

SRUK NEWS

Riding Pillion
How Lisa
overcomes her
Raynaud's
attacks

Doc Spot
Your questions
answered by
our medical
professional

New Heights

Rebecca raises awareness of early diagnosis of scleroderma after dreams dashed of climbing Mount Everest

Exploring
the Digestive
System



Event Calendar 2018

FEBRUARY

Raynaud's Awareness Month

15th - 18th - Fifth Systemic Sclerosis World Congress, Bordeaux

Weds 21st - SRUK Information Stand, Kellegren Centre for Rheumatology, Manchester Royal Infirmary

Thurs 22nd - Patient Information Day, RNHRD, Bath

Weds 28th - SRUK Information Stand, Alderhey

Weds 28th - Rare Disease Day

MARCH

Thurs 8th - SRUK Information Stand, Chapel Allerton Hospital, Leeds

Tues 20th - SRUK Information Stand, Sheffield Children's Hospital

Sat 24th - Scottish Pulmonary Vascular Unit PAH Conference, Golden Jubilee Conference Hotel, Glasgow

APRIL

Sun 8th - Asics Manchester Marathon

Fri 20th - SRUK Information Stand, QEUH, Glasgow

Sun 22nd - London Marathon

MAY

Sat 5th - Isle of White Challenge

Sat 19th - SRUK Information Stand, Royal Free Patient Day, London

TBC - SRUK Information Stand, Ystrad Mynach Hospital, Wales

Sat 26th & Sun 27th - Edinburgh Running Festival

JUNE

Scleroderma Awareness Month

Mon 11th - Patient Information Day, Salford Royal Hospital

Fri 29th - World Scleroderma Day

JULY

Sun 29th - Prudential Ride London

AUGUST

TBC - SRUK Information Stand, Aintree, Liverpool

SEPTEMBER

Mon 3rd - SRUK Charity Golf Day, High Barnet, London

Sat 8th - Thames Path Challenge, London

OCTOBER

SAVE THE DATE - Saturday 13th 2018

SRUK 3rd Annual Conference
De Vere Beaumont Estate, Windsor.

To register go online
www.sruk.co.uk/AC18

Sun 7th - Royal Parks Half Marathon, London

TBC - SRUK Information Stand, Sheffield Children's Hospital

NOVEMBER

TBC - SRUK Information Stand, Freeman's Hospital, Newcastle upon Tyne

Dear Supporters

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

We're looking forward to meeting even more of you in 2018 as we continue to visit clinics around the UK, work with you to shape our services and research and welcome you to the Annual Conference in Windsor.

It will soon be Raynaud's awareness month, and we want to ask for your help to build on the success of last year to spread awareness of the condition. Every action helps, whether it's putting up a poster in a GP surgery, community centre or local pharmacy to holding a coffee morning.

Keeping warm is the order of the day and Lisa Shawgi shares her personal story of her early years of Raynaud's, and how she rides pillion with her partner travelling all over the country and still manages to keep warm. Lisa is also asking for trialists to help with her PhD in assistive clothing for people with Raynaud's, so please get in touch if you'd like to help.

While Raynaud's is common, there's still little awareness of this condition, which we know is also the case for scleroderma. In this magazine we feature another rare disease – Myositis, an overlap syndrome some of our community will have. For more information on the different types, please go to page 11 and if you find it helpful for us to feature other associated conditions please let us know.

You told us that a major challenge for many of you are issues with eating and swallowing, processing food and dealing with incontinence. The organs that assist with these processes can often be affected by scleroderma and in this edition, we've got information on what you can do with some further treatment ideas on line.

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, walking challenges in the Isle of Wight in May and London in September. There are parachute jumps throughout the year and a charity golf day all planned in 2018. If you fancy arranging a supermarket or bucket collection in your area please do get in touch with the fundraising team who will be able to provide support and advice.

Thank you very much for your continued support. By uniting as a community, we really can make a difference to the future of everyone affected by Scleroderma and Raynaud's.

Very best wishes

Sue

sue.farrington@sruk.co.uk

 [@farrsue01](https://twitter.com/farrsue01)

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Doc Spot

Your questions answered by our medical professional, Prof. Denton

Could scleroderma be related to hormones? I have had an imbalance since being diagnosed but my GP is dismissive?

Scleroderma is much more frequent in women, so it is likely that hormones are relevant. However, since hormones such as oestrogen (female) and testosterone (male) influence very many cells and tissue, it is difficult to understand the precise mechanisms.

One possible mechanism thought to influence the immune system, are hormones, because almost all autoimmune diseases are more common in female patients.

Importantly, there is no evidence that treating hormonal imbalance is in any way harmful in scleroderma and so the normal medical treatments can generally be given, if needed.

Is anxiety a symptom of Scleroderma and Raynaud's? Since being diagnosed I have suffered badly, but never previously?

Any significant long-term illness can have an emotional impact and it is likely that in some patients this leads to anxiety or depression. Poor sleep is also often an issue and can be linked to physical symptoms of scleroderma.

Therefore, it is possible that new or worsening anxiety is an issue and it is certainly something to discuss with your clinical team. Sometimes these aspects of scleroderma are overlooked because priority may be given to testing for physical complications.

Are there any new treatments for bowel incontinence in the future?

Posterior tibial nerve stimulation (PTNS) had no benefit for me and I ended up with swollen ankles. I constantly have a cough and suffer from breathlessness.

Bowel incontinence is now much more appreciated in scleroderma and this is a very important complication of the disease.

Research is starting to define better the way in which this develops. It is a combination of damage to the nerves and blood vessels in the bowel wall, as well as weakness and scarring of the muscle tissue. Scleroderma may also worsen other factors such as prolapse of damage from childbirth.

The effectiveness of treatments depends what is the main factor in an individual patient. Treatments such as posterior tibial nerve stimulation (PTNS, image shown below) work by stimulating nerves and although this can work well it is not always helpful.

Hopefully, other new treatments will become available because of greater awareness and more research in this area. If there is progress managing incontinence in other medical contexts, the hope is, this may be applied to people with scleroderma in the future.



Credit: London Physiotherapy and Wellness Clinic

Can the contraceptive pill, contraceptive implant or injection have an impact on Raynaud's? It has been suggested that my Raynaud's may have been caused by taking the pill and wonder about the association with hormonal contraception.

Female hormones can affect blood vessels and it is often observed that Raynaud's severity improves in pregnancy when hormone levels are more stable and generally oestrogen levels higher. Although contraceptives that alter oestrogen or progesterone levels may impact on Raynaud's this is not always the case.

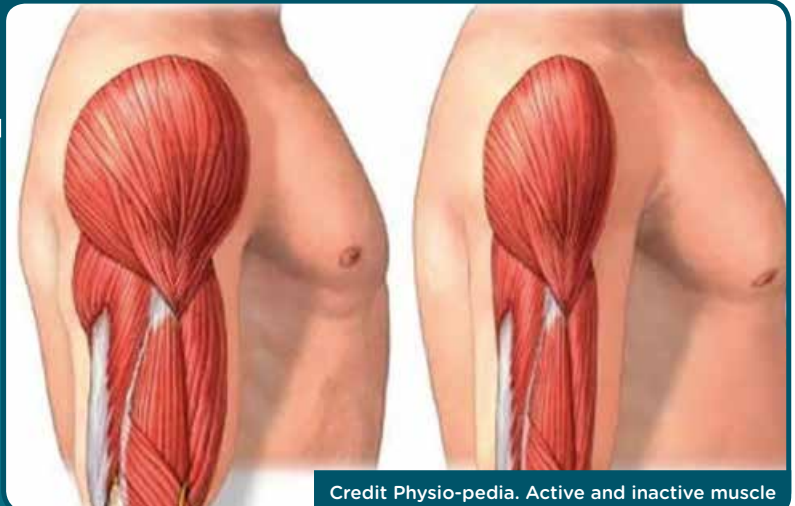
If Raynaud's develops or clearly worsens within a few weeks of starting or changing a hormonal contraceptive this is a good clue that stopping or changing this may be worthwhile.

Why is it so hard to get Raynaud's recognised as a disability rather than a condition? If it is a disability can you get help with heating costs etc?

