

## Scleroderma Family Day - 10th Anniversary - Saturday 21 May

### Spring Update on Departmental Clinical News

The past few months have been busy for the clinical unit. We have been working hard to juggle admissions. This has been a busy winter for the hospital and is a constant effort for the registrars and the admissions office.

There have been several major scleroderma-related conferences so far in 2005. The EULAR (EUSTAR) scleroderma group met in Budapest in January and ran a comprehensive course for rheumatologists interested in scleroderma. There was a meeting in Seville, Spain last month which Professor Black co-chaired and which highlighted important new potential treatments for scleroderma complications and the advances made recently in treating pulmonary hypertension. Later in the year we will have our 10<sup>th</sup> Anniversary Family Day. On the preceding day we will hold our Postgraduate scleroderma course at the Royal Free, aimed at Rheumatology trainees. We have some excellent speakers for these events and some have even agreed to speak at both meetings!

As ever we are hosting many international visitors to the unit. Mansoor Hosseini from Shiraz in Iran is continuing his research with us. In addition we are hosting a visiting rheumatology fellow from Greece for 3 months, participating in the prestigious EULAR exchange scheme, and have had medical students from Australia and Sweden so far in 2005 *Chris Denton*

### Laboratory Research -

Research continues to flourish and we have been awarded a number of research grants over the last few months to continue our studies into the causes of Raynaud's and Scleroderma. In addition our work has been accepted for publication in a number of scientific journals and has been presented by members of the research staff at National and International meetings. In particular our studies on the development of the disease and organ-based changes was presented at the Rheumatology meeting organised at University College in February and at the European meeting on systemic diseases in March. These presentations have generated much interest and discussions of collaborative endeavours. We have 3 new members of the department Drs Rachel Hoyles, Colin Hart and Christopher Hanks and we are about to appoint another post-doctoral scientist to the group. As we continue to advance our understanding of the underlying disease cause(s) in Raynaud's and Scleroderma we are presented with potential processes that may be useful targets for treatment.

#### We have been awarded the following grants:

*The Raynaud's and Scleroderma Association* - has funded a project grant to continue supporting Dr Yun-Liang Chen. We have also been awarded a clinical fellowship for Dr Hoyles. This is jointly funded by the Association and the ARC and is a collaborative grant between the Royal Free and Prof Ron du Bois/Dr Athol Wells at the Brompton.

*The Arthritis Research Campaign* - has funded a project grant in collaboration with Dr George Bou-Gharios at Hammersmith Hospital to study how we can inhibit collagen production in Scleroderma.

*The Scleroderma Society* - has funded equipment and vital reagents for a research study into scleroderma.

*The Rosetrees Trust* - have continued their support of our translation research which aims to move some of our work on Raynaud's and Scleroderma into clinical trials.

*The Oliver Bird Rheumatism Grant* - we have been awarded a research grant in collaboration with research centres in London to attract young scientific investigators into the field of rheumatology.

*David Abraham*

### Blood Flow Studies Lab Spring Update

Spring has started with European travel, and there is more in prospect for the summer. I've just returned from the 8th Meeting of the Polish Association of Thermology in the mountains of Zakopane, where most of Europe's leading medical thermographers were in attendance. Nearer to home, I also dropped into Great Ormond Street Hospital last week to give a seminar on thermography and capillaroscopy in paediatric medicine. In June I shall be in Vienna for the capillaroscopy session at the 2005 EULAR congress, and July sees me briefly in Glasgow, where Prof Harper from Great Ormond Street Hospital will be presenting our work on imaging localised scleroderma in children. Certainly a year for collecting airmiles so far!

*Kevin Howell*

### Specialist Nursing News

Spring is here again and this year has brought changes for the specialist nursing team: Unfortunately, Jane will be leaving at the end of March to join the research and clinical trials team at the Hammersmith Hospital. However, we are lucky to have two new research and education nurses, Miriam and Louise, who have recently joined the team.

