

# SRUK NEWS

**My Life At 33,**  
Chloe's view  
on living  
with a rare  
condition

**Doc Spot**  
Your questions  
answered by  
our medical  
professional

**WIN a**  
family trip to  
**LAPLAND**

(see insert for details)

## Sights On A Bullseye

Robyn Bassett raises awareness of  
Raynaud's and shares her love of darts



# Event Calendar 2018

## MAY

- Sat 5th - Isle of White Challenge
- Sun 13th - Superhero Run, Regents Park, London
- Sat 19th - SRUK Information Stand, Royal Free Patient Day, London
- Sat 26th - London to Brighton Trek
- Sat 26th & Sun 27th - Edinburgh Running Festival

## JUNE

### Scleroderma Awareness Month

- Fri 8th - SRUK Information Stand Ystrad Mynach Hospital, Wales
- Mon 11th - Patient Information Day, Salford Royal Hospital
- Fri 29th - World Scleroderma Day
- Sat 30th - Cotswold Way Trek

## JULY

- Sat 21st - Jurassic Coast Trek
- Sun 29th - Prudential Ride London

## AUGUST

- Sat 11th - Wye Valley Trek
- TBC - SRUK Information Stand, Aintree, Liverpool

## SEPTEMBER

- Mon 3rd - SRUK Charity Golf Day, High Barnet, London
- Sat 8th - Thames Path Challenge, London

## OCTOBER



### SAVE THE DATE - Saturday 13th 2018

**SRUK 3rd Annual Conference**  
**De Vere Beaumont Estate, Windsor.**  
 To register go online  
[www.sruk.co.uk/AC18](http://www.sruk.co.uk/AC18)

- Sun 7th - Royal Parks Half Marathon, London
- TBC - SRUK Information Stand, Sheffield Children's Hospital

## NOVEMBER

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

Here at SRUK we strive to visit Scleroderma and Raynaud's clinics around the country. If you have suggestions on where we should visit next, then please send details of the hospital, consultant and nature of the clinic you attend to [info@sruk.co.uk](mailto:info@sruk.co.uk) and we'll get in touch to see if we can collaborate.

## Dear Supporters

**Welcome to our Spring edition of SRUK News. The warm weather looks as though it may finally have arrived - hoorah!**

Many thanks for your continued support during February and our Raynaud's Awareness Month, when you shared your stories, put up posters in your local areas and helped us reach an impressive 70 million people through broadcast and social media. Robyn Bassett from Scotland helped us reach the most Northern territories, read her story on page 7. We're looking forward to Scleroderma Awareness Month in June and are seeking your help again with various fundraising and awareness activities, so read on for more information.

Our programme for the 2018 Conference in Windsor is shaping up and we're really pleased that several top clinicians from around the country will be joining us. Take a look at the format of the day, we've got different break-out sessions for you to choose from and, new to this year, a session for family and carers.

In this edition we've a feature on fibromyalgia - a chronic condition that can cause pain all over the body, including muscle and joint pain, profound fatigue, disturbed sleep and a myriad of other symptoms. For those of you who experience this, you'll know how hard it is to get a diagnosis as a lot of the symptoms are similar to other auto immune conditions. For more information on symptoms, diagnosis and treatments, see page 17. If you find it helpful for us to feature other associated conditions, please let us know.


In our previous magazine we looked at eating, swallowing and processing food, and over the next few editions, we're looking at various foods and recipes to assist you. This time we're looking at inflammation, with recommendations from our community on what helps them combat symptoms, with more recipes to download, online. Chloe Aldred shares her health regime as she prepares to get married in September, read her personal story on page 21.

Our fantastic fundraisers have done it again, this year's marathon saw 6 runners taking part, raising to date over £19,000 for much needed funds to help support our community and valuable research.

Please help us raise more money this year by supporting one of our events, from a picnic in the park with some of your friends, to a walk around the Isle of Wight in May. We hope you can find something to suit your ability and inclination. Do get in touch with the fundraising team and let us know how you'd like to get involved. Thank you very much for your continued support.

Best wishes

Sue

[sue.farrington@sruk.co.uk](mailto:sue.farrington@sruk.co.uk)  
 @farrsue01

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# Doc Spot

Your questions answered by our medical professional, Prof. Denton

**I have Raynaud's and have been getting small painful blisters on my fingers for around 6 years. My doctor thinks these may be chilblains, is that all this is and how can they be treated?**

Chilblains are common and triggered by poor blood supply to the skin in the extremities leading to blood vessel damage and inflammation. Typically, they appear as itchy or painful lumps lasting for a few days.

In some cases, chilblains may be associated with blistering of overlying skin although there are other causes for blistering as well. Although both Raynaud's phenomenon and chilblains are due to cold exposure and poor blood supply they are not the same. Many Raynaud's sufferers never describe chilblains and vice versa. Chilblain discomfort can be helped by soothing ointments and creams. If severe, then systemic treatments may be necessary.



Credit: www.nhs.co.uk

**I have two of the Raynaud's symptoms and I wanted to get a test done. I saw on TV that you can ask for a free Raynaud's test from your GP. I asked but they said it's something they don't do. Where can I get this done please?**

Raynaud's phenomenon (RP) describes spasm of blood vessels induced by cold or by emotional stress and affecting the extremities, especially fingers although any vasoactive site can show Raynaud's (nose, tongue, feet, nipples etc.).

In the affected sites spasm leads to blanching, (area goes white/ pale) stagnation of venous blood resulting in blueness (cyanosis) and later returning blood can give redness.

This is termed triphasic Raynaud's. Although nearly all Raynaud's is primary and not associated with another medical condition, it is possible to identify associated rheumatic diseases (such as lupus, scleroderma or other connective tissue disease) using blood tests for antinuclear antibodies (ANA). In addition, examining the small blood vessels around the finger nail through performing a capillaroscopy, can also reveal risk of other disease linked to Raynaud's. To have these tests you can ask for a referral to a rheumatologist for assessment.

**My 26-year-old son was diagnosed with linear scleroderma when he was four years old. At that time, we were obviously very careful about live vaccines etc. Our question is whether it is safe for him to have vaccinations now for travel. He is in Australia now but wants to come home via other Asian countries in which case he would need to have vaccinations such as Hepatitis, Typhoid, anti-malaria, are these safe to have?**

Linear morphoea (sometimes called linear scleroderma) is the commonest form of scleroderma occurring in childhood. It does not involve internal organs and is a form of localised disease. It is important in childhood to be seen by a rheumatologist as treatment using drugs such as methotrexate may be needed.

Sometimes treatment continues for many years. In this case, if your son is on immunosuppression with drugs like methotrexate then "live vaccines" should be avoided but all others are safe.

If he is not on immunosuppression, then he can receive all recommended vaccinations for international travel. There is no medical evidence that the vaccination itself causes or worsens morphoea.

**I have read that if you have undifferentiated connective tissue disease (UCTD) then you cannot also have Scleroderma, but you can have Raynaud's. Is this correct?**

Like all medical conditions connective tissue diseases such as lupus (SLE), scleroderma or dermatomyositis are diagnosed, or classified,

according to agreed criteria. These are generally developed by experts who review the medical literature, use their experience of diagnosis and test possible criteria against real patient histories. For scleroderma the current criteria were developed in 2013 and are very important for clinical care and research to confidently identify cases of scleroderma. Some patients have features of a connective tissue disease, including Raynaud's phenomenon, but not enough to make a firm diagnosis.

