

SRUK Strategy 2017-2022

Unite for a better world



Our story

SRUK launched on 31st March 2016 and is a new charity formed by the merger of the Raynaud's & Scleroderma Association (RSA) and the Scleroderma Society.

SRUK brings together the support, expertise and passion of the two former organisations to create a strong new organisation focused on supporting people with Scleroderma and Raynaud's. Through funding and campaigning for research into the conditions, SRUK is building better understanding and treatment for everyone affected by them.



Whilst overseas I contracted Hepatitis C and this started a chain reaction that sent my body into shutdown. It hit me like an express train. After two years I was diagnosed with Diffuse Systemic Sclerosis. As far as I was concerned my life was over, I was only 32 years old.

I lost all my mobility, and was totally reliant for others for everything; I was unable to eat, weighing just 38 kilos. I spent six months in hospital and the next three years determined to get better. SRUK has helped me so much, I no longer feel like a person with a disability with no confidence.

Hannah Harris



Thanks to SRUK's supporters, I have funding that allows me to spend some of my week looking after patients, and the rest in the lab.

The lab time is really important because it allows me to work on research projects that could eventually lead to treatments that improve my patients' lives.

Dr. Francesco Del Galdo

Our life changing work is funded by the generosity of individuals like you. Help us to increase our investment in research and support even more families by donating today.

Text SRUK10 £10 to 70070 or visit www.sruk.co.uk/donate

We are SRUK

Scleroderma and Raynaud's UK (SRUK) is the only charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's.

Vision

Our vision is a world where no-one has their life limited by Scleroderma and Raynaud's.

Mission

Our mission is to improve the lives of everyone affected by Scleroderma and Raynaud's.

We do this by investing in research, improving awareness and understanding of the conditions and providing information and support to all those affected.

Values

Our values inform how we deliver our services, the choices we make and how we work with, support and develop our staff and volunteers.

SRUK is:

Collaborative in the way we work

Driven to see real change

Trusted because we are open and honest about the way we work

Compassionate because we always put the person first

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Unite for a better world

Scleroderma is a rare, chronic auto-immune condition affecting connective tissue and blood vessels. In the UK there are around 12,000 people diagnosed with the condition. The cause is unknown, and prognosis is poor, often leading to multi-organ dysfunction and premature death. Research is urgently needed to understand the cause of the condition and to improve treatment.

1 in 6 people are affected by Raynaud's. Primary Raynaud's phenomenon is common and usually symptoms are mild and manageable. Over-sensitivity of peripheral small blood vessels to temperature change leads to characteristic attacks with blood vessel constriction, loss of blood and oxygen from the exposed tissue (fingers, toes or other extremities) followed by excessive blood vessel dilation on warming. Attacks can very be painful.

Secondary Raynaud's phenomenon, which is more serious and can lead to ulceration and calcification, is associated with the presence of an auto-immune connective tissue disease and can often be the first indication of scleroderma.

Almost all patients diagnosed with scleroderma have secondary Raynaud's phenomenon. Treatment, other than to relieve symptoms, is relatively ineffective.

We are campaigning to create a better world for people with Scleroderma and Raynaud's

- A world where there is much greater awareness and understanding of the two conditions
- A world where diagnosis happens earlier
- A world where better treatment and care is available to everyone affected



We'll beat Scleroderma and Raynaud's by funding ground breaking research and we'll continue to support and empower those living with these conditions across the UK.

A strong legacy

The Raynaud's and Scleroderma Association (RSA) and the Scleroderma Society both had a rich history of providing excellent support services to the community and investing in research to improve knowledge and understanding of these conditions. The legacy that these charities have built will stand proudly as the backbone to the new charity Scleroderma & Raynaud's UK (SRUK).

Over the last thirty years we've seen, and been part of, some remarkable developments that have led to big improvements in the quality of life of people living with Scleroderma and Raynaud's.

Our understanding of these conditions has increased dramatically through biomedical research; as has our understanding of the treatments and interventions that can positively change someone's experience of living with Scleroderma and Raynaud's.

The medical and patient community has welcomed the establishment of SRUK, as by pulling together knowledge and research, SRUK will be able to invest in vital support services and provide a focused research strategy to make further advances in effective treatment.



