SCLERODERMA & RAYNAUD'S UK

SRUK NEWS

Hair Today, Gone Tomorrow

Mathew smashes his target!

Mum in a 'Million'

Claire and son Lewis raise awareness of Raynaud's to millions after both being diagnosed with the condition

Doc Spot

Your questions answered by our medical professional

1st Birthday Celebrations

Issue 5
Spring Edition
2017

Event Calendar 2017

APRIL

2nd – Manchester Marathon

24th – London Marathon

MAY

14th - Royal Free Family Day, London (Royal Free Patients Only)

26th - SRUK Information Stand, Royal Hospital for Sick Children, Glasgow

27th/28th – Edinburgh Running Festival

30th - SRUK Information Stand, Ninewells Hospital, Dundee

JUNE
SCLERODERMA AWARENESS MONTH

27th - Open Day, Salford Royal Hospital, Manchester

29th – World Scleroderma Day

29th – SRUK Information Stand, Royal Free Hospital, London

JULY

SRUK Information Stand, Great Ormond Street Hospital, London

30th – Prudential Ride London-Surrey 100

AUGUST

SRUK Information Stand, Aintree University Hospital, Liverpool

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

19th - London Bucket Collection

SEPTEMBER

3rd – Bear Grylls Survival Race, Edinburgh

9th – Thames Path Challenge

17th – Manchester Bucket Collection

16th September 9.30am-5pm
SRUK Annual Conference

De Vere Cranage Estate
Cheshire, CW4 8EW.

For further information and to book visit www.sruk.co.uk/conference or call 020 3893 5998

OCTOBER

8th – Bear Grylls Survival Race, London

17th - SRUK Information Stand, Sheffield Children's Hospital.

22nd – Bristol and Bath Marathon

SRUK Information Stand, Chapel Allerton, Leeds

NOVEMBER

SRUK Information Stand, Freemans Hospital, Newcastle

We will be visiting hospitals across the country to provide information and support. We are currently working with all the hospitals above to find a suitable date to visit and will be sharing the date on our website, social media and with people in the local area when this has been confirmed.

If you would like us to visit your local area to provide information, support an event or talk about the charity and the conditions then please get in touch with us at **info@sruk.co.uk** or **020 3893 5998**

Dear Supporters

Thank goodness the milder weather is finally on its way, but I know for many of you that doesn't necessarily mean your Raynaud's is any better, and so increasing public understanding and awareness is really important.

Thanks to everyone for joining our #raiseyourhands campaign. You helped us reach 169,000 people online and countless others due to the posters you put up in GP surgeries, community centres and libraries. We received dozens of phone calls every day from people seeking information and our helpline volunteers have done a sterling job in fielding the significant increase in calls we've experienced over the last few months. So, I'm pleased to report that all our efforts are working.

For many people with scleroderma, Raynaud's is often one of the first symptoms, but awareness of the conditions is very low. We hope that by creating greater awareness of Raynaud's this will eventually aid in early diagnosis and intervention of patients with scleroderma.

In the run up to World Scleroderma Day at the end of June, we'll be building on this work and joining forces with Dr Del Galdo and his team to run a mobile clinic in Leeds city centre, encouraging people who think they may have Raynaud's to come and get tested. This is part of a bigger piece of research being conducted to identify people at risk of secondary Raynaud's and scleroderma.

The Leeds mobile clinic will be a pilot and if successful we'll be working to hold the mobile clinic at more locations across the UK next year. Our campaign will examine the potential impact of late diagnosis of scleroderma, highlighting the urgent need for more research and funding.
Thanks to everyone who took part in the exercise to prioritise the key research topics of importance to you, which will help inform SRUK's research strategy, and you can find the results on pages 9-10.

In the coming months, we'll be adding more research content to the SRUK website to keep you up to date with what is happening, as well as reporting on the achievements of previous research grants which you helped fund. As you know we want to significantly increase our investment in research, which means we need to increase our fundraised income. We're looking for new fundraising ideas and so please do get in touch and share your thoughts with us.

Best wishes
Sue

Front cover image:
Mathew Barry and girlfriend, Becca, on their prom night

Celebrating our 1st year

Last year, you told us, that you wanted SRUK to:

- Invest in research
- Increase awareness and understanding
- Provide excellent support and information

So, this is what we have done....

31st March — Launch
Scleroderma & Raynaud's UK went live and the new website launched.

26th April — Reached Rheumatologists
Met key clinicians and researchers at the BSR conference in Glasgow and held first talks about establishing an alliance to improve care and services for rare autoimmune conditions.

1st June — Educated Health Practitioners
Featured as Unite/CPHVA's charity of the month - educating over 100,000 community health practitioners.

8th June — Increased Awareness in Europe
Attended EULAR congress, promoting SRUK and connecting with other European patient organisations and clinicians.

10th June — Increased Public Understanding
Launched our first public facing awareness campaign to increase awareness and understanding of Scleroderma and Raynaud's. We reached over 38 million people.

29th June — Global Awareness Campaign
World Scleroderma Day, we joined the global awareness campaign. Our social media campaign #KnowRaynauds, explaining the link between Scleroderma and Raynaud's, reached 108,000 people.

1st July — Funded Research
First SRUK research projects awarded funding, to improve knowledge and advance treatment for Scleroderma and Raynaud's.

2nd July — Supported Families
Our first family day, working alongside paediatric specialists provided a day of education and support to families with children affected by these conditions.

31st July — Strengthened Our Voice
SRUK joined forces with the British Society for Rheumatology (BSR), Lupus UK and Vasculitis UK to establish the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA).

3rd September — Annual Conference
Our first SRUK annual conference brought the community together to hear from leading specialists on the latest advancements in treatment and research.

10th November

Information Accredited
Achieved the Information Standard, accreditation confirming our commitment to producing clear, accurate, evidence-based information that you can rely on and trust.

14th January

Invested in Research
Shaped our research strategy through community involvement. 247 people told us what their research priorities were to direct our future investment in research.

1st February

Online Test identified Raynaud's
We supported 4,615 people during Raynaud's Awareness Month to identify if they could have Raynaud's through the launch of our first online test.

28th February

Increased Awareness of Raynaud's
Our #raiseyourhands campaign increased awareness and understanding of Raynaud's. We reached over 45,000 million people through broadcast media and 169,000 people on social media.

20th March

Developed Our Strategy
SRUK's first five-year strategy developed (2017 – 2021) to ensure we are focussed on achieving what you have told us you want.

31st March

Our 1st Birthday
SRUK celebrates 1 year of operation. Thank you to the community for the continued support we have received.

We would like to say thank you to the community for your continued support during our first year as a newly merged charity.

On the 31st March we released our timeline as an animation which was shared on our website and social media. If you would like to view the animated timeline simply head to the News section of our website and read 'Our 1st Birthday' article.

You can be a part of our story next year by donating today. Your donations will go towards funding research, increasing awareness and understanding of the conditions and improving information and support for people affected by Scleroderma and Raynaud's.

£10 could help connect 5 people to our helpline ensuring no one faces their condition alone.

£20 could support our visits to local clinics providing expert information and support.

£40 could provide a Raynaud's test in our mobile clinic, identifying those at risk of developing scleroderma.

You can donate via our website, by simply clicking on the donate button or by calling our team on 020 3893 5998. By donating online or via the phone you are saving us administration costs meaning more of your donation will go towards changing lives.

Doc Spot

Your questions answered by our medical professional, Prof. Denton

I think my daughter may have Raynaud's as her little toe keeps going completely white - how can my GP diagnose childhood Raynaud's?

It is difficult to diagnose Raynaud's in children, whose extremities are often much colder and prone to colour change, compared with adults.

Although Raynaud's can occur in young people, it is usually identified by very dramatic blue or red discoloration and complaints of pain or obvious problems with gripping objects or using hands.

Even when diagnosed, any medical treatment for Raynaud's would usually be delayed until teenage years when Raynaud's is more common and more drugs could be considered.

My 15 yr old son has had Morphea for about 6 years and in the last 18 months his wrist has become completely 'stuck' in ulnar drift position. I want to know what treatment is available. Also the doctors have said that the scleroderma may be affecting internal organs - what tests should I be asking for?

Morphoea describes all forms of localised scleroderma that affect the skin and underlying tissues but do not generally have any effect on internal organs such as the lungs, heart or blood vessels.

Very occasionally a patient with systemic sclerosis also develops skin morphoea but this is a coincidence of two diseases not progression between the conditions.

Morphoea is the commonest form of scleroderma to develop in children.

To exclude internal organ disease in any patient it is usual to perform standard heart, lung and kidney tests. In typical morphoea these are expected to be normal.

The effect of morphoea on bone and joint growth at the sites of skin change can lead to deformity as you describe, with bending of the wrist outwards ("ulnar") and may prompt a change in medical treatment. Physiotherapy and exercises are also important especially if the limbs are still growing.

