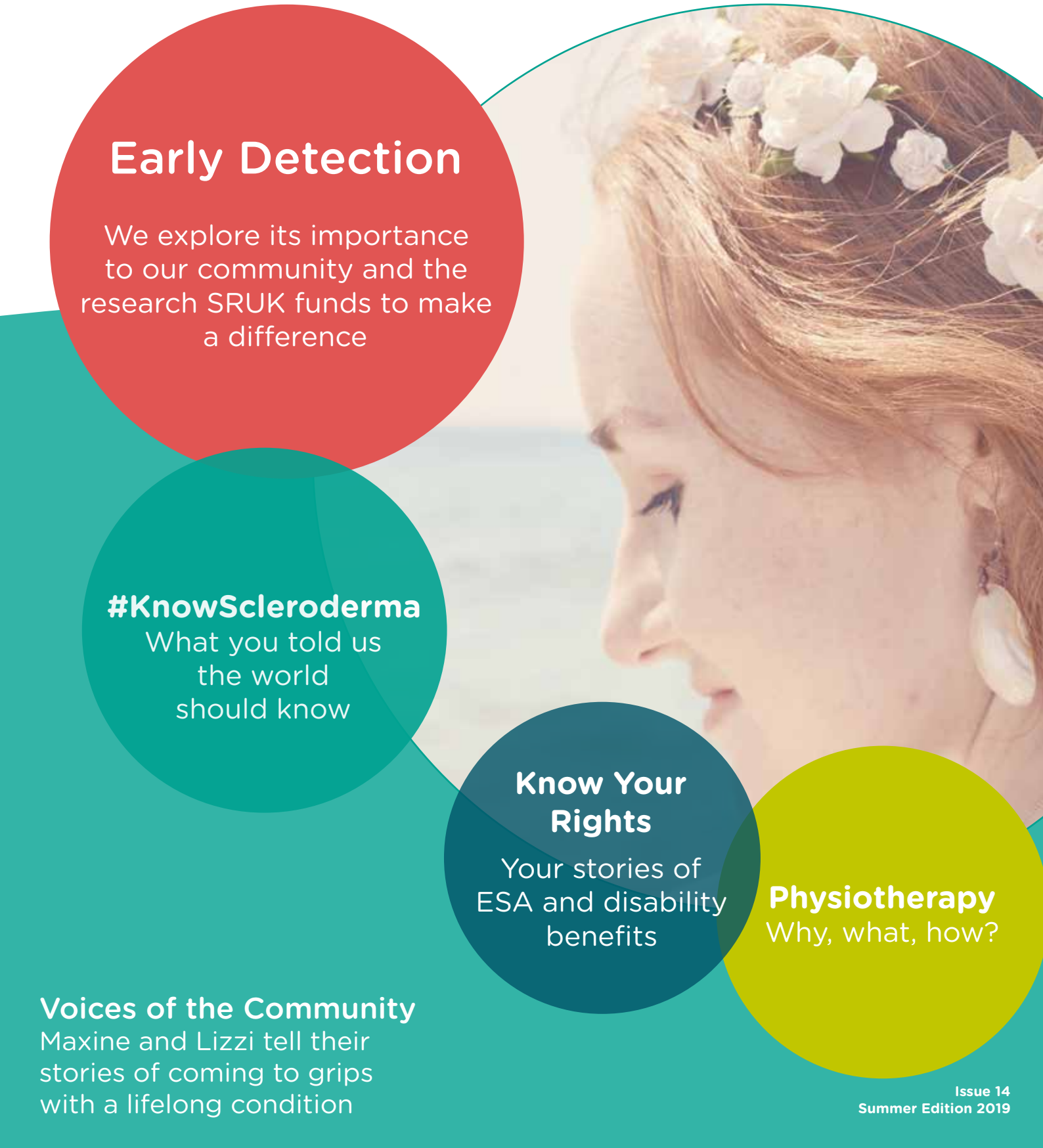
SCLERODERMA & RAYNAUD'S UK

SRUK NEWS



Early Detection

We explore its importance to our community and the research SRUK funds to make a difference

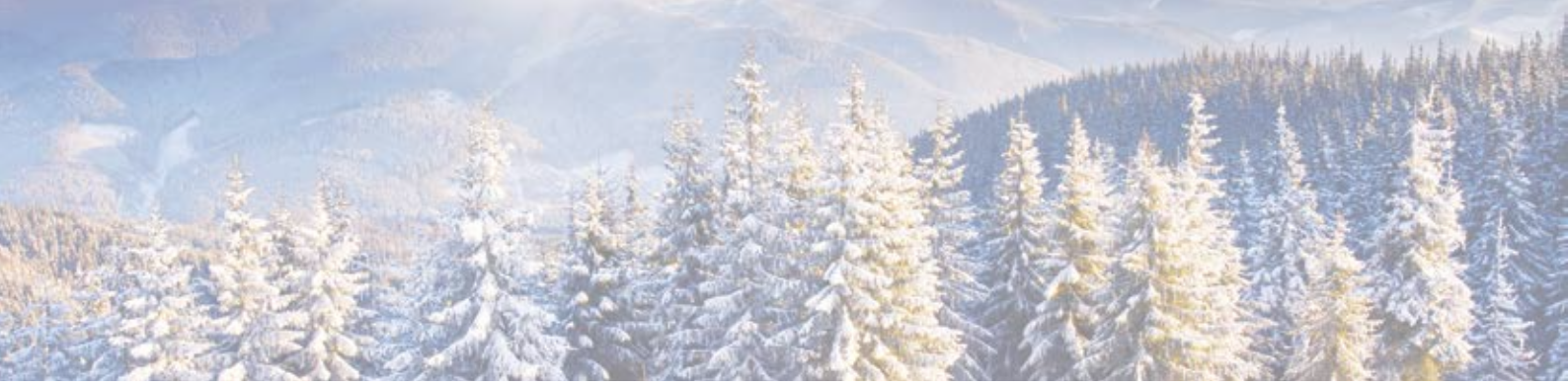
#KnowScleroderma
What you told us the world should know

Know Your Rights
Your stories of ESA and disability benefits

Physiotherapy
Why, what, how?

Voices of the Community
Maxine and Lizzi tell their stories of coming to grips with a lifelong condition

Issue 14
Summer Edition 2019



Here is our selection of SRUK Christmas Cards available for purchase this year, each pack contains 10 card.

Heart hands Christmas card	£3.99
People sledging Christmas card	£3.99
Robins Christmas card	£3.99
Group deer Christmas card	£3.99
Partridge Christmas card	£3.99
Tree (Tis the season) Christmas card	£3.99
Winter in the forest Christmas card	£3.99
Blue Angel Christmas card	£3.99
Snowman and moon Christmas card	£3.99
Blue Geese Gift Wrap and tags	£4.99
Red Sheep Gift Wrap and tags	£4.99
Dachshund Gift Wrap and tags	£4.99

NEW TO 2019

You can order your SRUK Christmas cards and gift wrap today by heading to our website www.srukshop.co.uk/ or calling us up on 0203 893 5998.

SCLERODERMA & RAYNAUD'S UK

Dear Supporters

Thanks to everyone who got involved in Scleroderma Awareness Month, for sharing your stories, putting up posters, hosting an information stand and fundraising for us.

We've had good press and radio coverage with a piece in ITV Granada. Increasing awareness and understanding of the signs and symptoms of Scleroderma is a vital step in helping to improve time to diagnosis.

In this edition of the magazine we've highlighted some of the research we've funded to improve our understanding of the early warning signs of the conditions.

One example is the work of Professor Ariane Herrick at the University of Manchester in developing nailbed micro capillaroscopy to help spot the early warning signs of Scleroderma. Another example is the SRUK funded study led by Professor Maya Buch in the University of Leeds to identify those people most at risk of developing heart problems.

As part of our commitment to furthering research into early detection, SRUK has already invested in a research study that will track people with secondary Raynaud's over a period of time to determine what the earliest indicators of scleroderma are.

