

newsletter of the Scleroderma Society

# Tightrope

February 2013



**The psychological  
impact of scleroderma**



# welcome



A huge welcome to the winter 2013 edition of Tightrope (if you have an opinion about the name fill out the survey), with the outgoing year proving to be an extremely positive year for the Scleroderma Society, I for one can't wait to see some of the improvements to be implemented by our staff and volunteers in the New Year and to this end please keep the questionnaires coming in; if you haven't received our extensive survey let us know!

It's so important that you complete one because it's your views that will help shape the future of the Scleroderma Society and how we can make a difference for people with scleroderma.

A huge thank you to all our supporters who have been raising awareness and funds throughout 2012. In December I attended a fabulous charity fashion show at Presdales School in Ware. The show was organised by the The Presdales Charity who chose the Scleroderma Society as their charity for the year 2012, there will be more about this and other events held by the school in the Spring edition but a huge thank you to all the models, committee and many others who helped out on the night, the local stands and businesses who provided samples and products for the complimentary bags that all helped to make this event so successful.

I would also like to register some special thanks to Lesley Matthews. If you have received a newsletter in the past couple of decades it is Lesley who would have packed it and posted it to you. Lesley has sent out absolutely thousands of newsletters. She has now decided to take a well earned rest. Thank you Lesley.

Our helpline has expanded to include Penny and Rosemary and we all attended a training course in November to brush up on our skills. As I write this on New Year 's Day the sun for once is shining and it's DRY, here's hoping that the extreme weather hasn't affected anyone too badly and that 2013 will see some respite from the rain, wishing you all a happy, peaceful and healthy as possible New Year!

Lots of Love

**Kim Fligelstone**  
Co-Chair

## still Tightrope?

Well, we are still called Tightrope. While some people have expressed a wish for a different name, we are still to come up with something else. Quite a few people have said that the name tightrope reflects how they feel about their experience of living with scleroderma. Please let us know what you think. All suggestions on names for the newsletter are most welcome.

Contact us... Telephone: 020 7000 1925  
Mail: The Scleroderma Society  
Bride House, 18-20 Bride Lane  
London EC4Y 8EE  
Email: info@sclerodermasociety.co.uk



## A new look

You will see from the front cover of the newsletter that we have changed our look. Rather than this being a complete redesign we have made changes to the tightrope walker which reflect the views of people who returned our survey. Overall, the majority of you liked the tightrope walker as it was felt that the



image really reflected how it felt to live with scleroderma. Some felt that it was a bit of a negative image. Bearing all that in mind, we have kept the tightrope walker but made her/him look in much more control. S/he now looks balanced and able to support him/herself with confidence across the wire. We hope you think that is a good reflection of what the Society hopes to do - support people to live their lives confidently.

We have also looked at ways in which we can use the sunflower, which has been adopted as the international symbol of scleroderma. The sunflower will now appear in a number of guises across our publications in order to complement our logo. Our leaflets will also carry a small panel on the back explaining the use of the sunflower. What do you think about the sunflower? Let us know if you have an opinion as to how we should be using it.

## introducing Amy...

I have just started as Executive Administrator here at the Scleroderma Society and am very excited about being here. It seems like a great charity, doing some really important work, and I am looking forward to working with our Chief Executive, Mike, and all our brilliant Trustees and Volunteers. I will be helping Mike with the general administration for the charity, while he continues to fundraise, and raise awareness and support for people with scleroderma.

I have worked in the Charity Sector for many years, most recently the British Institute of Human Rights, where I was PA and Office Coordinator for six years, working on running the office administration and finances as well as being PA to the Director. I have also worked for Alcohol Concern, and been a fundraiser for Amnesty International. Before this I worked in the Media Industry but soon found I preferred the third sector, and have worked for charities ever since.



# society news

*"our aim is to become the support group for people with scleroderma"*

## Annual General Meeting and Conference

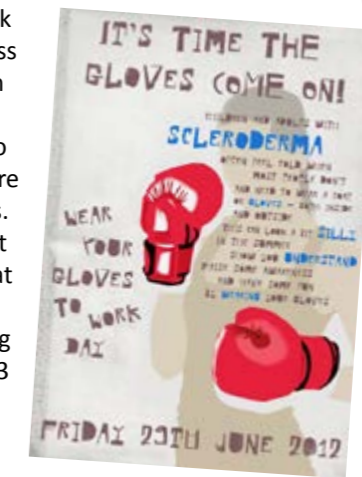
Here is a date for your diary. Our AGM and conference this year will be held on World Scleroderma Day - June 29th. We will again be holding the event in the Atrium at the Royal Free Hospital in Hampstead as this has continued to prove to be a very popular venue. However, in 2014 we will be looking to arrange more meetings in different parts of the country.

If you are a member you will get your official notification nearer the time, however, why not stick it in the diary now - we can promise you some excellent speakers and a really enjoyable day.

## Wear Your Gloves 2013

Last year was the inaugural Wear Your Gloves to Work Day. It was a great success with people up and down the country taking part. This year we would like to expand the day and we are currently planning events. Some of the feedback last year included the fact that many of you were not working. So we are taking that into account for 2013 and will just be concentrating on Wearing Gloves - no matter where you are.

