

SRUK NEWS

**Sara's journey
to acceptance
of a lifelong
diagnosis.**

**Scleroderma
Discriminates
by Gender
AND Race**

**Meet the
Scientists**

Insight into the lives of
researchers you help fund.

**7 handy
hints for
Keeping warm
this winter**

**Raynaud's
Awareness
Month 2019**

Event Calendar 2019

FEBRUARY

Raynaud's Awareness Month

1st February - SRUK Cosy up with a Coffee

6th February - Canary Wharf Station Collection

MARCH

24th March - London Landmarks Half Marathon

TBC - SRUK Information Stand, RNHRD, Bath

APRIL

8th April - Asics Manchester Marathon

28th April - Virgin Money London Marathon

MAY

TBC - SRUK Information Stand, QEUH, Glasgow

4th May - Isle of Wight Challenge

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

TBC - SRUK Information Stand, Royal Free Hospital London

29th June - Cotswold Way Trek

JULY

13th July - Race to the Stones

AUGUST

31st August - South Coast Trek

TBC - SRUK Information Stand, Alder Hey Children's Hospital, Liverpool

SEPTEMBER

7th September - Thames Bridge Trek

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 or **020 3893 5998**

Dear Supporters

Welcome to our January edition of the SRUK magazine and may I wish you all the very best for the year ahead.

It's Raynaud's Awareness Month, and you can help encourage others to #knowraynaud's and take The Test online if they might be affected. The Test will help them better understand their symptoms, get advice on how to avoid painful episodes, and be alert to changes that may indicate more serious illnesses.

Almost half of people have heard of Raynaud's, but very few can name the symptoms (just 5% in a recent survey). Please see page 12 to get involved by holding a Cosy Up coffee event or order your free action pack to raise awareness in your community.

As part of our drive to increase investment in research, I'm really pleased to announce that SRUK has been selected as the Longevity Forum's Science Partner for 2019. We were invited to pitch, to a room of scientists, on how working with Insilico Medicine, could transform our work. Insilico Medicine are a US based company applying artificial intelligence to drug discovery, biomarker development, and ageing research.

The partnership is worth around £250k and provides us with pro bono support to work with Insilico for a year. At the end of this work, we hope to have identified new drug compounds that could be taken forward into clinical trials to tackle Scleroderma more effectively, in all of its various forms.

We were also successful in our bid to the Microsoft Tech for Good program, which has paired us up with experts in 'big data' to explore how we can capture even more data from a SRUK funded study led by Dr Francesco del Galdo in Leeds. This study will follow people with secondary Raynaud's who are at risk of developing scleroderma to determine the early symptoms of the condition, as well as provide treatment.

Our partnership with the 'big data' experts means that we can explore the possibility of providing each study participant with trackers to collect real time data, such as heart rate and body temperature. We hope that by collecting as much data as possible, we can make significant progress in understanding how a person develops scleroderma and with that, be able to accelerate work towards finding a cure.

None of what we do would be possible without your generous donations and amazing fundraising efforts. If you fancy setting yourself a challenge in the New Year, we have full, half and mini marathons around the country, and various walking events, including our own Step Out for SRUK in June.

If you'd like to organise your own event, please do get in touch with the fundraising team and let us know how we can support you.

Very best wishes

Sue

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Doc Spot

Your questions answered by our medical professional, Prof. Denton

approaches. A large number of these have been reported helpful including antioxidant vitamins (e.g. Vit E, Vit C), fish oils, ginger, Gingko biloba and others. We always provide information about these approaches to patients with Raynaud's who are interested but responses can be variable and it may be worthwhile trying several different strategies before deciding what is best for an individual patient.

I have received a letter from my GP advising me to have the influenza vaccination due to my age (65). I have Raynaud's and Scleroderma, will this vaccine affect any of my medication or lead to side effects due to my conditions?

In general, if you have any chronic disease that could affect the lungs or are taking medication that reduces immune activity you should definitely have the influenza vaccination, as you will be more prone to this illness and to its complications. There is no evidence that vaccination worsens established scleroderma.

Are there any "alternative medications" that I can look into to treat my Raynaud's?

Raynaud's phenomenon occurs when blood vessels in the fingers and other extremities close down excessively in response to cold or emotional stress. In addition to "lifestyle" approaches such as stopping smoking, wearing multiple layers to maintain core temperature and the various gloves and other accessories available it can be useful to take medications to reduce the tendency to blood vessel spasm. This includes prescription drugs such as nifedipine, losartan and others. However many sufferers also benefit from vitamins and supplements (sometimes called pharmaco-nutrients). These might be considered "alternative" therapies but I prefer to see them as "complementary" to other

I have CREST and have recently started getting incredibly painful toes at night, which wakes me up. Is this normal? And do you know why?

There are many reasons to have pain in the toes in scleroderma. It can relate to altered circulation, arthritis or digital ulcers. CREST is a medical term that describes some patients with the limited form of systemic sclerosis. It is helpful as a shorthand name that describes some of the key features of the condition - calcinosis (chalky lumps under the skin), Raynaud's, oesophageal reflux, sclerodactyly (thickened skin on the fingers) and telangiectasia (red spots on the skin - especially hands and face).

CREST patients may develop other complications such as lung disease and also not all patients with scleroderma have the features of CREST and so in the UK it is a term that is falling out of favour. However, limited scleroderma can cause pain in many ways including ulcers, poor circulation and arthritis. It is important to look for these symptoms so that they can be treated. Occasionally patients develop pain due to nerve irritation in the feet and legs and this may respond to specific treatments for nerve pain.

Finally, some patients with Raynaud's also develop pain and burning discomfort after a Raynaud's attack that can be especially difficult at night - this condition is termed Erythromelalgia and can occur as a condition in its own right in some cases, without Raynaud's.

Is there any connection between Raynauds and Vascular Dementia? Both run in my family and I have Raynauds quite badly - no sign of dementia yet but I'm reaching that age fast!

There is no known association between Raynaud's or scleroderma and dementia. There have been some reports suggesting that in scleroderma that transient episodes of reduced brain blood flow might occur.

This is like the suggestion for organs such as the lungs and kidneys and whilst it is attractive to consider that spasm of multiple blood vessels might occur in Raynaud's formal research studies have not confirmed this.

There is a link between Raynaud's and migraines that can cause temporary visual or neurological deficit, but this is not associated with dementia. It is still uncertain whether scleroderma is associated with increased disease of large blood vessels, unlike other rheumatic disease such as systemic lupus erythematosus (SLE) where that is well established.

