

The Newsletter of The Scleroderma Society (UK)

A WORD

In January the Society attended a one-day conference at the Royal College of Physicians entitled "Working together to improve Rheumatology services". Three sessions focused on the particular viewpoints of people with musculoskeletal conditions, commissioners, clinicians and policy makers. Each gave their own perspective on current rheumatology services and the changes they thought needed to be made to improve services. I also attended a meeting in Florence, with a number of European scleroderma organisations, where we discussed the possibility of setting up a European Scleroderma Federation. If any one reading this has any expertise in setting up an Umbrella Group within Europe and would be willing to offer assistance please contact the Society.

February saw Jean Pearson and I attending Naomi Reay's scleroderma meeting in Halifax. It was well supported with some great talks and a lovely opportunity to meet up with Jennifer Ames and her husband who, like me, combined the meeting with a visit to family and friends. Jennifer lives in Powys, Wales and finds it hard to travel to meetings because of the distances involved.

March/April will see a new information leaflet "Scleroderma and the Fingers" and two updated leaflets, "Pulmonary Hypertension in Scleroderma" and "Scleroderma and the Foot". These are available free - just send an A5 SAE stating which one/s you would like.

ARMA networks (see page 3) in Morecambe Bay and South Birmingham would love to have someone from the Scleroderma Society involved. Are there any members in these areas who might be interested?

You will find enclosed a booking form for the AGM, which is on Saturday 29th July 2006. We have a person speaking about their experience of living and working with scleroderma, a Nurse Specialist and Clinical Scientist (Kevin Howel) as well as the Raffle and Q&A session. If you are not able to come to the AGM please do not hesitate to send in your questions.

Please don't forget to send articles for the newsletter to Carol and Roy, whom I am sure you will agree, are continuing to do a splendid job as our newsletter editors.

I hope by the time this reaches you Spring will be well and truly upon us.

Lol Kim

THE QUARTERLY NEWSLETTER OF THE SCLERODERMA SOCIETY

CHARITY REGISTRATION NUMBER: 286736

The Scleroderma Society 020 8961 4912

Helpline 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.

HELPERS AND LOCAL CONTACTS NEEDED

The work of the society involves attendance at various meetings to represent the interests of scleroderma patients. Would any members be willing to help with this work? If you would please contact Kim.

The Society would also love to have more local contacts in and around the country to help people with scleroderma meet up at a local level. If you would like to start a local group and want to know what it entails why don't you contact one of our local group contacts for more information.

Please send YOUR articles, etc.

for the next issue to Carol Sanders,
The Laurels, Westport, Langport, Somerset.

TA10 OBN Tel: 01460 281305

e-mail roy4sanders@aol.com

Closing date for contributions

16th June 2006

Area News

Hampshire

Contact: Liz and Steve
Holloway,
80, St. Agnes Place
Chichester. PO19 7TU
Tel: 01243 539466
lizemail99@btopenworld.com

The next meeting will be on Wednesday May 17th, at 7.00pm in the Orthopaedic Seminar Room on D level, Q.A. hospital. Colin Beevor, who most people already know and appreciate, is going to tell us about his job as a modern matron at QA. He will also be able to bring us up to date with all the changes going on there.

Any members, friends and family are very welcome. We look forward to seeing you. All our best wishes till then,
Liz and Steve

London & South East

Contact: Kim Fligelstone,
3 Caple Rd, Harlesden,
London. NW10 8AB
Tel: 020 8965 4094
info@sclerodermasociety.co.uk

The details of the next meeting will be in the Summer Edition of the Newsletter.

Edinburgh and East Scotland

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

Glasgow and West Scotland

For the time being please contact Frances Bain as Betsey Stephenson is recuperating from an extended hospital stay and operation earlier this year. Get well soon Betsey!

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

FROM THE MEMBERSHIP SECRETARY

It's subscription renewal time again! If you are due to renew your subscription, you will find two forms in the envelope with your newsletter. If there are no forms then you are not due to renew! The first form is for renewing your membership. The second is a record of the information we hold about you in our membership records.