Because Raynaud's is very common, affecting up to 1 in 10 individuals, and has varied impact and severity it is unlikely that it would be recognised as a disability, however it is certainly a relevant factor in considering how an illness affects your ability to perform everyday tasks and when severe complications occur or are a risk then this is something that should be taken into account when completing any forms for disability or other allowances.

If you have scleroderma or overlap conditions, what is the effect on muscles and muscle involvement?

The muscles can become involved in patients with systemic sclerosis in different ways. In a minority of people, the muscles can become inflamed ('myositis'). Typical symptoms of myositis include pain and weakness in the upper arms or thighs, often with morning stiffness



If money was not a consideration what is the best treatment for scleroderma?

This is a great question but impossible to answer because of the varied way in which scleroderma affects patients and the limited effectiveness of current therapies. There is no single "best treatment".

However, it is recognised that optimal care is delivered by an expert multidisciplinary team with strong links and good communication between local and specialist teams, that takes account of the specific needs of a patient and their family.

This can include expensive hospital based treatments such as high cost drugs or even procedures like "stem cell transplant".

At a time when NHS funding is under pressure it is important to work hard to ensure that the right treatment is available to the appropriate patient at the right time. This needs good teamwork and partnership between patients, the healthcare team and organisations such as SRUK.

Lisa holds a ‘Masters class’ for those with Raynaud’s



Lisa Shawgi, 37, from Nottingham has lived with Raynaud’s since her teenage years. We speak to her about how the condition has developed and why she has decided to focus her PhD on an area that could help thousands of people, in the future.

Lisa originally grew up in The Sudan and moved to Ireland when she was 15 years old.

“I was in my late teens when large red welts started appearing on my hands, which turned out to be chilblains. After months of tests, we found out I had Raynaud’s. I had always remained cool (often cold) in a very hot country, while the rest of my family were melting from the heat in The Sudan, so this diagnosis made sense to me”

Unfortunately, moving to a cold country brought her Raynaud’s to the surface. Other symptoms manifested themselves as well, such as, feeling extremely lethargic and joint pain. Lisa also, suddenly, lost a huge amount of weight, shedding 56 lb’s (4 stone) in 4-6 months.

“There would be days where all I wanted to do was sleep, not having the energy to even walk down the street to get the bus to college. My local GP put it down to depression as he reported all blood tests were normal, but my Mum and I knew it had to be something else”



Lisa, with Fiance Scot and soon to be step son, Henry 11, enjoyed a day out at Windsor Castle

After several months, Lisa was finally diagnosed with Lupus and was given medication to assist with symptoms.

“I take Adalat and Hydroxychloroquine* twice a day and sometimes, several doses of steroids are necessary when my hands are at their worst. The medication I am on gives me head aches and have to get my eyes tested once a year, at least, as it might cause some issues. It’s still difficult to find the right balance of medication and is something we are still working on.”

“It has made me stronger in character and more determined to succeed in whatever I wish to achieve.”

Lisa’s family and close friends have an understanding of her condition, and are very supportive. They know what she needs to stay healthy and always take this into consideration when organizing events and social arrangements.

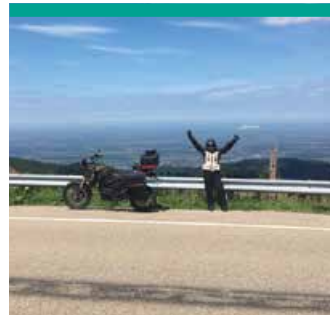
Lisa told us: “I have had to change my life style completely. It has taken several years to learn how to best manage my conditions and it is, and will always remain a challenge. I do my best to stay away from dairy and gluten in my diet. I have learned to listen to my body when it needs rest. I do my best to get a good night sleep. Exercise helps to keep my joints flexible and improve my blood circulation, and it helps towards my mental well-being as well. I also decided to do a lot of research and look at suggestions from others. It is really trial and error as to see what works for you personally, but worth the time.”

*Hydroxychloroquine is a well-tolerated medication for various rheumatologic and dermatologic conditions. Its main side effects are gastrointestinal upset, skin rash, headache, and ocular toxicity (eye problems). Within the eye, hydroxychloroquine may negatively impact the cornea, the ciliary body, and the retina, so it’s important to get your eyes tested once a year if you are taking this medication, to monitor any potential changes.

Lisa has also discovered the joy of biking, since her fiancé introduced her to it recently.

“I manage with the help of my partner and absolutely love it!! We have motor biked all over England, Scotland and Europe this year! It requires a lot of prep to avoid my Raynaud’s flaring up and it helps that my partner supports me with the prep and checks in to make sure I’m warm enough whilst riding along. I have heated glove liners which work wonders and wear multiple layers of the right warm clothing. It’s all about making sure you prepare for all conditions”

Lisa is currently doing a PhD at the School of Architecture at Nottingham Trent University. With a history of designing fashion wear, she decided to involve her condition and work towards something that other people may benefit from in the future. She is currently developing ‘assistive/ therapeutic’ clothing for people with connective tissue related conditions. Sessions are going well but Lisa is looking to recruit some more people before the study closes at the end of March 2018.



“It is important to tell others of your condition as it explains why you may not be able to do certain things. There are days when you can feel frustrated at not being able to carry out simple tasks, but having a great support network really helps with your mental attitude! It may be your family, friends or a charity. Being able to talk to someone with a positive attitude helps you keeps you positive”

Future fashion: assistive clothing for Raynaud’s

Clothing is an integral part of our lives and yet if you have difficulties putting on or taking off garments, struggle to stay warm or need additional physical support, every day can prove challenging.

With Raynaud’s it can be difficult to prevent your extremities from getting cold, and research has led to the use of insulated lining and fabric containing silver, which keep more heat in/ prevent heat loss and can prevent or reduce the severity of attacks.

To gain a better understanding of the difficulties associated with living with Raynaud’s, scleroderma and several other conditions, including diabetes and arthritis, research is being carried out at Nottingham Trent University into supporting these hidden disabilities through textile developments.



Lisa reviewing samples with colleague Sarah Walker (left)

“As someone living with Raynaud’s, it is an area of research particularly close to my heart and I’m extremely keen to include the Raynaud’s community.”

Participants will be invited to take part in structured discussions and/or workshops before the end of March 2018, either face to face, or via skype link.

To find out more or to take part in Lisa Shawgi’s research programme visit www.sruk.co.uk/research/take-part

Lisa was awarded funding to carry out this research from The AHRC-funded Midlands3Cities Doctoral Training Partnership (M3C)



BBC2's "Trust Me, I'm A Doctor" features Raynaud's

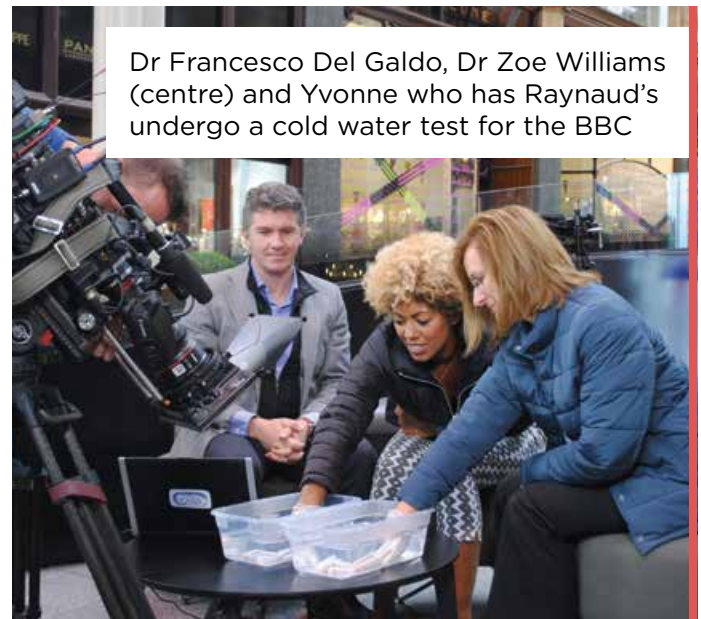
We are delighted to announce that on Wednesday 17th January we featured on the BBC Two Programme, Trust Me I'm a Doctor.

Raynaud's has never been featured on the BBC before and so this episode was groundbreaking for SRUK and the Raynaud's community.

