

The Newsletter of The Scleroderma Society (UK)

A Word from Kim

April was quite a busy time: I went to Milan to the 11th Giornata Italiana per La Lotta alla Sclerodermia (GILS) annual meeting representing the Society. Also there was the Association Des Sclérodermiques De France, the Scleroderma Foundation from the USA and the Association Romande des Sclérodermiques from Switzerland. The meeting was well attended with around 500 attendees. Fortunately Carla Crosti the president of GILS who organised the meeting, included translators. This made life much easier for us all. We each did a presentation about how our respective organisations functioned and I guess it's no surprise that we all had similar goals. To help people with scleroderma, to educate and raise awareness of scleroderma and to raise funds for research. Then it was back to the UK and off to the British Society for Rheumatology Annual Meeting in Birmingham, where we had a stand with our user information leaflets to give to doctors & health professionals. At the end of the BSR I drove down the M5 and M4 to Cardiff to stay with Belinda as we were attending the 'Skin Care Campaign', 'Skin Information Day' in Caerleon. This event was well attended although I thought more people with scleroderma might be there! See inside for details of next Information Days.

I spent May Bank Holiday in Yorkshire with friends and managed to catch up with Jean and Jim Pearson who live close by. We met up in Skipton at a Steam Canal Boat Fair. The weather was unseasonably glorious until we left the pub when a real gale was brewing (excuse the pun). The 12th of May was the South Wales meeting at Belinda's house. It was lovely seeing people to whom I had spoken to on the phone, putting a face to their names. The rest of May was taken up with meetings for the Standards of Care Reference Group, ARMA and the Royal Free Family Day.

As I write this it's only the 16th of June but it's been packed so far. I did a short presentation about the Society at the Skin Care Campaign Forum meeting, which will be followed up by an article, then over to Vienna for EULAR, the European League against Rheumatism annual congress. Vienna sounds like a wonderful location but I can honestly say that between representing the Social Leagues, attending sessions about scleroderma and finally meeting other Scleroderma Support Groups from Belgium, Canada, Germany, Holland, Hungary, Italy, Spain and the USA, I didn't see any of it! Although I must say that the Underground system works like a dream. I never had to wait more than two minutes for a train. However they are similar to the UK in that you need to be quite mobile as there were lots of stairs to negotiate. I nearly forgot, Jane Inight, our previous newsletter editor and I finally got to meet each other. It was a great pleasure as we had only communicated on the phone or by email, Jane brought with her some very special note-lets designed by herself for us to sell at the Summer Fair on the 18th. More about the Fair and the event organised by Pat Culpin in Hants in the next edition.

Before I close I would just like to say what a welcome addition Steve Holloway is as Membership and Deputy Secretary for the Society. You will notice some changes regarding the AGM and this is thanks to Steve who is bringing us into line with our articles of memorandum, with which we have to comply. Steve and Liz also attended the Scleroderma Support Groups meeting on the 10th June at considerable cost to themselves. Their support was invaluable and hopefully we will see the benefit (for everyone with scleroderma) of these meetings in the future. I do hope that wherever you are, you have a wonderful summer! And of course I hope to see as many of you as possible at the Summer Conference & AGM!

Till next time...

Lol Kim

**THE QUARTERLY NEWSLETTER OF THE
SCLERODERMA SOCIETY**

CHARITY REGISTRATION NUMBER: 286736

The Scleroderma Society 020 8961 4912

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.*

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 19th September
2005**

Hampshire

Contact: Liz and Steve Holloway,
15 Carne Place, Port Solent,
Portsmouth, PO6 4SY.
Tel: 023 9237 4176 & Email
lizemail99@btopenworld.com

On Wednesday May 18th we met in Queen Alexandra hospital in Cosham. Sixteen of us eventually found our way to the Orthopaedic seminar room which Colin Beevor kindly organised for us. We were very pleased to welcome Dr. Sanjeev Menon from St. Richard's in Chichester as our speaker. He brought slides to illustrate his talk on the outreach programme in West Sussex. I think most would envy the facilities at Bognor Regis Hospital--much of the work fuelled by patients' efforts. A date has been set in September for a visit from a member of the Royal Free medical team. It was all most interesting and afterwards Dr. Menon very willingly joined in a question and answer session and general chat. Many thanks to all those who attended. It was good to see well-known faces and to welcome Christine and Caroline who joined us for the first time. Hope you all enjoy the summer. All best wishes, Liz & Steve

