



 SCLERODERMA  
& RAYNAUD'S UK

# SRUK and Corporate Fundraising

# What is Scleroderma?

**Scleroderma is a rare condition and affects 19,000 people in the UK - which does also mean that it can take several years before it is diagnosed**

Scleroderma is an autoimmune disease which means the body's natural immune system becomes overactive and attacks healthy tissue. Scleroderma comes from the Greek 'sclero' meaning hard, and 'derma' meaning skin.

Scleroderma can affect anyone of any age, but is more common in women than men, it can cause significant physical disability and is life threatening in some cases.

Hardening of the skin can often be the first noticeable symptom of scleroderma, as the body starts to produce too much collagen. The collagen build up can affect the skin, joints, tendons and internal organs causing scarring and stopping the effected parts from functioning normally.

Scleroderma is a complex condition and each individual will experience different symptoms. Involvement of organs such as the heart, lungs and gastrointestinal system is common. People living with scleroderma often experience a significant impact on their quality of life due to their painful and often debilitating symptoms. Scleroderma has been likened to 'having your body turn to stone'.

"This disease can make you feel isolated, because it's rare people don't understand how our illness affects us. I've also had to be my own advocate searching for treatments and looking after my ulcers because, apart from the specialists, health professionals don't know enough about it"



**The first clues of scleroderma are often:**

- **Sore swollen fingers or aching joints.**
- **Raynaud's phenomenon**
- **Reflux or heartburn**

**There's currently no cure, but there are various therapies and medical treatments available. These can reduce the impact of the disease and slow its progression.**



# What is Raynaud's?

Raynaud's, also referred to as Raynaud's disease or Raynaud's Phenomenon, is a common condition where the small blood vessels in the extremities such as the fingers or toes are extremely sensitive to changes in temperature. People with Raynaud's will experience colour changes as well as numbness and pain usually in their hands or toes.

As the blood begins to flow back into affected areas after an attack, people can experience stinging or throbbing pain. Deb described it "as though someone had smashed them with a hammer!"

**Raynaud's is very common and affects 10 million people in the UK - 1 in 6 - and yet our recent research shows that more than 24 million adults don't know any of the signs of Raynaud's.**

## Common Symptoms of Raynaud's:

- Cold fingers and toes
- Colour changes in your skin in response to changes in temperature or stress
- Colour changes in the affected area from white to blue and then red
- Numbness, tingling or pain in the affected area
- Stinging or throbbing pain upon warming or stress relief

"If I'm just going shopping, walking around the supermarket, which has chilled areas, I can get a Raynaud's attack. I'll be in quite a lot of pain and then I've got to get my cards out to pay, but I can't feel anything because there's no blood in my fingertips."

Deb's fingers during a Raynaud's Attack



# About SRUK

Scleroderma & Raynaud's UK (SRUK) is the only UK Charity dedicated to improving the lives of people with scleroderma and Raynaud's. We provide support and information, we improve awareness and we fund ground breaking research to ultimately try to find a cure. Our aim is to reach out to every single person who has scleroderma and Raynaud's providing them with the information and support they need.

**Our work is informed by and developed with our community who are at the heart of everything we do.**

## We fund research

We fund innovative and ground-breaking research into scleroderma and Raynaud's, and ensure that the results are translated into real life benefits for our community as quickly as possible. Our research strategy was developed with our Community Research panel of patients, clinicians and industry experts and focusses on 4 key areas: Quality of Life, Early Detection, Precision Medicine and Understanding Causes.

## We provide support

Being there for our community whenever they need us is paramount, We do this through our helpline, local support contacts, support groups and our online forum. We also run educational events and host an annual conference to bring people together to learn and share experiences.

## We provide information

Our website and publications are accredited through the Patient Information Forum. We consult with professionals, specialists and our community to ensure that we are providing relevant, creditable, understandable and up-to-date information and that we are addressing any gaps in available information.