Please will you check the details and make corrections if necessary? Please then sign both forms and return them to me.

Members who receive their newsletter by email will receive these forms in the post. Life and Honorary members will receive the second form only with their copy of the newsletter. I look forward to hearing from you all very soon!

Best wishes,
Steve Holloway,
Membership Secretary

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

Our AGM will be on Saturday the 29th July, at the Royal Free Hospital. Please let us know if you have a topic that you would like covered at the meeting.

Portsmouth Skin Information Day, at Portsmouth University on Saturday 8th April.

Royal Free Family Day, in the Atrium at the Royal Free Hospital on Saturday 13th May.

Scleroderma Society Hampshire local group on Wednesday 17th May, see Area News.

SAD NEWS

Our sincere condolences go to the families of Rosemary Mills, Patricia Saggars and Anita Stenhouse who have sadly passed away.

Many thanks to family and friends of Rosemary and Patricia who sent donations in their memory.

RECLAIMING TRAVEL EXPENSES FOR HOSPITAL NHS

APPOINTMENTS:

Patients can reclaim travel expenses if they are receiving any of the following types of benefit:

Income support
HG2 or HG3 certificate
Jobseeker's allowance – income based.

Working families tax credit or disabled tax credit.
Tax credit exemption certificate
Pension credit.

In order to reclaim fares for public transport costs, ask a member of staff in the department you are attending, to complete a travel expenses claim form, which they will have copies of. This confirms your attendance on the day.

NEW PATIENT'S CORNER

So here I am – a “new kid on the block” – recently diagnosed anyway – and looking forward to creating a positive side to this condition. I want to use all I can from my background – as a mother and grandmother, as a Human Resources professional for over 25 years, as a Pulmonary Hypertension patient, as a daughter whose mother also had Raynaud's and scleroderma over 30 years ago and now as a Raynaud's / scleroderma patient myself with the added concern that my own daughter has also developed Raynaud's.

All these experiences, I hope, can be converted into knowledge and actions that will enable me to understand and cope with my own condition and changes that will take place over the coming years. Keeping ahead of developments for my daughter as well as helping others. I would like to find out more about this condition. Perhaps by meeting up with other patients local to myself. I live near Stamford and could drive to anyone else within reasonable distance, who would welcome a visitor / fellow patient. Or perhaps we could get together a small local group. Or if you prefer just a conversation, then my phone number is available below, and of course there is always email!

I would also like to form links between the groups with which I am currently involved. I have recently taken over the leadership of the Papworth Support Group and hope to increase participation by the members. I have also joined the Patient Experience Panel based at Papworth Hospital and am involved with the Pulmonary Hypertension Association. At the excellent Annual Conference last October I met up with a small group of fellow PH / scleroderma patients and we exchanged some information but this was limited by the short time available. Perhaps this year's Conference (October 6th to 8th) to be held in Nottingham will allow more structured time for discussions within sub-groups like ours. If I get some interest from you about this I could lobby the Conference organisers on our behalf!

The PHA 'Inaugural Meeting' to lobby for direct funding for treatments was held at the Houses of Parliament last December. It was attended by MPs, PH patients and carers plus clinicians - over 150 in total. I was asked to speak about my experiences of diagnosis and treatment as an example of the experiences of most other PH patients. It took four years with initial diagnosis of hay-fever then marginal asthma to explain my breathlessness and fatigue until a deep vein thrombosis and pulmonary emboli prompted the battery of tests to confirm my real condition of Pulmonary Hypertension.

As I moved house at the end of last year I had to “take a rain check” on the voluntary work I had undertaken on the Greeter desk. This year Papworth have decided not to run the Annual Fund-raising Fete. So I will not need to make the many, many phone calls I made last year asking for free plants which helped us to raise a record amount for plant sales on the fete day. I am sure though that other opportunities will arise and if this article does prompt any interest, ideas or questions, please contact me – I would love to hear from you. Kay Atkin

01780 444345 kay.atkin@btinternet.com.