Area News

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

London & South East

Contact: Kim Fligelstone,
3 Caple Rd, Harlesden,
London. NW10 8AB
Tel: 020 8965 4094
Email:
info@sclerodermasociety.co.uk
The date for the Christmas meeting is Thursday December 1st at 7.30pm in the Rheumatology Library on the Lower Ground Floor (opposite the main lifts) at the Royal Free Hospital, Pond Street, Hampstead, NW3 2QG. Nearest tube: Belsize Park on the Northern Line and Silver Link line at Hampstead Heath. Dr Geraldine Brough is going to talk about Calcinosis and related problems. Please bring a small wrapped gift for the Christmas bran tub. We will have the usual mince pies, refreshments and it will be the last chance to buy Christmas cards!

Hope to see you there. Kim

Other Contacts

Edinburgh and East Scotland

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

South Wales

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

Glasgow and West Scotland

Contact: Betsey Stephenson,
23 First Avenue,
Bearsden,
Glasgow. G61 2JD
Tel: 0141 942 0723

East Midlands

Contact: Bill Forman,
12 Newstead Avenue,
Radcliffe on Trent,
Nottingham. NG12 1DF
Tel: 0115 8451736
Email:
william.forman@ntlworld.com

SKIN CARE INFORMATION DAYS DIARY DATES

Blackburn on the 24th September
Cambridge on the 19th November
Details will be sent out later

23rd AGM/CONFERENCE

July 30th 2005 1.00pm

THE ROYAL FREE HOSPITAL LONDON NW3 2QG PROGRAMME

PHYSIOTHERAPY AND OCCUPATIONAL THERAPY IN SCLERODERMA

Mary Hanania and Phoung Quach

LIVING & WORKING WITH SCLERODERMA

Sally Saunderson and Yun wan

SCLERODERMA IN 2005 – HAVE WE MADE PROGRESS?

Dame Carol Black Professor of Rheumatology

QUESTIONS & ANSWER SESSION

Co-Chairs: Dame Carol Black/Dr Chris Denton

OCCUPATIONAL THERAPY (OT)

I am looking for examples of good practice that you have received from Occupational Therapists. Also examples of assistance that has been given but not really helped. For example, have you been referred to an OT either by your GP or Consultant and used an aid or adaptation that has made a positive difference to the quality of your every day life. Another example could be wrist splints, did they make a difference? I want to hear from you if you have had a positive **or** negative experience or have tips to pass on which will help others.

I am also interested to find out if you have never been referred to an OT but are having difficulty in the home, food preparation, household chores, personal hygiene and dressing for example.

Many thanks. Kim

PROFESSOR CAROL BLACK BECOMES A DAME IN THE QUEEN'S BIRTHDAY HONOURS LIST

Professor Carol Black has been made a Dame in the Queen's Birthday Honours list. Dame Carol, Professor of Rheumatology at the Royal Free Hospital and President of the Royal College of Physicians, has been honoured for her services to medicine.

Dame Carol has aimed to bring the Collegiate body and the specialist societies, working closely with patients, into an effective force for improving health and healthcare in this country. She has sought to establish collaborative relationships with statutory and independent bodies, working with the NHS to improve the standards of healthcare. Dame Carol is an international expert in systemic sclerosis; in 2002 she was awarded a CBE for her work in this area.

Commenting on the honour, Dame Carol said:

"I am delighted to receive this honour, not just personally but because it truly reflects the part of the College in improving the health and medical care of people in this country."

Scleroderma-Like Disorders or Pseudoscleroderma Spectrum Diseases In memory of Patricia Holloway

Dear Scleroderma Society Members

Most articles in the Scleroderma Society Newsletter discuss various topics on systemic sclerosis (SSc), a connective tissue disease that affects the skin and the internal organs. In this issue of the Newsletter I will discuss scleredema and scleromyxoedema, which belong to the *scleroderma-like disorders*, also called *pseudoscleroderma spectrum conditions*. They may, in part, resemble SSc and cause diagnostic confusion.