I have had a 6 month course of cyclophosphamide given every four weeks intravenously. I am currently feeling really good and wanted to know whether this will last?

Cyclophosphamide is a chemotherapy drug that reduces immune system overactivity and has been shown to benefit skin and lung fibrosis in scleroderma.

Although it can have side effects these are much less when given as a monthly intravenous treatment than tablets every day. Usually treatment is followed by tablet therapy with another immune suppressive such as mycophenolate mofetil for at least 18 months (often longer) to maintain the benefit that can wear off otherwise.

I have been diagnosed with scleroderma, do I need to stay out of the sun?

There is no evidence that scleroderma is aggravated by sun exposure, unlike related diseases such as lupus (SLE) or dermatomyositis, where sun exposure can definitely worsen skin rashes and may aggravate internal organ disease.

However, it is still sensible to use high factor sunblock and protect the skin. If you are taking immunosuppression such as mycophenolate mofetil it is advised to avoid sun exposure as there can be increased risk of sun induced skin cancers, although this is rare.

Diffuse scleroderma is often associated with increased pigment in the skin, so patients can become generally much darker, but this is not necessarily associated with worsening skin fibrosis.

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

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

I have Lichen Sclerosus (LS) and I've often wondered how the "sclerosus" aspect of LS relates to scleroderma?

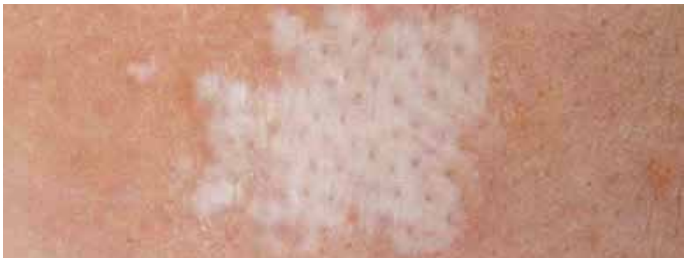
Lichen sclerosus is a distinct skin disease from scleroderma with a somewhat similar name.

It causes inflammation, itching and thickening in some area but later the affected skin can becomes very thin.

When a biopsy (sample) of skin is examined under the microscope the appearance of lichen sclerosus is very different from morphoea but occasionally the conditions occur together in the same patient.

Sclerosis means "hard" and the skin can be hard or locally thicken in scleroderma and in lichen sclerosus, hence the similar names.

Find out more about Lichen Sclerosus on pg. 15-17.



What affect does Raynaud's have on blood tests?

Raynaud's that is not associated with any underlying disease, termed primary Raynaud's is not associated with any blood test abnormality and so blood tests can be important in making the diagnosis.

In secondary Raynauds there can be associated connective tissue or rheumatic diseases and blood tests such as antinuclear antibody (ANA) may be found.

These tests are useful in diagnosing cases of secondary Raynaud's. They can also predict cases of Raynaud's that are at increased risk of progressing to a defined disease such as scleroderma or lupus in the future.

Together with microscopic examination of the small blood vessels around the finger nails (capillaroscopy) these ANA blood tests are very sensitive and have strong predictive value if positive and are even more reassuring that no connective tissue disease progression will occur when they are negative.

Do you have a question you want answering? Send it in to info@sruk.co.uk or call 020 3893 5998

Football is tricky, but as long as I layer up and wear gloves it's OK. I do feel quite self-conscious

Mum in a 'Million'

Claire, (41) and Lewis (13) Miller from Shropshire assist in raising awareness of the conditions by telling their story and the challenges of doing every-day tasks.

When I was younger, I used to do a lot of dance and amateur dramatics, and I remember rehearsals being in a very old, cold village hall. My fingers would regularly go white and numb but I just ignored it and the feeling would eventually return. It wasn't until I was in my 20s that the condition worsened and I felt I needed to seek help.

By this point, I was living in Scotland with my now-husband. We used to go out walking a lot and I remember my fingers being extremely painful, to the point of making me feel nauseous and dizzy.

I have numb fingers for most of the winter, this is the worst time of year for me but spring and autumn are pretty bad as well, because they're the times you maybe don't have the gloves or the extra layers, to cope when the temperature suddenly drops.

A lot of the problems I have tend to be when it's wet and windy, and you get that wind chill. I have gloves in every coat, every fleece and hoodie that I own, just for going out and about, and as soon as they get a bit damp then that's just horrendous, too, so I have a spare pair with me as well.

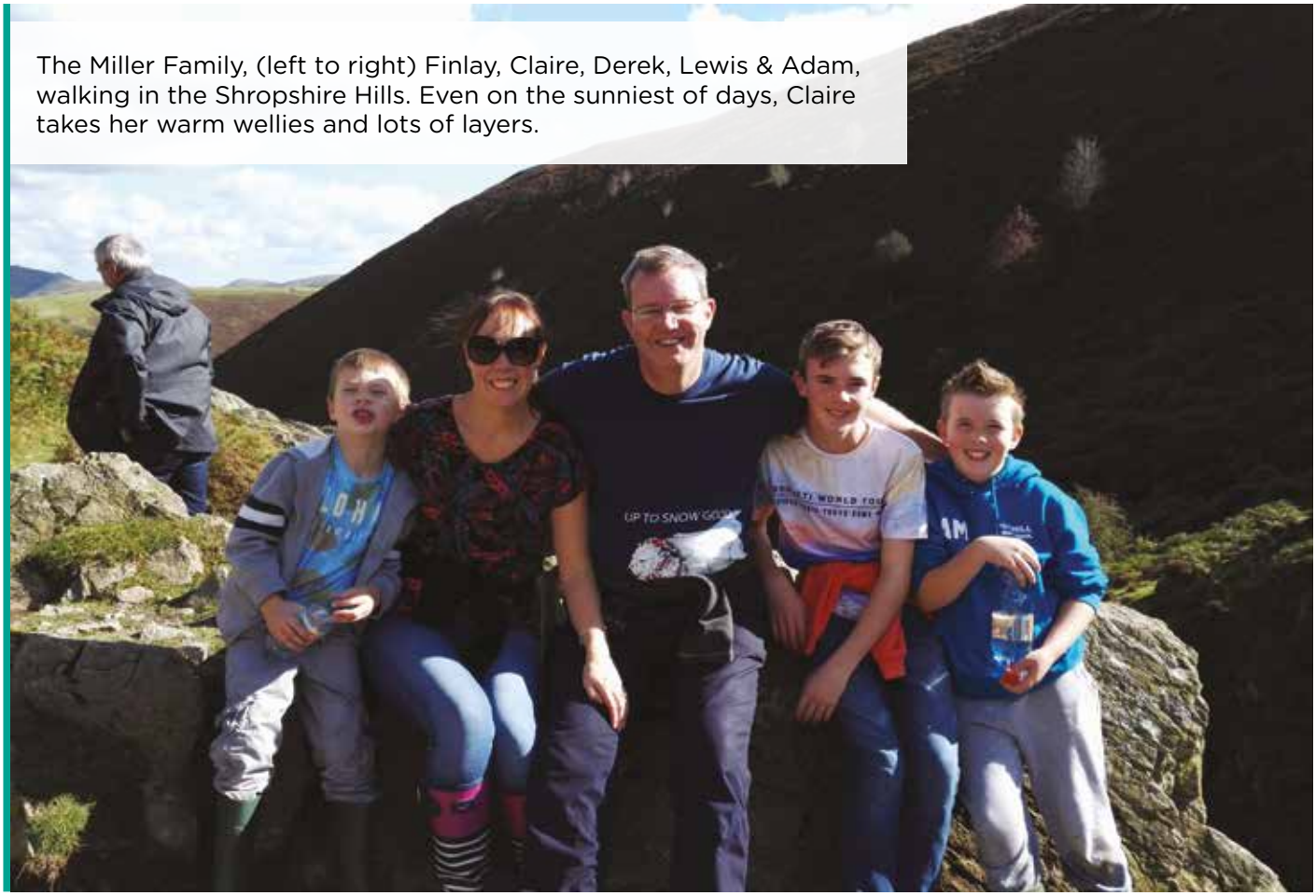
My fingers have the classic symptoms and will go white and numb. It's usually the same two that go first and if it's a bad flare, they'll all go. When it's particularly bad, it's extremely painful and they'll go blue and then red and there's quite a lot of pain when the circulation does return. You just have to sit and wait for it, you can't do anything about it, and it can take up to an hour for that to come back.

I have been diagnosed with Raynaud's since my 20's and I now make sure I have Nifedipine with me, so I can take one when I'm having an attack. I squeeze it under my tongue and it seems to shorten the length of them. It has definitely improved the frequency of attacks and I'm one of the lucky ones that has no side effects with the drug.

