

# SRUK NEWS



**Jay's Fight**  
Read how  
her story has  
been shared  
worldwide

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

**Spoon  
Theory  
Explained**

## Where There's A Will

William Bloodworth doesn't stop doing what he loves, thanks to his Nan.

# Autumn Raffle

We have some fantastic prizes to be won in this year's SRUK Autumn raffle.

This is your opportunity to win one of the following fantastic prizes:

- 1<sup>st</sup> A week's stay for six at a traditional cottage in the heart of Cornwall
- 2<sup>nd</sup> A long weekend for two in a beautiful Shepherds Hut in Somerset\*
- 3<sup>rd</sup> Two lucky winners will have exclusive access to dress rehearsals at the new season of plays at Shakespeare's Globe this Spring
- 4<sup>th</sup> Three full days of paintballing fun at any of the Delta Force branches around the UK
- 5<sup>th</sup> Dinner for two at any Bill's Restaurant across the UK
- 6<sup>th</sup> A day of fun, games and bowling in the UK's best arcade: Namco Funscape
- 7<sup>th</sup> Sainsbury's shopping vouchers
- 8<sup>th</sup> Allstore shopping vouchers
- 9<sup>th</sup> A family ticket to the London Wetlands



Once you have sold as many tickets as you can please either return the stubs with a cheque made payable to 'Scleroderma and Raynaud's UK' for the amount of tickets sold, or give the office a call on 020 3893 5998 to pay with a card.

If you would like to receive more books to sell in your local community please contact Henry on 020 3893 5998 or email [henry.mcginity@sruk.co.uk](mailto:henry.mcginity@sruk.co.uk)

**Please return cheques and/or stubs to:**

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

The competition is open until 22nd November and will be drawn on the 30th November. Winners will be notified by email and phone call.

You will find a book of tickets included in this magazine. Tickets are just £2.00 each and, not only could you be in with a chance to one of these fantastic prizes, you will also be supporting our vital work.

We would also encourage you to ask family and friends to buy raffle tickets for the chance to win. Every ticket that is sold will fund research and support.

We do not receive any government funding and so to continue our commitment to research, continue our investment in services, and continue to increase awareness and understanding, we rely on donations and fundraising.

Thank you  
for your  
support and  
good luck!

# Dear Supporters

It was great to see so many familiar faces and to welcome new members to SRUK's second annual conference. For those who couldn't make it, you can find videos of the presentations on our website. Thanks for your feedback, which is helping us to plan for next year, when we hope to see even more of you.

In this edition, we've some excellent articles, showcasing the spirit and energy of our community as well as the extraordinary work our clinicians and researchers do day in and day out. For children with Scleroderma and Raynaud's, this can be a difficult time for them and their families, so having the right support is critical. The Paediatric Rheumatology team at Alder Hey Children's NHS Foundation Trust in Liverpool, share with us, how they work across clinical care and research for children with localised and systemic scleroderma.

Fatigue is a common issue for our community and there's some excellent advice on understanding and managing this frustrating side effect on page 21.

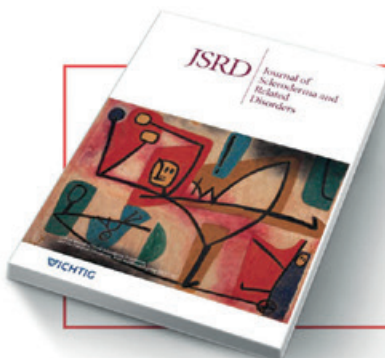
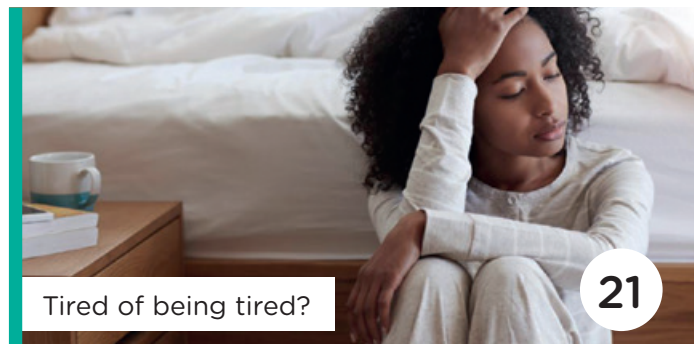
It's not long until Raynaud's Awareness Month in February and we would love to have your support again this year as we seek to increase awareness at a local and national level. Your stories, your participation and fundraising efforts, make all the difference.

Best wishes,  
Sue

sue.farrington@sruk.co.uk  
@farsue01



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Our members have been offered a reduced subscription to the JSRD - Journal of Scleroderma Related Disorders.

By subscribing you will be able to read published articles about research into scleroderma and will receive notifications when new content is published.

Enter the promo code **SRUK2018** into the green box on this page [sclerodermajournal.com/Product/Subscriptions](https://sclerodermajournal.com/Product/Subscriptions) to receive an online subscription to the journal for the remainder of 2017 and the whole of 2018 for 30 Euros (the usual price is 173 Euros).



# Doc Spot

Your questions answered by our medical professional, Prof. Denton

**Is there any connection between Raynaud's and Vascular Dementia? Both run in my family and I have Raynaud's quite badly - no sign of dementia yet but I'm reaching that age fast!**

There is no known association between Raynaud's or scleroderma and dementia. There have been some reports suggesting in scleroderma that transient episodes of reduced brain blood flow might occur.

This is like the suggestion for organs such as lung and kidney, and whilst it is attractive to consider that spasm of multiple blood vessels might occur in Raynaud's, formal research studies have not confirmed this.

There is a link between Raynaud's and migraine that can cause temporary visual or neurological deficit but this is not associated with dementia. It is still uncertain whether scleroderma is associated with increased disease of large blood vessels, unlike other rheumatic disease such as systemic lupus erythematosus (SLE) where that is well established. So, you can be reassured that there is not evidence for the link that you suggest in this question.

**For the past five months I have ongoing problems with eating. I am finding that although I can swallow food, after a few mouthfuls it feels like there is a lump in my throat and I am unable to continue with my meal.**

**The skin on my neck has become tight again as well. There have been a few occasions when I have experienced a strange feeling in my throat when it is really painful and I am unable to swallow or talk. Not sure this is connected?**

**I have lost 10kg in weight and have been admitted to hospital for NG feeding and further test, which so far have not shown anything except poor propulsive movement throughout the oesophagus.**

**Many of the symptoms seem to have progressed since starting Nifedipine and Sildenafil (for Raynaud's and finger ulcers). Is it possible that one or both of these can cause these symptoms?**

Patients with scleroderma almost always have difficulty with swallowing. This, most often, is reported as food sticking in the throat.

The reason is probably, that in scleroderma, the small blood vessels and nerves in the lower oesophagus (gullet) are damaged at an early stage of the disease.

This alters the normal co-ordinated contraction of muscle in the oesophagus that is important for swallowing and that occurs automatically every time we eat. This leads to poor seal at the junction between the oesophagus and stomach and allows acid stomach contents to regurgitate (reflux) backwards.

