

SRUK NEWS

Family and the Future

Chelsea shares her
story on coping
with Raynaud's

Summer Survival Guide

Keep your skin
protected

Pioneering Research

in Scleroderma
and Raynaud's

Doc Spot

Your questions
answered by
our medical
professional

Check
out our
new-look
shop



What we've been doing for you

31st
March

Scleroderma & Raynaud's UK went **live** and the new **website** launched.

5th
April

SRUK attended confidential **NICE meeting** for potential new treatment.

18th
April

Completed production of SRUK branded information **fact sheets**. Fact sheets can be downloaded from the website or ordered by calling our team: 01270 872776.

19th
April

Visited Leeds University and heard from Clinicians and Researchers about their work.

24th
April

Cheered on our runners from Team SRUK at the **London Marathon**. This year we have raised over £11,000.

26th
April

Met key Clinicians and Researcher at **BSR Conference** in Glasgow and had first talks about setting up an alliance to improve care and services for people with rare, autoimmune rheumatic conditions.

14th
May

Attended **Family Day** at the Royal Free Hospital.

17th
May

Met with the **Association of Medical Research Charities (AMRC)** to discuss SRUK membership.

1st
June

New **functionality** added to the **website** with a pay in fundraising button and improved search function.

1st
June

Featured as Unite and Community Practitioners and Health Visitors Association (CPHVA) **charity of the month** - increasing awareness and educating community health professionals about Scleroderma and Raynaud's.

8th
June

Attended EULAR (European League against Rheumatism) congress to represent FESCA (Federation of European Scleroderma Associations) and all the European patient organisations - raising the profile of Scleroderma and Raynaud's amongst European clinicians and organisations.

14th
June

Launched our **first public facing awareness campaign**. This campaign focused on spotting the signs of Raynaud's and how the condition links to the rare condition of scleroderma.

29th
June

World Scleroderma Day (WSD) we joined the world in sharing the official WSD video and our social media campaign #KnowRaynauds reached 108,184 people.

1st
July

First research **funding grants awarded** to improve knowledge and advance treatment for Scleroderma and Raynaud's.

2nd
July

Our first **family day** where, working alongside paediatric specialists, we provided a day of education and support to families with children affected by Scleroderma and Raynaud's.

Dear Supporters

I can't believe that it's nearly a year since I started as the first employee of Scleroderma & Raynaud's UK. So much has happened over the last twelve months and I've met so many amazing and inspirational people, both here in the UK and from across the globe. Whether it's been at the World Scleroderma Congress, at FESCA events or local support group meetings, it is clear that our community all have something in common, which is an absolute determination to make other people's lives better, either volunteering on the Helpline, supporting one another at local groups or providing the best quality healthcare.

But there has been one individual without whose determination, drive and dedication we certainly would not be where we are today. I know that she meant a lot to many of you and so it only seems right that we find a fitting way to honour the memory of Anne Mawdsley. The other week I chatted with Harry, her husband, to get his thoughts, so that we can begin to consider how we might best recognise and commemorate all that she achieved for everyone affected by Scleroderma and Raynaud's.

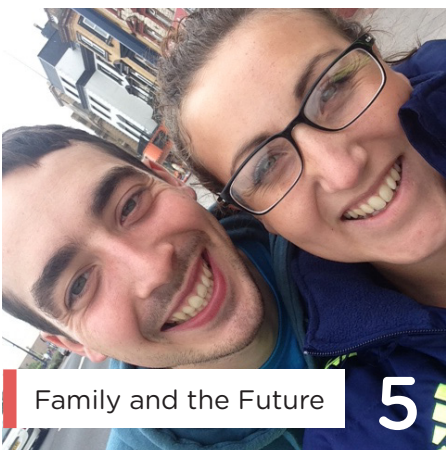
At the annual conference I hope to be able to share with you our ideas. I'm delighted that we'll be joined at the conference by our President and Vice Presidents, Professor Dame Carol Black, Professor Chris Denton and Professor Ariane Herrick who continue to offer invaluable guidance and support to the community. Patients sharing their experiences, clinicians providing practical hints and tips and researchers updating us on the very latest advancements, will also join us.

I hope to meet many of you at this year's conference.

Best wishes,
Sue



- 3 Doc Spot
- 5 Family and the Future
- 7 Prevention is Key this Summer
- 9 Pay in your Fundraising Online
- 10 London Marathon
- 11 Summer Survival Guide
- 13 Increasing Awareness
- 15 Charity of the Month
- 16 World Scleroderma Day
- 17 Sjögren's Syndrome
- 19 Pioneering Research
- 21 On Being Positive
- 23 The BSR/BHPR Guidelines
- 24 Get Involved in Research
- 25 Shop Products





Doc Spot

Your questions answered by our medical professional, Prof. Denton

What are the side effects of sildenafil?

Sildenafil works by opening up blood vessels and was originally developed as a possible treatment for high blood pressure.

In clinical trials for blood pressure, unexpected effects on erectile function in male patients were reported and this led to it being developed as a treatment for erectile dysfunction. Thus one of its main medical uses was originally identified as a “side effect”. It was later found that other blood vessels also benefited in the lungs and extremities and so it is now used for pulmonary hypertension, digital ulcers and severe Raynaud’s phenomenon.

Side effects include effects of dilating blood vessels such as nosebleeds or headache. It can also lower blood pressure and cause dizziness, visual or hearing disturbance. These effects can be serious and should be discussed with your doctor if they occur as, if severe, you may need to stop the drug. It can also interact with other drugs that lower blood pressure or treat angina.

A particular risk is the interaction with nitrates that might be used for angina treatment or in some cases of Raynaud’s. Nitrate side effects of headache or fainting might be seriously worsened and generally these drugs should not be combined.

Overall, sildenafil and other drugs in this class (e.g. tadalafil) are well tolerated and have few side effects.

Does scleroderma get better in the summer months?

It is well recognised that Raynaud’s phenomenon is less of a problem in the summer although it can still occur when there are changes in temperature, for instance entering an air conditioned building in warm weather. Some patients find that change in temperature is more important than actual temperature.

For the same reason, complications such as digital ulcers are usually worse in the winter months. It has also been suggested that complications such as scleroderma renal crisis, that are associated with blood vessel spasm, might occur more often in the winter.

However generally, scleroderma is not influenced by the time of year. In overlap connective tissue diseases, that have features of dermatomyositis or lupus as well as scleroderma, sun exposure may worsen rashes and other features and so sun should be avoided to minimise UV exposure and a high factor sunblock should be used.

Can wax baths really help my Raynaud’s?

Low melting point wax can be used in scleroderma and to help symptoms. The wax is melted and then the hands dipped in and removed. This is repeated and builds up a layer of wax that can be peeled off and this can relieve pain, stiffness and encourage skin hydration and softening. This often benefits those with Raynaud’s Phenomenon but should not be used if the skin is broken or ulcerated. Many patients choose to purchase a wax bath and perform this treatment at home although it is also used by physiotherapists in hospitals. The wax must have a low melting point or severe burns may occur. You should discuss this treatment with your nurses or scleroderma team to make sure it is suitable for you if you wish to try.

Can you get Raynaud's all over the body?

Raynaud's phenomenon (RP) describes the medical condition that results from episodes of spasm of the blood vessels in response to cold or emotional stress. It can occur in the absence of any other medical condition when it is termed primary RP or in association with a disease such as scleroderma, when it is extreme secondary RP.

Both forms of RP can affect any part of the body that has temperature regulated circulation. RP attacks occur when blood is diverted from the extremities and this can occur when the body perceives cold or when blood is being diverted to the muscles. It is part of a general stress response.

It can affect the hands, feet, knees, ears, nose or tongue. There are also reports that RP may cause spasm of internal organ blood vessels such as the heart - this is controversial but some patients definitely report cold associated chest pain other relevant symptoms. In all cases medications that reduce blood vessel spasm such as nifedipine and other agents may be helpful.

What is pre-scleroderma?