## We drive change

We make our voices heard with decision-makers and politicians, pushing scleroderma and Raynaud's to the top of the health and social care agenda. We work in partnership with other organisations to make certain that we are amplifying our message to be heard by those who have the power to make change.

**SRUK relies entirely on the support of our community - we do not receive any government funding so your fundraising is vital to us. Your support will help us achieve our mission to improve the lives of everyone affected by scleroderma and Raynaud's.**

# How can I support SRUK at work?

## Employee Fundraising

Take on a personal challenge or run a community/workplace event such a quiz, auction or bake sale. Our handy A-Z of fundraising ideas will help you get started!

## Charity of the Year

Does your workplace choose charity partners? These could be in your local office, region, or national. If you'd like to nominate SRUK as your workplace charity partner, see what your employer is looking for, and let us know if there is an opportunity, application or nomination that we can help you with. We'd love to hear from you.

## Challenge Events

You, your team or office could sign up for a challenge event to raise money for SRUK. Whether you want to run, trek, cycle, skydive or do your own thing, we've got something for everyone and we'll support you every step of the way. Our fundraising team can help you pick the right challenge, provide tips on sharing your sponsorship page and personal story, and we'll be there to cheer you on (either virtually or in person) when your challenge is underway. You can find our upcoming events on our website. It is worth asking if your employer will pay for the cost of your event place, or match-fund your fundraising.

## Is your fundraising eligible for match funding?

Some employers offer match funding pots for employee fundraising. This could be a couple of hundred pounds per employee, or sometimes up to £2,000. If you're currently fundraising, or planning to fundraise for SRUK, contact your company HR team or Charity Committee and ask them if they will match your fundraising/donations.

# How can I support SRUK at work?

## Sponsorship and Corporate Donations

Your marketing team, or charity committee may have a sponsorship or donation budget from the business. We run an annual conference and offer sponsorship and exhibitor opportunities, which is the perfect opportunity to reach our audience and community of people living with scleroderma & Raynaud's, researchers and healthcare professionals. Other sponsorship and project funding opportunities are available, so please ask for our latest vacancies

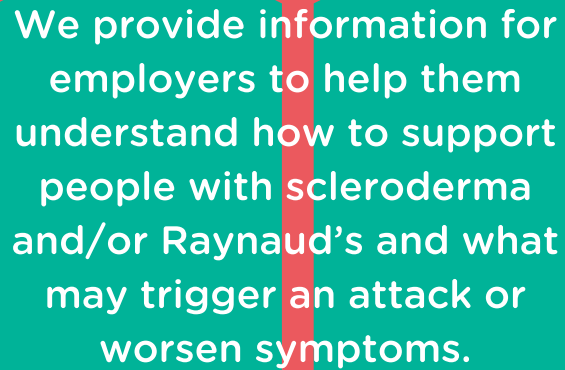
## Customer Donations

Would you like to engage your customers? Having a charity tie in at point of sale, and online can increase a customer experience and feeling of warmth towards your brand. Get in touch with us to see what would be possible, or to arrange for a collection tin to be sent out.

## Payroll Giving

Have you thought about donating to SRUK before tax gets taken out of your salary? Contact us or your HR team about payroll giving. It is a tax efficient way to make a regular, monthly or weekly donation to our work, directly from your pay; helping us to support those affected by scleroderma and Raynaud's.

# How can SRUK support you and your organisation?



We provide information for employers to help them understand how to support people with scleroderma and/or Raynaud's and what may trigger an attack or worsen symptoms.



Our ongoing programme of webinars has covered a range of topics from dealing with fatigue to help with welfare benefits.



Our support groups, helpline and information services are available to help support any of your employees that are affected by scleroderma & Raynaud's.

## DID YOU KNOW?

Opening windows or lowering the temperature of air-conditioning can make an office environment a very uncomfortable place for someone with Raynaud's.

Whilst fundraising for SRUK, you will be supported by our expert team of fundraisers who will be on hand to help make your fundraising a huge success, and provide advice, ideas and help at every stage.



**However you are able to support  
us, we are truly grateful**

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