

**MERRY  
CHRISTMAS**

From all of us

Christmas 2013

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

## Dear Friends

The Festive Season is here, and I would like to wish you all a joyous time over Christmas and the New Year.

I have watched the progress of the Centre with great interest during the year, and was particularly pleased to be able to join the International Scleroderma Workshop in Boston.

This year has also seen Anne Mawdsley step down as CEO of the Raynaud's and Scleroderma Association. Anne has contributed so much to the care of patients, and raised millions for research - and I wanted to pay my own tribute to her. I am pleased to see that Anne's talents will not be wasted and will be used to help patients through her new Helpline. Finally I am very pleased to see the Scleroderma Society and the Association working more closely together.

**Dame Carol Black**

## Clinical update on scleroderma service

### Professor Chris Denton

There are many challenges providing a service for a complex disease like scleroderma and I am grateful to have such an excellent team who see opportunities as well as challenges as we work hard to develop and improve the scleroderma service and also respond to the changing NHS environment and reforms. Two positive aspects have been the move of our scleroderma and pulmonary hypertension outpatient clinics into the new Institute of Immunity and Transplantation. Located in refurbished space on the second floor of the hospital the bright and colourful environment is bringing a modern feel to the clinics. More importantly we have used the move to restructure clinics and make the experience more appropriate. Supported by excellent staff in the Institute this is working well so far. We now run two scleroderma clinics a week rather than one all day clinic. This helped to balance workloads and tests better. For patients requiring hospital based treatments like iloprost we are taking advantage of the expanded ambulatory unit (PITU), also on the second floor. This is working well with patients staying the hotel opposite the Royal Free and coming daily for treatment. Clearly this does not work for everyone and we are working with the hospital to try and ensure we can access beds for inpatient treatment when necessary. Well publicised pressures on the NHS can make this challenging, especially in the winter and so this is "work in progress".

We are sad to say goodbye to some really excellent medical staff over the past 12 months including Dr Vincent Sobanski, who returns to his previous scleroderma unit in France after one year with us and Dr Bernadette Lynch who has been appointed as a rheumatology consultant in Southend. However, others have joined and we particularly welcome Dr Jasmin Raja is visiting for 12 months from Malaysia, sponsored by the Royal College of Physicians to train in scleroderma, and Dr Edward Stern has joined from the renal department to undertake research on scleroderma renal crisis. We are also delighted that many overseas doctors are able to visit and learn from our centre and this helps to provide a great international feel to the department.





## Research at the Royal Free Hospital – Professor David Abraham and colleagues

As we approach the end of 2013 we have been in our new laboratory facilities on the 2nd floor of the Medical school for over 2 years, so now seems a good time to look back at our achievements over the last 12 months. Our research into Raynaud's and scleroderma continues to thrive, widen and develop into new and productive areas of investigation. We are pursuing new areas of study including better laboratory models to investigate scleroderma pulmonary arterial hypertension and lung fibrosis, studies focussed on skin disease and the role of stem cells and cross talk between the epidermis and dermis in skin fibrosis, and the alterations within small and large blood vessels which are characteristic features of Raynaud's and scleroderma. In particular, we are embarking upon studies to understand in more detail the role of endothelial cell progenitors in scleroderma. These cells are believed to be important in repairing the cell layer that line the blood vessels which are critical in regulating blood flow and pressure. Another exciting area we are exploring is the genetics of scleroderma. These approaches are allowing us to discover new molecules that are differentially expressed in scleroderma. We can then take these molecules and move them forward in our drug discovery programme. One appears to be important in the development of pulmonary arterial hypertension and the other in pulmonary fibrosis. These form part of our translational biology programme, where we are moving as rapidly as possible from basic science research into applied studies, which we hope will lead to the initiation of clinical trials. We have also been developing more research interactions with industry, which is important as we move even closer towards these clinical trials. Our collaborations within the Royal Free, the UK (including the Brompton Hospital) and internationally are flourishing and now include Germany, Canada and Australia. Some of our work has been presented at biomedical symposia with presentations at the American College of Rheumatology in San Diego, British Society for Rheumatology, the scleroderma research workshop in Boston, Yale University fibrosis symposium, the International CCN growth factor meeting in Nice and the endothelin conference in Tokyo. These are high-profile meetings where our work has been showcased to the International biomedical community, with very positive feedback. We have also organised several meetings including the international cardiovascular biology and medicine workshop held at the Royal College of Physicians, and the London Rheumatology research meeting, and have coordinated a multidisciplinary approach to study fibrosis with a new consortium of experts working at UCL and Royal Free.