This leads to inflammation and sometimes scarring (stricture). Acid reflux and muscle spasm can also cause throat pain or difficulty speaking. This can be treated by drugs suppressing stomach acid (such as omeprazole and related agents) that are given to most scleroderma patients.

Other drugs that help restore normal muscle contractions can also be given (e.g. metoclopramide). It is possible that drugs which relax blood vessels such as sildenafil or nifedipine could also affect smooth muscle in the gullet.

This is uncommon but if you think the symptoms are worse with this treatment please discuss with your medical team as they may suggest trying different treatment or altering the current doses, or adding additional agents.

I just wondered if you had any advice on how to deal with scar tissue left from healing ulcers.

They take months to heal, and leave yellowish scar tissue, like a scab, which again takes ages to come off, only to be replaced by another one! It can be pretty sore at this stage too.

I keep my hands moisturised and always wear nitrile gloves if they're going to get wet, but haven't quite solved this one.

The healing of ulcers on the fingertips and elsewhere in scleroderma is a major problem for patients.

This is because the ulcers result from poor blood supply to the skin and blood supply is critically important for normal healing. Treatment for Raynaud's or that improve blood supply such as sildenafil might also help healing but this has not been shown in formal clinical trials.

Therefore, local care such as creams and moisturisers to soften skin and prompt treatment of infection with antibiotics is important. Improving the healing of ulcers is a subject of intense medical research and hopefully better drugs and other agents will be available in the future.

**I've been prescribed Adalat nifedipine today but I've read through the leaflet and am shocked by the side effects.**

**Should I take this drug?**

Nifedipine, also called Adalat (the commercial name for one formulation) is a very standard drug for Raynaud's phenomenon and is commonly prescribed for patients with the condition. It can help both the primary form of Raynaud's and when the Raynaud's is secondary to another disease such as scleroderma.

It works by blocking the flow of calcium in smooth muscle cells in blood vessel walls and this relaxes the muscle and reduces spasm that leads to a Raynaud's attack. The drug is generally safe and is in widespread use for high blood pressure.

However, because it opens blood vessels it can lower normal blood pressure, causing headache and dizziness, and by opening blood vessel in the legs it can lead to fluid accumulation around the ankles with swelling. Usually these side effects are mild but sometimes they can prevent the drug being used.

There are alternative drugs that can be tried if necessary but if your doctor has recommended nifedipine it would be sensible to try this first and discuss any side effects if they occur.

I started Adalat two weeks ago and have been mostly ok. I've had an increase in headaches, flushes and urination. I take 5mg three times a day. The whitening of my fingers has indeed decreased, but the rate they go bright and boiling hot has increased. Which I think is unrelated to Raynaud's.

But GP didn't quite understand that when I have a Raynaud's attack, the blood comes back in normally. The redness and heat happens when my hands are totally normal. Since Thursday though, I feel as if I've been hit by a bus. Would some side effects come on after two weeks?

The reduction in frequency of whitening of the fingers is most likely due to the intended effect of nifedipine to reduce spasm of blood vessel in the fingers that is the first stage of a Raynaud's attack.

However, the other later phases such as redness and burning discomfort might not respond, as these are not directly caused by blood vessel spasm.

Also, the adalat (nifedipine) may have side effects such as a lowering of blood pressure. If you have had normal or low blood pressure before taking the drug then this may be sufficient to make you feel very unwell and so you should consult your doctor to see if a change in dose or alternative medication might be considered. As part of this assessment you should have your blood pressure checked.



# Successful Annual Conference 2017

**Our SRUK 2017 Conference became one of the highlights of the year when over 150 people came together for the weekend in September.**

From all over the country we had people from the Scleroderma and Raynaud's community attending to receive the latest information from top specialists on medical and research advancements along with informative patient speaker breakout sessions. Feedback on the day, has been fantastic.

“A huge amount of information was shared on the day. It was good to meet other people with the conditions” - **Angela**

This year our Vice President, Ariane Herrick, chaired the day and after a talk from Sue about SRUK's achievements one year on, Peter Lanyon, President of BSR, talked about rare rheumatic conditions, the future landscape. People living with rare diseases often report that they find it difficult to access the care that they need.

This has been acknowledged by the Department of Health's publication of the UK Strategy for Rare Diseases in 2013, and more recently NHS England has made a commitment to produce an implementation plan.

Peter's talk explored how this might lead to opportunities for improving the care for people living with rare autoimmune rheumatic diseases, focusing on the need for individuals and organisations to work closely together to try and achieve this.

Prof. Chris Denton, Consultant Rheumatologist at the Royal Free Hospital, London, talked about the current thinking around the causes of scleroderma?



The fact that scleroderma is a rare disease and has diverse patterns of clinical involvement makes it immediately apparent that what causes scleroderma is likely to be uncommon, and that it is probably a combination of things that determines how it develops once started.

Although we do not know the precise cause, Professor Denton shared that research over the past two decades has shed light on possible triggers and what factors may increase the risk of developing the disease.

This in turn is opening up new possibilities for treatment and also in assessing patients so that treatments can become more precise.

“It's easier to understand the conditions when you attend an event like this. The group sessions went into detail I wasn't aware of, so I feel very educated and informed” - **Alan**

The sessions after the coffee break were equally engaging. Dr Hughes discussed the mechanisms and causes of Raynaud's and suggested that by better understanding the causes, we can better treat the symptoms of painful Raynaud's attacks and help develop new targeted treatments, free of side effects.



The sociable side of the conference



Kim Fligelstone on the SRUK Support & Information Stand

He presented an overview of the current strategies in place to treat the progression of Raynaud's, including the latest developments

Back in March we invited Dr John Pauling to share his talk on nine tests to diagnose and predict the future in scleroderma. His talk this September, showed things had advanced further, and he talked about 10 tests. He went on to describe the clinical features associated with the autoantibodies found in systemic sclerosis and newer techniques that are allowing more hospitals to look for these antibodies in suspected scleroderma.

Dr Francesco Del Galdo and Amy Baker completed our morning sessions as a duo. By identifying characteristics and traits of people with secondary Raynaud's, the aim is to build a clinical and biomarker dataset that will inform future research aimed to identify predictive markers of severity and progression towards Scleroderma.

“A great opportunity to hear about the latest research, to meet doctors and researchers working on scleroderma, as well as the opportunity to network, meet, and talk to others with the conditions” - **Isobel**

Francesco and Amy talked about the recent Transit campaign and shared some key results from this pilot study in Leeds.

We had a range of exhibitors during lunchtime with support from the Royal Free and Salford Royal Hospitals, along with a range of SRUK stands.

During the afternoon we had different break-out sessions from Professor Herrick, Professor Peter Butler, Dr Elizabeth Harrison and Dr Cate Orteu.

These were supported by our patient speakers Diane Unsworth, Mike Corbett and Lynn Steblecki who all gave personal insights into living with the condition and how they cope with particular symptoms, their approach to treatments, and shared best practice.

