



Dear Friends

May I wish you all a very Happy Christmas and joyous New Year.

It gives me great pleasure to see the success and growth of the Unit under the excellent leadership of Professor Denton and Professor Abraham. The Unit has a very high standing in Europe and the wider world, I hear so many good things about and I feel very proud. In the summer we will host the International Scleroderma Research Workshop in Cambridge. This is an opportunity for us to gather together all the key players in the basic research field whose work can translate into clinical benefit for patients.

Enjoy the festive season.



Professor Dame Carol Black

Clinical Scleroderma Service News – Professor Chris Denton

The clinical team has seen some staff changes over the past few months. Dr Emma Derrett-Smith, a key member of the team over recent years, is on maternity leave with her baby (Eleanor). Emma hopes to return to the unit next year and continue with her clinical work and research into scleroderma. On a similar note (is a trend emerging?) we will greatly miss Dr Svetlana Nihtyanova when she leaves at the end of November, again to go on maternity leave. Svetlana has been a valuable member of the scleroderma team over several years - we all wish her every joy and happiness for the future.

There have been some important additions to the team that should also be highlighted. Dr Pia Moinzadeh has joined us from Professor Thomas Krieg's unit in Cologne, Germany. Professor Krieg is one of the major European experts on scleroderma and has spoken at our Royal Free Scleroderma Family Day. It is an exciting opportunity to strengthen links between our two institutions and Pia is involved in both clinical work and laboratory research. Pia is a dermatologist and is also strengthening our links with Dr Cate Orteu and others in the dermatology department. Another new face is Dr Shamin Lamabadusuriya. Shamin comes highly recommended, and joins us from his senior registrar post in rheumatology in Sri Lanka and is working for part of the week at the Royal Free and part of the week in Professor Chakravarty's department at Queen's Hospital in Romford. In addition to these staff members we continue to host visitors to the department, including Bettina Grønhøj Meakin, a very talented medical student from Denmark and Dr Simona Gindea an excellent rheumatologist who recently completed specialist rheumatology training at the Albert Einstein Medical School in New York. It is a high priority for the unit to provide education and stimulation to students and doctors, some of whom we hope will eventually specialize in rheumatology and scleroderma.

In the clinical unit we continue to be as busy as ever and have also had to respond to the challenge of some of our clinical activity moving back to the 5th floor of the hospital – you may remember that we have been on that level before. The PITU (Planned Investigation and Treatment Unit) has relocated from its rather splendid location on the 2nd floor but the dedicated nursing and support staff remain unchanged and we are all doing our best to minimize disruption. So in summary, we are as busy as ever but excited by a growing interest and priority for scleroderma inside and outside the hospital, including more clinical trial activity than ever, as outlined by Rachel on Page 4.

Scleroderma Family Day at The Royal Free – Saturday 14 May 2011

Scleroderma Day is as always one of our favourite days. Details of the programme will be available in our Spring Newsletter. We have included a book of raffle tickets with this Newsletter. Thank you all so much for purchasing our raffle tickets - the sale of which 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.

Scleroderma Website – www.scleroderma-royalfree.org.uk

We have given our website a much needed overhaul. The website is up and running but is very much a work in progress and we aim to make the final adjustments to pages and insert up to date content over the next few weeks.

Pamela





Laboratory and Research News – David Abraham

As we move towards the end of the first decade of the 21st Century, it is a good time to reflect on the progress that has been made in Raynaud's and Scleroderma research over the past year. Research is progressing well and there have been some major achievements that we would like to share with you.

Some of our achievements and advances in the last 12 months:

- We have been looking at disease biomarkers and have identified some proteins which look very promising candidates that may be useful in assessing changes in disease.
- We have been looking more closely at blood vessel involvement in Scleroderma and have identified a key pathway that seems to control vessel thickening in pulmonary hypertension.
- We have developed a new model which we believe we will very useful to study fibrosis and scarring in Scleroderma.
- We have been looking in more detail at the role of the epithelium in scleroderma and these studies have lead to the discovery of a potentially important pathway in scleroderma.

New Research laboratories

Another very important development at the Royal Free is the building of new research facilities for the Department of Rheumatology to study Raynaud's and Scleroderma. This is part of an on-going major new refurbishment programme funding jointly by the Royal Free Hospital and University College London, costing nearly £10 million. The new facilities will house our fundamental science and translational research activities, including our studies into the cells and factors that are involved and our efforts to identify and test new treatments for Raynaud's and Scleroderma and biomarkers to assess extent of disease, progression and response to therapy. The research facilities are due to be completed by late spring of 2011, and we hope to be able to show them to you at our annual Family Day in May.

