



Dear Friends

This Christmas is different for those of us who are close to the world of Raynaud's and Scleroderma. It is now a world without Anne Mawdsley and we all mourn this fact. We must however celebrate and give thanks for the wonderful force for good that Anne was. Everything she did was for patients – and she did so much. She would have wished her work to continue and grow. So in wishing you all peace, joy and happiness over the festive season and into the New Year may I ask us all to renew our efforts to care for and support those with Scleroderma or other Connective Tissue Diseases.

I have been very busy this past year, both in Cambridge and in my work for Government. Some of my government work has been concerned with how we can enable people with long-term conditions to stay in work, which so many of them want to do – and also how employers can support employees who are providing essential caring services to a family member- both of great relevance to Raynaud's and Scleroderma.

I keep close to the work of the Centre at the Royal Free, and am delighted with all that it is doing in both research and clinical care.

Dame Carol Black

Clinical update - challenges and opportunities for scleroderma in 2015

The scleroderma clinical service continues to expand and develop around the three main parts of the unit, the outpatient clinical area in the new Institute of Immunity and Transplantation, the day unit (PITU – planned investigations and treatment unit) both on the second floor of the hospital and the inpatients that are usually accommodated on 11th floor. Linked to this is the very expert clinical trials team that manages a large number of studies including some new projects looking at potential oral therapies for Raynaud's and new potential approaches for scleroderma. Two recently completed clinical trials that our centre was very active in were presented at the American College of Rheumatology meeting in USA in November and it is very encouraging to start seeing the first steps towards new treatment approaches for systemic sclerosis. In addition, we have worked with our colleagues in transplant haematology to make sure that the emerging option of "stem cell transplant" is available for appropriate cases of severe systemic sclerosis. We were closely involved in the early testing of this treatment that appears to be helpful in selected cases but may also have high risks. Delivering our service within the Institute gives us close access to the relevant expertise for this new approach. Within the unit we are delighted to continue to have a series of excellent visiting doctors. As well as fellows from Portugal, Italy, Argentina, Chile, Spain and Australia, we had Dr Shamila Shah, a professor from India visit us this year and have Dr Jasmin Raja from Malaysia sponsored by the Royal College of Physicians in London. Our overseas visitors are a valued asset to the centre and help to strengthen links for research and clinical care. The end of the year was marked by the very sad death of Anne Mawdsley. Through her work as founder and chief executive of the Raynaud's and Scleroderma Association and more recently her Scleroderma Care and support website Anne devoted much of her life to advancing scleroderma and will be missed by all of us in the department. We all feel a great debt to Anne but personally I am confident that the momentum for progress that she established will continue, which is what she would have wished and expected. I hope as many as possible of our readers will be able to join us on 16th May for the annual Family Day. Family Day started in 1995 and in 2015 will be celebrating our 20th anniversary.

Professor Chris Denton



News from the Laboratory – David Abraham

It has been a fairly busy and exciting summer and autumn here at the Royal Free, with our translational research moving forward rapidly, several important events taking place, new research grants awarded and new staff joining the group. We have made significant in-roads in a number of areas of study. These include identifying new genetic markers in scleroderma, unraveling in more detail the complex processes involving cells and molecules which cause inflammation and blood vessel occlusion in pulmonary hypertension, and dissecting out the key factors that drive tissue scarring and fibrosis. These exciting research discoveries allow us to move very quickly from laboratory studies into pre-clinical models which help us to assess whether we can transfer the work into proof-of-mechanism studies which may lead to new clinical trials. It is important to point out that we do not work in isolation, but have a number of successful and productive collaborations local and also around the UK, and at the international level.

Much of our research studies have been or will be presented at the major conference and workshop around the world including British Society for Rheumatology, the American College of Rheumatology, the American Thoracic Society, and at EULAR. These are among the most prestigious meetings in the academic calendar, and it is important that our work is present at these events to raise our profile and receive positive-feedback.

We are extremely grateful to the Raynaud's and Scleroderma Association, the Scleroderma Society and the Rosetrees Trust for their continued support and for the research and the grants we have been awarded this year. This funding has been essential in allowing us to pursue our biomedical research studies into the causes of Raynaud's and Scleroderma and the identification of pathways which may lead to new treatments.

Meetings and events

We have been involved in organising several successful symposia this year including a 2-day meeting at The Wellcome Trust to discuss Fibrosis with a focus on the disease process, patient management and new treatments. This meeting assembled the entire UK community working on Fibrosis and provided a forum for discussion and interactions leading to the development of future avenues of study. We also organised the 9th cardiovascular and translational medicine workshop and the Royal College of Physicians, which had an excellent attendance and covered areas central to Raynaud's and scleroderma including blood vessel damage and pulmonary arterial hypertension (PAH). Two of our staff, Dr Sandra Guerra and Ms Athina Dritsoula attended a meeting in Spain, which in addition to a delivery lecture and discussion also provided some expert training in the analysis of genetics and gene function. Sandra and Athina are now using the expertise they acquired in their research activities.