So, you can be reassured that there is no evidence for the link that you suggest in this question

I have recently lost my voice and antibiotics are not helping. Is my loss of voice linked to my scleroderma?

Systemic sclerosis (scleroderma) can affect the voice in a number of ways. Firstly, as with other related conditions such as Sjogrens syndrome there can be a reduction in the amount or quality of secretions in the throat and larynx (voice box) that normally lubricate the vocal cords. This can cause hoarseness. Secondly, the cords sometimes become inflamed or scarred and when ENT doctors examine them they are reported to be thickened. This can also affect the voice.

Thirdly, there is tendency to get irritation and damage to the vocal cords from infection or reflux symptoms. In scleroderma there is more tendency to develop infections and for them to be more prolonged. Finally, there is occasionally weakness of the nerves and muscles in the throat that could be relevant. In summary, scleroderma can affect the voice in several possible ways, although total loss of voice would be very uncommon. It is important to have an assessment by an ENT specialist and to remember that not everything medical that occurs is due directly to the scleroderma so it is important to have the proper assessments and discuss any concerns with your doctors.



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



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



[/WeAreSRUK](https://www.facebook.com/wearesruk)

Beating Scleroderma and Raynaud's with AI: Microsoft and SRUK team up to advance research

Microsoft and Tech Trust have awarded SRUK a grant to pursue our ongoing project with one of Microsoft's leading AI partners as part of their 'AI for Good' programme. This will contribute towards the collection of lifestyle data, which will be used as part of a research project we fund studying a cohort of 400 patients with secondary Raynaud's syndrome.

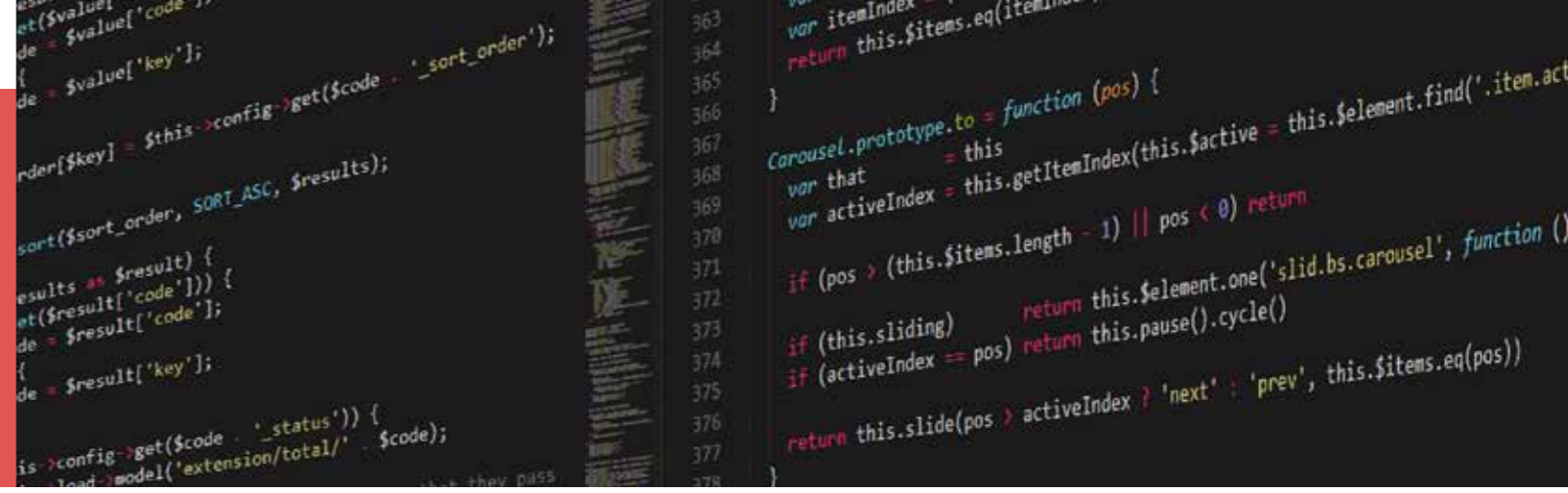
This fantastic achievement means that we will receive expert guidance to support our vital research into Scleroderma and Raynaud's. Through this partnership our research will be driven another step forward and sets a precedent for many more projects to come.

AI technology is an essential tool for resolving healthcare issues and enabling a better quality of life, treatment and diagnosis for people suffering from rare medical conditions such as scleroderma and Raynaud's.

We hope to eventually share our findings with the wider rare disease community as a means of providing guidance to other organisations in the field, and build a better understanding of the potential uses of AI tools in the sector.



Data, like thermal images, are crucial to better understand Raynaud's'



As an example of a project by a medical research charity that has been part of the AI for Good programme previously, Cystic Fibrosis Trust's 'Cracking the cystic fibrosis code' project, recently partnered with the Alan Turing Institute (the national institute for data science and artificial intelligence) to use advanced machine learning techniques on UK Cystic Fibrosis Registry data taken from 99% of people diagnosed. From AI analysis of this data, they were able to better spot patterns in behaviour, symptoms and treatment effects.

Along a similar vein, SRUK will utilise our involvement with the programme to develop systems to capture and analyse large datasets to support our research projects - an incredibly exciting development in our search to find effective treatments for scleroderma and Raynaud's and a further step in the direction of eventually finding a cure.



Speaking at the launch event held by Tech Trust, Eve Joseph, UK Responsibility Manager and Tech4Good Lead at Microsoft said:

"This AI4Good partnership with the Tech Trust is looking to uncover sparks of ideas - ideas which our talented AI partners can share their expertise on and help grow. Technology can only truly change people's lives when they have access to the capabilities and benefits it provides - this pilot is aiming to bring these capabilities to our charity sector and hopefully make this rather daunting prospect a little more real."

She added: "I cannot wait to uncover the relevance and impact AI can have within the sector. It would be wonderful to find ideas such as the Children's Society using live translation to overcome language barriers within their work."

Gaining support for our research from corporate sponsors like Microsoft is vital to our mission of reducing the impact of Scleroderma and Raynaud's on people's lives. We're extremely happy to be able to share this news and hope you are as excited about the future of the research as we are.

Mutant NOS1: A new diagnostic marker of Raynaud's Phenomenon?

