

Scleroderma News Summer 2007



Kim Fligelstone

A WORD

This is short and sweet as I'm just about to leave for EULAR in Barcelona. I finally moved at the end of April (thanks for all the cards) and managed to unpack for a week and then went to the BSR (British Society for Rheumatology) at the International Congress Centre in Birmingham. This was a great opportunity to catch up with the doctors and health professionals to pass on our new address and advice line number. Whilst at the BSR we were asked to attend the Essex Rheumatology Road Show on July 4th which will be held at Highlands House in Chelmsford.

We had a gloriously sunny day at the Regents Park 'Walk for Skin' on 20th May, although I understand that not all the venues were so fortunate.

STOP PRESS Professor Alan Tyndall from Basel will be joining us to talk about Stem Cell treatment and Scleroderma at our 25th AGM/Conference on 28th July. I look forward to seeing as many of you as possible. Please phone the advice line if you need a booking form or have any queries.

All that's left is for me to wish you all a long and warm summer!

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

Lol Kim

Inside This Issue: Page

Area News	2
New Website	3
Physiotherapy & Scleroderma	4-6
Fundraising	7-8
Christmas Cards	9
Our Finances	10
Stepping Out State-side	11
AGM	12

Please send YOUR articles to Carol Sanders,
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TA10 OBN Tel: 01460 281305
e-mail roy4sanders@aol.com
Closing date for contributions
14th September 2007

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

Area News

London and South East Group

New Contact Details:

Kim Fligelstone
6 Portishead House
Westbourne Park Road
London W2 5UP
Tel: 020 7229 4750

The next meeting is on Thursday 6th September at 7.30 in the Rheumatology Library on the Lower Ground Floor (Opposite the main lifts) at the Royal Free Hospital..

Hants and West Sussex

Contact:

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

On Wednesday May 2nd we held our local meeting in QA hospital as usual. Colin Beevor organises the room and refreshments for us and for this we are always grateful. This time he sent out details of the meeting to a great many local patients, of which 27 turned up. This is a remarkable number and gave us a chance to meet new people with Scleroderma and their families. Colin also provided an opportunity to look round the Rheumatology Department and several people took advantage of this.

Paula White, despite feeling quite ill, talked about her work as a Pulmonary Hypertension nurse specialist, PAH itself, and, in particular, the way it af-

fects Scleroderma patients. It was both interesting and informative and made me, and I'm sure others, really aware of the importance of those annual lung function and heart tests. Many thanks to Paula.

In January, Tracey James attended a meeting at QA on our behalf, to launch an ARMA Local Network steering group with the aim of improving patient service provision at local level. She gave us an outline of this meeting and we were then able to have a general discussion with input from Colin and Paula. It was decided that it would be useful for Tracey to attend the next meeting and she very kindly agreed.

During the evening we sold some lovely knitted toys made by Tracey's aunt, Mrs Patricia Hunt, in memory of her brother Robert Moore. The sale of these raised £15 for the Society and we would like to thank Mrs Hunt very much indeed. More of her toys will be on sale at the Ashington (W.Sussex) Fair in the summer. Check the new-look website for details nearer the time!

There are quite a few members in the Sussex area and we are looking into more accessible venues for a meeting for them, though of course anyone is more than welcome at any of the meetings. The next one already organised is on November 16th at the Southern Electricity Sports and Social club in

Drayton. This will be our last chance to use the club so we are making the most of it and Liz is hoping to get there this time! It will start at about 7.00 and be along the same lines as last year. There will be a reminder in the next newsletter.

We hope you all have a wonderful summer and as good health as possible,
Liz and Steve

OTHER CONTACTS

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 above

South Wales

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

YELLOW BASILICON

Does anyone know where the above ointment can be purchased? One of our members has used it successfully to 'draw out' calcium deposits from her fingers but can no longer get it! Modern 'drawing ointments' are not as effective she says. If you can help please contact the society.

NEW WEBSITE



Scleroderma Society
Supporting people with Scleroderma for 25 years

info@sclerodermasociety.co.uk
Tel: 0800 311 2756
Registered Charity No: 286736

About Us About Scleroderma Join Us Useful Links Fundraising News Message Board Local Groups Contact Us

About The Scleroderma Society
Find out more about Scleroderma
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ADVICE LINE:
Scleroderma Society
Advice Line is now
0800 311 2756.
Calls from UK
mainland are free.

