

First
Edition

Scleroderma & Raynaud's UK



HOW I
FOUGHT BACK
AGAINST MY
SCLERODERMA

READ ALEX'S
STORY

REGISTER
FOR SRUK'S
FIRST ANNUAL
CONFERENCE



“This is my second conference. I have both Raynaud’s and scleroderma and just meeting up with others is lovely.”
[2015]

Annual Conference

Scleroderma & Raynaud’s UK first annual conference will be held on Saturday 3rd September in London.

The Annual Conference has always been a highlight of the year, bringing together the Scleroderma and Raynaud’s community from across the UK to receive the latest information from top specialists on medical and research advancements.

We will be using feedback you gave in 2015 to design an event that has you at the very heart. The programme will be developed with topics you want to hear about, so you feel informed and empowered to better manage your condition.

‘As a newly diagnosed individual, I have found today to be invaluable in terms of both clinical developments and how others are coping with the condition. It has been an excellent day.’ [2015]

We will be working with you to create an event that meets your needs and requirements. We have established a working group of people diagnosed with Scleroderma and/or Raynaud’s to inform us of what would make SRUK’s first annual conference, the best conference yet.

‘Fantastic informative ‘plain-speaking’ speakers’ [2015]

We will be committing time for networking so you can meet one another, share stories and find friendship. You have told us that building a network of support with people that share similar experiences is so beneficial that we will be making sure you have the opportunity to do just that.

If you are interested in attending SRUK’s first annual conference, you can register your interest today to receive all the latest news and updates. Simply call our friendly team on 01270 872776.

P.S. If you are a paid member of SRUK this event will be free to attend.

‘95% ranked our previous conference as very good or excellent’ [2015]

Your Magazine, Your Way

We wanted to celebrate Scleroderma & Raynaud’s UK (SRUK) going live by releasing the first SRUK magazine. To make sure our future issues have features that are of interest to you, we would like your feedback. If you have a comment or suggestion on how we can improve future issues then call our team on **01270 872776** or email: **info@sruk.co.uk**

The Name Game

Your magazine needs a name! If you have a suggestion for what SRUK’s magazine should be called then let us know by **31st April 2016**. We will be creating a shortlist and then asking you to vote on your favourite via our website and social media.

"The Raynaud's and Scleroderma Association (RSA) and the Scleroderma Society both have a rich history of providing excellent support services to the community and investing in research to improve knowledge and understanding of these conditions. The legacy that these charities have built will stand proudly as the backbone to the new charity Scleroderma & Raynaud's UK (SRUK).

The medical and patient community has welcomed the establishment of SRUK, as by pulling together knowledge and research SRUK will be able to invest in vital support services and provide a focused research strategy to make further advances in effective treatment.

I am honoured and delighted to show my support by becoming President of SRUK, and look forward to a bright future for the Scleroderma and Raynaud's community."

Dame Carol Black, President

"It is a great honour to welcome our President, Dame Carol Black and Vice-Presidents, Prof. Chris Denton and Prof. Ariane Herrick to Scleroderma & Raynaud's UK (SRUK).

The Board is pleased to receive the continued support and knowledge from the President and Vice-Presidents brought forward from the many years served with the Raynaud's and Scleroderma Association (RSA) and Scleroderma Society.

As an organisation we have overcome the technical and logistical aspects of a merge and the achievements of SRUK within a short 9 months provide us with great reassurance that SRUK will continue to develop and deliver excellent provisions for the community.

I look forward to the year ahead and being a part of a new era with SRUK."

Jeremy Pearson, Chair

Welcome to the first edition of SRUK's magazine, featuring your stories, covering your issues and bringing you the very latest from the world of research.

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SRUK may be a new charity, but it benefits from the combined history of nearly 60 years as a result of the two organisations coming together. Over the years, countless individuals have given up their time to raise money, promote greater awareness of the conditions and support each other.

SRUK will build on this legacy, continuing to support the community but also reaching out to the many more people affected by Scleroderma and Raynaud's, who may not be aware that help and support is available.

SRUK's vision is a world where no-one has their life limited by Scleroderma and Raynaud's.

We will achieve this by investing in research, improving awareness and understanding of the conditions and providing information and support to all those affected.