We would like to make members of the Society aware of these very rare conditions, for your information and interest. We do not intend to induce any doubt regarding your current diagnosis.

Scleroderma-like disorders (or *pseudoscleroderma spectrum conditions*) are characterised by excessive skin fibrosis but should be differentiated from systemic sclerosis. These conditions include:

- 1) localised forms of scleroderma: *morphoea* and *linear scleroderma*.
- 2) fibrosing disorders including: *fasciitis with eosinophilia*, *eosinophilia-myalgia syndrome*, *toxic oil syndrome*, *nephrogenic fibrosing dermatopathy*.
- 3) sclerotic or fibromucinous disorders (see footnote): *scleredema* and *scleromyxoedema*.

Most of you might be familiar with the localised forms of scleroderma or the fibrosing disorders, which are more common than *sclerotic or fibromucinous* disorders. The latter conditions are extremely rare and their prevalence has not been estimated: frequency was estimated once, in 1965, with 223 cases of *scleredema* reported worldwide at that time. At the Royal Free Hospital a few patients with scleredema have been followed-up: this short article is dedicated to Patricia, who suffered from scleredema.

Although frequently misdiagnosed as systemic sclerosis, *scleroderma-like disorders* are distinguishable from SSc by the clinical pattern of skin involvement and the absence of the following: 1) Raynaud's phenomenon, 2) scleroderma-specific autoantibodies, 3) abnormalities of the nailfold capillaries on capillaroscopy 4) internal organ involvement in most patients. Biopsy findings of the involved skin can be similar in *scleroderma-like disorders* and in systemic sclerosis and therefore skin biopsy is less helpful in differential diagnosis.

Scleredema was first described by Buschke in 1902 [1]; its onset has been linked to acute respiratory tract infection, diabetes mellitus or monoclonal gammopathy (see footnote). Scleredema is characterised by more or less widespread sclerotic skin changes, usually of the neck, shoulders, arms and thighs. The hands are typically spared. Internal organ involvement is extremely rare and it's even debatable if it occurs at all. The course of the disease is usually benign and the prognosis is good, with a spontaneous resolution after a few years. This is good news as, so far, there are no specific therapies that have been found to be effective. However, cases with monoclonal gammopathy can be complicated by malignant haematological conditions such as multiple myeloma (MM) (see footnote) or AL amyloidosis (see footnote).

Scleromyxoedema (also called "*papular mucinosis*") is characterised by the presence of lichenoid papules (which can be better described as "raised spots that look like the surface of an old rock") that join together to form "confluent plaques" with extensive skin thickening and hardening. Scleromyxoedema can occur

anywhere on the skin, and, unlike scleredema, may also involve the hands. Systemic involvement is extremely rare and even questionable, but some authors have suggested the involvement of the heart, lungs, muscles or of the peripheral nervous system, which means the disease is able to mimic SSc. As for scleredema, there may be an association with diabetes mellitus and monoclonal gammopathy.

The diagnosis of *scleroderma-like disorders* may be difficult and a clear distinction between scleredema and scleromyxoedema may be tricky. This is because the diagnosis is clinical, as there are neither specific blood tests nor typical findings on skin biopsy. The patients are often mistakenly diagnosed with systemic sclerosis, and, as a result of this, managed inappropriately. In the case of *scleredema* and *scleromyxoedema*, regular follow-up and blood testing, in particular the search for monoclonal gammopathy by the laboratory test [called serum protein electrophoresis (see footnote)] are mandatory for early diagnosis of the potentially serious haematological complications mentioned here [2].

Many thanks to Bill Holloway, Patricia's husband.

Dr Magdalena Dziadzio, Azienda Sanitaria Unica Regionale, Marche, Ancona, Italy

References

[1] Buschke A. Über Scleroderm (1902). Berliner Klinische Wochenschrift; 39:955-7.