(Pre-scleroderma) is a concept that can be confusing to doctors and patients but does have some value. One limitation is that there is no formal definition at the moment although relevant research is ongoing. Like any complex long term disease, scleroderma (in its various forms) can take time to develop and so there will be individuals where some features that may reflect scleroderma have developed (such as Raynaud's phenomenon) but not enough to make a definite diagnosis (of scleroderma).

However not all such cases will necessarily progress and so it is important to look at each patient individually to determine what features they have. The term is most often applied to patients with Raynaud's phenomenon, positive antinuclear antibodies (ANA) and abnormal nail fold capillaries. Studies suggest that a substantial number of these cases (but not all) will later develop scleroderma or a related connective tissue disease over the next 5 years. From a practical viewpoint when a patient is given this label or diagnosis they should ask what features they have so that they understand it better.

What are the differences between complementary and alternative medicine and conventional medicine?



Complementary and alternative medicine:

- Tends to be holistic and includes therapies from various historical and cultural backgrounds.
- Often you will need to take an active part in your own treatment with lifestyle changes (e.g. diet, exercise, nutrition, meditation or psychological exercises).
- Features therapies that are diverse in nature and origins.
- Most therapies are not currently considered part of evidenced-based Western medicine.

Wax-baths are currently considered as complementary or alternative medicine due to the lack of evidence based research to show the benefits of this therapy.

Conventional medicine:

- Mainly focuses on understanding and correcting the underlying problems that are causing symptoms. In many instances these are not fully understood, although there have been major advances in recent years.
- Is often criticised for treating your condition and not you as a person, expecting you to accept the diagnosis and treatment.
- Is increasingly recognising the importance of your involvement and choice in your treatment.

Often both conventional and complementary and alternative therapies are used - this is called integrated medicine. If you would like to explore what complementary and alternative therapies are available to you then speak with your GP or consultant.



Chelsea's hands during a Raynaud's attack

Family and the Future

Chelsea Wood, 26 from Dudley, has had challenges with Raynaud's from a very early age. Also diagnosed with MCTD and hyperthyroidism, Chelsea shares her story very openly on her diagnosis, coping daily with the conditions and how life shouldn't stop.

Early Condition

"I was clinically diagnosed with Raynaud's when I was 15, a condition that I later found out my mother had. The doctors told me that I would grow out of it however, my condition got worse and at the age of 17 I was sent to see a consultant Rheumatologist at Russells Hall Hospital.

After being seen, I was given some medication (Nifedipine) and was also referred to a consultant cardiologist. When with the Cardiologist, I was given several tests including an MRI scan to check blood flow. It was later concluded that I would undergo surgery for a Bi lateral Thoracic Sympathectomy, which still did not improve my condition. I went back to see the Rheumatologist who then diagnosed me with mixed connective tissue disease.

Since 2008, I have been put onto numerous amounts of medication, steroid infusions and steroid injections with no further improvement to my condition. I have also had several hospital admissions for Iloprost infusions the most recent being in October 2014 yet, unfortunately, there is still no improvement.

In early 2015, I attended two appointments at Salford Hospital under Professor Ariane Herrick, the first appointment saw me go through rigorous testing on my hands and feet which included a Doppler test of the wrists and ankles, a stress test on my fingers and looking at the capillaries of my fingers through a microscope. A few weeks later I saw Professor Herrick who decided that the Doppler test and microscopic capillary test were fine however, the stress test confirmed that I have a severe case of Raynaud's Syndrome. At the point that I attended this appointment, I was 6 weeks pregnant and therefore would have to wait until my baby was born until a treatment programme was put in place.

Pregnancy Bliss

During my 9-month pregnancy, my Raynaud's and MCTD symptoms improved greatly with some days having no symptoms at all, something unheard of in my life. Unfortunately, during my 52-hour labour with Toby, he released meconium inside me and so I was given 4 intravenous doses of antibiotics to ensure that neither of us became ill. What's more, 5 days postpartum, all of my normal symptoms returned. Since having my baby, it would seem that my immune system crashed as I became fairly unwell, suffering from a kidney infection, pleurisy and having continuous pins and needles in my forearms and fingers.

Chelsea and 'amazing' husband Ian



Their son, Toby



In my career I have worked in several schools, once I worked with Year 5 in a primary school when I had a Raynaud's attack whilst teaching. One of my new pupils asked me what was wrong with my fingers and when I explained he replied, "Wow! You're a real life smurf", to which my teaching assistant and I burst out laughing.

My diagnosis is extremely difficult and affects most aspects of my daily life but when my doctor told me that, at 23, giving up work was my best option, I was more determined to keep on going. Since then I struggle through work everyday, working for a premiership football team working with under privileged children and children that have been excluded from school.

Since having my baby, Toby, my husband has been absolutely amazing, he has had to have a few days off work whilst I got through the pleurisy but it has made our relationship so much stronger. He really understands that I will have bad days especially during the winter but he keeps on telling me that he is really proud of how well I am coping with being a new mum and that it has made me an even stronger person than I was before.

I am very lucky that my husband understands my condition inside out and he cares for me daily, helping me out with tasks that I cannot do such as cooking or walking the dog in winter. My family are amazing but due to my conditions I suffer with some mental health problems all of which keep my family on their toes at times. They never complain and are always there to help me but I know that it

affects them at times. Now that Toby is 6 months old I am beginning to get into a routine that is working for everyone and he keeps me so active and positive that the depression that I used to feel due to my conditions is alleviated as I have something much more positive and important to focus on.

New Challenges Ahead

After spending a few months eating in restaurants that apparently cater for babies, I realised just how shocking it was to get decent food for both of you. They seem to compromise at certain things so I'm in the very infant stages of opening my own baby restaurant because finding a child friendly place to eat these days is so hard.

My attitude has become even more positive since having my son as I realise that focusing on developing my son and making him a good person is more important and to show him not to let obstacles in life get you down but to find ways around them."

Prevention is key this summer

Summer can bring some relief if Raynaud's affects you, as the warmer weather can help to reduce the number of attacks.

However with the British weather it is difficult to know if the day will be full of sunshine or whether we will hit a cold spell mid afternoon and the evenings can get chilly.

So this summer don't get caught out, use our useful tips to help prevent a Raynaud's attack.

1 Carry a pair of gloves with you

Pop them in your bag so if the weather turns or you need to touch something cold you have them to hand.

2 Accessorise with a scarf/shawl

Not only is it light weight to wear or carry but if the air conditioning is on low you can wrap yourself up to keep warmer.

3 Use napkins to hold cold drinks

Cold drinks can be extremely refreshing but try to put a barrier between your skin and the drink, you can pull out your gloves or use a bunch of napkins to hold the drink.

4 Blankets for chilly evenings

The evenings can get cold so if you are heading outside take a blanket with you for that BBQ or to the beach.

5 Portable heaters

Portable heaters can be great to keep you warm without heating the whole house.

6 Cosy slippers

If you have hard wood floors then make sure to slip on your cosy slippers at nighttime.



We have invested £9.5 million into research

Scleroderma & Raynaud's UK received a strong legacy from both the Raynaud's & Scleroderma Association (RSA) and Scleroderma Society (SS) in terms of the contribution both charities made to research.

Both charities understood the importance of research and that investment would lead to a better understanding of the conditions, effective treatments and new treatment pathways. Due to this, £9.5 million has been invested into research, to date.

Case Study

Implantable Loop Recorder, University of Leeds

We invested £75,000.00 into a project looking at identifying heart involvement in Systemic Sclerosis.

The study highlights the need to identify patients at risk of heart disease to offer them monitoring that could save lives by the early detection and treatment of life-threatening heart rhythm abnormalities.

Scleroderma can affect the heart in many ways – disturbing the conduction system controlling heart rhythm or compromising the heart muscle, valves, and the heart's external lining. Despite the fact that heart involvement is common in scleroderma, many patients do not experience any heart symptoms at all, leading to a potentially dangerous situation of unmonitored heart disease.