Last year we had schools, individuals,



and companies involved. People got involved from as far away as Argentina, and all over Europe. There are many ways in which you can get involved with Wear Your Gloves 2013. You can write a letter to your local paper or MP raising awareness of scleroderma (we will have some examples nearer the time). You can put a poster up in your window, or take one to your local GP surgery. If you would like to, we are always looking for people who are prepared to do local radio or newspaper interviews. If you would like to get involved with Wear Your Gloves 2013 why not drop us a line. We would be delighted to hear from you.

## Survey

Thanks to the many of you who have taken the time to fill in our survey. We appreciate that it was quite long and detailed and took some time, however, the information that we are collecting has been of great use and will make a real difference to our services in the future. If you have not filled out a survey or would like us to send you a copy please email us at info@sclerodermasociety.co.uk or call 020 7000 1925. To return a survey you can just drop it into an envelope addressed simply FREEPOST SCLERODERMA.

The Scleroderma Society helpline is staffed entirely by volunteers and is open 7 days a week for 12 hours each day. The helpline receives around 40 calls per month from people with established scleroderma as well as from those who have been newly diagnosed. If you haven't used our help line and you would like to talk to someone why not think about talking to one of our volunteers. They are...

# just a call away



The helpline continues to operate from 9am to 9pm every day and is now approved by the Helpline Association. This means that we conform to standards of excellence in how we operate and all our volunteers have regular training.

The adjacent photo was taken at our recent training day in November with Arthritis Care.

I was able to secure some funding for the training from the Rochford Rotary for which I am very grateful.

As I write this feature for the newsletter we are approaching Christmas, which I love, but it brings with it all the preparations and stresses, for example, the cold weather the hustle and bustle in the shops and generally getting organised but our volunteers still give up their precious time without interruption for which I am so thankful.

We have seven volunteers staffing the helpline now from Monday through to Sunday (9am to 9pm) on a weekly rota. Liz, Kim, Belinda, Paula, Penny, Rosemary and myself - I hope you enjoy reading our stories. None of our volunteers are medically qualified and therefore we cannot give advice on drugs, medical diagnosis or other areas that must be left to the professional experts. However, we can listen to you, point you in the right direction through the medical maze and give you information and most importantly support.

## Kim

### Thinking back to the beginning..

The helpline came about quite organically. The previous Chairman Pam Webster was always at the end of the telephone and when she retired I realised we were becoming more well known and that it wasn't possible for one person to be on call all the time

and started recruiting people. The first volunteers, still on the helpline, were Liz, Belinda and myself. I think initially we called the helpline an advice line but soon realised that this was not appropriate as none of us are medically trained. Other charity advice lines were changing the name to helplines and it

is I hope a perfect description of what we do to help people, which could be listening, sign posting to the appropriate place be it a medical specialist, organisation, or another person with scleroderma. Anyway as we got busier Liz took over the running of the helpline and this is where I pass over to Liz...

## Liz

I have been privileged to be one of the Helpline volunteers for at least nine years, and during that time took on the role of manager. It was a really interesting time involving both personal and group training sessions, with a great deal of help and encouragement from Arthritis Care. Then I realised how capable Helena would be in this role, and she has proved me right!

I originally trained as a teacher, but as a family we moved around a lot, in this country and abroad and it became difficult. Over the years I found I was becoming more and more involved with Helpline volunteering. I trained and worked for Parents Anonymous, Woking Crisis Line and Citizens Advice Bureau in various parts of the country. The latter two covered anything and everything. At least with the Scleroderma Society Helpline I'm usually on home ground!

The person you talk to may also have Scleroderma but as we know everyone is different and the manifestations from patient to patient are varied and complex. Therefore, we refrain from swapping backgrounds and symptoms' but try to listen positively to your issues and try to help you with your particular problems.

You may be worrying about a symptom, where to get help, or you may want hints and tips that we as a group have come across. For example, special aids to help with your daily life, cooking utensils with special handles, opening devices or maybe what creams are available to moisten the skin.

My speciality seems to be SHOES, as you will know by the time you reach the end of the newsletter.

## Helena

Helpline Manager ([helena@sclerodermasociety.co.uk](mailto:helena@sclerodermasociety.co.uk))



## Rosemary

I am a retired administrator and Company Secretary. I spent 18 years working in and around London Docklands during its regeneration and during that time I was involved with a number charitable/voluntary organisations as a treasurer, director and trustee. Eight years ago I met someone who has scleroderma and we became great friends. Like most people, I had never heard of the illness but over the years I have learned a great deal about it by asking questions, reading available information and accompanying my friend on hospital appointments. I am new to the helpline but will work hard to contribute to the excellent work of the volunteers.

## Penny

I was diagnosed with Diffuse Systemic Scleroderma 4 years ago. I met Helena in the Royal Free Hospital when we were both in there for Iloprost treatment, she suggested I might join the Helpline Team.

I have been a Picture Restorer for 40 years but I do have experience of voluntary work. When I lived in London I volunteered for The Samaritans and the Adult Literacy scheme. Since living in Norfolk I have been a Trustee of the local RSPCA branch and ultimately Chair. I resigned in 2011 as the task was becoming very stressful, something to be avoided with Scleroderma.

I feel that I have been very lucky to have had the marvellous treatment that I have received at the Royal Free and would like to try and put something back.