You want to be able to do anything you want to do, not think: 'Oh, I can't do that because . . .' and that's something my eldest son Lewis, who also has Raynaud's, has found as well.

Lewis: It seems as if Raynaud's is hereditary in our family and my mum thinks she probably had it when she was younger as well, quite mildly, as she remembers her fingers going white and numb but never did anything about it. I was diagnosed last year and see a Paediatric Rheumatologist yearly. The indications are it is primary Raynaud's, like my mum. I take Nifedipine also, which has really helped my symptoms. I started to experience symptoms when I was about 10, we didn't seek help until a while later. It has affected my sports, I used to play a lot of tennis but had to stop playing during colder months as I struggled to hold the racquet.

Football is tricky, but as long as I layer up and wear gloves it's OK. I do feel quite self- conscious, I don't want to be different and be wrapped up in summer so sometimes I don't wear my coat or gloves, when perhaps I should.



The Miller Family, (left to right) Finlay, Claire, Derek, Lewis & Adam, walking in the Shropshire Hills. Even on the sunniest of days, Claire takes her warm wellies and lots of layers.

Claire: I also have two younger boys, so our house is very busy doing everyday tasks like cooking and washing! I struggle to stand on the touchline watching my boys play football - cold feet, cold everything — what I tend to do is sit in the car, as much as possible, and stand out when the match is on. Everything just has to be planned ahead. If it's particularly cold, putting the gloves on the radiator before I go out, getting my welly boots out of the garage so they warm up first because I get mild Raynaud's in my toes as well.

A problem I always have, is putting washing out on the line. Whatever time of year it is, that's always really hard because the clothes are cold coming out of the wash and, if there's a bit of a cold breeze, by the time you've done it you can't feel your fingers. It can make things difficult, even going to the supermarket and getting things out of the fridge or freezer aisles, by the time I get to the checkout to pay I can't feel my fingers to get my card out to put in the machine — I feel like an old woman.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Even chopping veg can be a danger for me

Claire Miller explains everyday problems she and son face in constant battle with Raynaud's

By Alex Skuse

Only when I laugh

Medical Notes

Claire & Lewis's coverage reached over 25 million people with press and online articles.

Chopping vegetables is also a problem. I try to get the vegetables out in plenty of time to warm up to room temperature, particularly things that take a lot of peeling. If you mess that up, you're liable to lose a finger, so if I haven't got them out in time I have to get my husband to do it — which is no bad thing!

I work in a hospital as a Respiratory Specialist Nurse. Thankfully my new office is in the main building, so once I've warmed up from walking in I'm good to go! I used to be a Research Sister in the Clinical Trials Team and whilst it's fortunate that hospitals are warm environments, unfortunately, that office wasn't in the main building and I have to go in and out of the building several times each day, which means I'd risk an attack.

I wanted to get involved with SRUK because having lived with the condition for so long I feel it's really important more people know about it. If it means more people get treatment earlier, then that's great. I'd also like more people to know that if you have Raynaud's you're not just being "a bit wussy", a little breeze or slight drop in temperature can a have big impact on you! Keep up the good work SRUK!

Identifying Research Priorities

We had a fantastic response to our January questionnaire, which aimed to determine your priorities when it comes to medical research funded by SRUK.

As a small charity, it is important that we target our funds so they have the most impact and inform you, our supporters, how we are helping meet your needs.

Research topics and responses

With input from our trustees and clinicians, we identified 13 research topics and asked you to rank them from 1 to 13, with 1 being the highest priority. The survey closed in the middle of February and we received 253 complete and 27 incomplete responses.

Of the total 280 responses, the majority of respondents identified themselves as a patient, relative, carer or supporter, with 2.4% describing themselves as healthcare professionals and 1.6% as researchers. Nearly 70% of the respondents were aged 60 or older, with 90.3% of the paper forms being returned by people in this age bracket. 13% of respondents gave their gender as male, 87% as female and one person skipped this question.

There were a number of research topics that were clearly identified as being more important than others, with 26% of people choosing causes of Scleroderma and Raynaud's as their top priority, 20% choosing new and safer treatments, 18% choosing improved and earlier detection and diagnosis, and 11% choosing detection of progression, complications and response to treatment. New and safer treatments was in people's top 3 priorities in over 50% of responses. Health economics, epidemiology and financial impact were considered low priorities for the majority of respondents.

Top priorities

Based on average scores from the 253 answers received to the question, in order of preference the top 5 priorities are:

1 NEW AND SAFER TREATMENTS

2 DETECTION OF PROGRESSION, COMPLICATIONS AND RESPONSE TO TREATMENT

3 IMPROVED AND EARLIER DETECTION AND DIAGNOSIS

4 CAUSES OF SCLERODERMA AND RAYNAUD'S PHENOMENON

5 EDUCATION OF HEALTHCARE PROFESSIONALS

There are a limited number of treatments available for the management of Scleroderma and Raynaud's phenomenon, and there is no cure. The treatments that are available have side-effects that can have a negative impact on quality of life.

The responses we received reflect this and the need to identify treatments with fewer side-effects.

Detection of progression, complications and response to treatment is important as this leads to earlier, more effective treatments, with the hope of giving a better long term prognosis.

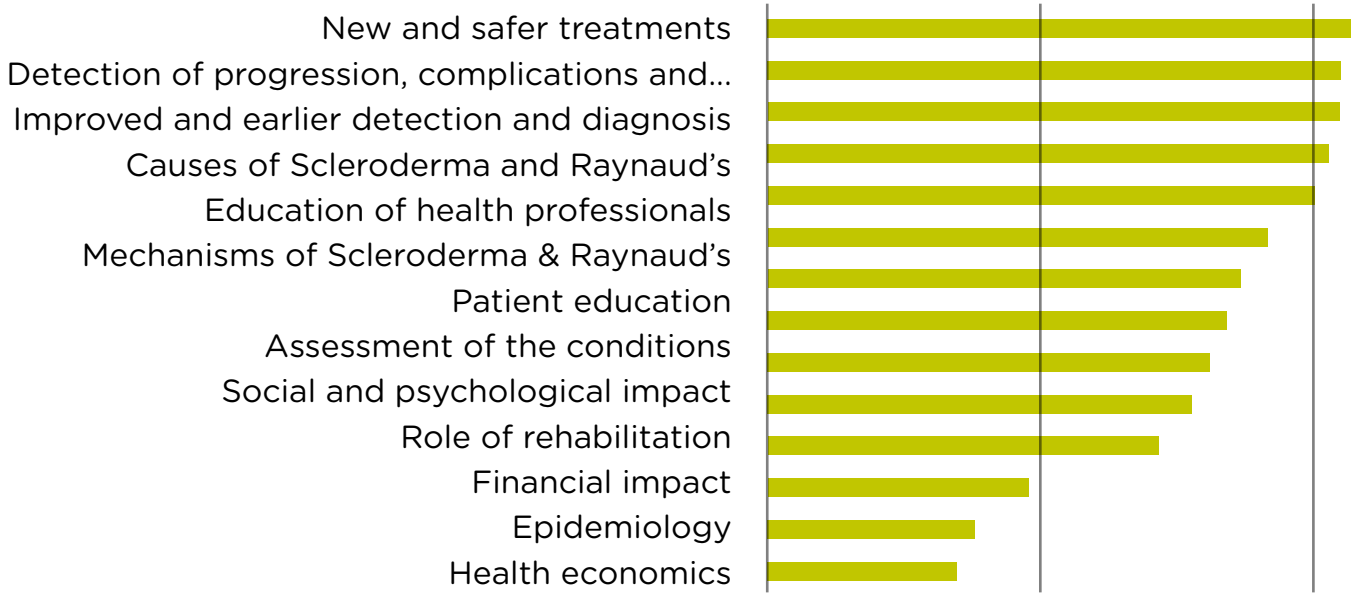
Improving our understanding of the causes of Scleroderma and Raynaud's will lead the direction of future research by revealing possible triggers and drug targets.

For example, previous research has helped us identify biological markers that indicate a predisposition to the subtypes of scleroderma, and identify genetic markers to assist in the diagnosis of these conditions.

Education of healthcare professionals has been highlighted by this survey as an area that needs improvement to ensure people are correctly diagnosed and receive the right treatment and care at an earlier point in time.

Future investment in research

The top 5 priorities identified from your feedback will be used to inform our research strategy. The research strategy will give us direction as to how to invest our money, in order to have the greatest impact on your lives. The research strategy will be published on our website shortly.



Successful Raynaud's Awareness Campaign during February

We reached over 45 million people!

Thanks to all our supporters, partners, clinical experts and other external organisations for contributing to the most successful Raynaud's Awareness Month campaign to date.

