



**MERRY  
CHRISTMAS**

From all of us

Christmas 2012

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

## Dear Friends

Another year has gone by very so quickly but it has been a hugely successful one for the Centre at the Royal Free. It has been really successful in terms of both clinical and basic research grants. I am very proud of everyone who works within the Centre and who try so very hard to improve patient care and understand the complexities of scleroderma and related conditions.

Some of you will have heard that I have been appointed Principal of Newnham College in Cambridge and one of the great pleasures is that there are some very bright medical students!

I wish you all a very happy Christmas and peaceful New Year.

**Dame Carol Black**

## Clinical update December 2012– Professor Chris Denton

The past 12 months has been exciting and busy for the clinical scleroderma service. In addition to the challenges of seeing more patients in the clinic we are now deeply immersed in the annual difficulty of finding enough hospital beds for our inpatient treatment. Development of the ambulatory care facility has continued with many more of our patients requiring iloprost treatment receiving it in the day ward and staying, when necessary, in the hotel opposite The Royal Free Hospital overnight. This has allowed more cases to be treated and reduced the number of last minute cancellations of beds. We still have the facility to admit scleroderma and Raynaud's cases for iloprost as conventional inpatients when this is necessary for medical reasons. The ambulatory facility is a focus of growth and development for the hospital and for this reason we have moved base back to the second floor of the main hospital – pending building work to expand the ambulatory facility. In addition, we hope that when the new Institute of Immunology opens in 2013 we may hold some of our clinics in new and much more attractive facilities. Watch this space and I will report back in the next newsletter.

Our clinical research efforts have been rewarded by several recent research grants, including two from the Medical Research Council. This is especially pleasing as such grants are very competitive. We have a collaborative grant with Dr Toby Maher and Professor Athol Wells at the Royal Brompton Hospital to study new treatments for lung fibrosis and another MRC grant at the Royal Free to examine treatment of kidney disease in scleroderma. In addition many other trials are ongoing for digital ulcers, Raynaud's, scleroderma and pulmonary hypertension. These will be presented in more detail at the next Scleroderma Family Day in May.

In the clinic and on the wards we have been fortunate to have many overseas visitors to assist and to learn from spending time at the Royal Free. In the last 12 months this includes visitors from Argentina, Portugal, Spain and most recently Ireland and France. In particular we welcome Dr Bernadette Lynch, a rheumatologist from Ireland who is joining us for a year, and Dr Vincent Sobanski who will be with us for 12 months working on scleroderma and pulmonary hypertension. Vincent comes from a major scleroderma unit headed by Professor Eric Hachulla in Lille in France. We are delighted that Dr Niamh Quillinan has recently been appointed as a senior research fellow between Royal Free, Queens Hospital Romford and the Bedfordshire and Hertfordshire Postgraduate Medical School. This is part of a new research initiative that includes closer working links with Professor Chakravarty who is based at Queens Hospital and with whom we have established important clinical and research links. Niamh has been with us for the past 3 years studying novel scleroderma treatments and will now develop the new research projects.

So you can see that we are as busy as ever – it just remains to wish all our patients and their families Merry Christmas and a Happy New Year.





# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



## Research Update –Professor David Abraham and colleagues

We have now been occupying our new laboratory facilities on the 2nd floor of the Medical school block for 12 months and this new environment has allowed the Raynaud's and Scleroderma research unit to continue to flourish and expand. We are developing new areas of enquiry including better laboratory models to investigate scleroderma skin and lung fibrosis and pulmonary hypertension, to examine potential heart problems, and the changes in blood vessels that accompany Raynaud's and Scleroderma. Along with our clinical colleagues we are discovering new molecules to move forward our drug discovery programme. The last few months have been a particularly exciting time as we have filed a patent on some of our work relating to pulmonary hypertension and are embarking on developing a new research theme that we hope will lead to a new clinical trial. We have also been developing more research interactions with drug companies and industry, which is important as we move even closer towards clinical trials. Our collaborations with Professor Wells and Dr Renzoni at the Brompton Hospital have been continuing at a pace along with our on-going interactions with the vascular research group, and Professor Hamilton, Mr Baker and Ms Tsui.

In addition, some of our research work has been presented at biomedical symposia including presentations at the American College of Rheumatology, the British Society for Rheumatology, the European Tissue Repair workshop and at the Keystone Symposium in the USA. These are high-profile meetings where our work has been showcased to the biomedical community, and we have received a tremendous amount of positive feedback. Several meetings have also been organised by the unit including the International cardiovascular biology and medicine workshop held at the Royal College of Physicians, and the London Rheumatology research meeting.

## New Staff

A number of new research staff have joined the group: Mr Adrian Gilbane and Mr Robert Good who are both studying for their doctorate looking at blood vessels in scleroderma and lung disease respectively; Dr Sarah Trinder, whose research interests are centered on pulmonary arterial hypertension; Dr Sandra Guerra a geneticist and Dr Ioannis Papaioannou, a functional cell biologist who are both working closely with Dr Carmen Fonseca on the genetics of scleroderma; Dr Blandine Poulet, a new group leader with a research interest in the response of tissue to injury and tissue repair; Ms Rebecca Alade, who is working closely with Dr Voon Ong on IL-6 signaling in scleroderma; Mr Wasabha Ramanayake, from Brunel University who is working on a research project involving models of skin fibrosis.