Research support and New Research Grants Awarded

We receive exceptional and continued support from **Arthritis Research UK** (formerly the Arthritis Research Campaign) 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 and funding for pilot projects from other biomedical charities including the Rosetrees Trust, and The Scleroderma Society. Since May 2010 we have been awarded the following research grants:

Arthritis Research UK – have awarded us a five year, 2nd renewal of our Programme grant to study the pathogenesis of Scleroderma.

The Raynaud's and Scleroderma Association – have awarded us in collaboration with Dr Sarah Howat at King's College a project grant to study blood vessels in Scleroderma.

Medical Research Council - have awarded us in collaboration with Dr Robin McNulty UCL main campus, a project grant to study inflammation in lung disease in Scleroderma.

PhD studentships – We have been awarded three PhD studentships. These are to study: Eye scarring in collaboration with Drs John Dart, Valerie Saw and Julie Daniels at Moorfield's eye Hospital; The role of iloprost and sildenafil in treating fibrosis in collaboration with Professor Lucie Clapp and Dr Adrian Hobbs at the main UCL campus; and to examine in more detail peripheral vascular diseases in collaboration with Dr Janice Tsui in vascular surgery at the Royal Free Hospital.

MD Studentship – was awarded to Dr Hemanshu Patel from the circulation foundation to study responses to infection in vascular disease in collaboration with vascular surgery.

New Research Staff

There are four members of the research team. Ms Bhaja Abdi joined us in July to look at aspects of biomarkers in Systemic Sclerosis and also involved in genetics studies of SSc with Dr Carmen Fonseca. This is part of our ongoing collaboration with Professor Athol Wells and Elizabeth Renzoni at the Brompton Hospital. Also Sarah Dale, Binara Rupsinghe and Rebekkah Yu have joined our team as students.

National and International Meetings

Our research staff attended and presented our work at both the International workshop on Scleroderma research in Boston and at the American College of Rheumatology meeting in the US. These are to of the most important meeting in the academic calendar. In addition the these meeting and the British Society of Rheumatology, our work was presented and received much attention and awards, at several smaller national and international symposia including, the British Matrix Biology meeting in Manchester, the European Wound Healing Society meeting in Belgium, and at the 6th CCN Growth Factor meeting held in Belfast Ireland. Attendance at these symposia is vital to broadcast our research as widely as possible and to obtain critical feed-back to help steer our future endeavours. We also hosted our 5th workshop on cardiovascular biology held at the Royal College of Physicians in September. This intensive one-day workshop covers key areas of the cardiovascular system in health and disease, and now with over 100 participants is firmly established in the academic symposia calendar.

Next year will be a busy year for us as we plan to hold both our 12th International Workshop on Scleroderma research at Trinity College Cambridge in the summer, our 6th workshop on Cardiovascular Biology in London in September, and are co-organising the 7th CCN Growth Factor meeting to be held in Vancouver, Canada in the autumn.





Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



Microvascular Lab – Dr Kevin Howell

I thought you'd all like to see a photo from back in the summer, taken at the University of Glamorgan graduation ceremony, where I received my doctorate. Glamorgan academic gowns are particularly elaborate and colourful!

L-to-R: Prof. Rod Thomas (one of my examiners), KH, Prof. Francis Ring (Head of the Medical Imaging Group at the University of Glamorgan Faculty of Advanced Technology).



Back at the Royal Free, we have made a few IT improvements over the summer. All thermography and capillaroscopy results are now reported via the hospital's on-line system for physiological measurements. This means that all the doctors can see recent results from the thermography lab on the computer screen in front of them when you attend clinic. There is no paper record to file (or lose!) and we make considerable savings on paper and colour printing costs.

In the run-up to Christmas we expect the usual very busy winter clinics. I am also "on-the-road" keeping three commitments: a weekend trip to Vienna to present a thermography paper in November, a lecture in December about infrared to the Royal Photographic Society's "Good Picture Symposium" in London, and a visit to the Institute of Physics in Engineering and Medicine in York to speak to trainees in Physiological Measurement about career options. By the holidays I will certainly be ready for a short rest!

I wish everyone a very Merry Christmas and a Happy New Year.

Scleroderma Nurses

This year has brought a few changes to the Scleroderma team. Nike Akinsulire is now working alongside Louise and Tani running the Rheumatology drug monitoring service full time. Some of you may already know her from the clinic. Jakub is the new Outpatients charge nurse in Rheumatology so you will meet him too next time you come to the clinic. We are delighted to have two such talented nurses join the department.

Tani has recently spent a week in the Rheumatology department in Florence, Italy sharing best practice with the scleroderma nurses there. Her particular focus was learning how they manage and treat digital ulcers. This experience was exciting and informative and will guide us in helping you with problems you have with digital ulcers. Tani would like to thank all of you who have returned your sexual problems questionnaire. If you have not sent yours back yet – it's not too late, Tani is keen for more information!

