

SRUK NEWS

Simi Soken:
How my problem
became my
passion!



#RaiseYourHands

United to
increase awareness
of Raynaud's
this February

Doc Spot

Your questions
answered by
our medical
professional

Check out
some of our
great products
srukshop.co.uk



Event Calendar 2017

JANUARY

SRUK Information Stand, Queen Alexandra Hospital, Portsmouth

FEBRUARY

RAYNAUD'S AWARENESS MONTH

28th - Rare Disease Day

MARCH

SRUK Information Stand, RNHRD, Bath

30th - Patient Information Day, Bath

APRIL

2nd - Manchester Marathon

SRUK Information Stand, Salford Royal Hospital, Salford

24th - London Marathon

MAY

SRUK Information Stand, Ninewells Hospital, Dundee

SRUK Information Stand, Royal Hospital for Sick Children, Glasgow

28th/29th - Edinburgh Running Festival

JUNE

SCLERODERMA AWARENESS MONTH

29th - World Scleroderma Day

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

JULY

SRUK Information Stand, Great Ormond Street Hospital, London

30th - Prudential Ride London-Surrey 100

AUGUST

6th - Bear Grylls Survival Race, Cambridge

SRUK Information Stand, Aintree University Hospital, Liverpool

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

SEPTEMBER

3rd - Bear Grylls Survival Race, Edinburgh

9th - Thames Path Challenge

16th September SRUK Annual Conference, Manchester

24th - Bear Grylls Survival Race, Manchester

OCTOBER

8th - Bear Grylls Survival Race, London

22nd - Bristol and Bath Marathon

SRUK Information Stand, Chapel Allerton, Leeds

NOVEMBER

SRUK Information Stand, Freemans Hospital, Newcastle

DECEMBER

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

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

Dear Supporters

January is often a time to reflect on the past year, on what went well, what we could have done differently or better and on setting goals for the year ahead.

At SRUK we're pleased to report that the transition phase to create one organisation is now complete and we'd like to thank each and every one of you for your support during SRUK's first year of operation.

We're now looking forward and planning our work over the next 5 years. You told us that there needs to be far greater awareness of the conditions; improvements in time to diagnosis with timely and effective interventions and an increase in funding for research.

It's only by working together that we will achieve the growth needed to bring about real transformation and change. Your involvement is key to this success and in this edition of the magazine we've highlighted a number of ways where your support will make a real difference. For Raynaud's awareness month we're asking everyone to #raiseyourhand to increase visibility of both conditions. For most people with Scleroderma, Raynaud's is often one of the first symptoms, but awareness of the condition is very low. We hope that creating a greater awareness of Raynaud's will eventually aid in early diagnosis and intervention of patients with scleroderma.

Over the next five years we want to significantly increase our investment in research. Our scientists and researchers have achieved so much and continue to be at the forefront of pioneering developments. Right now, there are exciting trials taking place that may lead to better or new treatments becoming available.

We want to build on the breakthroughs of recent years and with your support continue to help our researchers find the answers we need. This year every member of the SRUK team will be taking on a fundraising challenge. We'd love to hear what you've got planned and do get in touch if you need any support with your activity.

By uniting as a community, we really can make a difference to the future of everyone affected by Scleroderma and Raynaud's.

Best wishes,
Sue



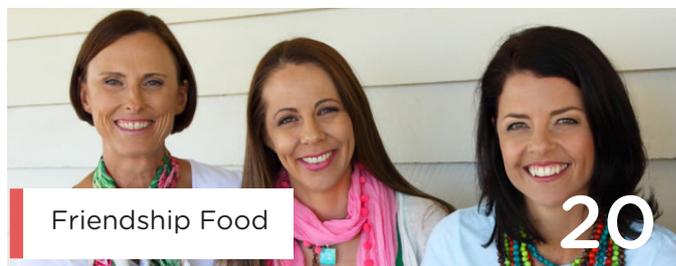
Raise Your Hands

#raiseyourhands

Raise your hands

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Doc Spot

Your questions answered by our medical professional, Prof. Denton

I have been suffering from ulcerated finger tips, well I have had one. The Rheumatologist gave me Iloprost and antibiotics which did not help. No other help offered. Got so desperate I went to seek help from a Chinese herbalist. I want to know what can be done to help heal ulcers.

Fingertip (digital) ulcers occur in scleroderma due to a number of different reasons but in most cases at least part of the cause is a poor blood supply due to blood vessel damage that occurs with scleroderma and associated Raynaud's phenomenon. Ulcers over the tip of the fingers are especially difficult and may lead to severe pain. Treatments have improved and include drugs to open up blood supply including iloprost given as a "drip" over several hours at a time, usually for 3 to 5 consecutive days. Other drugs include tablets of sildenafil and in some cases Bosentan, which is used to reduce development of digital ulcers in severe cases. Local dressing and pain killers are important and sometimes antibiotics to treat infection. Over time ulcers generally heal but this can take several months. In some cases local surgery can be used to help them to heal or to improve blood supply. Complementary treatments, such as Chinese herbal approaches, are not usually any better than conventional approaches but some patients choose to use them in addition to other medical treatment. Despite recent progress ulcers remain a big problem in scleroderma and better treatments are needed.

How common is it to have Raynaud's affecting the nipple and what treatments are available, especially for breastfeeding mothers?

Raynaud's can affect any part of the body that has a circulation that can respond to temperature change and this includes the nipples. In some patients this is a significant problem that has been helped by local application of GTN ointment that is normally used to treat cardiac pain (angina). It is not a licensed treatment but has been reported to be helpful in some cases. GTN can however cause headaches and must not be combined with certain other tablets such as sildenafil. Before considering this it is important to discuss with your doctor if it might be safe or appropriate. Otherwise the same approaches that help other Raynaud's symptoms including vasodilator tablets (e.g. nifedipine and others), maintaining warm temperature centrally with multiple thermal insulating layers and avoiding possible triggers such as caffeine or tobacco. Fortunately it is rarely an issue for breastfeeding mothers - a time when drug treatments are best avoided and topical treatments often not possible.

2 years ago I started suffering a lot from constipation and problems with bowel movement. I am treated with Rezolor and Normalax - seems to help the constipation a bit, but unfortunately, I'm "leaking" my bowel content... Not fun..I wanted to ask - is there any treatment out there for this specific bowel symptom? Or is a healthy diet the only answer for me?

Involvement of the bowel is very common in scleroderma and it is often an alternating pattern of constipation and looseness of the motion. The looser motion can be a particular challenge as in scleroderma the muscles that maintain a seal at the anus are weakened and so leakage

or soiling can occur. Often the best approach is to try and find a compromise in treatments, to experiment with changes in diet or to consider a drug like “loperamide” if the motion is too liquid. Unfortunately such approaches may worsen constipation. There are other approaches being researched to help treat leakage but these are not yet available in the clinic – one is an electrical stimulation of nerves (PTNS) at the ankle and we have been testing that in a research project in our centre in collaboration with bowel specialists at University College Hospital.

I was diagnosed with Scleroderma and Raynaud’s in 1985. Last year my husband was diagnosed with exactly the same condition. How unusual is it for a couple to have these illnesses? Could my scleroderma possibly have been transmitted?

It is remarkably rare for more than one person in the same household to have scleroderma. Although some aspects of the disease may occur in other family members, such as Raynaud’s phenomenon it is unlikely that this will lead to more severe problems in most cases. This probably reflects the fact that Raynaud’s may be a risk factor for scleroderma development in some cases and Raynaud’s often runs in families. However since husband and wife are unrelated this cannot explain co-occurrence of scleroderma. I think in this case it will remain a medical mystery and I am sure your doctors would be interested to discuss this with you. I am certain that you cannot pass on scleroderma – it is definitely not a transmissible disease.

Do you have a question that you want answered?
Send it in to us at info@sruk.co.uk or call our team on 020 3893 5998

What problems can occur in the mouth if you have scleroderma and what treatments are there to help?

Scleroderma can affect the connective tissue around the mouth in a number of ways. Sometimes the skin around the mouth becomes tight and this limits the range of opening. This is a problem for dental care and can be improved in some cases with regular stretching exercises. In later stage disease the lips can become thin and wrinkles increase around the mouth. In some cases this can be helped with surgery, including fat injections but this is a socialized approach that needs discussion with your doctors. Another common effect is on the saliva and soft tissues around the gums and teeth.

Unfortunately this makes dental disease very common in scleroderma. Treatments for this are limited to trying to optimize dental care and oral hygiene, which can be hard when mouth opening is restricted and other approaches such as artificial saliva spray.

I have just undergone my first course of Iloprost and wonder how long it takes before it kicks in?

Iloprost is a synthetic form of the natural substance prostacyclin that opens up blood vessels and improves circulation. There may be some immediate benefit from Iloprost during infusion but the maximum effect seems to occur around 6 weeks after treatment is complete. This is likely to reflect the beneficial effect on blood vessels and their lining cells (the endothelium).

Are menieres-like symptoms attributable to scleroderma and/or other connective tissue diseases...and if they are, why?