## Research Funding

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 and the Rosetrees Trust. This portfolio of funding supports biomedical research studies into the role of genes, molecules and cells in Raynaud's and Scleroderma. There have been a number of new research grants awarded to the Unit. These included project grant support from the Raynaud's and Scleroderma Association and Arthritis Research UK along with industry led studies, and a PhD studentship supported by the Nightingale Trust. These are essential awards and long-term funding initiatives, which provide the core research programmes within the unit.

## Capillaroscopy and thermography – Dr. Kevin Howell

It has been an exceptionally busy year for all sorts of reasons. I was lucky enough to be able to attend the London 2012 Olympic Games this summer in my capacity as a tennis official, which was an unforgettable experience. Apologies to those of you who had their investigations slightly delayed by my absence during the summer – I think we have now managed to catch up in time for the winter.

On the research front, we have now completed our input to the CAP study and results are being analysed centrally. Thank you to everyone who gave their time to have their nailfold capillaries studied over last winter. A collaboration is now under way with Manchester University and several other European centres looking at the reliability and reproducibility of the scoring of capillary images.

Some of you met my MSc. student Rosie Richards earlier in the year. Rosie's project investigated thermography of the eyes, and whether this could predict core body temperature. Although the results suggested thermography may be of limited value for this task, the project was well-regarded by the examiners and Rosie passed her MSc. with a distinction. Thanks to those of you who gave 10 minutes to Rosie to have your temperature measured at the eye and under the tongue. I was in Porto in September presenting some thermography work, and at that meeting I was elected General Secretary of the European Association of Thermology. You can learn more about the Association's work at [www.europanthermology.com](http://www.europanthermology.com)

Merry Christmas and a Happy New Year!



# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital

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

We have had a busy year with new projects and continue to find ways to improve our service for you. The patient support group meeting we established at the end of 2010 is still going strong and our patients are finding it helpful. During this year we had speakers such as the dietician, physiotherapist and our complimentary therapist. These speakers have been very informative and the patients enjoyed the sessions. We had varied attendance and we are still growing. Our next meeting will be on the 15th March 2013, 1400hrs- 1600hrs in the Rheumatology Library, Lower Ground Floor, and all are welcome. We hope to have more exciting speakers and activities in the future.

Louise has been working with our dermatologist Dr Orteu in a combined rheumatology dermatology clinic once a week, for our patients' continuity of care. Tani started the digital ulcer clinic in June, the clinic is run every Tuesday morning and patients can self refer.



We hope you had a good year, and we wish you a Merry Christmas and a Happy New Year.

N.B. PITU ward is moving to 2nd Floor with effect from 5th November.

## **Pulmonary Hypertension Team**

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

The PH service remains as busy as ever and the New Year promises some expansion to our clinic capacity, which will hopefully improve the experience of visiting us. We are hoping to start a further Out – Reach service in Brighton shortly and other locations are in the planning phase.

Sally, Adele and Joanna continue with their academic studies, along side clinical commitments. On the administration side, Alison is now joined by Anna who was appointed permanently in October. Some of you may remember Anna when she worked with us in 2008-2009.

We have welcomed Jacqueline Ullman to the team. Jacqueline is providing counseling services to PH patients and their families. Many patients have found this very useful along side clinical services. We thank the PHA-UK charity for funding this project.

Wishing you a Merry Christmas and a Happy New Year!

## **Kim Fligelstone**

My name is Kim, I have had scleroderma for 25 years and am generally available on Tuesday and Wednesdays if anyone would like to phone or pop in for a chat, do 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 but we are all affected by scleroderma in different ways and I would love to hear from you if you want to talk Tel: 020 7794 0500 ext 35131.

Keith Hunt, who pioneered and manages complimentary services at the Royal Free, was awarded an MBE for his invaluable work earlier this year. Keith has always been supportive of people with scleroderma and when possible one of his team will give you a massage during an inpatient stay. Ask the ward staff to contact complimentary services. Keith gave an inspirational talk at the RF local group on the 19th October the next meeting is the 15th March 2013 [contact Tani: 0207 830 2326 for more detail].

Activity Pacing - A European study looking at how people with rheumatic diseases pace themselves in order to manage their condition is underway. I would love to hear from anyone who has found specific ways to manage their activities and time to get the most benefit out of life whilst living with scleroderma.

You can email me at [kim.fligelstone@nhs.net](mailto:kim.fligelstone@nhs.net) or [kim@sclerodermasociety.co.uk](mailto:kim@sclerodermasociety.co.uk) or telephone 0207 229 4750 or 0207 794 0500 ext 35131 on Tuesday and Wednesday.