I have only done 3 sessions so far on the Helpline but I have found it very interesting and have had my confidence and knowledge increased by a very useful and enjoyable training session in London in November.

## Paula

Hi my name is Paula and I have lived with scleroderma for 20 years. Whilst being first diagnosed I remember feeling very worried but grateful that I could start a treatment plan and learn more about the condition. Over the years I myself rang the helpline for information which I found very useful. While I learned more and more about the condition I also learned more about how to be a better self-manager.

As I became more and more knowledgeable I thought I could perhaps pass it on to others who are living with this complicated condition so I volunteered to go on the helpline. All calls are different as we as people are and found it satisfying to help others and maybe allay a few fears they might have and most of all to listen and let them know that we care.

I also went on to become a volunteer Tutor for the Educating Patients Programme (epp) which is a 6 week free course for people who live with long term health conditions. It helps people to become good self-managers by giving them the tools they need to help with pain/fatigue, communication, dealing with difficult emotions etc. I am now an assessor with epp. Volunteering has helped me come to terms with this condition and its good for the well being by helping others.

## Belinda



I was diagnosed with scleroderma in 2000 and joined the society around 2001. I have been doing the helpline for about 9 years, then the scheduling for about 8 years, which when I started there were only four of us. This has now increased to seven.

I became a help liner (as it seems that is what people call us) after talking to Kim. She asked if I would like to do it and after a little thought decided to try it. The calls have always been very interesting as are all the people with or without scleroderma, some of the calls are very sad but a lot of them are very uplifting, especially when you end the call and the person on the end of the line has had a cry then ended with a laugh.

We try to be good listeners and hopefully get the person on the right track to help them come to terms with their illness. When I was first diagnosed I obtained most of my information about scleroderma from the internet and to be honest most of this was quite frightening. I feel that being part of the helpline team enables me to help people allay some of their concerns. So as a by-line anyone can volunteer, the society encourages people to do so, if you have some spare time why don't you give it a try, just like I did, you might find you like it.

The Helplines Association  
Member

# fatigue

Scleroderma brings with it a great deal of clinical and medical issues. The immediate concentration is clearly on your physical health, however, what is often ignored or overlooked is the psychological impact of scleroderma and the wider affect that it can have on your life. Whether it is the impact of fatigue on your everyday life or the impact of scleroderma on your ability to work, it is vital to recognise this side of living with scleroderma. We recently attended a seminar at Sint Maartenskliniek in Nijmegen. Here are some of the highlights...

## the psychological impact of scleroderma

### There is some evidence that Cognitive Behavioural Therapy is helpful in long term conditions. So what is CBT?

Cognitive behavioural therapy (CBT) is a talking therapy that can help you manage your problems by changing the way you think and behave. CBT cannot remove your problems, but can help you manage them in a more positive way. It encourages you to examine how your actions can affect how you think and feel. Talking and changing your behaviour can change how you think (cognitive) and what you do (behaviour). This can make you feel better about life.

### When is CBT used?

CBT has been shown to be particularly helpful at tackling problems such as anxiety, depression, post-traumatic stress disorder (PTSD) and eating disorders. Unlike other types of talking treatments, such as psychotherapy, CBT deals with your current problems, rather than focusing on issues from your past. It looks for practical ways to improve your state of mind on a daily basis.

CBT can also be used to treat people with long-term health conditions, such as arthritis and irritable bowel syndrome (IBS). CBT cannot cure the physical symptoms of these health conditions, but can help people cope better with them.

source: NHS Choices

We want to hear about your stories. We are especially interested in how scleroderma has impacted on you psychologically. We know that, for instance, many people have reported problems within their relationships both with friends and family as well as with their partners. Others have talked about the frustration that they have felt as a result of having to curtail their work or other activity. An important part of living with scleroderma is dealing with its psychological impact. If you have a story that you think might help other people please send it to us.

### Getting in a SPIN

SPIN is a new project based in Canada but expanding across the USA and to parts of Europe. The Scleroderma Society is keen to encourage the take-up of SPIN in the UK. SPIN stands for **Scleroderma Patient-centered Intervention Network**. Over the next years, the SPIN project plans to develop a set of psychosocial interventions that are accessible, cost-effective, and can be delivered on an ongoing basis to people living with scleroderma. To make the interventions cost effective and available to everyone, the project plans to make them available online and eventually, they will be available through patient organisations such as the Scleroderma Society. SPIN is initially concentrating on **emotional distress, hand function, body image and self-management**. This is a potentially important intervention which could have a positive impact on the lives of thousands. One of the problems with rare diseases such as scleroderma is that there is typically no access to psychological interventions which are relative to the specific disease. SPIN will change this. We hope that it will be possible for UK patients to sign up for SPIN as soon as possible. If you would like to sign up you will need to do this via your hospital rheumatologist. Why not ask them about SPIN and whether they are getting involved at your next appointment.