“I am honoured and delighted to be the President of SRUK, and look forward to a bright future for the Scleroderma and Raynaud's community.”

Dame Carol Black
President

A growing movement

SRUK overcame the technical and logistical aspects of a merge within a short 9 months and the achievements of SRUK over the past year provide us with great reassurance that the new organisation will continue to develop and deliver excellent provisions for the community.

There is still much to do, but as our understanding of Scleroderma and Raynaud's has grown, so too has the number of people who have joined our cause. We have a solid network of members and volunteers across the UK who have been involved in shaping the new organisation and our first strategy.

There are thousands more who generously and regularly donate or fundraise to help us invest in world-class research and continue to provide support and information to those who need it.



“It is this community that makes us strong. I look forward to the next phase and being a part of a new era with SRUK.”

Jeremy Pearson
Chair

Our ambition

SRUK has two goals, which drive all of its activities.

The impact of Scleroderma and Raynaud's on people's lives is minimised

A cure for Scleroderma and Raynauds is found



1. The impact of Scleroderma and Raynaud's on people's lives is minimised

While the severity of symptoms of both conditions can vary, the quality of life of all those affected is reduced to some degree. This can be through both physical symptoms and the emotional impact of social isolation. This can have an impact on confidence, work and family life.

SRUK's work is important in ensuring that these negative effects are reduced as far as possible to allow individuals with the conditions and their families to thrive even after a diagnosis.

2. A cure for Scleroderma and Raynaud's is found

All of SRUK's activities are based on the assumption that the best treatment and ultimate aim is a cure for both conditions.

For those already diagnosed and their families, this would mean an end to their symptoms and the ability to resume their previous lives as well as potentially saving their lives

For those not yet diagnosed, it would reduce the length of time over which they need to live with the symptoms and mean that a diagnosis would no longer lead to a lifelong condition.

Research into finding a successful cure may also lead to discoveries for the treatment and cure of a range of other conditions, meaning that many more lives are improved and possibly saved.

Aims

To deliver these goals we will:



Increase awareness of Scleroderma and Raynaud's with the Public and Health Professionals.



Enable more people with Scleroderma and Raynaud's to manage their conditions through access to high quality information, support and guidance.



Ensure all people with Scleroderma and Raynaud's, across the UK have access to high quality, integrated health and social care services, which are responsive to their needs, and recognise them as equal partners in their care.



Ensure that research funded by SRUK translates into better prevention, diagnosis and treatment outcomes.

Our organisation

SRUK may be a new charity, but it benefits from the combined history of nearly 60 years thanks to the formal decision to merge the RSA and Scleroderma Society in June 2015.

SRUK will build on the legacy provided by these two great organisations, continuing to support the community but also reaching out to the many more people affected by Scleroderma and Raynaud's, who may not be aware that help and support is available.

This is your organisation and we will work together to achieve our vision of a world where no-one has their life limited by Scleroderma and Raynaud's.

Our strategy

Whether you have Scleroderma or Raynaud's, or know someone with the conditions as a family member, friend, colleague or patient, you have an important part to play in beating these conditions.

None of us can do it alone. We can only do it together. And it is this collaborative, united approach that is at the heart of the SRUK's 2017-2021 strategy.

When we began to develop a new strategy to guide our plans from 2017 to 2021, we started by asking people affected by Scleroderma and Raynaud's what was important to them.

This process helped us identify two core goals, a set of outcomes that underpin our strategy, and the objectives that will help us achieve these goals, which we have shared in this document.

We need you

We'll continue to fund innovative Scleroderma and Raynaud's research, influence the development of high-quality services and support, and bring the community together locally, nationally and virtually.

You are integral to our success and what can be achieved for those living and affected by Scleroderma and Raynaud's.



“I feel very positive about the change we can achieve together, to improve the lives of everyone affected by Scleroderma and Raynaud's.”

Sue Farrington
Chief Executive



Awareness

To increase awareness of Scleroderma and Raynaud's with the Public and Health Professionals.

Why is this important?

Even though 1 in 6 people in the UK have Raynaud's and a further 12,000 people Scleroderma, there is a serious lack of awareness of both conditions. Despite being as common as hay fever and arthritis in the UK, over three quarters of people have never heard of Raynaud's or Scleroderma and don't know anything about the symptoms.