Research Support

We have been awarded several research grants over the last months. These include support from the Raynaud's and Scleroderma Association to study B cells in scleroderma which is a collaboration with Dr Voon Ong here at the Royal Free and Professor Rizgar Mageed at QMUL, funding to examine the genetics of lung diseases in scleroderma, a project led by Dr Carmen Fonseca and a project grant to Dr Richard Stratton to study the functional activities of fibroblast in scleroderma. The latter project is being performed by one of our previous and successful students who has now returned to London from Japan – Dr Angela Tam. A research grant from the Scleroderma Society to Dr Markella Ponticos and Athina Dritsoula is supporting a study into PAH and a grant awarded to Dr Alan Holmes from the MRC confidence in concept initiative is funding a drug discovery project in scleroderma. We are also working closely with the pharmaceutical industry and we have agreed two collaborations one with UCB Celltech and one with Boehringer Ingelheim to support two PhD students. We also have another PhD student who has just started, this position is provided via a PhD programme in Medicine jointly funded by the Rosetrees Trust and the Royal Free Charity.

New laboratory staff and staff successes

With our grant successes we have a number of new staff who have joined the group. Our new PhD students are Ms Joanna Verneau and Ms Zeinab Taki, and we have two new research staff who have joined us from Brunel University, Ms Freda Fearon and Ms Nyra Castillo. I would also like to let you know that we have had two students who have successfully completed their PhD studies this year and have been awarded their doctorates - Dr Angela Tam and Dr Joanna Nikitorowicz. They should both be congratulated.

International visitors

The research department has hosted a number of international visitors to the group this year, who have carried out research at the Royal Free. To highlight just two: Dr Thomas Andersen visited from the University of Aarhus, Denmark spent six months on a collaboration to study the immune system in scleroderma and Dr Femke Heindryckx visited from the Uppsala University to study common mechanisms in tissue scarring and fibrosis. In addition we have also hosted visits from some of the world leaders in scleroderma research who came to the Royal Free included Professor John Varga from Northwestern University in Chicago USA, Professor Thomas Krieg from the University of Cologne and Professor Kristofer Rubin from Uppsala University in Sweden. These visitors shared their research experience and gave lectures providing mutual benefit across international boundaries.



Xmas Newsletter - Scleroderma Unit - Royal Free Hospital

Clinical Trials News

This year has really flown by and we are saying goodbye to 2014. Our transition of seeing patients in the Institute of Immunity and Transplantation has been smooth especially with positive feedbacks from the patients themselves. We have had a few staff changes with Ruth Staunton who has left her post as a research nurse. A couple of undergraduates were working with us during their summer months to provide administrative support. We will also be recruiting a Rheumatology clinical trials nurse to support the research work both at the Royal Free and the newly merged Chase Farm and Barnet Hospital.

A couple of trials that have completed recently;

DETECT: The study developed the first evidence-based detection pathway of PAH in systemic sclerosis (SSc). This enabled earlier identification of PAH in patients with mild symptom. It also demonstrated that PAH is more common within this group of SSc patients than previously studied.

DUAL 2: This study is now completed and results are being fully analysed. There was no clear advantage of Macitentan but this may reflect better treatment of digital ulcers now and a low number of new ulcers in the study.

Sanofi: The results of this study are encouraging showing a trend of improvement in skin fibrosis and the potential value of targeting a specific pathway (LPA1) in scleroderma. Results were being presented at a major conference in USA in November.

We have a number of on-going and new trials at present which include the following;

Scleroderma trials:

DUO Registry: The initial report confirms the early occurrence and high frequency of digital ulcers in scleroderma patients with different groups of antibodies.

Tocilizumab: This study is almost coming to a completion with 3 patients scheduled for their final visit in early 2015.

Selezipag: This is an exciting new study for patients with secondary Raynaud's which started in November and will be running over the winter. Please do call the clinical trials team if you are interested or would like to find out more about the study. We also have 2 new studies focusing on the skin which will be starting in early 2015.

General Rheumatology:

CAIN 2312 and 2318: We have recruited a total number of 7 Psoriatic Arthritis patients for both studies. Most of the patients are finding improvement to their condition.

PAH Trials:

310: This study is progressing well with the patients being closely monitored with regular telephone calls and 3 monthly visits as part of the study schedule.