Raynaud's phenomenon (RP) is characterised by the sudden constriction of arteries, normally in the fingers but also affecting the toes, alongside a variety of skin colour changes, such as white, blue, purple and red. As many as 10 million people in the UK are thought to be affected by this condition, making it as common as hay fever, however there is limited knowledge of it in both the general population and in the medical field. This means that further research into diagnosis and treatment is crucial for improving many of the population's quality of life.

The degree of constriction experienced by arteries and arterioles relative to their most dilated state is referred to as vascular tone and is maintained by the balance between vasoconstrictors and vasodilators within the blood vessel walls. Vasoconstrictors narrow the blood vessels, decreasing the blood flow, whilst vasodilators widen the blood vessels, increasing the blood flow. In response to the cold, blood vessels will be narrowed. As vascular tone is a critical feature of RP, there has been scientific interest in observing whether genetic variation is causing a shift in the balance between vasoconstrictors and vasodilators in favour of excessive vasoconstriction, thus leading to RP symptoms.

A team led by Sabrina Munir at King's College London examined the effect of single nucleotide polymorphisms (SNPs) in genes which encode temperature-responsive ion channels, vasodilators and vasoconstrictors. An SNP represents the change of a single DNA building block in our genetic blueprint, which could lead to mutations in the gene. The subjects of the study were twins enrolled in the NIHR BRC BioResource TwinsUK adult twin registry.

One SNP in the NOS1 gene was determined as being significantly associated with RP. Furthermore, this variant is present in relevant tissues to RP, such as the skin and the mucosa of the oesophagus. In a healthy body, NOS1 encodes neuronal nitric oxide synthase (nNOS), which is required to produce nitric oxide (NO). NO is a vasodilator and is responsible for mediating vasodilation following exposure to the cold. When NOS1 is mutated, NO is not produced, and so blood vessels remain constricted, leading to limited blood flow and RP symptoms.



There are several potentially useful implications of this result. RP can be difficult to detect in patients, and so the presence of this SNP may be indicative of the presence of the disease or act as a measure of how likely the individual is to develop the disease. Furthermore, this variant may represent a novel therapeutic target, with one possible strategy being to administer NO as a drug to compensate for the lack of it. Research is currently being conducted at the University of Dundee and the University of St Andrews into NO donor drugs to assess their efficacy as vasodilators.

The role of behaviour change interventions in the management of Raynaud's

Raynaud's phenomenon, the excessive constriction of blood vessels due to cold exposure and emotional stress, can have a dramatic effect on the quality of a person's life. This is due to attacks resulting in pain and a burning or tingling sensation, which may cause loss of function and distress. It is a fairly common condition, affecting approximately 5% of the population, and is associated with characteristic colour changes in the fingers and toes. Vasodilator medications, which function to open up blood vessels in order to restore blood flow into the hands and feet, can have adverse effects, therefore much attention is given to self-management measures.

Although self-management measures are almost always included in medical recommendations for Raynaud's, the advice does not extend beyond avoiding cold exposure, limiting heat loss, stopping smoking, increasing exercise and reducing stress levels. Behavioural and lifestyle changes such as these are difficult to implement successfully, with between 30-50% of patients showing poor adherence to these recommendations. This is perhaps because there has been limited research on the efficacy and adoption of lifestyle interventions. There is an evident need for evaluation, as up to a third of Raynaud's episodes are stress or anxiety related, and the remainder associated with cold exposure; this means that episodes are potentially avoidable.

A literature review conducted by Dr J Daniels, Dr J Pauling and Professor C Eccleston, and published in the British Medical Journal, aimed to evaluate the efficiency of behaviour change interventions for Raynaud's and identify how these could be used for future treatment development. 'Behaviour change interventions' are changes which aim to achieve symptomatic relief of Raynaud's through advised and sustained change in patient behaviour, by improving either physical or psychological well-being. Despite the huge impact of Raynaud's on quality of life, the development of behavioural and lifestyle interventions in similar conditions, and the significant potential benefit of self-management interventions (given the importance of cold exposure and stress as Raynaud's factors), there has been a surprising lack of therapy development and little work has been undertaken in this field in the last 20 years.

Although there is too little evidence to either support or refute the suggestions made by the National Institute of Health and Care Excellence (NICE), there is clear evidence for the effective treatment of anxiety in other long-term conditions, such as rheumatoid arthritis, and the importance attached to self-management in healthcare guidelines for Raynaud's. Therefore, there is a strong case for adopting similar interventions for scleroderma and Raynaud's, but there needs to be more investment into this area in order to build stronger guidelines that are built on evidence which is specific to the two conditions.

More research may mean a higher proportion of those living with scleroderma and Raynaud's are encouraged to heed this advice and improve their quality of life and wellbeing. SRUK urges all those living with Raynaud's to take on board the advice provided by medical professionals, such as stopping smoking and taking measures to stay as warm as possible, as together these will help to improve symptoms.

Meet the Scientists

Here at Scleroderma and Raynaud's UK, we invest in research to save lives. The more research we can conduct into both scleroderma and Raynaud's, the closer we get to having better treatments and eventually a cure. Thanks to your support, SRUK is able to work with a number of dedicated, inspiring scientists who all endeavor to further understand the 2 conditions. We do this to improve the quality of people's lives, and ultimately to save lives. Each research scientist has experienced varying journeys to accomplish their many impressive achievements. Here is a little insight into the lives of some of the researchers we fund, what keeps them in the laboratory and the future of research.

Dr Elizabeth Renzoni:

Elizabeth trained in medicine and then in respiratory medicine at the University of Siena, Italy. In 1999, she was awarded a European Respiratory Society research fellowship to study the genetics behind interstitial lung diseases (ILD) at the ILD Unit at Royal Brompton Hospital. She went on to complete a PhD in gene expression analysis in pulmonary fibrosis with Imperial College, London. Since 2006, Elizabeth has been working as a consultant respiratory physician at Royal Brompton Hospital in the ILD Unit and an honorary senior lecturer at Imperial College London. As the oesophagus is so often involved in scleroderma, SRUK have most recently funded a project led by Elizabeth which is assessing the role of chronic microaspiration (movement of small droplets from the stomach into the lungs) in pulmonary fibrosis.

What inspired your interest in scleroderma and Raynaud's?

