeding, therefore breastfeeding is best avoided whilst taking iloprost.

# Meet the Scientists

## Professor John Pauling:



### What got your interest in scleroderma and Raynaud's started?

My interest in systemic sclerosis arose from looking after people affected by the disease during the early stages of my rheumatology training. I was concerned by the limited number

of effective treatments that were available for patients and the large number of unanswered questions facing rheumatologists with regards to the causes of the disease. I greatly admired (and continue to do so) the fortitude and resilience of people who live with scleroderma. They are an inspiring group of people to look after and a continued source of motivation for me.

A number of people have inspired me along the way to develop my interest in scleroderma, among them my colleague at the RNHRD Ms Sue Brown MBE. Sue was supported by The Raynaud's & Scleroderma Association (RSA) for many years and was an incredibly hard-working, dedicated, caring clinician and a tireless patient advocate before her well-earned retirement. Ms Anne Mawdsley MBE was also a huge inspiration for me; strongly encouraging and supporting me personally to develop my clinical and academic interest in scleroderma.

I'm pleased to have seen improvements in the treatments available for people with scleroderma and recent evidence suggests our patients are doing better than previously but there is still a lot of work to do. Sadly, we remain some way off finding a cure for scleroderma but there are many people working hard to get us there.

### What key areas do you think are going to be really exciting for research over the next 5 years?

I believe we are on the cusp of some exciting breakthroughs in scleroderma and expect this to translate into further improvements in patient outcomes over the next 5 years. Much of the

vital 'underpinning science' (the laboratory work needed to identify new treatment targets) has now been translated into new drugs that are currently being tested in large multicentre clinical trials. We expect this will result in new treatment options for skin and lung involvement in scleroderma.

I also expect to see improvements in patient outcomes due to more widespread use of existing treatments. The falling costs of some drugs is allowing clinicians to use them earlier in the disease course and for different scleroderma manifestations (e.g. treatments initially restricted to management of pulmonary hypertension being used to manage Raynaud's symptoms). This could allow doctors to use drugs earlier in the disease course, potentially 'modifying' disease progression with fewer patients developing more advanced problems affecting the lungs, heart and kidneys. Scleroderma research is also providing us with better prognostic 'biomarkers' that are helping doctors identify people who are likely to remain stable versus those at risk of disease progression. These tools will also help doctors to treat certain patients more aggressively to prevent progression of the disease. The focus of research is shifting from improving survival to improving quality of life which will also result in important improvements in care for our patients.

### You get to throw a dream, once in a lifetime, dinner party - who would you invite (Can be anyone from history or present)?

Maurice Raynaud would be there of course! Raynaud was feted by his contemporaries as a "physician, savant, philosopher and man of letters" and his contribution to medical knowledge was wide-ranging. It'd be interesting to discuss his important contributions to medicine through the prism of 150 years of scientific progress and see whether Raynaud himself would demand a reappraisal of the current classification of his enduring medical eponym.

Having grown up on the same street as John Lennon (30-odd years apart!), we'd have plenty to talk about. I am a huge fan of his music, his honesty, his message and truly believe he'd still be making an important contribution to the public debate if he were still alive today.

Winston Churchill would have been a marvellous dinner companion. I admire his determination, resolution and ability to pick himself after failure. I bet he'd have a few good stories to tell over coffee as well!

## Finally, what is your one desert island disc?

Music is one of my great passions outside of medicine and so this is a tough one! I've chosen 'Beautiful Boy', written by John Lennon shortly before his death. It is packed full of fatherly advice, which I hope was later of help to his son and inspiration for the song, Sean. I have sung the song to my own sons at bedtime. Amongst the many wonderful lyrics is the following one reminding us that there are others there to help us and to enjoy the moment:

'Before you cross the street, take my hand. Life is what happens to you while you're busy making other plans'.

## Professor David Abraham:



As a young PhD student in the early 1980s, David worked at both Queen Elizabeth College and at the Institute of Rheumatology, where his research focussed on dermal fibroblasts (involved in scleroderma). He is now a Professor of Cell and Molecular Biology at UCL and Director of the Centre for Rheumatology and

Connective Tissue Diseases, where he continues to work on fibrosis. SRUK recently funded David and his team at UCL to investigate factors that contribute to the development of calcinosis in scleroderma patients.

## What inspired your interest in scleroderma and Raynaud's?

During my PhD, I was introduced to Dame Carol Black (SRUK's president), as my colleague Dr Irwin Olsen developed a collaboration with her looking into scleroderma-associated skin and lung fibrosis. This provided an opportunity to work with Carol and her clinical research fellows at the time, Dr Rama Vancheeswaran and Dr Salvatore Lupoli. Their passion and desire to understand the diseases to help them treat patients sparked my interest in scleroderma and I was able to harness my expertise in fibroblast biology to help understand the changes in scleroderma fibroblasts and fibrosis. This interest continues to this day.

## What key areas do you think are going to be really exciting for research over the next 5 years?

I think there are three areas that are going to be key to biomedical research over the coming years. Firstly, advances in genetics and epigenetics to understand in more detail how our genes are controlled and what underlies their dysregulation in disease. Secondly, the use of single cell analysis to provide in-depth phenotyping of cell populations within tissues, in order to define the role and impact of different cells on biological processes such as inflammation and tissue repair, and how they contribute to human disease. Finally, it is to harness these areas to improve our modes of treatment and develop clear approaches to precision medicine and targeted anti-fibrotic therapeutics.

