



Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



**MERRY
CHRISTMAS**

From us all

*

www.scleroderma-royalfree.org.uk

*

Christmas 2007

Dear Friends

A Happy Christmas and joyous New Year to all our patients and those who support and care for them at home.

I am delighted to see the Department go from strength to strength. Professor Denton and his team and the laboratory staff, led by Professor Abraham, are doing a marvelous job in what have been very challenging times in the NHS. We have been going through a continuous period of reform and change. During this time the staff have continued to deliver the highest possible level of service they could achieve. At the same time they have produced excellent research, secured important grant support and represented British Medicine abroad. With my various national roles I am extremely busy, I miss clinical practice but almost every working day I am in contact with the Department and participate in whatever way I can. I take great pride and joy in its success.

Dame Carol Black

Clinical care and research - Prof. Chris Denton

As winter approaches all of the scleroderma and Raynaud's clinics are fully booked and those of you attending the unit will appreciate that we sometimes struggle to fit everyone in. We have moved the Raynaud's clinic from its previous Thursday morning slot to create more space and this is working very well coordinated by Louise, Kevin and Svetlana. After a lot of hard work in the unit, culminating in two presentations in the USA at a major rheumatology congress, we are very sad to see Dr Angela Pakozdi move on to continue her training in internal medicine. However, we warmly welcome Dr Revadee Dejthevaporn from Thailand. Revadee is a trained rheumatologist who has come under the prestigious Royal College of Physicians sponsorship scheme to train in scleroderma and we hope that she will be with us for the next 2 years. Dr Emma Derrett-Smith has joined us to do research and will also help in the pulmonary hypertension and scleroderma clinics. Emma is making a habit of returning she was our house officer, then registrar and now is a research fellow funded for 3 years by the Arthritis Research Campaign. We have also said goodbye again to Dr Henry Penn, who was working on renal scleroderma. He is completing his MD degree but remains a regular visitor.

We have several exciting trials for scleroderma just about to start that demonstrate how our laboratory research is being translated into new potential treatments. One trial is using a new cream to block a protein called TGFbeta and the other is testing a drug called imatinib that has been useful in some cancers and has potential in scleroderma. These are international studies and help us to develop strong links with other scleroderma centres in Europe and USA.

Laboratory Research - Professor David Abraham

As we approach the end of 2007 it is important to look back over our achievements in scientific research over the past 12 months. The research work has progressed very well with a number of projects yielding new and exciting information about the disease processes in Raynaud's and Scleroderma. Some of our important findings include the genetic polymorphism that is associated with certain disease sub-sets, the increase in our understanding of the potential role of the epithelium in the disease process, and improvements in model systems that we use to test potential new therapeutic agents. These achievements have been made possible by the dedicated work of the laboratory scientists and continued support of our research funders.

This year we have been awarded Research and Equipment Grants by The Raynaud's and Scleroderma Association and The Welton Foundation - a joint three year project grant to study the pathogenesis of Scleroderma. The Arthritis Research Campaign - an equipment grant to expand and increase the productivity of our genetic research studies. [a joint venture with Drs Panos Pantelides, Elizabeth Renzoni and Professor Athol Wells at the Brompton Hospital. The Rosetrees Trust have continued their support of our basic research into Scleroderma with an emphasis on moving rapidly into clinical trials and patient treatment. The Scleroderma Society - equipment and project grant support to further our studies into fibrosis in Scleroderma.

Much of our research has been presented at scientific meetings. To highlight but a few - we presented at the British Society for Rheumatology and also at the American College of Rheumatology in Boston in November. Drs Shiwen, Garcia and Ms Korsia Khan presented on growth factors and oxidative stress in scleroderma [both posters and oral presentations]. We also held the 2nd International Vascular Biology Conference at the Royal Free in July. This was organised by the Depts of Rheumatology, Cardiology and Clinical Chemistry, with Drs Gerry Coghlan, Clive Handler and Michael Dashwood taking key roles.

New Laboratory Staff - we have three new members on the research team. Ms Lidia Lasecka joined us in July to study aspects of the tissue fibrosis of Scleroderma with Dr Gisela Lindahl. Dr Anna Nuttall has joined to work with Dr Richard Stratton on the role of the epithelium in scleroderma, and Dr Emma Derrett-Smith has joined Chris Denton to study some of the key factors involved in vessel disease.

All in all a very busy and exciting year - so far! And a very rosy picture for the future of Raynaud's and Scleroderma research at the Royal Free.



🔔 Xmas Newsletter - Scleroderma Unit - Royal Free Hospital 🔔

Thermography and Capillaroscopy Update - Kevin Howell

The second half of 2007 has been hectic as usual. Many of you are aware that my "other life" is as a tennis official, and this has taken me both to Wimbledon and (for the first time) to New York for the US Open this summer.