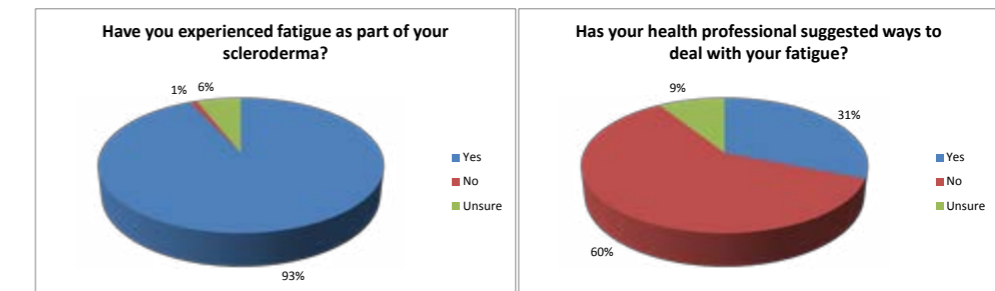
### What do patients want?

**Joep Welling from the Dutch patient group NVLE asked a question that we all need to think about.** What do patients want from their healthcare providers? Fundamentally Joep felt that what patients really wanted was the care and attention that they need. This involved proper listening on the part of the health care provider and above all time. Patients wanted unrushed time where they felt that they were getting sufficient attention and where they had the space to ask necessary questions. They also wanted to be kept well informed of what was happening to them and the treatment and other options that lay ahead. Do you agree with Joep? What do you want from your health professional. We are all very different and some of us do not like asking questions. How are you in the doctor's office, full of questions or quiet waiting for information?

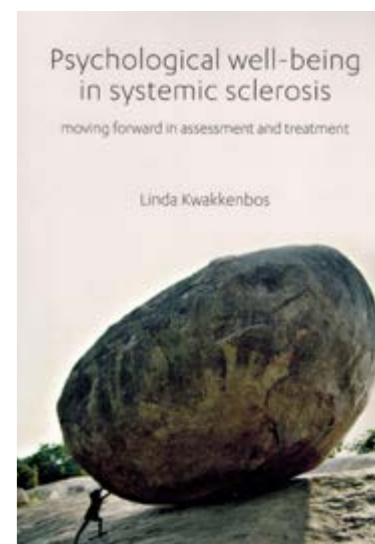
### Lets talk about fatigue

Christina Bode of the University of Twente presented international data that showed that fatigue was clearly elevated in patients with scleroderma and that it was the symptom that had the single largest impact on people living with scleroderma. However, she also stated that fatigue was overlooked in many cases and suggested that this was because there were no clear causes for the fatigue and no evidence based treatments available. She also suggested that because fatigue was invisible there was often social disapproval or lack of understanding of fatigue which was sometimes seen as laziness or as an excuse. These conclusions certainly fit with some recent research done by the Scleroderma Society which showed that only 1% of people felt that they had not been affected by fatigue (93% had experienced fatigue and 6% were unsure). When asked whether their health professionals had suggested ways of helping with the fatigue, only 31% said that they had been given support but almost 70% had not. We asked people to mark on a scale of 1 to 10 how much fatigue had impacted on them. The average score was seven out of 10, with almost 45% of respondents saying that fatigue had an impact of 8,9 or even 10 out of Ten.

Our survey also pointed to the problem of other people's attitude to fatigue. Some stated that while those close to them understood, the majority of people showed little understanding and were sometimes intolerant.



Linda Kwakkenbos is a Dutch psychologist who has specialised in the impact of scleroderma. She has recently become the co-ordinator of the SPIN programme, an innovative project which is planning to develop on line and distance interventions to support people with scleroderma. Linda recently organised a seminar at Sint Maartenskliniek in Nijmegen looking at the impact of depression, fatigue and work capability. We are currently seeking permission to publish the presentations from this seminar online. Please keep an eye on our website for more details as they become available.



# Helena's fabulous footwear



“Imelda Marcos has nothing on me, just ask my poor husband!”

When I was a child I hated my feet and I loathed buying shoes. Imagine a very tall, skinny, gangly-legged girl, with huge feet (size 6 feet before her teens). My parents were strict about foot care and shoes; I had to wear Tuff shoes for girls for school whilst my peers were in kitten heels. I would deliberately scrape my Tuffs along the pavement to wear them out on my long walk to school. I was such a nightmare that my mother delegated the shoe buying to my father. He was top dad the day he bought me a bright red pair of kitten heels as a treat but only for Sunday best.

I remember being so embarrassed about my feet that if I was asked out on a date I would not choose bowling, as the shoe size was on the back of the bowling shoe for everyone to see. I despaired of my feet and hated shoes. I would buy them too small, as I didn't want to size up again. I am now a size seven and a half but have to confess sometimes an eight.

Thanks to my parents I have straight slim feet and I stopped growing at a respectable 5ft 7ins so my size 8 is not an issue anymore but my shoe hatred has transformed itself into a shoe fetish! Imelda Marcos is not competition for me, I can assure you. Seriously, I cannot pass a shoe shop without going in or at least glancing at the window. I am sure my husband would like to usher me past every shoe shop and often tries, saying “Helena, do you really need any more shoes?” What a silly question, a girl cannot have enough shoes! Sadly, I have no designer Christian Louboutin, Jimmy Choos or Kurt Gieger's or 6-inch platform heels, not even 3-inch heels as I have scleroderma. At the last AGM I looked on with envy at Dame Carol Black's, L K Bennett high heels in nude patent, I literally could not take my eyes off them and I had to tell her that I just loved her shoes!