## You get to throw a dream, once in a lifetime, dinner party - who would you invite?

Hippocrates, Emmeline Pankhurst, Sir Alfred Ramsay, Richard Feynman, and Elizabeth Garret Anderson.

## Finally, what is your one desert island disc?

Can't Take My Eyes Off Of You - Frank Sinatra. It was the song my youngest daughter liked when she was a toddler, and she is now nearly 30 and remembers it to this day!

## Glossary:

- **Dermal fibroblasts:** cells found within skin, which are responsible for generating new connective tissue and allowing the skin to recover from injury.
- **Epigenetics:** the study of changes in organisms caused by modification of gene expression rather than alteration of the genetic code itself.
- **Single cell analysis:** the study of various cellular functions and processes, at a single cell level.
- **Phenotyping:** Defining the physical and biochemical characteristics of an organism, organ or cell, based upon both genes and environmental factors.
- **Precision medicine:** an emerging approach that is based on customising medical treatment according to the individual's specific genes, environment and lifestyle, so that the therapies are most optimal and appropriate.

# How we're raising awareness in 2019



## Raynaud's Awareness Month

For Raynaud's Awareness Month in February, we called on everyone to get to #KnowRaynauds by taking our online test in order to create greater awareness and understanding of the condition. We wanted to reach even more people and all our efforts have been rewarded, as we have had a much bigger impact this year than ever before! Since February, over 25,000 people have taken our online Raynaud's test, with more than 2,000 at once during a segment on BBC Breakfast where we talked about the test. That's in comparison to just under 6,000 in 2018, which is a truly phenomenal increase of 263%.

Nearly 8,000 members of our community engaged with the campaign across Social Media. Our press and PR coverage reached over 75 million people through various broadcast channels, including radio, press and magazines.

### Broadcast & Press - 75,000,000 reach

The 5th of February was a very busy day for SRUK's Chief Executive Sue Farrington with an interview on BBC Breakfast. We also had interviews with 24 local radio stations, and pieces in the Mirror, Daily Mail and other popular press.

### Online - 606,533 reach on our own channels

Many of you will have seen us kick off the month with a brand new animation showing the impact that Raynaud's can have on your day-to-day life, and promoting the online test. This gave us a fantastic start to the month with over 40,000 views across all our different channels.

### Cosy Up with a Coffee

We also managed to raise over £2,500 through all the events that you held throughout the month to cosy up with your friends and family for a coffee morning.

## Scleroderma Awareness Month

In June, we'll be promoting the signs and symptoms of Scleroderma using the #KnowScleroderma hashtag.

We've produced a new animation to help spread the word.

Support #KnowScleroderma by sharing to help raise awareness.



### World Scleroderma Day

Towards the tail-end of Scleroderma Awareness Month, we will celebrate World Scleroderma Day on the 29th June. This is a day where we unite across the globe to celebrate our inspirational community.

We've worked with the Federation of European Scleroderma Associations (FESCA) to drive awareness of this condition throughout the continent and beyond.

#### #KnowScleroderma

Our campaign aims to create greater awareness and understanding about the condition.

Find out about the symptoms and what you can do if you're worried.

Support #KnowScleroderma and fundraise.

We're asking that this summer when you organise a picnic with family, friends and colleagues that you do it to help take a step towards a cure for Scleroderma and Raynaud's.

New research finds 48% of people with scleroderma are not confident their GP knows enough about scleroderma. Help raise awareness by telling your story.

Find out what is happening for World Scleroderma Day on 29 June, what you can do to help and the impact from the campaign so far.

### Research saves lives

To date we've invested over £10 million into research but need your help. Scleroderma is still taking the lives of loved ones. Will you help us beat scleroderma? #KnowScleroderma, donate and fundraise to make a difference.

# Hannah's Story of Localised Scleroderma

Everything in my life changed when I found a strange bruise on my side, just a few months after a throat infection went septic and hospitalised me. At first, I did not think it was anything to worry about, but I had no idea that I had already said goodbye to my normal life.

Over the next ten years, my life would change dramatically and normal would become a distant memory.



**One bruise turned into several and I watched in horror as the mysterious lesions spread like wildfire up my rib cage. As an emotional 14-year-old, my mind immediately went to the worst-case scenario and I couldn't stop picturing myself strung up to machines fighting some mysterious illness. While my instincts may have been on the dramatic side, I wasn't far from the truth.**

My mum took me to the local GP but an impatient doctor dismissed me. She informed me that I had a rash caused by a belt. As the lesions were nowhere near where a belt would be, I was mystified. As more symptoms popped up, including stiff joints and nerve pain, I hounded my GP surgery for the next six months.

Following a lot of tearful doctor's appointments, a sympathetic GP listened and acknowledged that there might be an underlying problem, especially as I had also developed widespread chronic pain. I was referred to a rheumatologist and a dermatologist. I finally felt like I was one step closer to an answer.

My dermatologist assembled a team of consultants to diagnose me. I was the first case of my kind they'd seen and he had no idea where to start. In a matter of months my life became abnormal and revolved around finding a diagnosis.

Eventually I got one and quickly became accustomed to life as a guinea pig. My consultant's diagnosed me with lichen sclerosis and localised scleroderma. My rheumatologist confirmed that I had hypermobility and years later I was diagnosed with fibromyalgia and irritable bowel syndrome.

But, while I was being treated, my symptoms kept flaring up. I began losing dexterity in my hands and had to use laptops for all my exams.