“The highlight of the conference was meeting other people with the same problems. I'm a support to my wife who has the condition, we all exchanged ideas on the day” - **Stuart**

We are hugely grateful to our sponsors for this year's event, Actelion, Heat Holders, TDS Healthcare and Hot Rox.

### Not able to make it this year?

If you weren't able to attend this year's event, all speaker presentations are available online to watch [www.sruk.co.uk/get-involved/sruk-annual-conference/](http://www.sruk.co.uk/get-involved/sruk-annual-conference/)

### Our Sponsors & Your Support

At SRUK we believe everyone should have access to specialist information and the opportunity to build a support network, so each year we invest in conference to provide this.

If you are interested in becoming a sponsor at next year's event, or would like to help us cover conference costs to enable further investment in research then please get in touch with us today.

Follow the Twitter activity on #SRUKAC17

# Smile, And The World Smiles With You



**After Jay Virdee's diagnosis of multiple conditions, aged just 32, her world collapsed and her dreams were shattered.**

Jay Virdee, from Stoke Poges, previously enjoyed a successful and rewarding career as a teacher, working at Baylis Court School before becoming the head of IT at Wexham Sports College in Norway Drive, Slough.

But her teaching career came to an abrupt end when she began suffering from a number of debilitating physical ailments, such as repeated respiratory infections. Not long after this, Jay was diagnosed with overlap Mixed Connective Tissue Disease, the predominant conditions being both Systemic Sclerosis and Interstitial Lung Disease. Frustratingly, Jay had to give up work and consider her future whilst conserving every breath.

Her life is a daily struggle, never knowing how much she will be able to move, whether a trip to the shops will be possible or even how comfortable breathing will be.



Jays final farewell as a teacher

As those of you with scleroderma will know, your only battle isn't always just with the illness. On the surface Jay appears healthy, the damage to her skin can be hidden beneath her clothes and the worst effects of the disease are internal.

**"It is an invisible illness," she says. "I can feel it and I know it's there but I look normal. In fact, I can look like I am very well."**

She has had to convince sceptics she really is ill. A disabled parking badge in the car window and a heaving medicine cabinet are among the few visible clues. She is frequently told: "You look very well" or "You don't look disabled". Jay feels she is continually being asked to justify her illness whether it be to other drivers in the car park, peering at her as to why she has a blue badge or to neighbours wondering why she can't assist with the communal gardening project.

"Thankfully, being a teacher, I developed a sense of humour and usually have a measured and polite retort to those who question me," Jay explains. "I even asked one lady in a car park if she would like to come to my lung function assessment appointment with me, just to see if she had a response!"

She is challenged daily to 'change manage' her lifestyle on every level - from relationships and family, to friends, colleagues, acquaintances and neighbours. With chronic exhaustion and fatigue, Jay is not always able to attend occasions and therefore feels she misses out on some amazing life events.

"It is devastating to see a whole day or week go past, when previously I would have managed the IT education of up to 1000 children, team meetings and parents' evenings!"

Since Jay's diagnosis she has survived an unprovoked physical assault, resulting in needing significant dental work, had difficulties in dealing with employment issues and financial issues, such as the insurance company regarding her mortgage protection cover.





Jay with Bill Buckley at BBC Radio Berkshire

With no guaranteed, regular income and costly outgoings from her medication, to her mortgage, Jay shares that there is a real possibility she may be homeless within the year.

After bumping into a student she used to teach, she became inspired to raise the profile of the condition through social media to address some of these issues and also to start fundraising for her cause, as a necessity.

“I hope by raising awareness for rare autoimmune disorders this furthers both the understanding of invisible illnesses and recognizing them as disabilities. Scleroderma is currently not as efficiently diagnosed as cancer, diabetes or heart disease, so if we can elevate its profile and symptoms, hopefully, people will have a better prognosis, treatment options and that their disease is recognised by people as a chronic illness, which currently has no cure.”

As Jay became active and started up her fundraising page, she created local interest. Her local newspapers picked up on the story and very soon she was on BBC Today South and BBC news online. Her story appeared as the number one story trending on the BBC for 12 hours one Sunday in September, and her appearance on various radio and broadcast stations has had an effective reach, in just one month, of over 100 million people. A fantastic achievement.

When speaking to Jay, she is dynamic, bright, charming and very upbeat. However, plans to have children and dreams of a future happy family life have been abandoned, for the time being.

“I am very much aware of my functional ability. I have a fear of having children and leaving them in this world. But I offset that with the fact I’ve taught nearly 20,000 children.”

Jay is also conscious of the physical aspects, which can affect confidence and restrict mobility, functions and expressions that she used to be able to perform, something as simple as smiling is an effort as her skin tightens.

“I always had a really wide smile”, says Jay. “It was the first thing I did entering the classroom - it reassures, it opens up conversation... if I smile now I feel like everything is OK. I’m going to smile as much as I can, whilst I still can.



To read more about Jay’s story, visit [sruk.co.uk/jaysfight](http://sruk.co.uk/jaysfight) or visit Jay’s Facebook page: [www.facebook.com/jayschallenge/](http://www.facebook.com/jayschallenge/)



## BBC2 Features Raynaud's and the Importance of Early Diagnosis

You'll recall for World Scleroderma Day in June we launched our very first mobile clinic, which was situated Leeds city centre for a week.

Key physicians, fully trained in dealing with people with Scleroderma, along with several research nurses recruited walk-in patients to confirm a diagnosis of Raynaud's and if necessary people were referred to a GP practice or the regional centre for CTD and Scleroderma in Leeds for a follow-up appointment.

As a first ever pilot scheme for this condition, it created some media interest and joining us on site on day three was BBC's Trust me, I'm a Doctor with Dr Zoe Williams. Dr Williams, was joined by Julia Stokes, who has secondary Raynaud's and they undertook a cold water test so Zoe could understand what a Raynaud's spasm can feel like and how it can affect feeling in the fingers, leaving them numb and lifeless.

Dr Francesco Del Galdo discussed the key difference between Primary Raynaud's and Secondary Raynaud's, when this can be a sign of something more than just cold hands, and various treatments available to combat the condition.

This is the first time on national television that Raynaud's conditions have been covered, explaining both aspects, along with the importance



of early diagnosis and the urge for the general public not to ignore symptoms.

They will be able to take the Raynaud's test on our website if they are concerned and receive further information and support if necessary.

**BBC 'Trust me I'm a Doctor' airs on BBC 2 this winter, we'll be advertising the programme featuring Raynaud's, via our website as soon as we are alerted.**

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## Gardener's Delight

This October we also launched a campaign to raise awareness amongst gardening enthusiasts, so that they are able to get tested for the conditions and find ways to adapt their gardening skills as the winter months approach. Raynaud's attacks in particular are often linked to extreme changes in temperature, making gardening outside a real challenge - but there are some simple steps to take that can reduce the chances of an attack.

Following her diagnosis of both Raynaud's and Scleroderma, professional landscaper Sue Dryden has made practical changes to both her clothing and equipment to maximise her time outdoors, and reduce her chances of experiencing painful symptoms. Alongside SRUK she is encouraging other gardeners do the same.