These are termed undifferentiated CTD. Some cases may evolve into a defined condition by developing additional features, but others remain undifferentiated and are generally milder.

UCTD may require or benefit from some treatments used in defined conditions to improve symptoms or reduce the risk of progression.

**I have limited scleroderma, (my consultant thinks I have fibromyalgia too) with what I would consider minor skin involvement, I do I have Raynaud's, skin tightening and horrible red spots (telangiectasia) but it's not too bad.**

**My big problem is gastro paresis, which seems to get worse daily, what would you advise to treat this or what can I do at home?**



Telangiectasia on the face and lips

Scleroderma (systemic sclerosis) can be subdivided into limited or diffuse forms (subsets) based upon the extent of skin thickening and involvement. As suggested by the name, diffuse systemic sclerosis has more extensive skin changes that involve proximal limbs or chest and abdomen.

Some patients with limited systemic sclerosis have very little skin change but develop other typical features such as red spots (telangiectasias), calcinosis, Raynaud's and other features on testing such as altered nailfold capillaries or positive antinuclear antibodies (ANA). If sufficient features are present limited systemic sclerosis can be diagnosed. Often gut involvement including gastric paresis (slow stomach contraction and movement leading to sickness, bloating and reflux) is present, so you should discuss this with your doctors and may need to see a specialist gastroenterologist to receive advice on treatment.

**I would like to monitor my mother's oxygen levels like they do in hospital but due to her cold fingers a finger oximeter doesn't seem to work every well. Are there any devices that can monitor oxygen levels that don't attach to a fingertip?**

This is a common problem for patients with Raynaud's and Scleroderma. Typically, the blood oxygen level is measured using a light source passing through the skin and assessing the "colour" of the blood - red for high oxygen and blue for low oxygen. This is a routine assessment to check health and well-being in hospital. Unfortunately, in Raynaud's the blood is blue in the skin from poor blood supply and so this does not affect the oxygen level in the arterial circulation. So, levels look dangerously low but can be normal. There are probes that can be put on the earlobe or forehead that are more reliable in patients with Raynaud's and these may be used. However, it is important to explain that you have Raynaud's when this test is being done so that it can be considered. It is not something that is needed for most patients outside hospital unless there is severe lung or heart disease.



# Scleroderma & Raynaud's UK Annual Conference, Saturday 13th October

De Vere Beaumont Estate, Burfield Road, OLD WINDSOR, SL4 2JJ

**In 2017, we received 100% positive feedback from our Annual Conference and ALL our attendees said they would come to another SRUK Event.**

This year, you told us you would like to hear about understanding and managing the conditions, the links to other conditions, what research is going on and how you can get involved. The break-out sessions, which in 2017 included 'personal accounts' from some of our community, were also very well received so we'll be looking at bringing more of these to you on the day. Along with a NEW session specifically for family and carers of those with the condition.

You have also told us how lovely it is to meet people with the same conditions, talk about symptoms, discuss hints and tips that have helped you and share your experiences. The conference this year will give you time and space to do this and meet key clinicians in the field of Scleroderma and Raynaud's.

**"It was a chance meeting at the SRUK Annual Conference that I met Dr Del Galdo and showed him the blood tests my doctor had given me. We discussed them, and Dr Del Galdo said he was willing to book me an appointment a lot sooner than if I'd waited for the next one proposed with my doctor next May."**

Dorothy attended our conference in 2017

## Programme of events

To join us this year for the conference please head to [www.sruk.co.uk/AC18](http://www.sruk.co.uk/AC18) and follow the online booking form to reserve your space. We only have limited places which will be available on a first come first served basis. If you prefer to call someone in the office to help you with your booking please call 020 3893 5998 and one of our team members will be able to assist.

This year our conference is FREE to members and £25 to non-members. Donations along with any funds raised on the day will go towards the additional costs of putting on the conference.

Details of how to get to the venue, how to book accommodation and other hotel details such as room type and parking, can be found online.

Please note the below is a DRAFT programme of events and SRUK reserve the right to alter the programme at any time.

Time	Sessions	Speakers
10:00 - 10:05	Welcome from Chair	<b>Jeremy Pearson</b>
10:05 - 10:20	SRUK	<b>Sue Farrington</b> , Chief Executive, SRUK
10:20 - 10:50	The importance of patient and public involvement in research	<b>NIHR Representative</b> , Director for patients and public
10:50 - 11:20	BSR Guidelines and annual tests - What every patient should know	<b>Prof. Chris Denton</b> , Consultant Rheumatologist, Royal Free, London
11:20 - 11:30	<b>Coffee Break &amp; Supplier Stands</b>	
11:30 - 12:10	Biosimilars and biologics - What does personalisation mean for you?	<b>Prof. Ian Bruce</b> , Consultant Rheumatologist, MRI, Manchester
12:10 - 12:50	Plastic surgery - Pushing the boundaries of care	<b>Prof. Peter Butler</b> , Professor of Plastic & Reconstructive Surgery, Royal Free London. <b>Lynn Steblecki</b>
12:50 - 14:15	<b>Lunch Break</b>	
	<ol style="list-style-type: none"> <li><b>Face facts</b> - A look at facial, oral and dental care including microstomia and Sjogren's</li> <li>Practical advice on <b>Digital Ulcers and Calcinosis</b></li> <li><b>From top to tail</b> - looking at GI &amp; Bowel treatments and research</li> <li><b>Overlap conditions</b> and their relationship with Scleroderma</li> </ol>	<b>Dr Elizabeth Price</b> , Consultant Rheumatologist, Great Western, Swindon <b>Hannah Harris</b>  <b>Louise Parker</b> , Lead CTD Nurse, Royal Free, London Patient Speaker <b>TBC</b>  <b>Dr Voon Ong</b> , Consultant Rheumatologist, Royal Free, London <b>Lynne Lister</b>  <b>Prof. Ariane Herrick</b> , Consultant Rheumatologist, Salford Royal, Manchester Patient Speaker <b>TBC</b>  Wellbeing consultants <b>TBC</b> <b>Alison Corbett</b>
15:20 - 15:40	<b>Coffee Break</b>	
15:40 - 16:20	Top line results of research into SSc, FASST - 12 treatments in clinical trials	<b>Prof. Chris Denton</b> , Consultant Rheumatologist, Royal Free, London

If you have a topic you would like us to consider for the conference for future events or would like to tell your story during one of our sessions, please get in touch and tell us how you'd like to be involved at [info@sruk.co.uk](mailto:info@sruk.co.uk).

# Robyn's Sights On A Bullseye



Robyn Bassett, 19 from Cowdenbeath in Fife, fought for over 10 years to get a diagnosis of Raynaud's. She believes this now has links to her anxiety and how she copes with the condition. Her love of animals and playing darts has given her a new focus and passion to find ways to manage and continue to follow her dreams.

I was diagnosed 2 years ago with Primary Raynaud's at the age of 17. I had been having attacks since I could remember. At around 8 years old I would turn blue inside the house or outside, at 13 years old my fingers turned black in winter, from then on I have known something wasn't right. I would turn blue in the summer, my fingers, my toes and my lips.