Our coverage started pace in the UK with some editorial features in Arthritis Digest, Bella Magazine, Woman's Own, OT magazine and Weekly News, then as campaign momentum grew we featured in the Daily Mirror.

Our CE Sue Farrington was joined by key clinician John Pauling for lunch time interview on Radio Northampton and we also featured on Word on Health, a radio show that broadcasts 5 minute interviews on health conditions to over 100 radio stations, mainly in the UK but as far afield as Dubai.

Up in Scotland our Raynaud's story of the month heroes, **Claire & Lewis (see pg. 7-8)** were covered in The Sunday Post and Lorraine Jack, a local lady from Inverness with the condition and Amy Baker, Head of Engagement & Development at SRUK, had a live interview with Ally Bally on Radio Clyde during a prime time Sunday morning slot.

Over in Wales Dr Ceril Rhys-Dillon was interviewed about Raynaud's on Radio Cymru and 'Dr. Ann' talked about the condition on Prynhawn Da's television show on BBC S4c, encouraging people to find out more information via our website and to take the test.

We launched our #raiseyourhands campaign to increase awareness and understanding of Raynaud's and this year we;

- Developed an online test to help people establish whether they may have Raynaud's
- Shared videos of our supporters talking about their condition
- Organised a 'Cosy up with a Coffee' fundraiser
- Held an online specialist web chat focussed on increasing understanding of Raynaud's
- Shared your personal stories with local and national press to increase the reach of our campaign through press, radio and local TV.

Thanks to all the support #raiseyourhands received, we achieved the following:

100% of coverage mentioned the Raynaud's Test encouraging people to seek a diagnosis

384 people signed up to our e-news, a further 67 called the helpline, office and contacted us over email for further information

4,615 people took the test with 92.7% receiving a result of Raynaud's 459 people downloaded the Raynaud's Information Pack

Reached 169,115 people through social media, which engaged 318 people to like or follow SRUK

‘Get Tested’ at our mobile clinic in June

June is Scleroderma Awareness Month and on the 29th June we will be joining hands across the globe to celebrate World Scleroderma Day.

Throughout June we will be increasing awareness and understanding of scleroderma with a focus on getting earlier diagnosis of this condition.

We know that scleroderma is most active during year 3 – 5, after the first scleroderma symptom, so, if we can gain a diagnosis and start treatment before year 3, we should be able to limit the effects of the condition giving a better overall prognosis.

During June we are collaborating with Dr. Del Galdo, Head of scleroderma programme at Chapel Allerton Hospital, Leeds to identify people at risk of secondary Raynaud’s and scleroderma.

At the end of June we will be in Leeds city centre in our first mobile clinic, offering a capillaroscopy to passers-by and people who think they may have symptoms of Raynaud’s.

These tests will allow Dr. Del Galdo and his team to identify people at risk of secondary Raynaud’s and scleroderma.

Those showing certain results will be given information and a referral to Leeds Raynaud’s clinic for further tests, ensuring those at risk of scleroderma are closely monitored and if required treatment can begin.

This work will also contribute to a research study being conducted by Dr. Del Galdo to establish better figures on the prevalence and incidence of scleroderma – the number of people in the UK who have scleroderma and are at risk of developing the condition.

The Leeds mobile clinic will be a pilot and if successful we will be working to host the mobile clinic at more locations across the UK next year.

How long did it take you to get diagnosed?

Building on the coverage received in February, we will be releasing a press release to our media contacts to increase awareness and understanding of scleroderma and highlighting the link to Raynaud’s.

As part of this release we will be stating facts and figures about the length of time it currently takes to get a diagnosis – if you have been diagnosed with scleroderma and would like to support the campaign then you can take our online survey at: www.surveymonkey.co.uk/r/sclerodiagnosis or call our team on 020 3893 5998 and we will be happy to work through the questions over the phone.

Once again we’ll be working with you, our community to share your stories through video and press. We will be releasing our online campaign page at the end of April, so please head onto the website and look under the Get Involved section, to see what we are planning and how you can get involved.

29th June

As part of the global movement for World Scleroderma Day, we will be sharing the ‘scleroderma cannot take my smile’ campaign.

We would be delighted if you would like to send in photos of your smile to create a European collage you can send this via email to info@sruk.co.uk.

We will be sharing the official video and resource with you via the Get Involved section of our website.

Personal Independence Payment Explained

PIP is a benefit paid to people who have daily living and/or mobility needs to help with the extra costs of long-term illness or disability.

PIP can be paid regardless of your income, savings or National Insurance contribution record and is a tax-free benefit. You can get PIP even if you are working or studying. If you are a carer who has care needs, you can claim PIP for yourself and this will not affect your Carer's Allowance.

Getting PIP does not reduce other benefits, it may even increase them. If you have a carer then claiming PIP may help them to qualify for certain benefits (such as Carers Allowance). PIP may also entitle you and/or your carer to further help with council tax.

There are no restrictions on how you can spend your PIP money, and you do not have to spend it on paying for the care that you need. However, your council or trust can take PIP into account when calculating how much you might need to pay for any care services you receive.

How much is PIP worth?

Your PIP could amount to between £21.80 and £139.75 per week - this depends on how your condition affects you specifically, and not just the condition itself.

There are two components of PIP:

The daily living component: This helps to cover the extra costs that you may face if you need help doing everyday tasks.

The mobility component: This helps to cover extra costs that you may face if you have difficulties in getting around. It's paid at two different rates - a standard and an enhanced rate. The rate you are paid depends on whether your ability to carry out mobility activities is limited or severely limited.

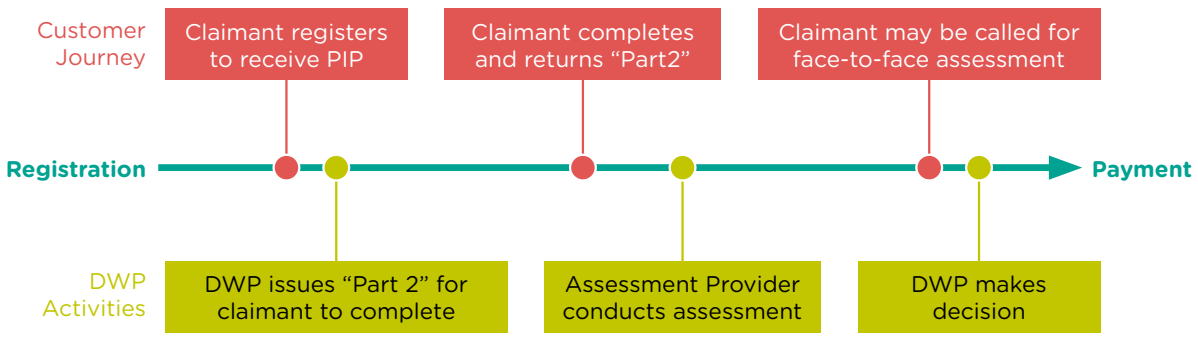
Each of the two components can be paid at either:

Standard rate: Where your ability to carry out daily living/ mobility activities is limited by your physical or mental condition

Enhanced rate: Where your ability to carry out daily living/ mobility activities is severely limited by your physical or mental condition

Standard		Enhanced	Standard		Enhanced
£55.10	Daily living component	£82.30	£21.80	Mobility component	£57.45

The Process



What to expect

"Fatigue/brain fog/pain/low mood it can be difficult for some to articulate themselves as to how difficult things are. On top of that, we want to appear positive. I found when helping people with their appeals that what has been said by an individual can be interpreted very differently to what is meant, perhaps, to fit the assessors' own perceptions." Anon

At the face-to-face consultation the health care professional will ask questions about your day-to-day life, your home, how you manage at work if you have a job, and about any social or leisure activities that you engage in (or have had to give up). They will often ask you to describe a typical day in your life and go through a list of activities, descriptors and pointers and it is worth looking at these and formulating your answers before you go, you can find more information about these on our website.

When answering, explain your difficulties as fully as you can, including ALL symptoms at their worst and try to word answers in a way that leaves no room for misinterpretation.

- Tell them about any pain or tiredness you feel, or would feel while carrying out each activity, and after you have carried it out
- Consider how you would feel if you had to do the same task repeatedly
- Tell them if you need reminding or encouraging to complete each activity

Photo credit: freestock.com

Don't overestimate your ability to do things. If your condition varies, let them know about what you are like on bad days as well as good days. The health care professional's opinion should not be based on a snapshot of your condition on the day of the consultation. They should consider the effects of your condition over time.

Before the consultation ends, the health care professional should give you an overview of their findings and invite you to ask questions and add or clarify anything you wish. You will not receive a formal decision at the consultation on whether you will be awarded PIP.

DWP makes the decision about your claim based on the results of the assessment, your application and any supporting evidence you include, you'll be given a score based on how much help you need. The more help you need, the higher the score you'll get, so it's important to really stress how the condition affects your daily life, in the worst scenarios.

