



**MERRY
CHRISTMAS**

From us all

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www.scleroderma-royalfree.org.uk

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Christmas 2011

Dear Friends

It always gives me great pleasure to write few words for the Christmas Newsletter. The Unit under Chris Denton and David Abraham is going from strength to strength, with our wonderful new laboratories in which to do our research. This work has recently been presented very successfully presented at the American Rheumatology meeting.

Christmas is such a busy period but I hope you will all have time to be with friends and family celebrating in the spirit of friendship and love.

I look forward to seeing you in May at Family Day

Dame Carol Black

Clinical update – Professor Chris Denton

The clinical service has undergone some important changes in the past 6 months. Dr Carmen Fonseca is now established as a senior member of the medical team in the scleroderma clinic, as well as continuing her laboratory research that focuses on genetics. She even finds time to organise the medical student teaching and run general rheumatology clinics. She is a real asset to the team. Another positive development has been the opportunity to increase our office space for the specialist nurses, clinical trials and the pulmonary hypertension service now that some of the laboratory scientists have moved into the state of the art new labs in the Medical School. This has helped us to better integrate our nursing services and we hope to further expand this part of the unit. There has been substantial reorganisation of our iloprost service over the summer. Now we are able to use the expanded facilities on the 5th floor (PITU) for most patients that need iloprost treatment. Infusions are given in a "day case" setting and patients can stay overnight in the hotel opposite the Royal Free or go home at night if they live locally. For many patients this works very well and we hope it will reduce cancellations and delays as we approach the busy winter months. We still have facilities to admit patients that need to come in to the hospital for iloprost and other therapies but as in all NHS hospitals we have to recognise the enormous pressure on beds that is a feature of normal life in any hospital these days. Our ward doctors and nurses are working hard to minimise cancellations and disruption.

In the scleroderma clinic we are hoping that Dr Svetlana Nihtyanova will soon return to join us part-time after having her baby earlier in the year. After a very successful year with us Dr Pia Moynadeh will soon return to Cologne to continue work in the large scleroderma unit there. We expect that our two units will continue to collaborate over the next few years. We have visiting doctors coming next year from Portugal and South America and I am sure that these visitors will continue to enrich the department and take scleroderma expertise back to other countries.

In conclusion then the unit continues to develop and we look forward to welcoming as many of you as possible at our annual "Scleroderma Family Day" on May 19th next year.

Laboratory and Research News – David Abraham

As we approach the end of the year it provides a good opportunity to look back over the last 12 months and to summarise the progress we have made in the laboratory research into Raynaud's and Scleroderma. The newsletter give us an occasion to highlight research areas of particular interest and to let you know about changes that have taken place in the department, our new staff and also share with you some of our main achievements.

New Research laboratories

We have recently moved into our new research facilities. These are situated on the 2nd floor of the Royal Free Hospital Medical School block just a short walk from the scleroderma clinics. These were built as part of an on-going major new refurbishment programme funded jointly by the Royal Free Hospital and University College London, and were officially opened in July by HRH Princess Royal. It is within these new research facilities that we carry-out our fundamental science and translational research activities. Please feel free to come and look around the new laboratories when you next visit the Royal Free Hospital.





Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



The main research and tissue laboratories on the 2nd floor

Achievements and advances in the last 12 months:

- We are looking more closely than ever at the disease process and organ involvement in scleroderma in order to identify key pathways that control the thickening of tissues and blood vessels leading to scarring, fibrosis and vessel disease.
- We have been examining biomarkers which we hope in the future can be used to plot the progress of disease and response to treatment.
- An important aspect of our work is to develop new model for scleroderma. We believe these improved models are essential to our studies unravelling the processes important in fibrosis and scarring in scleroderma.
- We have been looking in more detail at the use of non-invasive imaging techniques to assess the extent of skin and lung involvement in scleroderma.
- We have begun to explore the use of drug discovery and targeting technologies to assist us in determining the best candidates to examine in terms of the potential long-term benefit to patients.

A major part of our research work relies on the availability of tissue biopsies and blood samples which are provided by patients, their partners and relatives. These resources are absolutely essential to our continued success and progress in studying the disease process and facilitating the development of new and effective treatments.