Meniere’s syndrome describes the feeling of dizziness or room spinning that results from abnormal activity in the balance sensors of the inner ear. It may be associated with ringing or buzzing sensations (tinnitus) or poor hearing. It is not a specific complication of scleroderma although it is sometimes associated with some medication that is used in scleroderma patients such as hydroxychloroquine and others. Treatments for Meniere’s symptoms include drugs to reduce dizziness and these can usually be taken in scleroderma. Occasionally scleroderma and other connective tissue diseases can cause damage to the small blood vessels in the inner ear and so this may explain Meniere’s symptoms in a small number of cases. Treatment is the same as in the much commoner variety of the disease.

A Helping Hand

Harry Mawdsley, the husband of the late Anne Mawdsley MBE, wishes to offer a selection of cutlery and kitchen gadgets, such as can and tin openers, which someone with limited hand mobility may find helpful. If you are interested or wish to know more, please contact Harry through one of the following:

Address:

Little Poole House, 17A Church Road,
Alsager, Cheshire ST7 2HB.

Telephone: 01270 875167

Email: hp.mawdsley@gmail.com



My condition was diagnosed in my mid 20s when I moved to the UK, though in hindsight, I believe I suffered Raynaud's Phenomenon mildly, when I lived in Nigeria as a child and a young adult. I remember going to fetch items out of the freezer or deep freezer, always caused me quite some discomfort and considerable pain for a while afterwards.

When I complained to my GP about my Raynaud's symptoms and Chilblains, I was advised just to keep my hands and feet covered with gloves and good, well insulated boots or shoes for the colder temperatures. This method did not work completely for me and both my hands and feet remained always, so very cold.

I went back to see my GP and she prescribed some medication – Nifedipine. I have 'near perfect' blood pressure, so I was alarmed at the prospect of taking low blood pressure medication, however I went along with it anyway and got the most horrible headaches as a side effect. I stopped taking the medication regularly and only took them on days where I knew I would suffer if I didn't take precautionary measures.

The biggest challenge was taking my two boys to their football or rugby matches on those winter mornings. Watching and cheering on for 2-3 hours at sometimes sub-zero degrees was a true test of one's love.

Grocery shopping or even being in an air conditioned room in hot countries is enough to trigger my condition. This results in embarrassing moments when I struggle to load my shopping bags or ask for the air con to be turned up or off altogether whilst my flare subsides.

I understand my condition a bit better now and see it clearly as something needing to be monitored and managed. I do not want my neglect to lead to potential amputation so I do take it very seriously. Being a brown lady, when I try to explain to a white person the symptoms exhibited when I get a Raynaud's attack, they laugh when I say 'My



How my problem became my passion!

Simi Sokan, age 47, from Surrey, tells us her story of having Raynaud's Phenomenon for over two decades and how she decided to build a business after not finding any products that worked well enough to keep her warm.

fingers go white to begin with...' at that point I can tell, straight away, they have never experienced or encountered anyone with the condition. Then, when I show them the photo of my white fingers, the shocked look I get from them, makes me laugh!

My previous job was as an IT consultant for 17 years, but more recently after not being able to find the perfect solution to keep my feet warm, I have created, designed and developed SnugToes heatable slippers. This has meant I have been a home worker for the past 7 years, so that has helped with the exposure to the cold somewhat, although I take my product literally 'out onto the streets' and do trade fairs and market stalls, sometimes outdoors or in cold draughty buildings, so that's not always very good.

I keep my hands and feet warm all the time. I find indoors is the hardest because one takes for granted that you are indoors. The slippers sometimes don't help but when they are heated, my feet are happy. After 10 months of wearing my heatable slippers, my feet appear to be in a better state of health and therefore can withstand the outdoor cold a bit better.

Unfortunately, there is not much change with the hands but I find that wearing leather gloves lined with pure wool helps outdoors. Indoors, I heat up my heat pads (gel pads) and carry them around till my hands warm up.

I am hoping Snugtoes can be instrumental in bringing an affordable and simple solution to keeping feet warm for sufferers of cold feet, particularly those with circulatory problems. It's fantastic SRUK have listed my product on their website, we did some member trials and the feedback was really heartwarming, it's nice to know they work well for other people too. I always point people in the direction of their website if they have any Raynaud's type symptoms as it's important to be well informed, no matter how mild the condition.



I often wear a pair of my Snugtoes when I'm working on a stall, people may look at me rather oddly but at least I'm advocating my very own product.

If I could share a couple of tips they would be:

- Keep your feet clean and moisturised always, ensure they are well wrapped up, even whilst in indoors.
- Stepping out of the house into the cold with already cold hands and feet is never a good idea so try to warm them up before you go.
- Never go outdoors, even to the garage, without your gloves...and get a decent leather pair lined with lamb or sheepskin wool, or self warming ones.

I'm very lucky as I have a lovely family who help me and have a better understanding, now, about my condition. Also, having Jesus in my life and knowing that life goes on, no matter what, we simply have to do the best we can, at all times.



Buy a pair of SnugToes for just £20 with code NEW17 during Raynaud's Awareness Month, February and get a pair of HeatHolders socks for free.

Simply order online at www.srukshop.co.uk or over the phone 020 3893 5998 to keep your toes extra toasty this February.

A quick guide to Mindfulness



Miss Sarah Leggett & Dr Oliver Wilkinson on the principles and practices of mindfulness.

At our annual conference Miss Sarah Leggett and Dr Oliver Wilkinson, who are both part of Professor Ariane Herrick's team at Salford Royal NHS Foundation Trust, gave an interactive session on training the mind in order to assist with pain and relaxation.

Mindfulness has Buddhist origins which have been around for thousands of years. It is an awareness and acceptance of what is here, now.

Mindfulness is a simple technique that can be learnt by anyone and practiced anywhere.

Mindfulness when done correctly, can help to:-

- Reduce stress and improve symptoms of anxiety
- Help focus, improve creativity, and self control
- Has been shown to improve relationships

Practicing mindfulness throughout the day. To receive the most out of the practice 10 to 20 minutes should be dedicated a day to mindfulness meditation. Attention experts recommend also finding opportunities to practice mindfulness throughout your day by simply focusing completely on what you're doing, slowing down, and observing all of the physical and emotional sensations you are experiencing in that moment. You can practice mindfulness when you eat as you take time to really chew your food and concentrate on flavours and texture. You can practice mindfulness when you shave; as you smell your shaving cream, note the pleasure of applying a warm lather to your face, and slowly drag the razor across your stubble.

Incorporating short sessions of mindfulness throughout your day will strengthen and expand your attention span for the times when you really need it.

Mindfulness can also help you push back against distractions as they arise. If you're working on a task and feel that restless itch to go do something else, think to yourself, "Be here now." In that moment, bring your awareness to your body and

your breath. After a few seconds of focusing on your breath, you'll notice that the distraction is no longer present and that you're ready to get back to work.

Try this technique called 'mindful breathing'

- Somewhere comfortable, close your eyes...
- Focus on your breathing...
- Let go of your thoughts, worries, or tasks...

Do not criticise your mind for wandering, simply recognise it has wandered and bring it back to focus on your breathing.

A Cheats guide... to mindfulness

After the rise and rise of adult colouring-in books to help us reach a state of 'mindfulness', the popularity of other infant-inspired therapeutic activities has even started to prop up sales of old-fashioned books with words in.

"In the last couple of months two activity books have taken off - extreme dot-to-dot and a thing called querkle, which is extreme colour by numbers," said WH Smith chief executive Stephen Clarke.

Last year it was the sale of decorative colouring books to 'Colour yourself Calm', introduce you to 'Colour Therapy' and the art of mindfulness. If you would like to be creative with mindfulness then why not try one of these books.

Tell us, does mindfulness work for you and what technique do you find most useful. Let us know at info@sruk.co.uk and we'll share via our website, social media and magazine.

#KnowRaynauds



Since launching SRUK we have been dedicated to increasing awareness and understanding of the conditions.

You told us that awareness was really important to you and so in June 2016 we conducted a survey to understand just how much the general public knew about the condition.

Raynaud's affects approximately 10 million people yet our findings revealed that awareness and understanding was severely lacking. Our key findings include:

- Over three quarters of people have never heard of Raynaud's or don't know anything about the symptoms; **just 4% of people can confidently identify the symptoms of Raynaud's, falling to 1% for Scleroderma**
- Misinformation is rife with **35% of people worried they could pass Raynaud's on**, 43% concerned about passing on Scleroderma
- Worryingly, one in five and one in four people would be afraid to touch someone with Raynaud's and Scleroderma respectively; **roughly one in five people would be embarrassed to say they had the conditions**

Despite a quarter of people surveyed saying that they had experienced one or more of the most common symptoms repeatedly, only 10% on average have visited their GP about this. Although Raynaud's is more common in women than men, they are less likely to visit their GP if experiencing symptoms.

Since June we have been working with local and national press to help everyone get to #KnowRaynauds. Increasing understanding of what the condition is, the signs and symptoms to look out for and when to see a GP for medical advice.

We have reached over 45 million people and have continued to increase awareness during the Winter months with articles in the Telegraph and Woman Magazine.

We are determined to reach everyone affected by these conditions so they have access to information and support. We are also determined to get everyone aware of the signs of symptoms of both Scleroderma and Raynaud's.

During 2017 we will be escalating our work with local and national press, radio stations and TV companies. Our first features will be in Arthritis Digest, Your Local Lincs Magazine and Bella Magazine.