Back at the Royal Free, September saw the launch of a new clinic for primary Raynaud's phenomenon on Monday mornings. The idea is that patients can see a doctor in the clinic, a specialist nurse for Raynaud's advice, and have all necessary investigations such as capillaroscopy, thermography and blood tests on the same day. This clinic is proving to be quite effective: patients are seen quicker, and it frees some space in scleroderma clinic on Thursdays, which you will all appreciate is a very busy day for everyone.

Our unit continues to maintain close links with Great Ormond Street Hospital for the assessment of localised scleroderma (morphoea), and we published an important piece of research on the topic in the Arthritis and Rheumatism journal this summer.

Looking forward to 2008, there will be plenty to do. This (should!) be the year that the finishing touches are added to my PhD. I will continue to sit on the committee of the UK Thermography Association, and I have now also been asked to join the Physiological Measurement special interest group of the Institute of Physics and Engineering in Medicine. Prof. Maurizio Cutolo is organising the 3rd Course on Capillaroscopy and Rheumatic Diseases in Genoa in September 2008, and has asked me to join the teaching faculty once again.

All-in-all, there should be plenty to report back to you about next year. In the meantime, I wish you all a Merry Christmas and a Happy New Year!



The Raynaud's team: Svetlana, Kevin and Louise.

SPECIALIST NURSES

Scleroderma Team

There has been a welcome continuity to the specialist scleroderma nurses team this year, with Helen (Senior Specialist Nurse) and Rachel and Louise (Specialist Nurses) working hard to try and raise the profile of scleroderma and improve the quality of nursing care for people with this rare and often complicated condition.

As a world-renowned centre for the treatment of scleroderma it is important that we are also high profile at colleague and patient educational events. This year Helen has spoken at the National Scleroderma Study Day for Nurses and Healthcare Professionals in July and Louise gave a very well-received talk on "Setting Up a Raynaud's Clinic" at the Annual Conference of the Raynaud's and Scleroderma Association.

We have been involved in many aspects of the department's developments this year and some of you will see Louise in the new "One-Stop Clinic" for Raynaud's Phenomenon where patients can have specialist tests, see a doctor for diagnosis and a nurse for education and treatment advice all at the same visit. We are also helping to train nurses on the wards to take blood tests, which will hopefully benefit you on your next inpatient stay.

We are currently assessing and rewriting many of our information leaflets. However this is an ongoing process and if you have any suggestions regarding current leaflets, or subjects for new ones, then please do get in touch.

On a practical note this year we have moved from our previous office, which we shared with the Pulmonary Hypertension Nurses. The teams are lucky enough to be expanding and the Pulmonary Hypertension Nurses are now the sole occupants of our previously shared office. Please bear this in mind when trying to get hold of us. We are always happy to hear from you if you have a problem, query or suggestion and the best way to contact us is on the scleroderma help-line: 020 7830 2326.

We hope you all have a very merry Christmas and a happy new year.





Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



Pulmonary Hypertension Team

There has been continued rapid expansion of the PH service over the last year, keeping Clare, Sally and Alison (PH clerical assistant) very busy in 2007! We have just recruited a third nurse who will be starting in January. Adele will be bringing with her a wealth of cardiology and PH experience, having worked on Jenner Hoskins ward for 7 years. We are looking forward to welcoming Adele to the team, and hope she enjoys working with all of us!

We are delighted to announce that from early 2008 the PHA-UK will be providing financial support for a counseling service for patients attending the PH service at the Royal Free. We will be piloting a service where patients can request a referral to speak to a counsellor at the same time as their clinic visit.

Initially we plan to offer this service part time, however if it proves valuable and effective we will expand the hours of service further. Thanks to the PHA-UK for their continuing support.

Update from Sally

It has been nearly a year since I joined the Pulmonary Hypertension team at the Royal Free Hospital. My background in cardiology and medical nursing has certainly aided my move into the world of pulmonary hypertension. My previous experience has mainly been in the acute phase of illness. Having the opportunity to witness patients in all stages of wellness has indeed been an inspiration. Proving that all the good work undertaken around the country has made a real difference to people's lives.

I am still thoroughly enjoying my new role and it has been a pleasure to meet so many special people and their families. I would like to thank all the patients, families and my colleagues (particularly Clare) for all the help and support I have received with the transition into my new role. I look forward to many more years working with you all.



Merry Christmas and Happy 2008!

Satellite clinics

The four satellite clinics, linking the PH service at the Royal Free with Rheumatology centres in the UK, continue to expand and improve. The clinics were initially set up following patient feedback (from the annual patient satisfaction survey) back in 2003. One of the issues highlighted was the difficulties caused due to the long distances travelled to the specialist centres. The unit at the Royal Free already has close links with Rheumatology centres in the UK due to our national designation as the centre for PH associated with connective tissue disease. It seemed a natural progression to strengthen these links and develop a more 'patient friendly' service.

