

### **Clinical Care and Research - Professor Chris Denton**

The scleroderma service is as busy as ever, which is very positive but also raises substantial challenges, especially as the hospital struggles with the annual "bed crisis" due to emergency admissions. Whilst we have benefited from having the 5-day PITU (Planned Investigation and Treatment Unit) and access to hotel accommodation, there have been times when the PITU facility has been required for other cases. Major refurbishments at the Royal Free are on-going and we hope that this will improve the clinic environment. Non-rheumatology clinics are being moved to create more space. We wait for the summer to see if the air conditioning is any better!

There are several exciting new trials in scleroderma. One is an ointment that may block TGFbeta, a key factor in scleroderma fibrosis, and another is Glivec. This is an anti-cancer drug that has shown promise as a new treatment based on laboratory research. Translation of research projects from the laboratory to patients is always exciting. As usual, safety is the first priority and so all of these studies are being carefully conducted under the essential frameworks of the MHRA, a government body that regulates all drug trials.

We are keen to work closely with other centres and have organised sessions at the forthcoming British Society for Rheumatology meeting in Liverpool on lung fibrosis and also recently hosted the UK Scleroderma Study group meeting at the Royal Free Hospital.

### **Laboratory Research - Professor David Abraham**

It has been a hectic start to 2008, there have already been a number of Raynaud's and Scleroderma research meetings around the world at which we have presented. The research work has progressed very well with a number of projects yielding new and exciting information. We are continuing to learn more about the disease processes in Raynaud's and Scleroderma and the important cells and molecules involved. Much of the biomedical research work relies on the use of blood and white cells and the tissue samples (skin biopsies) that are given by our patients for research. These samples are absolutely vital for our research to continue and allow us to remain at the leading edge in Raynaud's and Scleroderma research in the world. We are extremely grateful for your support and would be very happy to give you a tour of the research laboratories on Family Day - to show you what we do.

We also have a busy next few months especially as we have our bi-annual Scleroderma research workshop, which will be held at Trinity College Cambridge in the summer. This is a collaboration with our colleagues in Europe and the USA; And the 3rd International Vascular Biology Conference at the Royal College of Physicians in the Autumn. This event is co-organised with Drs Gerry Coghlan, Clive Handler at RFH, and Prof Jeremy Pearson at King's College.

Recent grants we have been awarded are from:

- The Raynaud's and Scleroderma Association and The Welton Foundation - a joint three year project grant to study growth factors in Scleroderma.
- The Arthritis Research Campaign - an equipment grant for our genetic research studies.
- The Rosetrees Trust - have continued their support of our translational research programme into Scleroderma
- The Scleroderma Society - project grant to further our joint translational studies with the Brompton into signal transduction inhibitors in fibrosis

### **Specialist Nursing News - Helen, Rachel and Louise**

Spring is here again and developments continue in the scleroderma nursing team. As mentioned in the Christmas newsletter, Louise is now running the Raynaud's clinic on a Monday morning. The feedback so far has been positive and patients seem to appreciate being seen on a separate day rather than on our busy Thursday clinic. Helen & Louise remain busy educating both inpatients and outpatients, attending to the advice line and helping patients deal with the complexities of their disease. We are also hoping to expand the scleroderma nursing team further in the near future, which is exciting news for all of us. We would like to take this opportunity to congratulate Rachel who is currently on maternity leave after having her third baby, a boy, in March. We look forward to seeing you on Family day.

### **Pulmonary Hypertension Team**

It's nearly summer time and the PH service remains as busy as ever! Adele joined the team in January, and is fitting in well with Clare, Sally and Alison. Adele is the latest recruit to the PH Team. Some of you may already know her from Jenner Hoskin ward (12 South), whilst on the ward she had the opportunity to care for patients with Pulmonary Hypertension and/or Scleroderma during the acute phase of their illness. She has just completed her 3 month induction and is starting to get to grips with this challenging and exciting new role. We hope with the team expansion we will be able to improve the service currently offered. As always, feedback is welcome regarding all aspects of the pulmonary hypertension service. The 2008 audit, due in July, will be an opportunity for all users of the service to comment. We hope to see many of you at family day in May.

### **Thermography update - Kevin Howell**

There was a new arrival to the thermography lab this Easter - the FLIR A320G thermal camera. This is the latest in a succession of thermal imagers the scleroderma unit has owned over the years, and it means we can continue to offer temperature measurements of Raynaud's phenomenon and localised scleroderma for many years to come. Applying thermal imaging technology to medicine is the subject of my PhD thesis, now well under way, with a completion date of 2009. I'll keep you posted on this through the newsletter!

### **Family Day - Pamela**

Our Scleroderma Family Day this year is on **Saturday 17 May**. We are all looking forward to this and do hope you can join us. We have a very exciting programme this year as you can see overleaf. We also have lots of exciting raffle prizes. If you would like more tickets do let me know 01273 672686 or [pamela.yeomans@scleroderma-royalfree.org.uk](mailto:pamela.yeomans@scleroderma-royalfree.org.uk)



Scleroderma Family Day

Saturday 17 May 2008

The Atrium, Royal Free Hospital

Programme

09.30 - 10.00	<b>Registration and Coffee</b>	
10.00 – 10.15	Welcome and Introduction	Dame Carol Black
10.15 - 10.45	Work in Progress - Glivec in Scleroderma	Prof David Abraham Prof Chris Denton
10.45 - 11.15	NICE and nasty Part I – using NICE recommendations in rheumatology Part II - future treatment of pulmonary hypertension	Ms Jay Pang Dr Gerry Coghlan
11.15 - 11.45	Studying foot pain in scleroderma	Dr Maya Buch (Leeds)
11.45 – 12.15	Alternative approaches	Mr Keith Hunt
<b>12.15 - 14.00</b>	<b>Lunch break— discussion groups – see below</b>	
14.00 – 14.30	International Guest Speaker Sexual problems in scleroderma – a neglected area	Prof Ulrich Walker (Basel)
14.30 – 15.15	Questions and Answers – scleroderma on three continents Chris Denton                      London Ulrich Walker                      Basel Maya Buch                          Leeds and Ann Arbor (USA) Revadee Dejthevaporn              Thailand	
15.15	<b>Raffle</b>	

Lunchtime Discussions Groups / Demonstrations

Cosmetic Camouflage	Red Cross
Drug information/monitoring	John Farrell/Jay Pang
Education/Nursing	Helen/Clare/Rachel/Louise
Rheumatology Laboratory	Research Laboratory Staff
Thermal Camera	Mr K Howell
Oral problems	Eastman Dental Hospital
Massage	Mr K Hunt