I would like to thank everyone who has contributed to date to the development of SRUK, either by answering our surveys, contributing to discussions about the brand, our strategy or continuing to fundraise or provide support.

I feel very positive about the change we can achieve together, to improve the lives of everyone affected by Scleroderma and Raynaud's.

Sue Farrington, Chief Executive



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Does a diagnosis of localised scleroderma usually lead to a diagnosis of systemic sclerosis (systemic scleroderma)?

Scleroderma means “hard skin” and the term covers localised forms of scleroderma (also called morphea) and systemic sclerosis. In general, the localised forms (morphea) do not affect the blood vessels or internal organs and although they may need systemic drug treatments if severe they are usually regarded as less serious than systemic sclerosis.

Although a few patients may have both localised and systemic forms of scleroderma this is very rare and there is no evidence that one condition progresses to the other.

Is it safe to drink aloe vera gel and can it help with the symptoms of scleroderma?

This is a very topical question since there has been a lot of publicity about the potential benefits of drinking juice and supplements containing aloe vera. This builds upon the use of preparations that can be applied to the skin. Unfortunately, there is no medical evidence to support the use of this treatment.

I would be cautious about consuming anything unproven by mouth because these preparations are not tested and regulated like conventional medications and drugs but could cause allergies, side effects or interact with other drugs that have been prescribed.

Although I am generally in favour of adding supplements, vitamins and other complementary possible therapies to standard treatment for scleroderma, I think more research or evidence is needed about benefit and safety before I would recommend scleroderma patients drink aloe vera gel or juice. Having said that, some of the vitamins such as vitamin E and C that are in these preparations may be helpful but it is probably more sensible to take them as conventional supplements where the dose and amount is more controlled.

“There is no evidence to suggest one form of scleroderma progresses to the other”

DOC SPOT

Your questions answered by our resident medical professional Prof. Denton



I have recently lost my voice and antibiotics are not helping. Is my loss of voice linked to my scleroderma?

Systemic sclerosis (scleroderma) can affect the voice in a number of ways. First, as with other related conditions such as Sjögrens syndrome there can be a reduction in the amount or quality of secretions in the throat and larynx (voice box) that normally lubricate the vocal cords. This can cause hoarseness. Second, the cords sometimes become inflamed or scarred and when ENT doctors examine them they are reported to be thickened that can also affect the voice. Thirdly, there is tendency to get irritation and damage to the vocal cords from infection or reflux symptoms.

In scleroderma there is more tendency to develop infections and for them to be more prolonged.

Finally, there is occasionally weakness of the nerves and muscles in the throat that could be relevant. In summary, scleroderma can affect the voice in several possible ways, although total loss of voice would be very uncommon. It is important to have an assessment by an ENT specialist and to remember that not everything medical that occurs is due directly to the scleroderma, so it is important to have the proper assessments and discuss any concerns with your doctors.

“More research or evidence is needed about benefit and safety before I would recommend scleroderma patients drink aloe vera gel”

Can Hyperbaric Oxygen Therapy help Raynaud's or scleroderma?

Hyperbaric oxygen therapy is a very interesting medical approach that was first developed to treat the severe and potentially fatal condition of "decompression sickness", also called "the bends" due to severe joint pains that occur. This condition develops when a deep sea diver comes to the surface too quickly and bubbles of gas form in the blood. It is treated by going in a pressure chamber with high levels of oxygen (above the normal level in air - hence hyperbaric oxygen). There has been interest in this as a treatment for some forms of tissue damage including radiation tissue damage and severe skin ulcers and even for battlefield injuries. The mechanism of action is unclear but may include helping tissues that have poor blood supply to repair and also through treating infection as oxygen can kill some bacteria. There have been some reports of use in scleroderma for digital ulcers but no formal trials and at the moment it is not generally available as a treatment. In my opinion, other more proven approaches such as medical therapies for ulcers and severe Raynaud's are much more likely to be helpful. However, it is an area of medicine that may have future potential although there is no direct evidence for benefit in Raynaud's or scleroderma and it can be a dangerous treatment in some situations especially if a patient has certain types of lung disease.