By **Emma Bartley**

5 DECEMBER 2016 • 7:00AM

The cold never bothered me anyway” is a refrain I’ve become used to. Like numerous young girls the world over, my three-year-old daughter is obsessed with the Disney film Frozen, screeching the words to its title track at least once a day with the help of a singalong doll. Yet it was only on a march through our chilly Victorian house to turn off a noisy toy Elsa, its protagonist, that I realised I had something in common with the Snow Queen: like hers, my hands are often freezing, change colour in the cold and need to be kept in gloves where possible. I don’t have magical powers, though, but Raynaud’s phenomenon.

Raynaud’s is thought to affect one in six people in the UK, making it as common as arthritis or hay fever. Yet most of us have never heard of it – perhaps because it’s a relatively benign condition that can be summed up as over-sensitivity to the cold. Its key symptom is cold fingers and toes (though it can also affect the nose, ears and nipples) and the most obvious sign is when these extremities change colour, often going white due to cold or stress, then blue or purple, and finally red. Under the surface, the blood vessels supplying the area are narrowing, reducing circulation and causing discomfort; it isn’t serious but can be painful and inconvenient – and in rare cases may be a sign of an underlying condition.



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 through our campaigns, engaging events and sharing information, please contact tracey@sruk.co.uk.

Raise Your Hands for Raynaud's Awareness Month

Raynaud's Awareness Month (February) is fast approaching. Raynaud's and Scleroderma affects millions of us yet we often remain undiagnosed or left to deal with the impact alone. We're calling on everyone affected to unite and create a world where there is much greater awareness and understanding of the two conditions and their impact, a world where diagnosis happens earlier and much better treatment and care is available to everyone who is affected. Together, we can create a better world for people with Scleroderma and Raynaud's.

During February we need you to raise your hands and help increase awareness and understanding of Raynaud's and why it is important that everyone knows the signs and symptoms to look out for.

For 90% of people with scleroderma, Raynaud's was their first symptom; by making sure Raynaud's is diagnosed and managed we can improve diagnosis of related conditions.

Raise Your Hands this February and show your solidarity for people affected by Scleroderma and Raynaud's by taking part in the following activities.

Test Me

We will launch our online test to help people identify if they have any symptoms associated with Raynaud's and what to do next. Our test has been developed in collaboration with specialist clinicians to make sure it is a useful tool to aid diagnosis.

Our test will also support those identified with potential Raynaud's to check for changes in their symptoms as 1 in 10 people with Raynaud's go on to develop an autoimmune condition, like scleroderma. The sooner any changes are identified the quicker underlying conditions can be diagnosed and the sooner treatment can begin.

If you have friends or family that are showing signs of Raynaud's, encourage them to head to www.sruk.co.uk during February to take the test.

Specialist Web Talks

On Tuesday 31st January we will be launching our web chat series. On the last Tuesday of each month we will be joined by a specialist to talk about a particular medical topic.

Our first web chat will be with Tonia Moore, Chief Vascular Technician from Salford Royal who will be discussing "The difference between primary and secondary Raynaud's".

You can join this session on our website: www.sruk.co.uk/raiseyourhands on Tuesday 31st Jan. The chat will be followed by a live Q+A session on Twitter. If you have a question for Tonia you can submit this through our website ahead of the day.



Share your story

We will be sharing your stories during February. We have received interest from local and national press and are working with you to let readers know what life is like living with Raynaud's. Thank you to everyone who has shared their story so far and if you are interested in sharing your story with us and helping to increase understanding in your local area and across the UK then please do get in touch with us today. Contact us at info@sruk.co.uk or 020 3893 5998.

Cosy up with a Coffee

Get your friends, family or co-workers to unite for Raynaud's by organising a coffee morning. Cosy up with some cake and a coffee, and raise money to improve early diagnosis. You could have a baking session or encourage guests to bring along some cake, and charge by the slice and the cup!

With enough involvement from you we will make a huge difference for those with Raynaud's this Raynaud's Awareness Month!

Call 020 3893 5993 to receive your free 'Cosy up with a Coffee' fundraising pack or register online at www.sruk.co.uk/raiseyourhands.



Put up a poster

Along with your magazine you will find posters and flyers, please do consider displaying these in your local community to support people with Raynaud's, increase awareness and highlight the symptoms to look out for. We have made some suggestions on where you may be able to put these up to help everyone get to know Raynaud's.

Free Product with every purchase

Our suppliers always support our efforts during Raynaud's Awareness Month and this year Heat Holders are supporting us by giving away a FREE pair of Socks with every purchase from www.srukshop.co.uk throughout February. So go online during February, order your favourite Winter Warmers and receive your free gift today.



Raise Your Hands

We want you to raise your hands and show your support for Raynaud's Awareness Month on social media.

We want you to write, snap or film your experiences with Raynaud's. It may be about how the condition affects you or a short film showing you trying to complete a task i.e. undoing a button with your fingers.



WRITE IT SNAP IT FILM IT

#RaiseYourHands

f /WeAreSRUK /WeAreSRUK

We want to make everyone aware of how Raynaud's impact every day life by writing it, snapping it, filming it and sharing on social media with the hashtag #raiseyourhands

Download our social media kit from the Raise your hands webpage today and get involved this February: www.sruk.co.uk/raiseyourhands

Heat Saving Measures

Fiona Lyons, looks at ways to cut expenditure during months where we are time rich and financially poor after the outlay of Christmas. Plus a few simple measures we can take to cut existing costs, around the home.



Insulation - Insulating walls and lofts helps cut the costs of heating bills. Some energy companies offer free installation - check with them and see if you're eligible. Even if not, do consider insulating your home. It might be an expensive outlay, but in the long term it could save you £1,000s.

Draught-proofing - a sure-fire way to keep you warm for less. Excluders stop heat escaping in gaps between the door and the floor. The worst culprits are gaps under doors and windows that don't shut properly. For the doors, buy draft excluder strips from your local DIY store or if you're keen to save a few extra pennies and are feeling creative, you could make your own by using an old pair of woolly tights stuffed with some old socks or other stuffing materials, even just a rolled up towel plugging the gap will do the job.

For windows, get some cheap self-adhesive foam strips to plug any gaps in the surrounds. Plus, don't forget drafts from the keyhole and letterbox. Finally, while covering windows with cling film might sound a bit strange, it can work towards eliminating heat loss. This additional temporary layer traps air which helps stop heat escaping through the glass. It can then be removed as the weather starts to get warmer. In the longer term, it could be worth saving up for new double glazing which will last for years.

Window dressing - while it might feel cold, the sun may still be shining. Keep your windows uncovered during sunny spells so that the heat can make its way into your home. Just remember to close your curtains again once it starts getting dark. You could also consider investing in thermal lining for the curtains in the rooms you use the most. This alone can reduce heat loss by up to 25%.

Turn down your thermostat - The Energy Saving Trust affirms that reducing your heating by even one degree can help you save up to 10% on energy bills. You can compensate for this extra degree by wrapping up.

Wear layers - layering is important as thermal insulation is created between layers of clothing, so it makes more sense to wear many layers of clothing,

rather than just one thick layer. Remember to wear slippers or thick socks as well and you should stay nice and toasty.

Other things to have on hand are a hot water bottle and a hot drink. With all these things keeping you warm and cosy, you'll be less likely to feel the drop in degrees.

Block up unused fireplaces - heat from within a room literally escapes into the outdoors through open fireplaces- you can have your chimney capped but this could easily set you back a couple of hundred pounds. Another option is to install a chimney balloon. You can pick these up for less than £30 and the saving on heating costs could be substantial.

Leave the oven door open after cooking - this is an easy way to get an extra blast of warmth into your kitchen without reaching for the heating controls: after your food is ready and the oven is switched off, leave the door open so the excess heat can circulate round the room.

Reposition your sofa - if your sofa or any furniture is positioned in front of a radiator, heat is prevented from circulating out into the whole room fully. As the days and weeks become colder, rearrange your furniture away from radiators so when the heating comes on you feel the full effect. In the same way, positioning shelves above radiators helps to direct the heat most efficiently.

Closing doors - keeping doors closed when you're in a room makes sure that heat remains within the designated space.

Fill in gaps - there may be various gaps in your walls that are letting cold air in, around pipes and electrical sockets, for example. While these may have been filled in at the time of installation, the materials may have worn away. It's vital to check for holes around your home and give them some TLC by sealing them.

Scleroderma Clinical Services & Research in Bath



Dr John D Pauling, BMedSci, FRCP(Rheum), PhD, Senior Lecturer & Consultant Rheumatologist, Royal National Hospital for Rheumatic Diseases (part of the Royal United Hospitals NHS Foundation Trust), Upper Borough Walls, Bath, BA1 1RL; Department of Pharmacy and Pharmacology, University of Bath, Claverton Down Rd, Bath, BA2 7AY

Scleroderma clinical services at the Royal National Hospital for Rheumatic Diseases

The Royal National Hospital for Rheumatic Diseases (RNHRD) Connective Tissue Disease (CTD) service is led by Professor McHugh, Dr Ellie Korendowych and Dr John Pauling. Dr John Pauling leads the Raynaud's phenomenon (RP) and systemic sclerosis (SSc) clinic within the Bath Connective Tissue Disease service. The service currently manages the care of approximately 250 patients with systemic sclerosis. Dr John Pauling runs dedicated regional clinics alongside Dr Jay Suntharalingam, Dr Rob Mackenzie Ross and Dr Noeleen Foley for patients with scleroderma-related pulmonary arterial hypertension and interstitial lung disease. The scleroderma clinical service is also supported by Ms Sarah Smith (Scleroderma Clinical Nurse Specialist) and Ms Andrea Dowden (Scleroderma Research Nurse) who provide clinical support to patients and help them to participate in scleroderma research. The Raynaud's and Scleroderma service also works closely with Dr Darren Hart (Clinical Scientist) and Dr Jacqueline Shipley (Clinical Scientist) within our clinical measurement service who provide microvascular imaging support to both the clinical and research programmes.

