



The Scleroderma News

Autumn Issue
October 2006

The Newsletter of The Scleroderma Society (UK)

A Word from Kim

Hi Everyone, I trust you have all had an enjoyable summer. You will see from the fund raising section that some very enterprising children and their families have been very busy raising funds for the Society. Both Carmen McSweeney and Bradley Siggers wanted to do something for Scleroderma and enlisted the help of close family members who assisted them in organising the events. Then with the support of siblings, cousins, friends and family have had a successful summer raising funds - and perhaps just as importantly raising awareness of scleroderma as well.

The AGM was very well attended (with over 20 people turning up unexpectedly on the day). Next year, please send off your booking forms in advance so that we can cater for the right number of people! You will find Kevin Howell's talk inside. The date of next year's 25th AGM/conference is the 28th July so make a note in your diary.

November is Scleroderma Awareness Month. You may see a number of articles in the press, on radio and on television. Here's hoping for a very mild autumn to go with our better than average summer. **Lol**

Kim

In every newsletter, Kim thanks those who have raised money through fundraising and those who send donations to the society, often in memory of a relative or friend who has died. You may be as pleasantly surprised as I was to find out how much this all comes to. Looking at the figures for this financial year so far, 1st April to 30th August, we have received over £25,000 in donations. £6,500 of that has come from members fundraising efforts, £4,500 from legacies and gifts in memory of relatives and friends, and £14,000 from people, mostly members, who simply make generous donations from time to time - in this period there have been 130 donations. I haven't yet made our claim to the taxman for gift aid this year, but when I do, this will add a substantial extra amount to our fundraising and donation income. I think this is a fantastic effort by all those concerned. And we still have 7 months to go to the end of the financial year! In a future newsletter, I will look at how the money is spent.

Steve Holloway, Secretary

CHRISTMAS CARDS

Our two new designs (Snowman and New Robin - £3.50 per pack) are deservedly popular and going well. We still have some of the previous years' cards left (Santa, Angel, Victorian House and Previous Robin, all at £1.50 per pack). All packs contain ten cards and envelopes and the price includes p&p. If you have mislaid your order form, sent out with the last Newsletter, details are available on the Society's website.

(www.sclerodermasociety.co.uk) or telephone me, Anna Clark 01438 714406. My address for sending orders to is - 28 Hertford Road, Digswell, Welwyn Garden City, Herts. AL6 0DB.

Now also is the time for all you artists out there to create some designs for next year's cards, to reach me by the end of January please.

THE QUARTERLY NEWSLETTER OF THE SCLERODERMA SOCIETY

CHARITY REGISTRATION NUMBER:286736
The Scleroderma Society 020 8961 4912
Advice Line 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.

Please send YOUR articles, etc.

for the next issue to Carol Sanders,
The Laurels, Westport, Langport, Somerset.
TA10 0BN Tel: 01460 281305
email roy4sanders@aol.com
Closing date for contributions
15th December 2006

Area News

Hampshire

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

Celia and David Graham have kindly arranged for the next meeting to be held in the Southern Electric Social Club in Lower Drayton Lane (far end) in Drayton, Portsmouth. It will be a skittles evening on Friday Nov. 10th at 7.00 pm with fish/sausage/chicken and chip supper at £4 per head. Feel free to join us for skittles and/or chat only, but if you would like supper, please give me a ring. We will need an idea of numbers. Tracey James, a Hants member, is very generously hosting a curry night in the Balti House, Albert Road Southsea on December 19th at 7.00pm. All food and drink provided, but there will be a Society collecting box at the ready! Any members would be welcome and if you would like to go, please let Tracey know numbers.
tracey.james93@ntlworld.com or phone 02392 677476. This occasion is in memory of her father, Robert, who had Scleroderma and sadly died in April this year. W. Sussex members, Rosemary and Derek Taylor, are following their successful stall at the Ashington Summer Festival with two tables at the Lyndhurst Christmas Fayre. Rosemary's sister Linda will be running the stall at Lyndhurst on Sunday November 5th. Please support her if you can. Call Rosemary on 01903 892755 for more details.

Celia hosted an afternoon tea and I am delighted to report that she raised £220. She sold Christmas cards and her own beautiful hand-made cards for all occasions and there was a raffle. Many thanks. Great result!
All best wishes
Liz and Steve

London and South East

Contact: Kim Fligelstone,
3 Caple Rd, Harlesden,
London. NW10 8AB
Tel: 020 8965 4094
Email:
info@sclerodermasociety.co.uk
There will be a report in the next issue following the meeting on September 28th. Kim

TRUSTEES

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

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

stevemail99@btopenworld.com

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

LAY COMMITTEE MEMBERS

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

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

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

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.