[2] Dziadzio M, Anastassiades C, Potter M, Hawkins P, Gabrielli A, Brough G, Black C, Denton C. From scleredema to AL amyloidosis: a coincidence or disease progression? Review of the literature, Clin Rheumatol 2005; 24 (3), published online, *in press*.

Footnotes

Fibromucinous disorders represent a group of conditions, where both 1) skin fibrosis and 2) skin deposits of some sugars (called glycosaminoglycans) alone or in the form of mucin (ie in association with proteins called mucoproteins or proteoglycans), are present and make the skin more viscous. These deposits can be revealed by the analysis of the skin (specially prepared, stained and analysed under the microscope).

Monoclonal gammopathy is the presence of an abnormal immunoglobulin (a subclass of the proteins) in the blood. Normal immunoglobulins are necessary for our defence against various infections (mostly of the bacterial origin) and are produced by a subtype of the normal white blood cells called plasma cells. Abnormal, identical (monoclonal) plasma cells produce abnormal immunoglobulin, which is not able to play its role. Some patients with monoclonal gammopathy can progress and develop a condition called multiple myeloma (MM).

Multiple myeloma (MM) is a disease of the blood, caused by the infiltration of the bone marrow (which produces all blood cells: white cells, red cells and the platelets) by the abnormal plasma cells. These cells produce abnormal immunoglobulins described above. These immunoglobulins are then deposited in various internal organs, causing their dysfunction and, in severe cases, their failure. MM can be further complicated by systemic amyloidosis.

Systemic amyloidosis (AL amyloidosis) is a condition where the fragments of the immunoglobulins, also called "light chains", are present in the circulation; these light chains can be deposited in various organs forming typical insoluble amyloid fibrils, causing organ dysfunction and failure. Most internal organs can be affected but the involvement of the kidneys or of the heart can be fatal. A few therapies available at present are able to control (but not to cure) the disease, but they have to be started as soon as possible. There are other forms of amyloidosis (systemic or localized), for example systemic AA amyloidosis associated with chronic inflammatory diseases such as rheumatoid arthritis or localized cerebral A β amyloidosis of the brain (Alzheimer's disease) and many others.

Protein electrophoresis is a laboratory method for the analysis of the proteins present in the body fluids. The sample of the serum (which is a "liquid" part of the whole blood, separated from the blood cells and the clotting factors) is placed on a gel and the electrical current is applied. The proteins then "run" on the gel, with the speed depending on their molecular mass (ie how big they are) and their electrical charge. The electrophoretic graph is then generated and the quantity of each group of proteins (such as albumin, globulins and immunoglobulins) can be estimated.

OBSERVATIONAL STUDY OF TREATMENT OUTCOME IN EARLY DIFFUSE SCLERODERMA (SYSTEMIC SCLEROSIS)

Research is currently ongoing throughout the UK, observing patients with early diffuse scleroderma; within 3 years of onset of skin thickening. All rheumatologists in the UK are encouraged to include patients. The aim of this research is to compare the safety and efficacy of different treatment protocols in early diffuse disease. Clinicians select the treatment of their choice for each patient following normal practice. Involvement in this research does not affect normal treatment.

This research involves observing patients' disease progression over the course of 3 years, with clinic visits every few months.

The study focuses on patients whose skin involvement extends beyond the forearms, lower legs and face, as they often receive different kinds of treatment. We are looking at patients who are over 18 and under 70 years of age and have had skin involvement of less than 3 years. The study has been running now for over 4 years and approximately 120 patients have been included. We are very grateful to the Scleroderma Society for funding this research.

*If you are a patient or a clinician and would like some more information about this research, please contact Donna Taylor-Fesler (study co-ordinator) 0161 275 7146 ARC Epidemiology Unit, The University of Manchester
Donna.taylor-fesler@manchester.ac.uk*

MIAMI EXPERIENCE

Last year the PHA-UK offered sponsorship for a nurse from each of the pulmonary hypertension (PH) centres in the UK to attend the biennial American Pulmonary Hypertension Association conference in June. I was thrilled to be offered this opportunity to attend the conference, and I was really excited that I would be going to *Miami!!!*

I represented the pulmonary hypertension team from The Royal Free Hospital. The Hospital is part of the London consortium of PH NSCAG centres, including Hammersmith Hospital, Great Ormond Street and The Royal Brompton Hospital. At the Royal Free we predominantly care for people who have pulmonary hypertension associated with a connective tissue disease.

