

**MERRY  
CHRISTMAS**

From us all

\* [www.scleroderma-royalfree.org.uk](http://www.scleroderma-royalfree.org.uk) \*

Christmas 2008

### **Dear Friends**

I would like to take this opportunity to wish everyone a really Happy Christmas and New Year. It has been a very successful year for the Department, we hosted our international research workshop this summer in Cambridge – which was our best yet with a wonderful exchange of research ideas. Sadly the end of the year was clouded by the unexpected death of dear Rita, who was such a wonderful support to us all. It is really difficult to imagine the Department without her and we shall miss her greatly.

**Dame Carol Black**

### **Clinical Care and Research**

We are facing the usual challenge of keeping up with the need for Iloprost and other hospital based therapies of scleroderma patients as winter approaches and the hospital is busier with emergency medical cases. However, we are supported by an excellent team on PITU, who are becoming adept and achieving the impossible! We are also hoping to welcome a new specialist nurse to the scleroderma team. Tanaka has experience working in pulmonary hypertension and we are looking forward to her joining us in early 2009. We have had a very successful time at recent scientific meetings including a series of presentations in the USA at the American College of Rheumatology.

Our ability to link laboratory and clinical research has helped to progress new treatments and we are closely involved in several exciting trials including novel immunotherapy, Aimspro<sup>®</sup>, in established scleroderma, Glivec<sup>®</sup> in early stage scleroderma and a novel cream [P144] to treat skin fibrosis which targets a protein called TGFbeta. The Unit is very grateful to patients and their families for all the support we receive for our research and also to the charities that support this vital work including the Arthritis and Rheumatism Campaign, Raynaud's & Scleroderma Association, the Scleroderma Society, the Rosetrees Trust and the Scleroderma Research Foundation from the USA. Many of the studies that we are undertaking are international collaborations and provide an excellent opportunity for us to share the latest thoughts and practices in other major Scleroderma centres in Europe and North America.

**Professor Chris Denton**

### **Laboratory Research – Professor David Abraham**

#### **Research News**

The last 12 months have been a very exciting time in research, with a number of important breakthroughs in our studies into the disease process. We have published work on the role of free radicals and oxidant stress in scleroderma, the genetic programmes that control fibroblast function and activity in scarring and fibrosis, and the role of growth factors and chemokines in driving disease. We have also begun to study for the first time the involvement of the epidermis in scleroderma and in particular the way that different types of skin cells may interact and cause disease.

#### **Scientific Meetings**

Much of our work has also been presented at scientific meetings in the UK and abroad. A number of staff attended the American College of Rheumatology Meeting in San Francisco, presenting their work either as posters or lectures. Three of our posters showing the work of Nima Aden, Korska Khan and Svetlana Nihtyanova received special recommendations. Two talks were also given by Korska Khan.



### Research and other grants

This year we have been awarded a number of research, equipment and infrastructure grants.

- **The Raynaud's and Scleroderma Association** - has awarded us a programme grant to study the genetics of scleroderma. This is part of joint research studies with Professor Athol Wells, Drs Elizabeth Renzoni and Panos Pantelides at the Royal Brompton Hospital.
- **The Arthritis Research Campaign** - has awarded us a project grant to study the role of growth factor signalling in fibrosis
- **The Medical Research Council** - has awarded us a strategic programme grant to study models systems relevant to Raynaud's and Scleroderma
- **The Rosetrees Trust** - has continued to support our translational research studies
- **The Scleroderma Society** - has awarded us a grant for equipment
- **The Wolfson Foundation** - as part of the Department of Medicine's initiative in a joint application we have been awarded a grant for laboratory refurbishment

### New Developments and Staff

The Medical School and Hospital have joined forces to re-develop the research facilities at the Royal Free, and as part of a major £6.5 million investment programme, the research laboratories will be undergoing a major face-lift and refurbished to state-of-the-art biomedical research facilities. This activity is planned to start next summer.

We have three new members of the research team - Dr Audrey Dooley, Mr Dhiraj Joshi and Marta Zolnowska. They join the existing research team working on diverse projects aimed at understanding the key factors that control both the vascular complications of the disease and the excessive scarring and fibrosis.

### Thermography Lab - Kevin Howell

Autumn 2008 has been a time of European travel for me. Back in September I was in Genoa lecturing at the 3rd EULAR Course on Clinical Capillaroscopy. On 15th November I was in Vienna at the 21st Austrian Thermological Symposium, where a colleague presented our data comparing thermography to a new device for measuring blood flow in small vessels.

Winter should involve less travel: instead it will be a very busy period of clinics here in London, and I look forward to meeting those of you with appointments in the next few months.

My PhD is still on schedule to finish towards the end of 2009. Between now and then there will be a number of trips to visit my superior at the University of Glamorgan.



Merry Christmas and a Happy New Year!





# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



## **Specialist Nurses**

Helen, Rachel and Louise are working hard as always. We plan to have a new full-time nurse join the team in 2009. Rachel returned from maternity leave and has launched straight back into the deep end having expanded her role to include research projects into scleroderma, finger ulcers and their treatment. Louise's Raynaud's Clinic is very busy at this time of year but she has managed to find time to study for a Masters degree, which is hard work but enjoyable. Helen, as the senior nurse specialist, spends a good deal of her time dealing with paperwork, however she still enjoys having the opportunity to meet people in the clinic when taking a break from the development of the specialist nurses.

The scleroderma nurses have had a fruitful and educational year, and in addition to attending and speaking at conferences to raise awareness of scleroderma, Helen and Rachel were delighted to be asked to write a chapter on scleroderma for the forthcoming textbook 'The Oxford Handbook of Musculoskeletal Nursing'.