"We know that cardiac involvement in systemic sclerosis is associated with a very poor prognosis,

accounting for between 14 and 55 percent of deaths among patients with systemic sclerosis," said study lead author Dr. Lesley-Anne Bissell from the Musculoskeletal Biomedical Research Unit at the University of Leeds. "Early diagnosis and treatment to reduce the risk of complications is therefore essential and crucial for a positive outcome."

To date, the project has identified heart rhythm abnormalities in 15 patients, which will allow them to be carefully monitored and receive further potentially life saving treatment.

The project is due to be completed July 2017 and a full update will be provided on how this project is helping to change lives.

We are committed to continue our investment into research, as we believe that research holds the key to improving the lives of everyone affected by Scleroderma and Raynaud's. To continue investing in life-changing research we need your support.

You can make a difference today by donating to our research programme:

£25

could buy **30 petri dishes** to look at how cells respond to different drugs

£75

could buy a **wax bath** to research the benefits of this therapy

£50

could fund a **botox hand treatment** to look at the effects on Raynaud's

£100

could fund a **research nurse**, for a day, taking skin samples to better understand the progression of fibrosis

To donate today simply call our team on 01270 872776 or visit www.sruk.co.uk/donate



Pay in your Fundraising Online

We are delighted to introduce a brand new feature on our website to make it even easier for you to pay in your fundraising money.

We now have an option on our donate form to pay in fundraising; here you can enter the amount to pay in and the event that the money was raised from. Then simply complete the card details section and your fundraising will be received by the charity and added to your fundraising total.

If you are fundraising for us and have collected sponsorship money or cash from an event then why not pay in your fundraising online, it is quick and easy and saves the charity money on administration so more of your fundraising goes directly to improving the lives of people affected by Scleroderma and Raynaud's.

Our Fundraisers

Will Beach ran the Coventry Half Marathon and raised **£1,015**

The Burton on Trent local support group raised **£500** through community events

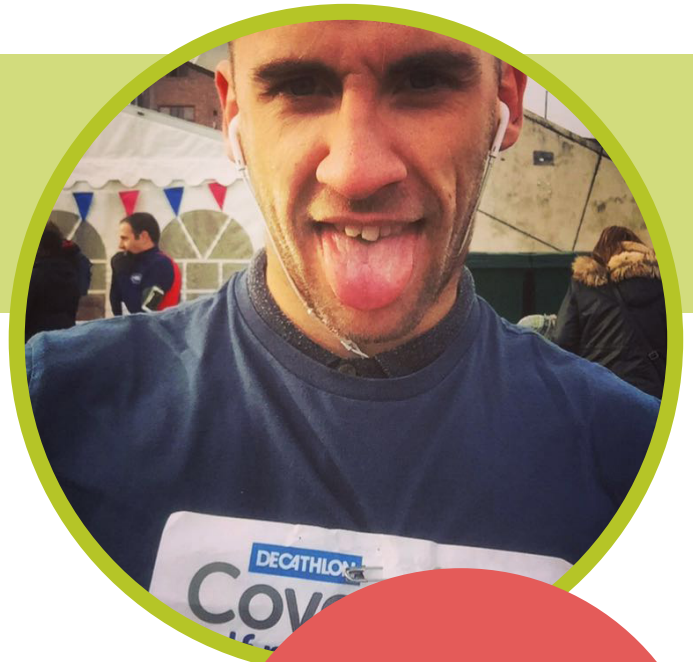
Emily organised a charity ball raising **£1,000** for SRUK

The Royal Artillery Officers took on the 3 peaks challenge and raised **£1,100**

Thank you to **Carol Wilkinson** and the **Dalton Grange Golf Club** for their donation of **£1,000**

Louise Shaw ran a charity stall during their monthly coffee morning raising **£143**

Kelly took on Brighton's 5k colour rush obstacle course to raise **£366**



Thank you to all our wonderful fundraisers

If you would like to take on a challenge or organise a fundraiser for us then speak with us today:
fundraising@sruk.co.uk
or 01270 872776.

This year we were delighted to welcome 5 runners to Team SRUK taking on the Virgin Money London Marathon. On April 24th it was an early start for Zoe Butler, Michael Corbett, Ian Cox, Stuart Harris and Charlotte Newlands as they made their way to the start line joining 40,000 other runners.

Team SRUK had trained in all weather, held cakes sales, dress down days and fundraising dinners to reach their fundraising target all for this one moment, to stand on the start line and take on the most iconic 26.2 mile marathon in the UK.

The atmosphere on the day was absolutely electric with the highest number of supporters taking to the streets to cheer on the fantastic runners. We were once again stationed at the half way point to cheer as loud as we could and encourage Team SRUK to keep going.

Team SRUK were amazing and all completed this year's London Marathon, crossing the finishing line and receiving their medal of honour.

We would like to thank Zoe, Michael, Ian, Stuart and Charlotte for running for us and raising a fantastic £11,804.15. Their fundraising will go towards improving the lives of people affected by Scleroderma and Raynaud's by contributing to our support services and research programme.

London Marathon




If you are inspired by Team SRUK and would like to join us at the Virgin Money London Marathon 2017 then get in touch today and we will send you an application form. Email fundraising@sruk.co.uk or call our team on 01270 872776.

Applications close on the 31st July 2016.

Getting ready to gather your friends and family around for a garden party or take a trip to the beach? It's important to remember to look after yourself, and your skin, as the weather begins to heat up.

Summer Survival Guide

Keeping your skin protected



Skin care is important for everyone during the summer to avoid skin damage and prevent burning. The sun can cause premature aging, wrinkles, marks, dry skin and getting sun burnt can increase your risk of developing skin cancer.

If you are affected by scleroderma it is important to be aware of sun damage, as the skin is more susceptible to UV rays. Those with Lupus can also be heavily affected as UV rays can aggravate symptoms, causing flares.

So to make sure your skin is protected this summer we have put together our 2016 summer survival guide:

1 Wear a Hat

There are numerous benefits to wearing a hat. Not only is a good way to keep protected from those UV rays, but they are also useful in keeping cool in the heat, especially if you're spending a large part of your day outside. Make sure that it is wide brimmed to cover all of those vulnerable areas such as your face, neck and ears.

2 Cover Up

Consider wearing long sleeved tops, trousers and long skirts made of close-weave fabrics so that sunlight is unable to pass through. Try to pick lightweight loose clothing so you don't run the risk of getting too hot! If you're really struggling and you can't find any light clothing, which keeps you protected, why not consider investing in some UV protective clothing? They're available from a wide variety of outdoor clothing stockists in the UK.

3 Time for the Shades

Sunglasses help to protect your vision from the bright light and the thinner, more sensitive skin around your eyes. Besides, who doesn't want to look like James Bond or Audrey Hepburn?

4 Slap on the Sunscreen

Sunscreen is a must this summer to protect yourself from the sun. Aim for one with a UVA 5 star rating and a Sun Protection Factor (SPF) 50 or over. If you are particularly light sensitive, it may be worthwhile speaking to your GP to see if you can get a prescription. If you plan to go out, and be outside for a while, make sure to apply sunscreen 30 minutes before you go and just before you leave the house to make sure that the sunscreen has had time to sink in and that you're fully protected.

5 It's About Time!

In the UK, the sun is at its strongest between 11am to 3pm - particularly in those warmer months between March and October. It's important to keep this in mind if you're planning days out so that you can prepare. Consider planning your day around these times or make sure that you have shade available nearby - especially if you're going to be out and about during midday. Why not consider stopping off in a café or restaurant or maybe going to look at an exhibit or do some shopping?

6 Stay Hydrated!

It's important to remember to drink plenty of liquids, especially if you're doing a lot of exercise or moving about during the day. No one wants to have their day disrupted by feeling light-headed or dizzy so make sure to keep topped up by drinking plenty of water.

7 Avoid the Sun

If you really have a tough time with the heat or light sensitivity, you might want to consider staying inside. That's doesn't mean you can't enjoy the season, though! Why not consider arranging an indoor barbeque or games night?

Don't forget, the sun is a main source of Vitamin D so if you're staying in, speak with your GP or pharmacist on whether supplements may be beneficial.



UV radiation covers three different categories: **UVA, UVB and UVC** (the latter of which doesn't penetrate the earth's atmosphere).

