



The Newsletter of The Scleroderma Society (UK)

A WORD

We have been busy over the past couple of months. January saw FESCA, the Federation for European Scleroderma Associations, meet in Bad Nauheim Germany - see inside for an update. On 31st January the second series of ARMA Standards of Care for Connective Tissue Diseases, Metabolic Bone Disease and Musculoskeletal Pain were launched at the Royal College of Surgeons. We are sending, by separate cover, the connective tissue standards to you direct. However if anyone would like either of the others please get in touch with Jennifer Newell on 020 7842 0910/11 or email jnewell@rheumatology.org.uk

In February the Raynaud's and Scleroderma Association celebrated their 25th Anniversary and the British Skin Foundation had a joint celebration to mark their 10th Anniversary and launch the 2007 Walk For Skin. See registration details enclosed.

Kay Atkin and Sally Saunderson attended a meeting at the National Institute for Clinical Excellence (NICE) in March regarding the PAH appraisal. I know many of you will have received the Impact Questionnaire, which will assist the Pulmonary Hypertension Association to submit useful information regarding treatments for PAH. Many thanks to those members who filled them out. I attended a meeting together with Beata Garay Toth from Hungary at EULAR house on EULAR/EUSTAR treatment recommendations for Scleroderma. This should be out during 2007. There are no miracle cures (what a surprise) but it was so interesting listening to the experts discuss treatments, some of which have no clinical trials to support their use. For example, protein pump inhibitors for oesophageal involvement, yet all the experts and Beata and I know that they work for the majority of people with scleroderma who experience reflux or indigestion.

I still haven't moved! It seems to be taking longer than the gestation of a baby elephant but hopefully by the next newsletter the whole process will be a dim and distant memory.

Happy Easter

Lol Kim

Please send YOUR articles, etc.

for the next issue to Carol Sanders,
The Laurels, Westport, Langport, Somerset.
TA10 0BN Tel: 01460 281305

e-mail roy4sanders@aol.com

Closing date for contributions

15th June 2007

THE SCLERODERMA SOCIETY HAS A NEW ADDRESS PO Box 581, Chichester, PO19 9EW

Goodbye to 3 Caple Road, Harlesden, London, NW10 8AB, the well-known address of the Scleroderma Society for many years. Actually this was Kim's address and Kim is in the process of moving.

The trustees decided that since we were going to have to change all our literature, leaflets, forms etc. we would take the opportunity to set up a PO Box Number address for the society.

THE SCLERODERMA SOCIETY ADVICE LINE HAS ALSO CHANGED

TO A FREEPHONE NUMBER 0800 311 2756

Dialling this number will reach the person on duty or enable a message to be left for them.

We hope you find our new service to be an improvement on what we had before. We believe it will mean fewer lost calls. The previous number was in Kim's house with an answer machine and so had to change.

THE QUARTERLY NEWSLETTER OF THE SCLERODERMA SOCIETY

THE SCLERODERMA SOCIETY

CHARITY REGISTRATION NUMBER: 286736

ADVICE LINE 0800 311 2756

Hours 9.00 till 9.00 7 days per week

www.sclerodermasociety.co.uk

info@sclerodermasociety.co.uk

The Scleroderma Society is not responsible for any information, news or views that appear in this newsletter.

LONDON & SOUTH EAST

Contact: Kim Fligelstone,
info@sclerodermasociety.co.uk
Because of my impending move
subject to contract etc. etc. I do
not have details of my new
address and telephone number;
hopefully this will be rectified
in the next newsletter. Of
course if you need to contact me
use the Advice line and
whoever is on call will take a
message.
Details of the next meeting in
the Summer Edition.