My skin tightening is getting better but I still seem to be losing fatty tissues - I have receding gums, thinning lips and loss of fatty tissue at my fingertips.

Is there anything I can do to manage this and is there any current research for loss of fatty tissues in scleroderma?

In some forms of scleroderma, both localised (morphea) and systemic sclerosis there can be a loss of fat tissue under the skin as the disease develops. This may become more prominent as the skin thickness improves, as described above.

It is an important observation as it shows that scleroderma is not just a disease of fibrosis but also in some cases of loss of connective tissue.

Research studies are now revealing a potential link between the processes of fibrosis and fat loss and this may help inform new treatments. In the meantime, sometimes a surgical procedure called Coleman fat transfer may be used to inject fat removed from one part of the body into a site where it is needed - such as the lips, but this treatment also needs more research studies to establish the best techniques and situations for it to be used. These studies are being planned or are ongoing in several centres around the world.

6 steps to fuller lips without surgery

- 1 LIP PRIMER**
Just a little dab rubbed in can make sure your lipstick, lip stain and even lip-gloss stay flawless.
- 2 CONCEAL LINES**
Concealing lines will help your lips stand out. Use a little concealer to buff away any lines.
- 3 USE LIP LINER**
Lip liner is a savior for thin lips. Apply lip liner to the outside edges of your lips to give them volume. Pick a color that works with your skin tone and goes with your lipstick colour - a matte base lip liner will give a more natural look.
- 4 APPLY A TOUCH OF WHITE EYELINER**
Adding a small amount of white eyeliner to the centre top and bottom edge of your lips will help give the illusion of plumpness.
- 5 APPLY LIGHT COLOURED LIPSTICK**
Always choose a light coloured lipstick, as this will help lips look fuller. Light doesn't mean dull - you can go for a bright colour just avoid dark, heavy tones.
- 6 ALWAYS WEAR LIP-GLOSS**
Lip-gloss will add shine to your lips and reflect light to make your lips appear naturally full.

BEFORE



AFTER





After 6 months of chemotherapy, my scleroderma was under control!

I noticed something was wrong when I was 13. I was training to become a dancer but my body became stiff and my skin looked tight and shiny, with my fingers being too painful to straighten. After lots of tests at Alder Hey Hospital, I was diagnosed with scleroderma, but with no organ involvement, they were not sure which type. I was told that if it's systemic sclerosis, I could only have 10 years to live, which was obviously incredibly difficult to hear. After trying a few different unsuccessful treatments, I was put onto Mycophenolate Mofetil (MMF) that, alongside steroid injections, worked really well.

About two years later, at the same time I transferred to Aintree Fazakarley Hospital, I had a bad flare up. New treatments were tried, but didn't work, so I was put back on MMF and steroids for a year. However, this wasn't working, and I wasn't given the option to try anything new in case it made me worse.

Rather than lose hope, I got another opinion from Professor Herrick at Salford Royal Hospital. Tests revealed I had morphea scleroderma, but the recommended UVA treatment had little effect on it, which now formed dark patches across my entire body.

My dermatologist wanted a second opinion by Doctor Goodfield at Chapel Allerton Hospital. I tried various treatments, but none worked and he advised the next step was low dose chemotherapy. This seemed extreme, but nothing else was working, so it was worth a shot. I was really scared, as anyone would be, however, it wasn't too bad after the initial treatment. I started MMF again and after 6 months of chemotherapy, my scleroderma was under control!

I feel grateful for the support I have received, especially from Mum and Dad, who are always there for me, and my boyfriend, Liam, who comes to my appointments, but most importantly makes me laugh and smile.

My condition has affected me a lot, positively and negatively. I appreciate things a lot more now that most would take for granted, particularly pain-free days and days out with friends and family. When I get upset about my condition, I remind myself of something I did that I am really proud of. When I was put on chemotherapy, I was in the final year of my degree but I didn't want to postpone it. I completed it on time with a 2:1 while on chemotherapy. It is important to stay positive and to appreciate every day and every moment.

After completing a degree in illustration and animation, Alex now teaches art.

Personal Story

Alex, 23, was diagnosed with scleroderma as a young teenager yet despite this, and the difficulty in finding the right treatment for her, has an incredibly positive outlook.