My scleroderma has taken its toll on my feet. For example at one stage when my whole body was swollen, I was going to work in size 9, and Clarks flat loafers. To enable me to walk any distance I bought some MBT trainers and sandals ([www.mbt.com/](http://www.mbt.com/)). I remember my son encouraging me by saying, “whatever you are wearing, I want some - you are springing along”. I was, too, in my new MBT's. Cushion Insoles are good but not a good look with a summer sandal. The loss of fatty tissue on the feet and the stiffness is a real issue but I refuse to let this stop me from wearing something at least a little attractive in the shoe department. I refuse to give in to fuddy duddy shoes that make me look like I am wearing shoeboxes!

On the bright side I still ogle shoes and shoe shops but I am looking for a different kind of shoe now and have spent years since having scleroderma researching fashionable, comfortable shoes. What I need is a flat or small-heeled shoe with a cushioned insole and support for the arch of my foot and a fairly thick outer sole; without this it is like walking on knives!

My shoe fetish and research has culminated in obviously lots of shoes but also a knowledge that I can share with fellow feet sufferers.

In conclusion Imelda Marcos has nothing on me, just ask my poor husband!

I am sure many of you have shoe hints/tips. Let's hear from the men, too! We could have an A-Z of comfortable shoes on our website!

## What and where. How to get your hands on Helena's recommendations...

Amongst my non-designer collection, I have lots of Geox which are extremely comfortable. Available from **Geox** shops or good shoe shops or online at [www.geox.com](http://www.geox.com)

**Tamaris**, a German make with a cushioned insole, do lovely pumps (from [www.rubbersole.co.uk/Tamaris](http://www.rubbersole.co.uk/Tamaris) and other suppliers).

**Sole Survivors** and **The Fit Shoe**, both available through NEXT shops and online (also in wide-fitting).

Sole Survivor: [www.next.co.uk/women/shoes/sole-survivor/1](http://www.next.co.uk/women/shoes/sole-survivor/1)

The Fit Shoe: [www.next.co.uk/women/shoes/the-fit-shoe/1](http://www.next.co.uk/women/shoes/the-fit-shoe/1)

Clarks Air / flexi and Mary Portas and warm lined are all good in wider width fittings too. Clarks shops or online at [www.clarks.co.uk](http://www.clarks.co.uk).

**Pavers do Fylfots, Sketchers, Padders** - comfort, lots of variety and several width fittings: [www.paversshoes.tv](http://www.paversshoes.tv)

**Hotters** - Hotter shops and online [www.hottershoes.com/](http://www.hottershoes.com/)

**Varca** sandals are great for summer: [www.varca.com/](http://www.varca.com/)

**Fittflops** are also great for summer: [www.fitflop.com/](http://www.fitflop.com/)

I have also tried **Gabor**, **Riva**, and **Camper**, **M&S** comfort fit.

# fundraising news



We have a limited number of places available for the **Ride London 100** event. This will be a really great day out and will take in much of the Olympic route both in London and Surrey. If you are looking for a challenge and love cycling then this might be the thing for you. We can help to support your fundraising and publicity before the event and will be on hand to make sure that you have a great day. Of the 8 places that we have been allocated, 4 have now been reserved. If you can't do it, we bet you know a keen cyclist who would love to.

**Fifty kilometers in twelve hours or 100km in 24 hours?** That is the challenge. The Thames Path Challenge takes in some fantastic countryside while offering a real challenge. This is not your average countryside walk. The event is fully supported with refreshment stops and help along the course. However, you will need to get into training. You can join the Scleroderma Society Team or walk with a friend or even solo with the company of your ipod. Contact us for details of how you can take part.



Ever thought about a cake sale?

You do not have to run a marathon, jump out of a 'plane or walk for 24 hours to make a difference. Cake sales and coffee mornings might seem old fashioned but they are great fun, sociable and raise vital funds to support people with scleroderma. If you would like some help to run one, we can provide posters, collecting tins and everything else you might need (except the cakes!). Give us a call.

**Thank you.** Donations between 22/09/12 and 31/01/13 were a magnificent £40,985. Thanks to all of you who gave to support the Scleroderma Society. We hope we have included everyone in the list below but apologies if we have left anyone out.