HAMPSHIRE

Contact: Liz and Steve
Holloway,
80 St. Agnes Place
Chichester. PO19 7TU
Tel: 01243 539466
lizemail99@btopenworld.com
Just a reminder that our next
meeting is on Wednesday, May
2nd, at 7.00pm in the Seminar
Room, North Building, Q.A.
Hospital. Paula Parkinson is a
nurse specialist in Pulmonary
Arterial Hypertension and she
has very kindly agreed to tell us
something of her work at Q.A.
Please give me a ring if you
have any queries about finding
the new building.
Tracey James attended a recent
conference as the representative
of the Hants branch. It was
convened by Colin Bevor on
behalf of the Arthritis and
Musculoskeletal Alliance,
working towards improving
health services at the local level.
Tracey will give an outline of
her day at the conference and a
chance to give an opinion on
present and future provision of
services to us.
Steve and I had a great day out
when we went to Brighton to
watch Gemma and Rachel
compete in the Sussex Beacon
half marathon. They raised
over £1700 for the Society.

Area News

Congratulations to both and very many
thanks.

I am delighted to announce that once
again Celia Graham's design has been
chosen to be one of our Christmas cards.
We are looking forward to seeing
everyone in May. In the meantime, best
wishes to all from Liz and Steve.

SOUTH WALES

Contact: Belinda Thomson
39 St Alban Avenue, Heath,
Cardiff, CF14 4AS
Tel: 02920 612690
bigb263@yahoo.com

EDINBURGH & EAST SCOTLAND

Contact: Frances Bain,
5 Swanspring Avenue,
Edinburgh.
EH10 6NL
Tel: 0131 477 1122
iainandfrancesbain@msn.com

GLASGOW & WEST SCOTLAND

For the time being please contact
Frances Bain as above.

DIARY DATES

Royal Free Family Day, in the
Atrium at the Royal Free
Hospital, on Saturday, 12th May.

Scleroderma Society Hampshire
local group on Wednesday 2nd
May.

Scleroderma Society AGM on
28th July. See booking form
enclosed.

*If anyone has any news to
go into this section of the
newsletter please send
details, preferably via
email, to Kim or to Carol
and Roy
roy4sanders@aol.com*

ANNUAL CONFERENCE AND AGM

To celebrate our 25th Anniversary we have a brilliant programme with an
international flavour. We are very excited that we will be joined by:

Dame Professor Carol Black. - also

Professor Marco Matucci Cerinic from Italy -- EUSTAR and Ulcers.

Dr Henry Penn -- Kidneys in Scleroderma.

Sister Naomi Rea -- Quality of Life Study.

And **Sonia Tello** is back by popular demand to inspire us all.

Of course we will have our annual Raffle, Christmas Cards for sale and
Anniversary T-Shirts to buy. We will have a poster exhibition to show
how research funds have been allocated since our 20th Anniversary. And
finally the Question and Answer session with our panel of experts. If you
are not able to join us, please send any questions you would like asked on
your behalf to our new address:

THE SCLERODERMA SOCIETY, PO BOX 581, CHICHESTER, PO19 9EW.

We really do need your booking forms back if you're planning to
come, so that we can cater for the right number of people and make sure
that we have enough chairs for attendees. As we have such a packed
programme we are starting earlier than usual. the AGM will be at
11.30am followed by lunch at midday and a full afternoon programme.

**We have a limited number of parking permits for the AGM. Please notify
Carol and Roy Sanders (contact details on front page) if you would like us
to arrange for a parking permit. We will need your car registration details.
Please note that if you have a disabled Blue Badge you can park in the
hospital grounds so you will not need a parking permit.**

UPDATE ON OBSERVATIONAL STUDY OF TREATMENT OF EARLY DIFFUSE SCLERODERMA

The Scleroderma Society is very generously funding a study investigating the safety and effectiveness of different treatments in people with early diffuse scleroderma. Diffuse scleroderma is that type of scleroderma in which skin thickening often progresses fairly rapidly and involves not only the face, hands, forearms and feet but also the upper arms, trunk and/or thighs. There is much that can be done to help people with scleroderma. For example, there are effective treatments for the oesophageal (gullet) symptoms and treatments which help Raynaud's phenomenon. However, at present there is no treatment which is known to improve or prevent progression of skin thickening in people with diffuse scleroderma.