Research commissioned by Scleroderma and Raynaud's UK (SRUK), found that 67% of people believe Raynaud's affects only one person in 5,000 or even less, when the actual figure is one in six, and just 4% can confidently identify the symptoms of Raynaud's, falling to 1% for Scleroderma.

33% of people with Raynaud's and Scleroderma said that the biggest challenge they have faced with their diagnosis is explaining their condition.

The consequence of this low awareness means many people either go undiagnosed or it takes too long and so access to treatment and care has been far too slow.

It also means that many of those people who are affected find it very difficult to talk to others about their condition and as many of the symptoms are invisible there is often the fear that they will not be believed.

What we will do:

Develop and deliver a series of public awareness campaigns

Develop a network of advocates and ambassadors to share information about the conditions with those affected, the healthcare community and the general public

Work with the media to improve coverage and reporting of Scleroderma and Raynaud's

Work with health professional bodies and organisations to increase awareness of these conditions

What this means for people with Scleroderma and Raynaud's:

- There is better media coverage of the conditions
- The public has greater awareness about Scleroderma and Raynaud's
- There is reduced stigma around Scleroderma and Raynaud's
- People affected by Scleroderma and Raynaud's have more confidence to talk about the condition and are better informed about their condition

"I have suspected I may have developed Raynaud's for some months now and thought I would let you know I heard about you from reading an article in The Weekly News. Thanks to your online test I am now convinced I have it and need to see my GP, thank you."

Diane,
Living with undiagnosed Raynaud's



“I had a miserable time breastfeeding my first baby, with no doctor, midwife or breastfeeding counsellor able to tell me why I was in so much pain. If they or I had known that Raynaud’s could be a factor in this my daughter and I would have been much happier in that first year.

When it came to writing about this for a national newspaper, SRUK understood completely, providing support and information. SRUK are working tirelessly to raise awareness and increase understanding to get this condition taken seriously.”

Emma Bartley
Journalist



Empowerment

Enable more people with Scleroderma and Raynaud's to manage their conditions through access to high quality information, support and guidance.

Why is this important?

Nearly 70% of people with Scleroderma and Raynaud's say that their biggest daily challenge is managing symptoms, closely followed by managing the condition as a whole.

Scleroderma and Raynaud's can affect a person's ability to be independent and to lead a full and active work and family life. Sometimes the simplest of daily activities, such as doing up buttons or opening objects, become difficult.

Scleroderma and Raynaud's affects the lives of many working people, who either retire early, give up work or reduce the number of hours they work because of their condition. This has an impact on their independence, self-esteem and on household incomes.

What we will do

Produce a wide range of information on the conditions and what people can do to self-manage their condition

Share information and guidance for people with Scleroderma and Raynaud's on their rights and entitlements

Support and develop active social media networks for those affected by the conditions

Connect and support people with Scleroderma and Raynaud's through a range of appropriate mechanisms

Provide a helpline, manned by volunteers, providing information and advice for those affected as well as signposting them on to more specialist support where needed

Mobilise people with Scleroderma and Raynaud's to become agents for change

What this means for people with Scleroderma and Raynaud's

- They do not feel alone
- Have more contact with others who understand the conditions
- Are more resilient and able to cope
- Have better knowledge of their rights and entitlements
- Know what they can do and use to help with the condition
- Can access the practical support they need
- Can manage their condition better

“Clinically accurate, high quality and accessible information is an imperative resource for patients in order for them to feel well informed, empowered and in control of their condition. It also provides important sign posting information and helps patients navigate their way through the healthcare system.”

Louise Parker

Lead Nurse, Inflammatory & Connective Tissue Disease, Royal Free Hospital, London



“I would like to say a big thank you to Scleroderma & Raynaud’s UK as without the work they do I would not have had the knowledge to pursue a diagnosis and get the treatment needed for our daughter.

Eliza is now receiving specialist treatment for her morphea and is doing well.”

Alison
Eliza’s mum



Healthcare

Ensure all people with Scleroderma and Raynaud's, across the UK have access to high quality, integrated health and social care services, which are responsive to their needs, and recognise them as equal partners in their care.

Why is this important?