DONATE ONLINE:
We have signed up
with [Justgiving.com](#) a
great on-line
sponsorship and
fundraising site.

Welcome to the Scleroderma Society Website

The **Scleroderma Society** is a registered charity (No.286736) founded in 1982.

The society's aims are to

- help and support people with **scleroderma**
- increase awareness of scleroderma
- fund scientific and medical research

Membership is open to anyone. Society members range from people who have the disease themselves, or have a relative or friend with the illness, to doctors and healthcare professionals with an interest in **scleroderma**. There is a small annual subscription which covers the cost of a quarterly **newsletter**.

The society is managed by and run by volunteers. Our trustees are elected by the membership every three years. Members come from all over the UK. Where there is sufficient interest, regional groups meet **locally**. Members keep in touch via a quarterly newsletter and our **Internet message board**. We also exchange newsletters with other groups around the world.

We are very privileged to have Professor Dame Carol Black as our president and Professor Chris Denton and Dr Anane Herrick as our vice presidents.

Please explore this website to find out more about **scleroderma**, how we provide help and support to those who have scleroderma and how you can support us by **joining** the Scleroderma Society or by making a **donation**.



Steve Holloway

MEMBERSHIP NEWS

Since the April Newsletter went out with membership renewal forms, 174 members have renewed their membership of the society. This is a great response. Many of you very kindly took the opportunity to send an extra donation with your subscription and we are extremely grateful for this. It is my usual practice not to send receipts for renewals and accompanying donations, but if you would like a receipt, please let me know.

As I write this in the middle of June, membership of the society stands at 512, but there are 52 members who have not yet renewed. I have put a reminder in with your newsletter if you are one of the 52. If there is no reminder, then you have nothing to do!

Since the beginning of April, we have welcomed 19 new members, and we hope to see many of them at local group meetings and the AGM & Conference in July.

If you would be interested in joining a local group, or even helping to set one up, please let Kim know. Email

info@sclerodermasociety.co.uk or write to her at PO Box 581, Chichester, PO19 9EW. Local groups can be whatever you want them to be!

Steve Holloway

Steve Holloway

In June we launched The Scleroderma Society's new website. The address is the same as the old site www.sclerodermasociety.co.uk

I would like to thank Mike Ash for all the work he has put in to make this new site.

In building the new site we have tried to create a "fresh" image for the society, and to present ourselves in a professional way. You will notice immediately our new logo, which we have started to use elsewhere this year.

We have removed things that are impossible to keep up to date and we have re-written much of the basic information.

The new site keeps many of the features of the old site (e.g. the very popular message board) and introduces a number of new features:

- Availability of our leaflets for reading on line and downloading
- Our newsletters including back numbers on line and downloadable – we intend to stay one issue behind the current issue so that members have an advantage over non members
- All our membership forms available to download
- A calendar of events
- More focus on fundraising – more to do here!!

Please have a look and let me know of any errors and any changes you would like to see. We think it's easy to use! If it's not please let me know and suggest how it could be improved. If you have ideas for additional sections or subsections, please let me know. It is very easy to add these. For example, I think we need a section about the grants we make and how to apply to us for a grant. I'll be adding that section shortly. An important consideration is that whatever we have on the site is up to date. If you want to see something that will need frequent updating, you must be prepared to take the responsibility for keeping it up to date. Links to other sites are also a good idea – we already have a number of these, but we can always add more.

PHYSIOTHERAPY AND SCLERODERMA

THIS IS TO BE A NEW LEAFLET

What is Physiotherapy?

Physiotherapy is a healthcare discipline concerned with human function and movement, and maximising patient potential. Your physiotherapist should be able to advise you on a home exercise programme to keep you as active and mobile as possible, they will also discuss what kind of exercise could suit you best and will give you tips on how best to deal with the problems you may encounter from your scleroderma.

Why Exercise?

Exercise has many beneficial effects and these apply as much to you as to someone without scleroderma. Some of the benefits are that it:

- | | |
|--|------------------------------------|
| Increases muscle strength | Increases or maintains flexibility |
| Improves general fitness | Improves balance |
| Increases sense of general well being | Protects thinning bones |
| Aids digestion | Aids sleep |
| Helps control weight | Helps overcome fatigue |
| Gives a sense of personal control over one's disease process | |

In other words, exercise makes you feel fitter, healthier and can lift your mood. It can increase your independence and improve your social life. It can also help to improve function and your ability to cope with everyday tasks and situations.