I have been fascinated by connective tissue diseases from the start of my medical journey. The unit where I trained in Siena was a centre for interstitial lung diseases, and there I saw many patients with scleroderma, which instigated my interest with this disease and in looking into mechanisms that might allow us to understand more about the different pathways involved and potential new treatments. I soon became aware of the work being done at the Royal Brompton and Royal Free hospitals, through the collaboration initiated by Dame Margaret Turner Warwick, a pioneer in the field of ILD, and Dame Carol Black, who set up the largest referral centre in the UK for patients with scleroderma. Upon reading about the extensive research being conducted by Dr Ron du Bois and Professor Athol Wells, I decided to come to the Brompton to be involved in research in scleroderma-associated lung disease. Here, I have been fortunate to work in close collaboration with the Royal Free Rheumatology specialists and researchers including Professor Chris Denton, Professor David Abraham, Dr Voon Ong and Dr Xu Shi-Wen. The immune system and how our bodies can recognise the multitude of substances different from our own has always been of huge interest to me. In scleroderma and other connective tissue diseases this fine balance is out of kilter; exactly

how this together with other pathways leads to scarring is yet to be discovered.

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

Lung fibrosis is a frequent complication of scleroderma, and in a minority of individuals, this fibrosis is progressive. Some features of this symptom are similar to other fibrotic lung diseases, such as idiopathic pulmonary fibrosis (IPF), although it is important to note that patients with scleroderma-associated lung fibrosis tend to do much better than those with IPF. Two drugs have recently been found to be effective in the treatment of IPF, as they can slow down the progression of lung fibrosis, and so these same drugs are also being trialled in scleroderma-associated lung fibrosis, with the first results expected over the next year. I believe in the next five years, there will continue to be interconnections between discoveries and treatment options from the field of IPF to scleroderma-associated lung disease.

Although this is promising, there are also major differences between the two, as the genetics of lung scarring are very different in scleroderma compared to IPF. The immune system plays a much more prominent role in the development and progression of lung fibrosis than in IPF. Immunosuppressive treatments can prevent progression in a substantial number of patients with scleroderma, although there is a small but significant group of patients whose lung fibrosis continues to progress despite currently available treatments. There are promising trials currently ongoing investigating a number of agents that regulate the immune system and we are eagerly awaiting the results.

Finally, for a disease about which we still have so much to learn, it is crucial that we continue to recruit patients into research, and that patients become increasingly involved in the designing and shaping of research to highlight what are the most important aspects and to help guide researchers towards patient-centred outcomes.

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

Jane Austen, Mozart, Oscar Wilde, Charles Darwin, Leonardo da Vinci, Roberto Benigni.

Finally, what is your one desert island disc?

Mozart's Le Nozze di Figaro

Professor Rizgar Mageed:

Rizgar graduated from the College of Pharmacy at Baghdad University, and went on to complete a PhD at the Royal London Hospital Medical School in 1985. He is now a Professor of Experimental Immunology at the Centre for Experimental Medicine and Rheumatology at Queen Mary University of London, as well as a fellow of the Royal College of Pathologists and of the Royal College of Physicians. In 2017, Rizgar and his team were awarded a grant by SRUK to research how abnormal immune cells are involved in patients with systemic sclerosis, which could potentially lead to the development of new, novel treatments by selectively targeting these.

What inspired your interest in scleroderma and Raynaud's?

Systemic sclerosis is an autoimmune disease in which the immune system attacks the self; a process akin to friendly fire. My first interest in the disease has a human side to it, from the experience I had of the suffering of a family friend. Having always had a keen interest in autoimmunity, I was always fascinated in understanding the causes behind it. I was enthused by colleagues at the Royal Free Hospital to join forces to explore causes of systemic sclerosis in the hope of developing new treatment strategies for patients.

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

Key areas that will be really exciting will be in combining new genomics, proteomics and metabolomics technologies to profile immune cells, interaction dynamics between these cells and with the environment for developing personalised medicines. These new approaches will help develop clearer understanding of what initiates diseases, predicting times of flare-ups and which organs are likely to be involved. This new understanding will help develop therapeutic modalities targeting different components of the immune system in different patients and at different stages of the disease process.

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

The one person that I would invite will be Nelson Mandela. For me, he represents all that is good in humanity.

Finally, what is your one desert island disc?

My one desert island disc will be for Luciano Pavarotti. I can never tire listening to his angelic voice.

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.

Pulmonary fibrosis: a respiratory disease, caused by scars forming in the lung tissues which lead to lung stiffening and breathing difficulties.

Genomics: the biology regarding the structure, function and evolution of set of genes or genetic material.

Proteomics: the analysis of the structure, function and interactions of proteins expressed by the genetic material of an organism.

Metabolomics: the study of small molecules, such as sugars and amino acids, that are involved in or products of metabolic reactions.



Raynaud's Awareness Month 2019

This month, throughout all of February, we are inviting people who might be affected by Raynaud's to take The Test (sruk.co.uk/testme) to get support and advice. We need your help to reach them!

There are millions of people affected by Raynaud's and many don't even know it. Our message is that while Raynaud's is not life-threatening, it can be extremely painful and debilitating and in some cases symptoms can indicate a more serious underlying condition. While almost half of people have heard of Raynaud's, very few people can name the symptoms (just 5% in our recent survey). That's why we are asking people to take The Test online and **##knowraynauds** to better understand, and manage, their symptoms.

The Test was developed with expert clinicians from Salford Royal and Bath Hospitals, and it lets people know whether they could have Raynaud's. The Test outcome also provides advice including tips to avoid painful episodes, and how to better **##knowraynauds** symptoms, and be alert to changes that may indicate more serious illnesses.

We'll be using digital media, press and radio to share the message with everyone (but especially women in their 20's and 30's) that, 'Raynaud's affects blood circulation, causing some areas of the body, such as fingers and toes, to feel numb or freezing cold in response to changes in temperature.

Everyday activities then become almost impossible, such as buttoning a coat, a trip down the frozen aisle of the supermarket or even turning the key in a front door. Heating in the home will often need to be turned up unusually high, and even air-conditioning in the summer can be extremely uncomfortable.'

**#KnowRaynauds
for Raynaud's
Awareness Month**

Here's how you can get involved.

While we're placing stories in the press and media, you can tackle the lack of understanding of Raynaud's by uniting with others and shouting **#KnowRaynauds** in your community during February. This month we need you to help increase awareness and understanding of Raynaud's and why it is important that everyone knows the signs and symptoms to look out for. For an action pack, visit sruk.co.uk/get-involved/raynauds-awareness-month/

Sue Farrington, SRUK Chief Executive said: "We know that despite a quarter of people saying that they had experienced symptoms, only 10% on average have visited their GP. This needs to change - Raynaud's can be a minor but uncomfortable inconvenience, but for those more seriously affected it's crucial that they seek medical treatment and support as early as possible. We hope with our online test people can self-manage the condition better, seek treatment where necessary but, above all, know that they are not alone."