# Patient Survey Questions

[www.surveymonkey.co.uk/r/SRUKpatientsurvey](http://www.surveymonkey.co.uk/r/SRUKpatientsurvey)

## Demographic data:

1. What is your gender?

- Male
- Female
- Non-binary
- Prefer not to say

2. Please select an age range:

- Under 18
- 18-29
- 30-44
- 45-59
- 60-69
- 70+

3. What region do you live in?

- London
- East Anglia
- East Midlands
- West Midlands
- South East
- South West
- North East
- North West
- Yorkshire and The Humber
- Northern Ireland
- Scotland
- Wales
- Europe
- Rest of the World

4. What conditions are you diagnosed with? (checklist)

- Scleroderma
- Limited
- Diffuse
- Localised
- Raynaud's
- Other

## Loneliness and concerns

10) When you are worried about the following, who do you turn to? (can tick multiple in each column)

	Your condition	Mental health	Relationships	Practical support	Loneliness
GP					
Consultant rheumatologist					
Specialist nurse					
Dermatologist					
Other specialist (please specify which)					

5. How long has it been since your diagnosis?

- Less than 1 year
- 1-5 years
- 5-15 years
- Over 15 years

## Medical Journey

6. How confident are you that the following health professionals know about your condition?

	Very confident	Fairly confident	Not confident	N/A
GP				
Consultant rheumatologist				
Specialist nurse				
Dermatologist				
Other specialist (please specify which)				

7. Did your GP refer you to a specialist to further investigate your condition?

- Yes. (if so, where did they refer you?)

- No.

8. How long did it take for you to receive treatment?

## Confidence to talk about condition:

9. How confident are you to talk about your condition? (checklist)

- Very confident
- Fairly confident
- Confident
- Not confident at all. (if so, what would help you feel more confident?)

11. What are you most worried about?

Only choose one out of the following.

- Rights and entitlements
- Managing my condition
- Accessing practical support
- Relationships
- Staying in work
- My future
- Nothing
- Other \_\_\_\_\_

**SRUK**

12. Do you engage with the information and news shared by SRUK?

- Yes.
- No.

If yes, go to Question 13a. If no, go to Question 14.

13a. Which of these channels have you engaged with before?

- Facebook
- Twitter
- Instagram
- Website
- Health Unlocked
- Helpline
- Publications
- Local support group
- Conferences

13b. On a scale of 1 to 5, how would you rate the following? (1 being least valuable and 5 being most valuable)

- Facebook
- Twitter
- Instagram
- Website
- Health Unlocked
- Helpline
- Publications
- Local support group
- Conferences

13c. Through the information provided by SRUK, how informed do you feel about your condition?

- Very informed
- Somewhat informed
- Uninformed

17. Is there anything else you would like to tell us?

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14. Through the support provided by SRUK, do you feel more able to cope with your condition?

- a) Yes, always
- b) Yes, sometimes
- c) No, never

If (a), go to Question 15. If (b) or (c), what could SRUK do to better help you with your condition?

- Specialist nurse on the helpline.
- Provide more information on the website about the conditions and research in this area.
- Help me join clinical trials.
- More information and tutorials on practical areas such as physiotherapy exercises and dressing ulcers.
- Other \_\_\_\_\_

15. Does SRUK help you feel less alone?

- a) Yes, always
- b) Yes, sometimes
- c) No, never

If (a), go to Question 16. If (b) or (c), what could SRUK do to help you feel less alone?

- Connect me with other members of the community.
- Organise more support groups across the country.
- Other \_\_\_\_\_

16. Did your health professional tell you about SRUK?

- Yes
- No

If (a), go to Question 17. If (b), where did you hear about SRUK?

- Google
- NHS website
- GP surgery/clinic notice board
- Family
- Friends
- Social media
- Other \_\_\_\_\_



I struggled with developing symptoms and hypersensitive skin. I wrestled with mobility issues and faced daily intense pain and never-ending fatigue.

**Although the symptoms were physical, they impacted my mental health too. As a self-conscious teenager, I was horrified by the mess of scars that were constantly changing on the surface of my skin. I hated them and what the condition had done to my life. I endured flare up after flare up, all treated with varying degrees of success, and I got lost in the medical whirlwind of my life.**

The ceaseless battle wore me down and nowadays I don't remember what it's like to feel well. I don't remember what it's like to live without pain and I certainly don't remember what it's like to feel nervous about needles or procedures.

For the longest time, I obsessed over the loss I felt. I mourned my old life and I refused to embrace my new one. I resisted my condition with every ounce of strength I had and, as a result, began to identify with it too. I defined myself by it and my illness soon encroached on every aspect of my life – mental and physical.

I continued on in this cycle for years before I finally woke up to what I'd been doing. While chronic illness may be infuriating, I couldn't let it take more from me. By surrendering to its power, I'd lost my own.

I changed everything in my life to appease my condition's needs – from my career path to my daily routine – but what was the point of all that if I wasn't enjoying my life? I had to learn how to balance caring for my physical health with every other aspect of my life.