Be a Super Hero

Charity Golf Day



Always wanted to be a Super Hero? Well SRUK is giving you the opportunity to do just that. We have secured places at one of the most fun events across the country, the Super Hero Run.

The event takes place in London's Regent Park on Sunday 15th May 2016, with the spirit of the event being to take part so you can run, jog or walk 5 or 10k.

Registration Fee: £25
(and you get a free super hero costume!)
Minimum Sponsorship: £50.00

We only have a couple of spaces left and will provide you with support on training and fundraising. Sign up today by contacting Lucy: lucy.meek@sruk.co.uk or 01270 872776

We would like to invite you to SRUK's first charity golf day being held on Monday 20th June at the only Seve Ballesteros course in the UK. Enjoy an 18-hole round of golf on this beautiful and challenging course followed by a two-course meal.

All profits raised from the day will contribute towards funding life-changing programmes. Through SRUK's rich history we have invested £9.5 million into research and we are dedicated to continuing this commitment.

You can help us make sure this investment continues by joining us for a spectacular day on this picturesque course. The Shire Golf Club, London, is a disabled friendly venue and will provide golf carts and assistance to players on the day.

£300.00 per team of four or £85.00 per individual. Phone our friendly team to find out more and book: 01270 872776

Our Fundraisers

Nick Brackenbury and three friends drove rally cars from London to Mongolia and raised over £3,500!

Laura Fraser raised over £500 by doing a skydive.

Nancy, held a line dancing night and raised £100.

Marjorie Smallcorn, the mayor of Havant, hosted a fashion show and raised £165. Marjorie has raised a wonderful £5,000 during her time in office!

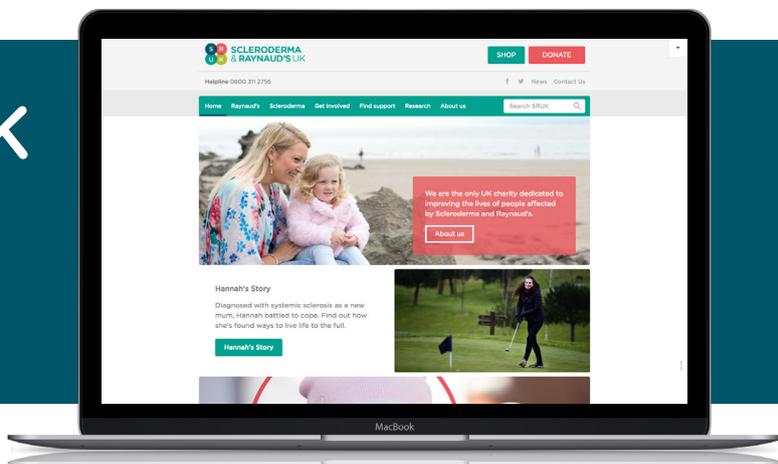
Yvonne Day raised £300 by hosting a psychic supper night.

If you would like to take on a challenge or organise a fundraiser for us then speak with Lucy today: lucy.meek@sruk.co.uk or 01270 872776.



WWW.SRUK.CO.UK GOES LIVE!

Here at SRUK, we're all delighted to share with you the new website which went LIVE on 1st April.



The website project was completed within a 3 month period and whilst creating a brand at the same time it has been a very busy few months. We are delighted to share our brand new website with you and would encourage you to log on to www.sruk.co.uk to explore the site.

We are here because of you. Scleroderma and Raynaud's UK (SRUK) is the only UK charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's.

We exist to improve awareness and understanding of these conditions, to support those affected, and ultimately to find a cure.

Our new website has been developed with you in mind and you can find all the usual features. We have dedicated

areas providing you with the latest information on Scleroderma and Raynaud's, as well as downloadable factsheets and personal stories.

Read about the current research going on in Scleroderma and Raynaud's, or see if you qualify for one of the trials going on throughout the country.

There is now an interactive map so you can find out what is available in your local area

You can locate specialist hospitals, local support contacts and see various events from fundraising activities to annual conference. You can pinpoint your location, find out further information and get involved. If you have a local event going on that you want us to publicise, just drop us a note here at info@sruk.co.uk, with the details.