We routinely undertake microvascular imaging as part of our clinical assessment of Raynaud's symptoms. These studies include nailfold capillaroscopy and thermal imaging which help clinicians to accurately diagnose Raynaud's phenomenon and systemic sclerosis. Our scleroderma clinical service is also supported by Juliet Dunphy (Immunology Laboratory, Royal United Hospitals, Bath), Ms Hui Lu and Dr Zoe Betteridge (University of Bath) who identify autoantibodies that help clinicians confirm a diagnosis of systemic sclerosis and predict the

likely disease course (more of which later). Earlier this year, we celebrated the retirement of our good friend and colleague Ms Sue Brown from our CTD service. Sue worked at the RNHRD for over 20 years, during which time she became the UK's first consultant nurse specialist in CTD, offering care and support to many hundreds of patients and families affected. Sue also led the British Healthcare Professional in Rheumatology CTD Special Interest Group. Sue had a specific interest in scleroderma. She has published research articles in this area and worked closely with (and was supported by) the Raynaud's & Scleroderma Association (now SRUK) for many years. She was an irreplaceable member of our team and all of her colleagues and patients wish her a very happy retirement after so many years dedicated service.

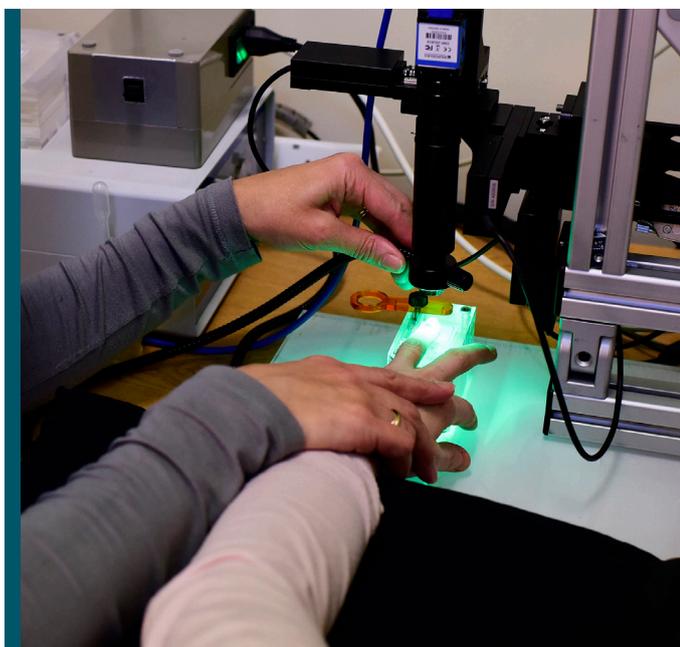
Scleroderma research in Bath

We have a longstanding research interest in scleroderma. Over the course of the last year, we have been recruiting patients to 2 interventional trials in systemic sclerosis and supported multicentre research studies undertaken by members of the UK Scleroderma Study Group (UK SSG).

We also have a range of scleroderma projects that we are currently leading in Bath (in conjunction with the University of Bath), many of which have only been possible due to the support of SRUK.

Investigating the links between poor blood supply and scar tissue formation in systemic sclerosis

Investigating the links between poor blood supply and scar tissue formation in systemic sclerosis
The Raynaud's & Scleroderma Association



We are collecting skin biopsy samples and growing scar tissue forming cells (fibroblasts) under experimental conditions to see how a reduced supply of oxygen and nutrients might influence their behaviour and their tendency to create new scar tissue. It is hoped this work will allow us to better understand the causes of systemic sclerosis and identify potential new treatment approaches.

Scleroderma Autoantibody Research

Antibodies are small proteins that circulate in the bloodstream and help us fight off infections. Many patients with autoimmune CTDs, such as systemic sclerosis, develop autoantibodies directed against 'self' proteins. Professor Neil McHugh's laboratory group, based at the University of Bath, has been screening blood samples from various UK scleroderma patients for the presence of known autoantibodies. Using these lab results with the clinical data collected from these research studies, we have been able to confirm that each autoantibody type helps defines a specific subgroup of patients, helping identify patients who are at a greater risk of particular additional disease complications.

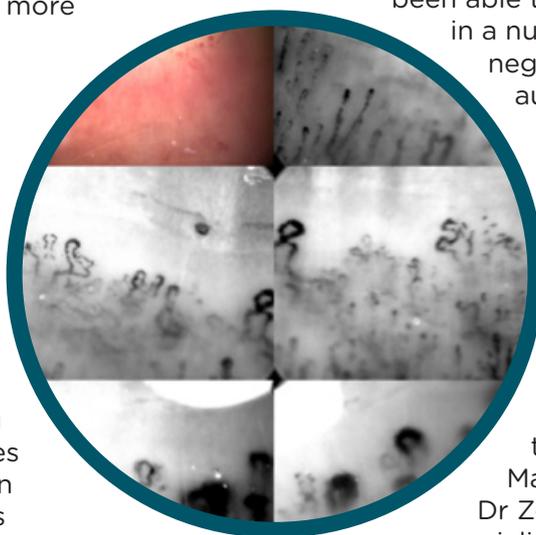
However, whilst our autoantibody screen found the majority of scleroderma patients to have a known autoantibody, a minority of patients were autoantibody negative by conventional testing methods. Through additional research and the development of novel screening methods, we have been able to identify a novel autoantibody in a number of these 'autoantibody negative' patients. This new autoantibody, anti-EIF2B, is more commonly found in patients with diffuse skin involvement and interstitial lung disease.

The Scleroderma Society (nowSRUK) has funded a project studying the presence of autoantibodies in a large cohort of patients with systemic sclerosis from the United States (led by Maureen Mayes). Ms Hui Lu and Dr Zoe Betteridge have undertaken specialist studies on these samples (such as protein immunoprecipitation) to identify rare scleroderma autoantibodies such as anti-EIF2B and other novel autoantibodies. Dr John Pauling presented the preliminary results of this work at the American College of Rheumatology annual conference in Washington in November 2016.

funded a 3-year research fellowship for Dr Victoria Flower under the supervision of Dr John Pauling. Vicky is investigating possible links between blood vessel abnormalities, inflammation and scar tissue formation (fibrosis) in systemic sclerosis. We are investigating the theory that poor blood flow may cause fibrosis and we are focusing specifically on changes in skin.

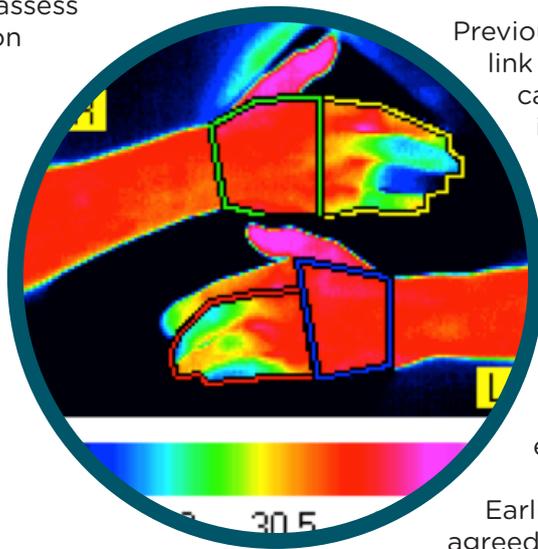
If blood flow is reduced, then our cells trigger a safety mechanism to try and increase blood flow again and minimize damage. Skin cells respond by producing a number of proteins (such as Hypoxia Inducible Factor [HIF] and Vascular Endothelial Growth Factor [VEGF]), which encourage new blood vessels to grow and carry more oxygen to the tissues. We are investigating the possibility that when the body is unable to maintain a sufficient flow of oxygen and other nutrients to the skin, this leads to the formation of scar tissue. This could identify an important driver of the characteristic skin thickening associated with systemic sclerosis.

Vicky's research is incorporating a number of specialist techniques for assessing blood flow and skin thickening in the skin of patients with systemic sclerosis. One method being used is High Frequency Ultrasound [HFUS] techniques to compare skin and blood vessel changes between people with and without Systemic sclerosis. We are then comparing this to levels of different proteins in the skin and blood to see if and how these change as the disease progresses.