Recently, I was prescribed Nifedipine and suffered some side effects, from dizziness to migraines I found the symptoms would not change, even if I altered my dosage. Dr McLaren at Victoria Hospital, Kirkcaldy has since prescribed me sildenafil and it seems to be working for me, so far.

Even though Raynaud's has been such a large part of my life for so many years, I'm slowly learning to live with it and accept that for now this is my lifestyle. It's so much more than simply my skin changing colour and has affected my well-being enormously. I have anxiety problems when I can feel an attack coming on and I get embarrassed about the changing colour of my hands, it's very hard to control how I feel. I still struggle to cope and don't really have anyone my age or local to me, dealing with the same thing I am. It's just hard when you don't feel in control of things.

I used to enjoy outdoor sports, especially football. I was a defender in a local team and I try to play a bit now but I can no longer play for long periods of time as I struggle with the cold and the pain in my toes, feet and hands. It takes me hours to get my hands and feet back to normal. The longest attack I've had lasted four hours, most of the time, I jump in the shower or huddle under lots of blankets to get warm again.

I attended Elmwood College, and was originally studying a farm working course which involved doing lots of practical work at a farm, working with animals. I struggled so much with the cold I went to the tutor to explain my situation. Whilst she was sympathetic she said I still couldn't wear any other protective clothing because it would startle the animals. As I wasn't allowed to wear hats or gloves, I've had to give it up for a more practical, health related course at Stenton Campus in Glenrothes.



Robyn with boyfriend, Cieran

"It also gives me pain to the point of tears, the horrible sensation of not being able to properly move your toes and fingers, the inability to tell people why your lips are blue without confusing them, the constant uncontrollable shaking and the hours it takes to heat back up and finally feel comfort in my skin again."

My other passion is playing darts, I've been playing for my county for a few years now. I find it hard to throw them as my hands are very cold and gripping the dart becomes a challenge.

When I'm on stage and struggle gripping them and then I get anxious about the game and how I'll perform. I try to stay warm and calm from roughly an hour before I play on the run up to the game.

It can be difficult because if I don't feel comfortable in my skin, I don't feel comfortable throwing and obviously with darts it's about having good control over your hands and fingers. This sport is something I aim to be great in. My goal is to become one of the top women players in Fife, I've represented Fife for 3 years now and I want to do it professionally, keep playing for my country and hopefully one day, make the Scotland squad.



Robyn's love of darts. Playing in a championship for Fife

I contacted SRUK a couple of years ago when I wasn't getting a diagnosis from my GP. They encouraged me to write down all the things that were happening like how frequent the attacks were, how long and what I thought the triggers might be. They also sent me some information sheets to take to the GP to share. With persistence I finally got a diagnosis and on top of that they have tested me for other related conditions, which so far have come back negative. This has allayed my fears that it isn't more than just Raynaud's and I can continue to cope day-to-day living with this condition.

I wanted to help with PR as a way of giving back to the charity. Telling my story was empowering and I have received lots of encouraging messages of support from family, friends and strangers who have read the article. I am grateful to my boyfriend Cieran and my family who continue to help me when I need it most. I won't let Raynaud's get the better of me, I'm young and have dreams to follow.

## Weekly News article created awareness for Raynaud's

Robyn told her story to The Weekly News and Scottish Evening Post Online, which reached over 370,000 people. Thanks to Robyn, this coverage has encouraged others to take the Raynaud's test online and visit their GP for a diagnosis.

If you have a story you would like to share, please get in touch with [tracey.spray@sruk.co.uk](mailto:tracey.spray@sruk.co.uk)



# Your Magazine, Your Say

Dear SRUK Team,

In your SRUK News you asked for suggestions to be considered for future issues, how about a page for short letters? People could make comments about articles and share their own experiences without it being a full-length feature. I do not have the condition myself but became a member in 2008 when my dear sister died. It would be nice to be able to contribute occasionally.

For instance, I read an article featuring Claire and Lewis Miller who both have Raynaud's which I found very moving. It would be really nice to let them know this via your magazine. Also, I think that the young people who have the condition are amazing and so brave, they deserve a medal.

Another idea might be to include a column of tips, which other readers find useful.

Yours Sincerely

*Mrs Dorothy McKown*

Mrs Dorothy McKown

Dear Mrs McKown,

Thank you for your lovely letter, and kind donation to the charity. We think both your suggestions are a great idea so we'll be inviting people to contribute via letter, or email and comment on features articles they read about, or suggest other areas they might like us to cover.

We will also be introducing a Readers Hints & Tips section for people to share what works for them, which we'll feature in our SRUK News, in order to help and assist others with the same conditions and in a similar situation.

kindest regards  
SRUK Team

Dear SRUK Team,

I have suspected I may have developed Raynaud's for some months now and thought I would let you know I heard about you from reading an article in The Weekly News. Thanks to your online test I am now convinced I have it and need to see my GP,

Thank you  
Diane

Dear Diane,

We are so glad you have the information to go and see your GP. Our work here at SRUK is making a positive change to the lives of people affected by the conditions, we hope you get the help you need.

kindest regards  
SRUK Team

Please send letters to:

SRUK, Bride House, 18-20 Bride Lane, London. EC4Y 8EE.

Email your letter, suggestion, hint or tip to [info@sruk.co.uk](mailto:info@sruk.co.uk),

or find us on our social media accounts  
[www.facebook.co.uk/WeAreSRUK](http://www.facebook.co.uk/WeAreSRUK)  
or [twitter.com/WeAreSRUK](https://twitter.com/WeAreSRUK).

# #KnowRaynaud's during February

Raynaud's Awareness Month 2018, we called on everyone to #KnowRaynaud's in order to create greater awareness and understanding of the condition.

The 1st of February was a very busy day for SRUK's CE Sue Farrington with radio interviews at 14 different stations, and a broadcast on the Chrissy B show, dedicated to health and well-being.

Our supporters have been sharing their stories and we featured in 23 different press, magazines and received coverage online, as well as 5 medical journals.

With your support we:



Reached **67 million** people through press coverage

Supported nearly **6,000** people to take our online test. With **92%** receiving a Raynaud's result.



Reached **over 315,000** on social media with over **8,000** people liking, sharing and engaging with our posts.



Had **53** people take part in our 'Cosy Up with a Coffee' raising **over £600** so far



From Radio Scilly, to BBC Radio Solent, TV3 in Ireland and some International reach, via on-line, we received some fantastic coverage, for a detailed list of our coverage to date, have a look at:

[www.sruk.co.uk/knowraynauds](http://www.sruk.co.uk/knowraynauds)

# #KnowScleroderma & How YOU Can Help?

**Scleroderma Awareness Month (June) is almost upon us and we're asking you to help us spread the word with our #KnowScleroderma campaign in 2018.**

SRUK is tackling the lack of understanding and awareness through our campaign on early diagnosis, encouraging more people to seek medical help and advice if they regularly experience one or more of the main symptoms.

## Getting Involved

We will be launching our #KnowScleroderma campaign with a bang on the 1st June, with a radio day to increase awareness and understanding of scleroderma across the UK.

We'll be visiting key clinics to support them during family days, we will be asking you to help us do some guerrilla media activity to get the Press talking about us and developing a poster and flyer for you to download during May.

Please do consider displaying these in your local community to support people in your area and raise awareness of the conditions.

We have made some suggestions on where you may be able to put these up in places in your community to help everyone get to understand the importance of early diagnosis and to seek medical attention if they are showing one or more of the symptoms.