UVA affects the elastin in the skin, leads to **sun-induced ageing** and can lead to **skin cancer**. UVA can penetrate window glass and penetrates more deeply than UVB.

UVB is the form of UV most responsible for **sunburn** and has strong links to different types of **skin cancer**.

*Information from British Association of Dermatologists (BAD)



Planning on going away? It's important to remember that it's not just direct sunlight that can be an issue as being near large expanses of water (such as a lake or pool) and even snow can cause problems as the sun's rays reflect. Make sure to follow these guidelines to make sure that you're fully protected, no matter where you are!

As long as you take care of yourself and make sure that you follow our tips and the advice from health professionals, there's no reason why you can't enjoy this summer.

Why not let us know what you have planned? Send us some of your summer photos on twitter (follow www.twitter.com/WeAreSRUK) or send us a message at info@sruk.co.uk.

Increasing Awareness

In our November survey you told us that you wanted SRUK to achieve greater awareness and understanding amongst medical professionals and the general public.

So, during June we launched our first public facing awareness campaign to highlight the signs and symptoms of Raynaud's and the link between Raynaud's and Scleroderma.

To ensure this campaign was credible we firstly conducted a piece of research. We asked the general public whether they knew about Scleroderma and Raynaud's and whether they could identify the symptoms. We were astounded by the results:

- Over three quarters of people have never heard of Raynaud's or don't know anything about the symptoms
- 67% of people believe Raynaud's affects only one person in 5,000 or even less, when the actual figure is one in six
- Just 4% are able to confidently identify the symptoms of Raynaud's, falling to 1% for Scleroderma
- Roughly one in five people would be embarrassed to say they had the conditions whilst 20% of people would be frightened to touch someone with Raynaud's and 24% someone with Scleroderma

Our research showed the importance of informing and educating the general public not only to ensure that anyone experiencing recurring symptoms sees their GP but also to reduce the stigma and misunderstanding surrounding the conditions.

To increase awareness we launched the campaign #KnowRaynauds. We know that for many people affected by scleroderma, Raynaud's was their first symptom and so by informing and educating the 10 million people (approximately) affected by Raynaud's we may be able to ensure earlier diagnosis.

We also know that many people with Raynaud's do ignore the symptoms and just get on with life, not knowing they have Raynaud's nor that treatment is available in many cases to help people cope with the painful and sometimes life-changing effects of the condition.

Our campaign highlighted the two conditions, the signs and symptoms to look out for, when to go and see a GP and the support SRUK can provide to those affected.

We are delighted to tell you that we have been featured in a range of local and national press, reaching an audience of **38,309,498**.

A BRAND NEW ATTITUDE woman&home



According to the NHS, as many as 10 million Brits suffer from Raynaud's disease, and most people with the condition don't know they have it.

The charity Scleroderma and Raynaud's UK (SRUK) state that Raynaud's disease occurs as often as hayfever and arthritis, but as few as 4% of the population have even heard of it.

In response to the public's lack of awareness, SRUK have launched a new campaign to educate people on the cause, symptoms and treatments for Raynaud's and scleroderma.

What is Raynaud's disease?

It is a condition that affects the bloody supply to the extremities, in particular fingers and toes, and can be triggered by anxiety, stress and exposure to cold temperatures.

The campaign has currently been featured in:

Huffington Post
Daily Express
Yours Magazine
Woman & Home
Evening Chronicle
The Journal
Glasgow South and
Eastwood Extra
Worcester News
Dudley News

Caroline Goldstein, from Bristol, a mum and former hospital doctor, began experiencing symptoms for Raynaud's phenomenon in her early twenties at medical school after finding her hands and feet would become extremely cold and painful.

She put it down to poor circulation but as her symptoms became worse and she got older, Caroline and was forced to manage the condition by carrying extra layers of clothes.

However, the condition got worse when Caroline had a baby.

"When I first started breast feeding I suddenly started to get really bad pain and noticed that the colour of my nipples had changed, but I didn't know what it was. They were going white and blue.

RELATED ARTICLES

It can lead to amputation and kidney failure, but what is diabetes?

REVEALED: Short course of radiotherapy 'as effective' as longer stint



Caroline, with her family

We would like to say a big thank you to everyone who supported this campaign by providing personal stories, sharing coverage and taking part in the #KnowRaynauds social media campaign.

If you are interested in sharing your story with us for future campaigns then we would love to hear from you.

Please get in touch with us on 01270 872776 or info@sruk.co.uk.



WELLCOME IMAGES

A heat map of two hands - one with Raynaud's, one without.

What is scleroderma?

Only a small number of patients with Raynaud's go on to develop a more serious connective tissue disease, scleroderma.

However this condition can cause disability and can even be life-threatening, which is why it's important to be diagnosed earlier.

Scleroderma is a rare, chronic disease of the immune system, blood vessels and connective tissue.

It is an autoimmune condition, meaning the immune system becomes overactive and attacks healthy tissue in the body.

The name of the condition comes from the Greek, 'sclero' for hard, and 'derma' for skin. This hardening of the skin can be one of the first noticeable symptoms of the condition, as the body produces too much collagen.

This excess collagen can affect the skin, joints, tendons and internal organs.

It causes scarring and stops the affected parts of the body from functioning normally.

The Extra

New research from charity Scleroderma and Raynaud's UK (SRUK) has revealed that thousands of people across Glasgow could be living with a condition that they know little or nothing about, and therefore not accessing the help they might need.

In fact Raynaud's, sometimes referred to as vibration white finger, is as common as hay fever or arthritis in the UK, yet over three quarters of people in Glasgow (77 per cent) have never heard of it or know nothing about the condition. Some Raynaud's patients go on to develop a more serious connective tissue disease, scleroderma - which can cause disability and can be life-threatening, - so it is important to pick this up early.

As a result, (SRUK) are launching a new campaign today to help people in Glasgow to spot the signs of these conditions and encourage them to seek advice and support if needed.

0 comments

HAVE YOUR SAY

Charity of the Month

We were thrilled to be nominated as Unite/CPHVA's charity of the month throughout June. We would like to say a big thank you to Jane Beach (Professional Officer for CPHVA) for nominating the charity and enabling us to work with community practitioners and health visitors to raise awareness of Scleroderma and Raynaud's.

CPHVA (Community Practitioners and Health Visitors Association) is the UK's leading professional organisation for health visitors, school nurses, nursery nurses and other community nurses working in primary care with a current membership of 100,000 health workers. Unite/CPHVA is a section of the Unite trade union, which is the largest union in the UK.

During June all Unite/CPHVA members received an 8-page briefing from SRUK which included information about the charity, the conditions, the signs and symptoms to look out for and how best to support patients they see within the community who may be affected by Scleroderma and Raynaud's.

Sue Farrington and Jane Beach also joined Helen Bird (Community Practitioner editor) for a webinar where the conditions were discussed in further depth and the relevance to community practitioners and school nurses highlighted.

On Tuesday 14th June we took part in CPHVA's Twitter Tuesday where we answered questions from health visitors and spoke about Scleroderma and Raynaud's. During Twitter Tuesday (7pm - 8pm) 619 tweets were sent and we reached 1,317,663 twitter feeds.

To the right you can see some of the comments that we received during Twitter Tuesday with many health visitors stating that they knew little about Scleroderma and Raynaud's and may have missed the symptoms in patients.

If you work for a medical organisation and would like to discuss working with SRUK to raise awareness of Scleroderma and Raynaud's amongst employees or members then please get in touch **01270 872776** or email **amy.baker@sruk.co.uk**

Raynaud's In Young Adults

Sally Millward, an Associate School Nurse in Redbridge covers around 20 schools in Ilford told us, "I have identified a couple of children with suspected Raynaud's who have gone on to be investigated further."

Sally, who has had Raynaud's since her teens understands first hand the challenges and how easy it is to mistake or simply ignore signs of Raynaud's. "I have had severe Raynaud's since the age of around 14/15. The moment I realised something was not quite right was when I was unable to pick up coins out of my purse due to my fingers being blue, numb and very painful. I remember it was the height of summer and other people were in shorts.