I was interested to learn about patient experiences in the USA, in particular those affected with PH related to connective tissue disease. In one of the discussion groups I attended patients stated that although they were under the care of doctors with specialist knowledge for their connective tissue disease, the care for pulmonary hypertension was often taking place at other hospitals, and that these centres were often not easy to identify. In an ideal world patients would like both centres of expertise in the same place. This is a service we are able to offer at the Royal Free.

The treatment, in the USA, for pulmonary hypertension associated with connective tissue disease is similar to the treatments available in the UK. Patients on advanced therapies identified that they would appreciate more support from health care professionals, particularly in the many places without a dedicated specialist pulmonary hypertension team.

One difference that I identified was the way in which patients receiving their PH prostacyclin therapy through a Hickman line were taught the skills to care for their infusion and line. The Hickman line would be inserted as a day procedure and a family member would be taught to care for the line. Patient education was carried out as an outpatient process, this heavily relied upon family participation and if patients did not live close to the hospital, they would stay in a hotel within close proximity of the hospital. At the Royal Free Hospital Hickman line insertion and patient teaching are performed whilst an inpatient.

I was fortunate enough to stay in the hotel where the conference was being held, which worked out well as there were plenty of early starts. The hotel was a short distance from South Beach, so I also got to sample some of the famous beach culture.

After the conference I took time out to do some sightseeing, and for the first time in my life I hired a car and drove on the *wrong* side of the road. I admit I

was very nervous, but fortunately my trip down to Key West was a straight road, so I didn't have to worry about any wrong turns. I would recommend this trip, as the scenery on the drive down was beautiful. On my journey back to South Beach I took the opportunity to pay a brief visit to the Everglades, where I was able to have a tour with a real life Park Ranger, named Larry.

I felt very privileged to be able to attend the conference, which brought together patients and healthcare professionals from all over the world to share experiences and expertise. I know it has helped to improve my understanding of how people are affected by pulmonary hypertension and hopefully in turn improved the care I provide for my patients at the Royal Free Hospital.

I would like to thank the PHA-UK for sponsoring me to attend this conference.

Joanna Smee Pulmonary Hypertension Nurse

To contact the PHA UK, PO Box 2760, Lewes, East Sussex, BN8 4WA, Helpline: 0800 389 8156

WHERE MEMBERS LIVE

Have you ever wondered if other members live near you?

Well now you can find out! This table shows how many members we have in each area defined by the first 2 letters in the post code. So if for example your post code begins KT, you can see that there are 9 members who also have a post code starting KT.

We have strict rules about giving out members details to anyone. We only give out details if a member has given us written permission. So, if you want to try to contact a member in your area, give Kim a call on 020 8965 4094, or email info@sclerodermasociety.co.uk Also let Kim know (020 8965 4094) if you wish to be added to the "contactable" list. (If your post code is not in the table, please let Steve know. It means the membership database needs correcting!)

Steve Holloway, Membership Secretary

AB	1	CT	5	GU	14	M1	1	PE	2	ST	5
AL	6	CV	10	H4	1	M2	1	PH	1	SW	14
B2	2	CW	1	HA	9	M3	1	PL	2	SY	2
B3	4	DD	1	HP	6	M4	1	PO	26	TA	3
B6	1	DE	3	HR	1	M6	4	PR	6	TN	5
B7	4	DG	1	HU	2	MA	1	QU	1	TQ	4
B9	4	DH	1	IG	2	ME	4	RG	8	TR	2
BA	4	DL	2	IL	1	MK	5	RH	11	TS	1
BB	1	DN	2	IP	4	N1	5	RM	3	TW	6
BD	3	DT	2	KA	2	N2	1	S	1	UB	1
BH	4	DY	2	KT	9	N4	1	S1	5	V4	1
BL	3	E1	3	KY	1	N5	1	S2	1	VI	1
BN	16	E4	2	L2	1	N8	1	S4	1	W1	2
BR	1	E9	1	L3	2	N9	1	SA	4	W2	1
BS	3	EH	5	L4	1	NE	7	SE	9	W4	2
BT	3	EN	3	L6	1	NG	5	SG	2	WA	2
CA	4	EX	3	LA	5	NN	5	SK	4	WD	5
CB	6	FY	1	LD	1	NP	8	SL	6	WF	3
CF	7	G1	1	LE	7	NR	4	SM	2	WR	2
CH	2	G3	1	LL	3	NS	1	SO	6	WS	2
CM	10	G4	2	LN	2	NW	16	SP	2	WV	2
CO	2	G6	3	LS	4	OX	6	SR	1		
CR	2	GL	3	LU	6	PA	3	SS	6		