Cosy Up Coffee

Will you host a Coffee morning (or afternoon) for Raynaud's Awareness month? We can send you everything you need in your own 'Cosy Up' pack, which includes a banner, balloons, sweepstake, collection boxes and posters.

It's a chance to raise awareness of Raynaud's and much needed funds, and get people talking about a common condition which is rarely discussed.

You can host your event at work, the local library, a community centre or even at home, anywhere - just get people talking about Raynaud's this month.



Order your free pack today at www.sruk.co.uk/cosy-up-with-coffee/ Or call 020 3893 5993



Scleroderma Discriminates based on Race as well as Gender

At Scleroderma and Raynaud's UK, we want to ensure that everyone who is living with these conditions receives the full support and access to healthcare that they deserve. In order for us to do this, we are working to fully understand just how many people in the UK live with the conditions, as well as their ethnic background.

A lot of us know that scleroderma affects 5 times more women than it does men. What many people may not realise is that there is significant evidence from the United States to suggest that the condition affects more African Americans and Native Americans.

We care about reaching every member of our community and want to raise awareness that the impact on people and families is the same regardless of ethnicity. We thought you would be interested in this article written by Dontaira Terrell, a Florida University graduate and journalist. She wrote in Ebony magazine, a US based publication, about her paternal grandmother's experience with scleroderma.

More than five years have passed since the death of my paternal grandmother. She was charismatic, comedic and warm-loving. Grandma was a force to be reckoned with. She would take in neighborhood children as her own and, as the family matriarch, she kept us all together, and could whip up a meal that'll leave you begging for more!

Regardless, of what time of day you visited, she was always in good spirits and always had a hot plate to send you home with. Grandma had an insatiable appetite for life, never missed a family event or Sunday morning church service. But that's not all! She also had the snap back and quick wit of a 20 something year old. Get 'slick at the mouth' and she would quickly put you back in place before you thought about taking your next breath. As you can see, in my eyes she was more than just my grandmother—she was a role model.

Imagine my disbelief and shock when I received the phone call, "It doesn't look good. The doctors called 'code blue' on Grandma." Code blue=cardiac arrest.

She was healthy, she was happy, she was vivacious at all times but in reality no one knew how badly she was ill. Grandma suffered in silence for years, and eventually passed away from a rare disease known as scleroderma. Also known as systematic sclerosis, scleroderma is an ongoing, progressive, autoimmune disease which attacks the connective tissues of the body. The meaning behind scleroderma is "hardening" of the skin and the effects and severity of the disease vary from each person. Additionally, auto immune diseases cause the immune system to counteract, subsequently producing more collagen than necessary.

Scleroderma has not gained widespread attention as other diseases affecting women. I'd wager that most of you reading this haven't heard of this incurable, lifetime illness. Although rare, it is more common in women than men at a ratio of 4:1. Studies have found scleroderma to be more prevalent among African Americans than any other race. This disease is often misdiagnosed or overlooked because it has similar traits to the more common, and treatable, rheumatoid arthritis.

Unfortunately, there are many unanswered questions regarding scleroderma, including its cause. Many suggest, although not hereditary, there is a chromosome factor relating to family members which may expose them to a higher risk of developing other autoimmune system diseases such as rheumatoid arthritis, lupus or thyroid disease. This typically occurs at a greater level for those of African American and Native American descent.

Additionally, although any age group can develop scleroderma, the onset of the disease begins on a more frequent basis between the ages of 25-55. Studies show it is more apparent in African American women beginning at an earlier stage. Although there are no known cures, individualized treatment options are available to manage and offset symptoms. As with most diseases, early detection is always best.

Unfortunately, many African American women, like my grandmother, have an increasingly higher risk of developing scleroderma in the more life threatening state. Although she may have experienced the previously mentioned symptoms on a daily basis for years, the disease took its toll by slowly but surely shutting down various organs, eventually leading to her death.

I have made it my crusade to let as many people as possible know about this scleroderma, as a way to honor my own lost loved one. If even one person is able to benefit from my story by catching this disease at an early stage, my Grandma's suffering was not in vain.

Dontaira Terrell is a Florida A&M University graduate, Ohio native and lifestyle journalist. Her work has appeared in dozens of national media outlets including the HuffPost, BET, VH1, Shondaland, and ESPN's The Undeclared. You can follow @dontairaterrell on Twitter and Instagram, or visit dontairaterrell.com Reprinted with permission, Dontaira Terrell



<https://www.ebony.com/health/what-you-need-to-know-about-scleroderma-304/>

Memories of Love

This February many couples will be marking Valentine's Day on the 14th by celebrating their love and partnerships. In our community we also often think of those that have lost a loved one, and the family members that we miss.