At the age of 18 when I had moved to London from Wiltshire to do my Nurse training, I went to see a new GP as I had a chest infection. He took one look at my blue hands and informed me that I needed to go directly to A&E. I explained that being an asthmatic for some time, that it was normal for me to have blue hands, I knew my chest infection was not severe enough to warrant A&E. The GP was deeply concerned and explained that the chest infection was "the least of my problems" and that if I didn't go straight to A&E I could "lose my hands".

"I went to see my GP who totally dismissed the problem and without any examination of my hands (or any other part of my body), simply said it was a "problem with circulation" and to "keep my hands warm". Therefore, I got used to wearing gloves all year round and thought little of it."



I was seen in Charing Cross Hospital triage, admitted and put on a heparin infusion immediately. Following that admission, where a full examination highlighted other abnormalities such as calcium on my fingers and elbows, I was later diagnosed with CREST syndrome (also known as Limited scleroderma). My example of Raynaud's went on to become something much more serious, so it should never be overlooked or not taken seriously.

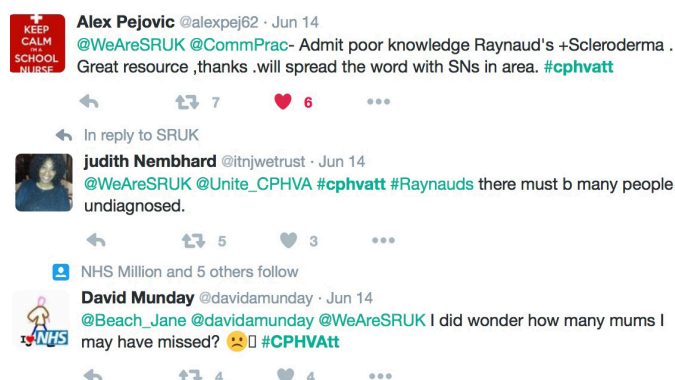
"Children with Raynaud's don't just need to wear additional clothing during outside activities but may need to wear gloves during class sessions. Schools can be very stringent about rules and regulations and how they want pupils to dress, so this is where a School Nurse can assist. They can help mediate by outlining the child's requirements, in collaboration with parents and then negotiate with the school Governors' special dispensations, thereby ensuring that every one knows what the allowances are for that particular child."

CJ, age 13 from Sheffield had some issues with her school and her parents had a couple of meetings with the headmaster to discuss her challenges in the hope of support and care from them. "I get very cold, even in summer. I would want to wear gloves all the time if I could but I'm not allowed. I hate gym because I know it's going to be freezing and I'm not allowed to wear any extra clothes."

"CJ's condition is serious enough that we had to go in for a review with the Headmaster. They thought she was playing up and wanting to bend the rules for reasons like 'fashion' but what they didn't realise is that CJ wants to fit in, she doesn't want to be different, so hasn't spoken up before now." says Cindi, CJ's Mum. "Her condition is now so severe it cannot be ignored, we are worried about long term effects on her health and are glad we've been able to work with the school teachers to work on best measures for both".

For information and literature on the condition or for more on spotting the key signs, contact one of the team here at SRUK on 01270 872776.

You can see all the work we have been doing with Unite/CPHVA by visiting: <http://www.unitetheunion.org/> and searching 'charity of the month'.



This year the theme for World Scleroderma Day was 'hand in hand' and during the month of June we worked hand in hand with FESCA (Federation of European Scleroderma Associations), Unite/CPHVA, local and national press and the community to raise awareness of Scleroderma and Raynaud's.

Scleroderma organisations across the globe have been sharing the official World Scleroderma Day video. The video was developed by a Professor in Spain and is based upon a mother telling her child a fairytale with scleroderma being at the very centre of the story. If you have not yet seen the video then visit the News section of our website (www.sruk.co.uk) and view the 'Help us to raise awareness this World Scleroderma Day' article.

World Scleroderma Day



World Scleroderma Day is celebrated each year on the 29th June. This day was founded by FESCA in 2009 to show solidarity, celebrate the positivity and resilience of everyone affected by scleroderma and increase awareness of the condition on a national, European and global level.

Our #KnowRaynauds campaign was launched during June to raise awareness of Scleroderma and Raynaud's on the run up to World Scleroderma Day. During the 29th June our social media campaign received lots of interaction with the community sharing stories, sharing posts and taking 'hand in hand' photos to spread awareness of scleroderma.

We would like to thank everyone who helped spread awareness during the day, by sharing our posts our #KnowRaynauds campaign reached 108,184.

And a huge thank you to those who held a Hot Cuppa and Cake fundraiser to raise vital funds for SRUK during World Scleroderma Day 2016.

Today is #WorldSclerodermaDay. Please share your experience of the condition so we can spot the signs sooner.

<https://www.sruk.co.uk/scleroderma/>

SRUK SCLERODERMA & RAYNAUD'S UK

#KnowRaynauds
sruk.co.uk/spot-signs

#KnowRaynauds
Colour changes in your fingers and toes when it's cold or you're stressed.
Tingling, numbness or pain in your fingers and toes.
Stinging and throbbing pain upon warming up or stress.

A small number of those affected by Raynaud's will develop scleroderma.
If we get to #KnowRaynauds now, scleroderma may be diagnosed earlier.
This World Scleroderma Day please join hand in hand and help us raise awareness of the signs of these conditions.

Please text **CURE25 £10 to 70070**

Like Comment Share

57 Top Comments

Sjögren's Syndrome

Sjögren's (pronounced Show-grin's) syndrome is an autoimmune disorder. The body's immune system attacks glands that secrete fluid, such as the tear and saliva glands. Many people diagnosed with scleroderma may also be diagnosed with another autoimmune condition such as Sjögren's.

The effects of Sjögren's syndrome can be widespread. Certain glands become inflamed, which reduces the production of tears and saliva, causing the main symptoms of Sjögren's syndrome, which are dry eyes and dry mouth. In women, (who are most commonly affected) the glands that keep the vagina moist can also be affected, leading to vaginal dryness.



Dry Eyes

There is a deficiency of the watery component of the tears. This leads to poor wetting and lubrication of the surface of the eye, injury to the surface cells and a feeling of grittiness in the eye. There may be a burning or stinging sensation in the eyes or a tiredness or heaviness of the eyelids.

Discomfort to bright lights is common, and intermittent redness of the eye may occur. Mucus production can also be disturbed due to a loss of goblet cells. Long strands of mucus may form rolls which accumulate in the lower part of the tear sac. These may sometimes attach to the corneal surface as filaments and the lids may drag on these, causing bouts of pain.

Preserved drops

The majority of artificial tears contain a preservative, which enables the drops to be used for one month after opening the container. The presence of the preservative inhibits the growth of any bacterial contaminants that could enter the opened bottle and cause an infection in the eye.

Preservative-free preparations

For individuals who experience sensitivity to preparations containing preservatives it may be worth considering the use of preservative-free drops. These can be made up specifically by the hospital pharmacy and can only be used for a limited period of time (usually a single dose) to prevent the risk of bacterial contamination.

Using drops

Artificial tears are available on prescription and over the counter depending on the chosen preparation. It is sometimes necessary to try a variety of preparations to see which one you find the most effective and practical. Not all preserved drops for example, contain the same polymers or have the same formulation.

Practical tips:

- Avoid dry, air-conditioned environments.
- Use humidifiers and have plenty of plants with large leaves around the house to improve the humidity of your indoor environment.
- Moisture chamber glasses can be custom made and worn as a method of conserving tears. The side shields around the frame of the glasses, creates a humid environment around the eye and greatly reduces any evaporation.