PEOPLE LOOKING FOR CONTACT WITH OTHERS

Margaret Turner, of Bracknell, has had Systemic Scleroderma since Sept. 2000 and would like to compare with anyone in a similar situation. She is also diabetic. 01344 456989 turnermag2@aol.com

Ann Harris has had Scleromyxoedema and systemic scleroderma since 1991 and has just been diagnosed with osteoporosis. Ann is especially keen to have contact with anyone diagnosed with scleromyxoedema. 20 Windsor Drive, West Wittering, Chichester, PO20 8EG. 01243 671301.

Nicola Harrison has Limited Scleroderma and Osteoarthritis and would love to hear from anyone living in the Leicester area. 07766 404451

Computer Needed

A gentleman with systemic sclerosis in the Bury area would greatly benefit from a computer. Does anyone have a computer that they are not using and would like to donate? It doesn't matter if it's not up to date but it should be suitable for use on the Internet. If you can help please contact Kim on 020 8965 4094

NOTE FROM OUR MEMBERSHIP SECRETARY

Our membership year begins on the 1st of April. Since that date we have welcomed 26 new members to the society. This puts our total membership at 513. This year 161 members were due to renew their membership. So far, up to 17th June, 91 members have renewed leaving 70 outstanding. Thank you to all of you who have already renewed. And a special thankyou to those members new and old who also very kindly made a donation in addition to their subscription. These donations totalled £218. We don't send out receipts for renewals, to save money on postage. If you would like a receipt however, please let me have a SAE. If you are one of the 70 who have not yet renewed, you will see (05) printed on the label on the envelope that this newsletter came in. We hope to hear from you soon! A renewal form is with your newsletter. If you do not wish to renew, we'd still like to hear from you so that we can understand why. If we don't hear from you at all by the end of July, we will assume that you no longer wish to be a member and we will stop sending the newsletter. Finally, if you have any membership queries, please give me a call on 023 9237 4176 or send me an email at stevemail99@btopenworld.com
Steve Holloway, Membership Secretary

E-mail addresses of members happy for contact-

Welcome to Our New Members

Dr David Abraham, Mrs Caroline Wickham, Mrs Melanie Hewitt, Mrs Pauline Hand, Mr Richard Rogers, Mr Alan Brain, Ms Lydia Smith, Miss Ritu Papat, Mr Patrick Worboys, Mrs Lorna Worboys, Mrs Pam Shirley, Mrs Rosalind Meese Grove, Ms Sonia Tello, Ms Fiona Fokias, Mrs Helen Kokkinos, Ms Anona Morgan, Ms Susan Higgins, Mrs R Karia, Alexandra Pou, Mr Mark Poor, Mrs Sandra Tandy, Mrs Christine King, Mrs Shelley Giorgi, Mrs Ita Ryan, Miss Emma Dintinger, Dr Bernard Coleiro. A Warm Welcome to you all.



SCLERODERMA FAMILY DAY

This is the Society's stand at the Royal Free' 10th Family Day in May, if you look closely you can see one of our tee shirts.

Standing Bob and Anne Hall, Caroline Walker, Kim and sitting Yun Sian Ng.

Fundraising

Thank you to the Co-op in Hilsea, Portsmouth and their customers. They have one of our collection boxes on the counter that has raised £310.13 in the last year. Thanks to Anne Collins who sent £20 from the Sugar Loaf Pub in Shefford, collection box No. 36 and Shirley Deane who sent £25 from collection box No. 40.