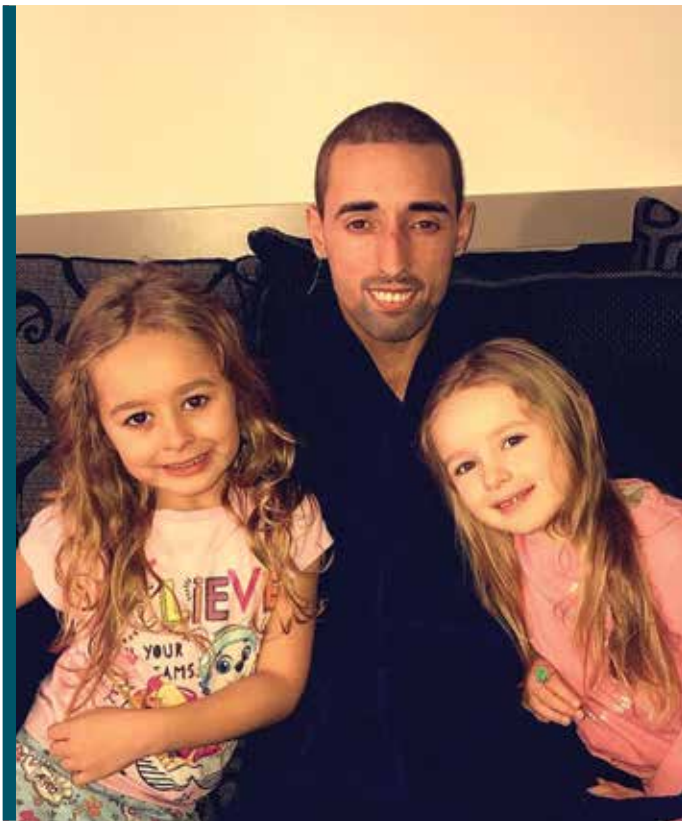


So, I embraced the abnormality of it all and made a conscious effort to acknowledge all the great things too, including my partner, my family, my friends and my career. I accepted my illness but also realised that it is the least interesting thing about me.

Hearing about SRUK's work and joining their Youth Advisory Board opened up my world. I met other young people facing the same difficulties, people who refused to be defined by their condition. Eventually, I saw myself in the same light, as someone worth more than the obscure medical jargon clouding up their life.

I may struggle every day but I am so much more than my illnesses and I'm excited to see how I will continue to grow in the future. Sickness is a part of me, but that's all it is, a singular part.





**Travis Munn, 25** shares his experience of systemic scleroderma after his symptoms forced him to give up a career in professional football. Now four months on from receiving a stem cell transplant, he is feeling stronger and he is eager to return to his football days. He lives in Derby with his wife Harriet and their two daughters, Freya, five, Bella, three.

## What were your first symptoms of the condition?

I was playing professional football, I was really fit and in good shape. I could run for hours without a problem and then it all went downhill really quickly. At the end of the season in 2015, I was one of the least fit players on the team, whereas at the start of the season, I'd been one of the fittest. My fingers started to go blue, I lost a load of weight and I started stiffening up. Then I got an ulcer on my finger that wouldn't repair but it got worse and worse, and eventually got infected. I had it checked out and was put on antibiotics and thought no more of it, but it still didn't clear up.

## Can you tell me about your diagnosis?

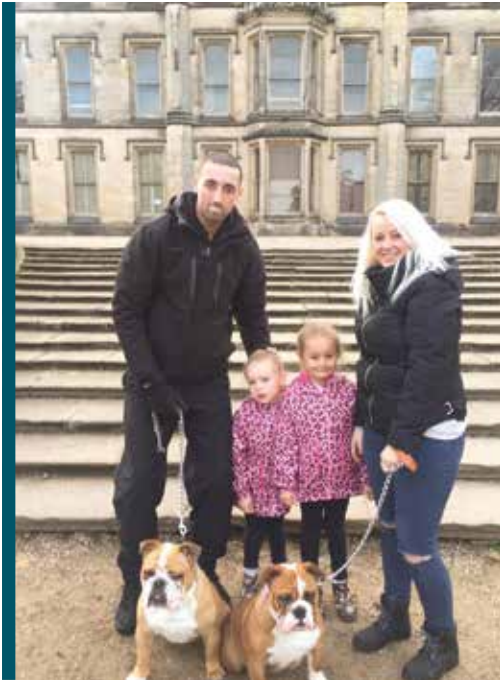
I went to see my physiotherapist, showed him my blue fingers and he recommended I go to hospital to get checked out. I finally got a rheumatology referral. About a year later, I was told that it was systemic scleroderma. As it was very early stages, I didn't think much of it. But once I started doing my own research, I realised that it was life threatening and there was no cure.

## How did you hear about the stem cell transplant?

I read up on a stem cell transplant treatment after I saw a piece about a marathon runner who had it and went back to running marathons. I was continually going downhill so I asked my doctors if I could do it. It was inevitable that the condition was going to take over my body, so I knew I needed to get the stem cell transplant before it was too far gone for me to be allowed to have it. At the time, my hospital said no. I was really disheartened. I considered doing fundraising and going over to America to get it done. I emailed the specialist in America who actually put me onto Professor Denton. I went down to see him and they tested me to see if I'd be able to get through the treatment without putting myself in more danger.

## When did you have it and what did it involve?

I had the treatment between November and December 2018. First, I went in for one day of chemo and then went home for a week. On another day they took the stem cells out of my body. I went home for another week or two and then I was admitted to the transplant ward. I had to be in an isolated clean room to lower the risk of me picking up any infection. I wasn't allowed any visitors who might be sick and everyone had to clean him or herself before coming in. I had chemo for seven



days followed by one day of rest and then they put my stem cells back in. Then it was just a matter of resting and having other supplementary treatments, like blood and platelets. Afterwards, my immune system wouldn't come back up to normal levels. I had to have daily injections in my stomach to boost it.