ARMA Local Networks

Arthritis and Musculoskeletal Alliance

ARMA UK is currently developing Local Networks across England in a Department of Health-funded project that brings together service users, clinicians and allied health professionals to improve local service provision. In addition to monitoring local developments, the networks will press for the implementation of ARMA's Standards of Care and other national policy initiatives, and campaign on local service issues for people with musculoskeletal conditions.

All ARMA member organisations are invited to nominate a local representative to each Local Network site. We are also looking for champions to start new ARMA Local Networks in 2006. If you would like to get involved in an existing network or find out about starting a network in your area, please contact the ARMA Local Networks Project Manager, Gillian Econopouly on 0207 842 0910 or by email at geconopouly@rheumatology.org.uk

Current sites:

South Birmingham, Leeds, Morecambe Bay, Norfolk & Norwich, Nottinghamshire, North Yorkshire, Truro and Whipps Cross (East London)

CALCINOSIS

Summary of the talk presented to the London and South East Group by Geraldine Brough

Calcinosis is a significant source of pain and disability in patients with scleroderma. As yet there is no known cure. The literature reveals a paucity of studies of its treatment. There are no pharmacological treatments to prevent or eliminate calcinosis. Reported rates of calcinosis in scleroderma patients vary between 20 and 40 percent. Yet Xrays confirm an additional 20 percent making the prevalence probably much higher.

Scleroderma is not the only connective tissue disease associated with calcinosis. Reports indicate about 17 percent of patients with systemic lupus erythematosus and between 30 and 70 percent of patients with dermatomyositis are affected by this condition.

So, what do we know about the causes of calcinosis? It is known to occur in damaged tissue for whatever reason and also in low vascularised tissue. So does hypoxia, or low oxygenation, play a role? We know that there seems to be a relationship between calcinosis and severe Raynaud's.

Calcium and phosphate in normal tissues are close to their saturation. Abnormal levels of calcium and phosphorus will lead to calcification in normal tissues. Such conditions arise in hyperparathyroidism and in some cases of malignant cancer where there is an associated rise in serum calcium. Calcification is then found as firm nodules located just below the skin around the large joints.

In renal failure, where there is again alteration of concentration of calcium and phosphorus, calcification occurs in the blood vessel walls leading to thrombosis and death of tissues which are supplied by those vessels.

In connective tissue diseases such as systemic sclerosis the calcium/ phosphorus levels in the blood are normal and calcinosis usually occurs around pressure sites such as finger tips, forearms, elbows, ears, buttocks, hips, knees and feet where it usually arises as nodules, plaques or large masses. Many of these sites are in the periphery and therefore subject to poorer circulation and reduced temperatures. These factors are all thought to contribute to calcinosis formation.

So what treatments have been tried and do we have any evidence of their effectiveness or even of their mechanism of action?

There are anecdotal reports for the use of Warfarin, colchicine and probenecid (drugs used in acute gout), bisphosphonates (normally used for the treatment of osteoporosis), anti-TNF agents (used in rheumatoid arthritis) and diltiazem (a calcium channel blocker used extensively in the treatment of hypertension and for effective relief of Raynaud's phenomenon).

Surgical treatment (occasionally with the use of a dental drill) is effective for temporarily debulking larger troublesome lesions, while smaller superficial lesions may respond to carbon dioxide laser.

Recent studies (Shetty S et al), using a small number of patients, have looked at driving a small current into the skin and replacing the calcium carbonate with acetate to form a more soluble compound. Ultrasound was then applied. Results showed only a small reduction of calcium on Xray and further studies are ongoing.

Minocycline is known to have antibiotic, anti-inflammatory and calcium binding activities as well as inhibiting some of the enzymes associated with laying down excess collagen. We have tried this in a number of patients in our unit with reduction in inflammation and possible progression of calcinotic lesions in a few who could tolerate this treatment. However the effects are small and we still do not have either an effective treatment or adequate mechanisms to prevent calcinosis occurring.

We do know however that if and when these lesions become infected, they should be treated early with the most appropriate antibiotic for an adequate period of time in order to affect the best outcome for the patient in terms of pain relief and restoration of function.