Research Funding: New Research Grants and staff

We receive exceptional and continued support from **Arthritis Research UK** and the **Raynaud's and Scleroderma Association**, to study disease mechanisms, organ involvement and to develop new treatments. In addition we have also received vital pump-priming funding from other biomedical charities including the Rosetrees Trust who have provided continued support to study growth factor regulation in scleroderma, and The Scleroderma Society for funding to support for pilot projects. This year other major research funding, grants and fellowships include:

Arthritis Research UK – have awarded Dr Emma Derrett-Smith an Arthritis Research UK Career Progression Fellowship
The Raynaud's and Scleroderma Association – have awarded us in collaboration with Professor Athol Wells a 2-year extension to our joint programme grant to study lung disease in scleroderma.

Medical Research Council - have awarded us consortium status. This initiative led by UCL brings together all the prominent researchers in the UK who have an interest in scarring and fibrosis. Dr Alan Holmes has recently re-joined the department as a **Group Leader**. He has spent the last six year on 'sabbatical' working in big pharma. His research, funded by **Arthritis Research UK**, will focus on pulmonary hypertension and fibrosis, seeking to discover the critical mechanisms leading to these disease complications, and developing our drug discovery programme. Dr Sarah Trinder has also recently joined us having completed her PhD at UCL on pulmonary hypertension. We feel both Alan and Sarah make valuable additions to our growing research group.

In addition, we have two new **PhD students**. Mr Adrian Gilbane, who has joined us from the University of Aberdeen to study pulmonary arterial hypertension and Mr Surya Rayapureddi from UCL to study mechanisms of scarring and fibrosis. These research projects are funded in partnership between industry and UCL.

We also have a new **MD Student**, Mr Ali Navi. He bridges our continued collaboration studying blood vessel diseases with vascular surgery at the Royal Free.

National and International Meetings

This summer we held our 12th International Workshop on Scleroderma research at Trinity College Cambridge. This workshop was attended by over 250 participants from around the world including scientists, clinician scientists, and trainees at all levels as well as biomedical science students. This workshop has gone from strength to strength and represents the main international forum for scleroderma research. We also held our 6th workshop on Cardiovascular Biology and Diseases at the Royal College of Physicians in London in September. This one-day intensive symposium had nearly 200 attendees with interests in the cardiovascular and pulmonary system in health and disease, and is now firmly established as a major workshop in the academic calendar.

A number of our staff have presented work both as lectures and poster abstracts at national and international conferences, including the London Matrix Group, the British Society for Matrix Biology, British Society of Rheumatology earlier in the year, and recently presentations at the American College of Rheumatology annual conference in Chicago, and the international Fibrosis meeting in Vancouver. Our presence at these meeting is essential to showcase as widely as possible the breadth and depth of our research programme and to obtain critical and constructive comments and feedback to help direct our on-going and future research endeavours.



Capillaroscopy and thermography – Dr. Kevin Howell



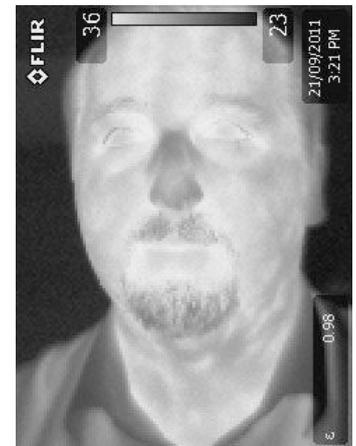
Things remain very busy within the microvascular lab. The CAP study has now recruited half of the required patients, but there is still some way to go this winter!

CAP involves fifty specialist scleroderma centres across Europe, and will help researchers to understand which aspects of the changes occurring to nailfold capillaries in scleroderma are predictive of digital ulceration.

We also remain very active in thermography, and further research using thermal imaging to assess Raynaud's phenomenon is in the planning stage.

This winter, I will also be supervising the MSc. project of my colleague Rosie Richards, who is a trainee Clinical Scientist doing part of her training at the Royal Free. Rosie is interested in thermography of the face (see example image), and whether the temperature of the eyes in a thermal image is representative of "core" body temperature (which we would normally measure under a patient's tongue with a thermometer). There will be more information available from Rosie during some of the winter scleroderma clinics: please give her ten minutes of your time if you are able to whilst waiting for your appointment. We are presenting some early findings from this work at a symposium in Vienna which, as I write, is just four days away.