### News about the research Staff

A number of staff have recently joined the group: Mr Toby Clements and Ms Mary Tarruela are both studying for their science degree with us and are looking at biomarkers in scleroderma and developing new assays to assess scarring in scleroderma. We are also joined by a new British Heart Foundation PhD student Miss Athina Dristoula who is studying the regulation of blood vessels in scleroderma pulmonary arterial hypertension. Ms Grace Chu has joined the department to study the role of growth factors on the production of collagen in models of skin fibrosis. One of our previous students, Ms Angela Tam, was successful in obtaining a Japanese foundation fellowship to work on a joint project aimed at examining auto-antibodies and blood vessel damage in scleroderma in collaboration with Professor Kuwana an international leading expert based in Tokyo University.

### Research Funding

We have been successful with a number of research grants recently. We have been awarded a Raynaud's and Scleroderma Association project grant to study stem cells in fibrosis (Dr Richard Stratton), an MRC translational award to investigate renal disease (Professor Chris Denton) and a joint project grant funded by the Royal Free Charity and the Rosetrees trust to study growth factor signaling in scleroderma. We have also been awarded an important equipment grant (Ms Korsia Khan) from the Scleroderma Society to enhance our research in cell and molecular biology. We are very grateful for the continued programme and project grant support of Arthritis Research UK and the Raynaud's and Scleroderma Association and project grant funding from the Scleroderma Society. This portfolio of funding supports our overall biomedical research studies into Raynaud's and scleroderma as well as investigating novel approaches to treatment.

### Microvascular Diagnostics – Dr. Kevin Howell

This year's big news is the move of our capillaroscopy and thermography service from the lower ground floor to a new "Microvascular Diagnostics" laboratory in the Institute of Immunity and Transplantation. We now have a bright and spacious environment suitable for the demands of our busy clinics, and many patients have commented on the great improvement to our facilities in 2013. A big "thank you" to the Institute project team and Royal Free Estates department, who ensured we were able to transfer the entire lab to its new home over just one week back in May.

Our research and training activities continue apace - particularly in the field of capillaroscopy. We have contributed to the analysis of capillaroscopic images for a study co-ordinated by Manchester University, and I recently travelled to Dublin to assist Tallaght Hospital with establishing a capillaroscopy service. I have also written a comprehensive article on microvascular imaging with my colleague Dr. John Allen at the Freeman Hospital in Newcastle: this is currently undergoing review.

I look forward to meeting some of you in the Institute during 2014. Merry Christmas and a Happy New Year!



# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital

## **Scleroderma Nurses – Louise & Tani**

The past 12 months have just flown by and we have been busy as ever. We continue providing support through our advice line and seeing patients in the clinic and the wards. Our London Support group is ongoing and this year we managed to conduct a Young Scleroderma afternoon as well. Our next Support Group will be in early April, for more information please get in contact with us on 0207 8302326.

PITU expansion has been quite a success so far as we have increased the number of people coming to have iloprost per week. Also most patients are happy with staying in the hotel overnight rather than being inpatients.

We hope in the next year we will continue to improve the services we provide for our patients.

Wishing you a lovely Christmas and a Happy New Year!

## **Pulmonary Hypertension Team**

I hope you are all looking forward to Christmas and the New Year as much as us!

As we approach the end of 2013, it is a good opportunity to reflect on the exciting developments in the PH team over the last 12 months. We have now established an outreach clinic in Brighton, which is already receiving positive feedback from patients. The PH service continues to grow. We now have 9 outreach clinics in total, ensuring that a greater number of our patients can receive their care closer to their homes.

