

Christmas Newsletter

www.scleroderma-royalfree.org.uk

*Scleroderma Unit
The Royal Free Hospital -
December 2006*

Seasons Greetings from all at The Scleroderma Research Unit

Dear Friends

It is a real pleasure to have the opportunity to write some introductory remarks for the Christmas Newsletter. The first thing is to wish you all a very happy Christmas and New Year. The past year has been a very exciting one for the department, with some exciting achievements in our research work, our new clinical trials and a steady improvement in the understanding and treatment of scleroderma and Raynaud's. One of the most important and happy events to happen this year is that Dr Christopher Denton has become a Professor. This is an excellent achievement in a very competitive world.

The last few months have brought many changes in my working life — I stepped down as resident of the Royal College of Physicians, after four busy and very enjoyable years, and have acquired some new national roles. They are Chairman of the Academy of Medical Royal Colleges, National Director for Health & Work and Chairman of the Nuffield Trust. I still manage to have almost daily contact with member of the Department and am deeply interested in everything that goes on.

With best wishes

Dame Carol Black



Update on the Clinical Scleroderma Service at the Royal Free

These remain exciting but challenging times within the NHS. We have been busier than ever in the scleroderma clinic, the pulmonary hypertension service and the wards. The development of PITU as the main ward for our scleroderma and Raynaud's patients receiving iloprost and other essential treatments has proved very successful and we are cancelling far fewer patients' admissions due to lack of beds. However, we are very grateful to the ward nurses for being imaginative and flexible when necessary. Other cases mostly go to Jenner-Hoskin ward or to medical beds in the hospital. As usual, the unit gets busier as the weather gets colder and Raynaud's related problems become more severe.

We will be sad to lose Dr Maresa Carulli at the end of December. Maresa has been a valuable member of the team in the scleroderma clinic for the past 4 years but is now a fully trained rheumatology specialist and will initially be taking up a locum consultant post at Wexham Park Hospital. On the clinical research front, we have had a high profile at recent research conferences including two oral presentations at the American College of Rheumatology meeting. Dr Henry Penn has been helping two scleroderma specialists in Uruguay in their study of gravitational stress as a treatment for scleroderma. More of this in future newsletters I am sure.

Professor Chris Denton



Laboratory and Research News : Professor David Abraham

As we approach the end of another year, I feel it is worthwhile to look back over what we have achieved in the last 12 months. The laboratory research has moved forward at a rapid pace with a number of important studies into Raynaud's and Scleroderma yielding useful results. We have continued our mission to understand in great detail the Raynaud's and Scleroderma disease process and to assist in the development of new and better treatments.

I would like to highlight a few of these studies, which I think are particularly important and exciting. Studies carried out by Dr Carmen Fonseca and Dr Gisela Lindahl have identified important genetic differences between normal individuals and different Scleroderma patients. These genetic markers may be useful to pick-out different sub-sets of the diseases process, perhaps with different organ involvement, and also will help in our endeavours to develop new targeted therapies.

In addition, pre-clinical studies carried out by Dr Xu Shiwen and Dr Vineeth Rajkumar, have been aimed at using selective inhibitors that block the activities of growth factors. These very exciting studies have produced good results and we are hoping that these will lead very shortly into the development of a clinical trial.

Finally, work on a project carried by Dr Elizabeth Renzoni, and recently joined by Gillian Aggrey-Fynn, and assisted by Dr Jill Norman and Ms Korsa Khan have begun to look in more detail at specific factors expressed in Scleroderma and which regulate the level of expression of scleroderma-specific genes. These studies are looking very promising indeed.

Much of our research work was presented and the 9th International workshop and Scleroderma Research. This took place at the end of July in Boston USA, and is one of the most important research and clinical symposium on Scleroderma, which takes place once every two years. The Department at the Royal Free Hospital co-organises this symposium, and the next one will take place in the UK in the summer of 2008.

Research personnel and support.

We have a number of additions to the laboratory. Ms Gillian Aggrey-Fynn has joined the group on a

project funded by The Raynaud's and Scleroderma Association. Dr Masaomi Yamasaki has also joined the laboratory on a sabbatical from Japan. Masaomi has an interest in scleroderma and in particular the blood vessel complications. Dr Anna Nuttal has joined us and

is working with Dr Richard Stratton on understanding the role of the epithelium in Scleroderma. This is a new and very exciting area of study which is being pioneered at the Royal Free.

Two other joint research projects are also underway with Dr George Bou-Gharios at Imperial College and Dr Mark Eastwood at the University of Westminster. These projects are very exiting and utilise expertise in the regulation of collagen and bio-mechanics to study important aspects of the scleroderma disease process in order to find new ways of treating the disease.

Over the last year we are very fortunate to have received research funding from the following organisations: The Raynaud's and Scleroderma Association, The Arthritis Research Campaign, The Welton Foundation, The Scleroderma Society, and the Rosetrees Trust. We are also very grateful to all the patients and their relatives for their donations which have helped us to purchase items of useful laboratory equipment.

David Abraham

Fundraising

We very much appreciate the funds you raise on our behalf — many thanks to Jason for his charity football matches; Joan for running the marathon; The Graphite Trust for adopting us on behalf of Corin; and everyone else who kindly donated funds to the Unit.



News From Our Specialist Nurses Helen Clare Rachel & Louise

Christmas is once again nearly upon us and 2006 has been another very busy year for the specialist nursing team.

There have been some changes to the scleroderma and pulmonary hypertension specialist nursing teams. Helen Wilson (Rheumatology Senior Nurse Specialist) Clare Das (Pulmonary Hypertension Nurse Specialist) Rachel Ochiel (Clinical Trials Nurse) and Louise Davis (Research & Education Nurse) make up the current team.

