

Christmas Newsletter

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*Scleroderma Unit
The Royal Free Hospital -
December 2005*

Seasons Greetings from all at The Scleroderma Research Unit

Dear Friends

This year has flown by even more quickly than the last one and there have been even more demands on my time as President of the Royal College of Physicians, I very much miss the out-patient days at the Royal Free. I know they are hectically busy but they give everyone who works in them a very real sense of team working. We see patients and their partners who we have come to know very well and also have the pleasure and opportunity to meet new patients. I have, despite this busyness, managed to lecture at conferences both at home and as far away as Uruguay and will be Visiting Professor in America just after Christmas. Drs Denton, Abraham and Coghlan have kept in regular, sometimes daily, contact and have made me feel very much part of the Unit

I wish you all a very joyous Christmas and New Year

Dame Carol Black



Clinical Activities for Scleroderma at the Royal Free

The past few months have been typically busy in the clinic and on the wards. There have been major reorganisations of the inpatient facilities within all of the medical specialities at the Royal Free. As a result of this we are now able to admit patients to the day treatment unit and offer overnight accommodation in South House, self-contained accommodation on site for patients who wish to stay close to the hospital. This system is now starting to work well for iloprost infusions and we hope will allow us to offer a more predictable and consistent service with fewer cancellations of beds. Our other inpatients are now staying on Garrett Anderson ward or on the renal or cardiac wards when necessary.

In the clinic we are delighted to welcome Dr Carmen Fonseca who is a rheumatologist from Mexico who has been working in the laboratory for several years but who is also now spending some time each week in the scleroderma clinic. This integration is helping to advance our genetics research by allowing detailed features of each scleroderma case to be linked with the new genetic results.

There are exciting new trial results coming out. Recent studies that have been positive for scleroderma include RAPIDS-2, a trial of bosentan (an endothelin blocker used in pulmonary hypertension) for finger ulcers in scleroderma and two studies of immunosuppression in scleroderma lung fibrosis. These include one study (FAST) led by Professor Ron du Bois and Professor Black of the Brompton and Royal Free hospitals respectively. The FAST results were presented recently at a major USA medical conference by Dr Rachel Hoyles who is working with me and Athol Wells. With more trials about to start and others reporting results soon this is a very productive time for clinical research in scleroderma.

Dr Chris Denton



Laboratory and Research News : Dr David Abraham

As we rapidly approach the end of another year it is a good time to reflect back and see what we have achieved over the past months. The laboratory work has progressed well, with the discovery of new and important findings. We continue to work on understanding Raynaud's and Scleroderma; what starts the diseases, what drives the diseases, why certain organs are affected, and how the vascular, inflammation and fibrotic phases of the disease process are linked. We also continue our studies on the genetics in collaboration with Professors Ron du Bois, Athol Wells and Ken Welsh at the Brompton Hospital. Here we are trying to identify the complement of disease-specific genes that are important in disease susceptibility and progression pathogenesis. Our research has a major emphasis on translational studies, which means that we attempt to move from basic scientific research through pre-clinical studies and on into the management and treatment of patients as rapidly as possible. Our research has had a direct impact upon a number of completed clinical trials and also those that are currently taking place. These include the use of iloprost (for blood vessel problems), bosentan (endothelin blockade) and anti-TGFbeta antibodies (for fibrosis). As we continue to make advances in our appreciation of Raynaud's and Scleroderma we will be able to provide valuable information to help in the development of specific, targeted and effective treatments.

We have three new members of staff Robina Aslam, Ester Akanho, and Henry Penn, who are working on aspects of disease process including the genetics and blood vessels problems.

These achievements have been made possible by considerable research support from a number of organisations. These **Research Grants** are from;

The Arthritis Research Campaign – with the renewal of our programme grant for the next five years.

The British Heart Foundation – with a research award to examine how scars form within blood vessels.

The Raynaud's and Scleroderma Association – with research awards to study the early stages of scleroderma and the role of reactive oxygen species derived from blood cells.

The Rosetrees Trust – with support for a pre-clinical study into dermal fibrosis.

The Scleroderma Society – with support for studies, and equipment to examine in more detail the changes in the skin of scleroderma patients, and gene expression changes.