Mrs V Allton, Mrs. Sylvia Anderson, Mrs C Anton, Mr VW Ash, Mr. Nigel Bacon, Mr R Bain, Mrs. Marion Baker, Mrs C Barszcz, Mr A Bell, Mr C Benson, Mrs. Rita Boulton, Mr M Bradshaw, Mr. Alan Brain, Anne Marie Brenchley, Ms D Brett, Mr M Bridges, Ms J Bridgland, Mr Paul Britton, Mr. Jack Brown, Mrs. Chris Buckledee, Mrs. Terry Cane, Mrs. Leslie Case, Mrs S Chapman, Ms Sylvia Child, Mrs E Clifton, Mrs. Rosa Lucia Cole, Mr W Colman, Mr M Constantinou, Mrs J Coppock, Mrs Y Crann, Mr. Downing, Mrs. Jean Elkington, Mrs Loreen Elkington, Miss D Evers, Mr W Ferguson, Ms J Fernandes, Miss G Firth, Mrs. Beryl Fletcher, Mrs. June Gardner, Mrs K Glynn, Mrs P Goodridge, Mrs R Goodwin, David Grimes, Mr B Grimwood, Ms S Groves-Raines, Mrs. BD Guest, Mrs Iris Guscott, Mrs. Doreen Hadland, Miss A Hague, Mrs P Hale, Mr L Harris, Ms Margaret Harriss, Rosemary Heading, Mrs. Barbara Hessey, Mr G Hicks, The Rt. Hon. the Lord Higgins, K.B.E., D.L., Mr Frank Hill, Fedora Hiscock, Mr S Holloway, Mrs S Horn, Mrs. Sue Howat, Mr R Hyde, Mrs. Tracey James, Mrs Christine Jones, P Kennedy, Ms D Kennell, Mrs N Kerr, Mrs. Carol Kinson, Mr M Knights, Miss J Lawlor, Ms H Lester, Mrs Sonia Lewis, Mr D Lomas, Mrs L Lovett, Mr T Lowe, Mrs N Lucas, Mrs JR MacDougal, Mrs L Marsh, Miss L Martin, Dr J McShane, Miss Eileen McSherry, Mrs J Merchant, Mr. Alan Mills, Mrs. J Molloy, Mr W Moore, Miss C Morecroft, Mrs J Muldoon, Mrs Maureen Munks, Mr A Nash, Miss HA Neath, Mr & Mrs S Niechcial, Mrs E Norris, Mrs. Carole Ogilvie, Pauline Pagan, Mrs. Mary Page, Mrs E Peabody, Mr. Oris Pemberton, Mr R Peters, Mrs G Phillips, Mrs R Pitman, Mrs. Diana Platts, Mrs A Raimondi, Mr M Ransom, Ms W Rapa, Mrs S Reid, Mrs J Robinson, Cindy Roch, Mrs Dianne Roebuck, Mrs E Rosato, Dr M Rosendaal, Mrs I Rutherford, Miss JM Rutterford, Ms T Selby, Mrs S Simpson, Mrs. Marjorie Skinner, Mrs RA Smith, Mrs J Smith, Miss J Springett, Mrs Linda Stewart, Mrs. Valerie Storey, Mrs L Sutton, Ms L Taylor, Miss H Thorman, Ms Elizabeth Thornton, Mrs A Thorpe, Mr C Thorpe, Mrs S Turner, Mr D Tyler, Michael Vidler, Mrs K Wade, Mrs Catherine Ward, Mrs. Julie Watson, Mrs. Deborah Webb, Mrs H Webb, Penny Wheeler, Mr D Whitaker, Mrs B White, Mrs. Meg Williams, Mrs J Wilson, Ms H Wilson, Mr J Wilson, Mrs S Wiltshire, Mrs C Winston, Mrs. Lorna Worboys, Mrs. Marion Worledge.



## Skydive for the Scleroderma Society

Did you know that we can now organise for you to skydive for the Scleroderma Society? We can organise sponsored jumps all over the country. If you can raise £350 in sponsorship and would like to make a difference while having the ride of your life why not give it a go.

# GET INVOLVED!

Getting involved with the Scleroderma Society is not all about fundraising - although that is great too. There are plenty of other things that we need help with and plenty of other things that you can do. We need all kinds of skills and all kinds of support. For instance, would you like to be involved in making sure that our publications are useful and accessible? Would you like to help out at our central London office (we can help by paying volunteer travel and lunch) or are there things you would like to do from home such as proof reading or online research for us. We need you and all help - from an hour a month to a lot more is always welcome. We are currently compiling a list of volunteers who are willing to help out in different ways. If you would like to get involved call Amy at the office.

## Resources

From pens to wrist bands to plastic and cardboard collecting boxes. We have resources that can help you raise awareness and funds. Let us know what you need and we will see if we can supply it. We will also create posters and leaflets for your event. Contact Tony for more details.



# Ask a pharmacist

Jay Pang is a Principal Pharmacist in Medical Specialties at the Royal Free Hospital. Jay will be looking at some of the more common medications that are used in scleroderma. This time she looks at common treatments for reflux and other gastric problems

Gastroesophageal reflux disease (GORD) is very common in scleroderma and is the cause of heartburn and acid regurgitation. It is important to treat GORD both for comfort and relief of symptoms, and also to prevent complications such as stricture and oesophageal ulcers. Proton pump inhibitors (PPIs) including omeprazole (Losec) and lansoprazole (Zoton) are the best treatment for these symptoms. They work by reducing the release of acid in the stomach. These medicines should be taken about 30 minutes before food.

If you have problems swallowing, you can ask your Doctor for dispersible tablets which dissolve on your tongue. If you find your symptoms are worse at night, take your PPI in the evening. PPIs are usually taken once daily, but if your symptoms are not controlled then your Doctor may increase your dose or the number of times you take your medicine each day.

You can also take indigestion remedies such as Gaviscon if you find this helpful. These should be taken when symptoms occur or are expected, usually after meals and at bedtime. Antacids may reduce the absorption of your other medicines (including your PPI) so you should leave at least a 2 hour gap before and after taking your indigestion remedy and your other medicines. A large range of antacids are available to buy, and work in slightly different ways. If one is not effective or is causing constipation or diarrhoea, it is useful to discuss this with your Doctor or Pharmacist to look at alternatives. Liquid antacids are also thought to be better than tablet preparations.

If the reflux is still troublesome, your Doctor may add another medicine – the H2 receptor antagonists such as ranitidine (Zantac). These medicines also stop the release of acid into your stomach and act in a different way to the PPIs. Ranitidine is also available as a liquid or dissolvable tablets.