Raynaud's Research

Virtually all patients with systemic sclerosis experience Raynaud's phenomenon, and it can be a difficult area to assess and monitor as the condition develops. Dr John Pauling co-chairs an international Scleroderma Clinical Trials Consortium (SCTC) Vascular Working Group, which aims to develop better methods for assessing and managing vascular problems such as Raynaud's in systemic sclerosis. The SCTC has recently funded research in Bath to explore patients' experience of Raynaud's phenomenon in systemic sclerosis. We are currently undertaking a detailed questionnaire-based study of >100 patients with systemic sclerosis to better understand the character of Raynaud's symptoms experienced by people with systemic sclerosis. This work is being supported by Dr Tracy Frech who runs a large scleroderma programme in Utah in the USA. One of our registrars (Liz Reilly) shall be taking some time out of her specialty training to help with the analysis of this study. We are also running patient focus groups in Bath, Pittsburgh (Dr Robyn Domsic) and New Orleans (Dr Lesley Ann Saketoo) to further explore the patient experience of Raynaud's in scleroderma. The analysis of this work is being supported by Professor Sarah Hewlett's qualitative research team in Bristol. It is hoped this work will lead to new methods for assessing Raynaud's symptoms that could be used in clinical trials and observational studies to support new treatment options for Raynaud's phenomenon in systemic sclerosis.



Investigating the association between systemic sclerosis and cancer

Previous research suggests there is a link between systemic sclerosis and cancer. This has obvious important implications for the way we evaluate and manage our patients but might also be telling us something valuable about the causes of systemic sclerosis. We need to better understand which cancers occur in systemic sclerosis and when they occur in the disease course. Understanding this might facilitate earlier detection or even prevention.

Earlier this year, the newly formed SRUK agreed to part-fund a large epidemiological study investigating the association between systemic sclerosis and cancer using the Clinical Practice Research Datalink which contains medical information from >10 million UK residents. The study has also obtained funding from the Bath Institute for Rheumatic Diseases (BIRD). The study shall be undertaken by Alison Nightingale, Anita McGrogan, John Pauling and other members of Professor McHugh's pharmacoepidemiology research team at the University of Bath. Work is expected to start soon and will allow us to report up to date figures on the frequency of systemic sclerosis in the UK (it is thought our current estimates are probably too low) and better understand the links between cancer and systemic sclerosis.

We look forward to updating you on the progress of this work and the other scleroderma research studies described above in future editions of SRUK news.

Scleroderma Education in Bath

We are very passionate about patient education at the Royal National Hospital for Rheumatic Diseases. **We are holding our next patient education event for scleroderma on Thursday 30th March 2017 from 1-5pm.** The event will be held at the Royal National Hospital for Rheumatic Diseases in the centre of Bath and is free to patients and their families from anywhere in the UK. Space is limited to 60 delegates and we would encourage you to register for the event on the SRUK website or via the Bath Institute for Rheumatic Diseases (01225 336363) or via email (BIRD@birdbath.org.uk) so that we can make adequate plans for catering. We look forward to welcoming Sue and other members of the SRUK team at the event and hope to see you there!

Q&A with Professor Magalon



We speak with Prof. Magalon about a new treatment for hand dysfunction using the patient's own cells to reverse the effects of fibrosis. This research is still in the clinical trial stage and it could be a few years before it is available to people affected by hand dysfunction but this research showcases innovations in the treatment of scleroderma and Raynaud's.

What are you looking into with your research?

Hand involvement is common in systemic sclerosis (SSc). Hand involvement can be extremely debilitating for conducting work and daily activities.

To date, clinical care for the hand relies on vasodilators, protection against cold and trauma, and regular physiotherapy. No anti-fibrotic therapy has proven effective and immunosuppressive drugs have only limited effects on the articular symptoms of the hands.

For over a decade, fat grafting has been commonly used in plastic surgery to reconstruct soft tissue defects caused by ageing, trauma, chronic wounds and the filling of loss of substance. The regenerative properties of adipose tissue (used for the storage of fat) appeared to us promising in the treatment of the hands of SSc patients.

We aimed to assess the safety and efficacy of adipose-derived stromal vascular fraction (ADSVF) in SSc patients with hand disability. The SCLERADEC I trial was a 12 patient, single arm, open label study led by Drs. Brigitte Granel (internal medicine) and Guy Magalon (plastic surgeon) under Prof Florence Sabatier of the Cell Therapy Department Marseille Hospital Center and University.

What is the process that you are using to treat hand dysfunction?

We use the autologous (that means the patient's own cells) adipose-derived stromal vascular fraction (ADSVF) to improve hand disorder in SSc. The SVF is composed of a range of cells that has been reported to possess

multiple angiogenic (new blood vessels form from pre-existing vessels), anti-inflammatory, immune modifying and regenerative properties.

Several studies have been carried out to assess the therapeutic role of these cells in SSc patients. In addition to the SCLERADEC 1 pilot trial, two randomised double blind, placebo-controlled (inactive medicine) clinical trials with this form of ADSVF are ongoing: Scleroderma Treatment with Celution Processed Adipose-Derived Regenerative Cells (STAR) in the USA and SCLERADEC 2 in France. This innovative cell therapy is therefore not currently available to SSc patients unless they are registered in a clinical trial.

Briefly, the adipose tissue collected and SVF are injected into the fingers during day surgery. To collect the tissue, liposuction of the fat (abdomen, hips, or internal side of the thighs) is performed. It takes less than 2 hours to then obtain the ADSVF before the cells are injected into the hands on each side of the finger above the fist knuckle. Both hands are treated over a period of approximately 20 min.

How is this currently helping people affected by scleroderma?

Our first pilot clinical trial outlined the safety and feasibility of the autologous SVF cells injected into the hands of patients with SSc. Preliminary assessments at 6 months suggested potential efficacy that needed to be confirmed in a randomized placebo-controlled trial on a larger population. The enrolled patients have been followed and multiple patient-reported outcomes showed sustained improvement even 2 years after the surgical procedure. A decrease in the number of digital ulcers was noted. Mobility, strength and fibrosis of the hand also have shown improvement.

Have you encountered any difficulties with your research?

The French Drug Agency has classified ADSVF as an Advanced Therapy Medicinal Product, which means that the production and validation of this therapy needs to meet the good manufacturing practice levels normally required for pharmaceutical industry. This level is extremely difficult to reach for university hospitals and authorisation to conduct clinical trials take several months or several years.

When do you expect your research to be concluded and what are your hopes for this treatment?

As previously mentioned, two randomized double blind, placebo-controlled clinical trials using ADSVF in SSc patients are ongoing: STAR in the USA and SCLERADEC 2 in France. The results from both trials should be obtained in 2017.

What can we expect to see from research over the next 5 years?

First, we hope this innovative cell therapy for SSc patients will be rapidly applied in clinical practice if both clinical trials demonstrate that ADSVF cell-based therapy is beneficial in the treatment of hand dysfunction. This will offer a new treatment for patients.

In the future we could see a cryopreserved dose of ADSVF, which would allow repeat ADSVF injection. An approach for the systemic delivery of ADSVF to treat pulmonary problems in SSc patients may also be developed.

Innovative treatment for facial fibrosis

Professor Peter Butler has been using the technique of injecting the patient's own cells to treat fibrosis in facial tissues for over 10 years with exciting results.

Tightening of the tissues of the face and mouth secondary to fibrosis is a prominent feature of scleroderma. Facial fibrosis greatly impacts the quality of life of patients and most often leads to problems with eating, speaking and dental care. Professor Peter Butler, Professor of Plastic and Reconstructive Surgery at the Royal Free Hospital London, has been treating scleroderma patients at the Royal Free for over 10 years with some very exciting results.

Professor Butler is pioneering an innovative new treatment option to treat fibrosis of the face and other tissues. The technique is known as autologous lipotransfer and utilises the patient's own cells to reconstruct facial tissue and reverse the effects of fibrosis and internal scarring.

The procedure is minimally invasive and is performed as a day surgery. The patient's own fat tissue is collected and by processing is enriched with the patient's stem cells. The resulting tissue mixture is then carefully microinjected into the affected facial and mouth tissues. Over 100 patients have undergone treatment by Prof Butler with this technique, and the results are remarkable, with improvement in mouth opening and softening of facial tissues. Facial volume is enhanced, but most strikingly the effects of facial fibrosis are reversed. This has had profound effects on the patient's quality of life and has restored facial mobility and mouth function.

This treatment has allowed severely affected patients to receive proper dental care again and has noticeably improved their sense of wellbeing and outlook. The other exciting thing to emerge from this research work is that to date there is no effective disease modifying treatment option for scleroderma and no available treatment to reverse the effects of fibrosis. This technique has the potential to be enhanced to find a new treatment for scleroderma systemically.

Autologous stem-cell enriched lipotransfer offers an exciting new treatment option for facial SSc and other forms of fibrosis. Professor Butler, director of the newly formed Charles Wolfson Centre of Reconstructive Surgery in collaboration with Professor Chris Denton and Professor David Abrahams of the Centre of Rheumatology at the Royal Free Hospital are conducting this research work.

Lynn shares with us her story and how life has changed since receiving treatment. Lynn was one of Prof Butler's first patients 10 years ago. She has systemic scleroderma and when diagnosed was a part time model. For Lynn this made her extremely aware of her facial changes.

"The skin on my face was mask like, tight and shiny, my mouth opening very limited and my dentist struggled to access my back teeth. After my first autologous lipotransfer I noticed a significant difference, my skin became softer and more pliable. Now after three treatments, I can eat real food now as chewing and mouth opening has improved. My skin is no longer shiny and the mask like appearance has gone. I feel so much more confident in my own skin."

Lynn is working with Prof. Butler to access funding for a clinical trial into this innovative treatment and is interested to hear from anyone who has undergone the treatment. Call us on 020 3893 5998.