For this reason in 2001 the UK Systemic Sclerosis Study Group (a group of doctors interested in scleroderma) set up a study to examine the effects of different treatments for diffuse scleroderma. These treatments were selected on the basis that all might be helpful, but required further study. The design of the study is 'observational'. This means that doctors select for each person what they feel is likely to be the best approach to treatment for him/her, and then monitor things carefully according to standard guidelines. Doctors from throughout the UK have

been invited to take part. Because everyone in the study is monitored in the same way, it should be possible to make some comparisons between the different treatments. It must be emphasised that this is not what is called a 'controlled clinical trial'. Some readers will have participated in controlled clinical trials when people are randomised (as in the toss of a coin) to receive either one treatment or another, but usually neither the patient nor the doctor knows which treatment he/she is on. The observational study described here is a different type of study, but nonetheless important information will be obtained.

So far 150 people with diffuse scleroderma have been included into the study. Of these 40 have been followed for 3 years. The variables which we are measuring to check up on progress include the skin score (many readers will be familiar with this, when the doctor pinches the skin at a number of different places to assess the degree of thickening), tests of breathing and of kidney function, and questionnaires about everyday living activities. The study is ongoing. We are currently undertaking some preliminary analysis of the results so far. The study has highlighted to doctors in the UK the importance of careful monitoring of people with early diffuse scleroderma, and should indicate which treatments should be examined further. As always, our ultimate aim is to identify safe and effective treatments. Dr Ariane Herrick

Annual Subscription Renewal

April is the time for annual subscriptions to the Scleroderma Society to be renewed. There are 229 members due to renew this year and I really hope that all of you will think that being a member of the Scleroderma Society is worthwhile and certainly worth £5!

If your subscription renewal is due, you will find a renewal form in the envelope with your newsletter. If you receive the newsletter by email, I will send you a renewal form separately. The renewal form also gives you the option to change the way you pay (i.e. from cheque to Standing Order or vice versa) and to sign up for Gift Aid if you haven't already done so. If there is no renewal form in your envelope, then you are not due to renew this year and no action is required.

Gift Aid

In 2006-07 the society has received over £2,000 in Gift Aid from HM Revenue & Customs (the tax man!). This is a fantastic result and it's thanks to our members and event sponsors who sign up for Gift Aid.

If you are a UK Standard Rate taxpayer, please consider Gift Aiding your subscriptions and other donations if you have not already done so. It means quite simply that the society can claim 28 pence for every £1 you donate, including your subscription. So a £5 subscription becomes £6.40. I have put the necessary form in with your subscription renewal form if you are not already signed up. You only need to sign once. I do the rest!

Data Protection

During the course of the year, the Scleroderma Society has become registered under the Data Protection Act because we keep and process personal information related to your membership of the society on a computer. It is therefore extremely important that this information is as accurate and up to date as possible. To help us achieve this, if your subscription is due for renewal this year, I have enclosed a page in your newsletter envelope showing what information we hold about you. Please check it carefully and let me know of any changes that need to be made by marking the changes on the enclosed sheet and returning it to me.

Steve Holloway 01243 539 466

FESCA UPDATE at GILS International Conference, Milan 10th March 2007

It was a pleasure to attend another GILS conference. I was there in 2005 when Carla first mentioned the possibility of all the Scleroderma organisations in Europe joining together to form an Umbrella Group. I'm very pleased to tell you that this year FESCA, the Federation of European Scleroderma Associations, was registered with the Notary in Belgium. We have 11 member countries at present and hope that more will join. Countries so far are:- Belgium, Cyprus, France, Germany, Holland, Hungary, Ireland, Italy, Portugal, Spain and the UK. We have 14 Associations as Belgium, Italy and the UK have 2 each. This means that each country has two votes.