What Types of Exercise Should I Do?

Everyone should have a fitness programme that includes at least flexibility, strength and general conditioning or aerobic components. These exercises could well be as a part of things you do at home such as stair climbing, walking, cooking and other household jobs.

1) Flexibility / Stretches

One of the characteristic features of scleroderma is skin tightening and consequent decreased movement or stiffness at joints. With this skin tightening there is also some tightening of underlying muscles. Stretches will not prevent skin tightening, but they will loosen off any tightened tissues under the skin.

Getting into a routine of daily stretches will allow you to minimalise the effects of the scleroderma on your movements. Many patients also say their stretching exercises give aid in their pain relief.



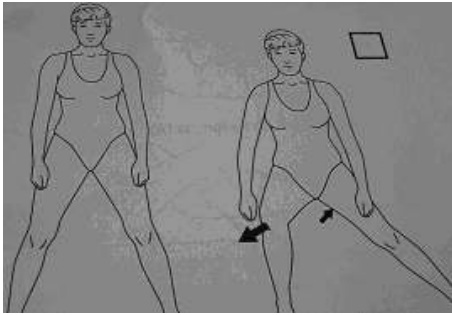
the hip until a firm but comfortable stretch is felt at the back of thigh and knee.

HIPS, KNEES AND ANKLES

Standing hamstring stretch: stand with one leg in front of you. Keep this leg straight. Bend the back knee and place your hands above the straight knee for support. Keep your back straight and bend forwards at



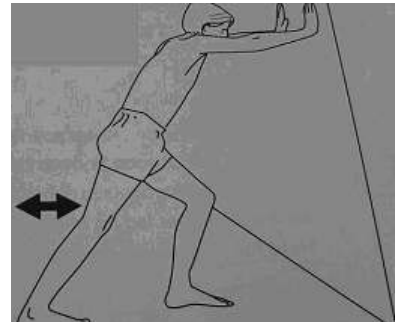
Quadriceps stretch: In standing, bend your knee behind you. If you can, grasp your ankle with your hand and pull your foot towards your bottom until you can feel a firm but comfortable stretch at the front of your thigh.



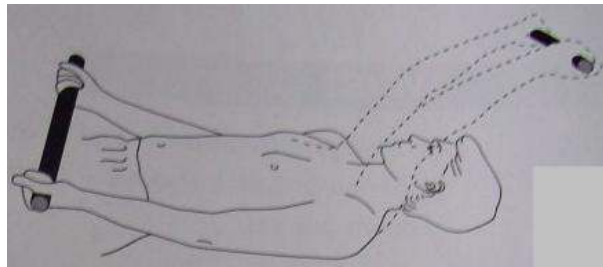
If you can not grasp your ankle, or you feel unsteady on your feet then put a chair behind you, put the leg on the chair with the knee bent as far as possible and then lean back onto the chair to feel the stretch.

Inner thigh stretch: Stand with your legs apart, feet facing forwards. Lean across to one side by bending that knee – keep the other knee

straight – until you feel a firm but comfortable stretch in your inner thigh / groin.



Calf stretch: Stand facing a wall; put one leg out behind you, keeping your knee straight and heel flat on the floor. Lean forwards until you can feel a firm but comfortable stretch in your calf.



SHOULDERS AND ELBOWS

Shoulder flexion stretch: Lie on your back on the bed with your arms by your side. Make sure you keep your elbows straight, lift both your arms up above your head. Holding a walking stick or similar may help with this exercise.



Hands behind head stretch: Whilst sitting down, place your hands behind your head and then push your elbows back.

Hands behind back stretch: Place your hands behind you, trying to reach the small of your back. Your palm should be facing outwards.



Elbow stretches: Bend and straighten your elbows, to get an extra stretch, use your other hand to push further to the extreme of the stretch.



(Please see the Society's "Scleroderma and the Fingers" booklet for hand exercises.)

NECK AND BACK

Neck side flexion: Whilst sitting, gently stretch your neck from side to side (taking your ear down towards the shoulder).



Neck flexion: Look up, stretching at the neck and not leaning to either side.





Neck rotation: Rotate to the left and then to the right, looking over your shoulder.

Whilst lying on your back on the bed with your knees bent up, gently roll your knees from side to side.

