

# Spring Newsletter

*The Newsletter of  
The Royal Free  
Hospital  
Scleroderma Unit  
Spring 2003*

## Scleroderma Family Day – Saturday 17 May

As we write our Spring Newsletter Easter is almost upon us and we are preparing for our Family Day. We all look forward to this very much indeed and hope you will be able to join us. We have some very interesting topics and speakers, lots of demonstrations and the opportunity for you to meet each. Please do try and come.

## Clinical News

We are delighted to welcome some new faces into the scleroderma clinic. Dr Maresa Carulli has joined us as a senior specialist registrar to work both in the pulmonary hypertension clinic with Dr Coghlan and also in the “general” scleroderma clinic. Maresa is almost fully trained as a rheumatologist and is also working in the laboratory doing research with Dr Denton. Dr Lynne Shand has joined the clinic. Lynne is more junior and is dipping her toe in the water to see if she would like to specialize in rheumatology. She has a strong general medical background and worked with Professor David Scott in Norwich before joining us. These new faces are working alongside Drs Denton and Brough and Professor Black as well as Drs Ong and Dziadzio in the scleroderma clinic. Unfortunately Dr Dev Mukerjee has now moved on – he will be much missed.

## Clinical Research

A number of new clinical research projects have been started. We are developing closer links with the vascular surgeons and have a new clinical fellow, Mr Adnan Alam, studying large blood vessels in scleroderma. Adnan is working with Mr Daryll Baker and other members of the department of surgery following up on exciting results we obtained last year in a preliminary study. You may be asked to help out with these studies, which are all painless! We are also continuing to work with Dr Ed Kingdon on kidney problems in scleroderma. Ed will be finishing off his work of the last several years on scleroderma now that he is a consultant in Brighton. As well as joining us in the clinic, Dr Lynne Shand is helping consolidate and develop the scleroderma clinical database – and very politely but firmly making sure all the clinic doctors fill in the datasheets. This is critical to our research projects and her efforts are much appreciated. We are also very actively developing links with paediatricians and dermatologists to try and make progress in understanding scleroderma in children. The need for this was emphasised at the recent, and highly successful, Scleroderma Family Weekend in Chester, organised by the Raynaud's and Scleroderma Association.

## Travel and meetings

In February we held our 2 day scleroderma postgraduate course at the Royal Free. This has become a biennial event and attracts high quality speakers and delegates from the UK and abroad. This year we were fortunate to have Drs Joe Korn and Barbara White from the USA. They are both major figures in scleroderma in North America. From Europe Drs Alain Mauviel and Oliver Distler presented laboratory work on scleroderma. Together with an extensive panel of UK experts the course was able to provide a state-of-the-art education to doctors and scientists about developments and progress in scleroderma. As well as organizing this course, members of the department have also been travelling abroad to lecture and to develop new clinical trials in scleroderma. Chris Denton has visited France, Switzerland and (well almost –) Amsterdam to lecture or help develop clinical trials in scleroderma.

*Chris Denton*

## Research and Laboratory News

It has been a very good start to 2003 in the research laboratory, we have a number of new staff, have been awarded a number of research grants and we have recently presented some of the research work in Manchester. Basic science studies are essential in our long-term fight against Raynaud's and Scleroderma, and

our ability to understand and treat diseases. Presenting our work in the national arena also helps in many ways; increasing the profile of the disease and to spark more widespread interest.

*David Abraham*

## Research and Equipment Grants

We have been awarded the following grants:

**The Golden Charitable Trust** - have continued their long-term support of our basic translation research in scleroderma. This has allowed us to look in great depth into the pathways that control proteins important in scleroderma.

**The Scleroderma Research and Development Action Committee** – has awarded us a project grant to study the integrity of blood vessels in Raynaud's and Scleroderma. This work will be performed by Mr Vineeth Rajkumar in the laboratory.

**The Arthritis Research Campaign** - We have 3 ARC BSc studentships for training medical students to work in the laboratory. These are ongoing research projects on Raynaud's and scleroderma.

**The Welton Foundation** – has awarded us funding to recruit a Senior Research Scientist to the department from the Biotechnology industry. These studies are aimed at assisting our clinical colleagues in the development and implementation of effective treatments for scleroderma.