I am very proud to have been elected the first President of FESCA together with the first Vice President, Ann Tyrell Kennedy from Ireland. The first secretary is Ana Aja Pando from Spain and the first Treasurer is Claude Ginoux from France. Carla has been working on FESCA's logo and almost all members present at our last meeting in Bad Nauheim in Germany have a job to do.

All of us are on a sharp learning curve as an umbrella group is very different from our collective expertise of running national organisations. However, we have a large remit and due to time constraints do not have the time to itemise each objective. Together we will endeavour to promote the advancement of knowledge, research and information in the field of Scleroderma within medical, governmental and social arenas and increase awareness amongst the medical profession and general public. One of our first tasks is to write to the Italian Government to inform them that Scleroderma is a rare condition and needs to be reclassified as such. It is my hope that FESCA will improve parity of care for all people with Scleroderma throughout the EU and indeed the world.

Many thanks for the kind hospitality of GILS.

Kim Fligelstone

Ask The Expert

Q. I have very painful feet - why and what can be done?

A. Pain is due to a combination of factors. There is often loss of connective tissue or the soft padding on the sole of the feet which tends to cushion the pressure between the bones and the floor. So one feels as though one is walking on pebbles and this can be quite painful with the development of hard callous on the sole. We would recommend wearing insoles to the shoes.

Raynauds also contributes to the pain particularly in cold weather and this can be treated with a variety of medications or a lumbar sympathectomy. We are always mindful of the role of the large vessels contributing to the circulation in the feet, so we sometimes arrange to do vascular studies to see if there is an obstruction to these arteries which might be amenable to surgery and thus improve the circulation to the legs and feet as a whole.

Q. What is a lumbar sympathectomy?

A. Normally small arteries or arterioles are kept partially shut by the sympathetic nerves. If the tissues need more blood the nerves become less active and the blood vessels widen in order to let more blood through. The sympathetic nerves travel down the back adjacent to the spinal column. These can be disrupted by an injection of phenol, under local anaesthetic, to improve the symptoms of Raynauds of the feet. This is usually preceded by a temporary injection on one side in order for the patient to experience the benefit before consenting to the permanent injection. Generally some relief is felt immediately but it may take some time before maximum benefit is felt. Side effects include increased dryness of the skin, occasional burning sensation of the extremities and swelling of the legs.

TRUSTEES

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01442 879129

Caren Eales,

AREA CONTACTS (page 2)

Liz Holloway, Belinda Thomson, Frances
Bain.

THE ARMA STANDARDS OF CARE BOOKLET

In the near future (or maybe already) a hefty booklet will arrive on your doormat! This is the 'ARMA Standards of Care' for people with CTD (Connective Tissue Disease). One of a series of standards of care. It is designed to assist people with Scleroderma and other CTDs in leading independent lives. The standards cover three themes:

- Access to information, support and knowledge that optimise health for everyone and enable self-management.
- Access to the right services that enable early diagnosis and treatment.
- Access to ongoing and responsive treatment and support.

The standards are intended to define what services are appropriate under these themes and put forward ways of providing them effectively. They are based on the experiences and preferences of people with CTD and on available evidence and good practice.

The working group convenors included our very own Kim.

So take the time to have a look through the booklet and see if there is anything that will help you in your dealings with the health professionals etc.

And if you do use the standards with some success please let us know!

PEOPLE LOOKING FOR CONTACT WITH OTHERS

Adult en coupe de sabre

New member Roseanne Watson has had Linear scleroderma "en coupe de sabre" since she was a young child but didn't receive a diagnosis until she was 30, around 16 years ago! Roseanne would love to have contact with any adults who have the same condition. You can email Roseanne at: roseannewtsn@yahoo.co.uk or telephone: 01854 612752

CONGRATULATIONS

Congratulations to Dr. Magdalena Dziadzio and Dr. Roy Smith on the birth of their son, Adam, who was born at the Royal Free on 3rd February 2007 and weighed 4.2 Kgs.