Mid back twists: Whilst sat on a chair, twist to one side to feel a stretch in the mid-back.



Low back rolling:

FACE

Most people find these exercises easier to do when facing a mirror. You'll stretch more effectively if you perform these with the skin warmed up, for instance after a hot shower or bath.

- a) Lift the eyebrows and then lower them.
- b) Squeeze your eyes closed tightly.
- c) Wink tightly with either eye.
- d) Frown your forehead to wrinkle the bridge of your nose, raise your upper lip to increase the stretch.
- e) Flare your nostrils.
- f) Close your lips hard.
- g) Cover your teeth with your lips, and then open your mouth as wide as you can.
- h) Bare your teeth and open the mouth as far as you can.
- i) Push the jaw forward to produce an underbite.
- j) Grin as widely as you can, without showing the teeth.

2) Muscle Strengthening

The effects of scleroderma may affect your posture and range of movement, both of these problems will have a knock on effect on your muscle strength. You may have problems with your diet, and so not be getting enough nutrition to keep your muscles strong. Or you may well be less active than previously.

You can maintain your muscle strength by keeping as active as possible. You may need to perform some specific exercises to keep specific muscles strong or to re-strengthen muscles that have become weak. Your physiotherapist should be able to assess you and decide if any of your muscles need these specific treatments.

3) General Conditioning / Aerobic Exercise

It is important to try and do some gentle cardio-vascular or aerobic exercise regularly. Well recognised advice states that you should aim to do 20-30 minutes, 4-5 times a week. How much you can manage and what is an appropriate exercise may vary depending on the activity of your scleroderma. Examples of cardio-vascular exercise include: walking, swimming, going up and down stairs, cycling, aerobics classes and keep fit classes.

From The Editors

We hope you like the new format of the newsletter. We want to use it more widely within the community and decided that we needed to add a bit of colour.

In our website there is an excellent, easy to use message board so we are no longer listing email addresses. We encourage you to use the message board regularly to keep in touch with other members. If, however, you would like a list of members wishing email contact, for personal use only, we will keep the list up to date and you can request one from the society.

Roy and Carol Sanders

Thank you for the warm welcome I received in the last newsletter – I am really pleased to be involved in the fundraising and hope I can be of value.

Our fantastic fundraising news is about **Richard Bennett** who ran in the



Louise Cecil



2007 Flora London Marathon to raise money for the society. Richard, whose partner Gail Tytherleigh suffers from scleroderma, not only completed the race in a very creditable 4hrs 50mins, running all the way, he raised **£31,000** from sponsorship! This is an outstanding achievement and on behalf of all members of the society I offer Richard our grateful thanks. Thanks also to all of Richard's relatives and friends who worked so hard to help him raise so much money, and of course to all his sponsors. Richard's story – why he wanted to run the marathon – can be found in the Spring 2007 edition of Scleroderma News.

I would also like to mention some other people who have been doing very serious money-making activities lately.

Alan Hall organised a Golf Day at Old Thorns Golf Club in Liphook. It sounds a fantastic day which went into the evening and raised £263. Many thanks to Old Thorns Golf Club,

St. James Cricket Club, Prince of Wales Lodge of Fareham, all participants and particularly Alan, Anne and Bob Hall.

Shaun Brennand arranged a dance in the local village hall and raised £315. Thank you to Shaun, Laureen Saggars, and the Morland Pub – very much appreciated.

In addition, in the period 14th March to 30th May, we have received donations and gifts totalling just over £7,900 from the following people. A big 'Thank You' to all of you. If I've missed anyone out, please accept my apologies.