Other Contacts

Edinburgh and East Scotland

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

LOOKING FOR CONTACT

My name is Brett and I have had linear scleroderma, "en coup de sabre" since childhood, nearly 30 years now. I am interested in hearing from anyone who has the same condition. You can contact me through e-mail: aaahbevan@yahoo.co.uk

GRANT AWARD

Mr Alan Holmes, BSc, Department of Rheumatology, Royal Free and University College Medical School.

The Society has made an award of £4,882.70 for Equipment and Consumables for:-

'Expression and regulation of the CCN family of Genes in SSc'.

The aims of the project are
1) To identify if other members of the CNN family of genes are over expressed in SSc.

2) To determine the expression of these members in involved, uninvolved SSc fibroblasts compared to normal fibroblasts.

3) To determine the effect of pharmacological inhibitors on the expression of CTGF in SSc cells to determine the mechanisms of over expression.

Microvascular Measurement of Systemic and Localised Scleroderma

Presented at the Scleroderma Society AGM/Conference 29th July 2006

Kevin Howell, Clinical Scientist, Royal Free Hospital

Many specialist centres that deal with connective tissue disorders have the ability to study the microcirculation (small blood vessels) in skin, and we have this facility at the Royal Free Hospital. Such measurements are important because the microvessels are involved in both systemic and localised scleroderma (morphoea).

In systemic scleroderma, the patient suffers from Raynaud's phenomenon in the great majority of cases. This is caused by a constriction of the small skin blood vessels in the fingers and toes on exposure to cold, and leads to cold, numb digits that can become blue, white, or red. We also know that in systemic scleroderma, there can be changes to the size and number of skin capillaries at the base of the fingernails, which is less likely to occur in patients who have only primary (standalone) Raynaud's phenomenon. At the Royal Free, we have also formed a close collaboration with Great Ormond Street Hospital to perform measurements of localised scleroderma (morphoea), which is the commonest form of scleroderma seen in children. In morphoea, fibrosis is limited to only the skin and the structures just beneath, there is no internal organ involvement. However, it is very important to treat active morphoea promptly to reduce the risk of limb deformities as normal tissue grows in the child, but the sclerodermatous skin does not. We know that active, extending morphoea begins as an inflamed area, with increased blood flow in the small skin blood vessels. So again in this case, measurements from the microcirculation can be extremely important in judging whether morphoea is, or remains, active.

Below are some examples of the equipment and techniques we have available at the Royal Free to make small vessel measurements in connective tissue diseases.

THERMOGRAPHY FOR ASSESSING RAYNAUD'S PHENOMENON

We know that patients with Raynaud's phenomenon have fingers which will warm more slowly than normal after they are cooled. Detecting this is the basis behind *thermography with cold challenge*. This involves placing the hands in disposable gloves to keep them dry, then plunging both hands in water at a temperature of 15°C for a minute. We

then monitor the speed at which the hands become warm again using a thermal imager, which produces a colour-coded (or grey-scale) image showing the temperature across the surface of the hands.

Figure 1 shows a healthy pair of hands ten minutes after they were cooled in

water: the hands are shown as warm (light shade) in the image. Figure 2 shows the hands of a Raynaud's phenomenon patient ten minutes after cooling. In this case, the hands remain dark, implying a cold skin temperature.

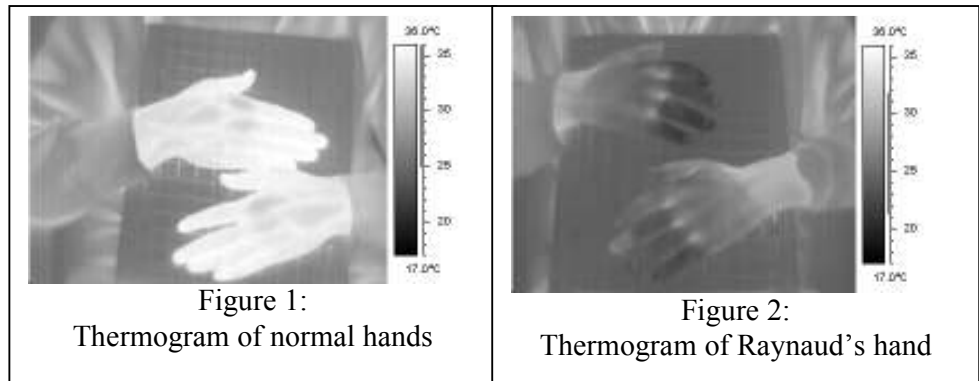


Figure 1:
Thermogram of normal hands

Figure 2:
Thermogram of Raynaud's hand

CAPILLAROSCOPY

We check the nailfold capillaries using a simple optical microscope (150x magnification). The skin is illuminated by a bright light source and coated near the nail