It is essential that people with Scleroderma and Raynaud's have timely access to relevant professionals, who are informed about the conditions and the options available.

While there is no cure, early access to treatment can slow the progression of the disease. The scarring which results from scleroderma is irreversible unlike in Rheumatoid Arthritis, making the importance of early diagnosis critical.

The multisystem nature of Scleroderma often requires simultaneous care across several specialties. This can often result in fragmented care, with poor communication and delayed decision making leading to patients feeling 'lost' in the system.

We want to ensure that everyone with Scleroderma and Raynaud's, wherever they live and whatever their circumstances, gets the responsive and person-centred support they need.

What we will do

Work more closely with the NHS and healthcare professionals to ensure more and better information is available at the point of diagnosis; ensuring SRUK is there from diagnosis onwards

Work in collaboration to ensure the voice of those with Scleroderma and Raynaud's is represented in relation to any changes or reforms across the health, social care and welfare system

Ensure more people living with Scleroderma and Raynaud's have access to and directly benefit from a wider range of effective self-management support services

Work in collaboration to develop national audits for rare auto-immune conditions to drive local service improvement through monitoring, involving people with Scleroderma and severe Raynaud's

What this means for people with Scleroderma and Raynaud's

- Healthcare Professionals have greater understanding about Scleroderma and Raynaud's
- Healthcare Professionals give better advice to people with Scleroderma and Raynaud's
- GPs refer people with symptoms to the appropriate specialist
- People with Scleroderma and Raynaud's are diagnosed quicker
- People with Scleroderma and Raynaud's are treated sooner
- There is improved access to the best treatments

“Empowering clinicians and patients with greater knowledge is vitally important in order to tackle fundamental issues, including delays in diagnosis, coordination of care and access to effective treatment.”

James Carver,
Member of European Parliament



“My scleroderma wasn’t diagnosed for nearly 10 years, even though I had Raynaud’s, tight skin and reflux. In the end, it was my severe breathing difficulties that flagged it up.

Due to late diagnosis the extent of my disability is huge because my lungs, skin, heart, kidneys and gastrointestinal tract are all affected. Because of this I am very breathless and tired so it is difficult for me to do anything.

My condition is so severe now that a lot of the new treatments aren’t able to help me. I believe if I were diagnosed sooner my condition would have been treatable.”

Grace



Research

Ensure that research funded by SRUK translates into better prevention, diagnosis and treatment outcomes.

Why is this important?

Finding a cure remains a high priority for members, but of equal importance is access to effective, less toxic treatments. While there are more treatments available for Scleroderma and secondary Raynaud's than there were fifteen years ago, there is still a huge unmet need for patients.

To date, the RSA, Scleroderma Society and SRUK have invested over £10 million on research being carried out into Raynaud's phenomenon and Scleroderma in the UK. Research we've funded has led to breakthroughs in our understanding of Raynaud's and Scleroderma, leading to earlier diagnosis, better monitoring and the identification of various biological processes.

But there is still huge untapped potential. In the last years, new technologies such as innovative diagnostics or breakthroughs in our understanding of molecular biology, have emerged. More collaboration within and outside the research community and with patients will be vital to bring new insights to drive forward our ambition to bring new effective treatments to market.

What we will do

Develop a research strategy to ensure the most effective use of the charity's limited resources

Measure, report and demonstrate the impact of the research we fund across the UK

Identify and invest in a new generation of Scleroderma and Raynaud's researchers

Provide specific grant funding to stimulate innovation in Scleroderma and Raynaud's science

Seek partnerships and collaborations to increase the amount of money made available for Scleroderma and Raynaud's research across the UK

Develop a team of research volunteers to ensure only the most relevant research for people with Scleroderma and Raynaud's is funded and delivered

What this means for people with Scleroderma and Raynaud's

- Promising teams are attracted to Scleroderma and Raynaud's research
- Existing funds are invested more effectively
- More money is invested into Scleroderma and Raynaud's research
- There is better understanding of the causes and mechanisms underlying Scleroderma and Raynaud's
- New and more effective treatments are developed for Scleroderma and Raynaud's
- New ways of preventing and curing Scleroderma and Raynaud's are developed

“This condition needs a cure to eliminate the severe chronic pain and suffering. Through SRUK's research programme, I know that better treatments and a cure will be discovered”

Hilda,
Community Member



“Funding from SRUK has enabled me to run a pilot project identifying heart involvement in scleroderma patients, who are showing no signs of heart involvement clinically.