We would like to take this opportunity to offer our congratulations to Rachel, and husband Nick on the safe arrival of their son, Ralph Michael on 21st March 2005

#### *The following clinical trials are still on going:*

1. **SSTEP** - a 5-year trial looking at the use of Iloprost tablets in lowering the incidence of heart attacks, angina and strokes.
2. **Infliximab** - patients with diffuse scleroderma receive a minimum of 5 infusions over the course last 48 weeks. The initial part of the trial will finish by summer of this year.
3. **Quins** - using quinapril tablets in the prevention of vascular damage in scleroderma. This will finish by the end of this year.
4. **Rapids 2** - using a study drug bosentan and a placebo for patients with digital ulcers.
5. **BUILD 2** - using a study drug bosentan and a placebo in the prevention of interstitial lung fibrosis.
6. **ARIES/STRIDE** - For patients with pulmonary hypertension, looking at a new tablet to slow down the progression of PH.
7. **EARLY** - using a licensed therapy (Bosentan) to treat patients with mild PH.

*If you are interested in taking part in future please contact Miriam, Louise, Helen on 020 7830 2326 or Clare/Joanna on 020 7472 6354*

### Family Day

2005 celebrates the 10th Anniversary of Scleroderma Family Day - Saturday 21st May we are all very much all looking forward to this special day and do hope you can join us - Please see programme overleaf].

**Fundraising:** Jason Rudolph is kindly running the London Marathon on behalf of the Unit - please see [www.justgiving.com](http://www.justgiving.com)

09.30 - 10.00	<b>Registration and Coffee</b>	
10.00 – 10.10	<b><u>Welcome and Introduction</u></b>	<i>Professor C Black</i>
10.10 - 10.45	<b>Psychology of chronic diseases</b>	<i>Dr R Persaud, The Maudsley Hospital</i>
	<b><u>The Ends of The Spectrum – Childhood SSc &amp; Localised Diseases in Adults</u></b>	
10.45 - 11.15	<b>Childhood Scleroderma &amp; Raynaud's</b>	<i>Professor P Woo</i>
11.15 - 11.45	<b>Localised Scleroderma</b>	<i>Dr C Orteu/Dr C Denton</i>
11.45 - 12.15	<b>Calcinosis</b>	<i>Dr A Herrick</i>
12.15 - 12.30	<b>Scleroderma under the microscope</b>	<i>Dr D Abraham</i>
12.30 - 13.45	<b>Lunch— see below</b>	
	<b><u>Challenges in Management</u></b>	
13.45 - 14.15	<b>Scleroderma—a view from the Netherlands</b>	<i>Dr F van den Hoogen</i>
14.15 - 14.45	<b>Stem Cell Transplantation for scleroderma</b>	<i>Dr D Farge</i>
14.45 - 15.15	<b>Neurological aspects of scleroderma</b>	<i>Dr C Moore, St Mary's Portsmouth</i>
15.15 - 15.45	<b>Biological Therapies for Scleroderma</b>	<i>Dr C Denton</i>
	<b><u>Round Table Discussion - Patient Advocacy in a Rare Disease</u></b>	
15.45 - 16.15	<b>Synergy Between Patient Organisations &amp; Health Care Systems</b>	<i>Chair: Professor C Black/ Dr C Denton</i>
	Raynaud's & Scleroderma Association; Scleroderma Society; Pulmonary Hypertension Association	
16.15	<b>Raffle</b>	
	<b><u>Lunchtime Discussion Groups / Demonstrations</u></b>	
Cosmetic Camouflage		<i>Red Cross</i>
Drug information/monitoring		<i>John Farrell/Ms H Atkinson</i>
Education/Nursing		<i>Helen/Clare/Miriam</i>
Heart in Scleroderma		<i>Dr G Coghlan</i>
Oral problems		<i>Dr J Buchanan, Eastman Dental Hosp</i>
Orthopaedic Surgery		<i>Mr N Goddard</i>
Physiotherapy/Occupational Therapy		<i>PT Dept</i>
Massage		<i>Mr K Hunt</i>
Rheumatology Laboratory Demonstrations		<i>Research Laboratory Staff</i>
Surgical Issues		<i>Mr G Ogunbuyi/Mr D Baker</i> <i>Prof G Hamilton</i>
Thermal Imaging		<i>Mr K Howell</i>
Women's issues in SSc		<i>Miss S Tuck</i>