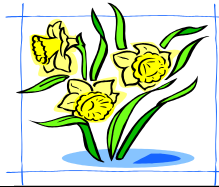


Spring Newsletter



Scleroderma Unit
The Royal Free
Hospital -
Spring 2004

New website address — www.scleroderma-royalfree.org.uk

Spring Update on Departmental Clinical News

We will be sad to lose Dr Magda Dziadzio from the clinic, as she must now return to Prof Gabrielli's Department in Italy. We have also said goodbye to Dr Noemí Garrido a rheumatologist from Professor Carreira's unit in Madrid. Dr Garrido has recently been replaced by a senior medical student Mary Beth from Dr Frank Arnett's group in Houston, Texas who has joined the Unit for one month and will be sitting in on some clinics over the next few weeks. We would also like to let you know that the opening session at the forthcoming BSR meeting in Edinburgh is on Scleroderma and 3 of our research reports have been selected for oral presentation. It is a major milestone in raising the profile of scleroderma within the UK rheumatology community to have a major session discussing this disease.

Chris Denton

Laboratory Research

Our overall research studies are to understand the root cause of Raynaud's and Scleroderma and to identify the key players in the diseases process. This information can be used to help better identify stages and different sub-sets of the disease and in the long-term, to develop more effective ways to treat patients. Some of our recent work has concentrated on the control of the genes that regulate the growth factors and cytokines that we believe to be important in the disease process and in developing better models in the laboratory to study the diseases progression. Three new members of staff, Drs Patricia Garcia and Teik Ho and Korsia Khan have joined the research team. They will be working on areas of study such as the blood vessels and the role of scarring and fibrosis.

We have been awarded a number of research grants, and are grateful to The Raynaud's and Scleroderma Association and The Rosetrees Trust, The Scleroderma Society and The ARC for their continued support.

Dr David Abraham

Blood Flow Studies Lab Spring Update

It's been a busy winter for our thermography service!

Our study of thermography for assessing localised scleroderma (morphoea), in partnership with GOS Hospital, is progressing well. Over 30 children attended for assessment by thermography and a variety of other techniques. Results so far are quite promising.

I'm assisting once again in running the UK's symposium on Medical Infrared Thermography which takes place in November at the National Physical Laboratory in Teddington.

Finally I'm very much looking forward to visiting Genoa in September, where I will be one of the lecturers on the 1st European Course on Capillaroscopy and Rheumatic Diseases. Prof Cutolo of the University of Genoa, deserves credit for arranging this course; it is a long-overdue idea.

Kevin Howell

WEBSITE RE-LAUNCH

We are updating and re-launching The Unit Website. It is not finished yet but is on line at www.scleroderma-royalfree.org.uk

Specialist Nursing News

One of the main focuses of the specialist nurses is running the trials into new treatments for scleroderma, pulmonary hypertension and related problems.

We have finally started the trial into **infliximab** in scleroderma. Those who have been following this will know that this has been eagerly anticipated. It is an intravenous drug which has been used with success in related conditions and it is hoped may lead to a new treatment for scleroderma. It is being trialled for patients with active diffuse scleroderma.

Trials Update – if you would like further information on any of the trials please do contact us on 020 7830 2326..

RAPIDS 2 – A follow-up trial from the original RAPIDS trial which indicated a drug called bosentan could help to prevent and heal finger ulcers. There is a placebo arm on this trial. The trial lasts approximately six months.

SSTEP – A 5 year trial investigating iloprost tablets preventing large blood vessel damage in scleroderma.

BUILD2 – A fairly new trial, also using bosentan and investigates whether it can treat, or prevent progression of, lung fibrosis. For patients with limited or diffuse scleroderma but you must have diagnosed lung fibrosis. A one year trial..

TRUST – This new trial is investigating whether the use of bosentan improves quality of life in patients with pulmonary hypertension. It lasts for one year.

Leo is looking at the results of the inhaled iloprost trial in Raynaud's to ascertain whether this treatment was helpful (whether or not they have scleroderma). Watch this space...

Our pulmonary hypertension service is developing well. The second weekly clinic is up and running and already full! Clare and Joanna wonder how they ever managed with only one.

Education remains one of our priorities. Helen and Rachel continue to talk regularly to patients, groups and to other health professionals. We look forward to seeing you in clinic.

Helen, Clare, Rachel, Leo and Joanna

Blister Study

Thank you to all the patients, their relatives and friends who took part in our study of CTGF in the plasma and blister fluid. The results were presented at the BSR in Edinburgh.

Magda

Thanks from Kim Fligelstone

To everyone who responded to my question in the Xmas Newsletter. If you would like a visit from me — I have had scleroderma for 16 years - whilst staying at the Royal Free please ask the ward clerk to call ext 5131. I am a patient not a counsellor and I work on Tuesdays & Wednesdays.

Kim

FAMILY DAY

We are all looking forward to seeing many of you on **Saturday 15 May** [please see draft programme overleaf].

09.30 - 10.00	Registration and Coffee	
10.00 - 10.15	Introduction to the Day	<i>Professor C Black</i>
10.15 - 11.00	How to deliver a service for a rare disease	Mr Martin Else/Prof C Black
11.00 - 11.45	Research Milestones	Dr David Abraham
11.45 - 12.30	Surgical treatment for scleroderma? Panel discussion from the audience	Chair Prof Carol Black Prof G Hamilton/Mr Daryll Baker Michael Brough/Nick Goddard Prof M Winslet/Mr G Ogunbuyi
12.30 - 14.00	Lunch	
14.00 - 14.45	Clinical Milestones	Dr Chris Denton
14.45 - 15.30	Shared care approaches to scleroderma	Dr G Coghlan/ Dr Chris Denton
15.30 - 16.15	The Role of Specialist Nurse	Helen Wilson and Team
16.15	Raffle	

Lunchtime Discussions Groups

Dermatology

Dr C Orteu

Neurological Issues

Mr T Wilson

Oral problems

Prof S Porter

Psychological Aspects

Dr G Lloyd

Women's issues in SSc

Miss S Tuck

Lunchtime Demonstrations – Around the Atrium

Cosmetic Camouflage

Red Cross

Drug information/monitoring

John Farrel/Ms H Atkinson

Education/Nursing

Helen/Rachel/Clare

EMGs

Mr B Youll

Physiotherapy

PT Dept

Massage

Mr K Hunt

Rheumatology Laboratory Demonstrations

Research Laboratory Staff

Thermal Camera

Mr K Howell