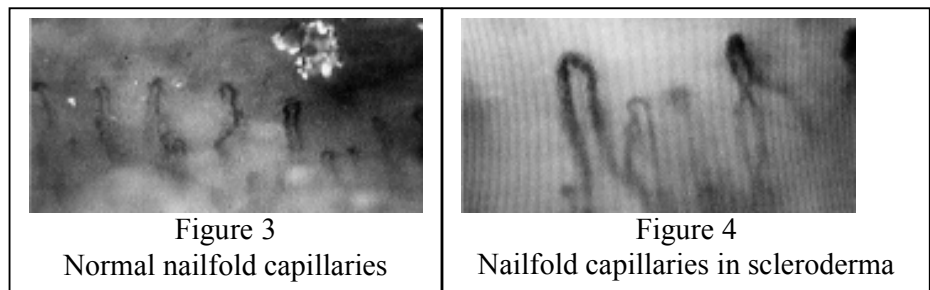


Figure 3
Normal nailfold capillaries

Figure 4
Nailfold capillaries in scleroderma

with a layer of nail varnish or oil to make the skin a little more transparent than normal. We can then video record the images obtained onto tape for storage. Figure 3 shows the capillaries from a healthy subject. The blood vessel loops are small and plentiful. Figure 4 shows the capillaries of a limited scleroderma patient, at the same magnification as in figure 3. In figure 4 we can see that the capillary vessels have become dilated (widened), and there are less loops visible in total.

THERMOGRAPHY IN LOCALISED SCLERODERMA (MORPHOEA)

Thermal imaging is also very useful for demonstrating that the areas of skin affected by localised scleroderma are hotter than surrounding normal skin, and therefore probably inflamed and “active.” Figure 5 is a thermogram of localised scleroderma affecting the left cheek in a child. This area is much warmer than the right cheek on the thermogram, so we can consider this thermogram “positive”, and the skin area inflamed. This patient went on to be treated with corticosteroids to reduce the inflammation.

Further research is now under way with Great Ormond Street Hospital, to investigate the use of other techniques such as ultrasound and laser Doppler flowmetry for assessing morphoea in addition to thermography.

This has been just a very brief overview of the importance that microvascular measurements have in assessing connective tissue diseases, but I hope it demonstrates that understanding the small vessels in skin is vital to us in scleroderma research.

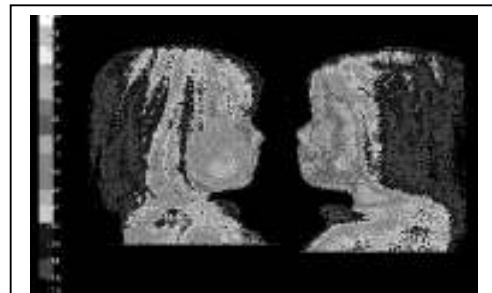


Figure5
Active morphoea affecting one side
of the face

FESCA ivzw (FEDERATION OF EUROPEAN SCLERODERMA ASSOCIATIONS)

Delegates from nine countries, Belgium, Cyprus, Hungary, Italy, Ireland, Germany, Netherlands, Spain and the UK met at EULAR in Amsterdam on the 22nd and 23rd June 2006 to thrash out the constitution for the Federation of European Scleroderma Associations. Everyone present signed the draft constitution on the 23rd June, which is to be ratified before the end of this year. The aim of the Federation is to support people with scleroderma by promoting the advancement of knowledge, research, and information in the field of scleroderma within medical, governmental, and social arenas, and by increasing awareness of the disease among the general public. Since June we have been joined by Portugal and expect more countries to join in the future. If anyone has any suggestions for worthwhile projects that FESCA could undertake we would love to hear from you.