The Society has received more donations in memory of Simon Siggers. "When Simon was alive he started a Formula 1 Grand Prix competition, when he became ill some of his mates continued to run it. Since his death it has been renamed as the Simon Siggers F1 Trophy. 10% of entry fees are donated to scleroderma. On presentation night many winners also donated some of their prize money as well raising a total of £112."

Colleagues in the I.S. Department at Sanofi Aventis in Dagenham make an annual donation to charity in lieu of sending Christmas cards and this year sent

their donation of £120 to the Scleroderma Society. Thanks to you all.

Many thanks to John Hibberd who telephoned the helpline and sent a lovely letter with a "contribution to society funds to say thank you for your kind response to my request for information."

PONTARDULAIS NEWS

Collection box No. 1, at Pontardulais Cricket Club was so full that it burst with £88 in it! Special thanks to Carol Phillips (Stewardess). Thanks also to Wendy and Anthony Richards at the Wheatsheaf Inn, whose collection box No. 23 raised £20.50.

"Over the past few years a Ladies Fun Day has been held at the Cricket Club for Charity and the first proceeds went to the Scleroderma Society and I'm pleased to say that this year's event on the 3rd September will also be for Scleroderma! This will be a 'Ladies Rounders Competition'. Let's hope the heatwave will continue"! Wyn & Mandy

MANY THANKS TO ANNE AND BOB HALL AND FAMILY

On Easter Sunday their son raised £230 by arranging a golf day. Cutting lawns around the estate where they live raised a further £82. A sum of £32 was also paid into our account from other fund raising activities.

On the 26th of August at Oxford their daughter Dianne, niece Louise and partner Tim are planning to take part in a sponsored Parachute Jump to raise funds for the Scleroderma Society. Any assistance with getting sponsors or donations towards the event will be greatly appreciated.

Contact Anne and Bob on 01428 727751 or "Longways" 53, Manorfields, Liphook, Hants, GU30 7BT. Please make cheques payable to the Scleroderma Society, sending them c/o the above address.

SAD NEWS

We have received donations in memory of Eve Lowe and Marian Last. Our thoughts are with their family and friends at this sad time.

CONGRATULATIONS

To Dr Maresa Carulli and her husband Andrew who have a new addition to their family. Dr Carulli gave birth to a healthy 9lb-baby boy on Saturday the 11th June.

**THE DECLARATION BELOW CONTAINS SOME
FACTS AND FIGURES TO LOBBY YOUR MEP**

WRITTEN DECLARATION ON RHEUMATIC DISEASES

The European Parliament, having regard to Rule 116 of its Rules and Procedures, is aware that:

- A. There are over 100 million people of all age groups in the EU with arthritis, that arthritis constitutes the greatest single cause of physical disability;
- B. Effective research will foster new therapies of rheumatic diseases, bringing enormous savings to the EU economy and to Member States;
- C. Rheumatic diseases can be serious, disabling and painful and that people affected frequently experience social exclusion and reduced life expectancy;
- D. People with rheumatic diseases can lead full and independent lives but require appropriate support.

And therefore calls on the Commission and Council to:

1.
 - Ensure that the EU's 7th Research Framework Programme makes rheumatic diseases one of its explicit priorities;
 - Ensure that the EU's new health strategy makes arthritis (musculoskeletal disorders) one of its priorities;
 - Strengthen legislation to outlaw disability discrimination through a specific Disability Directive;
 - Encourage Member States to take measures to ensure better access to the full range of treatments in all EU countries
2. Instruct the President to forward this declaration together with the names of signatories to the Council, the Commission and the Member States.