As part of the 5 year Research Strategy, SRUK will be investing more funds into research studies like these that will enable us to detect the conditions sooner.

We have had over 1,000 responses to the patient survey we put online and in the last magazine, so a big thanks to everyone who completed the survey. Your feedback is important to us.

It helps us understand what is working for you, where we need to improve and whether there are any services we're not covering which are importance to you. We will share the outcomes of the survey with you in the Autumn magazine.

Best wishes,
Sue

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Doc Spot

Your questions answered by our medical professional, Prof. Denton

Since I was young, I've always had really poor circulation. I had chilblains when I was in year six at school and since then it's been bad. I normally suffer with just my hands and feet but today my knees are really red and burning hot, my legs are also really cold. Is this linked to Raynaud's or could it be something else?

It is likely that you have primary Raynaud's based upon such a long history and onset as a child. This can be associated with episodes of more severe blood vessel damage due to sustained cold exposure leading to local inflammation and blood vessel damage affecting the hands and feet that results in painful, itchy lumps called chilblains.

This blood vessel damage is different from Raynaud's that describes episodes or "attacks" of poor blood flow to extremities triggered by cold or emotional stress. After the phase of Raynaud's associated with poor blood flow in extremities (white and blue) there can be a reactive increase in blood flow, and this may give warmth or burning sensation.

At its most severe this can sometimes lead to symptoms of another related condition called erythromelalgia.

My mother has been diagnosed with systemic scleroderma with severe gastrointestinal involvement. She is very weak and lost a lot of weight. She is now in the hospital and is receiving parenteral nutrition. Is there any possibility that she will be able to eat normal food?

Is there any medicine available that can help her to digest her food better, as well as stop her nausea and diarrhoea? At the moment she is doing a treatment with immunoglobulin every month for 6 months (she had already 2 sessions).

The gastrointestinal tract (bowel) is very frequently affected in systemic sclerosis, but severity varies from minor indigestion or constipation to much more severe difficulties with nutrition, pain and swelling of the abdomen.

This can lead to poor nutrition and unintentional weight loss. Weight loss is a priority to treat and supplementary feeding can be given sometimes via a "drip" infusion directly into the bloodstream, called parenteral nutrition. This preserves health but according to symptoms it may be possible to continue eating.

Thus, it is parenteral nutrition rather than total parenteral nutrition (also called TPN). Immunoglobulin (pooled human antibody) infusion is usually given every few weeks when there is overlap muscle inflammation (myositis).

It has been shown in some patients to improve bowel manifestations and this may reflect improved muscle function or blocking of antibodies affecting bowel. This is the subject of ongoing research.

If you have a question you would like to ask Professor Denton, or have a comment on some of the answers given, please email info@sruk.co.uk

My 9 year old daughter has been diagnosed with Cutaneous Morphea. She has had it for nearly 18 months, it is now down the left side of her body, on her stomach and mid back.

Will these scars disappear over time, or will they stay there forever? Is there any latest information on how it can be prevented?

Morphoea is a form of localised scleroderma and so internal organ and blood vessel damage are not a concern unlike in systemic sclerosis. However, it is the commonest form of scleroderma in children and can still be a difficult problem that requires expert assessment and treatment.

In the most serious cases it can affect growth of the affected part of the body and is unsightly. The best way to prevent or reduce progression of new areas is to take appropriate immunosuppressive treatment and this can be by tablet or injection and often combined with steroids or ointments. However, this needs to be decided by specialists due to the rarity of this condition and differing needs of patients. With treatment, although the affected skin improves over time it often can remain visible in the long term, for example being lighter or darker than surrounding skin.

Is there any link between lichen sclerosis and scleroderma?

Both lichen sclerosis and morphoea are skin conditions. There is no direct relationship between these two disorders but they do sometimes occur together in some patients and both can lead to patches of thickened or itchy skin.

They both result from an overactive inflammation response and diagnosis is confirmed by a dermatologist and might require a small sample of skin to be removed under local anaesthetic for diagnosis (skin biopsy). In lichen sclerosis the main changes in the biopsy are in the top levels of the skin whereas in morphoea the deeper layers of skin, called the dermis are affected. Treatments for morphoea and lichen sclerosis may be similar but in general steroid creams are used more in lichen sclerosis and immunosuppression used for morphoea.

How do I heal digital ulcers? Is there a way to completely prevent them?

Digital ulcers (DU) are a common major problem in SSc. Treatment needs a combination of local measures and therapies for Raynaud's phenomenon. Therapies are needed to treat DU and speed up healing, and to try and reduce the formation of future ulcers.

For healing and prevention, the most severe cases may benefit from drip treatment (infusion) with iloprost, and tablet therapies such as sildenafil or bosentan, the latter being effective in reducing or preventing DU. A combination of these approaches is often required to reduce or prevent new ulcers as well as help established DU to heal.

I'm 22 and have scleroderma. I am also a Personal Trainer and being a PT I am always looking to gain muscle. I understand that due to my condition, my body produces too much collagen. However, I was also once told previously that due to my condition, I can't 'over do it' on protein. As I would like to gain muscle mass, I need to take a protein shake either before or after training, and so I was wondering if this is correct?

There is no evidence that high protein diet is harmful and in general good nutrition in a key aspect of coping with the problems of systemic sclerosis (scleroderma) to avoid secondary complication. Collagen is the most abundant protein in the body but also is overproduced in scarring and fibrosis. In the longer-term collagen can be reduced. So, in summary you can certainly take whatever protein supplement you wish and these will not aggravate systemic sclerosis. Exercise is considered very helpful for maintaining strength stamina and may even improve other symptoms such as breathlessness. Exercise is emerging as a promising additional approach to treatment of SSc as in many other long-term diseases.

Early Detection

For patients with scleroderma, early detection is crucial. It can make a world of difference when fighting a disease as unpredictable as this one. In order to highlight the importance of early detection, we have collated anecdotes from our community members about their experiences with early detection, or lack thereof.

Eliza and Eleanor

Georgina Pantano, 33, has systemic scleroderma and Raynaud's phenomenon, but it was a battle to get a diagnosis. After struggling to find answers in the UK, Georgina eventually travelled to Poland where she was diagnosed in a matter of days.

Ultimately she started her treatment in Poland before returning to the UK. Her symptoms were repeatedly overlooked for 18 months but she is now receiving the necessary treatment to maintain her health.

She said: "When I was first diagnosed I felt very overwhelmed, I couldn't really process it to begin with. I was very much in denial and angry. I was adamant to fly back to the U.K. and get back to work and carry on as normal.

"My family had to intervene and almost force me back to hospital in Poland, where I started treatment and ended up staying for the following year. It has impacted my life hugely, I had to leave my job and put my career as a beauty therapist behind me.

"Physically I can no longer use my hands the way I used to and chronic fatigue is a big issue and affects what I can do everyday. I would say to people trying to get diagnosed, never give up, there's always someone to reach out to."

For Alison Beesley, she was able to receive a swift diagnosis for one daughter but when her eldest daughter first showed symptoms, it took 14 months to receive an official diagnosis.

She said: "Eliza was diagnosed at four and a half but it took 14 months to get an actual diagnosis. Thankfully Eleanor was diagnosed a lot quicker when she was five."

Ashton Rains, 28, was diagnosed in two parts. At age 15, she was diagnosed with Raynauds by a local GP but she was not diagnosed with systemic scleroderma until she was 20.

She said: "After my diagnosis of Raynaud's, I began to experience chest pain, breathlessness and mild back/joint pain. My GP then referred me to a Rheumatologist, who ran some X-Ray's and blood tests, and sent a referral to The Royal Free Hospital for further testing.

> **"Although my diagnosis was relatively smooth, earlier detection of the severity of my lung involvement could have prevented me from having such invasive treatment so early on and at such a young age**

"It is there that my official diagnosis of Systemic Scleroderma was given.

"I also believe that if I had been sent to hand therapy at the beginning of my diagnosis twelve years ago as a preventative - and not only for the first time in November 2018 - my hands would not be in the state that they are now."