THE OBJECTIVES OF FESCA:

- To collect and distribute information on all aspects of scleroderma, both in the medical and sociological areas of the disease.
- To foster excellence in education and research, with a view to improving treatment and patient care.
- To assist in improving the knowledge of the disease for people with scleroderma and among members of the health, welfare, and medical professions, and governmental bodies.
- To encourage and/or undertake surveys, research projects, and clinical trials related to the disease, and the publication of the results of any such research.
- To strive to establish parity of treatment and knowledge across Europe among people with scleroderma.
- To promote awareness and recognition of the disease to the general public throughout Europe.
- To gain representation on any european or international body whose interests could be of benefit to members of FESCA.
- To do all other such lawful things as are necessary for the attainment of the above objectives.

Claudine Delhove Droulez from Belgium and Peter Bakker from the Netherlands are the interim



FESCA Delegates

management team until January 2007. Ann Tyrell Kennedy from Ireland and Karlheinz Schonemann from Germany represented FESCA at the EUSTAR business meeting on the 24th June.

Beata Garay-Toth from Hungary and Kim Fligelstone from the UK represented FESCA at the EUSTAR Scleroderma Recommendations Meeting on 2nd – 3rd October 2006.

A little bit of trivia: FESCA

is to be registered in Belgium and the initials ivzw are required by law for non profit organisations.

EULAR

“EULAR Explained” is an extract from the PARE Manifesto newsletter issue 12 Winter 2005

What do the EULAR Social Leagues do? What is PARE Manifesto? How are both connected with EULAR? Is the AAA a new organisation?

Over the past years, the PARE Manifesto Steering Group has been confronted with these questions many times. This has been the reason for developing a guideline which aims to explain the connections between the groups within EULAR and explain abbreviations. Please find below an explanation describing how EULAR is the umbrella organisation and explaining the roles of the EULAR Social Leagues.

The European League Against Rheumatism (EULAR) was founded in 1947. It aims to promote, stimulate and support the research, prevention, treatment and rehabilitation of rheumatic diseases. Forty-three scientific organisations and 30 patient organisations are members of EULAR to date. Under its roof, medical organisations, the allied health professional organisations and the patient organisations work together. All are committed to raising awareness of arthritis/rheumatism and to improve the quality of life of those living with the condition. The organisation is based in Kilchberg/Zurich, Switzerland and the EULAR secretariat provides the overall support for its members. EULAR has three main groups – rheumatologists, allied health professionals working in rheumatology, and patient/user organisations (known as the Social Leagues of EULAR). The EULAR Social Leagues promote the development of user-led organisations on a national as well as on an international level. The Social Leagues are organisations which support people with arthritis/rheumatism at a national level. The organisations differ across Europe in terms of size, structure and activities, but they work with and for people with arthritis/rheumatism in that country. Activities may include lobbying at the national level. For example:

- Raising awareness of the disease.
- Defending the civil rights of people with arthritis.
- Having access to the latest and most appropriate treatments.

They also provide information on the different conditions specifically developed for a non-medical audience as well as offering contact between people with the same problems caused by the disease. Many of the Social Leagues provide a variety of services for people. For example, self-help groups, physiotherapy, social programmes, psychological assistance, information, events with specialists, telephone help lines, self-management promotion, etc. Some Social Leagues are ‘umbrella organisations’ bringing together self-help groups for people with different musculoskeletal conditions. The Social Leagues across Europe work together via the EULAR Social Leagues Standing Committee. Each member country is represented with one delegate in the Committee.

The aims are:

- To develop strong networks of effective, user-led organisations of people with arthritis and other musculoskeletal conditions.
- To ensure the voice of people with arthritis and other musculoskeletal conditions is heard and acted upon by decision-makers at a European level.
- To create powerful alliances which make a difference to the lives of people with arthritis and other musculoskeletal conditions.

To achieve this, the Committee organises a range of high quality activities and programmes, such as a major educational exchange visit programme, an annual programme at the EULAR congress (usually in the first weeks of June) and an annual stand-alone conference in the autumn (APOM). The Social Leagues have a strong history and a high profile within EULAR. They are represented within the EULAR Executive Committee: the EULAR Vice President, Social Leagues is elected by the EULAR General Assembly. The other representative for the Social Leagues is the Chair of the Social Leagues Standing Committee who is nominated by the national leagues for ratification at the General Assembly of EULAR. The Social Leagues Standing Committee meets once a year on the occasion of the EULAR congress to review progress and plan future activities. Social Leagues activities are supported by the EULAR Social Leagues secretariat. For political lobbying and awareness raising, the EULAR Social Leagues have established a special core task force: the People with Arthritis/Rheumatism in Europe (PARE) Manifesto and its steering group. *(End of Extract)*