References:

Calcinosis in Rheumatic Diseases N.Boulman et al. *Seminars in Arthritis and Rheumatism* 2005

Treatment of cutaneous calcinosis in limited systemic sclerosis with minocycline. L.P Robertson et al *Annals of Rheumatic Diseases* 2003; 62:267-269

A pilot study of acetic acid iontophoresis and ultrasound in the treatment of systemic sclerosis-related calcinosis. *Rheumatology(Oxford)* 2005 April;44(4)536-538. Epub 2005 Jan.11

QUALITY OF LIFE IN SCLERODERMA

It will come as no surprise to know that there is an understanding that Scleroderma may affect your Quality of Life (QoL). As a Specialist Nurse in Scleroderma, the potential impact of this disease has become more and more evident to me over my years working with people who have Scleroderma. One of the vital things which appears to be missing from our armoury of assessments of this disease is a measure which can tell us how it affects the persons QoL instead of solely physical function or laboratory investigations.

With this in mind, I began a pilot study into the effects of Scleroderma on QoL in 2002 as part of a Masters degree. I am now taking this forward into the development of a measure/questionnaire which aims to capture the impact of Scleroderma on your QoL. This has been kindly supported by the Scleroderma Society and the School of Healthcare in the University of Leeds where I am based as a PhD student. Dr Chris Denton of The Royal Free Hospital, which holds the National Scleroderma Database, has also been supportive in this project and I am currently seeking approvals to allow me to work with The Royal Free Hospital in the development of this questionnaire.

So, I am grateful to yourselves and the Society both for your support and for this opportunity to update you as to my progress. The information which forms the basis of this questionnaire is gathered from people with Scleroderma through interviews or focus groups. So far, 24 interviews have been carried out and one focus group. The information people have given me has been both immense and enlightening and after completing several more interviews I will have enough information to form the first stage of the questionnaire.

Turning this information into a questionnaire which is statistically significant is the tricky part, and this will take place with support from the Psychometric Testing Laboratory based at the University of Leeds and headed by Professor Alan Tennant. This process will involve sending out hundreds of copies of the pilot questionnaire and other questionnaires already in use. This will be keeping me busy well into next year!

If you receive a questionnaire it would be greatly appreciated if you could complete and return it. It is vital to the progress of developing a QoL measure designed specifically to identify the impact of Scleroderma. It is hoped that this measure will be completed by the end of 2006 and I will keep you updated as to its progress.

Thanks to you all.

Naomi Reay RGN, RSCN, DN, SRCh, BSc, MA
University of Leeds

MARATHON ?

"Why would anyone want to run 26 miles 385 yards? It is a question that I have often asked myself when watching the pain and discomfort on TV that people are so evidently suffering with when taking part in the London Marathon. It is only when you talk to such people that you realise that each person has their own individual reason for pushing themselves to their physical limit. It maybe a lifetime's ambition, a physical challenge or in more cases than not to try and help a specific charitable cause, and this was certainly the major driver in my case. I wasn't brave enough to take on a full marathon but instead spent two of the first three Sundays in October running half marathons in firstly Bristol and then Swindon. Training had gone well throughout the summer. I was feeling good and bizarrely looking forward to putting my mind and body through such a torture. Then towards the end of August I picked up a case of shin splints! Shin splints? If I was going to get an injury, the least I wanted was something to show for my endeavour, a really nasty graze or a large dark blue bruise which would merit some sympathy but Shin Splints! I can assure you though, they do hurt and the only cure apart from the odd bit of physio and an ice pack is complete rest, which when you are planning to run more than 13 miles is not the ideal preparation. This rest though did give me the opportunity to learn more about Scleroderma as a result of my sister-in-law who was, and still is, suffering from a number of its debilitating symptoms. I must confess that I was blissfully unaware of its effect on an active middle aged mother of one. It had effected her to the extent that she is on the waiting list for a lung transplant, to help lengthen her life, and the Winter in particular is very hard going. It was this personal sense of wanting to do something to help that prompted me to run, not only for Joanne but also for the Scleroderma Society. I would be a liar if I was to say that running two half marathons was easy. however when compared to someone like Joanne, who has to deal with this condition on a daily basis and does so in such an unassuming and positive way, then my task does not compare in any shape or form. The work of the Scleroderma Society deserves increased awareness and I am certain that the funds that people are willing to raise or donate will be put to good use to try and lessen the suffering of the thousands of those people who are coping with this condition."