All that's left for me to say is Have a lovely Christmas and a healthy and happy New Year.





## Clinical Trials News – Rachel Ochiel & Team

Again this year the trials team have been extremely busy with some exciting new scleroderma trials for which we are actively recruiting.

The team has grown - we now have Tariq who joined us in January to provide administration support. Our team of Research Nurses has grown. Nike joined us in December last year from the Rheumatology Specialist Nurse team and is a real asset. Ruth missed the patients and her colleagues and returned in May. Rebeca who has a good background in clinical trials and Rheumatology also joined us in May. Sadly Anna moved on to a new role nearer home. We have new honorary members of the team – Rachel's daughter was born in June and Rachel returned from Maternity leave in October. Ivy has a son born in September and she will return to us early next year.

### 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

**ESOS:** A study to examine the effectiveness of approaches in the early management of patients with Diffuse Scleroderma

**DUAL 2:** A Study to assess Macitentan in patients with ischemic Digital Ulcers with systemic sclerosis to assess the efficacy, safety and tolerability of macitentan in patients with ischemic digital ulcers associated with systemic sclerosis.

**FaSScinatate:** A Study to Assess the Efficacy and Safety of Tocilizumab versus Placebo in Patients with Diffuse scleroderma

**CELGENE:** A study to evaluate Pomalidomide in patients with Diffuse scleroderma with Lung disease

#### Ongoing Pulmonary Hypertension trials

**SERAPHIN OIL:** 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 2:** A study to assess the long-term safety and tolerability of different doses of a new drug (BAY 63-2521), given to patients with Pulmonary Artery Hypertension

**GRIPHON:** A study to investigate the safety of new oral drug called Selexipag and whether it delays the worsening of pulmonary arterial hypertension

**COMPERA:** This is an international observational study to obtain long term data so that the treatment of pulmonary hypertension may be improved in future

**Reverse remodelling of pulmonary vasculopathy:** A Study to assess the treatment of pulmonary arterial hypertension with minimally invasive imaging techniques





# Xmas Newsletter - Scleroderma Unit - Royal Free Hospital



## Scleroderma Family Day – Saturday 18 May

As always we all very much look forward to Scleroderma Family Day in May. The programme is the final page of this Newsletter and looks really interesting. I hope you are able to join us. I will post some of the talks up on to our website after the meeting.

As many of you may know Keith, our fantastic massage therapist, has been awarded an MBE in the Queen’s birthday honours list, for services to complementary therapy. This is such great news. We are very grateful to Keith for his continued support of Family Day – I think he has been to all of them!

**Pamela**

## Fundraising

We would very much like to thank Tom Harvey & William Taper for their fantastic cycle ride. They rode 2600 miles across the USA in 30 days to raise money for two causes and Tom nominated us, in support of his sister, and has so far raised nearly £5000, which is amazing. If you would like to support their endeavour please go to:

<http://www.justgiving.com/USACycle-RoyalFreeCharity>

## Newsletter

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

We have included a book of raffle tickets with the Newsletter mailing. Money raised from our annual raffle helps us to buy essential pieces of equipment and this year we hope to raise a contribution for a new autoclave. If you do not wish to buy tickets please just throw them away, you do not need to return them.

If you have any questions about Family Day, the newsletter, 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 672686/020 7794 0500 x 33471 [Mondays].

## Contact Numbers

Clinical Trials	020 7317 7544
Kevin Howell	020 7472 6550
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NHS Secretariat	020 7830 2267
Millie Williams	020 7794 0432
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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 18th May 2013**

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

**Chair: Professor Chris Denton**

**DRAFT PROGRAMME**

09:30 – 10:00	Registration and Coffee	
10:00 - 10:15	Welcome to Family Day	Prof Chris Denton Prof David Abraham
10:15 - 10:40	Commissioning Rheumatology Services – Scleroderma. NHS Reforms	Laura Guest, CEO British Society Rheumatology
10:40 - 11:00	Laboratory/biology/research update	Prof David Abraham
11:00 - 11:20	Trials Update and new therapies	Prof Chris Denton
11:20 - 11:45	Plastic Surgery and scleroderma	Prof Peter Butler [tbc]
11:45 - 12:15	Nurse-led Ulcer Clinic	Ms Tanaka Ngozana
12:15 - 12:40	Incontinence	Dr Shamaila Butt
12:40 - 14:30	Lunch break— discussion groups – see below	
14:30 – 15:00	Scleroderma in France	Prof Eric Huchilla
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 and team
Skin Camouflage	Changing Faces formerly British Red Cross
Massage	Mr Keith Hunt, Complementary Therapies
Neurological Aspects of Scleroderma	Dr Bryan Youl
Physiotherapy	Physiotherapy Dept
Pulmonary Hypertension Education/nursing	Sally Reddecliffe/Adele Gallimore
Rheumatology Laboratory	Research Laboratory Staff
Scleroderma Education/Nursing	Tanaka Ngozana/Louise Parker
Surgery	Mr O Ogunbiyi
Thermography	Dr Kevin Howell