During the programme Dr. Zoe Williams spoke with Dr. Francesco Del Galdo, Head of Scleroderma Programme at Leeds Institute of Rheumatic and Musculoskeletal Medicine about the condition of Raynaud's, the two different types: Primary and Secondary Raynaud's and how the condition is diagnosed.

Dr. Williams met several people living with Raynaud's and underwent a cold-water test alongside Yvonne (pictured) and Julia, to show how thermography imaging is used to determine the severity of Raynaud's.

If you missed the episode you can catch up on demand by visiting: <http://www.bbc.co.uk/programmes/b004j9gn>



Dr Francesco Del Galdo, Dr Zoe Williams (centre) and Yvonne who has Raynaud's undergo a cold water test for the BBC

Find out how Raynaud's is diagnosed

We know that many people living with Raynaud's are unaware of how an official diagnosis can be made, so we have worked with the Raynaud's team at Chapel Allerton in Leeds to develop videos explaining the different tests used to diagnose Raynaud's. **You can view all of the videos online at: sruk.co.uk/tests**

The tests featured are:

Capillaroscopy - this is a non-invasive test where the clinician will use a microscope to look at the formation and structure of the capillaries (blood vessels) at the nailfold (the cuticle of the nail). The shapes of the blood vessels are a diagnostic marker for Raynaud's and connective tissue disease.

If you have a manicure ahead of the test, it is important to ensure the cuticle is not pushed back or cut. It is also helpful to have nail polish free nails for this test.





Cold Water Test - This is a functional test to see how the blood vessels in your hand react to cold water. You will be asked to place your hands under a thermography camera before the test begins. The water will be around 15 degrees and you will be asked to place your hands fully in the water for 1 minute. After 1 minute, you will be asked to remove your hands and using the thermal imaging camera the clinician will see how quickly your hands take to warm up. This test helps to diagnose the severity of Raynaud's.

As part of this test the clinician may also use Laser Doppler Imaging (LDI). This is a piece of equipment that uses infrared laser beams to create an image of the blood flow in the hands.

Success diagnosing Raynaud's in Leeds

As part of Scleroderma Awareness Month 2017 we held our first mobile clinic in Leeds city centre, diagnosing Raynaud's on the street and screening for scleroderma markers.

During the week we screened 623 people with 556 receiving a Raynaud's diagnosis. Everyone who received a Raynaud's diagnosis received a referral letter to the Raynaud's clinic at Chapel Allerton Leeds run by Dr. Francesco Del Galdo alongside information on Raynaud's and self-management from the charity.

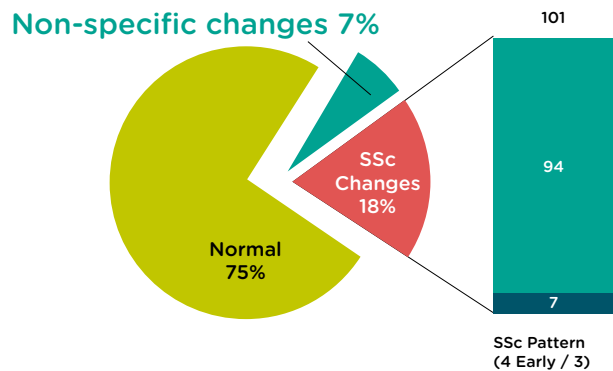
In order to diagnose Raynaud's, everyone who entered the clinic took part in a quick demographic questionnaire and a clinical screening before a capillaroscopy and thermography test was performed.

250 people (45%) were unaware of Raynaud's when they entered the clinic.

The capillaroscopy was conducted to look at the morphology of the capillaries (blood vessels) at the nailfold (the cuticle of the nail). The shapes of the blood vessels are a diagnostic marker for Raynaud's and connective tissue disease.

Out of the 556 people who received a Raynaud's diagnosis, 75% had a normal capillaroscopy, 7% had non-specific changes (meaning the results

were not normal but were not marker for a specific autoimmune condition) and 18% were showing changes related to scleroderma.



For this cohort of 18% it means that they can now be closely monitored by the scleroderma team in Leeds and any signs that the condition is developing can be quickly addressed.

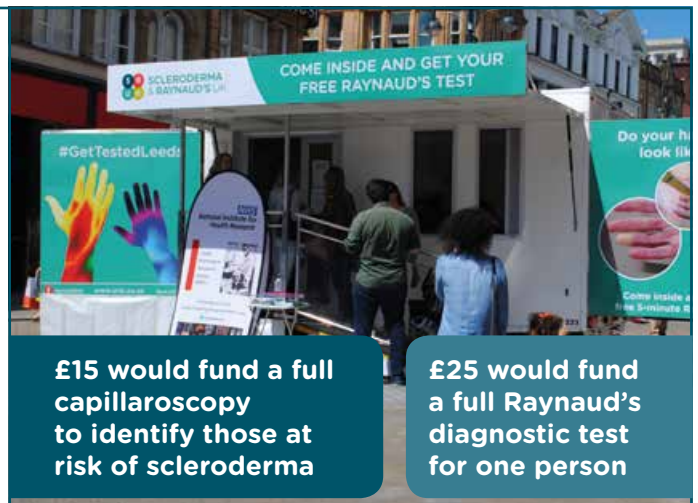
The mobile clinic was a huge success in not only diagnosing Raynaud's but also enabling very early diagnosis of scleroderma. It was due to this that BBC2's "Trust Me, I'm A Doctor" joined us on site to talk about the initiative and Raynaud's.

Help us fund another mobile clinic

When we launched our first mobile clinic in June 2017, we received 282 requests for the mobile clinic to visit other areas in the UK. There is a vital need for Raynaud's to be properly diagnosed and we want to bring the mobile clinic to more people this summer.

To do this we need your help. By donating today you can help us give more people the diagnosis they need and ensure that people showing early signs of scleroderma are cared for.

Donate today by calling or 020 3893 5998 or visiting www.sruk.co.uk/donate



Let's get to #KnowRaynaud's this February

Raynaud's Awareness Month takes place in February and we're asking you to help everyone get to #KnowRaynaud's.

During February we will be tackling the lack of understanding and awareness through our campaign #KnowRaynaud's, encouraging more people to seek medical help and advice if they regularly experience one or more Raynaud's symptom.

From our survey we know awareness of the condition is low and we need your help to change this:

- Over three quarters of people had never heard of Raynaud's
- Only 4% could confidently identify the symptoms of Raynaud's
- 35% of respondents thought that they could 'catch' the condition from someone else

We have a range of activities taking place in February for you to get involved with to tackle this lack of understanding.

Cosy Up with a Coffee

At SRUK we are only able to provide support to everyone affected by Raynaud's through fundraising. So this February we are asking you to hold a coffee morning to raise awareness and funds.

Your coffee morning will help us continue to be there for everyone with the condition, through our support services and research programme.

Get your friends, family and colleagues together and enjoy some cake and hot drinks. You may wish to ask everyone to bring cakes with them and have a competition to crown 'best baker' or 'cake decorator' depending on whether your friends bake or not.

Organising your coffee morning is simple with our free 'Cosy Up with a Coffee' pack. To get yours simply call 020 3893 5998 or email fundraising@sruk.co.uk

If all our magazine readers organised a coffee morning and raised just £25.00, together we would raise a massive £52,025.00.



Put Up an Awareness Poster

Inside your magazine you will find posters and flyers to help increase awareness and understanding of Raynaud's this February.

Please do consider displaying these in your local community to support people experiencing Raynaud's symptoms.

We have made some suggestions as to where you may be able to display these, to gain the greatest awareness in your community, these can be found on the reverse of the poster.