Merry Christmas and a Happy New Year to all of you!



Scleroderma Nurses

Hello to everyone, we cannot believe we are nearly at the end of 2011! Time just flies by.

We have had a busy year writing leaflets and liaising with other departments so we have the most up to date information available for you. Tani has produced very informative nutrition leaflet, which will be available shortly for you. I have linked in with the gastro physiology team so we have another expert team to refer you to if you are having problems your bowels or incontinence. Tani has written up and presented two posters at Rheumatology meetings this year. One of which is at the ACR (American College of Rheumatologists) which is the most prestigious meeting of the year.

On another note, we have had huge success with our patients support group meetings, which take place every three months here at the Royal Free in the Rheumatology Library – we had 18 people come along on the 28th October, which was a fantastic turnout and the feedback has been very positive. **If you would like to come along, the next meeting is on the 17th February 2012, 2:00-4:00pm in the Rheumatology Library, Lower Ground Floor.** You can participate as much or as little as you like and we try to organise a speaker for each meeting regarding different aspects of Scleroderma to make it as interesting as possible.

We hope you have a peaceful Christmas break and we look forward to seeing you soon.

Louise & Tani



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Pulmonary Hypertension Team

This year has brought fresh challenges and changes for the Pulmonary Hypertension service.

Many of you have met and welcomed Dr Benji Schreiber to the service. Benji has led on many service development projects since joining us. These continue to add value to the patient experience and efficiency of the service. One such project is the counseling service for patients diagnosed with pulmonary arterial hypertension. We hope that this will add a new dimension to the care the team already offer. Joanna Lansell joined the team in May of this year. We are very excited to have another experienced nurse within the team. Joanna will commence the first degree course in pulmonary hypertension at the end of this year. Further cementing her development and knowledge in this specialised area. Sally and Adele continue to work hard to provide clinical services and MSc level studies where they can. The service remains as busy as ever with expansion to our out-reach programmes and clinics based at the Royal Free.

The team continue to represent the service at national and international meetings. We look forward to working with you in 2012 and wish you a merry Christmas and a happy new year!

Best wishes

Sally Adele and Joanna



Clinical Trials News – Rachel Ochiel

The clinical trials team have had a very busy year in the clinical trials unit and are actively recruiting for trials. We have lots of studies, both pulmonary hypertension and rheumatology trials, at various different stages. Ivy continues to provide administrative support for the team. We have recently been joined by new research nurse Anna Stanton. Sadly Priscilla and Ruth left us. Ruth as commuting from Brighton and Priscilla moved outside London, we expect 2 new nurses to replace them soon. The addition of these research nurses has meant that we are now able to take on even more research studies. We also have a new data manager Lovia and administration support from Dipa.

Although delayed, we still plan to put results of the completed studies like the Sstep trial on to the website. We will also have a group email address you can contact us on and plan to send out a questionnaire to patients in the near future to help us audit our service.

We are currently recruiting for an exciting study called PISES, on this study we are looking for scleroderma patients with foot pain. If you would like to participate in any of our studies please contact the team on **0207 317 7544**. There are also more details of the studies on the website.

Some of our current studies are:

Ongoing Scleroderma Trials

DETECT - An observational study to find out Early, Simple and reliable methods to detect pulmonary Hypertension.

DUO Register - This is an observational study to follow-up patients with digital ulcers over the course of the disease. The outcome of this study will inform on how to improve patient care in the long run.

PISCES - A study to evaluate the use of a simple pressure-relieving insole in Scleroderma

ESOS - A study to examine the effectiveness of approaches in the early management on patients with Diffuse Scleroderma.

Ongoing Pulmonary Hypertension Trials

SERAPHIN - This is a study to find out the effect of a drug called macitentan in pulmonary arterial hypertension.