Georgina Foster, 30, has Raynaud's phenomenon and scleroderma and struggled to get a formal diagnosis for years, despite a gradual onset of symptoms. She was eventually told she had scleroderma in 2018 after a rheumatology specialist spotted her Raynaud's when she was receiving treatment for carpel tunnel syndrome.

She said: "I was having injections for carpel tunnel syndrome in the months leading up to this, and then this specialist spotted my Raynaud's. He referred me to his colleague and from there blood tests were taken to reveal my scleroderma.

"I had been suffering for many years trying to get my symptoms taken seriously by any GP. I had the usual 'cluster of symptoms', such as severe acid reflux, carpel tunnel syndrome, body aches, hot flushes, sickness, general feeling of weakness, vertigo, nose bleeds and of course Raynaud's.

"I felt like my body was spiraling out of control and yet the GP constantly treated each symptom denying there was anything worth doing longer term. It was thanks to my team of specialists above that joined the dots together and who ultimately saved my life."

Early Detection

A history of funding from SRUK

Scleroderma and Raynaud's UK, and our predecessors, have long recognised that detecting the conditions earlier are the key to ensuring that people live longer and better lives. A significant portion of funding over the last 30 years has gone to those studies which have extended our understanding of the early warning signs of the conditions.

Over the years SRUK, have funded studies conducted over time around a single focus area that has the potential to truly accelerate progress. One example of this is the support that the organisations have given researcher clinicians such as Professor Ariane Herrick at the University of Manchester in developing nailbed micro capillaroscopy. The smallest blood vessels we have in our bodies are called capillaries. In normal Raynaud's these capilaries are unaffected, but if the disease is progressing into scleroderma, it leaves its first marks on the tiny capillaries, scarring and distorting them. Spotting this damage gives doctors the best chance to get on top of the disease, minimizing the window where lasting systemic damage can occur.

Unfortunately, spotting this capillary damage reliably is hard. All people are built slightly differently, with no typical 'sign' of scleroderma. The solution is to monitor changes to the capillaries in the hand over time, but the hundreds of metres of capillaries in just one hand makes it hard to compare the same area. This difficulty means that it can be common for doctors to miss the warning signs, and finding a way to help has represented a technical challenge.

Over the last 12 years, SRUK (and the RSA and Scleroderma Society) have supported Professor Ariane Herrick in tackling this challenge. Professor Herrick's team was able to develop computer software that can weave individual images of capillaries into a detailed and highly reproduceable image at a glance, physicians are now able to visualise the entire nailbed, and compare it with the entire nailbed from a previous date to look for the signs of the disease. This means that the early indicators of scleroderma can now be monitored and therefore identified fairly early into the development of the condition.

Systemic sclerosis can represent a severe prognosis for many people, with as many as 1 in 3 people developing heart problems. Identifying the people at higher risk has been a challenge,

Help us fund more groundbreaking research

as heart involvement needs to be detected fairly early. As part of the commitment to early detection research, SRUK funded a study led by Professor Maya Buch in the University of Leeds to track people who are at risk of developing heart involvement.

Professor Buch used a technique that can provide detailed insight into the heart based on this variation. This relies on a technique called CMRI that uses magnets that are so powerful they make water molecules vibrate. Different tissues in the body have different amounts of water within them and so vibrate differently. By measuring this, CMRI can build a highly detailed image of the heart, one that can show the earliest signs of damage. This technique was tested on 20 people living with systemic sclerosis who showed no outward symptoms of heart involvement.

In testament to the power of this technique, a quarter of this test group were found to have the early signs of heart scarring. In order to understand more about the earliest symptoms, study members also had a monitoring device implanted in the upper chest, to monitor the heart for the earliest signs of any heart related issues. Through a combination of scanning and the implant, the results of this study have significant implications for identifying potentially life-threatening complications at the earliest stage.

As SRUK moves into the next stage of its work in accelerating research, we are committed to identify future potential technologies that can really ensure that patients feel the benefits of research sooner rather than later. Artificial Intelligence (AI) is a technology that has become hugely sophisticated and effective over the last five years and could prove to be invaluable in healthcare improvements in the future. AI can be used to analyse huge datasets and identify patterns of activity that could have implications for our understanding of the early symptoms of scleroderma.

As part of our commitment to furthering research into early detection, SRUK has already invested in a research study that will track people with secondary Raynaud's over a period of time to determine what the earliest indicators of scleroderma are.

We have also partnered with a technology company so that more information can be collected from the people taking part in the study. This partnership allows us to collect data such as lifestyle data, biometric data (e.g. heart and pulse rate) and how often someone will report a Raynaud's attack. This means that we can then take all of this data and use AI technologies to understand what the specific circumstances are that lead to someone developing the condition and crucially, what the key early warning signs are.

We can only continue ground breaking work such as this with your support. SRUK relies on the support of its community, including friends and families of people living with the conditions.

To do this we need your help. By donating today you can help us bring about a world where people living with scleroderma and Raynaud's live better and longer lives.

Donate today by heading to sruk.co.uk/donate or calling 020 3893 5998

#Know Scleroderma

For this year's Scleroderma Awareness Month SRUK launched a social media campaign - #KnowScleroderma – to encourage our community to share the things they wish that the world knew about scleroderma. To celebrate our community, we've collected some of the things you told us more people should know about this rare and debilitating condition. Share what you think the world needs to know about scleroderma using our hashtag #KnowScleroderma.

Georgina Pantano, who has systemic scleroderma, said:

"Something I wish people knew about scleroderma is how complicated and life-changing this disease is. No matter how it may look on the outside, whether we look well or like nothing is wrong, this disease really takes over our lives and makes every day extremely difficult."

Hannah Stevens, who has diffuse scleroderma and fibromyalgia, said:

"I wish everyone knew that the condition affects everyone very differently. Scleroderma may look a certain way on one person but it can be the polar opposite on another. So just because you know one person's scleroderma, doesn't mean you know everyone's."

Mario Meoli, who lives with systemic scleroderma, said:

"All the simple things in life, like doing your shoelaces up, trying to get some shoes on, putting a shirt on, are really, really hard. You have the pain to put up with, the medications to take and it's a constant cycle. I think the worst thing is probably losing your independence, not being able to drive the car, go to the shops, get on public transport, go to the pub with your family, or even hold a knife and fork, such simple things that you take for granted. It's a horrible thing and I wouldn't wish it on anybody.

Ashton Rains, who has systemic scleroderma, said:

"What I would love people to know about scleroderma is that, our symptoms vary from day-to-day. If you see me happy and smiling one day and in bed ill the next, that's because that's what scleroderma does."

Philip Beckett, who lost his daughter to a fight with this condition, said:

"What I'd like people to know about scleroderma is that it tends to mimic a lot of other diseases you can have, so it can easily not be diagnosed quick enough. So I would ask people to persist with their GP, everyone knows their body better than anyone else, so keep going back. If you're not certain what you've got, get to a rheumatologist and have it investigated. For my daughter, her first symptoms were sore arms and legs, fatigue and aching all over. So if you get similar symptoms, go to the doctor, keep checking things out, be persistent and don't ever let things just drift along."

Isla Taylor, who has systemic sclerosis, said:

"The one thing I wish the world knew about systemic sclerosis is that is a very rare condition that affects both the skin and internal organs. I need expert medical care and long-term support, which means I take daily medication, weekly injections and have lots of hospital appointments at Birmingham Children's Hospital. The staff are really nice!"

Sarah Cox, who has systemic scleroderma and has had multiple amputations on her digits, said:

"My main issue with this disease is the mental health implications that a long-term disease can have. This disease is progressive and at times it can be very difficult to cope with. Lots of people around you, although supportive, can take it for granted because they become desensitised to what you're managing. At times, this can mean they don't notice that you're not okay. It's always okay to put your hands up and say, 'I'm not okay'."

Employment Support Allowance

Many of our community will understand the difficulties that come with trying to secure disability benefits. As scleroderma is still a little known illness, it can take some hard work to secure the benefits you are entitled to. To help you figure out how to approach the process, we've asked members of our community to share their experiences.

