

Spring Newsletter

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Scleroderma Unit
The Royal Free
Hospital -
Spring 2006

Scleroderma Family Day - Saturday 13 May

Clinical Research and the Scleroderma Unit

This is a very exciting time for the clinical research projects as several have recently been completed and soon to be published in medical journals. In 2006 we have a number of new visitors joining the unit to learn about scleroderma research. Thus, we have just welcomed Dr Eva Triantafyllidou from Greece and Dr Saioa Eguiluz from Spain to the unit and both are training in scleroderma and undertaking research.

This is a challenging time for the Royal Free NHS Trust as it strives to improve services and increase efficiency. We have worked hard to develop more ambulatory (non-inpatient) care for scleroderma patients and have also been working with hospital managers who are reorganising wards. This has meant moving from Hopgood ward, to Garret Anderson ward and now probably to Jenner Hoskin ward for some of our scleroderma in patient beds. We are very fortunate to have such a committed team of doctors, specialist nurses and other professionals in developing, and we hope improving, our service and look forward to receiving feedback from our patients at the next Family Day.

Chris Denton

Laboratory Research

It has been a good start to 2006 in the Scleroderma and Raynaud's research laboratory. We have two new staff, Stella Ziaj and Colin Hart, and we have been awarded a number of research grants to continue our vital studies. Our work has also been accepted for the up coming British Society meeting for Rheumatology in Scotland. We are also organising two other important meetings in the Summer. Firstly, a meeting which focuses on the vascular complications of human diseases at the Royal College of Physicians in July. And secondly the International workshop on Scleroderma in Boston in August. All-in-all we have a very busy summer ahead. Presenting our work at these national and international meetings is incredibly important as it helps to increase the profile of the disease within the biomedical community world wide, sparks more widespread interest and attracts much needed support.

The research studies have progressed very well, we have focussed much more on the genetics of Scleroderma, lung disease, and examining some of the potentially important early initiators of diseases – the free radicals. These studies are being carried out by Drs Carmen Fonseca, Xu Shiwen and Rachel Hoyles, and Alan Holmes in the laboratory, and have been funded by the Arthritis Research Campaign and the Raynaud's and Scleroderma Association. These basic science and pre-clinical studies are essential in our battle against Raynaud's and Scleroderma, and our ability to understand and treat diseases.

Research Grants:

We have been awarded the following grants:

The Rosetrees Trust -have continued their support of our basic translation research in pre-clinical models of scleroderma.

The Scleroderma Society – has provided support to study kidney damage in Scleroderma

The Arthritis Research Campaign- has given us two BSc studentships to enable medical students to train and work in the laboratory.

The Raynaud's and Scleroderma Association -has continued their long-term support in our joint programme grant with the Professor du Bois at the Royal Brompton Hospital to study the genetics of scleroderma.

Professor David Abraham

Donations

We are always happy to receive donations from patients, their families and friends — we would like to thank The Graphite Trust [where one of young patient's mother works] for kindly donating £2000.00.

Blood Flow Studies Lab Spring Update

Right now seems to be a busy period for us, with high numbers of patients referred for thermography and capillaroscopy! Currently I am working with my colleague Marium Naeem (Medical Physics) on testing the National Physical Laboratory's prototype calibration equipment for medical thermal imagers. We hope this equipment will go on to be an invaluable resource for ensuring the accuracy of medical thermography, once it has passed the "field tests."

I am also beginning to turn my attention to later in the year. First of all, I am looking forward to speaking to you all on Scleroderma Family Day in May. We are also preparing presentations for the European Congress of Medical Thermography in Poland, and the EULAR Course on Capillaroscopy in Genoa. Both of these take place in September, but time flies, and these are sure to come around quickly! See you all in May.

Kevin Howell

Specialist Nursing News

Spring is here again and developments continue apace in the specialist nursing team. As usual we are very busy with the interesting mixture of talking to patients in clinics and on the wards, carrying out research and clinical trials and helping patients manage their various conditions and treatments.

Since Christmas Helen has returned to work following her maternity leave and we also extend a big welcome to our new clinical trials nurse, also called Rachel, who started with us at Easter, and will be managing all our clinical trials. If you are interested in taking part in a trial please call us on 020 7830 2326 to see if we have any trials which may be suitable for you.

The specialist nursing team shall be well-represented at Family Day on 13th May so we hope to see some of you there for a chat.

Helen, Clare, Rachel, Rachel and Louise.

Family Day

Our Scleroderma Family Day is on Saturday 13 May — which we are all looking forward to—we do hope you can join us — please see our programme overleaf.

09.30 - 10.00	Registration and Coffee	
10.00 – 10.15	<u>Welcome and Introduction</u>	Dame Carol Black
10.15 - 10.45	Integration of clinical & laboratory Research	Prof D Abraham/ Dr C Denton
10.45 - 11.15	Assessment of localised scleroderma	Mr K Howell
11.15 - 11.45	Scleroderma lung fibrosis	Dr R Hoyles
11.45 - 12.15	What is new in pulmonary hypertension	Dr C Handler/ Dr C Goghlan
12.15 - 12.45	Neurological aspects of scleroderma	Dr Bryan Youl
12.45 - 14.00	Lunch— see below	
14.00 - 14.30	A Dutch perspective of scleroderma	Dr F v den Hoogen
14.30-15.00	Foot problems in scleroderma	Ms A Megpara
15.00 - 16.00	Question and answer session Dr C Denton, Prof C Black, Dr F van den Hoogen, Dr C Coghlan, Pharmacy	Panel to include
16.00	Raffle	

Lunchtime Discussions Groups / Demonstrations

Cosmetic Camouflage	<i>Red Cross</i>
Drug information/monitoring	<i>John Farrell/Jay Pang</i>
Education/Nursing	<i>Helen/Clare/Rachel/Louise</i>
Oral problems	<i>Prof S Porter</i>
Gynaecological Problems	<i>Miss S Tuck</i>
Orthopaedic Surgery	<i>Mr N Goddard</i>
Physiotherapy/Occupational Therapy	<i>PT Dept</i>
Massage	<i>Mr K Hunt</i>
Rheumatology Laboratory	<i>Research Laboratory Staff</i>