Sally, Adele and Joanna continue with their academic studies, along side clinical commitments. Joanna will be going on maternity leave just before Christmas as she is expecting her first baby in January. On the administration side, Joanna Mash was appointed permanently in September and we would like to take this opportunity to welcome her to the team. Alison is currently on maternity leave and will return in the Summer.

Wishing you a Merry Christmas and a Happy New Year!

## **Kim Fligelstone**

Hello, my name is Kim, I have had scleroderma for 26 years and am generally available on Tuesday and Wednesdays if anyone would like to phone or pop in for a chat best to call or email before hand (see details below) as these days can change. I must emphasise I am not a counsellor, I just have lots of experience of living with scleroderma, although we are all affected by scleroderma in different ways, I would love to hear from you if you want to talk Tel: 020 7794 0500 ext 35131.

I expect most people reading this will have been to the new clinic rooms in the Institute, they are a vast improvement on the lower ground floor corridor. For those who haven't yet had the pleasure you go to the main entrance of the Hospital on the ground floor and take the lifts or stairs on the right of the reception desk to the second floor and follow signs to the Institute.

Lastly the 3rd Systemic Sclerosis World Congress will be held in Rome from the 4th – 6th February 2014 for a detailed programme about the patient congress visit <http://www/fesca-scleroderma.eu/> and click on congress log alternatively both the Scleroderma Society and the Raynaud's and Scleroderma Association have information on their websites. Registration is just 35 euros! I will be talking about breathlessness in scleroderma if anyone would like to contact me if you experience breathing difficulties and have any advice/tips you would like me to pass on I would be very grateful.

You can email me at [kim.fligelstone@nhs.net](mailto:kim.fligelstone@nhs.net) or [kim@sclerodermasociety.co.uk](mailto:kim@sclerodermasociety.co.uk). Telephone 0207 229 4750 or 0207 794 0500 ext 35131 on Tues and Wed leave a message if I'm not around and I'll get back to you asap.

All that's left for me to say is have a lovely Christmas and a Healthy and Happy New Year wherever you are. All being well I will be celebrating the festive Season in Vietnam.

Kim





# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



## Clinical Trials News – Rachel Ochiel & Team

The clinical trials team are now seeing patients in the Institute on the second floor. This new unit was officially opened by Prince Andrew in June who observed Rachel carrying out a patient's visit.

We have also had some changes in staff. Rebecca has left her post as a research nurse and we wish her all the best with her future endeavours. Two new members of staff have joined the team recently. Rebecca's position has been filled by former cardiac nurse Angelique Smit and recent graduate Isaac Muhuma has been added to the team to provide administrative support. RN Yvonne Tan will be joining us in the New Year. Of our current staff Dipa Ghedia has had a change of role and is now more directly involved with patient care. Dipa says 'I find this new job role much more exciting and fulfilling. It's great to be able to spend more time with our patients.'

This expansion of our workforce has enabled us to increase the number and expand the nature of trials we can run. We have a number of new studies running at the moment including the following...

### Ongoing Scleroderma Trials:

**Celegene:** A investigation into the safety and efficiency of pomalidomide in treating Systematic Sclerosis.

**Sanofi:** A study using a new drug called SAR100842 to treat patients with Diffuse Cutaneous Systemic Sclerosis.

### Ongoing PH Trials:

**310:** A study into the effects of taking the drug UT-15C (treprostinil diethanolamine) in conjunction with other prescribed oral PAH therapy.

**Bridge:** A genetic study for Pulmonary Hypertension.

### General Rheumatology:

In addition to PH and Scleroderma studies the team have expanded to running a number of general rheumatology trials. Trials nurse Nike, who is facilitating the running of these studies is excited about this development and the opportunity to work in these interesting new areas. These studies include:

**CAIN:** An exploration of how the drug Secukinumab affects patients with active psoriatic arthritis.

**Earth Explorer:** A study into the treatment of rheumatoid arthritis using Mavrilimumab.

Should you wish to participate in any of our studies or would like some additional information please contact the team on:

Tel: 0207 317 7544 - [rfh.clinicaltrials@nhs.net](mailto:rfh.clinicaltrials@nhs.net)

## Helplines

Raynaud's & Scleroderma Association	01270 872776
Scleroderma Society	0800 311 2756
Mrs Anne Mawdsley Anne has set up a helpline to give information, care and support patients, carers or health professional involved with Raynaud's and scleroderma from 1st January. <a href="http://www.raynaudsandscleroderma.co.uk">www.raynaudsandscleroderma.co.uk</a>	07530 810964
Tani & Louise at The Royal Free	020 7830 2326
Pulmonary Hypertension at The Royal Free	020 7472 6354





## Scleroderma Family Day – Saturday 17 May

Family Day for 2014 will be on Saturday 17 - the provisional programme is on page 6. The final programme with confirmed speakers will be up on our website in the New Year. I really enjoy Family Day - it is my opportunity to meet with patients, to meet with the patient societies and to hear very good talks. Hope to see you in May. If you are unable to attend we try to put as many of the talks as possible up on our website after the event.

Pamela

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## Fundraising

Thank you to all those who made generous donations to our research endeavours in the past you – it really does make a difference.

We have included as usual a book of raffle tickets with the Newsletter mailing. If you do not wish to buy tickets please just discard them, you do not need to return them. The money raised from the raffle goes towards buying essential pieces of equipment and this year we hope to purchase a new digital scanner for the laboratory, which will allow us to scan images of protein and DNA/RNA samples and obtain the level of expression of these molecules in scleroderma samples compared to control tissues. The scanner is able to analysis multiple samples, enabling us to perform them faster.

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## Newsletter

We hope you enjoy reading the Newsletter but if you prefer not to receive them 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, fundraising raffle or anything else, please do contact me at [pamela.yeomans@scleroderma-royalfree.org.uk](mailto:pamela.yeomans@scleroderma-royalfree.org.uk) or by phone on 01273 672686 or 020 7794 0500 x 33471 on Mondays.

## Contact Numbers

Clinical Trials	020 7317 7544
Kevin Howell	020 7794 0500 x 22516
Kim Fligelstone	020 7794 0500 x 35131
NHS Secretariat	020 7830 2267
Millie Williams	020 7794 0432
Norlan Dubissette	020 7794 0500 x 32909
Pamela Yeomans	01273 672686 [Monday x 33471]
Pulmonary Hypertension Nurses	020 7472 6354
Scleroderma Nurses Help-line	020 7830 2326

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# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



**Scleroderma Family Day – Saturday 17th May 2014**

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

**Chair: Professor Chris Denton**

## **PROVISIONAL PROGRAMME**

09:30 – 10:00	Registration and Coffee	
10:00 - 10:15	Welcome to Family Day	Prof Chris Denton Prof David Abraham
<b>EVIDENCE-BASED TREATMENTS FOR SCLERODERMA</b>		
10:15 - 10:40	Psychological Impact	To be announced
10:40 – 11:05	Update on Plastic Surgery approaches for Raynaud's phenomenon.	Clinical Fellow
11:05 – 11:30	Update of PAH advances for scleroderma	Dr Gerry Coghlan
11:30 – 11:55	Is stem cell transplant a cure for scleroderma?	To be announced
11:55 – 12:20	Is there a link between scleroderma and cancer?	Dr Voon Ong
12:20 - 14:00	Lunch break— discussion groups – see below	
14:00-15:00	International Research Collaborations in Scleroderma	Dr Oliver Distler
15:00	Raffle	

Lunchtime Discussions Groups /Demonstrations include

Clinical Trials	Rachel Ochiel and team
Drug information/monitoring	Jay Pang
Skin Camouflage	Changing Faces formerly British Red Cross
Massage	Mr Keith Hunt, Complementary Therapies
Pulmonary Hypertension Education/nursing	Sally Reddecliffe/Adele Gallimore
Rheumatology Laboratory	Research Laboratory Staff
Scleroderma Education/Nursing	Tanaka Ngozana/Louise Parker
Thermography	Dr Kevin Howell
Physio and OT	