- | | |
|----------------------------------|-----------------------------------|
| AM & V Arnold | Mrs CA Hill |
| Anglia Regional Coop | Mrs Carol E Davies |
| B Lauder | Mrs CO Buckledee |
| BA & A Raimondi | Mrs D Gibson |
| BD & EA Coleman | Mrs D Hadland |
| BM Lane & JF Lane | Mrs E Dyer |
| C & JM Miles | Mrs EE Harper |
| CL Jones & CA Jones | Mrs EG Stephenson |
| Connections Literary Magazine | Mrs FP Griffiths |
| DJ Harper | Mrs GR Chadburn |
| DJF & C Rees | Mrs Gwen Owen |
| FJ & VP Webb | Mrs H Kokkinos |
| G & E Emanuel | Mrs I Stanton |
| G & P Arkley | Mrs J Breeze |
| G Tytherleigh | Mrs J Childs |
| HW & BA Saunders | Mrs LAB Worboys |
| J Weir | Mrs LM Morton |
| JS & Mrs E M Heggie | Mrs LW Saggars |
| JV Grindle | Mrs M Williams |
| L McGrath | Mrs MY Brown |
| M & DD Griffiths | Mrs ND Warren |
| Margaret Starmer | Mrs PA Bridges |
| Miss FM Johnson | Mrs PA Goodchild |
| Miss J Coe | Mrs PM Hand |
| Miss PA Baxter | Mrs RJ Terry |
| Miss WI Newman | Mrs SK Dearden |
| MJ Webb | Mrs V Parry |
| Mr & Mrs DJ Asplin | Mrs W Hindley |
| Mr A Harkins & Mrs NA Harkins | P & N Davies |
| Mr A Hurdle | PA Aley |
| Mr BE Sherwood & Mrs MT Sherwood | PD Sweet & Mrs PI Sweet |
| Mr BG McKee & Mrs MI McKee | PJ Hack |
| Mr EJ Duggan | RA Smith |
| Mr GS & Mrs J Ames | RS & DJ Jones |
| Mr JJ Reid & Mrs M Reid | SF Kibble |
| Mr KV Boyman | St Albans Parent & Toddler Grp |
| Mr RA Webb | The Book People Limited |
| Mr RW Dille & Mrs JL Dille | The Centaur (JE Dobson) |
| Mr SP & Mrs C Todd | The W & M Morris Charitable Trust |
| Mr WG & Mrs E Shephard | Dr Karen Servilla |
| Mrs A McGlashan | Mrs Marilyn Dooley |
| Mrs AJ Robinson | Mrs Miriam Rathbone |
| | Helena Rozga |
| | Sonia Hanson |
| | The Health Foundation |

FUNDRAISING

In May we received a gift of 5,000 shares in a company called Toluna plc. Toluna are a European Market Research Company and Simon Barrell, our former Company Secretary, is a director. When he heard that Toluna were proposing to make a gift of shares to a charity, he put our name forward and promoted us. Thank you Toluna and Simon. The trustees consider this gift (around £10,000 at present value) to be a long term investment. They will discuss their investment strategy in a future newsletter.

And then there is Gift Aid. In the financial year ending 31st March 2007 the society received £2,455 in Gift Aid. We expect this figure to be even more in the current financial year. Thank you to all of you who have signed Gift Aid declarations. It really does make a difference.

We are also pleased with the response of those of you who support us on the internet by using the Everyclick.com search engine. Together you've raised over £200 since we joined the service last year. Find out more about this by visiting our website and clicking on the Everyclick.com logo.

In the next newsletter, we will have an article about the research projects we have supported in recent years.

In the past three months we have been very busy working on ideas to increase our fundraising. We particularly want to focus on raising money from sources other than our members who already contribute significant amounts every year.

New and now available are

Fundraising Information Packs - designed to support people who want to raise money for us and can be customised to suit each situation

Home Collecting Boxes – ideal to give to friends and relatives and to place in doctors' waiting rooms

Gift Aid Envelopes – hand these out on all occasions and make those pounds go further

I've included two Home Collecting Boxes and two Gift Aid Envelopes in your newsletter. If you would like more please contact me.

We are also preparing to make grant applications to companies and other grant awarding organisations. This is where we could make a big difference to our funds which in turn would assist medical research projects and, of course, member support. If you should know of any such companies who might be willing to receive a grant application or a presentation from us, please contact me.

Finally, for those of you who are internet savvy, have a look at the new Fundraising section of the society's new website. We can accept on-line donations, and on-line sponsorship pledges. We have an A-Z of fundraising ideas and a diary of forthcoming events. Please contact me with your ideas, your event dates and details and for any other requests for support with your fundraising efforts.

I hope to meet many of you at the 25th anniversary AGM & Conference on 28th July, where we are planning a special surprise addition to our fundraising opportunities!