OUR INVOLVEMENT

This year EULAR was in Amsterdam and I spent my time between the Social Leagues programme and FESCA. Sadly I couldn't attend everything but managed see a selection from a very interesting and diverse range of topics from "Health Economics", "International Campaigning", "Fatigue", "Paediatrics", "Relationships and Sexuality", "Goal Setting and Communication", "Team Care". Although many of the talks are about Arthritis in general (Rheumatoid Arthritis in particular) there is much to benefit someone with Scleroderma or any of the musculoskeletal conditions. The Relationships and Sexuality talk was very frank and dealt with many taboo issues that most patients would not generally discuss with their medical team or visa versa. But by breaking down the problems issue by issue and with serious commitment on both sides everyone seemed to benefit. The person with the condition, by facing the challenges with positive and practicable help and the medical team by breaking down the barriers and where they may have initially felt awkward about approaching the subject/s now had a huge wealth of experience and felt better equipped to help people having difficulties in the future.

It may come as no surprise to any of us to discover that most people with arthritis and musculoskeletal conditions share many challenges in common.

Next year EULAR is in Barcelona and patients can attend EULAR at reduced registration fees. See the EULAR Website for more details.

Kim

ARMA

The second stage of the ARMA Standards of Care is well underway and hopefully the three new standards, for "People with Metabolic Bone Disease", for "People with Regional Musculoskeletal Pain" and for "People with Connective Tissue Diseases" will be launched at the end of November. If any Specialists and Allied Health Professionals have examples of Good Practice specifically in the "Connective Tissue" area please go to <http://www.arma.uk.net/info.html> or contact Gillian Econopouly at geconopouly@rheumatology.org.uk.



SPOTLIGHT ON SCIENCE

This article is taken from the Arthritis Today Summer issue 2006 with kind permission of the Arthritis Research Campaign

Professor Chris Denton explains his work in a series of questions and answers.

What does your work involve?

As an academic rheumatologist my work is never dull. Although research is my first priority I also spend significant amounts of my time seeing patients with connective tissue disease, and also have responsibilities in teaching and management.

How long has ARC been funding you?

I have been very fortunate in obtaining long-term support for my work from ARC. I obtained my first grant, a Clinical Research Fellowship, in 1994 and have been supported in various ways since that time. Clinical research fellowships are invaluable in fostering and developing the careers of health professionals and basic scientists. The application process is an excellent chance to develop and refine a project and training environment, and having independent finance allows ARC fellows to go to work in the very best laboratories. All fellows meet once a year to discuss their work and this gives great encouragement and generates valuable collaborations. I have held an ARC senior research fellowship for the past six years.

What's the most important thing you have found out in the past 12 months? And why?

This is an exciting time for research in rheumatology and connective tissue diseases, including the condition scleroderma (systemic sclerosis) which is the main focus of my research and clinical work. Scleroderma causes fibrosis (or scarring) in the skin, joints and blood vessels and can affect the lungs, heart and kidneys in severe cases. During the past twelve months we have confirmed that blocking a key protein called TGF β can reverse some of the abnormal properties in cells from scleroderma patients. This is important as it demonstrated that fibrosis, once believed to be irreversible, may eventually be targeted by new treatments. Recent trials have also shown that blocking antibodies against TGF β can be safely given to patients with scleroderma.

What do you hope or expect to achieve as a result of your ARC funding?

There are many goals for a senior fellow, including achievement of project milestones gaining external funding to support a research programme. A major personal gain has been the securing of a long-term position at UCL based upon my work as a senior fellow.

What do you do in a typical day?

One of the great attractions of a medical career that combines clinical rheumatology with research is variety - no day is all that typical. However I prefer to start early on most days - usually on the computer responding to emails that have arrived overnight from colleagues. Next, as the hospital gets going I will deal with any urgent clinical problems. After this I can concentrate on laboratory issues, research, writing, reviewing. At the end of the day I am likely to be pestering colleagues in the laboratory to see how the day's experiments have gone - new data from the lab is what gives you a real buzz in research.

What is your greatest research achievement?

The achievement of which I am most proud is that I have successfully used some of the exciting progress in developmental biology and mouse genetics to better understand development of scarring or fibrosis in human rheumatic disease.

Why did you choose to do this work?