**So why help us?** Sadly, scleroderma awareness is still very low, only 1% of 2,000 people surveyed\*, recognise the condition and know what it is. We will be using case studies to highlight the need to connect these symptoms in the hope people can receive a diagnosis sooner.

**The top 3 signs of scleroderma are:**

- Raynaud's
- Swollen or puffy joints
- Reflux for more than 3 weeks

Join the campaign - Head to [www.sruk.co.uk/knowscleroderma](http://www.sruk.co.uk/knowscleroderma) to find out more

**S R U K SCLERODERMA & RAYNAUD'S UK**

### The Link to Scleroderma

For many people with Raynaud's it will be a mild inconvenience but for 1 in 10 people affected by Raynaud's they will go on to develop an autoimmune condition\* such as scleroderma.

Scleroderma is a rare autoimmune condition, which means the body starts attacking itself. In scleroderma the body overproduces collagen. This excess of collagen can affect the skin, joints, tendons and internal organs. It causes scarring and stops the affected parts of the body from functioning normally.

Scleroderma is SO RARE, but the early warning signs are there. These 3 symptoms are often the first clues:

- SO**re Swollen Fingers
- RA**ynaud's Phenomenon
- RE**flux and Heartburn

If you experience these 3 symptoms visit [www.sruk.co.uk](http://www.sruk.co.uk) and book an appointment to see your GP to request a blood test and capillaroscopy.

**S R U K SCLERODERMA & RAYNAUD'S UK** | **NHS choices** | Health & care information you can trust

[www.sruk.co.uk](http://www.sruk.co.uk) | 020 3893 5998 | @WeAreSRUK | /WeAreSRUK

\*Statistic provided by NHS Choices Registered Charity England and Wales No 1161828 © Scleroderma & Raynaud's UK 2018

## Share Your Story

As a community you have told us time and time again how powerful, educating and empowering it can be to read about another person with the same condition as you.

We are looking for people to work with us to create a strong PR story around their journey, so we can use this in a variety of ways.

You may think your story is no different to anyone else's but consider you have a rare condition, with only 12,000 people with scleroderma in the UK, your story will be unique and no doubt very special.

Help us to raise the profile of the condition and share details with our community in order to educate and help others cope with their condition and add your 'voice' to others who continue to assist.

\*SRUK independent ComRes poll 2016



Grace and her family, shared her story

Contact [info@sruk.co.uk](mailto:info@sruk.co.uk) or go online to [www.sruk.co.uk/share-your-story](http://www.sruk.co.uk/share-your-story)

[Twitter](#) [Facebook](#) [WeAreSRUK](#)

If you would like to get out and enjoy the sunshine whilst raising awareness and funds, then why not order one of our walking packs. You can walk a local route to a café or take on a longer 10-mile walk - whichever you choose our free walking pack will help you get the most out of your event.

You may decide that a picnic is enough for you but your family and friends could take on a walk to show their support.

Jo is walking 100 miles in June in honour of her teenage son Mat, who was diagnosed with scleroderma at the age of 8.

Jo said, "Mat has battled his condition from the age of 8 and so I wanted to really challenge myself in honour and support of him. I will be walking 100 miles to raise awareness and money for scleroderma this June."

It is going to be tough but not as tough as living with this terrible condition."

If you know someone with scleroderma and would like to show your support by walking this June, order your pack today by calling **020 3893 5998** or emailing [shauna.creamer@sruk.co.uk](mailto:shauna.creamer@sruk.co.uk)



## Partner For a Picnic

This summer we are asking all our community to enjoy the good weather and to partner up with friends and family and have a picnic.

We know that when the sun comes out we all love nothing more than getting together and enjoying a nice cold beverage and some finger food, with friends, family and even colleagues.

We are also launching this pack to help raise awareness during Scleroderma month in June.

Request your free fundraising and awareness pack today and help increase understanding of scleroderma whilst raising vital funds for SRUK.

Thank you to all who organised a Cosy up with a Coffee in February for Raynaud's Awareness month and helped us raise over £600 so far. If you have held your event and need to pay in your fundraising please call 020 3893 5998.



To request your free pack or to find out more please call **020 3893 5998** or email [shauna.creamer@sruk.co.uk](mailto:shauna.creamer@sruk.co.uk)



Source: Sartorius AG

## Early detection of Scleroderma and Raynaud's: Pipe dream or achievable goal?

Funding vital research into Scleroderma and Raynaud's is one of the key aims of SRUK. We believe that the research we fund has to work for the people who actually live with the condition day in and day out.

That is why in the spring of 2017 we asked you what your top research priorities would be. You came back to us with a clear mandate on the areas you wanted us to drive research in, including finding a cure and better treatments.

One of those areas you were keen to see SRUK invest more funding into was on working towards earlier detection and diagnosis of Scleroderma and Raynaud's. Biomarker research and development of diagnostic tools are currently an area of significant investment across the medical charity sector, and with good reason. If a condition like scleroderma, can be detected earlier through a blood test or a non-invasive diagnostic tool then it can be treated earlier, perhaps even prevented.

But with scleroderma the situation is more complex, as each scleroderma patient experiences their condition differently. This makes the effort to identify biomarkers more difficult. Biomarkers are classed as a group of biological molecules, such as proteins, that can be linked to specific pathogenic processes or diseases. Scleroderma can often present as a range of conditions, with multiple organ involvement, so each person with the condition could be potentially expressing a range of biomarkers thus making early detection all the more difficult.

A recent study by researchers based at the University of Silesia in Poland has identified two proteins that may be able to predict which organs will be involved in diffuse systemic sclerosis. C-reactive protein (CRP) and serum amyloid A (SAA) are two proteins that are normally produced during the acute phase of inflammation in the immune response. However, these proteins have also been linked to autoimmune conditions, including diffuse systemic sclerosis.

In this study, researchers looked at CRP and SAA levels in 33 patients with diffuse systemic sclerosis. Of these 33 patients, approximately 11 had already developed interstitial lung disease.

It should also be noted that the diagnostic onset of the condition amongst the 33 patients ranged from 3 months through to almost 16 years. As a control, the levels of CRP and SAA from this set of patients were also compared to CRP and SAA levels in a group of healthy volunteers.

The researchers found that CRP and SAA levels were significantly increased in the patients with diffuse systemic sclerosis, with similar levels seen across the entire group of patients. This is regardless of the length of time that had passed since a patient's diagnosis.

However, the researchers also found that patients who had developed interstitial lung disease, had significantly more elevated levels of CRP and SAA in their blood, than patients who had not yet developed lung complications. In particular, patients with lung complications had elevation levels of CRP at almost 6 times the levels of patients without lung involvement.

This is an intriguing result, suggesting that detection of CRP and SAA levels in the blood could potentially indicate lung involvement in diffuse systemic sclerosis before these additional symptoms develop.

As the researchers noted, further research needs to be conducted to fully draw out the link between these proteins and interstitial lung disease in systemic sclerosis. However, it is research like this that has the potential to allow us to detect not just early onset Scleroderma and Raynaud's but also how the conditions may develop.

This could then allow for targeted treatment, also known as precision medicine, which in turn could have a vast improvement on the day-to-day life of a person with these conditions.

We can take this one step further, and say that if we can predict how scleroderma may progress then we may even be able to completely prevent it from disrupting lives.