Georgina Foster:

What benefits do you receive? I have applied for a disabled badge but was declined.

What was the process like? Quite tedious and bureaucratic.

What was the assessment like? I think the confusion about autoimmune diseases, and especially scleroderma, means you are at the mercy of whether someone understands the complexities.

What advice would you give to others about applying? Feel no guilt and go in knowing it is your human right to acquire the help and support you need.

Julie Taylor for her daughter Isla:

What benefits do you receive? Disability Living Allowance. Applied in October 2017 and was awarded finally at tribunal last month.

What was the process like? Dreadful and hugely frustrating, as we had to go to tribunal to be awarded the care component.

What was the assessment like? It was unfair and difficult. Somehow the form seems set up for better-known conditions. Keeping a daily diary helped them to understand the situation and I made it clear in the tribunal that the system feels unjust when we should be putting our time and attention elsewhere, not fighting DWP as other people without rare conditions do not get put through it.

What advice would you give to others about applying? Don't give up or be put off if you are turned down. Ask for your mandatory reconsideration and go to tribunal if needed.

Matthew Barry:

What benefits do you receive? I have been on Personal Independence Payment since birth because I am registered blind (not due to scleroderma). I filled out a form for Employment Support Allowance and took it to a job centre where they turned me away saying ESA wasn't a thing anymore and I needed to apply for Universal Credit. They also told me it was basically the same but just under a different name. However I have just got my first payment from UC and it's half of what it would be if I were on ESA, so I'm not very happy about that.

What was the process like? Applying for universal credit is quite complex because there seems to be a lot of different versions, I had to go through a third party to make sense of it all and get an appointment sorted. As UC is through the job centre they aren't very forgiving with dates, if you miss too many appointments without 'good enough reasons' they can reduce or stop the payments.

What was the assessment like? I am yet to have a medical assessment for 'fit for work', there is a 4-6 month waiting list for an examination which I think is preposterous, in this time you have to provide sick notes from the GP saying you are not fit for work.

Georgina Pantano:

What benefits do you receive? In 2012 I was awarded ESA and DLA until it changed to PIP.

What was the process like? I found the process very overwhelming and stressful. A lot of forms to fill out, questions very difficult to answer and confusing. I was lucky in 2012 to find a charity in my town that offer help filling out benefit forms. They had a lady come in from the council that went through every question, explained what they're looking for, made sure I used the right wording, that I didn't miss any important points out or not to over look something myself.

What was the assessment like? I found it very stressful and my symptoms flared up because of the constant worry and pressure. I was extremely lucky to have an understanding assessor who suffered from Raynaud's. It was after the assessment that I felt some things were overlooked, points taken out of context and read by someone unfamiliar with scleroderma. I found it difficult to explain especially on paper when having to tick yes and no answers when this condition is so unpredictable.

What advice would you give to others about applying? The advice I'd give to make use of any services that can help you fill out forms. I believe it really helped me and gave me an insight to how questions need to be answered. Also, when answering questions think of it as if it were your worst day of symptoms to give a true account of living daily with such a debilitating rare condition.

Ashton Rains

What benefits do you receive? Currently on PIP.

What was it like going through the process? Assessment for ESA was fairly intense, and I could tell that I was being watched closely from the minute I walked into the building. I took my Dad along for support, along with all of my medical notes. She was a physiotherapist, and mentioned that she could see how bad my hands were and lack of physical movement. Explaining the scleroderma was hard, but she had looked it up so knew little bits. I explained everything in detail and thought about my absolute worst day when answering questions. I was honest.

What advice would you give to others about applying? Take someone with you, take as much evidence as you can - better to have too much than not enough.

Some of the benefits you, or your family member, might be entitled to include: Employment Support Allowance, Disabled Living Allowance, Personal Independence Payment, Universal Credit, Carer's Allowance, Attendance Allowance and Access to Work. You may also be eligible for a blue badge.

Refer to our basic guide on applying here: https://www.sruk.co.uk/scleroderma/managing-scleroderma/employment-support-allowance/

For information on benefits visit: www.gov.uk and for more detailed on your eligibility contact Citizen's Advice at 0344 411 1444

Voices of the Community

Proud mum Lizzi Hooks, 38, has lived with Raynaud's phenomenon for most of her life. Lizzi self-diagnosed with Raynaud's aged 14. Her symptoms – including a strong reaction to temperature changes – can make everything from grocery shopping to a paper cut difficult to manage. Although the condition comes with its trials, Lizzi keeps positive and is surrounded by a supporting, loving family who help manage daily tasks when her fingers fail her.

How does your condition affect you?

I feel cold a lot and I struggle with going to the supermarket, especially in the cold aisles. Picking things up and getting my card out of my purse can be difficult because I lose dexterity.

The pain in my fingers is the worst. In the winter I get dry and split skin and the smallest cut won't heal. My feet are also affected and I come out with white feet if I go into the sea. In the winter, if it's cold and icy I have to be extra careful about keeping my balance, as I don't always feel them.

Were you always aware that you might get Raynaud's?

Because my mum had it, it wasn't really a surprise, especially as my older brothers had it too. I kind of knew it was going to happen to me at some point. I wasn't worried about it all though.

Were you concerned about it when having your own children?

They may well develop it, but I can't do anything to prevent it so there's no point worrying about it.

How did your symptoms start?

It started with cold fingers and it went from there. I went to my GP first and got put on nifedipine, which I've been on ever since. I started wearing gloves everywhere and using other people to warm my hands up! I used to notice it a lot when camping with friends as a teenager, so I'd find the nights really difficult and I'd have to wear lots of extra layers.

As you've gotten older, how have the symptoms developed?

They've gradually gotten worse. For example, I find doing the supermarket shop really bad and it can be stress related too, so after a long day I might get an attack and I'll make myself a mug of hot water to hold. When the kids were very little, it was tricky to do up fiddly clasps and stuff on their clothes.

How do your family and friends support you?

When I go to the supermarket, I usually end up honking the horn for my husband when I get home. He knows that's the signal to put the kettle on for me to warm my hands up and he'll come out and bring the shopping in, so the honk equals, 'my hands are bad come and help me!'. My kids know that sometimes they'll have to help me with taking my shoes off and doing up buckles in the car and stuff like that. They'll always ask if I want the car seats heated up for my hands too, so they're used to it and they know sometimes I'll just need to go home because my hands are bad. They're growing up with it, so they don't know any different.

What is the most frustrating thing about the condition?

"For me, it's frustrating that I can't do everything that I want to do. Whenever I'm planning, I've always got in the back in my mind, are you going to be warm enough? I live by the beach but I can't really enjoy surfing or other water sports because I'm worried about getting too cold."

Why do people need to understand the condition?

A lot of people don't understand how difficult and impactful it can be on your life. People with Raynaud's, I find, often don't talk about it much. So people who don't understand how debilitating it can be. I think it's really important that we teach more about it so that when you see that person struggling to get their cards out in the supermarket, you might be more understanding. And if more people knew about it, then I probably wouldn't get so many funny looks when I ask for a mug of hot water from every café. So my advice to anyone else with the condition would be, make sure those closest to you are supportive, invest in plenty of pairs of mittens and buy a really good electric blanket!

Hairdresser Maxine Jackson, 49, was diagnosed with systemic sclerosis in May 2016, and also has several other related conditions. Despite her sensitivity to cold and decreased dexterity, she is determined to live her life to the fullest and carry on her passion – styling hair.

How do your conditions affect you on a daily basis?

They impact me in everything I do. It depends on the day though. It's difficult getting dressed, having a social life and everything in between. I'm just much slower, everything takes longer and it needs to be planned in advance. Even having a shower, getting dressed and getting ready to go out, takes a lot longer than it used to.

How does it impact your job?

I've lost a lot of clients due to the condition and it's impacted my work hugely. When I have days that it badly affects my wrists and hands, I struggle to twirl the brush, hold the hairdryer or hold heating tongs.