18 charities unite in the fight against skin disease

18 national charities have united this year for the 13 sponsored walks all over the UK on 13th and 20th of May in the fight against skin disease.

Thousands of people raised a staggering £160,000 at the first ever ‘Walk for Skin’ last year and hundreds have already registered for this year. All walks are located near cities, but in attractive country-side settings, so walkers can enjoy stunning scenery. Four new venues have been added, including London’s Regent’s Park, Windsor, Manchester and Birmingham. ‘Walk for Skin’ is proudly sponsored by Sanex and hopes to raise awareness and money towards vital research into all skin diseases.

To join the ‘Walk for Skin’, simply choose a venue near you and register free of charge, online at www.walkforskin.org.uk or by phone, on 0207 391 6341. Once registered, entrants will receive a sponsorship form, walkers’ pack and information about their chosen venue.

If anyone is interested in supporting the Scleroderma Society please also contact Caroline Walker at carolinew7@btinternet.com or telephone: 020 8876 1917. If you register on line please remember to add the Scleroderma Society as your charity. This entitles us to 50% of all sponsorship and gift aid raised by our supporters and please let Caroline know so that we can keep track of our fund-raisers.

Venues:

Sunday May 13th	Sunday May 20th
Newcastle- Beamish, Open Air Museum	Southampton- Beaulieu Motor Museum
Nottingham- Wollaton Deer Park	Cardiff- Cosmeston Lakes Country Park
Leeds- Bramham Park	Cheddar Gorge- Somerset
Norwich- University of East Anglia	Manchester- Tatton Park
Belfast- Belfast Castle	Windsor- Windsor Great Park
Edinburgh- Holyrood Park	London- Regent’s Park
	Birmingham- Lickey Hills Country Park

Charities involved:

- | | | |
|--------------------------|--|--------------------------------|
| British Skin Foundation | Vulval Health Awareness Campaign | Acne Support Group |
| National Eczema Society | Alopecia Help and Advice Scotland | Birthmark Support Group |
| Psoriasis Association | Hyperhidrosis Support Group | Herpes Virus Association |
| Scleroderma Society | British Association of Skin Camouflage | Psoriatic Arthropathy Alliance |
| Vitiligo Society | Wessex Cancer Trust’s MARC’s Line | Psoriasis Scotland |
| Ichthyosis Support Group | Pemphigus Vulgaris Network | Arthritis Link Volunteers |
| Changing Faces | | |

Join the ‘Walk for Skin’ and ease the suffering of people whose lives are blighted by skin disease.

SCLERODERMA SOCIETY FUNDRAISING

In recent years we have noticed an increase in the number of people, particularly members and their families, who have started and got involved in all kinds of fundraising activities for the Scleroderma Society. The money raised has enabled the society to go from strength to strength, supporting people with scleroderma, creating and improving awareness of scleroderma and funding medical and scientific research.

Fund-raisers often seek our support. For example they need sponsorship forms, T-shirts, leaflets, collecting boxes, etc.

Earlier this year the trustees decided that the society could benefit from the advice and help of a fundraising co-ordinator – someone who had experience of charitable fundraising, who could be our focal point when members and others ask for support for their fundraising activities. We also wanted that person to help us identify fundraising opportunities so that we could be proactive and not just wait for fund-raisers to approach us.

We are delighted to announce that member **Louise Cecil**, has agreed to take on this role for us. Louise has recent experience in the voluntary sector including capital campaign fundraising for the Hospice of St Francis near where she lives in

Berkhamstead. She also has many years' experience working in local government. Louise is already enthusiastically involved in helping us to improve the way we support fund-raisers and the trustees welcome her to the team on behalf of all members.