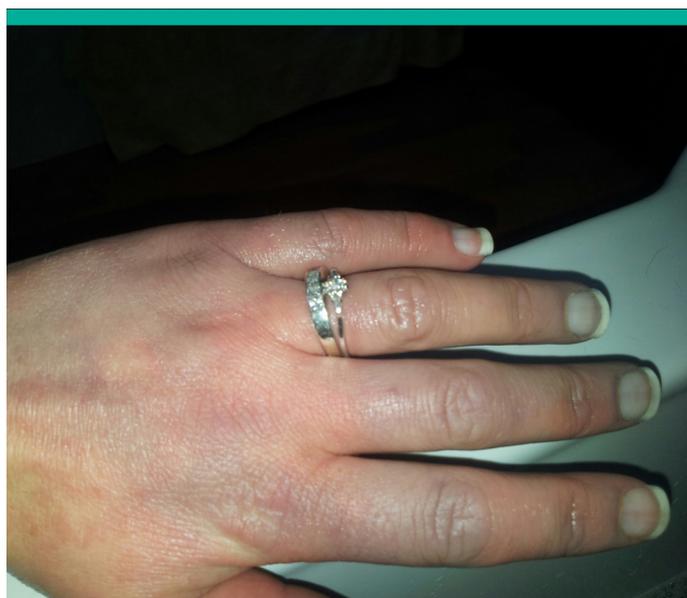
On Love, Laughter and Singing the Blues



Sian Morgan, 53, from Swansea, shares her journey of discovery. Read how an early Raynaud's diagnosis (and a late one of scleroderma) stopped her in her tracks, and how she remains focused on new challenges, her old love of music and a re-kindled love leading to her planning her wedding!

Looking back, I first developed symptoms of Systemic Sclerosis, Rheumatoid arthritis (RA) and Raynaud's Disease in the late 70s- noticeably at school and then whilst on holiday in France with my family.

I had noticed my fingers became swollen and tender, often turning white then blue, especially when swimming in the sea, and had aches & pains in all my joints and generally felt really unwell. I was obviously quite scared and worried and can remember coming home from school sitting close to a radiator for warmth wrapping my aching wrists in bandages.



The situation got steadily worse and I became severely ill with a form of Glandular fever and was admitted into a local hospital where doctors suggested I had Juvenile Rheumatoid Arthritis.

They recommended that I went to a London hospital, Northwick Park, as a diagnosis was difficult to make due to the complexity of all symptoms. At London they decided I had 'Mixed Connective Tissue Disorder' and that I didn't have any type of arthritis. I was placed on high dosages of steroids, which unfortunately helped created many negative side-effects such as 'moon face' appearance, thinning of skin, awful bruising and more. This, however, turned out to be the wrong diagnosis as in 1991 at the Royal Free and at the Royal Brompton they said I had Diffuse Scleroderma, R.A. and Raynaud's with, possibly, Pulmonary hypertension. This meant that I had been misdiagnosed for a full decade!

Dame Prof Carol Black, at the Royal Free, also discovered that I had heart and lung involvement and I was put on quite a strong drug to help stabilise me. It was a scary, difficult time but at least I had been properly diagnosed and felt I was being listened to as medical staff had been unable to help at my local hospital. My doctor stated that I'd almost 'hadn't pulled through' on a couple of occasions due to infections and complications. Looking back, my family and I were rather naïve and terrified at the time as well as very much in shock. Who can ever possibly prepare you for such events?

Although trying to keep positive and upbeat throughout my life, it has been difficult living with diffuse Scleroderma, alongside the other two diseases, as disease-modifying drugs etc were unavailable and hence I have suffered a lot of disfigurement as a result, plus bi-lateral hip replacements and further surgery to come. Emotionally it is very demanding as I've had to cope with many situations you could never

envisage which test one's social and survival skills to the limit.

Sadly, I haven't been able to have my own career, therefore often felt I had been unable to 'follow my dream'. Although this has always been a great loss in my life, I took a degree in Sociology & Psychology and have still done a lot of voluntary work for different organisations. Alongside that, I organised the only RA Support group in Swansea in the 90s, and have resumed singing in choirs and different bands as music and singing was, and still is, a major passion and love of mine. My Blues band raised funds for the association last year at a charity gig and we're hoping to do another gig this year. I also love to write short stories and poetry, and record any tunes or chords that come into my head.

"Laughter really is the best medicine..."

I think that it is important for anyone with these life-challenging, chronic diseases to find something you love to do and stick with it as best you can, as participating in something satisfying and fulfilling brings so much pleasure and happiness it distracts and takes your mind off all the pain and problems in your life.

Having a caring, supportive network of family and friends is a massive plus and I was very blessed that I was able to have my son Xande, who is now 20. I usually call him and have a moan or we go out for lunch and he teases me...laughter definitely is the best medicine! I also met, a few years ago, someone I knew as a teenager and next year he will be my husband, he must have been heaven sent!

"I have been engaged with the charity for a number of years now and wanted to volunteer for the Helpline as I realise I have quite a few crossover symptoms and may be able to assist after having first hand experience at the challenges.

Also if anyone over here in the Swansea area would like to meet for a chat and a coffee please get in touch with the charity.

I appreciate meeting people in a similar position to my own so that we can swap tips and stories as well as reassure and support each other in ways which people who don't have the illness can't. It's Important we grow our support network for future generations."

At SRUK we have volunteers across the country providing support on a local level by organising support group meetings or by being available via the phone or email. Our current local support contacts are:

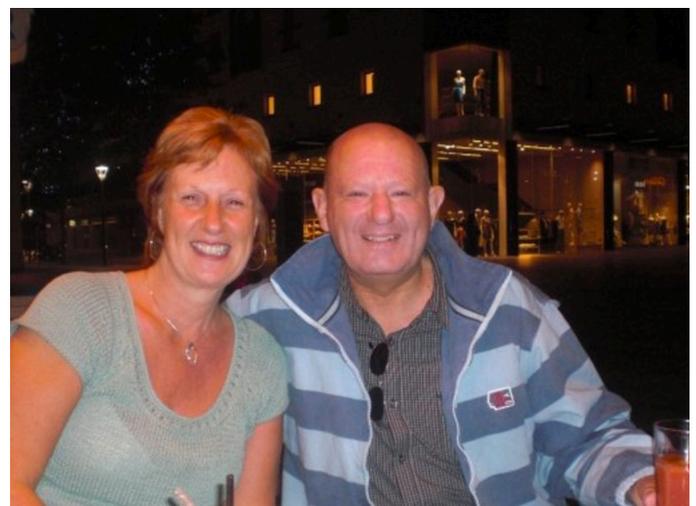
- | | |
|----------------------------|-------------------|
| Bedfordshire | Rita Boulton |
| Burton | Helen Nutland |
| Exeter | Mike Corbett |
| Hampshire | Tracey James |
| Merseyside | Diane Unsworth |
| Newcastle & Northumberland | Lindsay Wilkinson |
| Norfolk | Lucy Reeve |
| South London | Celia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

Share your story in our next issue

We would like to thank everyone who shares their story with us. Not only does it raise vital awareness of the conditions but it also provides support to those affected, letting them know that they are not alone.

We are all here to support one another and show that these conditions do not hold us back.

If you would like to share your story with the community or would like to help us increase awareness by working with our press contacts then please get in touch with us today. You can call or email Tracey on 020 3893 5998 or tracey.spray@sruk.co.uk



Michael shared his story with us for our June campaign

Helpline



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

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

Volunteers man our helpline: Belinda, Helena, Kim, Penny, Paula, Rosemary and Amelia who have many years of experience and training. Our volunteers update their skills regularly and having

external accreditation as members 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.

0800 311 2756

Specialist Nurses

Scleroderma specialist nurses, provide specialist clinical advice and support to people with scleroderma. They are usually the main point of contact for a person with scleroderma and they often act to co-ordinate services, referring someone on to a doctor, or a therapist, or other appropriate services.

Specialist Nurses also provide support and advice over the phone. If you have a medical query and would like to receive support please use the list below to find your local nurse.

Bath - Sarah Smith
0122 547 3458

Belfast - Audrey Hamilton
0289 056 1310

Leeds - Specialist Nurse Team
0113 392 4444

Liverpool - Jan Lamb & Jenny Fletcher
0151 529 3034

Manchester - Specialist Nurse Team
0161 206 0192

Newcastle Upon Tyne - Karen Walker
0191 223 1503

Portsmouth - Paula White & Julie Ingall
0239 228 6935

Royal Brompton - Lucy Pigram
020 7352 8121 ext 7112

Royal Free, London - Sally Reddecliffe & Adele Gallimore (For Pulmonary Hypertension Enquiries)
020 7472 6354

Royal Free, London - Specialist Nurse Team
020 7830 2326

Sheffield - Specialist Nurse Team
0114 271 3086

Friendship Food

Felicity was diagnosed with scleroderma in 2001 and wanted to explore natural remedies that led her on a culinary journey.

At the age of 29, I started to become sick. My skin became tight, my mouth was always dry and I was tired. Small things got me down, my psoriasis was red and raging, I had intestinal issues and heart-burn. My puffy fingers and feet were sore and stiff and I experienced shooting, throbbing pains up my arms. I felt sick when I got cold and calcium deposits started to develop under my skin. I was diagnosed with Scleroderma then Raynauds, followed by Oesophageal complications.