For hints and tips on gardening from Sue and to watch her videos visit [www.sruk.co.uk/gardening](http://www.sruk.co.uk/gardening)



# #KnowRaynauds & How YOU Can Help

During Raynaud's Awareness Month 2018 (February) we'll be asking you to help us spread the word with our #KnowRaynauds campaign.

The success of last year's campaign enabled us to reach over 39 million people through press, radio, television, online and through social media coverage. We are working with our media contacts to ensure we get even better coverage in 2018 about the condition, how to identify symptoms and ensure people understand how Raynaud's is linked to other auto immune conditions like scleroderma.

Our #KnowRaynauds campaign will encourage more people to seek medical help and advice if they regularly experience one or more of the main symptoms. To help identify if people may have Raynaud's, we have also devised as a short online test so they can find out in minutes if they have this condition and what to do next.

If you would like to take the test, please visit [www.sruk.co.uk/testme](http://www.sruk.co.uk/testme)

Many of you are aware that a small number of people with Raynaud's go on to develop more serious conditions and with an estimated 10 million people suspected of having Raynaud's we are still only scratching the surface.

## We need your help!

So, what can YOU do to help us spread awareness and increase understanding?

- In our January SRUK News you'll find posters and flyers within the edition along with suggestions on where you could put these up in places around your community to help everyone get to #KnowRaynauds and to take the online test.

Please help us distribute these in your area.

- Share your story about how you cope with your conditions, to help us with PR and educate people. Your stories are very powerful and we know these resonate with our community when they are shared.
- Do you have any connections with broadcasting?
- Do you work in the media? We would love to hear from you about how we can generate further publicity.

If you can support us or have any questions regarding the above, please contact [info@sruk.co.uk](mailto:info@sruk.co.uk). You can make a difference.



## Join us this Raynaud's Awareness Month and Cosy Up With A Coffee!

Last year you raised £493 by organising coffee mornings in your local community. This February, help us raise even more by ordering your free 'Cosy Up' pack today.

Together, we can create a better world for people with Scleroderma and Raynaud's by increasing awareness and understanding and investing even more into research.

Cosy up with friends, and family at home, in a coffee shop, at work or at your local community group. You can have a baking session yourself, encourage guests to bring along some cake, or simply head to the supermarket and stick the kettle on!

Hosting a Cosy Up with a Coffee event in your community is easy with our free guide. So, order yours today and make a difference to the lives of everyone affected by these conditions in 2018.



To receive your free 'Cosy Up' pack simply contact our fundraising team on 020 3893 5993 or [fundraising@sruk.co.uk](mailto:fundraising@sruk.co.uk)

# Scleroderma in Children, Clinical Services & Research in Liverpool

## Looking after the needs of children with scleroderma

Our multi-disciplinary team includes doctors, nurses, physiotherapists, occupational therapists, clinical psychologists, play specialists, and research nurses who work with families to deliver holistic care to children and young people with juvenile scleroderma.

The Paediatric Rheumatology team at Alder Hey Children's NHS Foundation Trust in Liverpool work closely across both clinical care and research for children with a number of conditions, including localised and systemic scleroderma

The team run a specialist scleroderma clinic, every two months with members of the Alder Hey Rheumatology team together with Dermatologists and a Rheumatologist who has expertise in scleroderma and looks after adults with this condition.

Young people can also be seen in other rheumatology clinics or our medical day unit if they need to be seen between the times of our specialist scleroderma clinics.

Should it be necessary, Alder Hey Children's Hospital can provide care from other specialities, for example paediatric respiratory or cardiology experts, and also can provide access to specialised radiology investigations which may be required for children and young people with scleroderma.



## Meet the team

### Doctors

The following consultants work across the Clinical Academic Department of Rheumatology, supported by a vibrant multi-disciplinary team: Dr Clare Pain, Dr Liza McCann, Dr Gavin Cleary, Dr Kamran Mahmood, Professor Michael Beresford and Professor Christian Hedrich. All of our doctors are experts in paediatric rheumatology conditions including scleroderma. The medical team includes doctors training in paediatric rheumatology and general paediatrics.

### Specialist nurses

Our Specialist Nursing team assist the consultants in their clinics. They support and educate patients by giving information on their condition and medications. They also help to organise any attendance on our day ward when required, which may include treatments or clinical reviews. The nurses offer support via telephone clinics if patients or parents require advice between visits. They also help to monitor blood test results that are taken when a young person is on drug treatment.

### Clinical Psychologists

Our Clinical Psychologists are trained in understanding how people think, feel, behave and relate to each other. They are present within the team to support children/young people alongside their families, in relation to any worries or concerns they may have regarding living with a rheumatology condition.

This may include considering the impact that health has upon the day to day things a young person may wish to do, how a person feels about their health condition, taking medications, being with friends, and attending school, etc. A clinical psychologist may be present at clinic appointments, and meets with the rest of the team regularly. They offer appointments to families as outpatients and, where appropriate, may also meet with families on the hospital wards.

### Physiotherapists

One of our physiotherapists often attends the scleroderma clinic as part of the multi-disciplinary team. In addition, our physiotherapists see young people with scleroderma in the physiotherapy



SRUK Image: 2016 Family Day

department for rehabilitation, helping to improve movement, muscle strength and stamina, to enable the young person to do daily activities (like playing and going to school).

### Occupational therapists

One of our occupational therapists is often present in the scleroderma clinic as part of the multi-disciplinary team. They will also see young people in the therapy department to help overcome difficulties they may be having with day to day tasks (like school work, playing and helping out at home). They may help young people to learn new skills or do things in a different way to encourage them to do things independently.

### Play Specialists

Our Play Specialists are trained to support children who are in hospital or who need medical treatment. They help young people find ways to cope with treatment or procedures including relaxation and distraction.

During the December clinic this year, SRUK will be visiting the Children's clinic. They will have a stand on the day with information leaflets and products that may assist those diagnosed with both scleroderma and Raynaud's to raise awareness of the charity, the work it does to support those affected with the conditions, and how people can get involved further.

# Research in Juvenile Scleroderma

**Dr Clare Pain, Consultant Paediatric Rheumatologist, is chair of the UK paediatric scleroderma Topic Specific Group. This is an open group of doctors, allied health professionals and parents who aim to facilitate research into juvenile scleroderma both in the UK and through links with other groups in Europe and North America.**

SRUK have funded a study, open from August 2017, which aims to develop better ways of assessing whether children with localised scleroderma have active disease (inflammation which may be amenable to treatment) or inactive disease which does not need drugs to control inflammation.

This will involve children seen at scleroderma clinics at Alder Hey, Manchester Children's and Leeds. Children will be asked to attend Salford Royal Hospital for assessment of their scleroderma including skin scores, patient questionnaires and imaging techniques. The UK paediatric scleroderma Topic Specific Group have also identified better treatments for scleroderma in children as a priority area and the group are working towards the development of clinical trials.