We look forward to seeing many of you in the 2009 and in the meantime Merry Christmas and a Happy New Year.

## **Pulmonary Hypertension Team**

It is nearly Christmas and the PH service remains as busy as ever! Clare, Sally, Adele and Alison have been out and about a lot. With the increase in the number of specialist nurses to three with Adele joining us earlier in the year, we have been able to attend many of the satellite clinics and take forward service development within the Royal Free. The nursing team have represented the PH unit by talking to various local and national meetings throughout the year – Adele and Sally are certainly becoming experts with their presentation skills!

Dr Peter Kabunga left the team in August to continue training in Edinburgh. We would like to welcome the new PH registrar Dr Christopher Valerio. He has several years experience in Cardiology and will join Dr Handler and Dr Coghlan in the medical team

## **Update from Adele**

Hello everyone. I can't believe that I have been in post almost a year now. I am thoroughly enjoying this interesting and challenging role. I have had the opportunity to attend many national and international meetings which has aided me in developing my knowledge of this complex disease. But most of all, I have particularly enjoyed getting to know you all over the past few months. I would like to take this opportunity to thank my colleagues for their continuing support and the warm welcome they have given me.

Wishing you all a wonderful Christmas and happy 2009!

## **Clinical Trials**

We continue to be very busy with lots of new and exciting studies. Sandra Zimba [research nurse] whom some of you may have already met joined the clinical trials team this year, together with Ivy Wanjiku, who provides admin support and Dr Niamh Qullinan, Research Fellow – who are all settling in well. We would like to take this opportunity to extend our gratitude to all those who continue to volunteer to take part in our trials. Many of you have also been asking about the outcome of some of the studies we have done – I would like to let you know that we are currently making arrangements to put the results of completed studies on the Scleroderma website some time next year. We are currently recruiting patients for the following ongoing Scleroderma and pulmonary hypertension studies. If you are interested in taking part please call 020 7317 7544. We are currently recruiting patients for the following trials:

### **Scleroderma Studies**

**P144:** This evaluates the efficacy and safety of the topical application of 'P144' for skin fibrosis.

**Norvartis Study:** Evaluates the efficacy and safety of an oral dose of ST1571 for diffuse patients with fibrosis.

**Aimspiro:** This is a study to test the safety and efficacy of AIMSPRO in diffuse systemic sclerosis.

**DETECT:** The main purpose of this study is to find out what screening, or which combination of simple tests best predicts which patients with scleroderma have pulmonary hypertension.

### **Pulmonary Hypertension Studies**

**Seraphin:** To evaluate the effects of ACT-064992 on Pulmonary Arterial Hypertension [PAH]





# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



## **Kim Fligelstone**

We have a patient in the Colchester area who would like to attend the Family Day in May. If you live in the area and would be prepared to give them a lift please let us know. Also one of our patients in Rheumatology has a nearly new, battery operated, Bath Chair (unseen) which is free providing the Chair can be collected from NW3 area in London. If you are interested in either of these please contact Pam Yeomans on Tel: 01273 672686 who is happy to liaise.

## **European Scleroderma Awareness Day**

Last year we had the exciting news regarding the formation of FESCA, the Federation for European Scleroderma Associations. In 2009 the first European Scleroderma Awareness Day will take place on June 29. The idea of having an annual day specially dedicated to people with scleroderma was launched during FESCA's first general assembly in January 2007 in Bad Nauheim. Member Associations discussed and approved successfully this idea, with the aim of giving people with scleroderma an international voice.

The date that was chosen for celebrating the first European Scleroderma Awareness Day is June 29 2009. Paul Klee, the internationally acclaimed German/Swiss artist, died from scleroderma on 29 June 1940. The theme of the first European Awareness Day will be 'More Than Skin Deep' and the day will coincide with the opening of VEDOSS [Very Early Diagnosis of Systemic Sclerosis] clinics across Europe. The event aims to raise awareness and increase understanding of scleroderma among the general public, politicians, and others, in order to make it a well-known disease and, in collaboration with healthcare professionals, to increase scleroderma education, treatments and care, so that ultimately a cure can be found. FESCA firmly believes that everyone with the disease should have the opportunity to receive appropriate access to the same level of care from fully informed healthcare professionals.

The Aims of the European Scleroderma Awareness Day:

- To raise awareness.
- Increase understanding and empower people with scleroderma.
- Let society know about the disease so that those with the disease do not feel isolated.
- Improve access to successful treatment and provide equal and consistent care for scleroderma across the globe

I will be away for a couple of months however, Pam will endeavour to help put anyone with queries in touch with the right people if you need help with a non medical item.

With best wishes for a Happy Christmas and a Peaceful and a Healthy as possible New Year.

Lol Kim

## **Scleroderma Family Day at The Royal Free**

**Saturday 09 May 2009**

Scleroderma Day is one of our favourite days. We will start to put the programme together in the New Year, if there are any areas that you would like us to include please let me know. We have included a book of raffle tickets with your Newsletter – the raffle raises much needed funds and we are very grateful to all of you who buy/sell tickets on our behalf. If you do not wish to use the tickets please discard them – you do not return them to us. If you would like more tickets please contact Pamela on 01273 672686 or [pamela.yeomans@scleroderma-royalfree.org.uk](mailto:pamela.yeomans@scleroderma-royalfree.org.uk).

**Newsletter** – We hope you enjoy reading our Newsletters. We send them out to all Raynaud's & Scleroderma patients who attend our clinics. If you would prefer to receive a paper-free copy via email please let me know – and of course if you refer not to receive one at all, I will take your name off the list. Pamela

## **Contact Numbers**

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