The satellite clinics run every 2-3 months in the following units:

- | | |
|---|--|
| <input checked="" type="checkbox"/> Royal United Hospital, Bath | <input checked="" type="checkbox"/> Queen Alexandra hospital, Portsmouth |
| <input checked="" type="checkbox"/> St Thomas' Hospital, London | <input checked="" type="checkbox"/> Ulster Hospital, Belfast |

Patients still get to see the Royal Free team as Dr Coghlan, Lead Consultant, and Sally or I attend each clinic (when workload allows us to escape from the Royal Free!). The patient receives a clinical review from the Specialist team and the local medical team. Feedback and audits have proven the value of this service for patients. It has also improved communication between the multi-disciplinary teams in the different hospital. All the satellite units have developed excellent local expertise.

We will continue to audit and improve the existing service, and have recently started a satellite clinic linked with the Sickle cell unit at Kings college Hospital, London, using the same framework. At present there are a limited number of patients we are able to see in the satellite units. If you would like further information on the service please speak to the PH team at your next appointment.

The PH Specialist nurses continue to work hard to deliver high quality care to all our patients. We received positive results from the 2007 PH service audit, and welcome feedback on any aspect of the service. The team continue to be involved in all the clinical, research and educational projects throughout the department and the hospital. We have all spoken at numerous meetings, maintaining the high profile of the PH service nationally and internationally.

Finally Congratulations to Dr Peter Kabunga, Pulmonary hypertension clinical research fellow, who won the Young investigator award in coronary pathophysiology and microcirculation for his research into early diagnosis, treatment and clinical outcomes for pulmonary hypertension. The award was presented to Dr Kabunga at the European society of Cardiology, held in Vienna in early September.





Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



Clinical Trials

Rachel Ochiel, the clinical trials nurse, whom some of you may have already met, continues to manage the clinical trials. We hope to have another clinical trials nurse working with Rachel, who is currently recruiting patients for several pulmonary hypertension trials. We are also about to start 2 new trials for patients with newly diagnosed diffuse disease. If you are interested in taking part in a trial please contact Rachel on 0207 317 7544.

Future trials:

We are recruiting for 2 Scleroderma studies which are due to start in the near future:

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

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

We are also recruiting for a Pulmonary Hypertension study which is due to start soon:

FREEDOM: The purpose of this study is to test oral Treprostinil in the treatment of Pulmonary Hypertension.

Ongoing Trials:

SSTEP: This is a five year trial, which started in 2002, looking at the use of Iloprost tablets in lowering the incidence of heart attacks, angina and strokes.

ARIES: A trial looking at the drug Ambrisentan in slowing down the progression of Pulmonary Arterial Hypertension.

RAPIDS-2: A trial looking at the use of the study drug Bosentan alongside a placebo for patients with digital ulcers.

Tadalafil: This study looks into the safety and efficacy of the drug Tadalafil in decreasing the symptoms of Pulmonary Hypertension.

TRIUMPH: The purpose of this study is to test inhaled Treprostinil in the treatment of Pulmonary Hypertension.

Kim Fligelstone

Hello, for those of you who are new my name is Kim and I have had diffuse systemic sclerosis for 20 years. 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 you can phone the hospital on 020 7794 0500 x 35131. I must stress I am not a counsellor but a person with the experience of Scleroderma. 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 and I'll get back to you when I can.

An exciting development during 2007 is the formation of FESCA, the Federation for European Scleroderma Associations. Organisations supporting people with scleroderma in Belgium, Cyprus, Denmark, France, Germany, Holland, Hungary, Ireland, Italy, Portugal, Spain and the UK have joined together "To make scleroderma a well-known disease and, in collaboration with healthcare professionals to secure Scleroderma education, treatments, care and ultimately a cure" We are just starting and one of our first tasks is to organise an annual EU Scleroderma awareness day. We have already participated in EUSTAR (Eular scleroderma trials and research group) recommendations for treatments in scleroderma and presented "the patients perspective" at the 2007 EUSTAR training session in Bad Nauheim and made presentations at EULAR (European League against Rheumatism) in June. We have a long way to go but hope you agree that by working together we can achieve so much more!

I hope that everyone has a lovely Christmas and a Peaceful and as Healthy a New Year as possible.

Scleroderma Family Day at The Royal Free

Saturday 17 May 2008

A date for your diary - we are currently putting the programme together - if there are any areas that you would like us to include please let me know. As you know our raffle is drawn at Family Day and we have enclosed a book of our raffle tickets with this Newsletter. The raffle raises much needed funds and we are very grateful to all of you who buy/sells tickets on our behalf. If you do not wish to buy tickets there is no need to return them to us - if you would like more tickets please contact Pamela on 01273 672686 or pamela.veomans@scleroderma-royalfree.org.uk



Fundraising - Thank you to everyone who raised money for us this year - special thanks [again] to Jason for his charity football matches and £800.00 cheque.

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 prefer not to receive one at all, I will take your name off the list. *Pamela*

Contact Numbers

NHS Secretariat 020 7830 2284

Nurses Help-line 020 7830 2326

Kevin Howell 020 7472 6550

Kim 020 7794 0500 x 35131

Scleroderma Appts 020 7830 2151

Clare 020 7472 6354

Millie 020 7794 0432

Admissions 0207 794 0500 x 35081