Juvenile systemic scleroderma is an extremely rare disease. Dr Foeldvari, Consultant Paediatric Rheumatologist in Hamburg, has set up an international cohort study in this rare disease.

The aims of the study are to better understand how systemic scleroderma affects children and young people, and to standardise how children are assessed, in particular for lung and heart involvement.

Children and young people in the UK can be part of this study. We are recruiting patients at Alder Hey and other paediatric rheumatology sites in the UK.

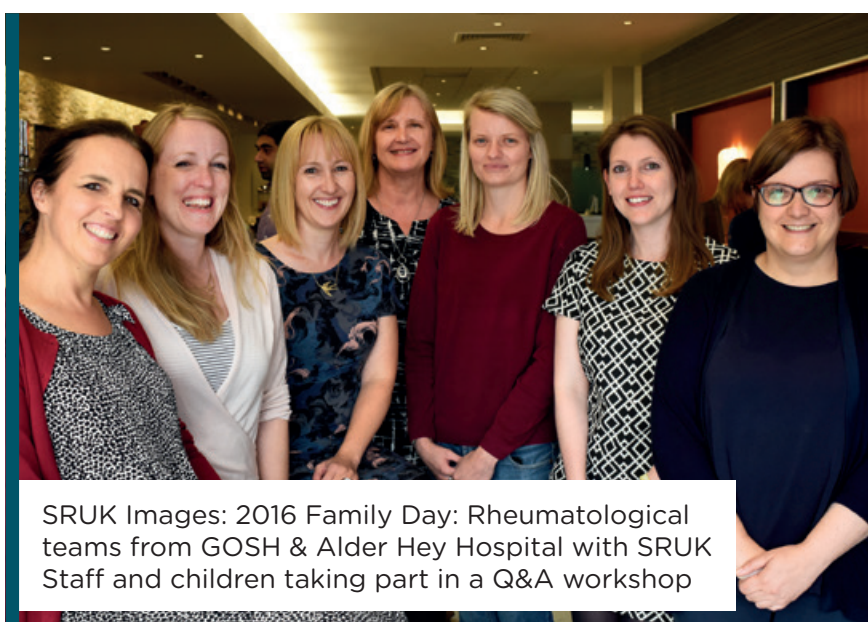
In 2016, SRUK in partnership with the paediatric rheumatology teams from Alder Hey and Great Ormond Street ran a family day for parents and children affected with juvenile scleroderma.

This involved talks from our team members and a session where we asked children and family about their research priorities. Main priorities were better treatment options for children, including drugs with fewer side effects.

Families were also keen to understand more about surgical procedures that may help with the complications of scleroderma. Other areas identified the need to understand the long-term outcomes better as well as understanding how better to assess the disease.

The comments from both children and families have been fed back to SRUK and the UK paediatric scleroderma group and incorporated into our research agenda for the future.

We think it is very important that children and parents are involved in setting research strategies so the needs of those with juvenile scleroderma are addressed.



SRUK Images: 2016 Family Day: Rheumatological teams from GOSH & Alder Hey Hospital with SRUK Staff and children taking part in a Q&A workshop



# Annual Paediatric and Adolescent Raynaud's Clinic

Grace's attacks are far less extreme now with her silver gloves. The gloves have had a huge positive impact on our lives."



Rheumatological Team at Sheffield Royal Hospital

We hear from Dr Anne-Marie McMahon about the success of a paediatric clinic in Sheffield Children's NHS Trust Hospital, bringing all aspects of care to those visiting outpatient appointments.

This innovative clinic was set up to help families focus on managing and preventing symptoms, and bringing the charity along with other experts, to the patients.

Shirley Armstrong, Rheumatology Team Co-ordinator, has organised the annual autumn event. The clinic is an opportunity for children with the condition to meet their medical professionals, to meet other young people with Raynaud's and to provide a support network. Some may be newly diagnosed coming to their first visit, others have follow up appointments.

The team of specialists, physiotherapists, pharmacists, occupational therapist, doctors and clinical nurse specialists come together along with the Raynaud's support charity, Scleroderma and Raynaud's UK.

Tracey Spray & Henry McGinty from Scleroderma and Raynaud's UK have joined the Sheffield Children's Hospital annual Raynaud's Clinic Initiative, for the last two years.

The charity are based in the waiting area, with a display filled with advice leaflets, information packs, body warming products and gadgets, with friendly and expert advice on how to keep extremities warmer and help ward off a Raynaud's attack. Coping strategies, and information for schools, to help teachers understand the condition and what extra allowances pupils with Raynaud's may need during the day are given to all patients. They all receive an SRUK bag with samples and leaflets signposting them to more information available on the SRUK website.



The clinic consultation has emphasis on the history, symptoms, cardiovascular assessment, recording standard BP, height and weight. Nurse led consultations are embedded as part of the clinic process.

The team pharmacist has a display in the clinic area and discusses the benefits and potential side effects of each medication with the patients individually; such as glyceryl trinitrate patches, nifedipine, and iloprost.

Feedback has been extremely positive, the children, and parents appreciated learning more about the condition, felt the clinic was supportive, with a multidisciplinary focus to advise on coping strategies.

This initiative demonstrates the significance of incorporating advice on preventative measures in this challenging condition. Collaboration with Scleroderma and Raynaud's UK has improved patient and staff experience with this innovative clinic model. Future work is planned to incorporate this clinic model in other rheumatological conditions both to improve patient and parent experience, and develop their support network

**The next clinic is being held in February 2018.**



William was given a thorough check-up by the consultant and bloods were taken at his first appointment - much to William's dismay! I was asked to email our photos to the consultant too so that they could have a copy. He was diagnosed with Raynaud's and we have been under their care since.

We have seen the Raynaud's charity SRUK, at the hospital twice now and they have been amazing, they gave William some wrist warmers which William loved wearing until he lost one at school one day.

We sent the last one to William's great grandma and asked her if she could make another one and a few weeks later we had three new sets. She is 94 and we haven't really explained to her why William has them, besides they keep his hands warm which then led her to making more for her friends grandchildren, we don't go anywhere without a pair.



William and Great Grandma Walker who knitted William's lost wrist warmer.

## Where there's a Will...

William Bloodworth, age 9, from Sheffield doesn't let his Raynaud's get in the way of his love of sports. William's mum Cheryl, describes the challenges her son has faced since he was diagnosed with Raynaud's age 7.

William helped me one morning at the start of 2014, he was six at the time, to scrape the ice from the car and on the way to school his hands started to go red and swell up. I always take photos of things like this just in case we ever need to show a doctor or someone. He warmed them up in class and he was fine.

This happened a few times in the mornings and I took him to the doctors who referred us to Sheffield children's hospital.

Our first appointment went well, we were prepared and went on the bus because parking is a complete nightmare but William didn't mind as it meant he was out of school for longer!

SRUK, the Raynaud's charity has given us a lot of information about Williams condition, which has really helped us to understand and try and help William with his day to day keeping warm.