National and International Meetings

Some of our research work has been presented at scientific meetings in the UK, across Europe and the USA as both abstract or poster presentation and lectures. In particular, in November many of the research and clinical staff attended the American College of Rheumatology (ACR) meeting in San Diego. Poster and oral communications presented by Drs Denton, Fonseca, Hoyles, Shiwen and Stratton were all well received and generated a lot of international interest. The ACR, with the British Society of Rheumatology (BSR) earlier in the year, is one of the major meetings in the academic calendar, and provides a very active forum and interactive environment to display our work. We have already submitted a number of communications to the forthcoming BSR meeting to be held in Glasgow next spring. These symposia also keep us informed of events and important activities relevant to scleroderma and Raynaud's that are taking place around the world. Our success at these prestigious symposia is vital in promoting and widening exposure and interest in Raynaud's and Scleroderma throughout the UK and abroad.



Dr Geraldine Brough

I continue to run the scleroderma clinics on Thursdays, alongside Dr Denton, as well as doing my general rheumatology clinics and teaching the medical students. I am about to re-start the combined Plastic surgery/ rheumatology service with Mr David Floyd. Mr Floyd has a particular interest in hand as well as plastic surgery.

In the New Year I am hoping to start some research into scleroderma bowel disease together with Dr Marcus Harbord from the Gastroenterology Unit.

This year I have involved myself with the 'Certificate in Medical Education' run by the Royal College of Medicine. This requires several research projects to be completed as well as learning a new language (education jargon)!

News From Our Nurse Specialists Helen Clare Rachel Joanna Louise



Thermography & Capillaroscopy Laboratory: Kevin Howell

The year has flown by and we can't quite believe it's Christmas time again. There has been much activity and many changes in the specialist nursing team for scleroderma and pulmonary hypertension (PH): Helen (Clinical Nurse Specialist), Clare (PH Specialist Nurse), Rachel (Education Nurse), Joanna (PH Nurse) and Louise (Research/Education Nurse), not forgetting our ever-helpful and long-suffering clerical assistant Sharon.

Our clinical trials nurse Jane left early in the year and was replaced briefly by Miriam, who has recently left and is now working in trials of new chemotherapies for cancer. She will be sorely missed. At time of going to press the process for the selection of a new trials nurse is under way and we hope to have someone in post in early 2006. This year we have also welcomed Louise Davis to the team, whom some of you will already have met.

The team have as usual been very busy with Clare in particular speaking at many meetings including the first national scleroderma study day for nurses in Bath and Joanna attending the PH Association patient conference. Changes at the Royal Free have meant that scleroderma and PH patients are now staying on different wards and so we have been kept busy ensuring that the staff on these wards are familiar with the care scleroderma patients require

As always we have many ongoing and forthcoming trials attempting to find effective therapies for scleroderma and PH. If you would any further information on any of them, or wish to take part in a future trial please contact the team on 020 7830 2326 or 020 7472 6354.

SSTEP – recruitment for this trial into the use of iloprost tablets has now finished. The trial is investigating whether scleroderma patients who take iloprost tablets report a lower incidence of heart attacks, angina and strokes.

INFLIXIMAB – this trial of a new treatment for early or worsening diffuse scleroderma is nearly finished and we await the results with interest.

ARIES / STRIDE – these two trials are both for patients with PH and are looking at two new tablet medications, ambrisentan and sitaxsentan to see whether they are useful treatments for slowing down progression of PAH.

TRUST/EARLY – these trials are looking at the use of bosentan at different stages of PH.

TADALAFIL – this new trial which is due to start soon will be looking at the use of a new drug, tadalafil in PH.

BIRD/ASSET – these two trials will be looking in to the use of bosentan in early renal crisis in scleroderma and in sickle cell.

On a personal note we offer congratulations to Rachel and Helen who have had a son and a daughter respectively this year. Rachel is now back at work and Helen will be returning in the New Year.

We would like to take the chance to wish you all a merry Christmas and a happy new year.