Luckily we were able to have four beautiful, healthy babies. During pregnancy I felt amazingly healthy but when our third baby was one, some of my old symptoms flared up again. I knew that there were drugs I could take to ease the severity of my symptoms but I thought I'd like to try something more natural before taking medication. I found a natural healer who told me to take myself off gluten, dairy, eggs, yeast, refined sugar, alcohol and caffeine, for 3 months then reintroduce each food type independently back into my diet to see if it triggered my symptoms.

This was no small feat for me as I love food. But after two weeks on the diet I felt amazing. I started bouncing out of bed with vibrant energy and my aches and pains simmered down. But the most amazing thing was how unbelievably positive I felt. I had a very clear purpose in life and that was to be the best person I could be.

The idea came for the recipe book shortly after starting the elimination diet - because there wasn't one on the market that could help me. I started tweaking and creating recipes so that I could eat the food during the three month diet. Then I thought I should put these recipes together into a book to help other people to feel good.

After the birth of our fourth baby my good friends Kate and Julie joined me to help finish the book. Together we created 'Friendship Food-Delicious Feelgood Food' and we started our Company. Our aim was and still is to help others find simple, achievable, affordable health options to help nourish the mind, body and spirit and to enable people to live a happy, healthy and productive life.

Since launching our book in May 2014, the response has been so humbling and overwhelming. So many people have joined the Friendship Food journey with us. We love feedback and helping people feel good. For more information about our recipes please go to www.friendshipfood.com.au.



Friendship Food Red Sauce

This has become an instant favourite with our families - a tomato sauce with no tomatoes! It's also ideal for anyone with arthritic symptoms or a nightshade sensitivity.

200 g onion, chopped
300 g zucchini, chopped
30 ml extra virgin olive oil
2 tsp salt
1 tsp cracked black pepper
15 g fresh garlic, chopped
10 g fresh turmeric, grated
Sauté the above ingredients in a large heavy based casserole dish (with a lid) until soft, then add:
400 g kent pumpkin, peeled and chopped
350 g beetroot, peeled and grated
2.5 cups water
1 cup coconut sugar
1 cup apple cider vinegar
Half tsp each of fresh thyme, oregano and basil, chopped

Bring all ingredients to the boil and mix. Reduce the heat and simmer with the lid on until the vegetables are soft. With a stick mixer or food processor, blitz until smooth. Seal well and store in the fridge or freeze in manageable amounts.

Lupus

In the last edition of SRUK Magazine we featured an article on erythromelalgia after a few requests for information on other conditions those with Scleroderma or Raynaud's might experience.

This time we share information about lupus, as around 20% of people with scleroderma, also have lupus as a cross over condition. If you have a particular condition you would like to understand more about, please get in touch with info@sruk.co.uk and share your thoughts as it's Your Magazine, Your Way.



Systemic Lupus Erythematosus (SLE), is an autoimmune condition, which causes inflammation and damage to the joints, muscles and other organs.

There are two other forms of the condition: Discoid lupus (DLE), is usually a condition of the skin alone although some patients may develop systemic lupus.

Drug-induced lupus (DILE), which can occur during the administration of certain drugs in susceptible individuals such as Hydralazine, Phenytoin and anti-TNF drugs. (In most cases, after treatment is stopped the symptoms of drug-induced lupus will be alleviated).

Symptoms of Systemic Lupus

While there are lots of different possible symptoms of lupus, the two most common symptoms are joint/ muscle aches and pains and extreme fatigue and weakness, although it is worth stressing, no two patients present with the same symptoms and they can vary in severity.

Other common signs include:

- Joint/ muscle aches and pains
- Extreme fatigue and weakness
- Butterfly rash over cheeks
- Kidney problems
- Oral/ nasal ulcers
- Hair loss
- Rashes from sunlight/ UV light
- Flue-like symptoms and/ or night sweats
- Raynaud's
- Seizures, mental illness or other cerebral problems
- Headaches, migraines

Who gets lupus?

Lupus is most prevalent in women (who are diagnosed nine times more often than men), and often occurs during the childbearing years. It can also occur in children of any age.

Afro-Caribbean, Asian and Eastern races, are statistically, more likely to develop lupus.

What causes lupus?

There are various elements that may cause someone to develop lupus such as puberty, the menopause, following childbirth and after trauma. It can also be triggered after a virus or after exposure to UV rays.

Lupus has also been found to be hereditary. Where there is a family history of the condition or other autoimmune illnesses such as rheumatoid arthritis or scleroderma.



Subacute Cutaneous Lupus



Discoid Lupus

How is it diagnosed?

As there is such a wide range of symptoms, lupus can be difficult to diagnose. A health professional may do an ANA (anti-nuclear antibody) test as well as a urine test to check for blood and protein.

Can it be treated?

Anti-inflammatory drugs can be used for patients who have mainly joint/ muscle pain as well as steroids such as prednisolone, and immunosuppressants (such as methotrexate and azathioprine) for those for whom the disease is more severe.

Antimalarials are the most commonly prescribed treatment for lupus. In addition to helping with skin and joints, they can help with fatigue, decrease cardiovascular risk, improve pregnancy outcomes and decrease frequency of lupus flares. Hydroxychloroquine and mepacrine are most commonly used.

Unfortunately, there is no cure for lupus yet but if the condition is monitored and a good treatment programme is put in place, the condition can usually be managed fairly well.



Discoid Lupus



Subacute Cutaneous Lupus



Butterfly Rash

Is there anything that can be done to help day-to-day?

Although it may be difficult, try to plan rest periods throughout the day and minimise stress by taking regular gentle exercise.

Keep good communication with your specialist team, advise them of any changes so they can monitor drug usage and assist with self help techniques.

Avoid sun exposure, wear a hat, moisturiser with factor 30 sunscreen as a minimum and cover up where you can. Many people with lupus can have factor 50+ sunscreen prescribed.

If you smoke try to stop as soon as possible. We know smoking causes circulatory problems and fibrosis of the lungs but for more information on reasons to stop smoking when you have lupus, they are outlined here www.lupus.org/answers/entry/smoking-and-lupus

Be aware of your own body and symptoms as these may signal a 'flare' (a time where symptoms may be triggered more severely due to environment or personal factors such as sunlight or stress). By speaking with your health professional during the earlier stages it may allow earlier treatment.

Raynaud's Phenomenon can often be a sign of lupus, when it is in its secondary form and occurs in a fifth of people with the condition.

Overlap syndromes: some patients with 'lupus' do not have pure SLE as described, but have overlapping features with other connective-tissue diseases, such as scleroderma, polymyositis, rheumatoid arthritis and Sjögren's syndrome. Symptoms such as chronic fatigue, joint aches and pains are common to several conditions so it's important if your symptoms change, you go back to your consulting team and get checked out.

Lupus Specialist Centres

Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, Bath BA1 1RL

Addenbrookes Hospital, Hills Rd, Cambridge CB2 0QQ

Manchester Royal Infirmary, Grafton Str, Manchester M13 9WL

Louise Coote Lupus Clinic, Guys Hospital, Great Maze Pond London SE1 9RT

UCLH, 235 Euston Rd, Fitzrovia, London NW1 2BU

Queen Elizabeth Hospital, Mindelsohn Way, Birmingham B15 2TH

Alder Hey Children's Hospital, E Prescott Rd, Liverpool L14 5AB

Private Practice

London Bridge Lupus Centre, London Bridge Hospital, 27 Tooley Street, London SE1 2PR (not NHS)
Tel: 020 7234 2155
Email: londonlupuscentre@hcahealthcare.co.uk

For further information people can contact LUPUS UK.

With thanks to Lupus UK for assisting with the content and imagery supplied for the article.

Get involved in Rare Disease Day and help represent Scleroderma

What is Rare Disease Day?

SRUK will be supporting Rare Disease Day this February to raise awareness amongst the public and decision-makers about rare diseases and their impact on patients' and carers lives. This will include policy makers, public authorities, industry representatives, researchers, educators, health professionals and anyone who has a genuine interest in rare diseases.

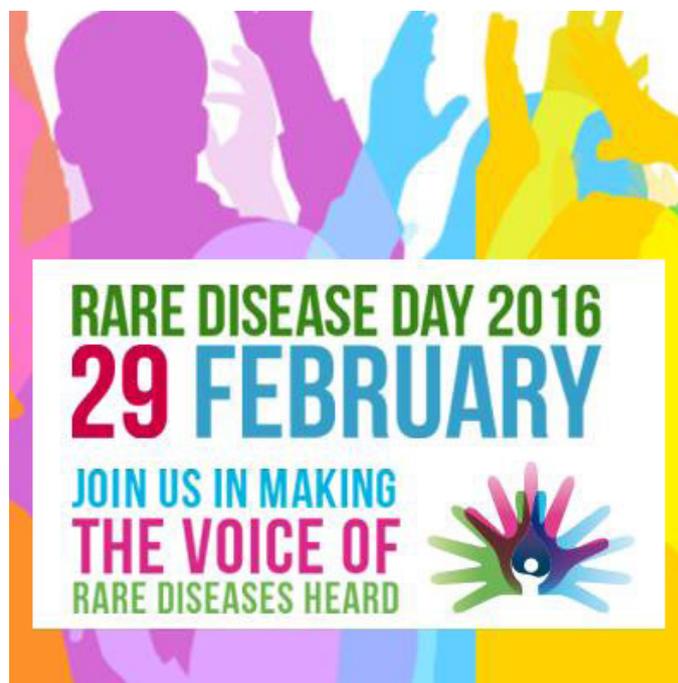
Show your support

Help raise awareness of scleroderma as a rare disease and talk to your friends about how your condition impacts your life. Why not send in your stories or photos by post, or email us and we can post your stories and photos on our website or social media (contact details found at the end of article).