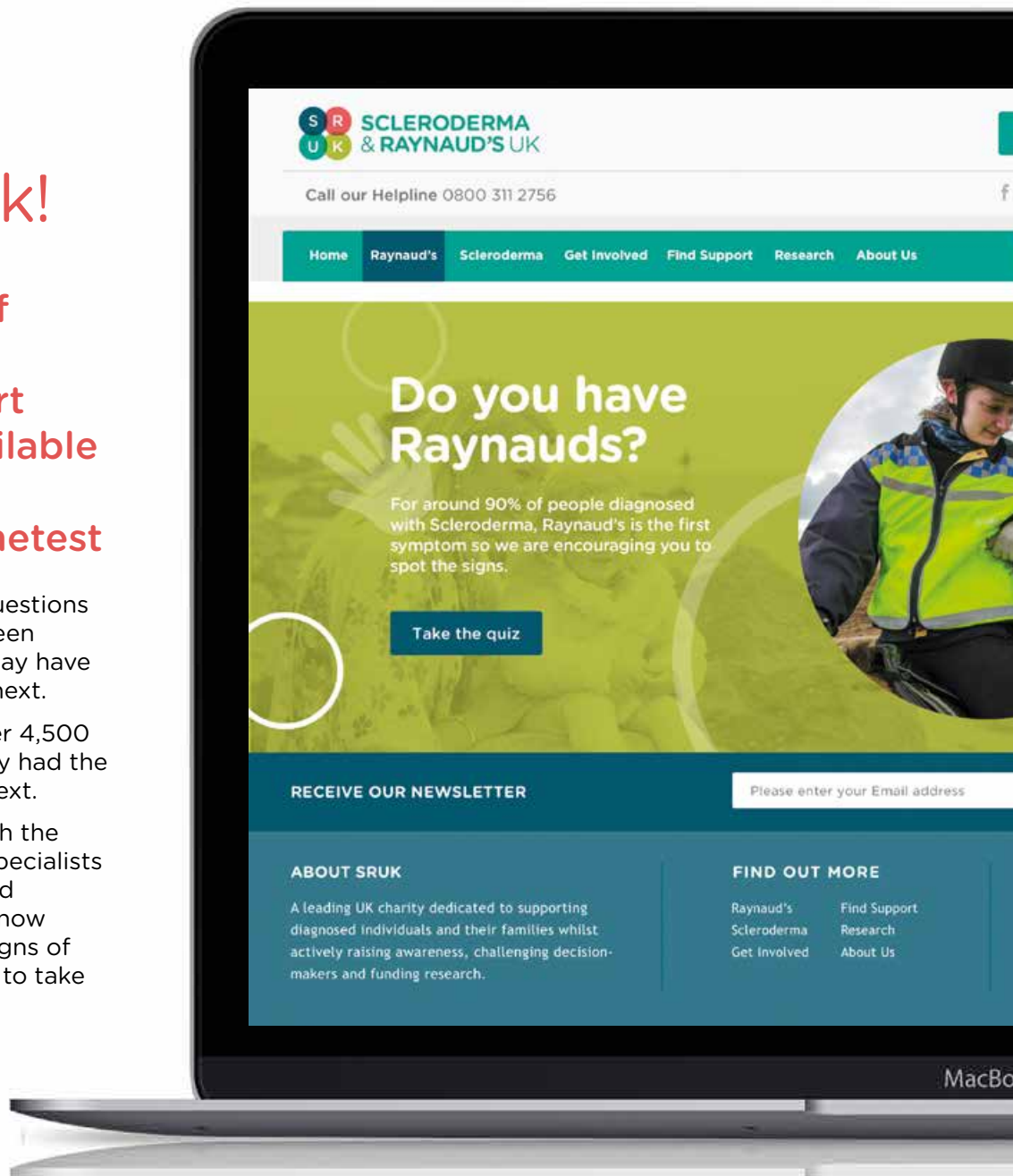
Our online Raynaud's Test is back!

To help identify if people may have Raynaud's, a short online test is available via our website: sruk.co.uk/takethetest

Users will answer 5 short questions and receive a diagnosis screen letting them know if they may have Raynaud's and what to do next.

Last year we supported over 4,500 people to understand if they had the condition and what to do next.

Our test was developed with the support of top Raynaud's specialists Professor Ariane Herrick and Dr John Pauling, so if you know someone who is showing signs of Raynaud's encourage them to take our test this February.



#firstflare

Take part in our social media campaign and share the moment you had your first Raynaud's symptom or attack in 2018.

Let us know where you were, what you were doing or post up a picture of your Raynaud's to spread awareness of the impact the condition has on your daily life.

Simply use the hashtag **#firstflare** and tag us **@WeAreSRUK** so we can share your post.

"#firstflare when you get in your car first thing on a cold morning. You set off and then your fingers become numb **@WeAreSRUK"**

@WeAreSRUK /WeAreSRUK

FREE Products Up For Grabs!

Shop during February and receive a FREE pair of Heat Holders socks RRP£7.

Visit www.sruk.co.uk and spend £10 or more during February to receive a FREE pair of socks (limited to one per person).

Keep an eye on SRUK's social media, we'll be giving away FREE products each week, so make sure you don't miss out!



Myositis Under The Microscope

Myositis is a rare condition that affects the muscles. The term myositis means “inflammation of the muscles” and it is usually caused by an underlying problem with the immune system, where it mistakenly attacks healthy tissue.

Types of Myositis

There are different types of myositis which all affect the muscles, including:

- **Polymyositis (PM):** which affects many different muscles, particularly the shoulders, hips and thigh muscles; it's more common in women and tends to affect people aged 30 to 60
- **Dermatomyositis (DM):** which as well as affecting the muscles causes a rash; it's also more common in women and affects both adults and children
- **Post-infectious reactive myositis:** which you can get after some viral infections and causes the muscles to become inflamed; this type of myositis is usually mild and settles without treatment
- **Inclusion body myositis (IBM):** which causes muscle weakness in the quadriceps (main thigh muscles), weakness in the forearm muscles that flex the fingers, and weakness in the muscles below the knee, which can cause foot drop, making it difficult to lift the front part of your foot and toes and causing the foot to drag on the ground when walking; IBM is more common in men and tends to occur after the age of 50.

Although the condition affects adults and children, the childhood form possibly has different underlying causes and behaves somewhat differently from the adult form. Children can be expected to make a complete recovery. However, Myositis is a rare disease in any of its forms.

Symptoms of Myositis

In most of these conditions, the voluntary muscles break down due to inflammation. The main symptom of these illnesses is muscular weakness which can vary from week to week or month to month, although it tends to get worse without treatment.

Other symptoms can include:

- Skin rash
- Muscle pain
- Fatigue
- Generally feeling unwell
- Trouble swallowing
- Shortness of breath

People often have difficulty climbing stairs, rising from a seated position, turning over in bed, raising their arms over their head, and grasping items with their hands, and many become prone to falls.



Dermatomyositis Photocredit: Healthline.com

Symptoms can appear gradually, over a period of months or even years, or it may develop more rapidly, within days or weeks.

In addition to the above, with dermatomyositis, red or purple-coloured rash often appears on the face (eyelids, nose and cheeks), back, upper chest, elbows, knees and knuckles.

The rash can be itchy or painful, and you may also get hard lumps of tissue under the skin called calcinosis.

The main signs are muscle weakness, painful or aching muscles, tripping or falling, and extreme tiredness after walking or standing. If you have any of these symptoms you should see your GP. Early detection and prompt treatment will provide people with the best possible chance of remission.

Treating Myositis

There are a number of ways to treat myositis, although there are no specific treatments for it.

- Exercise and physiotherapy might be prescribed according to your case
- Steroids are the main type of medication used to treat polymyositis and dermatomyositis. They can include creams and tablets
- Disease-modifying anti-rheumatic drugs (DMARDs) such as azathioprine, methotrexate, cyclophosphamide or mycophenolate suppress your immune system and help reduce inflammation
- Intravenous immunoglobulin therapy may be needed in very severe cases of myositis where severe muscle weakness is causing life-threatening breathing or swallowing problems
- Biologic therapies, may also play a part in managing myositis in people whose symptoms don't respond to conventional steroids and immunosuppressive medication

How do you get Myositis?

There may be a host of reasons why an individual develops Myositis, it is usually down to a number of factors both genetic and environmental, and nothing a particular individual has done themselves. Most doctors think that Myositis may be an autoimmune disease. Other doctors feel Myositis may be started by a virus or the combination of a viral infection and defective immune system.

Myositis and Overlap Syndrome

As with most autoimmune diseases, Myositis seems to enjoy company. Overlap Syndrome is where a patient is diagnosed with two or more autoimmune diseases such as Scleroderma or Lupus.

The treatment of overlap syndrome is mainly based on the use of corticosteroids and immunosuppressants.