I am a great believer that work chooses you, rather than the other way round. When it goes well there can be few more rewarding ways to work than in medical research and clinical rheumatology.

Do you ever think about how your work can help people with arthritis?

Research into fibrosis is already helping scleroderma patients but there is a long way to go. Ultimately it is hoped that very specific, targeted therapy will be possible - like in rheumatoid arthritis. Our research programme is focused on identifying and testing target proteins.

What would you do if you weren't a clinician/scientist?

Another branch of experimental science or medicine would probably suit my aptitudes - sadly a highly-paid career as a sportsman or in entertainment would not!

Professor Chris Denton is an ARC senior lecturer and consultant rheumatologist at the Centre for Rheumatology at the Royal Free and University College Medical School, Hampstead, London

Email addresses of members happy for contact-

EMAIL ADDRESSES

We have 175 members on our membership database who have told us what their email address is.

I recently sent an email to all these addresses with news about our registration with www.everyclick.com, the charity fundraising website (see my separate item).

50 of them were returned marked email address unknown!

This may be because we have recorded your email address incorrectly, or because you have changed your address.

Using email where we can is a good way to reduce our expenditure on postage and paper and it would be great to get our database really up to date in this respect.

If you have an email address, and if you are happy for it to be recorded on The Scleroderma Society membership database, please take a minute to send me a short email. My address is Stevemail99@btopenworld.com

Your email address will only be used to communicate with you directly – it will not be given to anyone else unless you have specifically agreed to that with Kim.

Steve Holloway, secretary

SAD NEWS

Liz Holloway's mother, Elizabeth Sanderson, a long time supporter of the Scleroderma Society, passed away during the summer. Many thanks to all who sent donations to the Society.

Betsey Stephenson's husband Norman had been battling with Parkinson's disease for 22 years and is now at peace.

CONGRATULATIONS

Since we last went to press we would like to congratulate Christopher P. Denton PhD FRCP who is now Professor of Rheumatology at the Centre for Rheumatology at the Royal Free Hospital, London.

David and Vicky Lennon celebrated their 40th Wedding Anniversary and asked their friends and family to send donations to the Society instead of giving them gifts.

MY STORY

In December 2000 I was diagnosed with Coeliac disease after months of not feeling well following a minor operation. I have followed a gluten-free diet ever since. A couple of years prior to this I was seen by a dermatologist as I had developed skin rashes on my face, elbows, wrist, legs and stomach. After a few months of taking tablets and applying creams I had a blood test and was told I have Scleroderma. By now I had also developed Raynaud's.

In 2004, I was referred to The Royal Free Hospital. I was diagnosed as having CREST. I suffer with heartburn and carpal tunnel syndrome.

My biggest concern is the problem I have with my bowels. I am also concerned about other scleroderma patients who have this problem and suffer in silence.

Almost on a daily basis I was losing stools without being aware or able to prevent this from happening. I reported this to my doctor at The Royal Free. The doctor was very sympathetic and explained that this was a common condition amongst scleroderma patients. The doctor arranged for a consultation with a specialist at the hospital. After my initial consultation, he arranged for tests and xrays to determine the extent of weakness of my anal muscles giving rise to the incontinence. These tests were carried out by a cheerful, knowledgeable and sympathetic specialist nurse. There followed another appointment with the consultant who explained the options open to me and sent me home with literature to ponder things over. I opted for a Silicone Bioplastique Injection. Some months later I was admitted to The Royal Free Hospital where I was given, under anesthetic, a number of injections of Silicone to bulk up the anal muscles. Two days later I was back at home.

Unfortunately for me the operation did not have the desired effect. My consultant explained that the operation is not successful in every case.

I am learning to manage my life with this condition. I am also due to meet again with my consultant to discuss other options.

The doctors and staff at the hospital were excellent and very understanding. There is such a stigma attached to anything to do with the bowels that a lot of people suffer in silence. This is such a shame. The more people understand that this is a very common condition, the better things will be for those who have it. Let us bring this subject out into the open and thereby make life easier for those living with this condition.

If you would like to get in touch with the author please contact The Society

Also see 'Ask The Expert' on the back page.

FUNDRAISING

Many thanks to the **London Road Co-op at Hilsea**, Portsmouth. Since July 2005 they have raised a further £428.39 with their collection box.

Mrs June Gardner sent £50 from a coffee morning in Walton-On-Naze

Derek and Rosemary Terry raised over **£300** in August by having a stall at the Ashington Festival in Sussex. It was a wonderful effort, supported by all their family.