Source: Sartorius AG

Lorna is supporting our research programme by leaving a gift to SRUK in her Will.



"I decided to leave a gift in my Will to the charity a few years ago.

The reason for my decision was, when I realised that research projects sponsored by the charity were carefully monitored and reported to the community. As a small charity, funds are limited and it relies entirely on donations, fundraising and legacies.

By leaving a gift I know that the money will go towards research and support for individuals diagnosed with Scleroderma and Raynaud's.

If you suffer from Scleroderma and/or Raynaud's or know someone who does, it makes sense to leave a gift in your Will, which will be tax free, to help provide essential funding for research and support." - Lorna

If you would like to know more about how a gift in your Will would help the charity please get in touch on 020 3893 5998.



# Iloprost Infusions Explained

Louise Parker, Lead Nurse for the Inflammatory & Connective Tissue Disease department at The Royal Free London NHS Foundation Trust helped develop this article looking at what an illoprost infusion entails and the different methods of administering the drug treatment.

## 1. What is iloprost?

Iloprost is a medication that can improve blood flow in individuals with circulatory problems. It does so by dilating (opening) the blood vessels, reducing clumping of red blood cells, and limiting damage in blood vessels. In this respect, iloprost can be looked at as a potential medication if you have ulcers of the fingers due to scleroderma, or if you are severely affected by Raynaud's.

## 2. How is it administered?

The administration of iloprost is done continuously for about six hours a day for 3-5 days in a row in hospital or a clinic. In some hospitals you stay on the ward for the three to five days, and in others you attend the day-case unit and then go home or to a hotel in the evenings. Blood pressure is also monitored throughout the infusion.

The infusion will be started at a low dose calculated based on your weight, which gradually increases so long as you are not experiencing side effects.

If side effects such as nausea, headaches, facial flushing or muscle cramps do develop, your dosage will be reduced again. Paracetamol and anti-sickness medication can also be used whilst you are undergoing treatment, and this can help to quickly relieve any side effects.

## 3. Ways to receive Iloprost?

### Intravenous Cannula

Iloprost is normally administered by drip through an intravenous (IV) cannula. This is a small plastic tube placed into a vein in the back of the hand or into the arm. A cannula will ensure that the Iloprost is administered directly into the bloodstream.

**There are some problems associated with infusion of iloprost through a cannula.**

**These can include the following:**

- Finding a vein through the skin
- Pain with insertion of the needle due to tough skin
- Damage to the blood vessels (scleroderma causes the blood vessel walls to harden and veins can burst when a cannula is inserted)
- Dislodgement of the cannula, and the need for reinsertion
- Inflammation of surrounding tissue

Alongside problems with insertion, the removal of the cannula must also be considered. After removal, you may also be left with a small bruise, but this should heal as normal. Your nurse will put a plaster over the area to keep it clean; this can be removed after a short time.

### Intravenous Midline

A midline is slightly different to a regular IV in that it is a longer cannula that is put into one of the large veins in your arm, usually in the bend of your elbow. In comparison to a regular IV, the cannula can stay there for a few weeks, and so will not need to be reinserted during an iloprost infusion.

A small procedure is needed to insert the midline at the beginning of your treatment but this can be done whilst you are sat in an armchair or on a bed.

As a midline can stay in overnight, there is a need to be careful when washing and changing to make sure it is not knocked.



## 4. Benefits

Although the prospect of an iloprost infusion can appear to be worrying due to associated side effects alongside issues with cannula insertion, it is important not to lose sight of the fact that risks are generally minimal, when examined against benefits.

With a successful infusion the benefits can be seen for Scleroderma and Raynaud's straight away, although it can sometimes take up to six weeks.

If very cold hands or feet have affected you, they could feel warmer immediately, and any ulcers may begin to improve within a few days. Iloprost's beneficial effects may carry on for weeks and sometimes even months after the infusion, improving your quality of life.

## 6. Next Steps

Usually, iloprost is prescribed if other drugs such as nifedipine haven't worked for you. Speak with your consultant rheumatologist or specialist team to discuss this further, and you can also discuss any concerns or worries you may have regarding the treatment generally should you have them.

As ever, our website [www.sruk.co.uk](http://www.sruk.co.uk) is full of information relating to treatment options for Scleroderma and Raynaud's.

**Thanks to Agatha and Sally for their input and use of imagery to support this article.**

“I have my treatment at the Royal Free and since they introduced the midline service for Iloprost, it has made a huge difference to my experience. I can now leave the hospital and not worry about knocking my cannula and can even go out shopping as I can hide the tubes.” - Agatha

At SRUK we are committed to the importance of patient choice. With the support of the Brian Norris Committee we have funded three ultrasound machines, which have been donated to the midline service team at PITU, Royal Free Hospital, London.

The midline service at the Royal Free is dedicated to exploring new ways to administer treatment for people affected by scleroderma, and is the first team in the UK offering midlines to administer iloprost to scleroderma patients.



# Understanding Fibromyalgia

Fibromyalgia, also known as fibromyalgia syndrome (FMS), is a chronic condition that characteristically causes pain all over the body, including muscle and joint pain, profound fatigue, disturbed sleep and a myriad of other symptoms.



The pain tends to be felt as diffuse aching or burning, often described as head to toe pain. It may be worse at some times than at others. It may also change location, usually becoming more severe in parts of the body that are used most.

The name fibromyalgia is made up from “fibro” for fibrous tissues such as tendons and ligaments; “my” indicating muscles; and “algia” meaning pain. The fatigue ranges from feeling tired, to the exhaustion of a flu-like illness. It may come and go and people can suddenly feel drained of all energy – as if someone just “pulled the plug”.

It can occur by itself or along with forms of arthritis or auto immune conditions like scleroderma. Although it is never fatal, it is usually difficult to manage and can cause significant disability and disruption of quality of life, it can also lead to depression and social isolation.

Fibromyalgia is a common illness, more common than rheumatoid arthritis\* and can even be more painful. People with mild to moderate cases of fibromyalgia are usually able to live a normal life, given the appropriate treatment.

If symptoms are severe, however, people may not be able to hold down a paying job or enjoy much of a social life.

## Fibromyalgia Symptoms

As well as widespread pain, people with fibromyalgia may also include:

- Increased sensitivity to pain
- Fatigue (extreme tiredness)
- Muscle stiffness
- Difficulty sleeping/unrefreshed sleep – waking up tired and stiff
- Problems with mental processes (known as “fibro-fog”) – cognitive problems including lack of concentration, temporary memory impairment and word mix up
- Clumsiness and dizziness
- Dryness in mouth, eyes and nose
- Headaches – ranging from ordinary types to migraine

- Irritable bowel syndrome (IBS) – a digestive condition alternating diarrhoea and constipation, sometimes accompanied by stomach pain, bloating or nausea
- Hypersensitivity to cold / heat changes in the weather and to noise, bright lights, smoke and other environmental factors
- Allergies

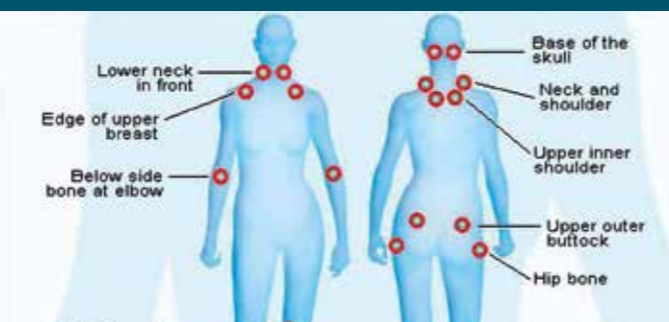
## Fibromyalgia Diagnosis

FMS is not new, but for most of the last century it was difficult to diagnose. Part of the problem has been that the condition could not be identified in the standard laboratory tests or x-rays. Moreover, many of its signs and symptoms are found in other conditions as well – especially in chronic fatigue syndrome (CFS).