Louise

fundraising@sclerodermasociety.co.uk

2007 CHRISTMAS CARDS



Cards are packed in tens and cost £3.50 (incl p&p)



CARDS FROM PREVIOUS YEARS



Packs of Snowman £2.50 (incl p&p)
Santa and Victorian House £1.50 (incl p&p)
Angel £1.00 (incl p&p)

**All cards will be available at our AGM / Conference
or can be purchased direct from
Anna Clark,
28 Hertford Road, Digswell, Welwyn, Herts. AL6 ODB
Tel: 01438 714406**

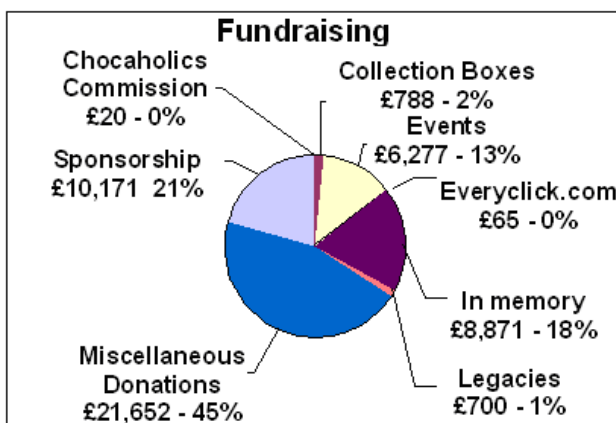
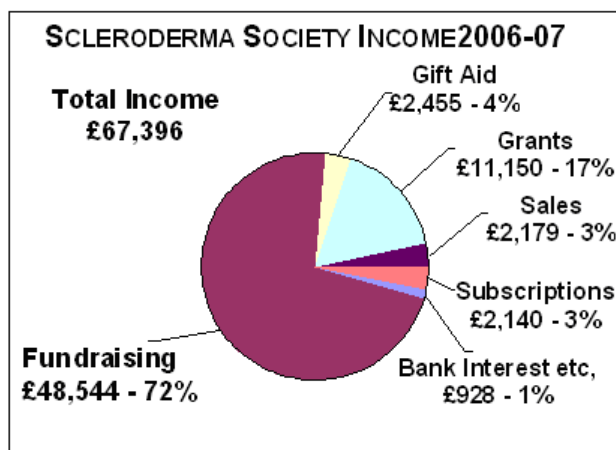
Please make all cheques payable to "THE SCLERODERMA SOCIETY"



OUR FINANCES

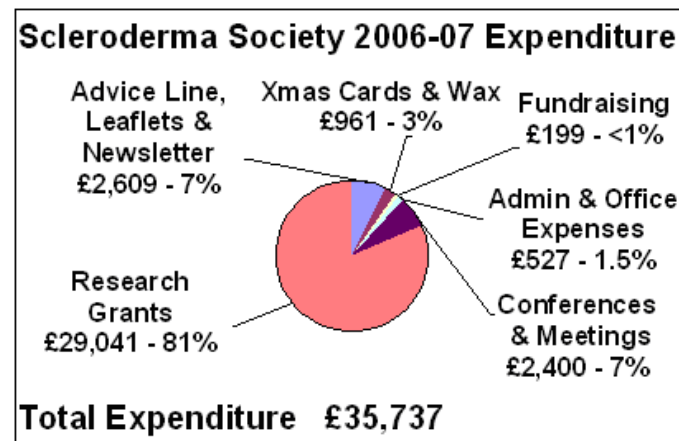
Financial update for the year 2006 to 2007

The Scleroderma Society has had a good year financially, and the accounts will be formally presented at the AGM in July for members' approval. The first two charts which follow show how our income of £67,396 for the year was made up.



You can see that most of our income comes from Fundraising, and from the second chart how this source of income is derived. A large proportion of this income comes directly from members, and we are extremely grateful for this. One of our aims, however, is to try to find other sources of income, not just from members, which ultimately will enable us to give more money to Research. As you can see from the Expenditure chart, we put very little resource into Fundraising at the moment.

The next chart shows how we spent our money.



We are very pleased to be able to show that 81% of what we spent went to Research Grants and less than 2% to Administration and office expenses.

The trustees intend to spend more on Fundraising in future years in order to significantly increase the amounts we raise to give to Research.

If you would like any further information about any of the numbers on these charts, or about our financial position generally, please contact me by email stevemail99@btopenworld.com or by telephone on 01243 539466. **Steve Holloway**

TRUSTEES: Chair - Kim Fligelstone, PO Box 581, Chichester, PO19 9EW
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 Caroline Walker, 23 Meredyth Road, Barnes, London SW13 0DS 020 8876 1917
 Louise Cecil, Flora Cottage, 27 The Square, Potten End, Near Berkhamstead Hertfordshire. HP4 2QT 01442 879129
 Caren Eales, Teddington, London.