The hospital have given us information sheets for Williams teachers so that they are aware of his condition and what they need to do for him. We don't want him to appear different to the other children but equally William's health is our priority.

Williams hands have never been as bad as they were back in 2014 but still get very cold at random times, for example, on a day in Castleton in July his hands were freezing and he said that they "feel funny."

William doesn't always notice when his hands are freezing so it's always a good excuse to get to hold his hands whilst we are out and about!

"We have a rechargeable hand warmer that normally stays in the car just incase we needs to warm him up."





William and his Dad, Paul at Yorkshire County Cricket Club



William, plays in the under 10s team for Yorkshire CCC, loves golf, and enjoys being outdoors



We are determined as a family that Raynaud's won't stop William doing what he loves and we just need to find ways to manage and prevent issues before they become a problem

At school William knows what he has to do if his hands “feel funny.” He normally puts them on the radiator, he says he can't put them under the hot water as it makes them tingle.

Although teachers are aware of William's condition and how to help him, the onus is on William to let them know if he has a problem, although he constantly gets reminded at playtime about keeping warm by one of the teaching assistants when playing outside.

Last summer we noticed that Williams toes were starting to peel and get itchy, I went to the chemist and got athletes' foot spray but this didn't help so we went to the doctors and they gave him some cream.

We presumed that he had athletes' foot but after a bit more advice from the charity, I now think that it may have been chilblains instead. We have a factsheet on that so know how to try to keep it at bay.

William is a very active nine year old who loves being outside. He does athletics, swimming, plays football, plays golf but his main sport at the moment is cricket, he is currently training with South Yorkshire schools cricket club as well as his normal club Harthill and has just played his first match for the under 10s.

# SRUK Shop

Christmas is on the way, so it's a good time to trade your old for new and buy some stocking fillers for others. You'll find some new products and some old favourites at [srukshop.co.uk](http://srukshop.co.uk) this winter.

Treat yourself or a loved one this Christmas Season



## HotRox Hand Warmers

HotRox hand warmers have three heat settings, Off, Medium and High. This allows for a heat cycle of up to six hours, easily long enough to keep you warm whatever you are doing. HotRox hand warmers are great for anything!! Walking, playing golf, horse riding, walking to work, commuting, working outdoors, fishing, shooting, working in a cold office, or those with medical conditions such as Raynaud's.

**£19.99**



**NEW**  
Introductory Offer, 10% off until 30.11.17\*

## Feel The Warmth Body Belt Pack

This new body belt uses far infrared technology to assist the body heat to transfer deep into muscle tissue which helps with blood flow and keeps your core temperature level.

**"It's easy to use, easy to clean, easy to charge, and definitely makes a difference helping with core temperature"**

Emma, Oxford

**£79.00\***



## SnugToes

Warm up freezing cold and painful feet with a cosy pair of SnugToes, the super snuggly slippers with handy removable heat pads. Just pop the heat pads in the microwave, slip them back into the slipper tops and enjoy the welcoming warmth. You'll have toasty toes in no time! Available in men's sizes in blue or ladies in beige.

**£22.00**



## Christmas Cards

Yes, it's that time of year again! SRUK Shop is proud to present its 2017 Christmas cards. Choose between our stunning Three Robins, Winter Scene and Sledging in the Winter.

**£3.99 per pack**



## Warmies Cosy Plushies

These adorable soft toys are a great way to keep warm. Ideal for children and adults alike, just pop them in the microwave to warm them up and enjoy some lavender scented hugs!

Choose between our penguin, dragon or our snowman. Not suitable for children under three.

**£10.00**

\*Introductory Offer for Feel The Warmth Body Belt Pack. See P19 for discount or use code **BELT17** at the checkout if purchasing online.

# Stocking Fillers



## Heatholder Socks

These thick thermal socks offer a 2.3 tog rating, promising warmth and extra protection against the cold. No matter what you are doing, whether it be spending time outdoors or curled up inside, these socks offer additional comfort in all environments.

**£7.00**



## Ladies Hat & Glove Gift Set

Packed together to create a perfect gift, this purple hat and glove set is fleece lined with patented yarn to keep you cosy and warm this Winter.

**£15.00 per set**



## Heat Holders Fleece Blanket

Relax with a Heat Holders premium fleece blanket-perfect for wrapping up warmly on those cold winter nights. It's incredible softness make it a must-have item or the perfect luxury Christmas gift. Dimensions: 180cm x 200cm.

**£25.00**



## 12% Silver Fibre Gloves

These gloves are seam free, flexible and will allow you to operate your mobile device and visit a cash point without having to remove them. Made using 12% silver thread woven on the inside, they have light stretch for improved fit and have been designed to accommodate swollen fingers.

**£20.00**



## Winter Survival Kits

Be winter ready with our winter survival kits.

**Each kit contains:**

- 1 pair of insoles
- 1 pair of gloves
- 1 pair of short socks
- 1 fuel grip
- 1 pack of Mycoal warmers

**£45.00 - £55.00**



## Mycoal Hand Warmers

These handy warmers can be quickly activated for instant warmth whenever you are out and about.

Just open the packet for seven hours of constant heat.

Please note these are disposable and cannot be reused once opened.

**£6.00 for four pairs**

## SRUK shop Product Details

Christmas Items	Cost	Qty	Size	Colour
Christmas Cards: Three Robins	£3.99			
Christmas Cards: Winter Scene	£3.99			
Christmas Cards: Sledging In The Winter	£3.99			
Snugtoes Ladies (S, M or L)	£22.00			Beige
Snugtoes Men (S, M or L)	£22.00			Blue
Heatholders Socks	£7.00		4-8	
Heatholders Socks	£7.00		6-11	
Warmies Penguin	£10.00			
Warmies Dragon	£10.00			
Warmies Snowman	£10.00			
HotRox Hand Warmers	£19.99			
Snuggle Up Blanket	£25.00			Chocolate
Feel The Warmth Body Belt (S,M,L,XL)	£79.00**			
<b>Stocking Fillers</b>				
Ladies Hat And Glove Gift Set	£15.00			
Fuelgrips	£2.50			
12% Silver Gloves (S/M or L/XL)	£20.00			Black
Winter Survival Kit	£45.00			
Mycoal Hand Warmers (4 packs)	£6.00			
<b>Silver Socks &amp; Gloves</b>				
8% Gloves Per Pair (XS or S-M or L/XL)	£9.50			
8% Fingerless Gloves (S-M or L/XL)	£9.50			
9% Short Socks Pair (S or M or L or XL )	£13.00			
12% Long Socks Pair (S or M or L or XL)	£16.00			
12% Short Socks Pair (S or M or L or XL)	£13.50			
12% Long Socks Pair (S or M or L or XL)	£16.50			
<b>Bundle Deals (please state sizes)</b>				
1 x 8% Silver Gloves & 1 x 9% Short Socks	£21.00			
3 x 9% Short Socks £30.00	£36.00			
2 x 8% Silver Gloves (Same Type)	£18.00			
2 x 8% Silver Gloves (1 x Fingers and 1 x Fingerless)	£18.00			
<b>Astec Items</b>				
Edge Bound Insoles (Sz UK 3-12)	£24.99			
Cut to Size Insoles	£24.99			
<b>Postage &amp; Packing Costs</b>				
Postage and packing for single items		£3.95		
Postage and packaging for multiple items		£1.00 extra per item		
<b>Total Order</b>				
	Total cost of goods			
**10% discount (£7.90) for Body Belt Pack orders before 30.11.17 or use code BELT17 online				
	Postage & Packaging			
To include a donation please add here				
	Total enclosed			

To place your order, complete your requirements overleaf along with your contact and delivery details below.