Two Canadian doctors developed a way of diagnosing fibromyalgia in the 1970s and in 1990 an international committee published requirements for diagnosis that are now widely accepted.

Once other medical conditions have been ruled out through tests such as a full blood count and a thyroid test the diagnosis depends on two main symptoms:

- Pain in all four quadrants of the body for at least three months together with
- Pain in at least 11 out of 18 tender point sites when they are pressed. The “tender points”, or spots of extreme tenderness, are rarely noticed by the patient until they are pressed.



The ‘tender points’ identified to diagnose fibromyalgia

## What Causes Fibromyalgia?

Fibromyalgia often develops after some sort of trauma that seems to act as a trigger, such as a fall or car accident, a viral infection, childbirth, an operation or an emotional event. Sometimes the condition begins without any obvious trigger. The actual cause of fibromyalgia has not yet been found. Over the past several years, however, research has produced some insights into this puzzling condition. For instance, it has been known that most people with fibromyalgia are deprived of deep restorative sleep. Current studies may find out how to improve the quality of sleep and some of the prescribed medicine is specifically aimed at addressing the lack of restorative sleep.

Research has identified a deficiency in Serotonin in the central nervous system coupled with a threefold increase in the neurotransmitter substance P, found in spinal fluid and which transmits pain signals. The effect is disordered sensory processing. The brain registers pain when others might experience a slight ache or stiffness. It is hoped that more research will discover the cause and result in more effective treatment.

## What is the standard treatment for fibromyalgia?

There is no cure for fibromyalgia, and there is no single treatment that will address all of the fibromyalgia symptoms. Instead a wide array of traditional and complementary treatments has been shown to be effective in treating this syndrome. A treatment programme may include a combination of medication, exercise, (both strengthening and aerobic conditioning) and behavioural techniques.

## What medication is used to treat fibromyalgia?

Medication does not deal with the underlying cause or causes of fibromyalgia but does help to relieve the symptoms. **Specific recommendations on treatments may include:**

- **Tramadol, an opioid analgesic** is recommended for the management of pain. Although other treatment options may include **simple analgesics** (such as paracetamol) and other weak opioids, nonsteroidal anti-inflammatory drugs (NSAIDs) have not been found to be effective. Corticosteroids and strong opioids are not recommended.
- **Antidepressants** are recommended for the treatment of FMS because they decrease pain and often improve function. Appropriate options may include tricyclic antidepressants such as **amitriptyline**, as well as newer drugs such as **fluoxetine, duloxetine and paroxetine**.
- **Pramipexole**, a treatment for Parkinson’s disease and restless legs syndrome, has been found to reduce pain in FMS.

- **Pregabalin** is an anti-epileptic drug that has also been found to help with pain in FMS patients.

## Are there complementary treatments for fibromyalgia?

Complementary therapies, although they are not well-tested, can help manage the symptoms of fibromyalgia. For instance **therapeutic massage** manipulates the muscles and soft tissues of the body and helps ease deep muscle pain. It also helps relieve pain of tender points, muscle spasms and tense muscles. Similarly myofascial release therapy, which works on a broader range of muscles, can gently stretch, soften, lengthen and realign the connective tissue to ease discomfort.

**Cognitive behavioural therapy (CBT)**, relaxation techniques and physiotherapy may help some patients. Moderately intense aerobic exercise at



least two or three times a week can help FMS symptoms, and although the scientific evidence may not be strong, the **benefits of exercise** for general health and feelings of well-being suggest its use should be encouraged. Hydrotherapy in a heated pool may also be beneficial.

Techniques such as **hypnosis, acupuncture and chiropractic** manipulation may help pain in individual cases, but further evaluation of these methods is required.

Along with complementary therapies, it is important to allow time each day to rest and relax. Relaxation therapies such as deep muscle relaxation or deep breathing exercises can help reduce the added stress that can trigger fibromyalgia symptoms. Having a regular bedtime is also important. Sleep is essential to allow the body to repair itself, for more on sleep read our article on Page 23.

\*Prevalence of Fibromyalgia: A Survey in Five European Countries (see [www.fmauk.org/prevalence](http://www.fmauk.org/prevalence) for details) put the prevalence of FM at between 2.9 and 4.7%.

For further information on Fibromyalgia and other auto immune associated conditions visit [www.sruk.co.uk/conditions/](http://www.sruk.co.uk/conditions/)

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

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

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

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



Specialist Nurses		
<b>Rheumatology Telephone Advice Line</b>		<b>01225 428823</b>
<b>Belfast</b>	Audrey Hamilton	0289 056 1310
<b>Leeds</b>	Specialist Nurse Team	0113 392 4444
<b>Liverpool</b>	Jan Lamb & Jenny Fletcher	0151 529 3034
<b>Manchester</b>	Specialist Nurse Team	0161 206 0192
<b>Newcastle Upon Tyne</b>	Karen Walker	0191 223 1503
<b>Portsmouth</b>	Paula White & Julie Ingall	0239 228 6935
<b>Royal Brompton</b>	Lucy Pigram	020 7352 8121 (Main Switchboard)
<b>Royal Free, London</b>	Sally Reddecliffe & Adele Gallimore (For Pulmonary Hypertension Enquiries)	020 7472 6354
<b>Royal Free, London</b>	Specialist Nurse Team	020 7830 2326
<b>Sheffield</b>	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	
<b>Bedfordshire</b>	Rita Boulton
<b>Burton</b>	Helen Nutland
<b>Exeter</b>	Mike Corbett
<b>Hampshire</b>	Tracey James
<b>Merseyside &amp; Cheshire</b>	Diane Unsworth
<b>Newcastle &amp; Northumberland</b>	Lindsay Wilkinson
<b>Norfolk</b>	Lucy Reeve
<b>South London</b>	Celia Bhinda
<b>South Wales</b>	Belinda Thompson

# Can Your Diet Help with Pain, Swelling & Inflammation?



One of the simplest causes of underlying inflammation, and one that we have a certain amount of control over is an 'inflammatory lifestyle', which includes factors of environmental toxin exposure, stress, and poor diet. As we can't always alter our surroundings, change jobs or remove our health conditions, what you put in your mouth is arguably one of the best ways you can impact your inflammatory status.

We look at some top tips from SRUK members who have tried and tested some foods which have helped lower their inflammation levels and brought a positive change to their wellbeing.