Since my last update it's been another busy period of conferences and travel! This year's EULAR meeting in Vienna had two sessions on capillaroscopy, and I was invited to speak at these. Among the former colleagues I met at the conference were Dr Dev Mukerjee and Dr Bernard Coleiro: many of you will remember them from their time at the Royal Free.

Closer to home, I helped in the organisation of the UK Thermography meeting once again this year. It was held at the National Physical Laboratory in Teddington in November. The first speaker was Prof John Harper of Great Ormond Street Hospital, who spoke about the collaboration between our unit and Great Ormond Street for imaging localised scleroderma patients. In fact, in total the Great Ormond Street / Royal Free team made three presentations to this meeting about our work with thermography.

I am involved in this meeting every year through sitting on the committee of the UK Thermography Association. This is a group that promotes the use of thermography in the UK for all reasons, not just medical applications. Our website at www.ukta.org is partly my work!

Planning is now under way for the next major European Thermography meeting in Zakopane, Poland in September 2006, which promises to be a very prestigious occasion!

Of course the mainstay of my work is still meeting patients and performing their vascular tests, and we now have a very successful microvascular service which can thoroughly investigate Raynaud's phenomenon and some of the aspects of scleroderma. One important part of this work is the growing number of patients the lab now sees who are referred from other hospitals for these investigations, which cannot be performed more locally. Often it is our own former colleagues like Dev, who have gone on to become consultants in their own right, who refer these patients. This is a fine example of how starting a medical career in scleroderma with us here at the Free "spreads the word" about the services we offer and makes them available to all, which is very much the wish of Professor Black and Dr. Denton.

A big team helps support the thermography lab: I am just the "front-end" that you all meet on the day. In particular I am grateful to Dr Roy Smith and his team in the Royal Free Medical Electronics Department for their support of our service, and to Dr Lisa Weibel at Great Ormond Street who now provides vital support to our localised scleroderma assessment service.

Finally I want to remind you all that we stock a supply of reusable hand warmers in my lab at a cost of £2.50 each. We are unable to offer a mail order service, but anyone who needs some warmers should see either myself or Rita during an out-patient visit.

Best wishes for a merry Christmas and a happy New Year!

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Talking About the Disease

My name is Kim Fligelstone. I have had scleroderma (Diffuse) since 1988. In 1991 I had a renal crisis and started dialysis which is kidney replacement therapy. Since then my condition appears to have stabilised and my mobility has vastly improved. I work in the Rheumatology unit part time and one of the nicest aspects for me is visiting patients on the ward, so if you would like to talk to a patient with experience [I am not a Counsellor or a therapist] then please ask the ward clerk to call Ext 5131 or you can call me at on 020 7794 0500 ext 5131 if you would like to chat on the phone, I work on Tuesdays and Wednesdays.

Finally—how about a massage next time you are an inpatient at the Royal Free? Keith Hunt has a team of volunteers who will come to the ward and give you a massage, just ask a member of staff on the ward to refer you to Keith's team.

Have a very Happy Christmas and as Healthy as possible New Year.

The Newsletter

We hope you enjoy receiving the Newsletters. Every patient who attends the Scleroderma and Raynaud's clinics is added to our Newsletter Mailing List — which is used solely for mailing out our twice yearly Newsletters. If you do not wish to receive the Newsletters or would like your name removed from the Mailing List, please let me know. You can write to me at The Scleroderma Unit or email me at

pamela.yeomans@scleroderma-royalfree.org.uk

Fundraising

We do so appreciate the efforts patients have made to fundraise on our behalf. Thanks you to all those who have raised funds on our behalf. We have two people who have offered to run the marathon for us next year, which is fantastic. Jason Rudolph ran it for us last year, which was fantastic.

Family Day Saturday 13 May 2006

A date for your diary in 2006. The programme for this day will be sent out as part of the Spring Newsletter. If there are any areas of your disease that you would like included in the programme please let us know and we will do our best to include them.

We have enclosed a book of raffle tickets — for the Family Day Draw. The raffle raises extremely valuable funds and we are very grateful to all those who buy tickets.

If you would like more raffle tickets please contact Pamela Yeomans on 01273 672686 or pamela.yeomans@scleroderma-royalfree.org.uk

How to Contact Us

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Via the switchboard on 020 7794 0500

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