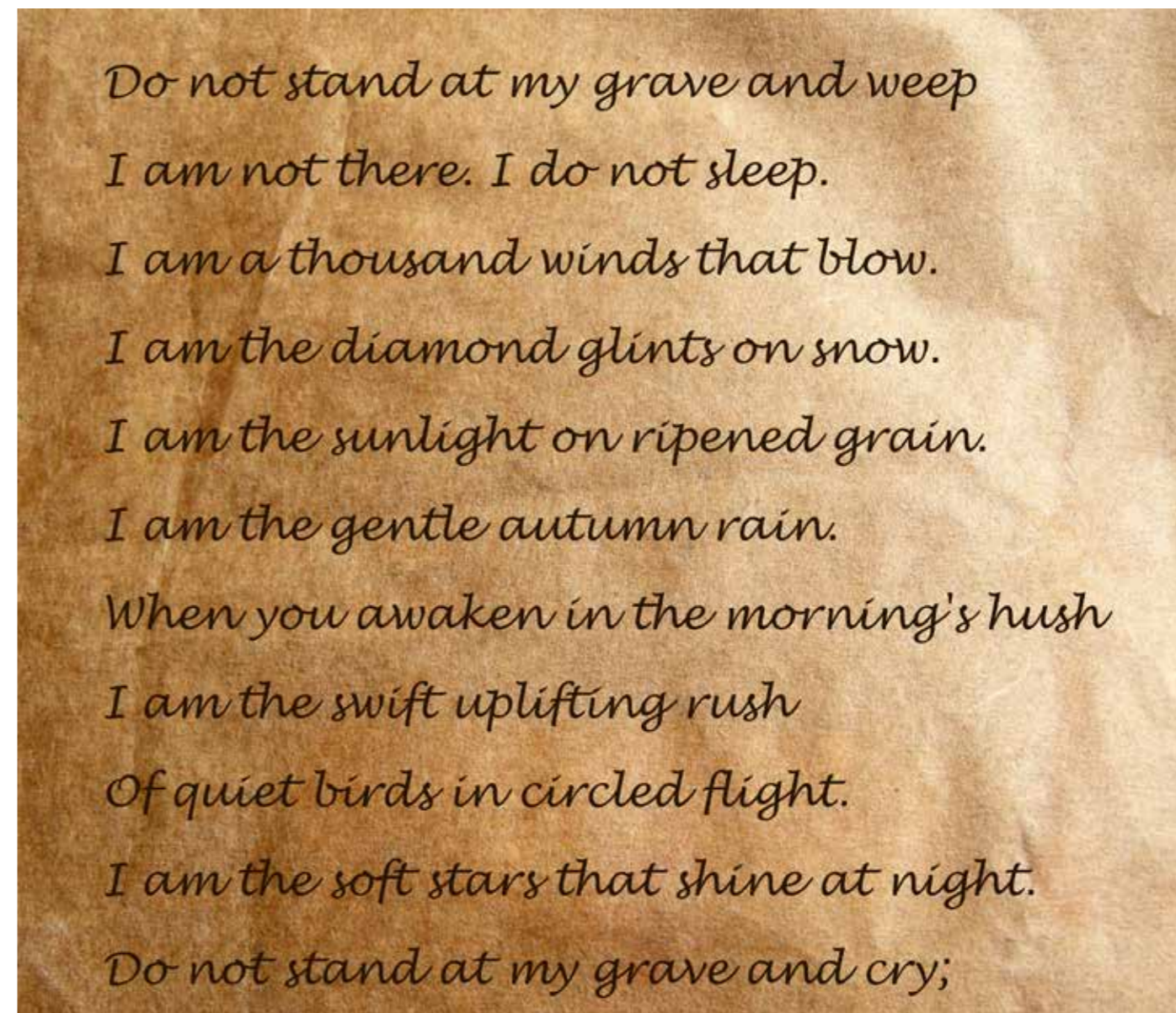
At the end of 2018 at SRUK we paused to read the many reasons people had given for supporting the charity during the year. We were humbled to see that more than half of you were donating to honour the memory of a loved one or friend. In your kind messages some of the words that came up most frequently were: memory, Mum, Mother, friend, research, help, work, passed, died, family, Wife, support, lost, hope, research, time, Christmas, and birthday.

Even this simple string of single words is packed with emotion. It reminds us of all the powerful stories shared with us, and of your hopes for better diagnosis, treatments, and a cure. It also clearly reflects how both Raynaud's and Scleroderma are so much more likely to affect the women in our families and communities than the men... our wives or partners, daughters, mothers, and grandmothers.

We are humbled by the trust you've place in us to deliver results in memory of loved ones. Your messages have been a poignant reminder of our duty to manage your contributions well and keep you updated on how your thoughtful gifts are working to make a difference and help people throughout the year.

Your gifts are indeed working today to: support those that are seeking a diagnosis, ensure medical professionals are alert to the conditions, help people seek the best support or treatment, give advice and information to family members... and, of course, to find cures for Raynaud's and Scleroderma.

We've produced these 'word clouds' from the messages people sent with their donations to share with you. We've also shared this beautiful poem by Mary Elizabeth Frye in the hope it will help anyone that is remembering someone this Valentines Day.



*Do not stand at my grave and weep
I am not there. I do not sleep.
I am a thousand winds that blow.
I am the diamond glints on snow.
I am the sunlight on ripened grain.
I am the gentle autumn rain.
When you awaken in the morning's hush
I am the swift uplifting rush
Of quiet birds in circled flight.
I am the soft stars that shine at night.
Do not stand at my grave and cry;*

About the poet

Mary Elizabeth Frye (Nov 1905 - Sept 2004) was an American poet and florist, best known for this one poem.



Elizabeth was born in Ohio and orphaned at the age of three. She was an avid reader with a remarkable memory. She sold flowers and eventually married Claud Frye, who ran a clothing business.

The poem for which she became famous was originally composed on a brown paper shopping bag, and was written for a young Jewish girl, Margaret Schwarzkopf, who had been staying with the Frye household and had been unable to visit her dying mother in Germany because of already mounting anti-Semitic violence in 1932.

Margaret was bereft when her mother died, heartbroken that she could never, "stand by my mother's grave and shed a tear." Mrs Frye picked up a brown paper bag, and wrote out this twelve line verse for Margaret.

People were so moved and comforted by the untitled verse, and Frye made many copies and circulated them privately. She never published or copyrighted the poem.



It all started on an ordinary day in October of 2015. I caught a light fever, but I was not concerned because I would usually get sick only once in a year around late autumn/winter with nothing more serious than a light fever. I just thought I would feel under the weather for a few days. This was true, only this time, I had a new symptom. My fingers went numb and they turned white when I went outside or when I was feeling cold.

As I expected after a few days the flu disappeared - but the numbness and the skin colour change stayed, for life - which I did not know back then. So, I visited my local General Practitioner, and the long months of examination after examination began. To be honest after the first day of experiencing the numbness, I Googled what it could be, so when I saw my GP, I already had a suspicion.

I still had to go and see a dermatologist, a neurologist, an ENT specialist, a dentist, a gynaecologist, a pulmonologist, a cardiologist, and an ophthalmologist. I spent a long time sitting in waiting rooms, and traveling to my appointments - all the while, I was in pain. Finally, in June 2016, I was referred to a specialist who confirmed what I had suspected all along. I had Raynaud's syndrome.

Going through all the doctors, I was diagnosed with primary Raynaud's. The specialist still wanted to run tests to see if I could have secondary Raynaud's, but in August 2016, I had to move to Denmark, as I got accepted to college there. My doctor strongly disapproved of me moving, because of the cold weather there - and we still were not finished with all the tests. So, I moved and with autumn and winter quickly approaching, I was in constant pain. Of course, by then, I learned to carry gloves with me, but I still got surprised by attacks many times. I was pretty much wearing gloves from September until May.