PPIs and H2 receptor antagonists are commonly used drugs which are usually taken long term to treat GORD, and most people do not experience any side effects. Stomach pain, nausea, constipation or diarrhoea may occur in some patients. The PPIs may also reduce the level of magnesium in your blood so your Doctor may do a blood test to check this. Taking a PPI especially over a period of more than one year, may slightly increase your risk of fracture in the hip, wrist or spine. Tell your doctor if you have osteoporosis or if you are taking steroids such as prednisolone as you may need to take medicines to protect your bones.

## faSScinate

A Systemic Sclerosis Research Study is starting recruitment. The faSScinate clinical study is evaluating the safety and efficacy of an investigational medication for patients with systemic sclerosis (sometimes called scleroderma).

Clinical trial participants must:

- Be aged 18 or older
- Have a clinical diagnosis of systemic sclerosis
- Have had systemic sclerosis for less than 5 years

Study participants will receive study related examinations, lab tests, and investigational medication. If you are interested in learning more about the study please visit the following link:

<http://apps.who.int/trialsearch/WA27788> to the World Health Organisation (WHO) international clinical trials registry platform or visit the link to clinicaltrials.gov on <http://www.ClinicalTrials.gov>

To receive further information on the study please email: [global.rocheagentechtrials@roche.com](mailto:global.rocheagentechtrials@roche.com)

See the power of Veil Camouflage Cream



Every month at Veil we highlight a skin problem that Veil Cover Cream can help conceal.

During the month of February we'd like to invite sufferers of Scleroderma to take the Veil Cover Cream Challenge by emailing us at [veil@bim-creative.com](mailto:veil@bim-creative.com)

If you agree to the terms & conditions we'll send you your free sample, so you too can experience the covering power of Veil Camouflage Cream.



[www.veilcovercream.com](http://www.veilcovercream.com)

## local contacts noticeboard

Liz Holloway is our local group co-ordinator. If you need more information on local groups contact the local co-ordinator or [liz@sclerodermasociety.co.uk](mailto:liz@sclerodermasociety.co.uk)

for more information on your local group activity go to our website where each local group has its own page. Please contact us if you would like to start a local group. We will support you to do this and it can be very rewarding. We are particularly in need of a local group in the North East of England.



Remember to sign up for this years Wear Your Gloves

West Sussex Local Group Meeting – 2.30pm on 23rd February 2013 at Findon Garden Centre, Rogers Farm, near Worthing, West Sx. BN14 0RE  
If you would like further details, please phone or email Jo or Lesley or feel free to just turn up on the day (details below.)

### Bedfordshire

Rita Boulton  
Tel: 01767 312544  
[ritaboulton@gmail.com](mailto:ritaboulton@gmail.com)

### Buckinghamshire & Hertfordshire

Marilyn York  
Tel: 077 0259 2387  
[andrewandmarilyn@btinternet.com](mailto:andrewandmarilyn@btinternet.com)

### Derbyshire, South Yorkshire Staffordshire & Cheshire

Diana Twigg  
Tel: 01298 24539  
[diana@sclerodermasociety.co.uk](mailto:diana@sclerodermasociety.co.uk)

### East Anglia

Jacky March  
Tel: 01394 286637  
[jacky@sclerodermasociety.co.uk](mailto:jacky@sclerodermasociety.co.uk)

### East Sussex

Rosanna Cliton  
Tel: 01424 426738  
[rosanna@sclerodermasociety.co.uk](mailto:rosanna@sclerodermasociety.co.uk)

### East Yorkshire

Lynn Hind  
Tel: 01482 354312  
[lynn.hind@hotmail.co.uk](mailto:lynn.hind@hotmail.co.uk)

### Essex, Kent and London

Amanda Thorpe  
Tel: 01702 344925  
[dollydumpling23@gmail.com](mailto:dollydumpling23@gmail.com)

### Hampshire

Tracey James  
Tel: 02392 677476  
[tracey.james93@ntlworld.com](mailto:tracey.james93@ntlworld.com)

### Lancashire and West Yorkshire

Sheila Procter  
Tel: 01282 429004  
[sheila@sclerodermasociety.co.uk](mailto:sheila@sclerodermasociety.co.uk)

### Merseyside

Helen Lingwood  
Tel: 0151 2801194  
[jonandhel@sky.com](mailto:jonandhel@sky.com)

### East Midlands

Cheryl Darch  
Tel: 0116 2717180  
[cheryl@sclerodermasociety.co.uk](mailto:cheryl@sclerodermasociety.co.uk)

### North Wales

Kate A Owen  
Tel: 01492 515834  
[kate.owen09@btinternet.com](mailto:kate.owen09@btinternet.com)

### Oxfordshire & Berkshire

Melanie Bowen  
Tel: 01865 517033  
[melanie@sclerodermasociety.co.uk](mailto:melanie@sclerodermasociety.co.uk)

### Mid Wales & Shropshire

Jennifer Ames  
Tel: 01544 267988  
[ames60@talktalk.net](mailto:ames60@talktalk.net)

### Scotland

Frances Bain  
Tel: 0131 477 1122  
[iainandfrancesbain@msn.com](mailto:iainandfrancesbain@msn.com)