Dry mouth - Xerostomia

The most common features of dry mouth are:

- Difficulty in eating dry foods
- Pain or discomfort when swallowing
- General mouth discomfort
- Poor ability to taste
- Denture problems
- Increased tooth decay
- Mouth and salivary gland infections
- Speech difficulties
- Oral Infections

Saliva substitutes

For individuals, with no functional salivary tissue the use of saliva substitutes in the form of gels and mouth sprays is the main line of treatment. Some of the products available in the market contain fluoride and are therefore recommended for individuals with their own dentition. Like artificial tear solutions, most formulations only last for a short while and so should be used as often as necessary. Saliva replacement gels are often favoured by many because they last longer and do not need to be used as regularly throughout the day.

Specially formulated dry-mouth toothpastes and mouthwashes are available and many people find these helpful although these are not available on prescription.

Saliva stimulants

The chewing of (sugar-free) gum and the eating of foods, which require vigorous chewing, can help to increase salivary flow. Some individuals find sucking acidic sweets effective, although it is important to remember that these can be damaging to teeth. Salagen® (pilocarpine) is the only oral agent available in the UK with the ability to stimulate salivary and tear flow. It works by directly stimulating remaining glandular tissue. Clinical experience suggested that it has a fairly slow onset of action and you should persevere with the treatment, often for several months to obtain maximum benefit.

Some people experience side effects with Salagen® such as sweating, urinary frequency, change of bowel habit and flushing but clinical experience suggests that tolerance develops over time and long-term benefits outweighs the short term discomfort. It can be helpful, to start with a low dose of 5mg once daily, and to wait until any such symptoms have subsided before increasing the dose. Many doctors will increase the dose at weekly, or longer intervals aiming to get three or four tablets daily for maximum benefit.

Sore mouth and ulcers

These can be treated with an antiseptic mouthwash, or more severe cases, where pain is a particular problem, an analgesic mouthwash or spray can be used instead. If ulcers or sores occur that do not respond to such simple treatment, further advice should be sought from your doctor or dentist.

Dental caries and oral hygiene

There are four simple precautions to take to help prevent the presence of dental caries:

- Avoid any sugar-containing drinks or snacks between meals and particularly before bed.
- Brush your teeth at least twice daily with a fluoride containing toothpaste.
- Use a fluoride containing mouthwash.
- Regular visits to the dentist are important.

Practical tips:

- If dryness at night is a particular problem, it is helpful to have a glass of water available next to the bed if needed.
- Spreading a teaspoonful of salad oil around the mouth or breaking a vitamin E capsule into the mouth last thing at night can also improve lubrication and prevent the mouth from drying out while you sleep.
- Avoid tea, coffee, alcohol and other caffeinated drinks. These can be de-hydrating.
- Re-hydrate the mouth throughout the day by taking small sips of water. Sucking on ice cubes can have a similar effect.

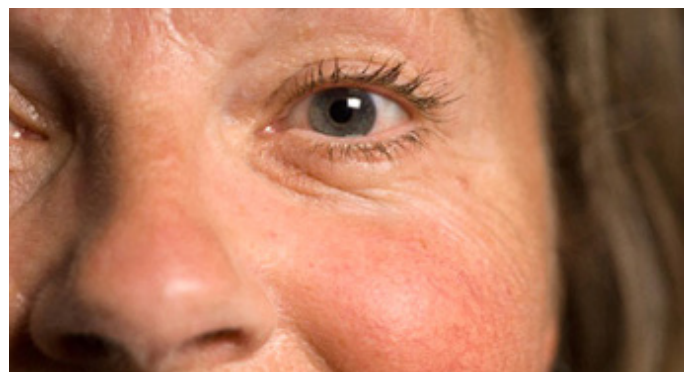
Failure of secretions

In addition to the typical dry eye and dry mouth symptoms, other secretions can be affected as well. Dryness of the air passages such as the nose and trachea can occur making the airways hypersensitive to irritants such as tobacco smoke. To help combat this problem, the use of humidifiers and saline nasal sprays are recommended.

Sweat glands can also be affected resulting in severe dryness of the skin, which may be sensitive to strong sunlight. Such problems can be avoided by showering rather than bathing and avoiding the use of strong soaps, replacing lost moisture with the use of aqueous creams and emollients.

The large bowel may be affected in a functional way, resulting in what is sometimes called 'irritable bowel syndrome'. This can cause lower abdominal pain and alteration in bowel habit. Treatment of this tends to consist of the increase of fibre (bran) within the diet and occasionally the use of antispasmodic drugs.

It is also common for many women to complain of vaginal dryness leading to the use of lubricants. While simple lubricants such as KY jelly may be satisfactory in the short term, such lubricating jellies tend to have a short lasting effect. For a more permanent solution, you may favour oestrogen creams or HRT. If required, there are non-hormonal alternatives available, which can be purchased over the counter.



If you experience any of the above symptoms then please speak with your GP or consultant regarding the best way to manage your symptoms.

This information has been produced in partnership with the British Sjögren's Syndrome Association.



Pioneering Research

in Scleroderma and Raynaud's at Leeds

The Scleroderma Research Programme in Leeds is a patient oriented multidisciplinary research programme led by Dr Del Galdo that comprises basic (to improve understanding of condition), translational (to use findings to enhance medical practice) and clinical research (determines the safety and effectiveness (efficacy) of medications, devices, diagnostic products and treatment regimens) on Scleroderma and Raynaud's. In collaboration with Profs Buch and Redmond the programme spans from clinical to mechanism, to cardiovascular and quality of life research in one of the most comprehensive and multidisciplinary research programmes internationally.

“The Translational research activity is the core of the programme. We aim to introduce into clinical practice blood and imaging tests to effectively measure activity and severity of Raynaud's and Scleroderma and to predict progression and response to treatment. The blood and imaging biomarkers of interest are being evaluated within the only NIHR (National Institute for Health Research) funded biomarker programme in Raynaud's and Scleroderma in UK.

The purpose of the project, supported by the NIHR LMBRU (Leeds Musculoskeletal Biomedical Research Unit) and DEC (Diagnostic Evidence Cooperative) is to confirm the clinical usefulness of using two imaging tests (no contrast MRI (Magnetic resonance imaging) and Optical Coherence tomography) and one blood test ('Sclero Test'); both discovered and patented in Leeds, these tests aim to predict which patients with Raynaud's progress to Scleroderma and in patients with scleroderma, who is at higher risk of developing severe skin or lung complications.

Both the blood and imaging biomarkers are currently tested within a multicenter observational study involving 10 centres across UK, so far, called STRIKE SSC (Stratification for the risk of progression of SSc). The study conducted by Dr Abignano and Dr Eng is currently open for enrollment with a target of 800 patients with Raynaud's and/or Scleroderma in the next 4 years. To minimise the time that patients have to spend for research, together with LMBRU PPI group (Public and Patient Involvement group), the Leeds team has streamlined a one stop event for all blood and imaging research tests that are carried out on the same day during one of the 4 Scleroderma and 2 Raynaud's clinics conducted weekly in Leeds. The successful outcome of the study will allow the use of a simple blood test to spare unnecessary investigations in patients that are not progressing and to focus NHS capacity and efforts on those patients that warrant more careful monitoring and examination for early detection and intervention.