DWP will send you a letter once they've made their decision, explaining why you do or don't get PIP. You will usually be notified of the outcome around 3 weeks after your assessment. If your claim is successful, you will get paid from the date the claim is registered, so it's important to begin proceedings as soon as possible, as the whole process can often take up to 4 months from starting the application to getting your money.

You can appeal if you're unhappy with the decision, the steps for this can be found on the DWP website, or in the documentation you were sent with your application form. There's also some useful information on our website with a link to 'Advice Now' an organisation specifically set up to assist with Mandatory Reconsiderations and appeals.

Photo credit: freestock.com

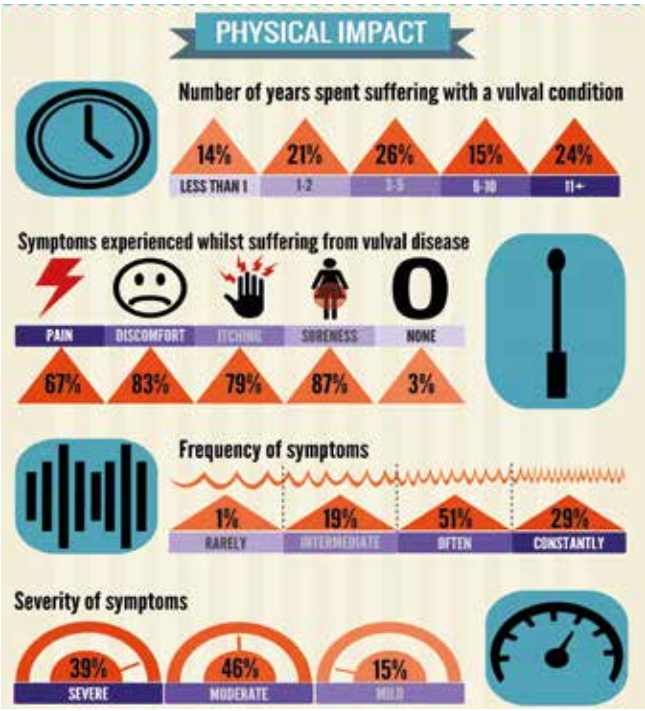
A copy of the table, activities and points used by the assessors is available on our website. For further information, a guide to applying for PIP and information on other health care schemes you may be eligible for, please visit our website, in the Managing Scleroderma/ UK Welfare benefits section.

Lichen Sclerosus

Lichen sclerosus (LS) is a long-term skin condition that mainly affects the skin of the genitals. It usually causes itching and white patches to appear on the affected skin.

Other areas of the body are also occasionally affected, including the upper arms, back, breasts and shoulders. LS is most common in women who have been through the menopause, although men and children are also sometimes affected.

It's not clear what causes LS, but it's thought to be related to overactivity of the immune system. It's not an infection and can't be spread to your partner or other people.



Friction or damage to the skin trigger LS and make it worse. This is called a 'Koebner response'. Irritation from urine leakage, or wearing incontinence pads or panty liners can make the problem worse.

Is LS hereditary?

Rarely, it can occur in relatives. It can be uncomfortable and distressing, but it's usually possible in most cases to control the symptoms with simple treatments.

Symptoms in women and girls

In women and girls, LS tends to affect the vulva (the skin around the entrance to the vagina) and the skin around the anus (back passage). Symptoms can include:

- small white areas that may increase in size and join together to form larger patches – these patches may become cracked and sore
- itchiness, which tends to be worse at night and may disturb sleep
- the skin becoming fragile and thin, or wrinkly and thickened
- red or purple blood blisters
- pain when having sex and/or passing stools

Without treatment, the vulva may gradually scar and shrink. This can make the entrance to the vagina narrower, which makes sex even more difficult and painful.

As a general rule, the patches on the general skin surface seldom itch much, but those in the genital area do, and can also be sore if the skin breaks down or cracks. In the genital area, the scar-like process can tighten the skin, and this can interfere with urination and with sexual intercourse. Tightening of the skin around the anus can lead to problems with constipation.

Symptoms in men and boys

In men and boys, LS tends to develop on the foreskin and end of the penis. The skin around the anus is rarely affected. Symptoms can include:

- sore or sometimes itchy white patches on the penis, particularly around the tip, but sometimes on the shaft
- the skin at the tip of the penis becoming firm and white
- difficulty pulling the foreskin back, which can make urination difficult and lead to painful erections if left untreated

For both men and women, it's often easy for a doctor to diagnose LS by asking about your symptoms and examining your skin. However, in some cases, a very simple procedure known as a biopsy, where a skin sample is taken for analysis, may be needled to help make the diagnosis.

How long does LS last?

For most people, LS is a long-term condition that lasts many years and may flare up and down over time. There's currently no cure, but symptoms can normally be controlled with steroid medication applied directly to the affected skin.

Occasionally, LS goes away on its own and doesn't come back, but this usually only occurs when children with the condition reach puberty.

Treatments for LS

Steroid creams and ointments

The main treatment for LS is steroid ointment or cream, which helps to control symptoms. It should be applied regularly, but relatively sparingly, to the affected areas of skin. Your doctor will advise you on how much to use, how frequently, and for how long. Generally, a 30g tube should last around three months.

When used appropriately, the risk of side effects such as thinning of the skin is very low. Symptoms tend to ease after a few weeks of treatment, but it may be a few months before your symptoms are fully under control. Steroid creams and ointments are very effective in most cases. However, if they don't help, other treatments may be suggested by a specialist.

Surgery

In a few cases, surgery may be needed to treat problems caused by LS. For example, a small operation may be needed to divide adhesions if the skin sticks together. If the condition causes a woman's vaginal opening to become very narrow, affecting sex, an operation to widen it may be suggested.

Men or boys may need surgery to remove the foreskin if steroid ointments or creams don't help and the foreskin becomes severely affected. This can result in the condition settling fully.

Self-help for lichen sclerosus

In addition to the above treatments, the following measures can help keep your symptoms under control:

1. Avoid washing with soap or bubble bath – use plain water or an emollient wash instead, such as aqueous cream (but avoid leaving aqueous cream on the skin after washing)
2. Avoid rubbing or scratching the area
3. Gently dab your genitals dry after urinating, to stop your urine irritating the skin
4. Apply a barrier cream, such as petroleum jelly, after washing, before and after urinating
5. Avoid wearing tight or restrictive clothes and wear underwear made from natural materials such as cotton or silk – women may find it helps to wear stockings rather than tights

For women who find sex painful, it may help to use a lubricant or a vaginal dilator.

There is a very small increased chance of developing cancer of the vulva or penis if you have lichen sclerosus. If any skin change develops which does not respond to steroid creams, in particular any skin thickening, soreness or ulceration lasting more than two weeks, you need to tell your doctor without delay. You may need a biopsy to test for skin cancer.

For more information about Lichen Sclerosus go to our associated symptoms & conditions section on our website found under Scleroderma.

With thanks to the British Association of Dermatologists (BAD), the Association of Lichen Sclerosus and Vulval Health and NHS Choices for assisting with the content and imagery supplied for the article.

Living with Lichen Sclerosus

Colette Barrere, from Suffolk, shares with us her experience of an intimate condition to raise awareness and to encourage others not to suffer in silence.

I think the Lupus and Erythromelalgia articles in recent issues of SRUK News are a great idea because I have these conditions plus Raynaud's and Lichen Sclerosus (LS) in my collection of overlapping diagnoses.

My mother was diagnosed with LS ten years ago, in her early 80s. For many years ma had been certain she "just had a yeast infection". Too shy and embarrassed to reach out, ma self-treated with over the counter products and diet. Finally, in desperation, she told me everything. I convinced her to consult a gynaecologist who said: you have the most advanced and severe LS our practice has ever seen.

Shortly after my mother's diagnosis, I too began to experience symptoms. My GP promptly referred me to our local Vulva Clinic where LS was diagnosed by gynaecology and dermatology consultants. The prescribed topical treatment plan helped immediately.

Six years on from diagnosis in Vulva Clinic, my LS has stopped in its tracks...way before becoming as severe as my mother's.

So, "Simples": I conscientiously comply with all my treatment plans + self-help techniques because they really work. Meanwhile my online LS forum helps me keep my version of LS in perspective. Since the diagnosis, gynaecology has referred me to Women Health Services (WHS) Physiotherapy for Sjogrens intimate dryness problems affecting my diethylstilbestrol (DES) internal birth defects.

Thanks to all this, I very seldom have LS lesions, tears, and splits. The fusing of thickened tissues has stopped, and I am much less troubled by relentless inflammation and itching.

