



**TRUSTEE - TREASURER**

**CANDIDATE INFORMATION PACK**

# Letter from our Chair

## APPOINTMENT OF TREASURER

Thank you for your interest in becoming a Trustee for Scleroderma & Raynaud's UK. We are looking to recruit a new Treasurer to join the Board with the skills, knowledge and experience to support the Chief Executive and the senior management team in delivering a bold and ambitious strategy and to provide appropriate oversight of the governance of SRUK.

The current Treasurer will be stepping down later this year at the end of their term and the Charity is looking to have a successor in place as soon as possible to ensure there is an orderly handover of responsibilities. The Treasurer will play a vital role in helping the Charity deliver its ambitions and plans for growth.

In addition to the key requirements of the trustee role, we are seeking to attract candidates who have financial qualifications and financial experience in any sector, preferably including exposure to charity finance and the Charities SORP.

Successful candidates will be able to demonstrate a strong commitment to SRUK's mission and values and an understanding of the opportunities and challenges we face.

SRUK has a clear ambition to achieve transformation and growth in terms of accelerating benefits to patients through research and support. As a new charity, building on strong long-term foundations laid by the two separate charities, we believe there is an opportunity for us to adapt to the current climate and become more entrepreneurial and commercial, particularly in relation to research. We want to invest in opportunities that will accelerate the progress from bench to bedside for the benefit of patients rather than be a passive funder of research.

SRUK recognises the importance of diversity and is seeking to attract the best talent and experience. SRUK is committed to increasing diversity across its Board. We encourage applications from all backgrounds.

Despite the current and ongoing challenges from Covid-19, our financial position remains strong, and we are very ambitious to drive change and play our role in accelerating tangible benefits for patients. I believe this is very exciting time to join this young but dynamic organisation and play a role in taking us to the next level.

**Professor Jeremy Pearson**  
**Chair, SRUK Trustees**

# 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.

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 built has provided a strong foundation for SRUK.

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

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.

As a new charity we believe there is an opportunity for us do things differently and to be more entrepreneurial and commercial, particularly in relation to research.

## To achieve this, we will:

- Invest in opportunities to accelerate benefits for patients
- Work in collaboration to leverage funding and expertise from industry, academia, health sector and other agencies
- Seek to develop new and alternative income streams

# 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

# Unite for a better world

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**

## The Conditions

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.

# Our ambition

We are the only charity in the UK supporting people with Scleroderma & Raynaud's. We currently support twenty-two thousand people in Britain, but our aim is to reach out to every single person who has a scleroderma or Raynaud's diagnosis, providing them with the information and support they need. We are here to improve awareness and understanding of these conditions, to support those affected, and ultimately, to find a cure.

As part of setting up the new organisation, we conducted market research with our community to fully understand the challenges they face and what outcomes they want SRUK to achieve.

The key challenges identified were:

- Lack of awareness
- Poor time to diagnosis
- Lack of effective treatments

SRUK has two goals, which drive all its activities.

## 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 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.**

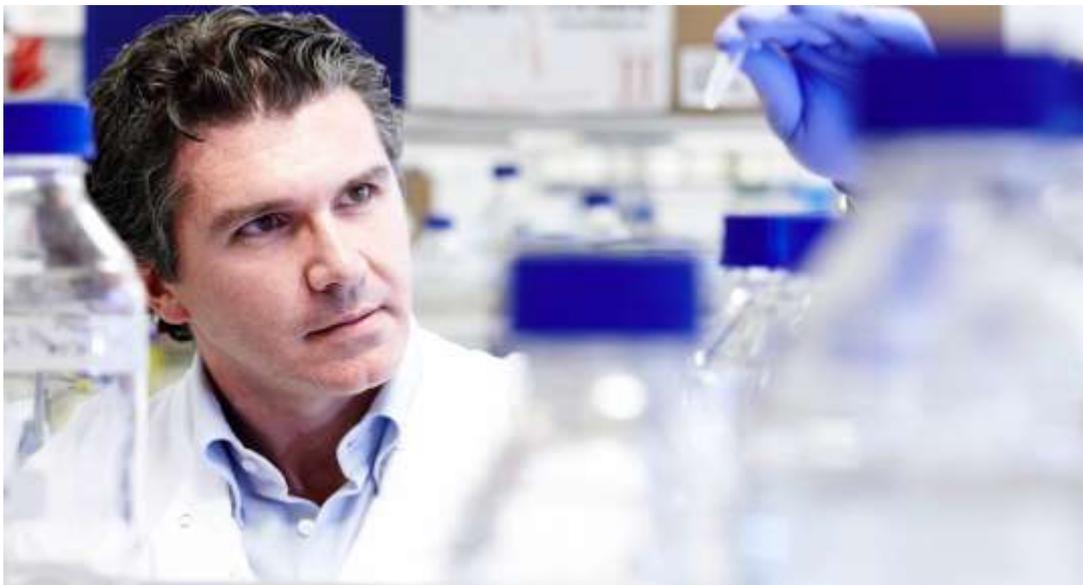
**For those not yet diagnosed, it would reduce the length of time over which they need to live with the symptoms and mean that a diagnosis would no longer lead to a lifelong condition.**