The pulmonary hypertension service continues to grow rapidly. Joanna Smee left us in June to work for the chronic fatigue service still within the Royal Free hospital and is being replaced by Sally Reddecliffe in November. Sally is an experienced cardiology nurse who is coming to us from Royal London Hospital. We hope to take on a third PH nurse by the end of next year.

Rachel Ochiel, whom some of you may have already met, is managing the clinical trials. Rachel is currently recruiting patients for several Pulmonary Hypertension trials and we are about to start an exciting new trial of a topical gel, which can be applied to the fingers of patients with Raynaud's Phenomenon. If you are interested in taking part in a trial please contact Rachel on 020 7317 7544.

The team continue to incorporate many different aspects of nursing care within their roles including, educating patients in clinic and on the ward. We offer support to patients and to staff to enable patients to manage their disease and various therapies effectively. We continue to carry out research and trials work for the department. The nurse – led advice lines also keep us very busy.

On a personal note congratulations again to Rachel Vincent who, since the spring update has also gone on maternity leave following the birth of her second baby in September.

We would like to take the chance to wish you a very Merry Christmas and a happy and healthy new year!

Helen, Clare, Rachel and Louise

Thermography & Capillaroscopy Laboratory: Kevin Howell

Since speaking to many of you at Scleroderma Family Day in the spring, things have remained busy!

In September I was in Poland for the 10th European Congress of Medical Thermology, and then in Italy a week later helping to teach the 2nd EULAR Course on Capillaroscopy and Rheumatic Diseases.

In Poland I presented a paper on "Procuring the Right Thermal Imager," which complemented nicely some of the other work delivered at the congress on thermal imaging equipment. The capillaroscopy course in Italy was a great success, with 120 rheumatologists in attendance from 25 countries. This means that, steadily, knowledge about the appropriate use of capillaroscopy to assist in the diagnosis of diseases such as scleroderma is reaching the doctors who need to know it.

My presentation at Scleroderma Family Day was about the assessment of localised scleroderma in children. That work, which is being carried out in association with our colleagues at Great Ormond Street Hospital, is continuing as I write. In October, a short paper by us on this topic was accepted by the British Journal of Dermatology, and we have more results in the pipeline being prepared for submission next year.

Our service for the provision of capillaroscopy and thermography in connective tissue diseases continues to grow, and I shall be visiting both the University College London Hospital and the Royal National Orthopaedic Hospital at their invitation in the coming weeks to present descriptions of the vascular service we offer. Many of the junior doctors you will have met at the Royal Free Hospital over the years find their way into more senior jobs in hospitals such as these, and I'm pleased to say they often take the message about how useful capillaroscopy and thermography can be with them.

Best wishes for a Merry Christmas and a Happy New Year from my lab!

Kevin



www.scleroderma-royalfree.org.uk

Talking About the Disease

Kim Fligelstone

Hello, for those of you who are new to the Scleroderma unit my name is Kim and I have had diffuse systemic sclerosis since 1988. If you are on any of the wards and would like a visit please ask one of the ward staff to phone ext: 35131 alternatively if you would like to talk to someone with Scleroderma you can phone the hospital on 020 7794 0500 and tap in the above extension number. I must stress I am not a counsellor but a person with the experience of Scleroderma for the past 18 years. I usually work in the unit on Tuesdays and Wednesdays, however I often have to swap due to other commitments in which case please leave a message with Millie or Sharon and I'll get back to you when I can. For those of you who have been coming to the Royal Free for some time you will have noticed that the wards have changed and many of you will probably have been to PITU the Planned Investigation and Treatment Unit where the majority of people will stay overnight in the Hostel and go to PITU during the day for treatment. Others may find themselves on Jenner Hoskins or a different ward, irrespective of where you are if you would like to receive a gentle massage ask the Nursing staff on the ward to refer you to Keith Hunt's team, then relax and enjoy! I hope that everyone has a lovely Christmas and a Peaceful and as Healthy a New Year as possible. Lol

Kim

The Newsletter

*We hope you enjoy receiving our bi-annual Newsletters. Every patient who attends the Scleroderma and Raynaud's clinics is added to our Newsletter Mailing List — which is used solely to mail out our Newsletters. If you do not wish to receive them or would like your name removed from the Mailing List, please let me know. You can write to me at The Scleroderma Unit or email me at **pamela.yeomans@scleroderma-royalfree.org.uk***

Family Day at The Royal Free

Saturday 12 May 2007

A date for your diary in 2007. The programme for this day will be sent out as part of the Spring Newsletter. If there are any areas of your disease that you would like included in the programme please let us know and we will do our best to include them.

We have enclosed a book of raffle tickets — for the Family Day Draw. The raffle raises extremely valuable funds and we are very grateful to all those who buy tickets. Prizes this year include a Harrods Teddy Bear, Tea at the Ritz, and a villa in Sardinia.

*If you do not wish to buy/sell the raffle tickets you do not need to return them—if you would like more raffle tickets please contact me either by phone on 01273 672686 or email **pamela.yeomans@scleroderma-royalfree.org.uk***



How to Contact Us

Direct

Ade	020 7830 2284
Helen/Rachel/Louise	020 7830 2326
Clare	020 7472 6354
Scleroderma Appts	020 7830 2151
Millie	020 7794 0432
Kevin Howell	020 7472 6550
Pamela	01273 672686

Via the switchboard on 020 7794 0500

Kim Fligelstone	Ext 35131
Admissions	Ext 35081