## What was the hardest part of the treatment?

Saying goodbye to my kids and wife was the hardest part of the treatment. I said goodbye to my family and friends for a month and part of me didn't know if I was even coming back. It took a toll on everyone but I had so much support from friends and family, with around 40 people shaving their heads in solidarity with me for a fundraiser.

It's 100% worth it though. They said it would take a year for me to repair but I'm already seeing benefits. I'm breathing better and my skin is loosening up. I'm looking to get back into work and potentially back into football. But I don't want to get too excited before I know for sure. I hope I can come back with a vengeance.

## Why did you push for the treatment?

I wasn't that unwell, my breathing was getting worse, but I couldn't carry on and just let it get worse. It was heartbreaking for my kids to see me that sick. I'd rather go out fighting than not. Waiting was just as risky as the treatment, so it was an easy decision.

## How has your outlook changed following the procedure?

I don't see scleroderma as a threat anymore. It's still early days but it's definitely ten times better. Everybody that I visit can see it my face, I'm not as gaunt anymore and just everything is better – I can even eat properly. In a nutshell, I just feel better. I'm looking to go on bike rides again with the family and go swimming too. All my friends are fitness fanatics and my whole life has been about football, so going from that life to being sick was really tough. To have a dream like that taken away from you is really tough, but I'm hoping this will change that. It's definitely made me appreciate life.

## How did your symptoms start to affect your football career?

I transferred from Mansfield Town FC to Boston United FC and my amazing manager Jason Lee, who is still a great friend, supported me a lot. I let him know what was happening and he understood how I was feeling. It was hard to take and it upset me a lot, especially as I didn't know what it was at the time. All I'd wanted to do was make my family proud, but that changed because of scleroderma. By the end of the season, I was so unfit and unhealthy. I had to put my career on hold but my old managers have stayed in close contact.

## Are you still hopeful that you could return to playing football?

I am hoping that I'll be able to go back to it eventually. My doctor has said we'll do a round of tests at the end of the year to see where I stand. With how I feel now, I think I could. If someone kicked a football in front of me right now, I'd go after it. My long-term goal is to go back to football. The little boy in me still wants to go back to it and chase that dream.

**What advice would you give other people seeking the same treatment?**

**Don't give up!**

# 6

## Tips for self management

### Self-management

#### What is self-management and how can it help?

Self-management is what an individual can do to manage their condition and to help maintain their wellbeing. How this is approached will differ from person to person, but fundamentally it revolves around making decisions to support a healthy lifestyle, whilst recognising the physical and emotional effects the disease can have. Both Raynaud's phenomenon and scleroderma can affect individuals to varying extents, so each person will need to understand what works best for them in helping them maintain a good quality of life.

Here at SRUK, we strongly encourage anyone who has been diagnosed with or thinks they may have Raynaud's or scleroderma to learn as much as possible about your condition, and to determine whether changing certain lifestyle factors may help, such as diet or stress levels. Paying attention to your emotions and communicating with a support network, whether it's family, friends or SRUK, will also be of benefit. Evidence has shown that people who have the knowledge and confidence in self-management skills tend to have better health outcomes.

## Physical self-management

### 1 Staying warm

Most people living with scleroderma will also have Raynaud's, where small blood vessels in extremities are over-sensitive to changes in temperature. For this reason, it is important to stay warm to avoid Raynaud's attacks. Here are some basic tips:

- Avoid sudden changes in temperature where possible
- Try and keep your body warm, especially your hands and feet
- Dress in thin, loose layers for maximum warmth. This means that layers can be taken off if too warm, and can be piled back on when cold
- Wear gloves and long socks when cold, and try hand-warmers and thermal insoles. Our shop stocks several, very popular choices: [www.srukshop.co.uk](http://www.srukshop.co.uk).

In addition to the weather, exposures to other cold environments can also trigger symptoms, such as cold aisles in supermarkets or air-conditioning in shops. Preparing for these situations may lessen the likelihood of a Raynaud's attack.

Wax bath therapy is intended to moisturise, soften the skin, improve blood circulation and reduce pain of joints. This approach uses paraffin wax that is soft and melts at a lower temperature than normal, therefore it does not cause any burns or blisters.

Paraffin wax is also known to help muscle relaxation and muscle movement. Those being treated with a paraffin wax bath are encouraged to build up several layers of wax and then gently peel it off, rounding into a ball of wax to use later. This action can also contribute to gentle manipulation of the soft tissue, encouraging wider blood flow.

### 2 Healthy lifestyle

Stress can also bring on Raynaud's symptoms, therefore by managing stress levels, such as by pacing yourself and being aware of when you may be taking on too much, can help you reduce Raynaud's symptoms. This can be achieved with gentle exercise, which can also help boost circulation by getting the blood flowing to the extremities. Exercise is also beneficial for keeping the heart, lungs and muscles healthy, and for keeping the skin supple. It is important to find something that is suitable to your abilities; walking, yoga and swimming are popular, low-impact exercises.

Stopping smoking is one of the most helpful ways of limiting symptoms, as this will help lower blood pressure and maintain good circulation throughout the body. There is lots of support available at

pharmacies and at GP surgeries to help you stop smoking; visit <https://www.nhs.uk/smokefree> for more advice and to download a Personal Quit Plan.