**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.**

# Our 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.



# Role description

## Location

London

## Time Commitment

Quarterly Board meetings held during the day. You may also be required to participate in occasional conference calls for a maximum of one and a half hours.

## Remuneration

Unpaid, expenses covered in line with policy

## Summary of Role

The Board of Trustees is responsible for providing appropriate oversight, governance and leadership to the charity in the pursuit of its strategies to fulfil its charitable purposes.

## Overall role of a treasurer is to:

- Maintain an overview of the Charity's affairs.
- Monitor and report on the financial health of the Charity.
- Ensure that proper financial records and procedures are maintained.

## General responsibilities:

- Ensure the Charity complies with its governing document, charity law, company law and any other relevant legislation or regulations.
- Ensure the Charity pursues its objects as defined in its governing document.
- Ensure the Charity applies its resources exclusively in pursuance of its objects.
- Contribute actively to the board of trustees' role in giving firm strategic direction to the Charity, setting overall policy, defining goals and setting targets and evaluating performance against agreed targets.
- Safeguard the good name and values of the Charity.
- Ensure the effective and efficient administration of the Charity.
- Ensure the financial stability of the Charity.
- Protect and manage the property of the Charity and ensure the proper investment of the Charity's funds.
- Use any specific skills, knowledge or experience they have to help the board of trustees reach sound decisions.

### Additional duties of the Treasurer:

- Oversee, approve and present budgets, management accounts and financial statements.
- Be assured that the financial resources of the Charity meet its present and future needs.
- Monitoring of cash flow.
- Ensure the charity has appropriate reserves policies.
- Support the preparation and presentation of financial reports to the board.
- Ensure appropriate accounting procedures and controls are in place and in compliance with the Charities SORP.
- Liaise with staff about financial matters.
- Advise on the financial implications of the Charity's strategic plans.
- Ensure the charity has an appropriate investment policy.
- Ensure there is no conflict between any investment held and the aims and objects of the Charity.
- Monitor the Charity's investment activity and ensuring its consistency with the Charity's policies and legal responsibilities.
- Ensure the Charity's compliance with legislation.
- Ensure equipment and assets are adequately maintained and insured.
- Ensure the financial accounts are prepared and disclosed in the form required by funders and the relevant statutory bodies, e.g. the Charity Commission and/or the Registrar of Companies.
- Lead on the appointment of the auditor/independent examiner and ensure that the accounts are scrutinised in the manner required (independent examination or audit) and any recommendations are implemented.
- Keep the board informed about its financial duties and responsibilities.
- Contribute to the fundraising strategy of the Charity.

# Person specification

All Trustees will have a strong track record at a senior leadership level and must be able to demonstrate:

## General

- Commitment to the mission of the Charity.
- Willingness to devote the necessary time and effort and champion the Charity's cause.
- Strategic vision.
- Confident leadership style.
- Good, independent judgement.
- Ability to think creatively.
- Excellent communications and listening skills.
- Willingness to speak their mind.
- Commercial financial acumen.
- Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship.
- Ability to work effectively as a member of a team.
- Ability to analyse proposals and examine their financial consequences.
- Preparedness to make recommendations to the board even if at times they are unpopular.
- Risk management experience.
- Willingness to be available to staff for advice and enquiries on an ad hoc basis.

## Specific

- Financial qualifications and financial experience in any sector, preferably including exposure to charity finance and the Charities SORP.

# How to apply

Please email a CV and cover letter indicating why you are interested in applying for the role and how you meet the role requirements to Marlijn Wijkhuizen at [marlijn@ep-uk.org](mailto:marlijn@ep-uk.org)

The **application deadline** is Thursday 27<sup>th</sup> of May 2021

**Interviews** will take place in the week commencing 14<sup>th</sup> June 2021

We will contact all applicants to confirm whether their application has been successful.

If you would like a call to discuss the role in more detail with the CE, please email to arrange a convenient time.

Shortlisted candidates will be asked to provide two referees.