"I have cut out sugar and caffeine from my diet which has helped me considerably. I take a non-dairy yoghurt mix daily with black cumin seed oil, turmeric, black pepper and honey which seemed to help me within about a month. I mentioned this to my consultant who was sceptical but my thinking is if my immune system is attacking itself, it's going to be inflamed somewhere. It continues to work for me, so whilst it does I'll keep taking it. I still have the occasional naughty treat, but I generally try to eat fresh foods. I've taken, what I felt was achievable, out of my diet and felt a great impact." - Chloe

"I struggled with inflammation in my gut and as I work with dietitians, took advantage of my colleagues and asked what could help. I was experiencing bloating cramps and diarrhoea. I was a vegetarian at the time and thought this was a healthy choice. My colleague Annette suggested I try a low residue diet. This means avoiding high fibre foods like onions, tomatoes, mushrooms and strawberries to name a few. So, I cut these foods out strictly for 3 months, to give my system time to recover. It was very hard to do and led to me adding fish and eventually meat into my diet. This worked really well, and I can now eat small amounts of high fibre foods and no longer have to totally exclude them. I am very careful about my amount of fibre overall and 5 a day is not for me!" - Julia



## Avocado & Egg on Toast

### Ingredients

- 1 slice of gluten-free bread
- 1 1/2 tsp ghee or dairy free spread
- 1/2 an avocado
- Handful of spinach
- 1 egg, poached or scrambled
- Red pepper flakes (optional)

### Method

Toast the gluten-free bread and top with ghee/dairy free spread

Spread the avocado onto the toast. Place fresh spinach leaves on top of the avocado and then top all with a poached or scrambled egg and finish it off with a sprinkle of red pepper flakes.

Enjoy as is or add a second piece of toast to make a sandwich.

### Why is this good for you?

When you buy pastured (not pasteurized) eggs they are a great source of protein that provides vitamin B12, selenium and healthy omega-3 fats. Protein helps to stabilize blood sugar, B12 keeps your nerves and red blood cells healthy and selenium is an antioxidant that protects cells from damage caused by inflammation. Ghee is beneficial for our digestive tract, a major part of our immune system. A healthy gut is better at nutrient absorption and fighting toxins, both of which are good for reducing inflammation. Avocados contain healthy fats that protect against inflammation, while the addition of dark leafy greens provide a wide range of health-supportive phytonutrients.

### Useful links

To view our other recipes recommended by our members go to [www.sruk.co.uk/nutrition](http://www.sruk.co.uk/nutrition) and look out for the downloads or links to other recipe sites for you to try. SRUK recommends speaking to your GP or consultant prior to changing your diet dramatically. What works for one person will not necessarily work for another.

# My Life & Loves

**Chloe Aldred, 33, from Lymm in Cheshire, shares her frustrations around the diagnosis of her condition. With a wedding on the horizon Chloe talks about how her fiancé, a change in her food and fitness are all helping in managing her condition.**



Chloe with Fiancé Danny

“Raynaud’s is hereditary in my family, my mum and grandma have it, but they aren’t affected by scleroderma. When I was 24/25 I went to the GP as it was very painful, and they said there wasn’t anything they could do for me.

I left it for a few years before I went to another GP, who then said that they could do something for my Raynaud’s, he put me on Nifedipine but advised me just to take it as and when I needed it. I continued to struggle for another year or so before seeking a third opinion and being referred to a consultant who said for the medication to take effect it should be taken regularly, so I started taking it twice a day.

At this point, I was also having acid reflux and went to the doctor’s 2-3 times with this problem. They just told me it was pretty common, gave me omeprazole to use once a day and on top of this I used other over the counter products when it was really bad.

During this time, I was a florist and often struggled with doing simple tasks because the environment had to be cold for the flowers to survive, I was always having Raynaud’s attacks which was really embarrassing, and I used to hide my hands a lot.

I also had them in water for most of the time and I developed sores on the ends of my fingers. When I went to the doctor to mention they weren’t healing, they just suggested it was down to using sharp equipment and ‘catching’ my fingers on florist wires.

Although I didn’t think what the GP was telling me was right, I had a niggling feeling there was more to it and ultimately, I had to make a choice and I sadly had to give up my job because of these ongoing symptoms.

My life at 33. A life of trying to fit naps into my social schedule due to the chronic fatigue systemic sclerosis causes. A life of waking up and taking a cocktail of tablets before I even have a cup of tea.

A year of planning my wedding, this year, hoping that my obsessive skin care regime keeps my skin from worsening whilst receiving results that my lungs are scarred from this life changing illness. Last year was full of difficult decisions after being offered a disease modifying drug that comes with potentially awful side effects but the hope of slowing the internal scarring down and the definite information that I couldn’t carry a child if I were on this drug.... 2015 was full of tears after my diagnosis of systemic sclerosis, and it was decided that I was now required to be seen by a rheumatology consultant who I continue to see every 3 months.



Chloe's hands when Raynaud's attack



Chloe walks Tala every day, sometimes twice, which assists in her well being.

I have gone from not even taking a pain killer when I have a headache to taking a lot of medication. It's scary....really scary. I'm positive, I know there is no cure, but I refuse to believe I will deteriorate.

I do everything in my power to stay fit and healthy. My dog Tala is a lifeline, she needs walking daily, so even when I don't feel like going out, it forces me to layer up, brave the cold and keeps my circulation going. I go to Yoga every week with my Mum, although the hall we practise in is usually cold, it's good to try and keep supple.

I have removed sugar and caffeine from my diet and take a concoction of Greek yoghurt, turmeric, black cumin seed oil and black pepper in the mornings which assists my inflammation, my consultant doesn't believe it's beneficial but it works for me!

My fiancé asked me to marry him when we were in Cyprus, I was oblivious to the proposal because he showed me a picture of him with Tala and I just thought they looked so cute together! We're getting married in Cyprus so I can wear a strappy wedding dress, rather than a coat.

All our family and friends are joining us and I can't wait to start the next phase of our lives together.

I recently had some good news, I have scar tissue on my oesophagus and lungs but I've recently had various tests to understand it's progression and, for now, I don't need to go on Mycophenelate, the disease modifying drug that is supposed to help slow down the progression of scar tissue on lungs.

Danny and I have plans for a child after our wedding in September, but I'm not sure how I'll cope when there are some days I can't even look after myself, we'll have to take each day by day.



Danny taking a selfie with Tala

Watch Chloe's personal story at [sruk.co.uk/chloe](http://sruk.co.uk/chloe)



photocredit pinnacletherapy.co.uk

# The Importance of Sleep

It may seem obvious that sleep is beneficial. Even without fully grasping what sleep does for us, we know that going without sleep for too long makes us feel terrible, and that getting a good night's sleep can make us feel ready to take on the world.

Scientists have gone to great lengths to fully understand sleep's benefits. In studies of humans and other animals, they have discovered that sleep plays a critical role in immune function, metabolism, memory, learning, and other vital functions.

Coping with a chronic illness or health condition can be stressful. Nearly all chronic illness results in some level of disruption to "normal" daily life and routines.

Another all-too frequent problem for people with chronic health problems is poor and insufficient sleep. The sleep problems associated with illness is an aspect of health management and treatment that isn't discussed.

A sleep survey conducted by Patients Like Me included 5,256 patient-members with a range of health conditions, and many reported chronic difficulties with sleep:

- 30% of respondents said they "rarely" or "never" got a good night's sleep
- 53% of those who believed they had a sleep problem had been dealing with their sleep difficulty for at least a year

It's not surprising that people coping with illness would report difficulties with sleep. The relationship (1) between sleep and pain is a complicated one.

Pain can create significant challenges to sleep, making it difficult to fall asleep and hard to stay asleep. At the same time, being short on sleep can make us more sensitive to pain.

