



PATIENT/CARER TRUSTEE

CANDIDATE INFORMATION PACK

LETTER FROM OUR CHAIR

APPOINTMENT OF PATIENT/CARER TRUSTEE

Thank you for your interest in becoming a Trustee for Scleroderma & Raynaud's UK. We are looking to recruit a new Patient Trustee 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.

In addition to the key requirements of the trustee role, we are looking for a patient with Scleroderma and/or Raynaud's or a carer for someone with these conditions. Previous Board experience or experience of representing the patient voice either within a healthcare or research setting is desirable. However, for this trustee role, it is essential that you are able to provide insight from a broad perspective not solely based on your own experience.

SRUK is committed to ensuring that patient voices are at the centre of our organisation, helping to shape our strategy, services and research programme. 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.

This is an exciting time to join the charity as we prepare to deliver on our five-year plan and budget, with 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:

- o Lack of awareness
- o Poor time to diagnosis
- o 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

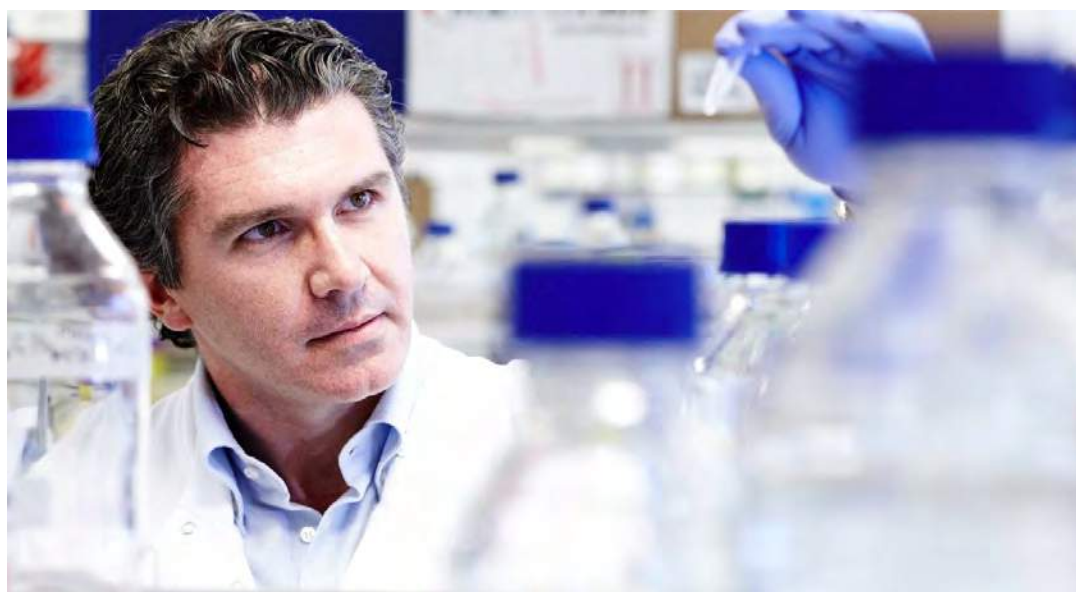
For those not yet diagnosed, it would reduce the length of time over which they need to live with the symptoms and mean that a diagnosis would no longer lead to a lifelong condition.

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. Board tenure of 3 years, with optional second term of 3 years.
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.

General responsibilities:

- Ensure the organisation complies with its governing document, charity law, company law and any other relevant legislation or regulations.
- Ensure the organisation pursues its objects as defined in its governing document.
- Ensure the organisation applies its resources exclusively in pursuance of its objects.
- Contribute actively to the board of trustees' role in giving firm strategic direction to the organisation, setting overall policy, defining goals and setting targets and evaluating performance against agreed targets.
- Safeguard the good name and values of the organisation.
- Ensure the effective and efficient administration of the organisation.
- Ensure the financial stability of the organisation.
- 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 to help the board of trustees reach sound decisions.

Person Specification

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

General

- Willingness to devote the necessary time and effort
- Strategic vision
- Good, independent judgement
- Ability to think creatively
- Willingness to speak their mind
- Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship
- Ability to work effectively as a member of a team
- Long term commitment to the organisation

Specific

- Experience of working at a senior management / leadership level.
- Ability to work as part of a team and willingness to take collective responsibility for the governance of the charity.
- Ability to work at a strategic and visionary level whilst understanding the detail and complexities of delivery, and the influencing skills needed to bring stakeholders along with plans.
- Strong communicator.
- Ability to analyse risks and opportunities and take a balanced approach to both.
- Extensive networks, and a willingness to draw on contacts as appropriate.

Patient/Carer Trustee

We are looking for a patient with Scleroderma and/or Raynaud's or who is a carer for someone with these conditions. It is important that you have previous experience of representing the patient voice either within a healthcare or research setting. You must be able to provide insight from a broad perspective not solely based on your own experience

In addition to the general Trustee requirements, the overall role of a Patient Trustee is to:

- Ensure patients' experiences are considered in decision-making.
- Support the Board and team in understanding real life experiences of patients and carers.
- Champion the diversity of patient views, and not just represent your own experience.

Based on previous experience you must be able to demonstrate the skills to:

- Constructively challenge, influence and support the Board to develop strategies with maximum impact for patients.
- Bring independent judgement and experience from a patient perspective.
- Work in a committee setting and be prepared to contribute actively to the discussions.
- Understand and evaluate a range of information and evidence.

HOW TO APPLY

Application closing date: end-of-day 22nd of January 2021. 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 Eastside Primetimers marlijn@ep-uk.org