**The Nightingale Charitable Trust** – have continued their support of our research studies and have awarded us a grant to fund an important clinical research study on growth factors in scleroderma

**The Raynaud's and Scleroderma Association** - has provided us with additional essential equipment support for our microscope.

## The Laboratory and New Staff

There are four new members of the research team. Najoun Taguri and Marianna Thomas having joined us to study aspects of cytokines and free radicals in Scleroderma. Drs Andrew Leask and Carmen Fonseca will both join the laboratory on May 1<sup>st</sup>. Dr Leask is from the Biotech Industry and will give us an added impetus in the translation research area and Carmen as many of you may remember trained at the Royal Free and now return to take up a position funded by a grant from **The Raynaud's and Scleroderma Association**. This grant is a joint grant between the Royal Free and Brompton Hospital and also supports Alan Holmes.

## The State of Play – Clinical Trials at the Royal Free

The **'QUINS'** trial is looking at the prevention of blood vessel damage - for patients with limited scleroderma who are happy to visit us every 3 months for 3 years.

The **'SSTEP'** trial of oral iloprost - for patients with either limited or diffuse scleroderma, it lasts 5 years- with visits every 6 months.

**Inhaled iloprost trial.** Investigating whether iloprost in the inhaled form could eventually replace iloprost through a drip. A 3 month study with six visits to the hospital.

**Sildenafil** is also known as Viagra® and works by opening up the blood vessels to improve circulation. This is for limited scleroderma patients who suffer at least seven Raynaud's attacks a week and involves taking tablets for a month with 5 visits over 8 weeks.

**If you would like more information please phone Leo, our new trials nurse [or any of the specialist nurses] on 020 7830 2326.**

## Terahertz imaging of scleroderma skin

If you are between 18 and 70, suffering from scleroderma would you be willing to give one or two small skin samples, at the Scleroderma Family Day. We also need 'healthy' skin if any friends/family are willing to help. If you would like to learn more about this please contact my colleague Liz Joyce at the Royal Free on 020 7830 2417.

*Kevin Howell*



**PROGRAMME**

Scleroderma Family Day  
The Atrium, Royal Free Hospital

Saturday 17 May 2003  
PROGRAMME

09.30 - 10.00	<b>Registration and Coffee</b>	
10.00 - 10.15	<b>Introduction to the Day</b>	<i>Professor C Black</i>
10.15 - 11.00	<b>Research Road Map – The Journey</b>	<i>Dr D Abraham &amp; Team</i>
11.00 - 11.45	<b>Clinical Overview</b>	<i>Dr C Denton &amp; Fellows</i>
11.45 - 12.30	<b>Medical Aspects of Scleroderma Panel Discussion – Questions from the audience</b>	<i>Dr G Coghlan- Pulmonary Hypertension Dr S Hunt – Dermatology SpR Brompton – Lungs Dr T Wilson – Neurological Complications</i>
12.30 - 14.00	<b>Lunch - <u>Demonstrations and Discussions</u></b>	<b>The Atrium – see below</b>
14.00 - 14.45	<b>European Scleroderma</b>	<i>Prof A Gabrielli/ Dr M Dziadzio Ancona, Italy</i>
14.45 - 15.15	<b>Drug Toxicity</b>	<i>Mr John Farrell</i>
15.15 – 16.00	<b>The Scleroderma Roadshow Taking SSc around the Country</b>	<i>Dr S Menon Dr C Denton</i>
	<b>Raffle</b>	

**Lunchtime Discussions Groups**

Women's issues in SSc  
Psychological Aspects  
Oral problems  
Surgical Aspects of SSc

*Miss S Tuck  
Dr G Lloyd  
Prof S Porter  
Mr M Brough  
Mr N Goddard  
Mr G Hamilton  
Mr G Ogunbuyi*

**Lunchtime Demonstrations – Around the Atrium**

Cosmetic Camouflage  
Drug information/monitoring  
Education/Nursing  
EMGs  
Occupational therapy  
Physiotherapy  
Podiatry  
Massage  
Rheumatology Laboratory Demonstrations  
Thermal Camera  
Vascular Imaging  
*Radiology*

*Red Cross  
Ms H Atkinson  
Helen/Rachel/Clare  
Mr B Youll  
OT  
Sophie  
Mr S Kriss  
Mr K Hunt  
Research Laboratory Staff  
Mr K Howell  
Radiology*