If you have ideas for fundraising activities, or if you would like support from the Scleroderma Society for a particular activity, please contact Louise direct, either by telephone on **01442 879129** or by email to fundraising@sclerodermasociety.co.uk

In future newsletters we are planning to have a fundraising section where Louise will keep us up to date with what's going on and feature fund-raisers and their outstanding efforts on behalf of the scleroderma society.

Louise is waiting to hear from you!



Fundraising for Scleroderma in Cheriton, Hampshire

I have been asked to write about our sale for the Newsletter and am happy to share this with you. On the afternoon of February 3rd this year the grand sum of £1,270 was raised at a Fayre in Cheriton Village Hall.

We started planning the event nearly six months in advance as the popular village hall had to be booked early. The last sale we held in Cheriton for the Scleroderma Society was in the summer season when there were lots of other fetes etc. So we thought that February was perhaps a better time of year for a fund raising event and we were proved right. Many people called to say they had unwanted gifts from Christmas or were turning out their kitchens, cupboards, lofts or their children's toy boxes etc. and very kindly donated their excess goods to the sale.

The sale was advertised for free for the two months before the date in the Cheriton Church and Village monthly magazine, in the nearest small town's 'What's On' magazine and on the village notice boards. The Hampshire Chronicle (our local newspaper) advertises events free for registered charities and we took advantage of this. We were also helped by the local 'Radio Solent' because they will broadcast a charity event a day or two before it happens.

Good friends and family rose to the challenge of helping on the day, if they were asked in good time.

We would never have managed without them. So many kind hearted, generous people from across the local area donated goods for sale on the various stalls. We were given four water colour paintings of houses in the village executed by a local amateur artist. Rather than put them in the sale, the owners of the houses were asked if they would like a pre-sale viewing and three of the paintings were snapped up for £125. A brand new sheepskin coat raised £40 (a bargain!) and an almost new lady's bike another £35. Rather than putting new or nearly new goods on the general bric-a-brac stall, a separate stall was set up and the dealers and bargain hunters made for this stall and it took over £300. The cake and provision stall was well supplied by the many good cooks in the area and quickly sold out. The books, tapes and CDs sold very well as did the toys. We received some great help from a gentleman who told us to put up the prices for the Star Wars and other film toys as they were collectable. He was right and we were most grateful.

The cream teas went down well, even in February! We let a stall to a lady selling Australian cosmetics and she put on a £1 a go lucky dip for us, which also gave her some new clients.

Last, but by no means least, was the success of the yellow Scleroderma Information Book Marks which were distributed to those who came to buy. Many more people now know something about Scleroderma and the Society, which can only be a good thing. Sincere thanks to all who helped make the sale such a success.

Pat Culpin and family.

RECENT DONATIONS

Eveline Bowditch, Trinant Ladies Club £50.

£425 from Friends and relatives of Mr and Mrs M Ransom (Maureen is a new member), in lieu of gifts on their 50th anniversary.

£47 from Justin Terry raised at a book event, where Justin works, in memory of his father Derek.

Mr and Mrs Whitmore, in memory of Brian Walmsley's mother who died recently - £20.

Doreen Hadland and friends in memory of Doreen's husband Derek - £50.

Staff Nurse Anita Haughton and nurses, in lieu of sending each other Xmas cards - £100.

Lee Todd, won £30 in a competition at work which he kindly donated.

A donation of £750 from Mr Nigel Mills in memory of his mother Rosemary.

Congratulations to Pat and Ray Griffiths from Llanelli who celebrated their Ruby Wedding Anniversary on March 4th. Pat and Ray asked their friends and family for donations to the Society instead of presents, in memory of Pat's sister, Arona Lynette

Williams, and we were delighted to receive £550. Thanks to the St Albans Parent and Toddler Group who sent £33 from their Christmas raffle.