This information has been taken from NHS Choices, Myositis UK and Understanding Myositis.org. For further information about the conditions please visit sruk.co.uk/myositis

A Hands-On Approach

Nicola is an Occupational Therapist who has been working at Salford Royal Hospital for the last 5 years. Over the past year she has been based in the Hand and Rheumatology service offering one-to-one and group sessions to individuals with a variety of conditions including Rheumatoid Arthritis, Osteoarthritis, Fibromyalgia and scleroderma.

We explore the effects of Scleroderma and Raynaud's on the hands and how this can be managed with treatments, aids and support from other services.



How can Raynaud's affect the hands?

Certain symptoms of Raynaud's can be quite debilitating as they can last for a number of hours impacting on the everyday use of the hands. This can affect an individual's ability to carry out personal care and also work and leisure activities.

Triggers of Raynaud's and treatments

To identify a suitable approach to treatment, it is important to explore the trigger for the onset of symptoms in each individual. Triggers include:

- Cold temperatures/a sudden drop in temperature
- Emotional distress (Stress/ anxiety)
- Certain lifestyle choices
e.g. stopping smoking, regular exercise (1)

Occupational Therapists working within Rheumatology are responsible for identifying any potential triggers and treating them accordingly. This involves carrying out a thorough interview detailing an individual's daily activities, including leisure and social activities. Through this the impact of certain lifestyle choices can be explored. Smoking nicotine is known to compromise circulation so stopping or reducing nicotine intake is likely to help with symptoms (2). In contrast, regular exercise is known to have a positive effect on circulation so introducing this into a weekly routine can improve symptoms.

Raynaud's is triggered by exposure to cold temperatures but it can also be due to a sudden reduction in temperature even in quite a warm climate (3). Wearing silver and/ or thick gloves/ socks in colder environments can help with

prevention and management of Raynaud's attacks. Gloves, socks or clothing made with pure silver fibres, help by reflecting 95% of the body's energy back to the skin.

This can make them a lot warmer compared to conventional socks, gloves or items of clothing. (4). It is also advised to wear layers (including thermal undergarments) to help increase the body's core temperature and retain warmth. It is important not to warm cold extremities (hand/feet) too quickly, for example by submerging in hot water, as this can cause damage to the blood vessels.

Relaxation techniques are beneficial for those whose Raynaud's is triggered by stress or anxiety. Stress is known to narrow the blood vessels (vasoconstriction) thus compromising circulation particularly to the extremities. By learning to manage stress and effectively use relaxation strategies, Raynaud's attacks and ulceration (secondary to poor circulation) may be prevented. Diaphragmatic breathing exercises can be used to help minimise anxiety in a stressful situation such as an acute onset of symptoms.

Muscle relaxation techniques, such as the tense and relax method, can have a dual benefit of promoting circulation and releasing tension. Guided imagery can be used to help reduce stress and help an individual succeed in making health-related behaviour changes (5).

Please see the website for more information on relaxation techniques.

How can scleroderma affect the hands?

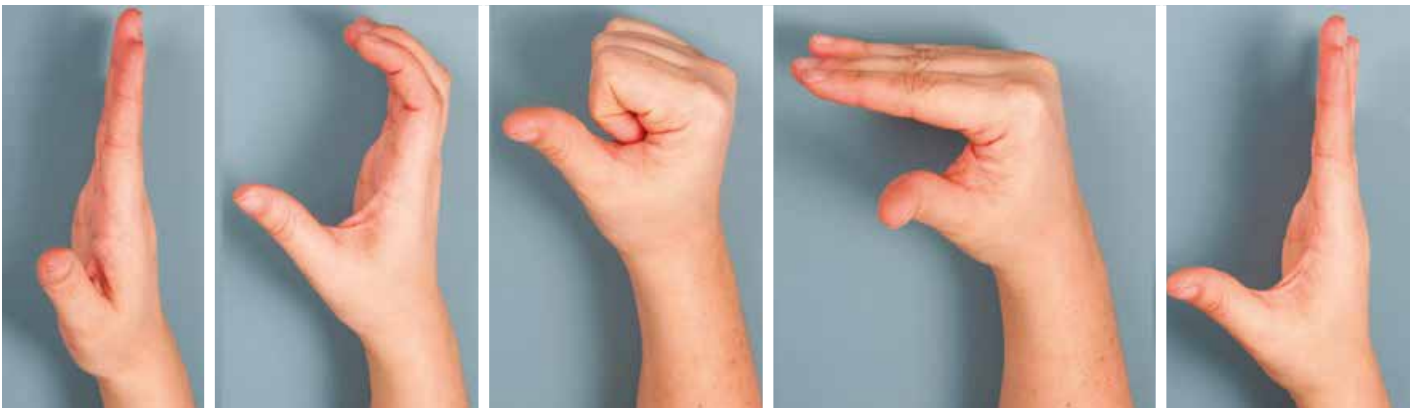
Many individuals with scleroderma experience tight hardened skin, which can become dry and itchy. As such, it is important to keep the skin well moisturised. Skin tightening of the hands in particular is very common.

This can be painful and significantly compromise the range of motion in the hands, impacting upon an individual's ability to carry out their daily activities. To try to reduce the impact on hand function Occupational Therapists can advise on preventative measures.

Preventative measures

Hand exercises can prevent or slow the progression of contractures. Contractures are where the soft tissue structures around a joint become tight and can shorten, leading to stiffness or deformity. Flexibility or stretching exercises are therefore best started straight away, ideally before there is any loss of range (6). **Hand exercises can help to:**

- Reduce pain, stiffness and swelling
- Improve joint flexibility and muscle strength
- Help to prevent the development of deformities



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It is beneficial to relax the muscles of the hands prior to stretching; this can be done by placing the hands on or under a warm wheat bag, in warm water or using a specialist wax bath (provided you have no dressings or open ulcers on the hands). It is important that hands are warmed slowly and gently and if using wax it is recommended that you seek advice from a Physiotherapist or Occupational Therapist.

Please see a selection of recommended exercises on the website www.sruk.co.uk/handsandfeet/ but be advised that it is always best to seek advice from a specialist therapist who can tailor an exercise programme to your individual needs. Where this is not possible, there are also excellent online video resources that can help to ensure you are completing the exercises correctly, such as that produced by expert Janet Poole (7).

Some people with Scleroderma feel that splints help in preventing the progression of contractures but there is currently limited research specific to splinting and scleroderma.

Provision of splints is based on an individual specialist assessment to identify the right type of splint and level of support for each individual, which needs to be closely monitored.

Utilising small aids, such as jar openers, right-angled knives or key turners can minimise the strain on joints, help to minimise discomfort and maximise independence.



A Hands-On Approach Continued.

Dealing with ulcers

Digital ulcers are seen in more than half of the individuals that have a diagnosis of scleroderma and often affect hand function. The combination of Raynaud's and skin changes experienced in Scleroderma leads to tissue breakdown, which can result in ulcers. To help prevent and manage digital ulcers it is recommended that you insulate hands from the cold, avoid direct contact with strong detergents and minimise exposure to bacteria. The advice given earlier in this article regarding prevention and management of Raynaud's symptoms will also help to reduce the risk of digital ulcers.

Repetitive pressure (referred to as "micro-trauma") can also cause skin breakdown and ulceration. Activities such as typing can increase the likelihood of ulcers developing on the fingertips. If joints become fixed in a bent position (contractures) it can also be common to develop ulcers over the knuckle areas, where the skin is particularly vulnerable due to being stretched and more likely to be accidentally knocked due to the joint position. Soft, stretchable Silipos® caps and/or sleeves can be worn to provide increased protection to fingers affected by ulcers during higher risk activities such as when typing. These are designed to protect the small joints or tips of the fingers from further micro trauma, thereby reducing associated pain and risk of ulceration.

Silipos® polymer gel is impregnated with medical-grade mineral oil to help soften tissue; the gel helps to reduce shearing forces and absorbs shock and friction (8). They come in different sizes and can also be trimmed to fit. These should come with an instruction leaflet detailing care, monitoring and wearing instructions and it is important that this is followed, as if fitted incorrectly they can cause problems with circulation.

For more information on Digital Ulcers go to www.sruk.co.uk/scleroderma/digital-ulcers/ and download a factsheet.

With thanks to Catherine McCoy, OT Advanced Practitioner at Salford Royal Trust for her valued input to this article.