Louise is now the Lead Nurse for Connective Tissue Disease so continues to work closely with Tani and the other specialist nursing teams to give as much support as we can to you.

Please let us know if we can help you by calling us on the advice line or we can arrange to see you in clinic or on the ward.

We wish you a peaceful Christmas and happy New Year. We look forward to seeing you soon.

Louise & Tani.

Pulmonary Hypertension Team

As we approach the end of 2010 it is a good opportunity to reflect on the exciting developments in the PH team over the last 12 months. We are very happy to welcome Dr Benjy Schreiber to our team – he has been appointed as the new pulmonary hypertension Consultant. We look forward to Dr Schreiber joining the service in early 2011. The one-stop clinic continues to expand – feedback from the patients has been very positive, as it has greatly reduced the number of visits patients need to make to the hospital. The team continues to work very hard – within the clinical area at the Royal Free, representing the unit at National and International meetings, and running our expanding satellite clinic service. Adele and Sally started their MSc studies in September – they are studying when they can - whilst continuing to deliver excellent patient care. Katie is working on several research projects within the service. Clare returned from Maternity leave in May, but will be going on maternity leave again in 2011 as she is expecting her 2nd baby in April! The team continue to be supported by Alison and Innes – our excellent clerical assistants - who keep the service running efficiently.

Wishing you a Merry Christmas and a Happy New Year!





Clinical Trials – Rachel Ochiel

We have had a very busy year in the clinical trials unit, we have lots of studies in various different stages. Ivy continues to provide admin support for the team. We have recently been joined by new research nurses: Karl Nanan, Ruth Staunton and Priscilla Sauramba. The addition of these research nurses has meant that we are now able to take on even more research studies. We also plan to put results of the completed studies like the Sstep trial on to the website. 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

1. DETECT - An observational study to find out Early, Simple and reliable methods to detect pulmonary Hypertension.
2. AIMSPRO - A study to see if AIMSPRO improves the quality of life in long standing Diffuse Scleroderma.
3. DISTOL - A study on the effect of a drug called Treprostinil diethanolamine (UT-15C) on digital ulcers in SSc patients.
4. 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.
5. PISCES- A study to evaluate the use of a simple pressure-relieving insole in Scleroderma
6. ESOS- A study to examine the effectiveness of approaches in the early management on patients with Diffuse Scleroderma.

Ongoing Pulmonary Hypertension Trials

1. SERAPHIN - This is a study to find out the effect of a drug called macitentan in pulmonary arterial hypertension.
2. FREEDOM STUDIES - Studies to see the effect of UT-15C sustained release tablets in pulmonary arterial hypertension
3. TRIUMPH - A study to find out the effect of Treprostinil Inhalation in the Management of severe Pulmonary
4. PATENT - A study to assess the safety & effectiveness of different doses of a new oral drug (BAY-63-251).
5. TADELAFIL - To evaluate the long term safety/efficacy of Tadalafil in the treatment of patients with pulmonary hypertension.
6. VOLT - An observational surveillance programme of Ambrisentan which is already licensed for the pulmonary hypertension.

Kim Fligelstone

Wow Christmas already, every year the months fly by faster than ever. Don't forget if you want to talk to a person with scleroderma on the phone you can call 0207794 0500 ext 35131, I'm not a counsellor/therapist but have had the systemic type of scleroderma for past 23 years. If I'm not in please leave your contact details with Millie.

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. Hannah Harris is a Royal Free patient and is volunteering to visit people with scleroderma on the ward. If you would like to see Hannah call her a week or so before you are due to come in on 07976 388645 or email Hannah@sclerodermasociety.co.uk Hannah has extensive knowledge about many things including aids and equipment to help at work.

Norlan Dubissette the Patient Pathway Coordinator has joined the Scleroderma Unit/Team, Norlan who coordinates tests with out patient appointments works Wednesday, Thursday and Friday Tel: 020 794 0500 Ext 32909

Take care have a very Happy Christmas & New Year and keep as healthy & warm as possible!

Newsletter

We hope you enjoy reading our Newsletters. We send them out to all Raynaud's and Scleroderma patients. If you would prefer not to receive them please let me know. A copy can also be downloaded from our website **Pamela**.

Contact Numbers

NHS Secretariat	020 7830 2284	Scleroderma Appts	020 7830 2151
Nurses Help-line	020 7830 2326	Clare	020 7472 6354
Kevin Howell	020 7472 6550	Millie	020 7794 0432
Kim	020 7794 0500 x 35131	Clinical Trials:	020 7317 7544
Norlan	020 7794 0500 x 32909		

MERRY CHRISTMAS