In December of 2016 I visited my GP in Denmark to see if he had any suggestions, but he also offered the use of gloves and keeping warm. In March the same year, I moved to a different town, where I also went to see my new GP. Finally, he prescribed some medication, but it only helped for a few weeks, though my symptoms got better with summer around the corner. A year later, in the winter of 2017 I also developed Raynaud's in my feet. I noticed it in late November, that my feet were numb, while walking home after school.

As a child winter was my favourite season and playing outside in the snow was my favourite activity. Though I still find winter and snow beautiful, I cannot wait for it to be over. Now, sometimes, it hurts to open up my laptop because the top is made of steel and it gets cold, for the same reason sometimes I cannot touch my phone while traveling. I have to wait until it warms



up. When I simply want to wash my hands, I have to wait and let the water run until it warms up. In restaurants, I cannot order any drinks with ice in them.

I take the trains to go to work and I like to sit by the window, but sometimes I have to change seats because the cold wind comes right at me through the invisible gaps at the edges of the window.

I carry at least two pairs of gloves and two heating pads with me all the time. I keep gloves in all my bags and coats. Even in the summer when I travel to the seaside in the warmest weather, I still have to pack a light coat, gloves, and heating pads.

It is better in the summer, but it does not go away. I have to put on gloves during grocery shopping when I buy something frozen or when I simply want to eat ice cream. I have not had ice cream in a cone for years.

Having Raynaud's has definitely made my life more difficult. Though I have to take it into consideration with everything I do and everywhere I go, I have learned to live with it and I try to prevent the attacks whenever I can.

I used to love being outside and hiking in the forests, even in winter. I loved going skating with my family to the local lake in my home town, I loved building snowmen and having snowball fights.

As a child winter was my favourite season and playing outside in the snow was my favourite activity. Now, though I still find winter and snow beautiful, I cannot wait for it to be over

My favourite thing was to go and walk around Christmas markets in December. Raynaud's has taken all that away from me.

The most difficult thing was accepting the fact that this disease will not go away and I have to live with it for the rest of my life.

My Fear of Cold

Sara Szigeti tells her story of the first Raynaud's attack she experienced and the challenge of accepting being diagnosed with a lifelong condition. If you'd like to share your own story please get in touch with our team on 020 3893 5998 or email info@sruk.co.uk



7

handy hints for keeping warm this winter

Keeping warm in winter, for many, is often not as easy as turning up the heater. Here are some helpful tips that will prevent illness worsening in the colder months and keep your body healthy.

1 Keep your home heated to above 18 degrees

If you have the resources, keeping your home heated to above 18 degrees is the government recommended temperature. To save money, choose only a few rooms to keep heated and set your heating to a timer that correlates to your work schedule. The best times to heat your home are when its coldest and when you're likely to be awake - early mornings and evenings. Remember to get your heating system checked regularly to ensure your safety.

2 Invest in good quality bedding

Buying good quality warm bedding such as duvets and blankets is a good long term investment. A cheap option is Ikea. Buying warm bedding, unlike using heating, is a one off payment and would last for many years. If you can't afford to make this investment in the first place, a great place to look for very cheap bedding is charity shops. Often, if there are none in the shop, you can ask the manager to give you a call as soon as any are donated.

3 Trap in your heat

If you can't afford insulation like double glazing and loft insulation, remember to close your curtains and keep the doors shut, trapping heat into the rooms you use the most. If you can't afford a draught excluder for under the doors, you can use old towels, pillows or cushions.

4 Get supplies in early

If your home is heated solely through fires and heating oil, ensure you have enough supplies to get you through the colder months as you may get snowed in. If you are too ill to collect your own firewood, coal or oil, don't feel ashamed to ask a friend, relative or neighbour to help you collect your winter supply.

5 Get professional advice

In England, contact the Energy Saving Advice Service (ESAS) for more advice on how to reduce fuel bills and make your home more energy efficient. ESAS can be contacted on 0300 123 1234 (9am to 8pm Monday to Friday).

For free and impartial advice in Scotland, including support on making your home warmer and cheaper to heat, contact Home Energy Scotland on 0808 808 2282.

If you live in Northern Ireland, free and impartial advice is available from Bryson Energy or you can call their Freephone number on 0800 142 2865.

For heating advice in Wales people can contact Nest on 0808 808 2244 or visit the Nest website. www.nest.com/uk/

6 Get financial help

The Winter Fuel Payment, The Cold Weather Payment and The Warm Home Discount Scheme are just a few government run schemes that offer financial help to those who can't afford to stay warm this winter. Head to <https://www.gov.uk/browse/benefits/heating> to see which you might be eligible for.

CONCLUSION

While it can be a difficult time of year for those with Raynaud's in particular, we hope that our recommendations will help to get you through these difficult months. And with winter coming, we want to put out as much useful information as possible. You can help make sure that we are able to do so by donating to us today. Every penny helps.

Support Services

Join a Support Group

Our Support Groups are there to support people with scleroderma or Raynaud's, their friends or family.

We have 7 Support Groups across the UK for people to come together to discuss and share issues around the conditions. Each Support Group has a Support Leader that runs the group and keeps in contact with all the members. All Group Leaders are volunteers who have experience of the condition themselves.

Some Support Groups are run by providing advice and information by email to member questions. Other groups are run as telephone meetings as it's sometimes difficult for members to attend meetings in person. Some meet in person, or are a mixture of the above depending on member needs.

If you have any questions about our Support Groups, you would like to join one, or indeed would like to set one up please contact us at supportercare@sruk.co.uk, or find out about the Support Group nearest to you at sruk.co.uk/local-groups/



Volunteer on our Helpline

We currently have eleven volunteers who man the helpline on a rota basis.

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

We are always keen to hear from people who have an understanding of Raynaud's and/or Scleroderma who may be interested in volunteering on our helpline.

Specialist Nurses

Help us find more specialist nurses to add to our list.

Scleroderma specialist nurses provide specialist clinical advice and support to people with scleroderma.

They are usually the main point of contact for a person with scleroderma and they often act to co-ordinate services, referring someone on to a doctor, or a therapist, or other appropriate services.

Specialist Nurses also provide support and advice over the phone. If you have a medical query and would like to receive support please use the list on the opposite page to find your local nurse. They can help you navigate the healthcare landscape to find the best quality of care for your condition.

We are especially interested in finding specialist nurses in Scotland, Wales and Northern Ireland, so if you know of any qualified nurses in these regions, please get in touch by calling our head office, or emailing info@sruk.co.uk.