Further reading and website references:

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7. You Can Improve Hand Function in Scleroderma, PowerPoint presentation (2013) M. Mayes, MD, MPH University of Texas - Houston ,J. Denay, BSN, MSN, CFNP Harbor Arthritis Center, J.L. Poole, PhD, OTR/L University of New Mexico.
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9. www.rehabmart.com



RARE DISEASE DAY®

Rare Diseases Day

28 February 2018

SRUK will be supporting Rare Diseases Day February 2018 to raise awareness amongst the public and decision-makers about rare diseases such as scleroderma and their impact on patients' and carers lives. For Rare Disease Day, which will be during Raynaud's Awareness Month in February 2018, we would be reaching out to members of the public, policy makers, public authorities, industry representatives, researchers, educators and health professionals to raise awareness.

Show your support

Help raise awareness of scleroderma together as a rare disease and talk to your friends about how a condition you have impacts your life. Here's how you can get involved:

Why not send in your stories or photos by post, or email us and we can post your stories and photos on our website or social media (contact details found at the end of article).

Get involved on social media with Facebook, Twitter and YouTube. Follow us and share posts using **#RareDiseaseDay**.

There are also some Rare Diseases Day resources that you can print out including posters to pin up, and banners which can be found on the Rare Diseases Day official website
<https://rarediseaseday.org/downloads>

Why we support it

There are over 6000 rare diseases, for most there is no cure, and this includes Scleroderma. Join us in making the voice of rare diseases heard. SRUK are supporting the day to represent people with scleroderma and their carers.

The more people understand the conditions, the more likely action will be taken, including research to find a cure, support provision across the community and policy changes for better lives when living with the conditions.

What is a rare disease?

In the EU, as many as 30 million people may be affected with a rare disease.

80% of rare diseases have identified genetic origins whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative.

Relatively common symptoms can often hide underlying rare diseases.

This leads to misdiagnosis and delaying treatment and can result in the patient's quality of life being affected, often a lack or loss of autonomy due to the chronic, progressive, degenerative, and frequently life-threatening aspects of the disease.

Contact:

Rare Diseases Day,
SRUK, 18-20 Bride Lane,
London, EC4Y 8EE

Email us at: info@sruk.co.uk

Help represent Scleroderma as a rare disease.

Information on Raynaud's Awareness Month can be found on <https://www.sruk.co.uk/get-involved/raynauds-awareness-month/>

New Heights, Put On Hold

Rebecca Willers (37) speaks to us about raising the profile of scleroderma, it's symptoms, early diagnosis and how her hopes of climbing Everest must go on hold.

Rebecca currently runs Shepreth Wildlife Park in Cambridgeshire, and when she reflects on her earlier days, she was a very healthy child and active teenager.

“Growing up in a zoo, I tended to be rolling around in the mud which must have been a good thing for my immune system, as I was never really ill as a child. I was always very studious and loved swimming. After sixth form I landed a job in a publishing house, so deferred my law degree at university. As a result of my, albeit short, career with the magazine, I ended up as a freelance journalist for many years after, but my passion was always for my zoo, so shortly after my 20th birthday I started working for my family's wildlife park and never looked back. My only regret was not going to university, so instead I took the Open University route and spent all my spare time completing a BSc (Hons) in Psychology, FdSc Zoo Management, Veterinary Assistant Diploma and an MBA. My next step was a PhD”

In the early days at the wildlife park Rebecca and the team would work crazy hours late into the night looking after the rescued animals, but in the latter years their focus moved to conserving endangered species. Rebecca launched a charity back in 2011 with the sole purpose of saving endangered species, including the opening of a dedicated hedgehog hospital, which now admits over 650 poorly and orphaned hedgehogs every year.



Hiking in the UK with friends



The charity came off the back of lots of fundraising they were already doing. Rebecca had started a few years before completing several sponsored open water swim events, including the English Channel (relay), this ignited her passion for extreme sports and from there she started climbing mountains, including Kilimanjaro.

In 2015, Rebecca was on a trek through the jungle with the Tiger Protection and Conservation Unit (TPCU) in Kerinci Seblat National Park in Indonesia. It was part of a sponsored event she had arranged with other UK zoo directors, in a bid to raise awareness and funding for the plight of the Sumatran tiger, as well as actively being involved in anti-poaching work. The teams were split into smaller units and spent their nights living rough in the jungle. Many of the UK team were ill throughout the trek, but despite sleeping in very close proximity, Rebecca remained healthy.

When she returned to the UK, Rebecca was hit by many symptoms over the next 18 months, including heart burn, chest pains, fatigue, weight loss, various virus', swollen hands, adverse allergic reactions, painful joints and shortness of breath. Each time these symptoms would be investigated nothing of any significance would result. She then developed Raynaud's during spring this year and when this continued into summer went to see her local GP who referred her to the rheumatology department for suspected arthritis.



Swollen, painful symptoms

She was eventually diagnosed (by phone call) with the disease in September 2017, before boarding a plane for an event in Hungary. "I hadn't heard of the disease before, so didn't really think anything of it at the time, my only concern was whether I could still climb Everest the following month and start a family. It was only when I mentioned it to a doctor at the event I was attending, that his response made me realise that I perhaps needed to do a bit more research into it.

I received the formal letter from the consultant when I returned the following week, having been researching on the internet myself, it was at this point I realised I had the diffuse form, which came as a bit of a shock." Rebecca, needed more answers, so investigated a way to see Professor Denton and very soon had a private appointment lined up.

"Prof Denton was amazing. He explained everything in a clear and precise manner. He was evidently interested in my situation and left me feeling very confident with the care I would receive.

"My symptoms began to manifest two years ago, however I'm still fortunate as many people are not lucky enough to have had such an early diagnosis"

I explained I had asked for an NHS referral to the Royal Free, as the leading experts in this condition, and he suggested that shared care with my hospital in Cambridge was the logical step forward, so I could still have all my tests locally. I have now been on methotrexate and Losartan for 2 months, and will be seeing Prof. Denton again in January to assess my progress with this medication"

Just this week, Rebecca has come to the end of her anxious wait to discover that it has not yet spread to her internal organs and is immensely happy.



Rebecca at work in the Zoo, before being diagnosed



Meeting the anti-poaching team in Sumatra 2009

"Animals are my life but now I sit in the zoo's office filling in paperwork avoiding the cold. I'm not sure what triggered the disease, the environment, a tropical parasite or perhaps this has just been in me all along, either way, I'm facing it head on. The scariest thing has been how rapid the onset has been so far, but having met with Prof. Denton I am now ready to face the next three years with confidence, which apparently is likely to be the most aggressive period for me having anti-RNA Polymerase III antibodies"



Climbing Snowdon with friends in 2017



With friends at the 'Survival 2016' event



Kayaking in East Anglia in 2016

“I felt I was letting people down, by not going on the trip, but I’m embracing a very positive attitude towards my condition, as I’m acutely aware of how lucky I am. I have always been a very positive, upbeat person and there is no way this condition will change that about me. As soon as I regain my energy levels I will be planning the next mountain challenge, just perhaps to a slightly warmer destination.”

Rebecca recently shared her story with the Daily Mail and obtained some incredible coverage worldwide, on-line and locally by appearing on ITV News, Anglia.

“It was great to raise the profile of scleroderma, however, the press do tend to sensationalise headlines. Whilst it’s frustrating to be edited in a way that people don’t get the full story, I hope it has overall started to get more people talking about the condition and its symptoms.

My hope would be for others to also get earlier diagnoses because of greater awareness. I have been overwhelmed by the global support people have given me, since this news piece, and how kind they have been to share various treatment ideas with me.

I plan to research these and share them with the SRUK in the hope that some of these may help fellow sufferers in the future”.

Rebecca shared that one of the hardest things to face, was being told she couldn’t go on a trip of a lifetime. She was forced to cancel a climb of Mount Everest, in aid of the Shepreth Wildlife Conservation Charity’s Hedgehog Hospital and TCPU’s team in Sumatra, after medical advice.

So, with her disease to conquer first, plans for the climb must go on hold.