We understand the benefits of building a network of friends and so take a look at joining our new SRUK community on HealthUnlocked. This online community allows you to post questions and talk about health related topics.

Donate using our new form with virtual card display so you can easily check your details

If you would like to get involved and support us to deliver vital services then take a look at our fundraising pages. Choose your next challenge or organise your own event with our helpful resources. If you've just had a bake sale or completed a charity fundraiser, don't send us a cheque, use our donations area to pay in your fundraising money quickly and easily online. This cuts down administration time, so even more of your donation goes towards vital research.

Easily find products on the new look shop

If you have bought products from the shop before that you have found beneficial, then check out the new look shop, you can now register and save your details which makes checking out the next time, so much quicker and easier.

The first 100 people to purchase from our new shop and use the code NEWME will receive 10% off everything they buy, but hurry, this is a launch offer so you'll have to be quick.



Interactive Map

This will be a free event for parents of children aged 12 and under who have been diagnosed with Scleroderma and/or Raynaud's, and will provide informative sessions led by specialist medical professionals along with fun activities for children to take part in throughout the day.



Our supporters often tell us that one of the hardest things about living with the conditions is feeling alone, and this can be especially difficult for families and young children. Speaking with other families who know what you're going through and building friendships can be extremely valuable.

We will be bringing together families from across the country, providing a space for parents and children to chat and share stories, as well as receive invaluable information from top specialists.

We are currently developing our programme for the day with the help of experts Dr. Despina Eleftheriou of Great Ormond Street Hospital, and Dr. Eileen Baildam of Alder Hey Children's NHS Foundation Trust. Sessions to be run will cover topics such as: how the conditions can affect children; the latest treatments and research; and how to help your children cope with their condition in terms of their mental and emotional health.

Find out more and book your place today: www.sruk.co.uk or call our team on 01270 872776

Family Weekend

We're pleased to announce our first-ever Family Weekend event, which will be taking place on Saturday 2nd July in Birmingham!

Eliza's Story

"I first noticed a small bruise about 1cm round on my 3 year old daughter, Eliza. It was just to the side of her left armpit and I remember thinking what a strange place to get a bruise.

The bruise didn't go away, so I started looking into what else it may be and stumbled across SRUK's website where I found information about morphea.

In early July we finally got to see the Dermatologist, she confirmed that Eliza did indeed have morphea. I left the surgery with an appointment for Dr McCann in 2 weeks time. Finally!

Our appointment at Alder Hey came and we were so relieved to be seen by someone who specialised in that area.

Eliza was examined and another patch found. They decided to treat it aggressively as the disease can be unpredictable in children and especially if crossing a joint, which Eliza's were. She started on Methotrexate that evening and given a date to return mid-august to start her I.V steroids.

The best news is that, so far, the patches have not increased in number or spread in size. The four patches she has have lightened in colour and are not quite as noticeable.

I would like to say a big thank you to SRUK as without the work they do I would not have had the knowledge I needed to pursue a diagnosis and get the treatment needed for our daughter."



Thank you to the Brian Norris Appeal for making this event possible

Positive breakthroughs in scleroderma research

Prof. Denton, Consultant Rheumatologist at the Royal Free Hospital, London opened the World Systemic Sclerosis Congress with a presentation on 'What is research doing for me?'. This uplifting and informative presentation highlighted the positive breakthroughs taking place in scleroderma research.

Prof. Denton highlighted the difference now compared to 15 years ago. Now we have access to effect treatments and within the UK work is taking place to develop pathways so patients can access treatments licensed for similar conditions i.e. Arthritis.

Three studies were discussed, all of which have given positive initial results with further studies taking place:

- 1. Recital** - conducting trials on the effectiveness of Rituximab as a treatment for lung fibrosis.
- 2. TGF Beta** - a successful trial blocking the TGF Beta protein to improve skin score (reduce skin thickening).
- 3. IL6** - licensed drug for other conditions (Arthritis) which improves inflammation. Initial trials have improved skin score and has shown potential that it could improve lung fibrosis.