As well as raising money, both events did a huge amount to increase awareness of scleroderma amongst family, friends and the general public.

Mrs Mary Dore of Alresford, Hants, raised £40 at a coffee morning to celebrate her goat having two kids!! *I think this is a first for the Society!*

Medical Student **Julia Flint** was inspired by her time training in Rheumatology at the Royal Free Hospital. She decided to raise funds, and awareness, of Scleroderma for the Society by cycling 1,000,000m around London. Julia collected

£1707 from her family and friends, although one of her "Godmothers" said "**she would rather pay Julia not to cycle in London**", which I quite understand.

WHEELIEBEANZATHON IN BOLTON

Suzanne Rothwell and her friend Tracey organised the wheeliebeanzathon on 26th August to raise funds for Scleroderma and Cancer Research, they collected £400 on the day and including sponsorship donations are hoping to raise a total of £2,800 which will be split between the two charities. Over half of the beans were donated by Morrisons Supermarket, the rest by members of the public, friends and family. They recycled the beans by giving them to a local pig farmer who came and took the bin and beans away after the event.

Suzanne and her seven-year-old son Josh then took part in the sponsored cycle ride in Crosby Ravensworth and Morland. The Society cannot thank Suzanne enough for her recent and past fund

raising successes - some of you may remember her parachute jump in 2003.

SPONSORED BIKE RIDE IN MEMORY OF SIMON
Simon died of Scleroderma on the 29th August 2003, aged 32. Since that day the locals in the Crosby Ravensworth and Morland area have supported any fund raising activities held for the Scleroderma Society.

My nephews Bradley and Jack Saggers unfortunately haven't been able to join in most of the activities because they were too young. They



both wanted to raise some money in memory of their Uncle. They talked to their parents, Mark and Lynne Saggers, Mark being Simon's brother. A sponsored bike ride was talked about and finally decided to be a good idea. Lynne and the boys asked if I would help and I agreed. August 20th was the date set, so I contacted Kim from the Scleroderma Society and got the sponsor forms. We thought perhaps half a dozen children and parents would do it - how wrong we were! We ended up with about seventeen children and fifteen parents. Locals from Crosby Ravensworth and Morland were all willing to help, some as marshals for the road junctions, some supplying drinks at the half way mark and most of them providing food for a buffet at the finish. Jim Betts was transported around the route by Philip Winder taking the photos for us.

The bike ride started at The Butchers Arms, Crosby Ravensworth by kind permission of Sue and Colin Wilson and ended at The Crown Inn, Morland also by kind permission of Shaun Brennand, a total of six miles.

Medals and certificates were presented to all the children taking part, and a raffle was also held for the children.

We were blessed with a fine day and support down the route. A total amount raised on the day was £1068, but since then the figure is rising.

The whole event couldn't have taken place if we didn't have the support from locals and my family, for which I am very grateful. Next year, I am told, the bike ride will be reversed and it will be a yearly

event in memory of Simon. *Sara & Co collected a magnificent £1261.65*

Sara Robertson

Mishali Ondhia raised over **£3000** in August with her dinner/dance in London. It was attended by



approximately 160 people and was altogether a great evening.

WALK FOR SKIN UPDATE

The Society received a cheque from the British Skin Foundation for £1,730.60 which includes 50% of all sponsorship raised by the walkers who nominated the Society and 50% of the gift aid reclaimable on those donations. A huge thank you to everyone who took part and just in case any of you are keen



Kim Receiving the Cheque for £1,730.60

to do it all over again, next year's Walk For Skin events will take place between 12th and 20th May. I'm just hoping for better weather!

PROUD GRANDMOTHER

After all the hot and humid days that we'd been having, it was a relief to turn up at Bracknell Sports Centre at 9 am on Monday, 7th August, and find that it was actually a bit chilly.

We'd been stocking up with bottles of water and Mars bars to keep up the energy of the four young people who were going to do the sponsored run for The Scleroderma Society.

They all went onto the track wearing their Scleroderma T-Shirts and finally they were off. There was Carmen McSweeney and her brother Scott, who are my grandchildren, and two of their best friends Becky Houston and her brother Ryan.

They ran and ran and when they got tired they walked a bit and then ran some more. It was amazing to watch the determination on their faces.

Thirteen of us had turned out to cheer them on and supply all the water and Mars bars and some of us even ran round with them once or twice. Each time they passed the beginning we shouted all the encouragement we could at the tops of our voices. Their little faces would light up and chins would go out and you could actually see the strength seeping back into their legs.