Please remember to add on Postage and Packing charge to your order.

Cheques can be made payable to Scleroderma & Raynaud's UK.

### Don't own a cheque book?

You can also shop online at [www.srukshop.co.uk](http://www.srukshop.co.uk)

Or call one of our advisors who would be happy to take your order and credit card details over the phone on **020 3893 5998**.



<b>Name</b>	
<b>Address</b>	
<b>Postcode</b>	
<b>Telephone</b>	
<b>Email</b>	

### Include a donation with your purchase

Scleroderma & Raynaud's UK does not receive any government funding and so relies on donations and fundraising to continue our vital work. By donating today you will be helping us to continue our investment into research, support even more people affected by the condition and continue our awareness work.

I have included a donation of

£

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Adding Gift Aid doesn't cost you a penny extra but adds an extra 25p to every £1 you donate. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Increase your donation to us by 25% by adding Gift Aid to your donation

I wish to add Gift Aid to my donation.

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Order early for Christmas  
and allow up to 14 working  
days for delivery.

For more products  
and information go to  
[www.srukshop.co.uk](http://www.srukshop.co.uk)  
or call **020 3893 5998**

# Understanding & Managing Fatigue

With Catherine McCoy, an Occupational Therapy Advanced Practitioner working within the Rheumatology Service at Salford Royal NHS Foundation Trust. Due to the specialist services provided for scleroderma at Salford Royal, she has developed expertise in supporting patients to manage the symptoms of scleroderma and works closely with the multi-disciplinary team, supporting people to manage their symptoms in order that they can maintain active and enjoyable lifestyles.



We talk to Catherine about understanding and managing one of the most frustrating side-effects of living with chronic conditions...fatigue.

Fatigue is a common issue for people living with chronic conditions. A study supported by the Scleroderma Research Foundation found that over 75% of people with scleroderma, experienced fatigue, and for 61% of these, it was reported to be one of the most distressing symptoms of the condition.

## 1. What is fatigue?

Some people may describe it as 'feeling tired.' It is in fact much more than that. Everybody gets tired from time to time; for most people this is usually after a late night or being particularly busy or active.

People living with conditions such as scleroderma, rheumatoid arthritis, fibromyalgia or lupus, can experience fatigue day after day, no matter what they have been doing or how much sleep they get.

They can also feel overwhelming physical and/or mental exhaustion just from doing simple everyday tasks. The effects of fatigue can significantly impact on your experience of pain, your mood and impair quality of life.

## 3. 'Boom' and 'bust' cycles

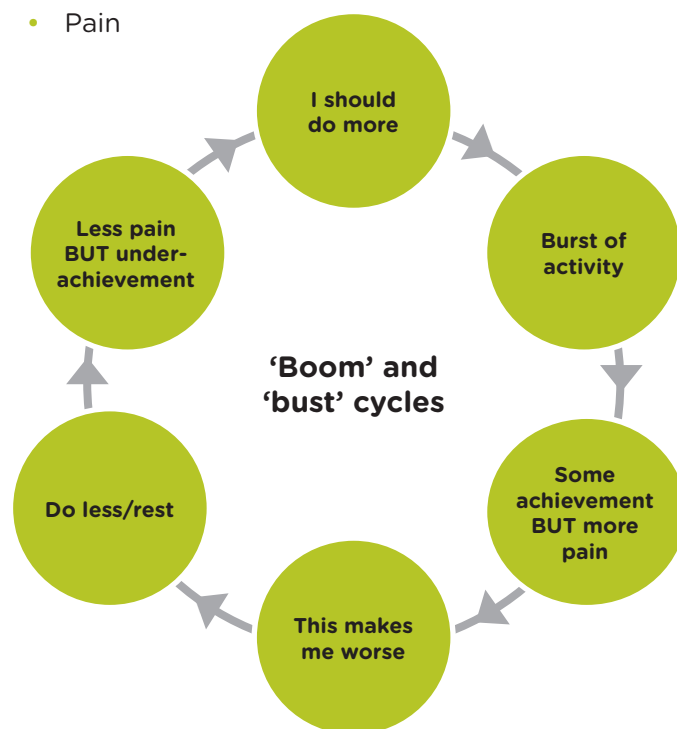
Symptoms of fatigue can vary over the course of days and weeks. Frustrations relating to the impact of scleroderma on your lifestyle can mean that on a 'good' day you may take the opportunity to do lots of tasks that you have been wanting or needing to do.

Unfortunately, the impact if this is often "doing too much" which can result in 'good' days being followed by 'bad' days. You may experience more pain and fatigue as a result of this burst of activity, and consequently are able to do less and need to rest.

## 2. What causes fatigue?

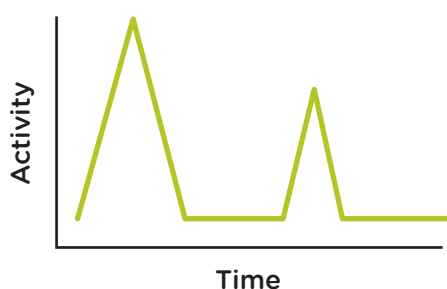
The reason fatigue is so commonly experienced is likely due to a number of factors such as;

- Physical and emotional effects of the living with your conditions
- Side effects of medication
- Weakness of muscles meaning that you use more energy to do everyday tasks that would usually be easy
- Sleep disturbance
- Pain



## 4. How can you better manage fatigue and activity levels?

Over/under activity cycling due to poor tracking

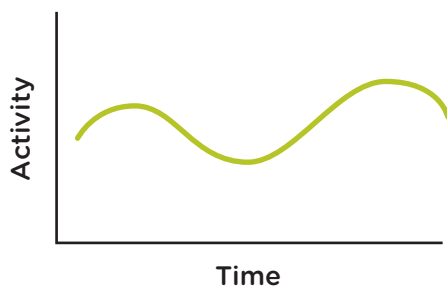


So how can you break into this cycle to better manage your activity and activity levels? Planning, prioritising and pacing activities can help you to take back control of your energy levels.