Everything takes me longer now, as I have to be extra careful and by the time I finish working, I'm in so much pain afterwards and my feet, knees and legs are swollen. I've gone from working five days a week to two or three days a week, because I can't do the hours that I used to.

How does it make you feel?

More so when I was on medication, it was depressing and it makes you think about death a lot. For 47 years I was in pretty good health, I've only had flu once in my life, but since I've been ill, I've had chest, throat infections and more. I went from being really healthy, working out three or four times a week, to struggling to walk down a flight of stairs without resting at the bottom. I've been depressed but now I'm focusing on the positive that I'm still here and able to carry on.

What keeps you motivated to push through?

Taking back a bit of control, in regards to my diet, has helped. Looking at the bright side of everything keeps me going, I'm still here and I can still do things, even if it takes me longer. I found a lot of strength from looking after my mum until she passed.

She was such a strong person and never wanted anyone to do anything for her, so I've kind of got her attitude. Talking about it helps a lot too. I'm more open now. For example, my sister used to cry a lot whenever I got new test results and then I'd end up consoling her, so I've asked her to try and keep it together at appointments because her being positive and being strong helps me to continue.

What do you think are some of the misconceptions around the condition?

Just because a person looks healthy, doesn't mean they are healthy. It's a severe condition, but because I appear to cope well to other people, they don't realise how much pain I'm in on a daily basis. It's so crippling and frustrating when people say, 'oh you look so well', when it's not the case.

They just think it's a skin condition that only alters your outer appearance. They have no idea that this condition traps your body in a skin that feels like hard leather. It fuses your joints in awkward positions and you're more sensitive to movement and touch. Clothing becomes your enemy and you have to choose clothing carefully.

Every single one of these things that I've mentioned causes a great deal of pain and that's just a miniscule insight into the symptoms of scleroderma. Scleroderma symptoms once diagnosed are unique to that sufferer. No two people with the condition have the exact same symptoms.

That's why I'm so passionate about doing awareness work. People need to understand that soft tissue is everywhere and it can impact your whole body, including internal organs. Battling with that on top of all the scleroderma symptoms is extremely tough.

You'll have multiple symptoms happening to you at once and it seems never ending, which takes a toll mentally and physically.

What do you wish more people knew about the condition?

If you've got a broken arm, people get it because they can see it, but this is so much harder to explain to people. It's a chronic condition and it's very difficult to be battling every day, especially when no one knows what it is.

It impacts you from the time you get up until the time you go to bed. Most people go to bed to rest, but that's where we deal with worse symptoms. I spend all night trying to find a comfortable position and it takes its toll.

But I swear by bathing in magnesium flakes for twenty minutes before bed, because it helps relax the muscles and sends you to sleep.

My Wife by Simon Gaskell

Simon Gaskell, Jane's husband tells us about Jane, her journey with scleroderma.

"Jane first noticed Raynaud's-type symptoms when she was a teenager and that she would become much more fatigued than her peers at that age. Although concerns about her health persisted, she was not diagnosed for almost another decade.

She noticed severe Raynaud's was affecting her in the Winter of 2004 when we were living in Edinburgh and Jane was completing her PhD in Botany. She was admitted to hospital early in 2005 and, despite exhaustive tests, was discharged without diagnosis. In March 2005, we moved to Brisbane, Australia. On the way to Australia, Jane noticed that she was coughing up orange mucus, then a few days later, she noticed what looked like burst blood vessels in her eyes.

An optician in Queensland checked her eyes and noticed the characteristic 'cotton wool' spots which indicated vasculitis. Despite these concerns, none of the doctors Jane saw in the first few weeks in Australia diagnosed her condition, and her lung condition deteriorated, eventually resulting in pneumonia. She was treated with a very high dose prednisolone which stopped her pneumonia but her lungs were left with permanent damage in terms of both capacity and oxygen diffusion.

Two months passed without any of her Doctors offering a firm diagnosis. After another very severe bout of Raynaud's, she was admitted to hospital in Brisbane and was finally given the diagnosis of scleroderma/polymyositis. She was primarily treated with azathioprine and prednisolone to control her illness and her lung and eye symptoms settled down.

After a year, she stopped taking azathioprine and swapped to mycophenalate/myfortic. Having been on relatively high dose prednisolone for a long time, Jane's blood pressure escalated to the point where her kidney function began to deteriorate about 12 months after her initial diagnosis. She was put onto higher doses of blood pressure

medication at that time and her blood pressure and kidney function slowly improved.

Jane found work at the University of Queensland, Brisbane Botanic Gardens, Brisbane City Council and Queensland Government on a part-time basis. When we returned to the UK, she worked for Wiltshire Wildlife Trust and Natural England, again on a part-time basis. It was always hard for her to get into work in the morning fatigue and her very frequent hospital appointments eventually made it too hard to continue.

In 2007, we returned to the UK where Jane was cared for in the Royal National Hospital for Rheumatic Diseases in Bath, firstly under Dr McHugh and then Dr Korendowych. Jane had a number of specialist consultants, she also regularly sought support from osteopaths, massage therapists, chiropodists, acupuncturists, occupational therapists, psychologists and podiatrists. Over the first few years, Jane's illness was mainly under control. Her kidney function, lung function and eyes were stable, but she continued to suffer from Raynaud's, skin complaints and pitting of her fingers.

In 2011, after having suffered bouts of severe fatigue, Jane was diagnosed with Addison's disease. She was prescribed hydrocortisone to help with getting through her daily life. She was also prescribed citalopram to help with anxiety/depression at this time. Throughout her illness, Jane needed to take omeprazole/esomeprazole to help with stomach pain and acid reflux.

In 2013, Jane's kidney function began to slowly deteriorate. She was prescribed different blood pressure medications in order to protect her kidneys. By the end of 2016, Jane was suffering repeated episodes of ill health – generally involving diarrhea, fainting, fatigue, migraine. Her kidney function continued to reduce and by the summer of 2017, she was put on the waiting list for a kidney transplant. She suffered from severe stomach pain, cramps, bloating and water retention.

Jane took a very active role in trying to understand her illness. She was a scientist and did her best to appreciate the medical basis for both her diagnosis and treatment – tracking down scientific papers, speaking to consultants and specialists and researching anything that could help her. She was very in tune with her body and tried to listen to whatever it was telling her.

Through a combination of working with her doctors and nurses, which included questioning their ideas (respectfully though persistently), being patient, paying close attention to her diet, exercise (in particular t'ai chi), mindfulness and enjoyable distractions (gardening, travel, spa breaks, art, pets), Jane found a balance which for most of the time post-diagnosis meant that she was able to live a fulfilling life without her condition impacting too greatly on her. The key to finding that balance was to never be too rigid about which of these things was most important at any one time.

Jane's illness influenced so much of her life that it was inevitable that it would affect our relationship. The amount and types of drugs that she had to take meant that we were unable to have children. She was unable to work full time straight after her diagnosis and then had to give up work completely in 2011. She was medically retired in 2015.

She was an incredibly gifted and ambitious woman, so this had a serious impact on many areas of our relationship as we became entirely dependent on my income. This, plus Jane's care, placed a burden of stress on me and it became very difficult to balance her need for emotional and physical support with my career, time together, looking after our household and finding time for myself.

The fatigue that Jane suffered impacted on our ability to socialize and spend time with friends and her need to be near the things she relied upon for comfort and treatment meant that we were rarely able to travel as widely as we had before her diagnosis.

By August 2017, Jane was having a lot of difficulty with food and drink. She had acute episodes of what she thought was IBS and her diet became significantly restricted. She was admitted to hospital in Bath with debilitating diarrhea and fatigue and was suffering with tremors. She was discharged a week later but then re-admitted to Southmead Hospital in Bristol under the kidney specialists there.

The tests undertaken on Jane at that time suggested that she did not yet need dialysis and she was discharged a week after admission with instructions to rest and recuperate.

A day after she was discharged, Jane had a heart attack and despite the best efforts of me, her parents, paramedics and doctors she died. She had had tests on her heart for all of the 12 years since diagnosis and, although there were abnormalities (the right hand side of her heart was slightly enlarged and there was an unusual second noise in her heart beat), nothing caused any of her specialists undue concern.