Whether or not an individual suffers from gastro-intestinal symptoms, it is crucial for people living with either Raynaud's or scleroderma to be aware of how nutrition plays a role in their symptoms. This is especially as the gut is affected in up to 90% of people with systemic sclerosis. You may need to try a combination of methods, either together or separately, to find a regime that works for you. Some people have trouble swallowing, digesting or maintaining weight, and it may be necessary to ask your doctor for referral to a dietician if you are struggling. Eating a balanced diet will help you manage your condition and stay healthy; some elements that should be included in your diet are::

- Calcium: essential for healthy bones. Sources include dairy products, fishes, green vegetables, seeds, nuts and fortified cereals.
- Vitamin D: needed to help absorb and utilise calcium. Obtained from sunlight, eggs, butter, margarine and cereals.
- Iron: important in making red blood cells, which carry oxygen around the body. Found in red meat, poultry, fish, eggs and leafy vegetables.
- Omega-3: helps to protect against many diseases, including heart disease, can reduce inflammation and is suggested to have a positive effect on mood. Sources include oily fish (sardines, salmon, tuna), rapeseed oil, walnuts and fortified eggs.

It is important to aim for 5 portions of fruit and vegetables per day. Aside from helping to maintain a healthy weight, they can help to reduce pain and inflammation, provide fibre and help to regulate blood pressure and blood fats. Protein-rich foods such as fish, beans, eggs and meat will help the body to grow and repair, aiding you in recovery from surgery or ulcers.

### 3 Skin care

Routine skin care is incredibly significant when living with Raynaud's and scleroderma. Keeping skin clean, dry and well moisturised are three simple things to remember. We especially recommend using moisturisers containing lanolin. Harsh, deodorised soaps should be avoided, and instead non-soap cleaners should be used.

For people with secondary Raynaud's, there is a risk of developing digital ulcers on fingers and toes. Ulcers should be dressed regularly but the frequency with which the dressings are changed will vary from person to person. Dressings will help to alleviate pain and prevent dirt and germs from entering the wound. Dressings must be as sterile as possible to reduce the chance of infection. We recommend that you see a nurse or GP initially to show you how to dress an ulcer so that you then know the best way to do it at home. They will also be able to tell you the best dressing for you, as there are several options. These include:

- Inadine: this is impregnated with iodine. This is licensed for use on infected ulcer wounds. If allergic to iodine this should not be used.
- Mepitel: made of a flexible polyamide net coated with soft silicon. It is easy to put on and shape to the ulcer.
- Allevyn: consists of a layer of foam about 4mm thick providing a cushion for maximum protection

Dressings and medication can be expensive, so a prescription pre-payment certificate (PPCs) may help to reduce costs, if you do not already receive free prescriptions. If you think an ulcer looks or feels infected, see a medical professional.

If you are concerned about the appearance of telangiectasia (clumps of tiny, broken blood vessels), you can learn to cover the area with specialist make-up, called skin camouflage. Our helpline (0800 311 2756) can direct you towards these services.

# Mental self-management

## 4 Mindfulness

The psychological impact of Raynaud's and scleroderma is equally important as the physical impact. Whether it is the stress of day-to-day activities or the impact of the conditions on work and relationships, it is vital to recognise this side of living with these conditions.

Mindfulness can be described as paying more attention to the present moment, to your own thoughts and feelings, and to the world around you. This can help all of us enjoy the world around us more and help manage levels of anxiety and stress, which improves mental wellbeing. Here is a useful mindfulness technique:

- Find a quiet, relaxed space.
- Close your eyes and focus on your breathing; inhale slowly for 3 seconds and exhale slowly for 3 seconds.
- Do not worry if your mind wanders, just acknowledge that this has happened and then bring your thoughts back to your breathing.
- Repeat this for as long as you like.

It may help you to pick a regular point in your day to do this. Yoga and tai-chi are also said to be effective in helping you become more mindful. Head to the Mental Health Foundation's website ([www.bemindful.co.uk](http://www.bemindful.co.uk)) for more information, an online mindfulness course, and details of mindfulness teachers in your area.

## 5 Fatigue

It is common to suffer from fatigue when living with an autoimmune condition, with people often describing how they 'hit a wall' of fatigue that makes it challenging to continue without rest. After a proper rest, the fatigue may improve, so this is a potential way of reducing its impact. Tips on avoiding fatigue are:

- Use technology where possible, e.g. a dishwasher or ergonomic device.
- Use a shopping trolley when out shopping.
- Place items you use frequently in easy to reach places.
- Buy pre-chopped vegetables.
- Simplify your day-to-day activities and ask for help when you need it.

If you think your drug treatment may be causing your fatigue, talk to your doctor about reviewing your treatment. They can also look for signs of other conditions that may be causing fatigue, as well as checking inflammation or anaemia levels.

## 6 Finding support

If Raynaud's or scleroderma are limiting your ability to work and lead a fulfilling life, please get in touch with us and we will do our best to help you. If your concerns are surrounding financial concerns, visit our UK benefits page on our website to find out more on government schemes.

We can also help put you in touch with local groups and other individuals who have the condition. You can also chat with other people who also have Raynaud's and scleroderma through our online community.

If you feel you are struggling with your mental health, we implore you not to suffer in silence and to speak to your GP about a referral to psychological support services. Services such as Samaritans also take calls 24/7 on 116 123. If you are a carer or know someone who is a carer, please head to [www.selfmanagementuk.org/](http://www.selfmanagementuk.org/)

# Support & Useful Contacts

Our SRUK Helpline is available to anyone who is affected by the conditions to receive support.



The helpline operates 365 days a year from 9am-7pm. This service does get busy so if the call goes to voicemail please leave your name and number and you will receive a call back within 24 hours.

We currently have eleven volunteers who man the helpline on a rota basis; Amelia, Brigid, Helena, Jean, Katherine, Kim, Liz, Paula, Penny, Rosemary & Susie.