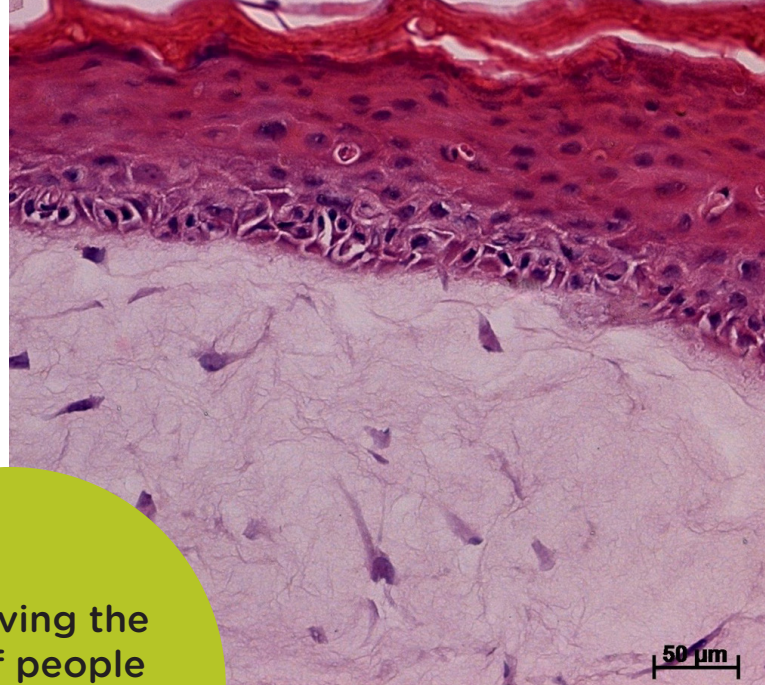
Within the same clinics patients are also invited to participate in another unique research study led by Prof. Buch that focuses on scleroderma-associated cardiac (heart) involvement (distinct from coronary artery disease and pulmonary hypertension) that is associated with up to 15% of deaths. Together with world-leading cardiovascular researchers and using sophisticated cardiac MRI, this is the first study to use an implantable loop recorder to detect abnormal heart rhythm. The aim of the study is to identify which patients are most at risk, how best to monitor for development and understand the basis for cardiac involvement - with the overall objective of early detection of scleroderma-cardiac involvement to be able to intervene with life-saving therapy.

One of the most comprehensive and multidisciplinary research programmes internationally

Also bridging the research/clinical service gap is a series of studies in the group led by Professor Redmond that explore the effects on quality of life of the peripheral (exterior) features of scleroderma, such as digital ulcers (DUs) and calcinosis.

Funded through two NIHR PhD fellowships, work by Begonya Alcacer-Pitarch and Lorraine Green has been exploring the effect of scleroderma on the blood and nerve supply to the hands and feet, and in particular trying to understand how these changes, combine with DUs and calcinosis and other consequences to affect quality of life.

This approach allows researchers to target specific features selectively, knowing that addressing these will lead to the greatest improvement in symptoms. Already the results of this initiative have been incorporated into NHS practice with the start-up of a multidisciplinary ulcer and calcinosis clinic, which provides access to a range of health professionals who can help manage these often neglected features. Alongside these local studies is a wider body of work with international collaborators in eight countries, which has developed, translated and validated a state of the art measure for capturing quality of life. This will allow us to pool research results from multiple centres in many countries and to develop studies that are larger and produce results that are more generally applicable. The international implementation of these types of clinical and research developments is also supported through initiatives such as the EULAR (European League Against Rheumatism), Scleroderma Health Professionals Network led by Prof Redmond and EUSTAR (European Scleroderma Trials and Research), a scleroderma research network to which the whole team contributes.



“Improving the lives of people with Raynaud’s and Scleroderma.”

The basic science research within the programme is the part that is ultimately aimed to identify key therapeutic targets (a “cure”) to prevent progression of Raynaud’s to Scleroderma and to prevent the onset of severe clinical manifestations of scleroderma. The research lab is hosted in the Wellcome Trust Brenner Building in St James University hospital where a team of 5 scientists work on different projects all aimed to identify the crucial links between inflammatory, vascular and fibrotic manifestations of Raynaud’s and Scleroderma. The lab has recently developed an in vitro skin 3D model to test experimental drugs in a human “organ-like” setting in vitro, avoiding both the burden and potential bias of experimentation on animals.”

Altogether led by Dr Del Galdo, Leeds hosts a team of 14 clinicians, health professionals and scientists that have made “improving the life of people with Raynaud’s and Scleroderma” their mission, and they nurture big hopes for the very near future. If you are interested in being involved in Dr Abignano and Dr Eng’s study please contact 0113 392 4484 or email s.eng@leeds.ac.uk



The Team

Francesco Del Galdo, Maya Buch, Antony Redmond, Giusepina Abignano, Jelena Blagojevic, Sokkhoe Eng, Raluca Dumitru, Lesley-Ann Bissel, Begoña Alcacher-Pitarch, Lorraine Green, Omid Shalbfaf, Rebecca Ross, Clarissa Corinaldesi, Jacobo Ellies, Vasiliki Liakouli

On being positive

I was diagnosed with Diffuse Systemic Scleroderma with lung fibrosis on 29th June 2012. Yes, World Scleroderma Day! Within a few weeks I found myself in intensive care at Whiston Hospital having a renal crisis then transferred to HDU at Liverpool with Kidney failure.

When things had calmed down a bit, I wanted to know more and first heard of RSA (now SRUK) by using Google! I found the website and its information to be really good. I contacted the local contact for Merseyside and met up. It was really great to meet someone with the same condition and I will always remember the first thing we did was compare hands!

As my condition stabilised a little, I wanted to get more involved and put my experiences of the condition to good use. Firstly I became a member of the patient reference group in the rheumatology department at St Helens Hospital, as they have and still are amazing, and I also applied to be a local contact with SRUK. Both of these give me an opportunity to spread awareness of the condition and some of its related challenges. I have met so many new friends it's lovely!

More recently, I have started to involve myself in fundraising. I held a stall at a local craft fair and sold some paintings I had done to raise money for my Rheumatology Department at St Helens Hospital (£250) my next paintings will raise money for Liverpool Renal Unit and SRUK!

As a Volunteer Recruitment Co-ordinator I get to meet all sorts of interesting people who want to volunteer their time to help run the centre (apart from a handful of part time staff, the centre is run by volunteers). People volunteer for all sorts of reasons, to gain experience in another area, for a career change, or to give back something to the community, and a lot of people I meet have a chronic illness or disability. They find it very hard to gain a place in the workplace but still have so much to offer.

I can relate to this as it is difficult to work as you did in the past as you have so many hospital



Trying to remain positive during the first weeks of tests, then diagnosis, were the worst weeks of my life.

appointments etc. and you can be off sick more than others. This is where I have been very lucky with my employers, they have been very accommodating to my situation and when I was first diagnosed I was off for 9 months. Upon my return they changed my job role (I previously had worked with the children's club as well, planning activities and co-ordinating the volunteers). I was on peritoneal dialysis and immunosuppressant therapy and the risk of working with up to 100 children was too great so I was allowed to swap from that to dealing solely with volunteers. On my bad days, my employers allow me to work at home on the administration side of things as I write all the training and recruiting documents and policies. I have, however, recently reduced my hours and trained up one of my colleagues to job share as I was finding it quite stressful because I had to cancel interviews with people due to me being ill and this caused problems whilst I was off.

Since receiving treatment, my lung fibrosis has reversed and there is no evidence of established fibrosis on my last scan so the treatment and care by Rheumatology, (I'm on mycophenolate) must be working. My kidneys have kicked back into life (about 28/ 30%) and I am no longer on dialysis thanks to the care of the Liverpool renal team. I continue to receive treatment at the Rheumatology Department at St Helens Hospital for scleroderma, attend the Royal Liverpool for my renal involvement and Whiston Hospital for my cardio involvement.

Despite the challenges, I am determined to stay positive and want to help others with scleroderma and Raynaud's and any research that I would be suitable for and can partake in. My attitude is to just get on with it, have a go and accept that you have to adapt to changes in life!

Benefits of remaining in work

Remaining in work is likely to be one of the most important goals for you and your family. Many people with Scleroderma and Raynaud's have work aspirations and continue in work as they wish with adaptations, where necessary.

Research shows that people in work tend to enjoy happier and healthier lives than people who are out of work. "For most people, their work is a key determinant of self-worth, family esteem, identity and standing within the community, besides, of course, material progress and a means of social participation and fulfilment" (Dame Carol Black). It has also been identified that people with health conditions, such as back pain, stress and depression, and high blood pressure find that getting back to work is often the best way to recover.


Your rights at work

Reasonable adjustments are changes to your job, workplace or equipment to ensure you are able to continue working or return to work. They are put in place to ensure that despite your disability you have the same access to doing everything that your non-disabled counterpart has. Reasonable adjustments that an employer should consider for people with Scleroderma and Raynaud's could include, but are not confined to:

- Looking in to flexible working hours to enable the employee to avoid rush hour transport, or working from home on days of fatigue or chronic pain.
- Additional breaks to also help combat the effects of fatigue.
- Adjusting roles and possibly transfer of some roles to other employees if a particular task is no longer possible. This could for instance include avoiding lifting heavy items.
- Providing specialised equipment to help alleviate the symptoms associated with scleroderma, for instance ergonomic keyboards to ease typing, back supports for office chairs and telephone headsets to free hands.
- Ensuring a warm environment.
- Adjustments to the premises for instance easier door opening.