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



New Year, New Challenge?

With January being the start of a new year, some of us find ourselves more motivated to start good habits or to incorporate something new into our lives, maybe it's the mentality of 'start as you mean to go on'. Regular exercise not only keeps you fit, but also increases flexibility and boosts your mood. One of the easiest ways to incorporate this into your daily life is to get walking - here's some of our top tips to get you started.

1. Start slowly

If you're not used to exercise, walk 10 minutes from home and then turn around and walk back. Increase this by a minute or two every day

2. If you're not slightly out of breath, it's not working

Make sure that you feel slightly out of breath and are perspiring slightly. This is a good indication that you're walking at the right pace.

3. Gradually increase the intensity

When your walk starts to feel easier, increase the intensity by taking longer strides and swinging your arms by your sides.

4. Consider walking on a treadmill

If you have knee, hip or joint problems, consider walking on a treadmill as they are cushioned which helps to reduce the impact on the body.

5. Look for soft ground outdoors

If you're walking outdoors, you might find it more comfortable to walk on soft ground instead of pavements.

6. Wear thin layers

Wear thin layers so that you can take something off if you get too warm. Depending on the weather and the distance you're walking, you might also want to carry a bottle of water, a snack, sunscreen, a sunhat and a waterproof jacket.

7. A little goes a long way....

Brisk walking counts as a moderate-intensity activity, provided that you set a pace where you feel a little bit out of breath but can still carry on a conversation.

Remember: Don't feel that you have to take long walks every day. It's best to try to make walking a part of your everyday routine.

If you're not already active, or have any health concerns, it's important to check with your doctor to find out if it's safe for you to start or increase your walking



Walks and Runs

This year we have a lot of exciting events coming up, as January is the time lots of people like to plan and set themselves a goal for the year ahead, we wanted to share some of the events we have coming up throughout the year that you can get involved with, exciting events coming up. As January is the time

We have events that you can Walk, Jog and Run all while raising awareness



Isle of Wight Challenge - 4th May 2019

This trek is a great opportunity to see the whole island, it will take you past the famous Needles, to Cowes at half way, then around back to base camp after a spectacular 106km journey with full support and great hospitality all the way.

You can register for as little as £40

All of our Trek events include the option for you to select your desired distance over your chosen duration. You can do either 25k, 53k or 106k; a variety of distances to accommodate your desired personal challenge.

You can also decide to complete your challenge in one day or over the full weekend.

Cotswold Way Trek - 29th June

Another option in the challenge trekking series, this route is available in a variety of distances of 25k, 50k or 100k to suit you. It's a Saturday morning start from Bath's historic Royal Crescent with the route taking you from all the way to Cheltenham with a variety of inclines through beautiful idyllic villages, if you're looking for a picturesque route this may be the one for you.

Race to the Stones - 13th July



This event is again a one day or weekend event option to suit you with an option of two distances of 50 or 100k depending on how much you wish to push yourself, you can tackle this route at your own pace in a walk, jog or run fashion to suit you.

A route of this distance is no small feat and will require training, it's the perfect opportunity to take your walking or running (if you're feeling hardcore) to the next level.

The route itself 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 onto the North Wessex Downs passing golden fields before the iconic finish where you'll walk between the towering stones of Avebury.

Registration for this event is £64 with a minimum sponsorship of £425

Thames Bridge - 7th September

Team SRUK will be taking in all the sights via a 25km zig-zagging across 16 bridges in central London. You'll have a chance to take in some of London's best loved sights such as Big Ben, the London Eye, Tower Bridge and more all along this fantastic route.



This mass participation event with over 2,000 walkers will be 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. 25km later, it's a finish line celebration in Southwark past the majestic Tower Bridge.

This event is great to do as a group, entry is £40 with an ask of raising £175 sponsorship.

We also have other treks available in a variety of locations such as the South Downs, the Peak District and across the Jurassic Coast, if any of those locations interest you please contact Shauna on 020 3893 5993 or email her on shauna.creamer@sruk.co.uk for more information.

Step Out for SRUK - June

This June during Scleroderma Awareness month we are asking our community that within the month of June you gather your friends and family and members of your local community to Step Out for SRUK, it really is more the merrier. You can walk a well-trodden route or create a new one yourself. We will supply you with banners and t-shirts for your event, hoping that great numbers of our walking community will attract attention and create a dialogue about Scleroderma during the awareness month.

£10 per person for your Step Out pack including an SRUK t-shirt. (Keep an eye out for the launch of our new design!)

Your guide to fundraising in-memory

Donate in memory

A wonderful way to remember a loved one is to make a donation to a charity close to their heart. If you make a donation in memory to SRUK, your gift could help support individuals diagnosed with Scleroderma and Raynaud's, or fund medical research to find treatments that provide a better quality of life.

We rely on the generous support of our community as we receive no government funding. Legacies and 'in memory' giving make up almost half of our funds, so we truly appreciate you thinking of us at this time.

Here are some ways to donate in memory:

Collections in lieu

Many people choose to ask family and friends for donations in lieu of flowers. If this is something you would like to do, we can offer support and advice. If you would like to organise this yourself we can provide donation envelopes, literature and collection boxes. Please get in touch on 020 3893 5998 and we'll send you what you need. You may wish to ask your funeral director to organise this on your behalf - if so, we would be happy to liaise directly. Your funeral director may find it helpful to know SRUK is registered with Memory Giving (memorygiving.com)

Special Date Collections

After the loss of a loved one, you may want to continue supporting SRUK. A lovely way to remember a loved one is to make a donation on a special date like a birthday or anniversary. You may even wish to create a donation page in memory so family and friends can remember together - Justgiving is one website that allows you to do this.

In Memory Page

You may wish to set up a permanent in memory page to remember your loved one, where friends and family can share stories, pictures, remember together and donate together.

Donate by post

Sometimes, friends and family choose to make a donation by cheque. If this is the case, cheques should be payable to 'Scleroderma & Raynaud's UK' and posted to Scleroderma & Raynaud's UK, Bride House, 18 - 20 Bride Lane, London, EC4Y 8EE.

We understand how challenging a time this can be, so please get in touch if there is anything we can do to make things easier, on 020 3893 5998 or info@sruk.co.uk



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

Donate to us
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Scleroderma & Raynaud's UK
Bride House, 18 - 20 Bride Lane,
London EC4Y 8EE

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
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 @WeAreSRUK  /WeAreSRUK

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