Yvette Sagers has now raised £810 from her beautiful hand made cards. Contact Yvette Tel: 01768 894057 or 07984831221. Belinda Thomson's son Alex Thomson and Hairdresser Andrew Picket took part in two separate fundraising activities and raised £300 - thanks to you both. Rachel Wade & Gemma Terry raised over £1700 for the Scleroderma Society in memory of their uncle Derek Terry, by completing the Sussex Beacon half marathon in Brighton in March. It was a fantastic effort by both girls, neither of whom had ever run anything like this distance before. Apparently they now have the running bug so we can expect to see more of them in the future! Well done Rachel & Gemma, and thank you from the Scleroderma Society

On 7th March, Liz and I gave a talk to the 'Out and About Social Club' in Liphook, Hampshire, about scleroderma, the work of the Scleroderma Society, and what it's like to have scleroderma. The Out & About Social Club donate their surplus funds to charity every year, and this year they very generously donated £500 to the Scleroderma Society. Mr Malcolm Meech, the chairman of Out and About presented the cheque. I would like to thank Malcolm and his committee and members for this kind donation. A special thank you to Ann and Bob Hall, members of the Scleroderma Society and committee members of the Out and About Club for promoting our cause. Liz and I enjoyed meeting the 60 or so people who turned up, most of whom had never heard of scleroderma before. We also enjoyed a lovely cheese & wine supper laid on by the club!

Steve Holloway

2007 Flora London Marathon

Please support our London Marathon runner, Richard Bennett. Richard is well on track with his preparations for the big event on 22nd April. Richard is aiming to raise at least £2,000 for the Scleroderma Society. Anyone can sponsor Richard and the easiest way is to visit his web page www.justgiving.com/richbenn where you read about Richard and why he is running the marathon, and you can sponsor him on line with a secure credit card transaction. Better still, send this link to your friends by email and ask them to support Richard too. The society only gets one guaranteed entry to the London Marathon every 5 years, so we need to make the most of this fantastic fundraising opportunity.

If you use the INTERNET, please JOIN EVERYCLICK. Everyclick is an Internet search engine that is free to join and free to use.

If you join as a Scleroderma Society supporter, the society gets money every time you make a search. So far we have 27 supporters who have raised £133. Go to

<http://www.everyclick.co.uk/uk/thescclerodermasociety>

USED POSTAGE STAMPS REMINDER

Member, Alison McGlashan of 10 Bothlyn Ave., Kirkintilloch, G66 3DU, telephone 0141 7752777, is still collecting used postage stamps on behalf of the Society. Please ensure that you have paid enough postage. If you are in the post office and they give you a label rather than stamps you can request stamps instead. The only sorting needed is into Foreign and British stamps, so please support her. alisonmcglashan@btinternet.com

Nurse Specialist Advice Lines

Rona McIvor

Woolmanhill Hospital, Aberdeen
01224 555 403

Sue Brown

RNHRD, Bath 01225 428823

Karen Walker (Scleroderma)

Freeman Hospital, Newcastle Upon Tyne
0191 2231503

Rachael Crackett & Julia De-Soyza (Pulmonary Hypertension)

Freeman Hospital, Newcastle Upon Tyne
0191 213 7418

Liz Wragg

Hope Hospital, Manchester 0161 206 0192

Sally Smith

General Infirmary, Leeds 0113 3922189

Steve McSwiggan

Ninewells Hospital, Dundee 01382 633957

Royal Free Hospital, London

Scleroderma 020 78302326

Pulmonary Hypertension 020 7472 6354

Lung Enquiries only - **Ross Ellis**

Brompton Hospital, London 020 7352 8121

(Bleep 7112)

Sally Marsh

Northampton General 01604 523849

Audrey Hamilton

Ulster Hospital **Belfast** 02890 561310

The Nurse Specialist Advice Lines are part funded by the Raynaud's and Scleroderma Association. **Please**

Note: These advice lines are for general inquiries.

Unfortunately it is impossible for any health professional to comment on individual treatment without seeing the patient.

If there is no reply, please leave a message with your telephone number.