If you would like further information on your rights at work then please contact us: info@sruk.co.uk or 01270 872776 and we will send you a publication on Your Rights in Employment.





What does
it mean for
patients?

The BSR/BHPR Guidelines for Scleroderma

Over the past 2 years an intensive amount of work has been undertaken to develop the first national UK guideline for treatment of scleroderma. This has been a group effort performed on behalf of the BSR (British Society of Rheumatology) and BHPR (British Health Professionals in Rheumatology) to develop an expert driven evidence based series of recommendations for the management of scleroderma.

It focuses on systemic sclerosis and has been a concerted effort from a dedicated group of experts, patients and healthcare professionals. The work is now completed and the full guideline is available on the BSR website [1] and an executive summary published in the international journal Rheumatology. Both of these documents are freely available.

These guidelines are important because they summarised the current best practice for treating the major complications of systemic sclerosis and also address the overall approach to disease management in the UK. They have been developed under the auspices of the SAGWG (Standards, Audit and Guidelines Working Group) of BSR that has developed a process that is accredited by NHS evidence. This is important since it means that the guideline is NICE accredited and should therefore be taken very seriously within the NHS as defining the standard of care for patients and access to therapies. Embedded within the guideline are important NHS England policies for the management of digital ulcers and the pathway developed for assessment and delivery of autologous stem cell transplantation for appropriate cases of diffuse systemic sclerosis.

The guideline process involved establishing a development group that included rheumatologist, scleroderma experts, pharmacists, allied healthcare professionals, specialist nurses, primary

care representatives and patients. In this way all aspects of the disease and management could be included. A comprehensive literature review of all the evidence supporting treatments for scleroderma was an important starting point and a group of dedicated clinical fellows undertook this work. There was a series of telephone and face to face meetings over 2 years that led to the development of the draft guideline. This was then reviewed by BSR SAGWG and by external referees. Comments were incorporated and the revised guideline was then finalised and submitted for open consultation so that anyone could comment and have input. After this process the final guideline was written, this was submitted for approval of BSR and then for publication in Rheumatology. After further external editorial peer review it has been finalised and is now being distributed amongst health professionals. [2].

This is not the end of the process since the guidelines are reviewed and updated every 5 years according to NHS Evidence protocols. This is a landmark for UK scleroderma patients and an important one at a time of major NHS change and also challenged and competition for resources for rare diseases. It complements the other recommendations being updated such as this of EULAR (European League Against Rheumatism) and the UKSSG (UK Scleroderma Study Group) best practice consensus documents [3].

**Professor Chris Denton, Royal Free Hospital and UCL Division of Medicine
Chair of the BSR/BHPR Scleroderma Guideline development working group**

References for more information:

1. <http://www.rheumatology.org.uk/resources/guidelines>
2. BSR Guideline executive summary – Rheumatology 2016 (in press)
3. UKSSG Consensus Best Practice Documents available at: <http://www.scleroderma-royalfree.org.uk/UKSSG.html>

We are working with colleagues from across Europe, America and Canada to understand the possible benefits of support groups.

Do you have scleroderma? Are you interested in helping advance research on scleroderma support groups? If so, please lend a hand by completing a short 10-15 minute survey!

How to Take Part

If you would like to take part then head onto the News section of our website: www.sruk.co.uk or call our team on **01270 872776** and we can work through the questionnaire over the phone.

Get Involved in Research

Cello Health Insight are conducting an international market research project on **systemic sclerosis or scleroderma with interstitial lung disease or fibrosis/scarring of the lungs**, on behalf of a pharmaceutical company. They are looking to gain an in-depth understanding of what it's like for people, both patients and carers, living with this condition.

The purpose of the research is to better understand the journey people go through with their condition, their experiences with treatments and anything that could help them along the way. Insights from you and other interviews will be gathered to foster a better understanding of scleroderma which may benefit future patients.

Your anonymous answers to the survey questions will provide a greater understanding of the important training and support needs of group leaders, as well as the reasons why people with scleroderma either attend or do not attend support groups.

The results from this survey will be used to increase the accessibility of scleroderma support groups and to structure these groups in a way that increases their ability to effectively meet the needs of members.



We are still looking for 4 people with the condition and 2 people linked to them in a support capacity. For this particular trial places will be given on a first come first placed basis, providing the criteria is met. You will also be rewarded for your time.

To receive a copy of the eligibility criteria and find out more about the trial email: info@sruk.co.uk or call our team on 01270 872776.

Hands



12% Silver Fibre Gloves

One of our best sellers, these gloves are seam free, flexible and will allow you to operate a mobile, cashpoint or even handle small change. Made using 12% pure silver thread they have light stretch for improved fit and comfort. Available in black or dark grey in sizes S/M or L/XL.

£19.50



Astec Zondo Self Heating Gloves

Latest innovation technology, tried and tested by members, these gloves keep your hands warm in any conditions, even when wet. Available in sizes XXS-XL.

Usually £42.99

SPECIAL PRICE £34.99



Mycoal Handwarmers

Once opened the disposable heat packs are activated by gently shaking or squeezing and can then be placed in your pocket, mitten or glove. Stay comfortable with up to seven hours of warmth. These come in a pack of four pairs.

£6.75



Astec Zondo Self-heating Insoles

These insoles are available in two versions, the newly designed 'cut to size' or 'bound', available in UK sizes 3-12.

Prices from £24.99-£29.99



Silver Fibre Socks

These socks contain 9% silver fibre, for added insulation, they have anti-microbial properties so are also appropriate for athletes' foot, diabetes and generally keeping feet well and warm.

£13.00



Mycoal Foot warmers

Once opened, the disposable heat packs are activated by gently shaking or squeezing and can then be placed at the toe end of your shoe. They are shaped for comfort and come in a pack of four pairs.

£6.75

Feet

Body



Blankets

Relax with a Heat Holders premium fleece blanket- perfect for wrapping up warmly on those chilly Summer nights. With a 1.4 tog rating, its generous size and incredible softness make it a must-have item for any barbeque or lazy days at home.

£24.99



Hat & Glove Gift Set

Heat Holders best sellers, boxed together to create a perfect gift. Both are fleece lined and use patented yarn to keep you cosy and warm.

£17.99



Heatease Body Warmer

Adhesive Body Warmers that last for up to 12 hours. Simply open the pack and expose to air to activate. Remove the protective backing and adhere the warmer to clothing, over the area where heat is required. Do not apply directly to skin.

£8 for 6



Jar Key

Gently lever the jarkey against the rim of a lid to release the vacuum inside the jar, making it easier to twist open.

£7.00



Fuelgrip™

A nifty little gadget, ideal for all vehicle owners who have difficulty holding the trigger on a fuel pump when filling up. Simply slide the Fuelgrip over the handle and under the trigger to keep your hands free and warm whilst the tank fills up. Fuelgrip can be stored inside your fuel cap or glovebox for ease of use. Everyone should own one of these!

£2.49



Ring Can Pull

Having tried various types of openers, we think that we have found one that is excellent. It has a good grip and is easy to use on all your canned drinks.

£4.00

Gadgets

Check out our New Range of SRUK merchandise. Just pop a pen or wristband in your basket to help increase awareness. If you would like to support the charity further by raising vital funds, go to www.sruk.co.uk/fundraising for great ideas and fundraising events you can get involved in.

T-Shirt
£9.99

Pen
£1.00

Wristband
£1.00

Shop online today at srukshop.co.uk or if you prefer call one of our friendly team on 01270 872776, who will help you place an order.

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 first 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 01270 872776 or email: info@sruk.co.uk

Donate to us
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 @WeAreSRUK  /WeAreSRUK

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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.