### This allows you to:

- Balance the day's activities to divide time into periods of rest and activity – not doing too much or too little. Aim to maintain an even level of activity over the day and through the course of the week
- Take regular breaks, change activities regularly and switch between light and heavier tasks where possible. Is there an easier way of doing an activity? Can you sit rather than stand, push rather than lift etc?
- Decide what is important to you and what you are happy to ask for help with/leave for somebody else to do
- On a good day stick to your plan to avoid overdoing things – don't wait for pain/fatigue before you stop
- On a bad day try to break up the activities more and take regular short breaks when needed

Leveling out activity by effective pacing



Unfortunately this is much easier said than done! To be able to incorporate this into your lifestyle takes practice and effort. When you first start trying to address this using an activity chart can help you to plan your week and also evaluate your activity and fatigue levels. Over time you will find that this becomes habit and it will take less conscious effort to plan your weeks and activities.

“I find the idea of colour coding activities really useful. On some days I say to my husband ‘I’ve had too much of a red day...I need some green time’ and he knows exactly what I mean”

## 5. Managing stress and using relaxation strategies

Fatigue levels in people with scleroderma are believed to be higher when experiencing poor quality sleep, significant pain and low mood. Managing stress and learning how to relax can help to reduce the impact of these factors.

Emotional stress causes blood vessels to narrow which can worsen symptoms and effects of Raynaud's. By identifying and managing the causes of stress you may be able to reduce the frequency and severity of Raynaud's attacks.

Like activity planning, relaxation strategies take time and practice to master. There are lots of different relaxation techniques and you often need to try a few before you find one that works well for you. While some people like to use relaxation to help them to get to sleep in an evening, it is also a good habit to build relaxation time into your day in order to help manage fatigue.

Exercise can also help people with fatigue, if fitness is improved you generally feel fitter, you'll feel an increase in well-being, strength and energy. Starting off slowly perhaps 5-10 mins a day, gradually increasing the amount of exercise or physical activity is the best way to start. Speak to your OT or physiotherapist for guidance and advice.

**Teresa Groundwater alerted us to The Spoon Theory, read about this overleaf.**

**You can find out more information about fatigue, download other useful pacing charts and read about Jane's experience in managing her condition at [www.sruk.co.uk/fatigue](http://www.sruk.co.uk/fatigue)**







































# Spoon Theory

This is a cut out and keep poster for you to allocate your energy (or spoons) to your daily tasks, it's also an easy way to get your friends and family to understand your chronic fatigue and how it affects you. Just work out your spoon level and give it a go, if it's too much, reduce your number and try again, until you feel well paced.



## How will I use my spoons today?

I have ..... spoons to use each day, therefore, I must choose wisely.

 Get out of bed 1x 	 Shower 2x 	 Attend social event 5x 	 Go out for coffee 5x 
 Drive 4x 	 Make a phone call 3x 	 Garden 5x 	 Work 5x 
 Play games 3x 	 Clean the house 5x 	 Have a meal 2x 	 Walk the dog 4x 
 Study 5x 	 Watch TV 3x 	 Ironing 5x 	 Exercise 4x 
 Shopping 4x 	 Read 2x 	 Catch public transport 4x 	 Cook 4x 

**Note:** A good guide is 20-25 spoons per day depending on your personal condition. If you exceed your daily limit, be aware that you will be taking spoons from tomorrow's allocation, so be sure to plan ahead accordingly.



# 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>		01225 428823
<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. SRUK is currently looking at our support offer to our community. We are researching what support means to you and hope to adapt our current services.

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
<b>West Midlands</b>	Jane Beach

We would be grateful if you would complete a short questionnaire online and share your views on support.

Discovering what our community needs is vital and your contribution, along with other research, will enable SRUK to develop our support services.

The survey should take ten minutes and closes on 30.11.17. The web link is: [www.surveymonkey.co.uk/r/sruk-support](http://www.surveymonkey.co.uk/r/sruk-support)

Please email [lucy.meek@sruk.co.uk](mailto:lucy.meek@sruk.co.uk) for further assistance.

# Thanks to our Fabulous Fundraisers

## Isle of Wight Challenge

The newest addition to our events calendar is a beautiful and flexible event around the glorious coast of the Isle of Wight. The event is inclusive of all fitness levels, with the quarter, half, and full island challenges ranging in length from a more relaxed day hike of 25km to the full challenge 106km.

Our first participant was Sharon Wilson, who took part in May of 2016. She took on the half island challenge and absolutely smashed it, raising £1420.56, completing the challenge, and doing it all with a big smile on her face!

Sharon herself had this to say:

“I completed the Isle of Wight half island challenge...what an event!! I met so many wonderful people, there was so much support including food and drink and the weather was glorious. The last 1.5km was walked in my socks...I lost a considerable amount of skin off my left heel but it was well worth it!!”



In May it all happens all over again and we want Team SRUK to be out in full force! Join us on the best trek in the UK and make a huge difference to people living with the conditions. Call our fundraising department on **020 3893 5993** to sign up today.

Government bodies do not fund us here at SRUK and we cannot do anything without the hard work and support of all our fundraisers and supporters.

**Ellie Bradley** received donations in lieu of gifts for her birthday this year and raised an astonishing **£2,455.00!**

Our sincerest thanks go out to **Nicolas Jewer** who competed in the beautiful Gloucester Marathon, finishing in under 4 hours while raising **£1,115.00!**

Skydiver **Sarah Everingham** raised an amazing **£675.00** with her first tandem jump!

**Graham Swift** took on the flight of a lifetime in the iconic Spitfire fighter plane and raised **£170.00** in the process!



# Team SRUK breeze through 100 miles at Ride London-Surrey 100

SRUK supporters turned out in force to cheer on our record breaking Ride 100 Cycle Team on Sunday 30th July 2017.

Our cheering point on Putney High Street offered fantastic views of one of the route's fastest points coming down Wimbledon Hill. We saw all of our riders passing the 90 mile point on their way to their finish in Central London, having left Stratford hours earlier and cycling 50 miles to the far side of the South Downs and back.

Eight riders started, and Eight riders finished, with **Andy Kinch, Jason Welch, and Peter Woodroffe** finishing first for Team SRUK in under six hours; a truly amazing time as a trio.

The rest of our team: **Helen Ould, David Seamans, Brett Van der Veen, and Charles Fielden**, all finished and have done themselves and the charity proud. It was fantastic to cheer them on as they went by and we hope the day was as enjoyable for them as it was for us.

Team SRUK has so far raised **£6,590.25**, with every penny going towards our life changing work, from supporting our helpline team to answer more calls to funding research projects to further our understanding and treatment of the conditions.

**If our amazing riders have inspired you to join them in this wonderful accomplishment, please call our events team on 020 3893 5993 to apply for the 2018 event.**

We have guaranteed places available and we can't wait to hear from you and begin building Team SRUK 2018.

Once again, our thanks go out to our fantastic riders and here's to another year of fundraising with the fantastic members of Team SRUK.



# 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)

Donate to us  
through our website  
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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.



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

[www.sruk.co.uk](http://www.sruk.co.uk)  
Helpline: 0800 311 2756  
Office: 020 3893 5998

We hope you enjoyed your edition of the SRUK magazine. If you have finished with your copy then please do pass it on to a friend or your local GP surgery. Alternatively pop it into your recycling and help us look after our planet.

 @WeAreSRUK  /WeAreSRUK

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