2 self-help tips:

for showering and bathing: I'm allergic to aqueous and barrier creams, but have discovered that my LS doesn't flare in reaction to Weleda's Calendula Shampoo & Body Wash so long as I always soak in Emulsiderm afterwards.

for intimacy: my LS doesn't play up if we use products from 'YES' the organic intimacy company. My GP gives me 'YES' Water Based Lubricant on repeat prescription.

Prescription topicals that help me most:

1. Dermovate: a very strong steroid. I use the ointment version because something in the cream makes me itch. My consultants insist: you needn't worry about steroid-thinning of tissue because you're combating thickening due to LS inflammatory process!

2. Emulsiderm: an antimicrobial cutaneous emulsion/water additive. I soak for a few minutes daily. I've found a porta-bidet that fits in loos and a squeezy bottle for my handbag.

3. Replens MD: a long lasting, hormone-free, easy to use vaginal moisturiser. My GP specifies the pre-filled wands version on my repeat prescriptions form.

The 'YES' website provides excellent information including professional testimonials and customer reviews by LS patients: www.yesyesyes.org

Our SRUK Helpline is available to anyone who would like to discuss Scleroderma and/or Raynaud's and receive support.

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

0800 311 2756

Volunteers man our helpline: Belinda, Helena, Kim, Penny, Paula, Rosemary, Amelia and Katherine who have many years of experience and training. Our volunteers update their skills regularly and having external accreditation as a member of the Helpline Partnership means that we conform to their standards of excellence.

If you call the helpline, the volunteer that you talk to may have Scleroderma and/or Raynaud's but as we know, everyone is different and the manifestations from person to person are varied and complex. Therefore, we refrain from swapping backgrounds and symptoms but listen positively to your issues and try to help you with your particular enquiry. After all the call is about you, not us.

Specialist Nurses		
Rheumatology telephone advice line		01225 428823
Belfast	Audrey Hamilton	0289 056 1310
Leeds	Specialist Nurse Team	0113 392 4444
Liverpool	Jan Lamb & Jenny Fletcher	0151 529 3034
Manchester	Specialist Nurse Team	0161 206 0192
Newcastle Upon Tyne	Karen Walker	0191 223 1503
Portsmouth	Paula White & Julie Ingall	0239 228 6935
Royal Brompton	Lucy Pigram	020 7352 8121 (main switchboard)
Royal Free, London	Sally Reddecliffe & Adele Gallimore (For Pulmonary Hypertension Enquiries)	020 7472 6354
Royal Free, London	Specialist Nurse Team	020 7830 2326
Sheffield	Specialist Nurse Team	0114 271 3086

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 put you in touch with your closest local support contact: 020 3893 5998

Local Support Contacts	
Bedfordshire	Rita Boulton
Burton	Helen Nutland
Exeter	Mike Corbett
Hampshire	Tracey James
Merseyside & Cheshire	Diane Unsworth
Newcastle & Northumberland	Lindsay Wilkinson
Norfolk	Lucy Reeve
South London	Celia Bhinda
South Wales	Belinda Thompson
West Midlands	Jane Beach

Meet ‘the unstoppable’ Mr Mathew Barry

Mathew (17) lives with his Mum, Joanna, Dad, Darren and has a brother, Liam (19) who is at University in Plymouth. Mathew and his mum talk about how he has been affected by a multitude of conditions from an early age, how school have accommodated his absence and how he became the talk of the town after a fabulous fundraising activity!

Joanna: Raynaud’s started to affect Mathew around the age of four he would just cry for no reason, or so I thought. Then we noticed his fingers were frequently blue/white at the ends, inflamed and became very painful when hit against objects, making daily tasks very difficult.

Then at the age of six Mathew spent 5 days in hospital with an infection and immediately after this he started to get very achy all over his body and certain food, caused him pain when he swallowed.

In the early days he had a lot of pain, his glands kept swelling up, he was tired all the time. All this was very slow progress with nothing really big enough to warrant taking him to the doctors, but during this time the Raynaud’s really affected him.

Mathew: Mum took me to our doctors, who said that it was Raynaud’s and if we went to see a consultant they would put me on tablets for the rest of my life, which was very hard to take in or understand, as I was very young. Even though I felt a bit anxious at the thought, I still wanted to see a consultant as the pain was so unbearable. When we saw the consultants’ they took one look at me and said I had Raynaud’s and scleroderma, so we got booked in for an echocardiogram and referred to The Royal Free.

Joanna: I’m very grateful to two local consultants who diagnosed Mathew and sent us to see Professor Denton at the Royal Free who referred us to GOSH, as Mathew was only 9, he needed paediatric care. Mathew was put on Methotraxate,

nifedipine and folic acid. Over time we tried various combinations of drugs and he is now on mycophenolate (MMF), nifedipine, esomprazole, ranitidine and domperidone.

Now, 17, for the last six years the main problem has been the oesophageal strictures and food getting stuck. I have lost count how many dilatations he has had and recurring problems during his early teens he also had a stent fitted but lost 2 kilos while this was in because he didn’t want to eat. I didn’t realize how much of our life revolves around food and eating until Mathew couldn’t. Mathew also has a needle phobia, which makes monthly blood tests and sedation very stressful, but thanks to a nurse at our doctors things are a little easier. Mathew has had a PEG (feeding tube) to take in extra calories via fortified milk, for about 4 years but as it kept getting infected he now drinks the milk. Mathew and and his brother have a visual impairment called ocular albinism and both are registered blind.

Our family, especially my sister Catherine has given us a lot of support through this journey, she has accompanied us on the long days when we’ve travelled to London had an eosphageal dilatation and travelled back, exhausted, and been there when I’ve needed extra support.

Mathew: I’m a student at Bexhill College, on the first interview to get in, I told the learning support coordinator that at secondary school I rarely attended a full week because of fatigue,

so because of this I'm only studying 2 subjects, instead of 3, this benefits me because I now have more time off college to recouperate and sleep, although I'm still struggling through the year with only 2 courses!!

The college has been very supportive when I joined, as my condition is almost invisible and I don't like to bring it up too much, they give me space and when I need them they are there for me and are very understanding if I need time off. At college I study Music performance and Fine Art, I really enjoy both and hope to have a career in one. I play guitar in a band at college and one out of college, so I need lots of practice! However, when I have finger ulcers it's not possible to play guitar as it is heavily dependent on your finger action. I play with a band called The Geoff Bellhouse Band, playing gigs around the East Sussex area. However, the gigs last 3-4 hours, with only one break which takes a toll on me and I get very tired and achey from standing with a guitar on my shoulder, but I don't let the ulcers or fatigue stop me from doing what I love.

Art on the other hand, is quite relaxing, I can do that when I am tired or having a 'rest' day, I've been drawing for as long, as I can remember and have got better over the years. I'm hoping to continue these hobbies going into work, as they are both subjects I enjoy.

Joanna: Mathew is a 17-year-old boy who should be out with his friends and enjoying time with his family but things can't just happen out of the blue, they must be planned. Mathew has a brilliant group of friends who know his limitations and will make sure when on a sleepover he gets the bed, and they have pizza in for him. He does need time to re-couperate after a trip out. I think the fatigue was the most difficult thing for us to understand and it was difficult for me to let him stay at home just because he was tired. When we saw Prof Denton at a local Hospital and he said "it's ok to do a 4 day week and rest the other day" it was such a relief to be told this as I was made to feel as though we were failing. Mathew attended Rye College for his secondary school in the final year he dropped 2 subject in his GCSE's so did six and passed them all! I have to admit I shed a tear, because it meant he could go to college and do the Art and Music courses that he wanted.

We are now transferring from paediatric to adult services and hopefully under the Royal Free and UCLH full time. We have met some great doctors and nurses along the way and will be eternally grateful for the support.

Mathew: I am seen by Dr Lopez at University College Hospital, Chris Denton at the Royal Free and our local hospital The Conquest also know me quite well due to pheripheral visits. I am quite happy to get away from the pediatric care after plenty of visits there, being 17 and visiting departments of hospitals with Disney characters and pretty flowers painted all over the walls is quite embarrassing. The UCLH has a wide range of patients so I presume I will be going there for the foreseeable future.

Joanna: Mathew has a massage once a month on his back as this gives him a lot of pain. He also went through CAMHS for his needle phobia which, sadly didn't help.

Mathews attitude towards his situation is very matter of fact and we are very proud of him for dealing with it day to day in the manner he does. His words "very annoying but unfortunate, there's no getting rid of it" ring true, you just have to get on with it, so we do! We try and make the best out of every situation and try and have a laugh along the way. He is an amazing young man who makes me proud even when I'm having to drag him out of bed in the morning.

Mathew: I do try to look on the bright side of things because being fed up will not change anything. I decided to raise money for SRUK to raise awareness of the condition and to make a statement. My parents are always telling me to get a haircut! So, I thought I would and raise money and awareness for a condition that affects me every day, at the same time.