To read more about Rebecca’s story and see her interview with ITV Anglia, please visit www.sruk.co.uk/personalstories/rebecca

Exploring The Digestive System

Many people with scleroderma have problems with eating, swallowing, digesting and passing food and sometimes drink. Studies suggest that nearly 90% of patients with scleroderma have some degree of gastrointestinal (GI), with approximately one half being symptomatic. Severe GI problems including malabsorption and intestinal pseudo-obstruction, are much less common, affecting less than 10%, during the first 9 years of illness.¹

Other research into this area, tells us it has several negative effects including:

- One of the most socially disruptive physical symptoms people have to cope with²
- Symptoms can be associated with sleep disturbance³
- It can have a negative influence on quality of life⁴

Eating & Swallowing

Once food enters the mouth cavity the function of the mouth area is to chew it up and make it more transportable into the stomach. One of the problems in scleroderma is that the size of the opening of the mouth can be reduced by the scarring that occurs in the tissues, making the mouth less mobile and less able to be opened wide. This makes it difficult for some people to eat large pieces of food.

Another problem may be due to Sjogren's syndrome, where there is a reduced production of saliva from the salivary glands. Saliva is necessary to lubricate the food so when chewed, it is softened and becomes more readily swallowed. In addition to Sjogren's Syndrome, some drugs can also cause a reduction in the production of saliva.

The Oesophagus

This is responsible for passing food down from the mouth to the stomach. The passage of food (past the diaphragm) is assisted by muscle contraction which is completely involuntary. However, for this contraction to work the muscle must be able to contract, the nervous control must be intact, and a valve must function at the lower end of the oesophagus to prevent food coming back up.

Around 50% of people with scleroderma have a problem in this area. This happens because there is a lack in the ability of the muscle to contract. Although very often the upper portion works quite well and food is moved down, when it gets to the point of the junction between the oesophagus and the stomach, (point 5 of diagram) the muscle contractions become inco-ordinate, causing very weak contractions, so the food isn't propelled forward and therefore stays at the opening.

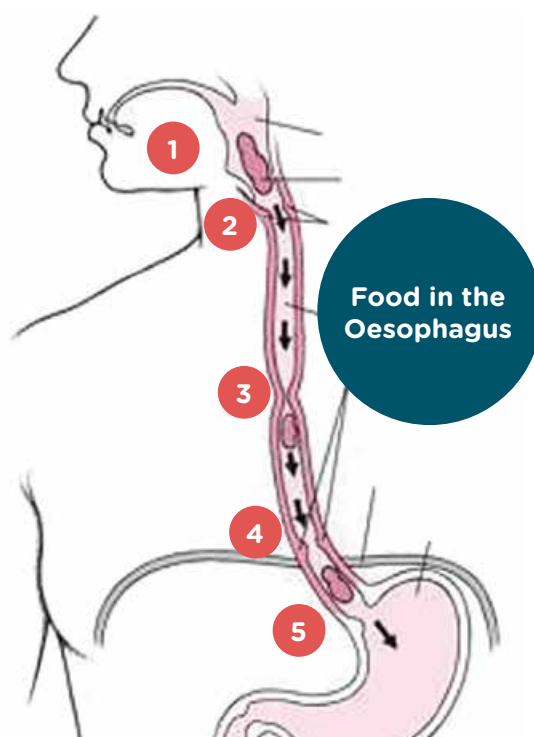
There is also a tightly controlled valve at this junction, which needs to stay relaxed for food to pass through. It also contracts to prevent food and stomach acid from coming back up (reflux).

What can help?

Eat bite size pieces of food

Have soups and liquid options

Do mouth exercises to improve mouth mobility



Exploring The Digestive System Continued.

pass through. It also contracts to prevent food and stomach acid from coming back up (reflux).

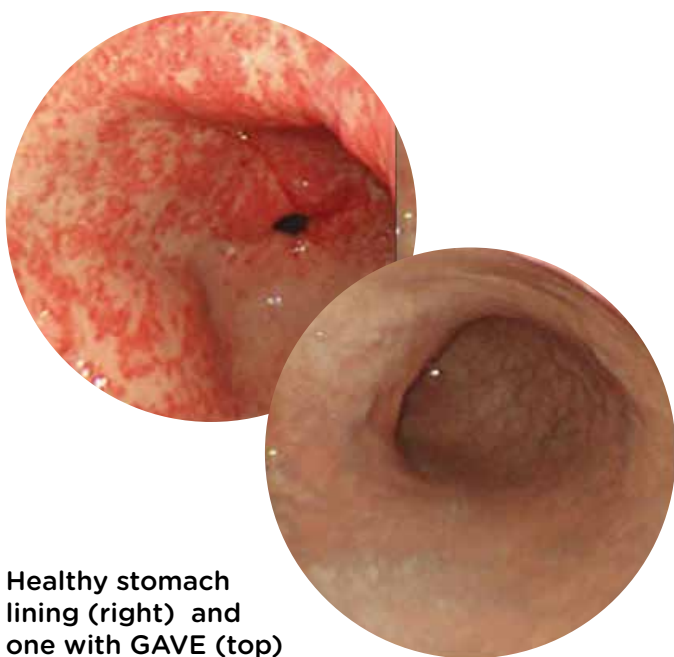
In people with scleroderma the valve can go into a tight spasm, rather than stay relaxed, which inhibits movement of food, or it may be unable to work and remain open.

When the food in the stomach refluxes into the oesophagus, it causes irritation and inflammation, due to the hydrochloric acid in the stomach. Continual inflammation can cause excessive scarring, producing a stricture, which is a tight band or narrowing of the area.

In most of cases, can be treated very effectively, by regular medication to reduce the production of stomach acid. A stricture can also be treated via surgery where a tube is passed down the throat, under general anaesthetic, and dilated to improve the widening.

The Stomach

The stomach breaks up food before releasing it into the small intestine. Often people with scleroderma report bloating, nausea after eating, indigestion and a feeling of being full after only a small meal. It is important to discuss this with your consultant to see what investigations may be done to understand what the problem may be. The course of treatment may be in line with any other symptoms such as diarrhoea or constipation, and where you feel your challenge is at its greatest.



Healthy stomach lining (right) and one with GAVE (top)

In a small proportion of people GAVE (gastric antral vascular ectasia 5) may be diagnosed.

Also known as Watermelon stomach, this is a condition in which the lining of the stomach bleeds, causing it to look like the characteristic stripes of a watermelon when viewed by endoscopy.

Signs and symptoms of watermelon stomach include blood in the stool, hematemesis (vomiting blood) and anaemia (A condition in which the blood does not have enough red blood cells to carry oxygen throughout the body) The exact cause of watermelon stomach is unknown; however, it is often diagnosed in people with other chronic conditions such as cirrhosis (scarring of the liver and poor liver function). Treatment can consist of surgery and/or medications to stop or control the bleeding.

The Small Intestine

This is another significant area in the gastrointestinal tract as the function of the small intestine is to absorb nourishment. The food, after it has been partially processed in the stomach, goes into the intestine where many enzymes break it down into simple products, which are then absorbed and used by the body. The intestinal tract moves food (because it can't stay fixed in one area), through contraction waves (peristalsis) in the same way as the oesophagus.

In a minority of people with scleroderma the food in the intestine cannot pass on correctly. The small intestine is normally sterile and contains no germs, but when there is an abnormality and the food doesn't move along freely, then there is a risk of overgrowth of bacteria. There is a breakdown of food products by bacteria which are irritating, and this produces diarrhoea. This diarrhoea has a major side effect, which is the problem of absorbing food, so the knock-on effect is weight loss, and not having enough nutrition in your diet.

People who appear to have this problem can easily be tested in a variety of ways and treatment with long term antibiotic cycles can be successful. Certain long-term antibiotics can be used to control bacteria growth in the bowel and help relieve that problem area.

What can help avoiding reflux?

Avoid triggers (e.g. spicy or fatty foods, fizzy drinks)

Avoid eating late at night

Eat smaller portions of food more frequently

Colon

Normally the colon's job is to slowly move food along the body, to absorb salt and water from stools and the presence of bacteria in the colon assist with this process. In people with scleroderma excess water can be removed causing hard stools and constipation.

Eating certain foods can help with this issue, or taking a laxative after consultation with a healthcare professional or pharmacist can help. It has been suggested that a high fibre diet, which may assist with diarrhoea, could make constipation worse.

In a study conducted by the RSA in 2010⁽⁶⁾, incontinence was the most reported problem and the main cause of poor quality of life.

The main concern is, however, often a combination of problems and 67% (from a survey of 1187 members) reported multiple bowel problems including diarrhoea, constipation, incontinence and rectal prolapse.