The ELCASA study has provided life saving treatments to two patients. The results will be used to secure support for a larger study, so we can introduce these improved methods of monitoring to real-world practice, improve patient outcomes and reduce sudden death.”

Prof. Maya Buch

Deputy Director of the Leeds Institute of Rheumatic & Musculoskeletal Medicine

Delivering our strategy

To deliver our strategy we will grow our income.

Why is this important?

All of our work to increase awareness, empower patients, improve healthcare and expand our research programme depends entirely on the generosity of our supporters, and the efforts of our volunteers and staff.

We believe research holds the key to a future in which no-one's life is limited by Scleroderma and Raynaud's. That's why we need to raise more money and increase our investment into pioneering and innovative research.

In the here and now, we need to do even more to support everyone affected by these conditions and to minimise the impact on daily lives to allow individuals with the conditions and their families, to thrive even after a diagnosis.

We aim to generate an annual income of £1 million

By Implementing our three year fundraising strategy to protect, grow and diversify income

Increasing community and event fundraising opportunities, enabling supporters to participate in events across the UK and fundraise locally

Strengthening company involvement by showcasing collaboration and corporate fundraising opportunities

Becoming a charity of choice for funders focusing on the charity's key areas

Adhering to processes and measures so our activities deliver against objectives and ensure our activities conform to the highest standard of regulation

“I decided to leave a gift to the charity when I realised that research projects sponsored by the charity were carefully monitored and reported to the community.

By leaving a gift I know that my money will go towards continued research and support for individuals diagnosed with Scleroderma and Raynaud's.”

Lorna

Legacy Pledger

“At Policyfast we understand our corporate responsibility and our Watnall office chose a charity close to our heart for Charity of the Year: Scleroderma and Raynaud's UK. Scleroderma is a condition one of our staff members has and we're more than proud to support SRUK's superb work.”

Brian

Office Manager, Policyfast

We cannot do this alone. Please help us get a step further to achieving our goals, by making a donation, leaving a gift in your Will, taking part in an event or getting your company to support us.



“My dad, who passed away in 2014, had scleroderma and I want to help the charity so other families can get help and advice when needed. I would also like to believe a cure could one day be found and helping fund SRUK research will help that happen sooner.”

Ian
Event Fundraiser

Delivering our strategy

To deliver our strategy we will work with you.

Why is this important

Everything we do will be informed by the needs and views of patients and key stakeholders, and we will use the strength of these insights to influence decision-makers.

By actively engaging patients, supporters, volunteers, clinicians and research professionals in our work, we will ensure that the services we provide are fit for purpose.

What we will do

We will attract and retain high quality staff and volunteers who share our values and believe passionately in our vision.

We will build on your insights to campaign for better services and public health policies in England, Northern Ireland, Scotland and Wales.

“Over the years I myself rang the helpline for information which I found very useful. While I learned more about the condition, I also learned to better self-manage.

I thought I could pass my knowledge on to others so I volunteered to join the helpline. All calls are different and I find it satisfying to help others, allay fears and most of all listen to the person on the end of the phone.”

Paula

Helpline Volunteer

“Being asked to be part of the community research panel means a huge deal to me, as someone suffering from Scleroderma and Raynaud’s. I’m excited to see where research can lead and help guide research funding in the most efficient and successful way possible through SRUK.”

Georgina

Research Panel Member

**To make a donation text SRUK10 £10 to 70070
or to take part in an event visit www.sruk.co.uk/events**

**Together we can improve the lives of everyone affected by
Scleroderma and Raynaud’s.**

“I was diagnosed with Diffuse Systemic Scleroderma with lung fibrosis on 29th June 2012. Yes, World Scleroderma Day! Within a few weeks I found myself in intensive care having a renal crisis and kidney failure. SRUK’s information was really informative and so when I got better I wanted to give back.

I am now a local support contact for SRUK, which gives me an opportunity to spread awareness of the condition and some of its related challenges. I have met so many new friends it’s lovely!”

Diane
Support Volunteer



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