Our volunteers update their skills regularly and having external accreditation, as a member of The Helpline Partnership, means that we conform to their standards of excellence.

If you call the helpline, the volunteer that you talk to may have Scleroderma and/or Raynaud's but as we know, everyone is different and the manifestations from person to person are varied and complex. Therefore, we refrain from swapping backgrounds and symptoms but listen positively to your issues and try to help you with your particular enquiry.

Specialist Nurses		
<b>Rheumatology Telephone Advice Line</b>		01225 428823
<b>Belfast</b>	Audrey Hamilton	0289 056 1310
<b>Leeds</b>	Specialist Nurse Team	0113 392 4444
<b>Liverpool</b>	Jan Lamb & Jenny Fletcher	0151 529 3034
<b>Manchester</b>	Specialist Nurse Team	0161 206 0192
<b>Newcastle Upon Tyne</b>	Karen Walker	0191 223 1503
<b>Portsmouth</b>	Julie Ingall	0239 228 6935
<b>Royal Brompton</b>	Lucy Pigram	020 7352 8121 (Main Switchboard)
<b>Royal Free, London</b>	Sally Reddecliffe & Adele Gallimore (For Pulmonary Hypertension Enquiries)	020 7472 6354
<b>Royal Free, London</b>	Specialist Nurse Team	020 7830 2326
<b>Sheffield</b>	Specialist Nurse Team	0114 271 3086

**We are working towards providing contacts at key hospitals in Wales, Ireland and Scotland please check the website for up to date information or call the Rheumatology telephone advice line (emboldened in green, listed above) with your medical query.**

## Local Support Contacts

Our local support contacts provide support on a local level by organising support group meetings or by being available to local residents via the phone or email. If you are interested in joining one of our local groups or wish to receive some support then please contact us and we will be happy to put you in touch with your **local support contact: 020 3893 5998**

Local Support Contacts	
Bedfordshire	Rita Boulton
Exeter	Mike Corbett
Hampshire	Tracey James
Merseyside & Cheshire	Diane Unsworth
Newcastle & Northumberland	Lindsay Wilkinson
Norfolk	Lucy Reeve
South London	Celia Bhinda
South Wales	Belinda Thompson
Leeds	Lynne Lister

# Step Out for SRUK



Trudi Shewan, 58, Suffolk, took part in the Isle of Wight Challenge in May 2017. Although she twisted her ankle on the 33-mile walk, she says the pain was worth it.

## What inspired you to fundraise?

I heard about SRUK through my daughter, who has scleroderma. I decided to do the fundraising to raise awareness for SRUK and to support sufferers of scleroderma.

## How did you prepare for the event?

Initially I was walking every day for at least half an hour, then I stepped it up to six miles every other day and then I increased it to three short walks and one long walk, of about 12 miles, every week. I did not do the full distance until the actual event. I also had to get a new pair of boots as I walked through my old pair! Thinking about the people who had donated money really kept me going. I didn't want to let anyone down!

## What was the highlight of the walk?

The highlight of the whole thing was finishing it! I would say it's the toughest thing I've ever done in my life.

## What was the toughest part?

Within the first three miles, I twisted my ankle tripping down a rabbit hole. It was such a wealth of emotions after all that training and suddenly thinking I wouldn't be able to do it. That moment when I actually crumpled to the floor, I just thought, 'I'm going to get up and do this. I don't care if I have to hobble all the way.' And I did!

## How did it feel when you crossed the finish line?

It was euphoric when I crossed but I was so drained. From a personal point of view, there was a huge sense of pride that I'd done it and that I'd raised nearly £1000 for SRUK.

## What advice would you give to other people wanting to fundraise for SRUK?

Try to do it with other people so you have a team around you! Doing it alone is hard.





# Upcoming Challenge Events



## Step Out and Partner Up for a Picnic - During Scleroderma Awareness Month (Anytime during June)

This year during the month of June we are asking for our community to help raise awareness and fundraise. You can Step Out to the park, streets or country side in force in your SRUK branded t-shirts on a walk as long or short as you choose, solo or as part of a group all in a bid to raise awareness of Scleroderma during Scleroderma awareness month.

### How Do I Step Out?

#### Pick a date and your starting point

Decide on a date during June that works best for you and decide where to want to begin. This could be at home, a park or a favourite local attraction.

#### Decide on a distance

Whether it be 1 mile or 50 you want to walk, if you want to include stopping points on your route like a tea shop or pub, it is completely up to you. You can go to Map O Meter [www.gb.mapometer.com/walking](http://www.gb.mapometer.com/walking) and Walk it [www.walkit.com](http://www.walkit.com) to help you plan your route.

#### Spread the word and bring your friends.

Get your family and friends to 'Step Out' with you to support Scleroderma & Raynaud's UK. Just let us know when, where and how many of you will be taking part and we can send you your t-shirts and banners.

#### Enjoy the day while raising funds

Make sure to keep hydrated and ask every friend who wants to join to donate just £10 to take part. Remember to take lots of photos and videos to share your wonderful achievement.

#### Send in your money

You can pay in your money online, pay in over the phone or send us a cheque, made payable to "Scleroderma & Raynaud's UK". We will then send you out a certificate to celebrate your achievement.

We are here to help you every step of the way, to give you ideas or just to talk about your event plans. You can get in touch today by emailing: [fundraising@sruk.co.uk](mailto:fundraising@sruk.co.uk) or by calling 020 3893 5993.