From living with Jane, her suggestion to others in the same situation, was to work out what is important to you and work out what you really enjoy doing. Do at least as many of the latter as the former i.e. if your commitments stop you from having fun, then really ask yourself whether those commitments are worth it.

Physiotherapy - why, what, how?

Skin changes are the most common symptom of all forms of scleroderma, with the severity varying from person to person. Tightening of the skin is one of the manifestations that are thought to have the most profound impact on the quality of life for someone living with scleroderma. Although there are several medicines that can help to limit the progression of skin tightening, physiotherapy exercises are another key management approach that can be taken to maintain skin movements around joints and overall suppleness.

Physiotherapy is an area of healthcare that relies on a variety of techniques to help restore movement and function when someone is affected by injury, illness or disability. Delivered by specially trained and regulated physiotherapists, a 'whole person' approach is utilised, whereby the patient is central in their own care through education, empowerment and participation in their treatment.

Physiotherapy can be helpful for people of all ages with a wide range of conditions, due to an often specifically tailored programme.

Physiotherapy is thought be especially beneficial for people who have problems affecting the:

- bones, joints and soft tissue – such as back pain, neck pain and sports injuries
- brain or nervous system – such as movement problems
- heart and circulation – such as rehabilitation after a heart attack
- lungs and breathing – such as chronic obstructive pulmonary disease

This service can be provided by physiotherapists as part of a multidisciplinary team in hospitals, GP surgeries and clinics, some sports teams and clubs, and even certain workplaces.

There are a range of at-home exercises that a person with scleroderma can do to act in the same effect.

Physiotherapists use a variety of approaches depending on the need of their patient, but they mainly revolve around:

- education and advice, by giving general suggestions about concerns that may be affecting daily lives, such as posture and correct lifting techniques to prevent injuries
- movement, tailored exercise and physical activity advice, where exercises are endorsed that will help specific problem areas of the body
- manual therapy, where the physiotherapist will use their hands to help alleviate any pain and stiffness, and to improve flexibility

As a whole, it is useful for there to be flexibility, strength and conditioning, and aerobic components in someone's fitness programme. If you are stretched for time, it is important to remember that these exercises do not have to be a separate aspect of the day as activities such as climbing the stairs, walking, cooking and other household tasks still count.

Before undertaking any changes to your physical activity regime, it is important that you discuss this with your medical team, especially if you are in any doubt about what level of activity is appropriate for you; it is critical to avoid over-exerting yourself.

Below are some exercises that can be done at home; for exercises that are specialised to yourself and your body's capabilities, please ask your doctor or specialist nurse to refer you to a physiotherapist. Stretches should be held for at least 10 seconds and performed three times daily for benefits to be seen.

Flexibility:

One of the main characteristics of scleroderma is skin tightening and consequent decreased movement/ stiffness at joints and muscles. Stretching will not prevent skin tightening, but it will help loosen any tightened tissues under the skin and many patients also say that their stretches do aid in pain relief.

Muscle strengthening:

Scleroderma can affect your posture and range of movement, which in turn will affect muscle strength. Compounded by problems in diet meaning that you are not getting enough nutrition to keep muscles strong, you may find yourself being less active than previously.

Muscle strength can be maintained by keeping as active as possible, within the limitations of your scleroderma. Some specific exercises may have to be performed so that muscle groups are kept strong or to re-strengthen certain areas. Your physiotherapist will be able to assess you and determine if any muscle groups need focussing on.

General conditioning/aerobic exercise:

It is important to try and do some gentle cardiovascular or aerobic exercise regularly. General advice states that you should aim to do 20 – 30 minutes, 4 -5 times a week, but how much you can manage and what level is appropriate will vary upon the nature of your scleroderma. Examples include swimming, aqua aerobics, cycling, and keep-fit classes.

For a list of local community exercise options, please ask for your healthcare professional or you can take a look at the Change4Life website.

Physiotherapists are available through the NHS and privately. If you are planning to see a physiotherapist privately, it is possible to do this by self-referral but this is not always possible with physiotherapists on the NHS.

Depending on where you live, you may be able to self-refer or you may need to visit your GP or consultant first, who may then refer you on to a physiotherapist. Some areas will offer a self-referral service – staff at your GP surgery or your local NHS Clinical Commissioning Group (CCG) or hospital will be able to tell you if this is available. Some physiotherapists also work in GP surgeries as the first point of contact for patients in need, so again it is worth confirming this with your GP surgery.

If choosing to see a physiotherapist privately, it is important that you check that they are a fully qualified member of a recognised professional body, such as the Chartered Society of Physiotherapy, and that they are registered with the Health and Care Professions Council.

Oral and Dental involvement in scleroderma: What happens and how can it be managed?

Recently, our community made us aware of a poll that was run online to understand the impact that the oral and dental complications of scleroderma can have on someone living with the condition.

We want to ensure that everyone has the support that they need, as well as the information to help manage the conditions as best as they can. We've selected some questions from the poll to answer here. Further information can be found in our factsheet 'Oral and Dental Aspects of Scleroderma' which is available on our online shop. Alternatively, you can call us at our head office line to receive a hard copy of this factsheet, free of charge.

I'm experiencing issues with my mouth, it's narrowing to the extent that dental treatment and eating are becoming difficult.

Microstomia, or 'reduced mouth opening', in SSc is caused by the tightening of the facial skin around the mouth. If the mouth opening becomes very small, it can have an impact on being able to eat, dental hygiene and speech. There is no evidence to show that it has ever progressed to a point where patients are ever unable to eat or speak.

Mouth stretching exercises are probably the best treatment for microstomia and have been shown to improve mouth opening and help with eating, dental hygiene and speaking. It's recommended that these exercises are performed once or twice a day, in front of a mirror. However, if you have sores around your mouth, you should avoid doing this as it may cause the sores to rupture.

I'm really worried about losing my teeth and about whether I'll experience tooth decay.

A lack of saliva increases susceptibility to dental decay (caries) and gum diseases (gingivitis), which can lead to tooth loss if left untreated.

Recent work has suggested that the progression of SSc can in itself affect the health of the gums and roots in people living with the condition. In addition to keeping the mouth moist, we recommend avoiding things that can affect dental hygiene such as cigarette smoking or having a high intake of refined sugar.

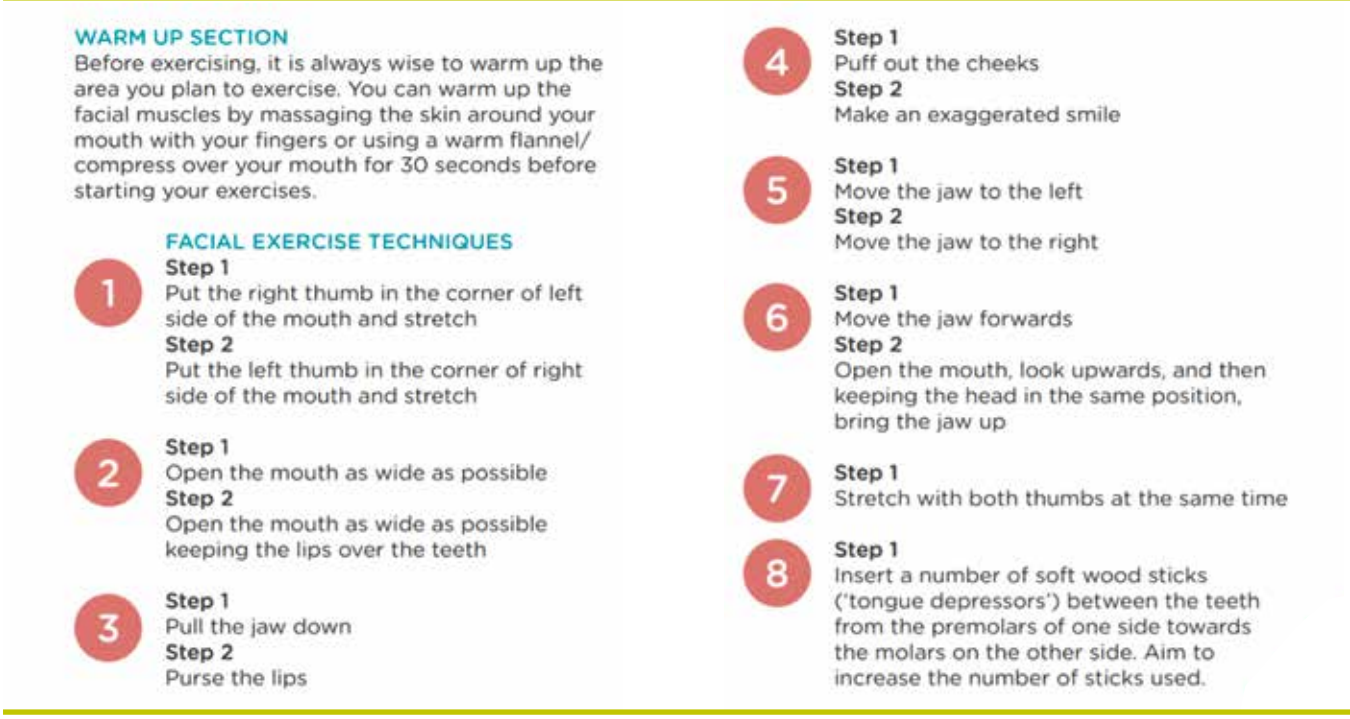
I have telangiectasia on my lips and mouth.