We spoke with Prof. Denton after his presentation and he said, "there is more research into scleroderma than ever before and it is helping to understand the disease better. This research includes a lot of international and national collaboration and builds upon the success of many previous projects including work funded by SRUK (SS and RSA) in the UK.

Despite this there is still an enormous unmet need for patients. Also the journey from research to new treatments is a long one but fortunately clinical trials are ongoing and hopefully will lead to new and better treatments for the skin, lung and other complications of scleroderma.

The exciting thing about current trials is that not only may they lead to better or new treatments but they also offer the potential to better understand the underlying causes of scleroderma and its complication."

[You can watch his presentation on 'What research is doing for me?' alongside the other presentations from congress on our website.](#)

"There is more research into scleroderma than ever before and it is helping to understand the disease better."

The 4th World Systemic Scleroderma Congress (WSSC) was held in Lisbon from the 18th - 20th February

This event brings together medical professionals who have devoted their work to treating people diagnosed with scleroderma. World scleroderma leaders led presentations and hands-on sessions looking at developments to treatment and medical best practice, with a focus on aspects of care to improve the quality of life for people with scleroderma worldwide.

Alongside the scientific congress organised by the World Scleroderma Foundation, a patient congress was held by the Federation of European Scleroderma Associations aisbl. (FESCA). Through our rich history SRUK is a founding member of FESCA, which was founded to provide information to people with scleroderma, increase awareness on an international level, and advocate for equitable treatments for people with scleroderma throughout Europe.

Ann Tyrrell Kennedy, President of FESCA summarised the importance of having a patient

congress at WSSC. "The fourth World Scleroderma Patient Congress, held by FESCA in Lisbon this February, was an event of great value to patients in many ways: it raised awareness of scleroderma to a high degree, it was a focus for the interchange of knowledge between patients and doctors, and it provided an opportunity for networking among affected people from many countries. For those with a rare disease, it proved both meaningful and moving to meet one another as well as to get advice from the top consultants worldwide. For the many hundreds of doctors present, it was an opportunity to learn more about how to diagnose and treat a little understood disease, and to hear the patient's perspective. The feedback has been extremely positive and I have been delighted."

Veronica attended the patient congress and told us, "I found it invaluable and extremely informative and I learned such a lot about living with and managing this disease."

Our helpline is manned by volunteers; Belinda, Kim, Penny, Paula, Rosemary and myself (Helena) who have many years of experience and training. We are here to help, we understand the challenges and difficulties you face and provide a confidential space to talk through your worries or concerns.

If you call the helpline, the volunteer that you talk to may also 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.

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.

0800
311 2756

"I apologise for being emotional but I feel so much better thank you for listening."

We are here for you,
when you need us

"I have just been diagnosed and was given your number. You're the first person I have spoken to with scleroderma thank you so much for talking to me."



Meet Rosemary

I started working as a volunteer on the helpline in November 2012. I volunteered because a close friend of mine has scleroderma. At that time I had known her for about 8 years, had asked her lots of questions about the condition and had accompanied her to hospital appointments, so I felt I knew quite a lot about it. But what I knew then was the tip of the iceberg. I have learned so much over the past 3 years from my conversations with callers.

Many of them are newly diagnosed and very concerned about having a condition that no one seems to have heard of.

They are always very grateful to speak to someone who is aware of the difficulties they might be experiencing and can point them in the direction of more information and support. A general lack of knowledge about the condition can make them feel lonely and isolated. I always tell people that I don't have scleroderma but so far no one has ever asked to be able to speak to someone who does.

It's always especially rewarding if, at the end of a conversation, the caller says 'thank you for your help, it's good to speak to someone who is sympathetic and understands what I'm talking about.'

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 as we fully establish SRUK we will be aiming to achieve even more. To help us do this we would like to ask you to make a couple of simple changes as to how you support us.

Renewing your membership online or over the phone: 01270 872776 will cut down our administration costs meaning we can invest more into supporting people.

Donate to us through our website www.sruk.co.uk by clicking the donate button or by phoning our friendly team on 01270 872776 using your debit/credit card.

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



We hope you enjoyed your first 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.

Helpline: 0800 311 2756

www.sruk.co.uk

 @WeAreSRUK  /WeAreSRUK

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