### South London

Celia Bhinda  
Tel: 020 8698 6294  
[mcbhinda@btinternet.com](mailto:mcbhinda@btinternet.com)

### South Wales

Belinda Thomson  
Tel: 02920 625056  
[belinda@sclerodermasociety.co.uk](mailto:belinda@sclerodermasociety.co.uk)

### Surrey

Nicky O'Shea  
Tel: 01483 764524  
[nicky.oshea@live.co.uk](mailto:nicky.oshea@live.co.uk)

### West Sussex

Joint contacts:  
Jo Frowde & Lesley Dodd  
Jo: 01403 741445 or 07922274167  
[jo@sclerodermasociety.co.uk](mailto:jo@sclerodermasociety.co.uk)  
Lesley: 01903 753971  
[lesleydodd@hotmail.co.uk](mailto:lesleydodd@hotmail.co.uk)

### Wiltshire and North Hampshire

Lynn Morton  
Tel: 01980 863444  
[lynnm@sclerodermasociety.co.uk](mailto:lynnm@sclerodermasociety.co.uk)

## Become a Scleroderma Society Champion

We are looking for scleroderma champions. Would you like to be one? It can involve as much or as little time as you can give. Sometimes it will be about writing a letter to your local news paper, at other times it might mean being available to take a call from someone with scleroderma in your county. We are hoping to build a small group of scleroderma champions who can help us spread the word throughout the country. We will provide you with direct support and it will be fun as well as fulfilling. Email us on [info@sclerodermasociety.co.uk](mailto:info@sclerodermasociety.co.uk) or call the office.



# Contacts

## Office

The Scleroderma Society  
Bride House, 18-20 Bride Lane  
London, EC4Y 8EE  
020 7000 1925  
info@sclerodermasociety.co.uk

## Chief Executive

### Mike Rich

020 7000 1925  
07977 487761  
mike@sclerodermasociety.co.uk

## Executive Administrator

### Amy Barrick

020 7000 1925  
amy@sclerodermasociety.co.uk

## Events & Fundraising Administrator

### Tony Myers

020 7000 1925  
tony@sclerodermasociety.co.uk

## Trustees

### Kim Fligelstone (Co-Chair)

020 7229 4750  
kim@sclerodermasociety.co.uk

### Richard Dodds (Co-Chair)

richard@sclerodermasociety.co.uk

### Steve Holloway (Secretary)

steve@sclerodermasociety.co.uk

### Susie Hoare

susie@sclerodermasociety.co.uk

### Helena Rozga

helena@sclerodermasociety.co.uk

## Events Calendar

calendar@sclerodermasociety.co.uk

## Helpline

The Scleroderma Society operates a free helpline. We cannot offer medical advice, but if you feel you need someone to talk to we can be a good listening ear and will help in any way we can, 09:00-21:00 every day. Tel: 0800 311 2756. Calls are free from UK landlines.

## Nurse Specialist Advice Lines

These nurse-led advice lines are for general inquiries only, not emergencies. If the nurse is unavailable, you may need to leave a message so he/she can call you back.

## Liverpool

### Aintree University Hospital

Jan Lamb  
0151 525 5980 bleep 2231

## Bath

### Royal National Hospital for Rheumatic Diseases

Sue Brown  
01225 428823

## Belfast

### Ulster Hospital

Audrey Hamilton  
02890 561310

## Dundee

### Ninewells Hospital

Steve McSwiggan  
01382 633957

## Leeds

### Chapel Allerton Hospital

Elizabeth Tyas  
0113 3923035

## London

### Royal Free Hospital

*Scleroderma queries:*  
020 783 02326  
*Pulmonary hypertension queries:*  
020 7472 6354

## London

### Royal Brompton Hospital

*Respiratory (lung) queries:*  
Lucy Pigram  
07758 8943 175

## Manchester

### Hope Hospital

Liz Wragg and Catherine Lambe  
0161 206 0192

## Newcastle

### Freeman Hospital

*Scleroderma queries:* Karen Walker  
0191 223 1503  
*Pulmonary hypertension queries:*  
Rachael Crackett / Julia De-Spyza  
0191 213 7418

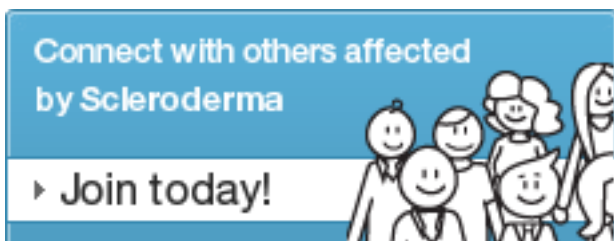
## Portsmouth

### Queen Alexandra Hospital

Paula White / Julie Ingold  
02392 286935

## Carer Support Group

The Carers' support group is run by Michael Thorpe. For more information, please contact Michael.  
01702 344 925  
michael@scleroderma.co.uk



Alongside the ISN Forums the Scleroderma Society have also set up a new and complementary community powered by HealthUnlocked. If you are a Facebook user you may already have seen advertisements for the forum pop up on your page. Why not give both the forums a go. Have a look round and meet and get support from many other people with scleroderma.

[www.sclerodermasociety.org.uk](http://www.sclerodermasociety.org.uk)

[info@sclerodermasociety.co.uk](mailto:info@sclerodermasociety.co.uk)

020 7000 1925