COMMITTEE MEMBERS

Chair - Kim Fligelstone, 3 Caple Road, Harlesden, London.
NW10 8AB 020 8961 4912

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

Membership Secretary - Steve Holloway, 15 Carne Place, Port
Solent, Portsmouth, PO6 4SY. 023 9237 4176,
stevemail99@btopenworld.com

Newsletter Co-ordinator - Lesley Matthews, 5 Park Cottages,
Manor Road, Hurstpierpoint, West Sussex. BN6 9UW 01273
831657

Newsletter Editors - Carol and Roy Sanders, The Laurels,
Westport, Langport, Somerset. TA10 OBN 01460 281305
roy4sanders@aol.com

Anna Clark, 28 Hertford Road, Digswell, Welwyn, Herts. AL6
ODB 01438 714406

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 and Steve Holloway, Bill
Forman, Belinda Thomson, Frances Bain, Betsey Stephenson.

***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

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.

Notice of the 2005 Annual General Meeting of

The Scleroderma Society

Charity Registration Number 286736

8 July 2005

Dear Member

You are invited to attend the 2005 AGM of The Scleroderma Society which will be held on Saturday 30th July 2005 at 1.45 pm in The Atrium at The Royal Free Hospital, Pond Street, London, NW3 2QG. There will be a buffet lunch available from 1.00pm and our Annual Conference will take place at the same venue, immediately following the AGM.

AGENDA

1. Apologies for absence
2. Approval of the minutes of the previous meeting
The minutes of the previous meeting will be available at the AGM
3. Matters arising from the minutes
4. Re-Election / Election of Trustees
 - a. Re-election of Professor Dame Carol Black DBE, CBE, PRCP as a Trustee
Art.42 of the Memorandum of Association requires one third of the elected trustees to retire from office at each AGM. Art 43 states that a retiring trustee shall be eligible for re-election. Prof. Black has indicated her willingness to stand for re-election.
 - b. Election of Ms Kim Fligelstone as a Trustee
As Chair of The Scleroderma Society, Kim is actually Chair of the Trustees and therefore should be a Trustee herself. Kim has indicated her willingness to stand for election.
5. Treasurer's Report
The income and expenditure account and balance sheet for the financial year ending 31 March 2005 will be available at the AGM
6. Approval of the Accounts
7. Appointment of Auditors
8. Chair's Report
Kim will present her annual report
9. Any Other Business

S H Holloway
Deputy Secretary

If you are unable to attend the AGM, you are entitled to vote by appointing a proxy to vote on your behalf. If you would like to do this, please complete the following form and return it to Steve Holloway, 15 Carne Place, Port Solent, Portsmouth, PO6 4SY to arrive not later than 28th July 2005.

I (insert your name) _____

of (insert your address) _____

a member of The Scleroderma Society, hereby appoint **Kim Fligelstone, Chair of The Scleroderma Society**

OR (enter the name of another person who will vote for you) _____

of (insert that person's address) _____

to vote for me and on my behalf at the Annual General Meeting of The Scleroderma Society to be held on 30th July 2005.

Signed _____ Date _____

THE SCLERODERMA SOCIETY CHRISTMAS CARD ORDER FORM

<u>No of packs</u> (10 cards/pack)	<u>Card Type</u>	<u>Cost (incl p&p)</u>	
.....	Angel	@ £3.50 (incl p&p)
.....	*Santa	@ £2.50 (incl p&p)
.....	*Robin	@ £2.50 (incl p&p)
.....	*Victorian House	@ £1.50 (incl p&p)
.....	*Fieldmouse	@ £1.50 (incl p&p)

(*limited stock available)

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Please make all cheques payable to "THE SCLERODERMA SOCIETY"

NB In the event that one card design is sold out would you accept the other design as a substitute? YES / NO

Please Use Block Capitals

NAME

ADDRESS

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TEL: (in case of query please)

Please return the completed form to:
Anna Clark, 28 Hertford Road, Digswell, Welwyn, Herts. AL6 ODB Tel: 01438 714406



Approximate Size 10.5 cm x 14.7 cm (4 1/4" x 5 3/4")



**Limited Numbers
of Cards From
2003 and 2004 are
available see
overleaf.**

GREETINGS INSIDE CARDS

Mouse, Angel &
Santa

*Merry Christmas and a
Happy New Year*

Victorian House & Robin

Seasons Greetings

See Over for Ordering
Details

Approximate size 6 1/4" x 4 1/4"
(155 x 108mm)