Simon Hawkins www.charitybusiness.com

E-mail addresses of members happy for contact-

POST CODE INFORMATION

As you see we have added the post code areas for those members who have given us their permission.

We hope that this will encourage members to communicate with others in their area. Please check your entry and if we have it wrong please let us know and we will try to get it right in the next edition of the newsletter.

roy4sanders@aol.com

COMMITTEE MEMBERS

Chair - Kim Fligelstone, 3 Caple Road, Harlesden, London. NW10 8AB 020 8965 4094

Treasurer - Simon Barrell, 11 Connaught Gardens, Berkhamsted, Herts. HP4 1SF

Membership Secretary - Steve Holloway, 80 St Agnes Place, Chichester, West Sussex, PO19 7TU. 01243 539466.

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Sally Saunderson, 5 Freshwood Drive, Hampshire, GU46 6DH. 01252 640330

Caroline Walker, 23 Meredyth Road, Barnes, London SW13 0DS 020 8876 1917

Area Contacts (*details see P 2*) Liz

Holloway, Belinda Thomson, Frances Bain, Betsey Stephenson.

PEOPLE LOOKING FOR CONTACT WITH OTHERS

Mrs June Gardner, 12 Rochford Way, Frinton Homelands, Walton-on-Naze, Essex, CO14 8RN. Tel: 01255 672510 would love to hear from anyone with scleroderma who lives nearby.

Does anyone know where you can buy a muff? If so please contact Valerie and Tommy Drogman on 02476 543791

FUNDRAISING

Many thanks to all fundraisers. Your efforts are really appreciated! Apologies if space doesn't allow us to print your name.

Handmade cards (From Yvette Sagers)

"I wanted to raise some more money after the balloon race. I feel that by raising money each year for scleroderma, I am trying to make a small difference. So, after much thought, I decided to make Christmas cards. I didn't have any idea if I would make any money, but I thought I would give it a go as I enjoy being creative. I have sold the cards at local shows during the summer. However I felt I needed to extend my range of cards-making baby cards, blank cards suitable for birthdays, weddings, anniversaries and specialist cards for specific people. Since making the cards I have made £200 for the Scleroderma Society and continue to sell them in local shops.

Not only do I hope to make lots of money for the Society in memory of my brother Simon who died two and a half years ago from the disease but also I hope they will create more awareness of scleroderma. I hope that people who receive the cards wonder what scleroderma is and attempt to find out about it.

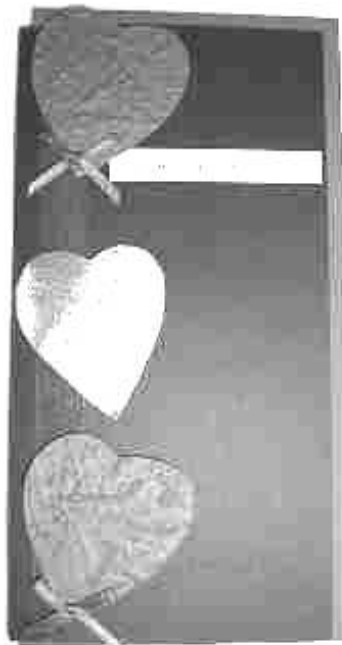
If anybody would like to buy the cards they are sold at £1.50 each or £5.00 for a pack of 5 plus postage. I am able to make bigger cards, but they will obviously cost more.

If any one does want to buy any cards, ring me on 07984 831221 or 017683 52483. Leave a message if I am not available and I will get back to you. All the proceeds will go to the Society."