Many medications also can interfere with sleep. Some common prescription and over-the-counter medications, including anti-depressants, blood pressure medication, and antibiotics, can be disruptive to sleep, due to a number of factors.

The stress and anxiety associated with coping with chronic illness can cause frequent interruptions to sleep, let alone actual symptoms, such as a fatigue which may have a negative impact.

### Tired But Wired

Yet the issue of sleep among people with chronic illnesses often remains overlooked. In the Patients Like Me survey, fewer than 15% of respondents had received a diagnosis of insomnia.

However, a majority of respondents reported experiencing symptoms of insomnia, including difficulty falling asleep and difficulty staying asleep, as well as waking feeling un-refreshed.

Scleroderma is associated with several types of sleep disruptions, including restless leg syndrome(2), research has shown that insomnia and other sleep disorders are significantly under-diagnosed among patients with chronic diseases.

### So, what can we do to overcome some of the difficulties?

We spoke to Martin Latham, a clinical nurse specialist at Leeds Hospital Sleep Service. He recommends a few hints and tips to ensure your sleep hygiene routine can be given the best chance of having an effect on your night-time slumber.

**"In order to get the best out of sleep, set yourself regular bed and awake times, and try to stick to these times. It's good to ensure your bedroom is cool, dark and we suggest not having a television or any electrical items in the bedroom, apart from your alarm clock as a regulator.**

Ideally don't drink caffeine 6 hours before bed-time, no alcohol after 8pm and some reports (3) have shown a benefit to bathing or showering before bed to help induce sleep, but you should give your body enough time to cool down afterwards. Time this about an hour and a half before you want to go to bed so your body is cool dry and ready for sleep. Daytime naps are alright between 2pm - 5pm but limit them to no more than 40 minutes and set your phone or kitchen timer to wake you and get you back up, otherwise this can have a knock-on effect into the night-time routine."

### Sleep Apnea

This is when people frequently stop breathing during sleep. The episodes can last for several seconds or longer. It results in unrefreshing sleep which can cause daytime sleepiness and fatigue. It is associated with many diseases, including high blood pressure, obesity, and heart problems. It is diagnosed with sleep laboratory studies, and typically treated with a CPAP machine, however other methods may include surgery, oxygen, medications, and throat exercises.

Lynne Lister from Leeds shared with us her experience of sleep apnea and how she now gets a good night's sleep by using a machine.

**"I always had very disturbed sleep and snoring was also a big problem (for my husband!), along with falling asleep during the day at the drop of a hat. I always thought that was down to having scleroderma, but apparently not".**

My sleep apnea started about 15 years ago, I was told that I stopped breathing in my sleep and went to see a specialist who said I had mild sleep apnea". As things progressed, about a year ago I attended a sleep clinic where they gave me a monitor over 24 hours, it registered my sleep patterns, then they looked at my results and they said a C PAP machine might help me with my sleep overall.



Photocredit: thoroughlyreviewed.com

A C Pap machine is a small machine that is on my bedside table plugged in all the time, you wear a mask that goes over your nose, or you can have a full-face mask if you prefer.

A long tube is attached to the small machine, which is attached to the mask on your face, it took me about 3 weeks to get used to it, but now it's part of my bed time routine, I don't even know I'm wearing it in bed. I now average 7 hours every night on it and the difference it makes is really positive.

I wouldn't be without it now and have recommended it to a lot of other people at the support group in Leeds with scleroderma."

With thanks to Martin Latham and Lynne Lister for assisting us with this article. Please visit [www.sruk.co.uk](http://www.sruk.co.uk), for further information about sleep.

Sources listed: [www.psychologytoday.com/us/blog/sleep-newzzz/201309/chronic-illness-and-insomnia](http://www.psychologytoday.com/us/blog/sleep-newzzz/201309/chronic-illness-and-insomnia)

1. <https://www.ncbi.nlm.nih.gov/pubmed/15798943>
2. <https://www.ncbi.nlm.nih.gov/pubmed/14592197>
3. <https://www.ncbi.nlm.nih.gov/m/pubmed/10408315>

# Our Amazing London Marathon Runners, Raise Over £19,000



## World Record Attempt for Ian

Ian Cox attempted to beat the Guinness World Record for best time ran in a marathon wearing a Star Wars costume...may the force be with him!

“My dad sadly passed away due to complication he had with Scleroderma in 2014, an illness he had for most of his life. He was and always will be a massive inspiration and guiding light in my life, I run in his memory and to help others who suffer with Scleroderma and Raynaud’s”.

If you feel inspired by Ian’s record attempt you can show your support by sponsoring him here [www.justgiving.com/fundraising/xwingrunner](http://www.justgiving.com/fundraising/xwingrunner) or text XWIN66 to 70070

Meet Tom, who is running his first Marathon for SRUK which falls one day before his mums one-year anniversary.

“I want to run in her memory and celebrate her life once again. It’s another opportunity to beat the drum, to hold the floor and shout about Scleroderma & Raynaud’s UK, to raise money and awareness - it’s a way of uniting as many people as possible for a common cause”.

Mum was my greatest teacher. Much of what she taught she did so without saying a word. One of the ways in which she showed herself was how she took on the challenges in front of her and, albeit this is a test of a different kind, I want to show myself in a similar way and be a credit to her.’



Meet Ian and Jason, brothers who are running the Marathon for their mum, who has lived with Scleroderma for over 33 years

The research that SRUK has undertaken over the years has been fundamental in allowing Mum to enjoy time with her grandchildren and family, and despite some tough days she continues to live independently.

We would like to say a huge thank you to all our London Marathon runners who took part in this year’s Marathon for SRUK. Well done to:

# Thank You to our Fantastic Fundraisers



Family and friends pulled together for a fantastic event, raising an incredible £3,509. From left to right: Lydia Travis, Julia Adamson, Pete & Heather Adamson, Amanda & Basil Nagle, Tom Adamson.

## Musical Memorial for Sue

6 months to the day Sue Travis passed away, Julia and Pete along with family and friends (above) organised a fantastic afternoon of live music, children’s activities, famous faces and an amazing raffle at Seven Miles Out, Stockport. Owners, John and Rosemary Barratt, with Linda Yarwood and Kevin Birchall hosted a second fundraiser and also raised money through employers Unite Union, to add to the amazing total of £3,509.

## Golf Thank You

We would also like to say a huge thank you to Hinckley Golf club for raising an amazing £4338.40 through a mixture of events including: golf days, bingo nights and a dinner dance. Steve Woodward, this years club Captain, chose SRUK as their charity of the year 17-18 as his father has lived with Scleroderma for the last 6 years.

If you are feeling inspired to help raise funds for SRUK why not come along to our Charity Golf Day on the 3rd of September.

## Daisy’s Charity Chop

Daisy Sephton, 11 cut her hair for SRUK on 28th March - she reached an epic £4,500 and raised £1,000 of that in just 24 hrs! Daisy’s cut hair is also being donated to the Little Princess Trust, who make wigs for children living with cancer.

“When my mum got diagnosed (at 24) they told her she would live for 10 years. My mum is now 40, so she has lived another 6 years which to me is amazing! If I did not have my wonderful funny mummy that would just crush my life.”



Daisy before and after the Charity Chop.

# 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](mailto:info@sruk.co.uk)

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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.

 @WeAreSRUK  /WeAreSRUK

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