Telangiectasia, caused by small dilated blood vessels, are sometimes evident around the mouth, lips or gums but do not cause any problems at this site. Concealers such as make up and lipstick can be helpful if you consider it to be unsightly.

I have recurring mouth ulcers, is there anything I can do?

Oral ulceration can be a feature of auto immune rheumatic diseases and can occur as a common side-effect of immunosuppressing drugs (such as MMF, cyclophosphamide, methotrexate), which are sometimes prescribed to people living with SSc. Recurrent oral ulceration may require a change of drug.

As with many oral complications, maintaining good oral hygiene can help prevent mouth ulceration. The best treatment for active mouth ulceration can be applying creams which contain a small amount of steroids such as hydrocortisone oromucosal tablets or Adcortyl in Orabase. Steroid inhalers can also be sprayed onto active ulcers to promote healing.



WARM UP SECTION

Before exercising, it is always wise to warm up the area you plan to exercise. You can warm up the facial muscles by massaging the skin around your mouth with your fingers or using a warm flannel/ compress over your mouth for 30 seconds before starting your exercises.

FACIAL EXERCISE TECHNIQUES

1. **Step 1** Put the right thumb in the corner of left side of the mouth and stretch
   Step 2 Put the left thumb in the corner of right side of the mouth and stretch
2. **Step 1** Open the mouth as wide as possible
   Step 2 Open the mouth as wide as possible keeping the lips over the teeth
3. **Step 1** Pull the jaw down
   Step 2 Purse the lips
4. **Step 1** Puff out the cheeks
   Step 2 Make an exaggerated smile
5. **Step 1** Move the jaw to the left
   Step 2 Move the jaw to the right
6. **Step 1** Move the jaw forwards
   Step 2 Open the mouth, look upwards, and then keeping the head in the same position, bring the jaw up
7. **Step 1** Stretch with both thumbs at the same time
8. **Step 1** Insert a number of soft wood sticks ('tongue depressors') between the teeth from the premolars of one side towards the molars on the other side. Aim to increase the number of sticks used.

My tolerance for regular toothpastes and mouthwash has decreased.

Toothpastes aid the removal of plaque and tartar, freshens the breath and can provide fluoride, which strengthen the outer surface of teeth. Fluoride mouthwashes (e.g. Fluorigard) are available and recommended for patients with a dry mouth (xerostomia) to reduce the risk of dental decay.

Some patients with dry mouth report local irritation with fluoride containing products and cannot tolerate them. Modern toothpastes also contain a foaming agent, Sodium Laurel or Laureth Sulphate (SLS), which can irritate mouth ulcers and may delay their healing.

There are a number of products that do not contain this ingredient (Corsodyl, greenpeople) and may be better for gum health and for people who experience frequent mouth ulcers. Difflam mouthwash may also be helpful in oral ulceration and is available over the counter.

I've noticed that my bottom lips feel sore and tight, and that there is some peeling on my lips.

Dryness of the mouth (xerostomia) is common in people living with SSc and is caused by the reduced formation of saliva, possibly due to inflammation or scar tissue formation within the salivary glands.

Lack of saliva can lead to soreness of the mouth and increases the likelihood of dental caries, gingivitis, fungal infections of the mouth and bacterial infections of the salivary glands. People living with the condition are also advised to avoid smoking and excessive alcohol which can also worsen oral dryness.

Chewing sugar-free gum or salivary stimulation tablets are a useful way of encouraging the salivary glands to produce more saliva. At least two chewing gums have been developed specifically for the management of dry mouth (Biotene dry mouth gum and BioXtra chewing gum).

Book Your Place Today SRUK Glasgow Conference

Saturday 12th October 2019

Radisson Blu Hotel, 301 Argyle St, Glasgow G2 8DL

Last year you told us that having a space to meet other people with the condition and hear from some of the country's top clinical specialists were of huge importance. We heard you and based on feedback from members, this year we are running smaller conferences, rather than one big conference, to allow for greater geographical coverage through the year. The first one has already taken place in Cambridge on the 27th July, and now we are gearing up the for second one.

The next upcoming conference will be held in Glasgow on Saturday 12th October from 1pm to 5pm at the Radisson Blu Hotel which is based inside Glasgow Central train station.

We have worked with clinicians based in Scotland to produce a programme of speakers who will talk about understanding and managing the conditions, as well as practical tips you can do now. What's even better is it's FREE to members and just £15 to non-members.

How do I see who is speaking?

For the most up to date version of the agenda, please visit our website www.sruk.co.uk

How do I book my place?

We now have an online booking system where you can book your place and if you aren't a member it will take payment. You can also call one of our friendly team on 020 3893 5998. The booking form will take you through several steps, on top of the registration process so you can advise us about:

1. If you require a disabled car parking space.
2. If anyone in your party: uses a wheelchair, requires a 'buddy' for the day, is partially sighted or requires a hearing loop.

How do I book my hotel accommodation?

If you would like to stay overnight in Glasgow, you can ring the Radisson Blu Hotel directly on 0141 204 3333 book a hotel room.

We would be delighted if you would join us for one of the highlights of the year. Please contact the conference booking number with any queries or if you do not have access to the internet we can book you on and take your requirement details. Conference Booking Phone 020 3893 5998 or email info@sruk.co.uk

Support & Useful Contacts

Our SRUK Helpline is available to anyone who is affected by the conditions to receive support.

0800 311 2756

The helpline operates 365 days a year from 9am-7pm. This service does get busy so if the call goes to voicemail please leave your name and number and you will receive a call back within 24 hours.

We currently have eleven volunteers who man the helpline on a rota basis; Amelia, Brigid, Helena, Jean, Katherine, Kim, Liz, Paula, Penny, Rosemary & Susie.

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

If you call the helpline, the volunteer that you talk to may have Scleroderma and/or Raynaud's but as we know, everyone is different and the manifestations from person to person are varied and complex. Therefore, we refrain from swapping backgrounds and symptoms but listen positively to your issues and try to help you with your particular enquiry.

Specialist Nurses		
Rheumatology Telephone Advice Line		01225 428823
Belfast	Audrey Hamilton	0289 056 1310
Leeds	Specialist Nurse Team	0113 392 4444
Liverpool	Jan Lamb & Jenny Fletcher	0151 529 3034
Manchester	Specialist Nurse Team	0161 206 0192
Newcastle Upon Tyne	Karen Walker	0191 223 1503
Portsmouth	Julie Ingall	0239 228 6935
Royal Brompton	Lucy Pigram	020 7352 8121 (Main Switchboard)
Royal Free, London	Sally Reddecliffe & Adele Gallimore (For Pulmonary Hypertension Enquiries)	020 7472 6354
Royal Free, London	Specialist Nurse Team	020 7830 2326
Sheffield	Specialist Nurse Team	0114 271 3086
We are working towards providing contacts at key hospitals in Wales, Ireland and Scotland please check the website for up to date information or call the Rheumatology telephone advice line (emboldened in green, listed above) with your medical query.		