Get involved with Rare Disease Day and Raynaud's Awareness Month in February on social media with Facebook, Twitter and YouTube. Follow us, share the posts and visit our website. There are also some Rare Disease Day resources that you can print out including posters to pin up, and banners which can be found on the official website <http://www.rarediseaseday.org/downloads>

What is a rare disease?

In the EU, as many as 30 million people may be affected with a rare disease. 80% of rare diseases have identified genetic origins whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. Relatively common symptoms can often hide underlying rare diseases. This leads to misdiagnosis and delaying treatment and can result in the patients quality of life being affected, often a lack or loss of autonomy due to the chronic, progressive, degenerative, and frequently life-threatening aspects of the disease.



Why we support it

There are over 6000 rare diseases, for most there is no cure, and this currently includes scleroderma and raynaud's. Join us in making the voice of rare diseases heard. SRUK are supporting the day to represent people with scleroderma and raynaud's, and their carers. The more people who understand the conditions the more likely action will be taken including research to find a cure, support provision across the community and policy changes for better lives when living with the conditions.

Contact

Rare Disease Day, SRUK, 18-20 Bride Lane, London, EC4Y 8EE. Email us at info@sruk.co.uk and find out more about the conditions online at sruk.co.uk/conditions



RAREDISEASEDAY.ORG

Help represent scleroderma as a rare disease.

SRUK Shop

Take advantage of UP TO 10% OFF selected products during January and February, only available to readers of the magazine, use the discount code NEW16 when you check out.

So shop today whilst offers are hot and stocks last at www.srukshop.co.uk



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 **SAVE 10% NOW £6.30**
Use code **NEW17** at checkout



Warmies Cosy Plushies

These favourite friends 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 3.

£10.00 **SAVE 10% NOW £9.00**
Use code **NEW17** at checkout



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 **SAVE 10% NOW £20.00**
Use code **NEW17** at checkout



Box of Mycoal Hand Warmers

These handy warmers can be quickly activated for instant warmth whenever you are out and about. Just open the packet for 7 hours of constant heat. Please note these are disposable and cannot be reused once opened. Box of 40.

£60.00 **SAVE 10% NOW £54.00**
Use code **NEW17** at checkout



Winter Survival Kit

Be Winter ready and save up to 15% with our winter Survival Kit

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 **SAVE 10% NOW £40.50**
Use code **NEW17** at checkout



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
SAVE 10% NOW £13.50
Use code **NEW17** at checkout

For more products and information go to www.srukshop.co.uk or call 020 3893 5998 where one of our friendly team will take your order.

Collect in your Community



There are many small things you can do to help us raise money, and one of the best is to set up a collection box in your local area. If you have a contact at a local shop, church, pub, or anywhere people may drop a few pennies in, get in touch!

These small gestures and small efforts are the backbone of what we do, without them we can't fund research or support projects, we can't provide the helpline or our information pages on the website, so please consider collecting in your community then get in touch.

Hayley has done just that and has made an incredible difference. This is her story.

"When I was 6, my dad was diagnosed with scleroderma. He was very sick through most of my childhood, he was frequently on oxygen and was always tired and in pain. He struggled hard, but he still managed to have fun, be active in the community with the Masons; and most crucially, to make us feel like an everyday family. We would still go on holiday; we'd still go camping or bike riding; he made sure we felt normal and that we were an ordinary family.

After he sadly passed, 12 good years after his diagnosis, I didn't want to think how many other people there were that had to go through the same thing. I felt so sorry for the other families who had to go it as well because I knew it wasn't easy, it's a condition that can't be helped, it's no one's fault, and in so many ways that makes it harder. This knowledge got to me more and more after my dad passed away and I started wondering what I could do to help; but it was years before I got in touch with SRUK to ask how I could help.

Obviously fundraising was brought up and along with my mum we decided we would contribute in any way that we could.

Unfortunately 2 years ago I started to get poorly myself. I was tested for scleroderma but thankfully it came back negative. This year I was finally diagnosed with Fibromyalgia, which presents with similar symptoms: largely chronic pain and chronic fatigue. These are obviously very difficult to live with, and like all those with scleroderma or any other chronic condition, I have had to adjust, change my life, get used to taking medication, but mostly just get on with it.

Although these issues make it tough, I have still been fundraising where and when I can. Collection boxes have been an absolute life saver, as I can organise them around my other issues and through them I have managed to raise nearly £500. Simply by having several boxes running at once and regularly checking up on the people running them. I have managed to make them a strong fundraising method! It's definitely a great way to fundraise and to make a difference within your community and I can't recommend that people get involved with it enough."

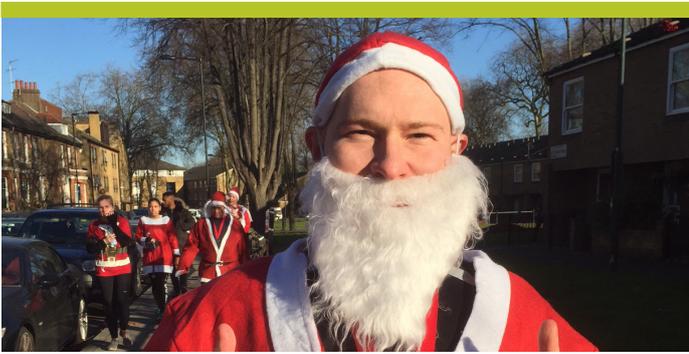
If you would like to get involved like Hayley did: please get in touch with Henry call the office on **020 3893 5993**.

Staff are up for the Challenge

The SRUK staff team are stepping up and joining you! The entire team will be taking up challenges over the next year to raise money and awareness across the country! From running Marathons, to 100km treks, to a post pregnancy family walk in the South Downs, we are pitching in and going the extra mile for all of you.

Our stories will be shared on social media and the website, so keep an eye on how much we are raising by following our Facebook and twitter accounts. I've no doubt it will be entertaining to watch!

Our Business Manager David has been the first through the gauntlet as he took on the Santa Run in Victoria Park.



"In early December I ran 10K for SRUK dressed as Santa for the annual Santa run in Victoria Park. It was a fantastic day and was great fun for all involved, with a free Santa suit provided to all runners, Santa's grotto for the kids, a dance warm up as well as a medal and much needed mince pie at the finish line! I'd like to take the opportunity to thank everyone who generously donated raising an amazing £357.50, including gift aid. I would definitely recommend this event to anyone thinking about fundraising for the charity as it was a lovely day and great fun for all the family."

**By David Kesel,
SRUK Business Manager**

Manchester Marathon

Didn't get a place in the London Marathon? Looking for a great first Marathon to run? Try the Manchester Marathon with SRUK!

A superfast course, great entertainment, outstanding crowd support and glorious finish at Emirates Old Trafford, the home of Lancashire Cricket Club, plus a medal and ASICS technical t-shirt for all finishers!

To give you an idea of how fast this course is, at the recent Aldi Manchester Half Marathon, 74% of the top 50 runners got a PB (personal best) or SB (season best). This race is your best chance to get a marathon PB.

Manchester is one of the UK's great cities and this is your opportunity to join 8,000 other runners around its hallowed streets! Achieve a PB, run your first marathon, put another notch on your running belt, or just do it for us, but join us this year at the Manchester Marathon!

Contact Henry today on 020 3893 5993 or email henry.mcginty@sruk.co.uk

Brave Battle

"In November 2014, my mum Marlene was diagnosed with systemic scleroderma. Like so many other people, including many of you, my dad and I had never heard of this illness. I didn't know what to expect. When it started out my mum was very weak, her joints were painful and she was constantly tired. By Christmas of that year, mum was really struggling. She kept being sick, and couldn't even keep water down. She was admitted to hospital and was there for 6 weeks. They tried everything but the sickness continued. Nothing helped, so in the end she had to be fed intravenously. Mum never complained about the pain or how she felt, as she wanted to keep everything "normal" but we all knew she was suffering. Even though she was unable to eat, she continued to cook for my dad and I and sat with us whilst we ate our meals. In June 2016 with her health deteriorating she was again admitted to hospital and sadly passed away on 2/7/16. Her wish was to raise awareness and funds so this wouldn't happen again.



Following the loss of my mum, my family, my boyfriend Steven, and my friends decided to do something to help others in the same situation, and we started fundraising for SRUK. Recently we held a local quiz night, which was a great success and raised over £2000, with more coming soon from a raffle.

SRUK Raffle

Thanks to all those who took part in the Winter Raffle! This year the raffle raised a magnificent £4,425.00. All the winners have now been informed and have been sent their prizes.

If you didn't receive a prize then we hope you'll have better luck next year!

Next year we are planning an 80s night (mums favourite) for her friends and family to continue the good work started with the quiz. We have a bag pack planned for January and will be pushing on with whatever we can come up with!

It's been fantastic to make such a difference and help out a cause so close to my heart."

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

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

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.

www.sruk.co.uk
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Office: 020 3893 5998

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