Anus

The core function of this area is to maintain continence. Key problems in those with scleroderma could be thinning and wasting away of the internal sphincter⁽⁷⁾ leading to incontinence which affects around 3rd of people with scleroderma.

An exercise regime can be considered such as pelvic floor retaining and other treatments such as sacral nerve stimulation and posterial tibial nerve stimulation, have reduced incontinence and improved symptoms therefore giving some reported improvements, overall.

What can help relieving constipation?

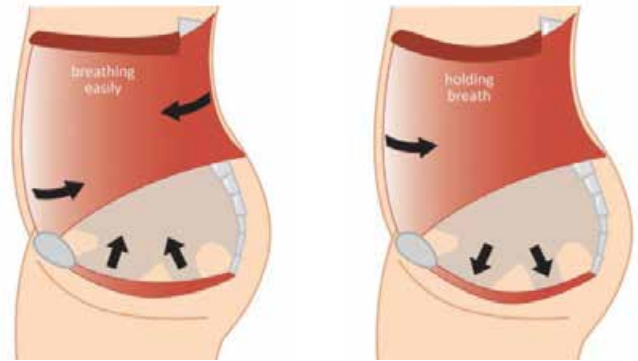
Eat prunes or dates every day

Gentle exercise may assist the bowel function

Drink plenty of water

Take a laxative if necessary (prucalopride)

Pelvic Floor Muscle Contraction



Correct action

The pelvic floor lifts, the deep abdominals draw in and there is no change in breathing

Incorrect action

Pulling the belly button in towards the backbone and holding your breath can cause bearing-down on pelvic floor

If you have any advice or information on what has worked well for you, that you would like to share with our community, please send details to info@sruk.co.uk.

Dr Harrison is a Consultant Gastroenterologist at Shrewsbury and Telford Hospitals NHS Trust, her sub-specialty interest is nutrition.

We invited Dr Harrison to explain the key problem areas, suggest some solutions and consider what is new in treatments at our conference in September 2017.

To watch her presentation 'From Top to Bottom' and for further information regarding GI issues please visit our website and download a factsheet www.sruk.co.uk/GI



References:

1. Stephanie A Kaye-Barrett, Up-To Date for Patients.2010.
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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 you receive a voicemail please leave your name and number and you will receive a call back within 24 hours.

Volunteers man our helpline: Belinda, Helena, Kim, Penny, Paula, Rosemary, Amelia and Katherine who have many years of experience and training. 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. **After all the call is about you, not us.**



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
Burton	Helen Nutland
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
West Midlands	Jane Beach



Up for a Challenge In 2018?

As we all huddle down for the winter, we can't help but look forward to our fantastic summer events and beyond! September sees the return of the absolutely fabulous Thames Path Challenge!

The Thames Path National Trail is unique, the only long distance walkway to follow a river for its entire length. With the urban beauty of South West London giving way to the scenic towns and villages of Surrey, it is a beautiful route from start to finish.



Nina and her daughter Priya took on the challenge in 2016 and raised a fantastic amount for the cause:

“We decided to do the Thames Path Challenge 2016 in support of SRUK because we have both found that very few people we meet have heard of scleroderma, and we feel strongly it is an area that needs greater public awareness in order to raise funds for research.

I have suffered from limited scleroderma myself since 1998 and two of my daughters have Raynaud's syndrome. I am fortunate that my illness still allows me to lead an active life, however I am aware of the many people with severe complications of scleroderma.

The Thames Path Challenge was a fantastic event to get involved in. We decided to walk the route, however saw many people jogging and running for a variety of charities. It was very well organised, with rest stops, refreshments and clear signposting all the way. Despite having rain nearly all day and finding the last 4 km quite tough going, it was a wonderful feeling to reach the finish line and receive a welcome glass of prosecco and our medals.”

Starting in Putney in southwest London and ending in Henley in Oxfordshire, you can challenge yourself to any of the 25km sections for a gentle day out, take on the 50km half course over the full day, or go all out and attempt a full 100km over two days! It's a fantastically open event to all levels of fitness and we can't wait to see you there!

If you would like to take part, contact the fundraising team on 020 3893 5993 or email fundraising@sruk.co.uk



Our Fantastic Fundraisers!

A massive thank you to **Sofia Casteneda** who ran our inaugural year at the Royal Parks Half Marathon, finishing in 2:32:36 and raising a wonderful **£550.00**.

Thank you and congratulations to **Dale Richards** and **William Thompson** who ran the Great North Run and raised an absolutely fantastic **£562.60**.

A huge shout out to **Kevin Lonergan** who got very filthy and raised a fantastic **£220.00** running the Tough Mudder North West.

Henry Leeson put in an absolutely phenomenal effort, raising **£3,277.61** from his strong finish at the 2017 Dublin Marathon.

Ashleigh Wallage ran the beautiful Henley 10k and raised a brilliant **£150.00**.



Henry Leeson running the Dublin Marathon

Pass SRUK, The Parcel!

Do you end up with a closet full of unwanted Christmas presents every year? Perfect gift, but just not for you! Why not donate them to a good cause!

Post us your unwanted gifts and we will sell them for you online, with all proceeds going to help all those across the UK living with Scleroderma and Raynaud's.

Go on, make a difference.

Post your gifts to:

SRUK Christmas Appeal
18-20 Bride Lane
London EC4Y 8EE



Photo Credit: Teksomolika, Freepik.com

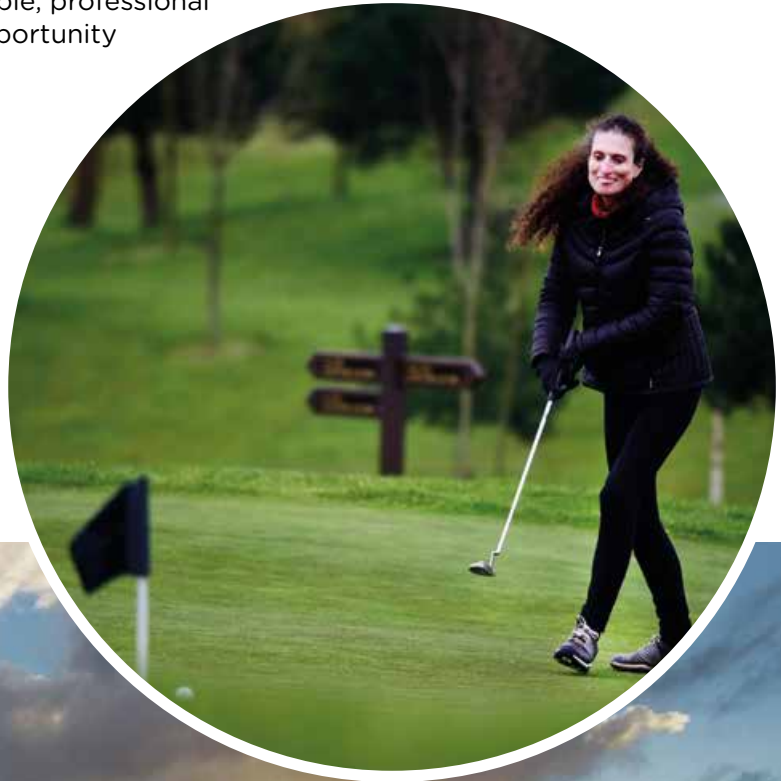
Find Flight On The Fairway

The second annual SRUK Charity Golf Day is once again taking place at the breath-taking Shire Golf Club, London. This is the only course in the UK designed by golfing legend Seve Ballesteros.

With beautiful lakes, wildlife, and an incredible, professional level set of 18 holes, this event is a great opportunity to play one of the best courses in the UK.

For just £75.00 per person play a round of 18 holes on this incredible course followed by a two-course lunch and awards for the best score, longest drive, and closest to the pin.

If you, or any of your friends and family are keen golfers, or you want to just give it a go, you can enter as an individual or as a team. Simply get in touch with us on 020 3893 5993 or by emailing fundraising@sruk.co.uk to register your interest today.



Ways to support us

Firstly, we would like to say thank you. By receiving this newsletter 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

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

www.sruk.co.uk
Helpline: 0800 311 2756
Office: 020 3893 5998

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.

 @WeAreSRUK  /WeAreSRUK

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