I have bought some of Yvettes cards and they are beautifully made, Kim

Dorset Charity Day

Monica Watson and her friend Sandie organised another Charity Day on December 2nd for scleroderma and a local children's hospice. They changed the date to December hoping to catch the Christmas Shoppers. Here's what happened:



"The charity day went well – considering... talk about the WORST weather this year! Rain and wind hit Dorset in gale proportions and it really showed in the number of people who came through the door. I had to swallow my disappointment and just hoped people would hang about inside and spend, spend, spend. How mercenary! Luckily everyone did - we had twelve brilliant stands – so much more professional than last year (one girl is apparently selling her jewellery to Liberty's).

On a positive note, we DID make money on the day, and everyone thoroughly enjoyed it as the hall was very cosy-warm and we provided lunches and the usual endless cakes..."

Monica
I should say the day went very well indeed, the Society received a cheque for £1,250!

Simon Hawkins raised £ 389 participating in two half marathons, see his account on Page 5.

Thanks to **Actelion Pharmaceuticals UK Ltd** who instead of sending out Christmas cards sent a donation of £100.

Diane Platts continues to sell bits of cars and cakes £60.

Mr and Mrs James saved £5.35 from coppers.

Mrs Bridges sent £10.

Jane Inight's popular notelets completely sold out at last year's Summer Fair and Jane will be sending some new designs in time for the Royal Free Family Day on May 13th.

Helen Cannon's husband raised £250 in sponsorship for a 10km race.

The Fountain Inn in Pontdardulais sent us £500 from various fund raising events.

The Annual **Simon Sagers Formula 1 Trophy** competition raised £70.

Jim Carver whom you may remember makes and refurbishes specialist Umbrellas gave two talks and sent us £50.

Diane and Richard Horner from the White Heart Inn, Hawes, West Yorkshire, raised £385 from various activities including collection box no 34 and Richard's annual birthday barbecue.

A huge thank you to **Gant UK Ltd** who recently had a mid season sale in Victoria and asked their customers for a £2 donation to the Society.

Caroline Walker and Kim went along over the three day period to hand out information about scleroderma and the Society. It was worth them being there just to raise awareness but the icing on the cake was a cheque for £4,850. Special thanks to Nick Drogman whose mother Valerie has scleroderma.

Ask The Expert

Q. What is the similarity between gout and scleroderma?

A. They are of course very different diseases but they both have the tendency in a few patients to precipitate calcific deposits in the skin. About one fifth of patients with scleroderma will have calcification overlying pressure areas in the skin which are often painful and difficult to eradicate. In gout some patients with long standing disease will deposit urate in the skin over joints and again pressure areas. These may be removed by appropriate treatment of their gout.

Q. I have localized scleroderma and have had a cataract operation. I now have a film appearing over the same eye and wonder if it's connected with scleroderma?

A. The first thing to emphasise here is that localized scleroderma does not affect other organs other than skin and underlying muscles and occasionally growing bones in children. If you have noticed any new symptoms following your recent surgery you should consult your doctor who will refer you either to an ophthalmologist or back to the surgeon who operated on you. It may be something very simple like dry eyes which is common and often presents with the symptoms you describe but eyes are special and you should always seek expert advice when it comes to eye symptoms.

Q. Are yellow eyeballs a sign of scleroderma?

A. Yellow eyeballs are usually a sign of advanced jaundice if they are truly yellow. Some people have a suggestion of a yellow tint to the eye but may not be jaundiced. There is an association between some types of liver disease and scleroderma. You would be well advised to talk to your doctor who can confirm whether your symptoms are truly significant / pathological. He may well use a blood test to confirm this.

Q. Does scleroderma cause the ageing process?

A. No we are all undergoing the ageing process. If you mean by ageing the normal aches and pains associated with getting older we know that there is an increased incidence of musculo-skeletal problems associated with systemic sclerosis and again you would be advised to seek medical opinion in case the symptoms you are experiencing are due to another medical problem which requires diagnosis and appropriate treatment.

Nurse Specialist Helplines



Anabel Smith

Woolmar Hill Hospital, **Aberdeen**
01224 555 403

Sue Brown

RNHRD, **Bath** 01225 447997

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 545531

Audrey Hamilton

Ulster Hospital **Belfast** 02890 561310

The Nurse Specialist Helplines are part funded by the Raynaud's and Scleroderma Association.

Please Note: These helplines 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.