Local Support Contacts

Our local support contacts provide support on a local level by organising support group meetings or by being available to local residents via the phone or email. If you are interested in joining one of our local groups or wish to receive some support then please contact us and we will be happy to put you in touch with your **local support contact: 020 3893 5998**

Local Support Contacts	
Bedfordshire	Rita Boulton
Exeter	Mike Corbett
Hampshire	Tracey James
Merseyside & Cheshire	Diane Unsworth
Norfolk	Lucy Reeve
South London	Celia Bhinda
South Wales	Belinda Thompson
Leeds	Lynne Lister
Worcestershire	Shirley Lynch
Burton	Helen Nutland

Meet Our Fundraisers Shining A Spotlight On The Importance Of Early Detection

As a charity, our community of fundraisers are crucial to the work that we do. They help us raise awareness, educate people about the reality of Scleroderma and Raynaud's phenomenon and raise money for SRUK to channel into research and awareness projects. In this issue, we are shining a spotlight on two fundraisers who are particularly passionate about the importance of early detection.

Thomas Jones', 28, mother Karen had systemic scleroderma and Raynaud's phenomenon and, after a string of related illnesses, she ultimately lost her fight with the condition last year. Following a lengthy diagnostic process, Karen was diagnosed in 1999. However, she had been unwell for a while before she finally received a full diagnosis.

During Karen's lifetime she took part in every available medical study and gave interviews on the condition to raise public awareness. Following in her footsteps, Thomas has arranged an evening of show stopping entertainment featuring his own band Quaintest Show on Earth at the stunning Old Courts Theatre in Wigan to raise awareness of the condition. He is also aiming to raise £500 for SRUK and in the name of his mum.

He said: "It's a very nasty disease and it doesn't get much attention because it affects less people, but it's just as important to know about. It took a while for my mum to get a diagnosis.

"We met a lot very confused people. She just kept going higher up the chain until someone was able to give her a diagnosis.

"It's really important for people in the medical community to know more about it, especially for people who take blood from patients with sensitive skin.

"Even if we can make it another thing for doctors to look out for, it would make a difference. There's no reason why it shouldn't be in the public consciousness and I hope to see more people talking about it."

In the future, Thomas plans to host a fundraiser every June to commemorate his mum, and to shine a spotlight on the condition during Scleroderma Awareness Month.

To donate to Thomas's fundraiser please visit:
https://www.justgiving.com/fundraising/qsoe

If you would like to help us make a difference to the lives of people living with Scleroderma and Raynaud's phenomenon, then please reach out anytime, we'd love to have you!

Just like his fellow fundraiser, Philip Beckett, 56, is eager to see more progress in the early detection of systemic scleroderma. Philip lost his daughter Lauren Beckett, aged 28, after she developed an aggressive form of systemic scleroderma, which was initially misdiagnosed as fibromyalgia.

In the weeks before her death, Lauren was due to see a rheumatologist but she had repeatedly visited her physician in an effort to get to the bottom of her health problems.

Unfortunately, Lauren was not diagnosed with scleroderma until she was in intensive care after developing acute renal crisis.

Philip said: "Doctors initially thought it was fibromyalgia and didn't investigate deeply enough. It's not really the doctor's fault as they can only go on what they can see, but to me they didn't move fast enough.

"We need to be getting people to relevant consultants as soon as possible, especially as Lauren had been back multiple times due to the aching, massive fatigue and pain.

"They just kept giving her different medications for the fibromyalgia. If they'd have gotten her into the rheumatologist at Christmas, and she died at Easter, they may well have found it and got on top of it and she may well be here today."

As we learn more about both conditions, Philip hopes to see more people diagnosed earlier so that patients get the help they need when they need it most.

He continued: "There should to be extra training for doctors and more information sharing so we can get people diagnosed earlier. Hopefully the new scleroderma booklet will help a lot.

"It would be great if we had more specialist units in the country too. Having only one isolated hospital is just not enough. Further training in the subject for clinicians would make a huge difference. Even if the specialists don't know and have to ask other experts, then it delays treatment."

To donate to Philip's fundraiser please visit:
https://www.justgiving.com/fundraising/philip-beckett

Largest EVER Team SRUK Smashed the London Marathon.

Marathon Madness

With summer approaching and winter being a thing of the past it can only mean one thing, its marathon season!

This year we had more runners taking part in marathons across the UK on behalf of us than ever before, not only fundraising incredible amounts but also helping raise awareness. Every time someone wears one of our running vests, its an opportunity for someone to discover us and what we do. We couldn't be more proud of each and every one of our runners, here are but a few:

London Marathon

We would like to say a HUGE thank you to all of our 15 London Marathon runners who took part this year in aid of SRUK, it was our biggest London Marathon to date not only for the amount of runners we had taking part but also for our cheer station which had over 20 people, a mixture of family and friends, cheering our runners on as they passed us at Mile 14 and 21.

It was an incredible day and our amazing team together raised over £26,455 for SRUK. Thank you to Paul, Jack, Ross, Kate, Hannah, Max, Jane, Ewa, Andrew, Marcus, Sharon, Paul, James, Bob and Jake.

Manchester Marathon

This year we had three runners taking on the Manchester Marathon. Henry ran in memory of his sister Ruth who passed away 27 years ago while brother and sister Mike and Kim ran in memory of their mother Lesley. Together they raised nearly £3,000!

Edinburgh Marathon

Simon took part in this year's Edinburgh Marathon in memory of his dear friend Jennifer, who passed away in February. He raised an incredible £1,120 in her memory and to help others who lived with scleroderma like Jennifer.

Paris Marathon

Amy raised £345 by taking part in the Paris Marathon in memory of her uncle Nigel who passed away on Christmas eve.

Thank you

Alexandra Marler

At the beginning of the year Alexandra was approached to see if she would like to be one of the artists to take part in a charity event in her home town of Haslemere in Surrey. There are a number of sculptures, this year it was Haslemere Hounds, that get decorated and painted, then sold for charity at an auction! She asked if her charity could be SRUK and they kindly agreed.

Alexandra called her hound 'Sirius the Dog Star'! He took her many hours to paint, including the actual constellation and other planets and stars! A very generous lady, a stranger to Alex, who wishes to remain anonymous, fell in love with Sirius and offered a huge amount of money for him!

It had been a very emotional time for Alexandra, as someone who has scleroderma and advanced lung fibrosis, she sometimes finds it hard to feel that she is making a difference in the world.

But we are delighted to say that Sirius sold for £15000! And the entire donation has gone to SRUK and will be used to make a real difference to all with the disease.

Scleroderma and Raynaud's UK won £1,000 from the Movement for Good award

Ecclesiastical Insurance awarded £1000 to SRUK after members of the public were invited to nominate causes close to their hearts, so a huge thank you to our community and everyone that nominated us or helped spread the word to friends and family!

The money raised by our fantastic fundraisers is invested in research, helps raise awareness, continue to empower the community with better knowledge and support.

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 for how SRUK can further support the community then we would love to hear from you.

Your Magazine, Your Way

Thanks to everyone who provided feedback on the last issue of the magazine. We know that not all comments have been covered in this issue but we will be working hard to cover your feedback in future issues. Your feedback is really important to us. If you have a comment or suggestion on how we can improve future issues then call our team on 020 3893 5998 or email: info@sruk.co.uk

Donate to us through our website www.sruk.co.uk by clicking the donate button or by phoning our friendly team on 020 3893 5998 using your debit/credit card.

Your card details are not stored by the charity and the systems used to process your payment are secure.

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

@WeAreSRUK /WeAreSRUK

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.