FREEDOM STUDIES - Studies to see the effect of UT-15C sustained release tablets in pulmonary arterial hypertension

AMBITION - A study comparing the effect on time to clinical failure of initial combination therapy (ambrisentan and tadalafil) and initial monotherapy (ambrisentan or tadalafil) in subjects with pulmonary arterial hypertension).

PATENT - A study to assess the safety & effectiveness of different doses of a new oral drug (BAY-63-251).

TADELAFIL - To evaluate the long term safety/efficacy of Tadalafil in the treatment of patients with pulmonary hypertension.

VOLT - An observational surveillance programme of Ambrisentan which is already licensed for the pulmonary hypertension.





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Kim Fligelstone

Hi everybody

Another year passes by quicker than ever. I'm still at the hospital 2 days a week if you would like to call me on 0207 794 0500 ext 35131 or meet for a coffee. I'm not a counselor/therapist but have had the systemic type of scleroderma for the past 24 years. If I'm not in please leave your contact details with Millie and I'll get back to you when I can.

Whilst on the ward - If you would like a massage just ask one of the ward staff to get in touch with Complimentary Therapy Services run by Keith Hunt to book one.

The 3 monthly patient support group meetings organised by Tani and Louise are going from strength to strength, the last one at the end of October had the best attendance so far. Psychologist Dr Alex Clark talked about the psychological affects of self image with an emphasis on facial changes. The date for next meeting is on 17th February 2pm – 4pm Hope to see you there!

Have a very Happy Christmas & New Year and keep as healthy & warm as possible!

Kim

Scleroderma Family Day

Saturday 19 May

As always we all very much look forward to Scleroderma Family Day. The programme is now the last page of this Newsletter and looks really interesting. I hope many of you will join us. I also hope to put some of the talks up on the website after the meeting.

Newsletter

The Christmas Newsletter is the annual Newsletter from the Scleroderma Unit and we hope you enjoy reading it. If you would prefer not to receive the Newsletter please let me know and I will take you off the list. A copy can also be downloaded from our website.

If you have any questions about Family Day, the newsletter, or anything else, please do feel free to contact me at pamela.yeomans@scleroderma-royalfree.org.uk. or by phone on 01273 672686/020 7794 0500 x 33471 [Mondays].

Pamela

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Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



Scleroderma Family Day - Saturday 19th May 2012

The Atrium, Royal Free Hospital, Pond Street, London NW3 2QG

Chair: Professor Chris Denton

The difficult bits – the daily burden of scleroderma

09:30 - 10:00	Registration and Coffee	
10:00 - 10:15	Welcome to Family Day	Prof Chris Denton Prof David Abraham
10:15 - 10:30	The bowel in scleroderma – a new look at an old problem	Dr Charlie Murray
10:30 - 10:50	"From Mexico with love" - my personal journey from bench to bedside	Dr Carmen Fonseca
10:50 - 11:10	Scleroderma renal crisis	Dr Mark Harber
11:10 - 11:30	New clinical trials for scleroderma	Dr Voon Ong Ms Rachel Ochiel
11:30 - 12:00	Stem cell treatments for scleroderma in the UK and the Netherlands	Prof Jaap van Laar Clinical Rheumatologist Newcastle University
12:00 - 12:30	The feet in scleroderma	Mr Stephen Kriss
12:30 - 14:30	Lunch break— discussion groups – see below	
14:30 - 15:00	Patient Focused Care - bringing together two units, a new initiative - University of Bedford, Royal Free and Queens	Prof Kuntal Chakravarty
15:00 - 15:30	Questions and Answers	
15:30	Raffle	

Lunchtime Discussions Groups /Demonstrations include

Clinical Trials	Rachel Ochiel and team
Drug information/monitoring	Jay Pang/Aoife Tynan
Skin Camouflage	Changing Faces formerly British Red Cross
Massage	Mr Keith Hunt, Complementary Therapies
Neurological Aspects of Scleroderma	Bryan Youl
Pulmonary Hypertension Education/nursing	Sally Reddecliffe/Adele Gallimore
Rheumatology Laboratory	Research Laboratory Staff
Scleroderma Education/Nursing	Tanaka Ngcozana/Louise Parker
Surgery	Mr O Ogunbiyi, Mr Nick Goddard
Thermography	Dr Kevin Howell