It was Carmen's idea to do the run, so her Mum contacted Kim at the Society who supplied the T-shirts, bookmarks to give to our sponsors, posters to display in the Sports Centre and also a copy of the sponsor form which we were able to print off the computer.

They all made it to the end and we were all very proud of them, especially me. I have Scleroderma and that is why they did the run, to raise money for more research. Between them they have raised £485.

By the way, the ages of the children are Carmen and Becky 12, Ryan 9, and Scott 8. I think they are just amazing!! Thanks to all four of you, and hope you had a lovely summer holiday.

Margaret Turner

HANDMADE BIRTHDAY AND CHRISTMAS CARDS

The sale of homemade birthday cards has been fantastic. Thank you for the support I have received from very generous customers that have either suffered a loss of a loved one from the disease or have Scleroderma. Up to date, I have raised £510 through the sale of my cards.

Just to remind members of the society, I have Christmas cards to sell in aid of the society. An assortment of cards are available at a cost of £6.00 for a packet of 5. Postage is in addition to this cost.

Individual cards can also be purchased and special cards can be made with messages suitable for loved ones. These can range from £1.50-£2.00 depending on requirements.

Are you stuck for Christmas present ideas? How about sending packs of blank cards as gifts to friends and family? They not only make a nice gift but they attempt to raise awareness of this dreadful disease. Every little helps.

You can contact me on 01768 894057 or 07984831221. If I am not available, please leave a message and I will get back to you.

Please continue to support my fund raising, and I hope to hear from you soon!

Yvette Saggars

TO ALL SURFERS

Raise money for **The Scleroderma Society** just by searching the web!

We are always looking for ways to raise money, and here is an interesting one for those of you who use the Internet.

www.everyclick.com is an internet search engine with a big difference - it donates half its revenues to charity!

It does not cost us, or you, a penny so please use it to support The Scleroderma Society.

Just type

www.everyclick.com/uk/thescclerodermasociety and you will be taken to the search page, already set up as a Scleroderma Society supporter.

If you visit www.everyclick.com be sure to look for **The Scleroderma Society** – the ‘**The**’ is important! The search engine is easy to use and you can see how many searches have been made by our supporters and how much has been raised by clicking on the words **The Scleroderma Society** on the home page.

Please give it a go. If you would like further information or assistance, please let me know. You could also pass this on to your friends and family so that they can help us raise funds too.
Steve Holloway

TRAVEL INSURANCE

We have been informed that a member has secured yearly travel insurance from Nationwide (£75 for a couple) with medical (scleroderma) problems disclosed.

Ask The Expert

Q. I have scleroderma and want to leave my body to medical science. How do I go about this?

A. You will need to express this wish with your Consultant, who is looking after you. I guess when you say furthering modern science you mean Scleroderma research and not for anatomical dissection which would involve a totally different approach. If you make known your desire to your medical team, they will make sure that a post mortem takes place (not an easy assumption these days after the Alder Hey experience). Then the removal of certain organ tissues can be appropriately saved either in preservative or other medium, depending on what the pathologist is looking for. This does need to be clarified beforehand and you are quite right to specify this at this stage.

Q. Has there been any research on probiotics being helpful for bloating?

A. There is documented evidence for symptomatic relief of bloating after use of probiotics particularly in small bowel disease. Various theories have been postulated for this including stabilising the bowel wall as far as the bacteria attached to it are concerned and even thoughts about regulating the immune system. But generally they have received a good publicity. Certainly we are advising their use in patients with small bowel symptoms caused by their scleroderma.

Q. Is there any non surgical treatment for faecal incontinence?

A. We have tried various options including creams and anal plugs but these have not proven to be successful or acceptable options by our patients. Pelvic floor exercises and biofeedback techniques, which is a form of training patients to increase tone in the pelvic floor, are options. Other treatments include prevention of diarrhoea and bulking of the stools using either fibogel or imodium. These are helpful as incontinence becomes more of a problem if the stools are loose. Incontinence may not be progressive and sometimes patients are prepared to manage their bowels as outlined above and also wear an incontinence pad in case of an accident. If symptoms do progress it is always advisable to visualise the muscles of the anal canal and rectum with the aid of an ultrasound and measure the pressures inside the rectum so that appropriate advice can be given to each individual specifically.

Nurse Specialist Helplines



Rona McIvor

Woolmanhill 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 523849

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.