

Spring Newsletter

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**Scleroderma Unit
The Royal Free
Hospital -
April 2007**

Scleroderma Family Day - Saturday 12 May

Clinical Update on Scleroderma— new faces and old hands

The clinical unit is as busy as ever – and we continue to struggle for space in the clinic area. There are plans to relocate the out-patient work to a more suitable part of the hospital and anyone who has attended the clinic on a Thursday will agree that we need more space. In the clinic we have been delighted to welcome Dr Angela Pakozdi from Hungary. Angela is working on several projects and training in scleroderma. She has previously spent time in excellent units in USA and Hungary. We all worked very hard on clinical trials over the winter – especially on a trial of nitroglycerine for Raynaud's. This study, featured in the national press, is part of an American trial to develop new ointments for severe Raynaud's. Several of the clinical research projects have been presented at major scientific meetings. Dr Henry Penn is travelling to Japan to present his work on renal crisis at this year's scleroderma workshop – a major achievement— all the more impressive considering he recently broke his arm playing hockey and was using the computer one-handed. **Chris Denton**

Laboratory Research

It has been an excellent start to 2007 within the laboratory. We have a number of new staff, and have been awarded several research grants both scientific staff and to purchase much needed equipment.. We have also recently presented some of our important scientific research work in the UK, Europe and the USA. These studies have raised a lot of interest within the scientific community and have led to the initiation of discussion leading to the implementation of clinical trials. Presenting our work in these forums helps in many ways; increasing the profile of the diseases, sparking more widespread interest and attracting high calibre scientists and clinical colleagues into the field.

Research and Equipment Grants

We have been awarded the following grants:

The Raynaud's and Scleroderma Association - has provided us with substantial project grant support to extend our studies into the genetics of growth factors in Scleroderma.

The Rosetrees Charitable Trust - have continued their long-term support of our basic translation research in Raynaud's and scleroderma, and have also provide funding for equipment.

The Welton Foundation – has awarded us part-funding to recruit a Senior Research Scientist to study aspects of fibroblast activity in scleroderma

The Scleroderma Society – have awarded us funding to purchase essential scientific equipment for analysis of gene expression

The Laboratory and New Staff

There are three new members of the research team. Dr Patricia de Winter and Dr Audrey Dooley have joined us to study aspects of the pathogenesis of Scleroderma. In addition, Dr Anthea Tennant-Eyles has joined the group to work on endothelial cell biology, and Dr Sarah Howat has re-joined the group back from maternity leave. Finally Ms Gillian Aggrey-Fynn has joined the department to study the control of gene regulation in scleroderma. These positions are funded by vital grants from **The Raynaud's and Scleroderma Association, the Arthritis Research Campaign**. We are extremely grateful to our supporters, who provide significant funding to enable us to carry-out cutting edge translation research, and also to the patients for their continued support and help in our important studies.

David Abraham

Specialist Nursing News

In the Christmas newsletter we mentioned that we had a new team member, Sally, who is working with Clare looking after the Pulmonary Hypertension patients. Many of you will have met Sally by now and we are pleased to say she is a great asset.

Rachel Ochiel is very busy managing the clinical trials and we are currently advertising for another trials nurse to help her. She has had a very hectic winter dealing with an exciting new trial of a topical gel for patients with Raynaud's Phenomenon which has just finished. She is currently recruiting patients for several Pulmonary Hypertension trials and there are some new ones in the pipeline. If you are interested in taking part in a trial please contact Rachel on 020 7317 7544.

The Specialist Nursing team look forward to meeting new patients and catching up with those of you we know at The Family Day in May. **Helen, Clare, Sally, Avril, Rachel and Louise.**

Blood Flow Studies Update

I'm writing this piece on the way back from Wexham Park Hospital, where I've been giving a presentation. I am increasingly "on the road" and have made similar visits in the last few months to Basildon Hospital, the Royal National Orthopaedic Hospital, and University College Hospital. This all results in more referrals, so we are succeeding in increasing the awareness about capillaroscopy and thermography in scleroderma!

Back in February, insomniacs amongst you might have seen the Royal Free's contribution to the BBC's Class Clips schools science programme for GCSE students. The infrared section of the programme featured thermography and Raynaud's phenomenon in our thermography lab.

It's also been a tremendously busy period in our relationship with Great Ormond Street Hospital and research into localised scleroderma (morphoea) in children. A study on treatment outcomes was published in December and a case study featuring a thermogram of morphoea in one of our patients has just been accepted for publication by the Journal of Pediatrics. A further, large study on blood flow measurements in localised scleroderma is undergoing the peer review process as I write.

I hope to see as many of you as possible at Scleroderma Family Day this year. Until then, best wishes from deepest Berkshire!

Kevin Howell

Scleroderma Society

The Scleroderma Society has a new address

PO Box 581, Chichester, PO19 9EW
and an Advice Line: **0800 311 2756**.

Please send all correspondence from the 2nd April 2007 to the new address— all correspondence sent to the old address will be forwarded on.



Family Day

Our Scleroderma Family Day is **on Saturday 12 May** — which we are all looking forward to—we do hope you can join us — please see programme overleaf.

09.30 - 10.00	Registration and Coffee	
10.00 – 10.15	<u>Welcome and Introduction</u>	<i>Dame Carol Black</i>
10.15 - 10.45	Laboratory research under the microscope	<i>Prof David Abraham</i>
10.45 - 11.15	What is new for digital ulcers?	<i>Prof Chris Denton</i>
11.15 - 11.30	Heating Aids and Gadgets	<i>Fiona Trotter, Raynauds & SSc Assoc</i>
11.30 - 12.00	Overlap syndromes – a particular challenge	<i>Dr David D’Cruz</i>
12.00 - 12.30	The heart of the matter	<i>Dr Clive Handler</i>
12.30 - 14.00	Lunch break — discussion groups – see below	
14.00 - 15.00	Question and answer session - Special focus on hand problems Prof C Denton, Prof C Black, Mr N Goddard, Mr D Floyd, Physio/OT/ Specialist Nurses,	
15.00-15.30	An outreach perspective of scleroderma	<i>Prof K Chakravarty</i>
15.45	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>Dr A Hegarty Eastman Dental Hospital</i>
Gynaecological Problems	<i>Miss S Tuck</i>
Massage	<i>Mr K Hunt</i>
Rheumatology Laboratory	<i>Research Laboratory Staff</i>
Thermal Camera	<i>Mr K Howell</i>