Joanna: We were all watching as Mathews locks were shaved off, it was a very empowering stance to take and it certainly got people talking. We were in the local paper and raised £2,000, considering he loves his hair so much it was a really big deal. Liam made a video of the event which can still be viewed on youtube, Mathew's brave shave. We are now trying to think of something else to do, so answers on a postcard please!

I do worry about Mathew's future but continue to be positive, I hope he is happy in whatever he does and stays on an even keel and the disease doesn't progress too much. I also hope there is eventually enough knowledge and understanding for scientists/doctors to get a cure so people with the condition are not robbed of having a good quality of life.

Results of Research we have Invested in

In spring last year we awarded our first research grants, following on from the work of the Raynaud's & Scleroderma Association (RSA) and Scleroderma Society, which had been supporting research into both conditions in this way since the 1980s.

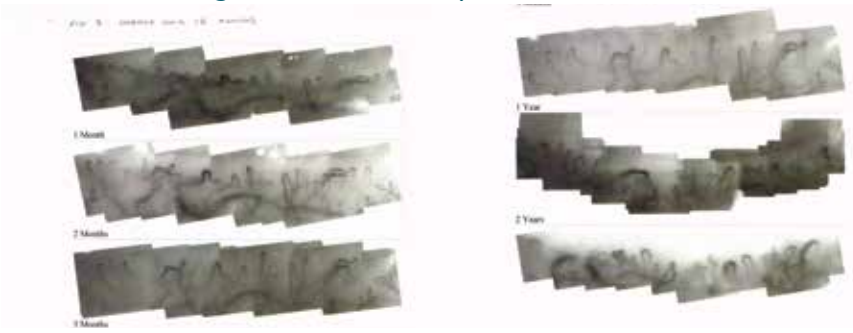
In this article, we take a look back at research projects that have been supported in the past 10 years and their outcomes. We also consider how these research programmes might impact the management of Scleroderma and Raynaud's phenomenon in the coming years.

Nailfold capillaroscopy in Raynaud's

At Hope Hospital, Professor Ariane Herrick and her team have been developing the use of computerised nailfold video capillaroscopy to monitor changes in capillaries over time in people with primary and secondary Raynaud's phenomenon. Several awards have been made relating to this work covering the period from the early 2000s to 2016.

Software developed by Professor Herrick's team through an RSA grant has enabled capillaries, seen under the microscope, to be visualised at very high resolution so the state of the same few capillaries can be tracked. The software has been enhanced to measure capillary width, density, shape and form, which assists with disease classification. Studying the same capillaries at each visit means that changes can be identified and monitored. The software is also able to join together high-resolution images so the whole nailfold can be seen and tracked over time.

Images taken from computerised nailfold video



This tool helps clinicians to see how well treatments work. The absorption of drugs across the skin can be monitored using vasodilation (the relaxation) of capillaries as a measure of response. It is hoped that the development of a robust scoring system to measure these changes, will enable nailfold capillaroscopy to reduce the number of people needed for trials. This will enable the scleroderma research community to evaluate a large number of drugs over the next 5 years.

Treatment of bowl dysfunction in scleroderma

The gastrointestinal tract is affected in 70-90% of scleroderma patients[1] and typical symptoms include constipation, diarrhoea and faecal incontinence. These symptoms are often not discussed by the patient due to embarrassment, and may not be effectively managed as the cause is not well understood and treatments are not always effective. Dr Anton Emmanuel, who works in the Department of Gastroenterology and Nutrition at University College London, undertook two studies relating to bowel dysfunction in scleroderma between 2012 and 2015.

Posterior tibial nerve stimulation (PTNS) was trialled for the treatment of faecal incontinence due to muscle abnormalities. Sacral nerve stimulation, where the bowel nerves are stimulated by electrical

impulses from an implant in the buttock, has shown some benefits in scleroderma, however it is not widely available and is invasive.

As PTNS is less invasive – a nerve in the lower leg is stimulated by electrical impulses from a small needle – and is effective in treating constipation and incontinence in people without scleroderma. This pilot study evaluated whether PTNS would be suitable for patients with faecal incontinence related to scleroderma. Patients receiving PTNS in the pilot study had a reduction in the number of faecal incontinence episodes and improved symptom scores compared to those who had placebo stimulation (with no electrical impulse from the needle).

Constipation in scleroderma is common but is poorly responsive to laxative treatment, which worsens bloating and pain and predisposes people to faecal incontinence. Prucalopride is a non-laxative treatment that accelerates the rate of movement through the gut by acting on nerves and muscle in the intestine. It is currently licensed for constipation in women. If it proves effective against placebo in a trial in scleroderma patients, it could reduce referrals for more invasive treatments for constipation such as rectal irrigation and manual dis-impaction or surgery.

Identifying life-threating arrhythmias in scleroderma

Relatively recent studies suggest that 20–25% of people with scleroderma have clinical evidence of myocardial disease (heart disease).[2] Implantable loop recorders (ILRs) have been used in the general population to identify people at risk of life-threatening arrhythmias, and who therefore need implantable cardioverter-defibrillators (pacemakers).

As part of a wider investigation into cardiac involvement in scleroderma, Dr Maya Buch and her group at the University of Leeds have been studying the use of ILRs in identifying scleroderma patients who would benefit from more accurate cardiac testing or evaluation. It is also hoped that the study will improve our understanding of the correlation between abnormal cardiac function and clinical outcome.

This small study is using novel methods to analyse the small structures and vessels of the heart and monitor its electrical changes. Within the first year, data recorded by the ILRs revealed that one out of the 20 patients who had received an implant needed a pacemaker and one had a previously undiagnosed arrhythmia, which was then treated with medication.

This study is due to finish later this year. The results are eagerly awaited and we will publish the results on our website. The positive initial results from this pilot study support the need for a larger trial of ILR use in people with scleroderma and suggest that ILRs could have an important role in identifying individuals in need of interventions such as medications and pacemakers.

References

1. Tian X-P, Zhang. Gastrointestinal complications of systemic sclerosis. World J Gastroenterol 2013;19:7062–8
2. Champion HC. The heart in scleroderma. Rehum Dis Clin North Am 2008;34:181-viii

Natural and Over-The-Counter Therapies

People are often keen to avoid prescription medications, if possible, and like to try natural therapies first. These are available from many pharmacies and supermarkets as well as from health food stores.

It is recommended that anyone affected by scleroderma take the following vitamins, as their antioxidant effect will help to protect blood vessels from the damage which scleroderma causes:

Vitamin C (ascorbic acid) 500 - 1000mg daily

Vitamin E (tocopheryl acetate) 200 - 400mg daily

In addition to vitamins C and E there are many treatments you can try. You may take more than one treatment at a time, however it is best to only start taking one new one at a time, in order to be able to identify whether it works.

There is limited research into these treatments, however many people do find them to be effective for Raynaud's phenomenon:

Gamolenic Acid (GLA) **approx 320mg daily.**
You can get GLA in several ways:

- It can be bought on its own
- It can be found in evening primrose, starflower and linseed/flaxseed oils, in which case you need to work out how many of the oil capsules you need to take to get the correct dose of GLA. Try to find capsules with a high level of GLA so you don't have to take too many.
- It can be found in Omega-3 fish oils. Either Maxepa 10000mg daily (5 capsules twice each day) or Omacor 4000mg daily (4 capsules) will provide the recommended amount of GLA. These two fish oils are available on prescription.

"I try and combat my Raynaud's symptoms with nifedipine, losartan and sildenafil medication and regular iloprost treatments, along with alternative medicines including high doses of vitamins E & C and evening primrose oil."
Sally, Essex

You only need to choose one of these ways of getting GLA. Many people find that GLA is very effective, however it may take up to eight weeks to see the full benefit. If there is no benefit after taking GLA for 3 months then stop and try something else.

Gingko Biloba Up to 240mg daily in three doses. Some people find that this produces a significant reduction in their Raynaud's symptoms.

Ginger 2000mg – 4000mg daily.

Hawthorn, cayenne, magnesium, horse chestnut, dong quai, and prickly ash are also often used for treatment of circulation problems and some people report benefits in Raynaud's Phenomenon. You should speak to a complementary therapy specialist for advice on the best dosage for you.

Dietary Changes Dietary changes to try to help Raynaud's Phenomenon include increasing consumption of omega-3 oils and antioxidant vitamins (particularly C & E). Using and eating more traditionally warming foods such as ginger, cayenne peppers and chillies can also help.

Sometimes natural and over-the-counter therapies are not enough and it is necessary to take prescription medications. You should tell your doctor and pharmacist about all natural and prescription medicines you are taking so that they can check for any interactions.