## Partner up for a Picnic

Alternatively, you can host a picnic as part of our Partner Up for a Picnic Event, by inviting friends and family around for a summer feast with sandwiches or a BBQ. Whatever you find yourself doing this SAM make sure to take lots of photos and either tag us online @WeAreSRUK or send us the photos to share, not only to help inspire but to keep the conversation going throughout June.

## Race to the Stones - 13th July

Registration Fee: £64.00 Minimum Sponsorship: £425.00



The route passes up and along the high ground South West from Lewknor in Oxfordshire to the Thames crossing at Goring. From this point the route rises up onto the North Wessex

Downs passing golden fields before the iconic finish where you'll walk between the towering stones of Avebury.

You can choose to do either 25, 50 or 100km distance, depending on your preference and you can either choose to do your desired distance all in one go or over the course of a weekend, the choice is yours. We already have a team of 11 taking part, so you can choose to join them or submit your own team to take on the Cotswold's challenge.

## Thames Bridge Trek - 25k walk - 7th September

Registration fee: £40 Minimum sponsorship: £175

This is a 25km walk through London across 16 bridges, it really is the best way to see the capital! You'll be able to take in all the sights on this central London trek, whether it's Big Ben, the London Eye, or Tower Bridge, you'll be able to tick them all off on this fantastic route. Join 2,000 walkers as we venture across the Capital taking in unrivalled views of the skyline from its best vantage points by the River Thames. Setting out from Putney Bridge - we head downstream towards the City, zig-zagging over the array of historic bridges - each with its own fascinating story - and a mid point stop in Vauxhall for some snacks & drinks, with a finish line celebration in Southwark past the majestic Tower Bridge.

We already have 5 walkers taking part, so again you can join them or submit your own team the choice is yours.

# Thank You

As we are an entirely funded by voluntary income, we are completely reliant on the support of our amazing community and here are some of the events you have held to help raise awareness and fundraise for us.



Yun Wah Wan held two coffee morning in Birmingham and Leicestershire and raised an amazing £880.

Siobhan Hollis, who is our current cake champion held her event and raised a fantastic £400, here are a glimpse of some of her delicious cakes from the day.

Angela Hopkinson made her event a real community day with members of her local church came along, including her Vicar, who conducted the raffle and raised an amazing £145

We event hosted our on Cosy Up Event here in the office, the perfect event for a Friday afternoon.

This year our community together raised nearly £2000 during RAM from coffee mornings and the benefit of using it as a conversation starter is invaluable.

Remember if you have held your event and have photos please send them across as we'd love to see them and share them with the community or if you are yet to host your event, no need to panic, you can do it anytime across the upcoming months.





### London Landmarks Half Marathon

At the end of March we had ten runners compete in the London Landmarks Half Marathon, the event is only in its second year and it's already one of the most popular half marathons in the UK. This is the first year that SRUK have been a charity partner and what an amazing day it was. Together our 10 runners raised £8,000.

Well done to Leslie, Prerana, Carissa, Nikhita, Laura, Alex, James, Aimee, Julie and James, you were amazing and did SRUK proud.



### Magic Mike

We would like to say a huge thank you to Mike for setting himself the incredible challenge of taking part in the White Collar Boxing event in memory of his young daughter Sophie, who passed away late last year. He committed months of training to prepare and on the night not only did Mike win his match and help raise awareness but he also managed to fundraise over £5132 for which we are incredibly grateful.



### Tori Bird

The Bird family have been holding a wide variety of events since Tori's passing last year, in the UK and abroad in the US, including taking part in bike rides, a whole school Swimathon and others, together raising an incredible £12,400 for the Tori Bird Fund. The family want to create a lasting legacy for Tori to fund ground breaking research and help increase awareness.



### Lauren Beckett

After Lauren passed away from the condition in the middle of last year, her father Philip and her family have held a wide variety of events to help raise awareness and fundraise for SRUK to further our mission of highlighting the importance of accurate and early diagnosis. Philip's employers BNI Norfolk donated the proceeds from their awards dinner and auction. Philip organised and hosted a Casino night, has held multiple collections and has several friends and colleagues taking part in running events this year, all in memory of Lauren and so far, raising an astonishing £22,157, with even more events to take place this year including a Masquerade Charity Strictly Ball and a work summer raffle.

We are so grateful to all our fundraisers, and we find it incredibly inspiring that those who have lost someone, then decide to arrange and host events on behalf of SRUK in one of their most difficult and painful times. Above is just a few examples of that from within our community but we are grateful and appreciative beyond words for every single one of you. of that from within our community but we are grateful and appreciative beyond words for every single one of you.

We are so thankful to all those who hold events in aid of SRUK, we wouldn't be here without you, if you have recently held an event please let us know and send us your photos to our address or you can email them to our Community and Events fundraiser Shauna at [shauna.creamer@sruk.co.uk](mailto:shauna.creamer@sruk.co.uk) or if you have any questions about how to host your own event and would like support please get in touch and feel free to call us on 02038935993.

# 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.

## Your Magazine, Your Way

Thanks to everyone who provided feedback on the last issue of the magazine. We know that not all comments have been covered in this issue but we will be working hard to cover your feedback in future issues. Your feedback is really important to us. If you have a comment or suggestion on how we can improve future issues then call our team on 020 3893 5998 or email: [info@sruk.co.uk](mailto:info@sruk.co.uk)

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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 pop it into your recycling and help us look after our planet.

[www.sruk.co.uk](http://www.sruk.co.uk)  
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