AREA CONTACTS (page 2): Liz Holloway, Belinda Thomson, Frances Bain.

STEPPING OUT STATESIDE

It's a quarter to eight on a grey and overcast Sunday morning and my partner and I are beginning an eighty five minute drive to Ot-siningo Park, in Binghamton, New York State. Every year the Scleroderma Foundation of the USA organises a large number of 'Stepping Out for A Cure' sponsored walks across the country and we are about to attend the walk arranged by the Tri-state Chapter, based in Binghamton.



Sally Saunderson

This is the fifth walk organised by Tri-State Executive Director, Rosemary Markoff and her team of volunteers, and by the time we arrived just after the beginning of registration at 9am base camp is already buzzing. There were queues to register and pick up the goodie bag that included a T-shirt and baseball cap, and there was a huge



Setting Out on the Walk

range of refreshments laid out for everyone (useful as we'd left too early for breakfast!). There were several families with children in buggies, and some with dogs in tow, most of the assorted hounds sporting Foundation neckties attached to their collars. Three hundred people had been expected but the turnout was obviously well above that.

A huge amount of support had been given to the event from companies large and small and from individuals. There was the large range of raffle prizes, all the refreshments and after the walk a local restaurant called Moe's brought along a van load of Mexican food. The nearby radio station had provided the music, and the DJ was

doing his fourth year with the event and apparently did an average of eleven of these events each season. The whole occasion had a very social and party atmosphere and we talked to many people who were coming back for the second or third time. One group, Team Costello, were walking for the fourth time, their original team of four girls having expanded to forty strong. They didn't quite make the prize for largest team, however, as that went to one that numbered forty four. Several groups large and small were walking in memory of someone close, and we heard quite a few of their stories over coffee. A minute's silence was held before the start of the walk to remember everyone.

We had been 'adopted' by the team led by the Chairman of the Chapter, Bob Trueman and walked round with them. The route was a two mile circuit within the park, on good, level paths making it easy for everyone to complete. At the end, after Moe's corn chips and salsa, there were trophies awarded for the largest amount raised by an individual (\$1500/£750) and by a team (\$3329/roughly £1,664).

But the best thing about the whole day was talking to so many people who are all doing the same things that we are doing over here. Raising funds for research, and just as importantly raising the level of awareness about Scleroderma and all the support there is for the people who live with it. They were a great bunch of people who were hugely welcoming to a couple of travellers from the UK. And the rain held off till we were halfway back down the inter-state. Result!!!!

Sally Saunderson

Nurse Specialist Advice Lines

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)	Karen Walker (Scleroderma) Freeman Hospital, NEWCASTLE UPON TYNE 0191 2231503
Rona McIvor Woolmanhill Hospital ABERDEEN 01224 555 403	Liz Wragg Hope Hospital, MANCHESTER 0161 206 0192	Rachael Crackett & Julia De-Soyza (Pulmonary Hypertension) Freeman Hospital, NEWCASTLE UPON TYNE 0191 213 7418
Audrey Hamilton Ulster Hospital BELFAST 02890 561310	Sally Marsh NORTHAMPTON General 01604 523849	Sally Smith General Infirmary, LEEDS 0113 3922189
Steve McSwiggan Newells Hospital, DUNDEE 01382 633957	Sue Brown RNHRD, BATH 01225 447997	

The Nurse Specialist Advice Lines are part funded by the Raynaud's and Scleroderma Association. These advice lines are for general inquiries not emergencies; you will probably need to leave a message.

25th Anniversary **Annual Conference and AGM**

To be held in the Atrium at the Royal Free Hospital 28th July
To celebrate our 25th Anniversary we have a brilliant programme with an international flavour.

Professor Dame Carol Black
Professor Marco Matucci Cerinic from Italy -- EUSTAR and Ulcers
Professor Alan Tyndall from Basel Stem Cell treatment and Scleroderma
Dr Henry Penn -- Kidneys in Scleroderma
Sister Naomi Rea -- Quality of Life Study
Sonia Tello is back by popular demand to inspire us all

As well as the usual raffle and sales we will have a poster exhibition to show how research funds have been allocated since our 20th Anniversary.

Finally the Question and Answer session with our panel of experts.

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.