It is safe to take these prescription medications in combination with the natural therapies. By improving the circulation these will help to treat Raynaud's and treat and prevent digital ulcers. These will take up to three weeks to take full effect but do not need to be taken permanently if you don't want to. It is quite common for them to be taken only in winter each year however they are safe to be taken permanently.

You may have to try several natural remedies until you find the one, which works best for you. Side effects may include headaches, dizziness, flushing or low blood pressure. To try and avoid side effects it is recommended to start on a lower dose for a few days and go up to the full dose gradually.

Losartan 25mg-100mg daily or other angiotensin II receptor antagonists

Diltiazem 60mg three times daily or other calcium channel blockers

Fluoxetine 20mg-40mg daily or other serotonin reuptake antagonists

Simvastatin 10mg-40mg daily at night should be considered in all patients with elevated cholesterol and sometimes in other cases as there is limited evidence it may help prevent digital ulcers

Clopidogrel 75mg daily is only used for people with digital ulcers

The following treatments are used in cases where people have tried many different therapies yet still suffer with digital ulcers. They are only available in exceptional circumstances under the supervision of a specialist clinic:

Sildenafil 25mg three times a day

Bosentan 62.5mg to 125mg twice daily

Find out more about natural therapies and prescribed medication by visiting the Scleroderma, Treatments section of our website.

Thanks to Louise Parker and the Rheumatology Department at the Royal Free Hospital for working with us to provide this information.

Have you tried any natural therapies that have worked for you, or discovered one not on this list? Share your experiences with us at info@sruk.co.uk

Thank you to our wonderful corporate fundraisers!

Thanks to Rachel Rudofsky and the rest of Tricor Services Europe LLP for raising £443.74 at their 'Cosy Up with a Coffee' event for this year's Raynaud's Awareness Month!

We would also like to thank Policyfast for choosing us as their 2016 charity of the year!

"At Policyfast we understand our corporate responsibility, so we raise money for charities throughout the year. For 2016 our Watnall office chose a charity close to our heart: Scleroderma and Raynaud's UK. Scleroderma is a condition one of our staff members has and we're more than proud to support SRUK's superb work and raise awareness.

We have raised £650, which we have presented to SRUK and know it will be put to good use. This was collected by money raised from our weekly dress down Fridays, and from the sale of chocolate, crisps and drinks to our staff."

If you know of any companies that might wish to partner with us or do any fundraising please get in touch with Amy at amy.baker@sruk.co.uk or 020 3893 5991

Thames Path Challenge

Now that spring has sprung around the UK, we all want to be outside in the sunshine! Enjoy the British countryside and do your bit by joining us at the Thames Path Challenge this September.

The Thames Path National Trail is unique, with its beautiful scenery steeped in history. Setting out from urban London, the path winds through scenic villages and historic towns — it's the only long distance path to follow a river for most of its length.

Starting in Putney in the southwest London and ending in Henley in Oxfordshire, you can take on any of the 25km legs along its route, the first 50km of the path or go all out and tackle the full 100km of this scenic corner of South East England! Walk, jog, run or stumble, you can take on the challenge at your own pace!

Nina and her daughter Priya took on the event last year and raised a fantastic £500.00 for the charity:

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

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

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

Join us at this years Thames Path Challenge and walk alongside our CE Sue to help raise vital funds for the charity.

If you would like to know more please visit the Get Involved, Events section of the website or get in touch with Henry at henry.mcginty@sruk.co.uk or 020 3893 5993

Join us Nationwide for Community Collections!

This year we are running street collections all around the UK to increase awareness and raise money to support people affected by Scleroderma and Raynaud's.

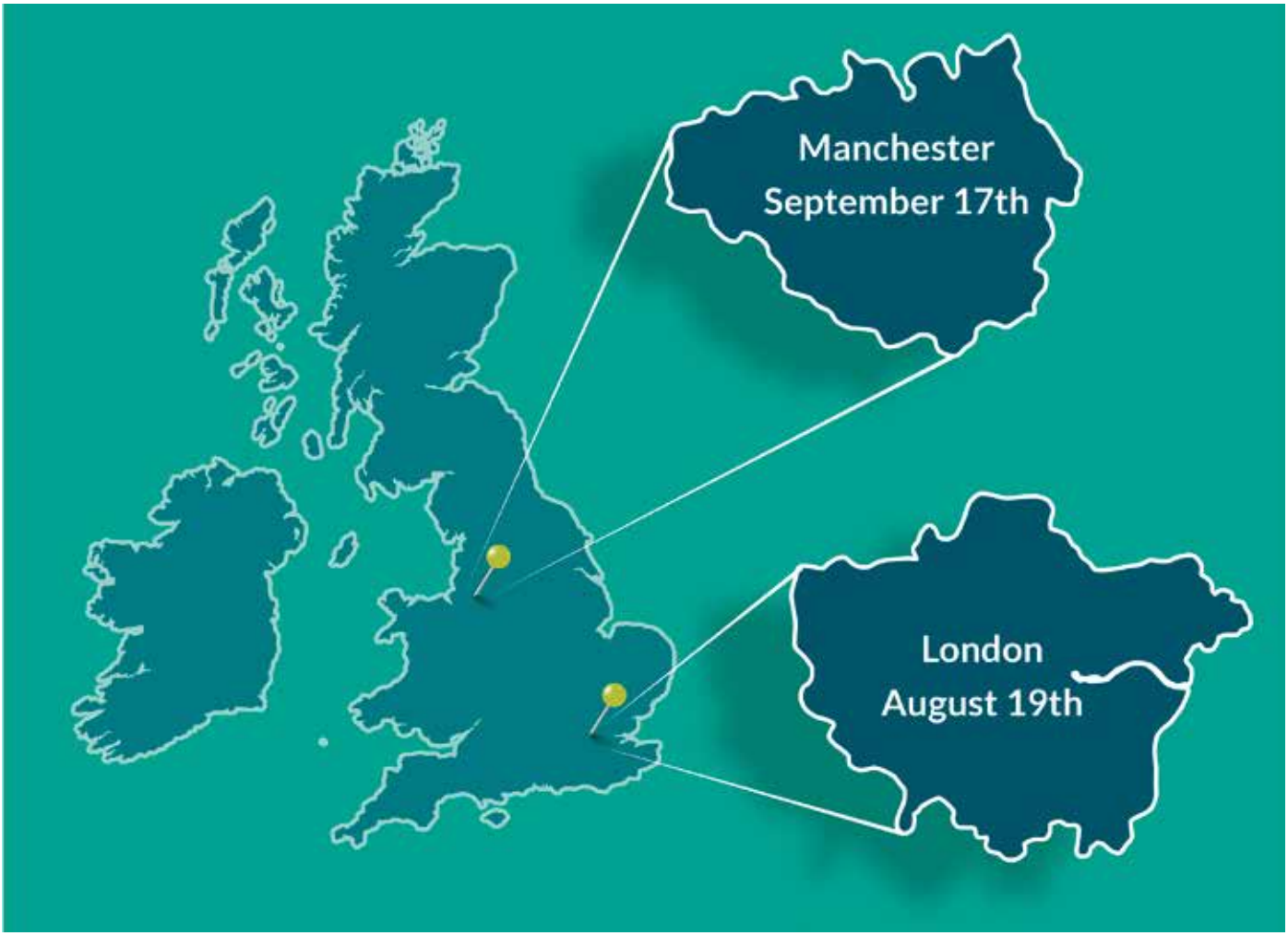
Community fundraising is at the core of everything we do here at SRUK. We receive no government funding, so we rely on you fundraising in your communities to further research into the conditions.

With this in mind we are going to be out on UK city streets with buckets in hand, raising awareness and collecting money in order to support everyone affected by Scleroderma and Raynaud's.

Street collections are a fantastic way of meeting people face to face, talking about the conditions, and passers by know about the services that SRUK offers - services that those affected by the condition rely on every day. By getting out into the streets, we are letting people across the UK who would otherwise have no exposure to the condition or the charity, know that we exist and how they can help.

So far, we have two collections planned in Manchester City Centre and London. If you would like us to come to your local town or city to run a collection, we would be delighted to work with you to raise awareness in your local area. If you think your town is fit to bursting with charitable spirit, then get in touch and let us know where we should be. We will arrange everything for the street collection, all you need to bring is your local expertise and any friends and family to join me on the day.

For more information and to let us know you will be coming along, please get in touch with Henry at henry.mcginty@sruk.co.uk or 020 3893 5993



Ways to support us

Firstly, we would like to say thank you. By receiving this newsletter you are helping us to continue our vital work to make a difference to the lives of people affected by Scleroderma and Raynaud's.

We could not achieve as much as we do without you and we are always striving to achieve more. If you have an idea as to how SRUK can further support the community then we would love to hear from you.

Your Magazine, Your Way

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

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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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.