National Cohort: The purpose of this study is to set up a national cohort study of patients with idiopathic and heritable forms of Pulmonary Arterial Hypertension. The data gathered would help to provide a basis for future research and prevention studies and/or clinical trials targeting the genetic pathway. It would also ascertain genetic or environmental triggers for this disease.

Scleroderma Specialist Nurse – Louise & Annalyn

There has been change this year with the specialist nursing team. Tani left us in August and we were joined by Annalyn in July. Some of you may have already met Annalyn in clinic or ward round. I am delighted to report that we will be joined by a third nurse – Joseph in December. We continue to provide nurse led initiatives including the Raynaud's clinic and the digital ulcer clinic. Louise also provides support to the Dermatology service once a week for the joint clinic there which some of our patients attend. We have spent just over a year now in The Institute which has proved a great success and we find a much improved clinic space for everyone. The expansion of PITU is also working well and we have rapidly filled our capacity there for patients requiring Iloprost and other infusions.

We hope with an additional team member that we will be able to provide more cover for the advice line and also the outreach service where the team here come to other hospitals around the country to support scleroderma clinics closer to you.

We wish you all a peaceful and relaxing Christmas and look forward to seeing you soon.

Pulmonary Hypertension Team

As we approach the end of 2014, it is a good opportunity to reflect on the exciting developments in the PH service over the last 12 months. The Service remains as busy as ever and the new year promises further expansion to our clinic capacity, which will hopefully improve the experience of patients visiting us. We are in the process of establishing an outreach clinic in Margate and the first clinic is scheduled for the end of January 2015. We now have 10 outreach clinics in total, ensuring that a greater number of our patients can receive their care closer to their homes. We have also redesigned our intravenous therapy patient pathway to minimise the amount of time patients are required to spend in hospital. This has proven to be very successful and has reduced the inpatient admission time by half.

Sally and Adele continue with their MSc studies, alongside their clinical commitments. Joanna had a baby boy called Stanley in January and is due to return from maternity leave very soon. In February, we welcomed our new nurse, Matie and she has proven to be a fantastic addition to the nursing team. The team continues to be supported by Jo, Sarah, Cathal and Alison – our excellent administration team who continue to keep the service running efficiently.

Wishing you a Merry Christmas and a Happy New Year!



Microvascular Diagnostics – Dr. Kevin Howell

The Microvascular Diagnostics service has now been established in its new home within the Institute of Immunity and Transplantation for 18 months, and many visitors comment on the bright and spacious environment. Certainly our new facilities have helped us to provide a more efficient service in comfortable surroundings for our patients.

This autumn has been a busy period: we continue to provide capillaroscopy and thermography services to all the Raynaud's and scleroderma clinics, but I have also been "on-the-road" teaching capillaroscopy techniques to other rheumatology centres in Basildon and Margate. At around the time you read this I will be at University College Hospital in central London, explaining how our service can contribute to care of their patients.

We continue to contribute to research and publish our findings, which is the key aim of everyone who has their base within the Institute. Back in the spring I completed a significant review article on microvascular imaging techniques with my colleague Dr. John Allen at the Freeman Hospital in Newcastle. This article was accepted for publication in "Physiological Measurement," the leading journal in its field. I have also been advising colleagues at Wrocław University of Environmental and Life Sciences in Poland on thermographic techniques in equine medicine: we have published one paper in the Journal of Equine Veterinary Science, and another article is currently in review.

Back in July the Institute hosted the first seminar of Medical Infrared Thermography London ("MIRTL"), which will be a forum for thermography researchers to present their work to others in an informal setting prior to publishing their work. MIRTL will be administered by the Institute, which reflects our position as one of London's leading centres for medical thermography. Along with other members of the European Association of Thermology board, I attended the "ThermoMed 2014" thermography conference in Frankfurt in September.

Finally, this winter, Matt Adams from the Royal Free vascular lab will be gathering data in my lab for his MSc. project. Matt is going to compare thermography findings after cold challenge of the hands with the findings about blood flow at the wrist as measured by an ultrasound probe.

Merry Christmas and a Happy New Year to you all!

Kim Fligelstone

Hello, my name is Kim, I have had systemic scleroderma for 27 years and am generally available on Tuesday and Wednesdays if anyone would like to phone or pop in for a chat, it's best to call or email beforehand (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 as you are probably aware we are all affected by scleroderma in different ways, I would love to hear from you if you want to talk

When coming to clinic make sure you bring warm clothing/gloves because the air conditioning can be a little too efficient at times for those of us with Raynaud's.

If your ever on the ward and would like a gentle massage please let your nurse know and they will contact complimentary therapy, this is a voluntary service and donations are very welcome.

Lung Function Department

Access to Lung Function (PITU area 3) is via the **main hospital lifts** on the second floor (not the lifts to PITU or The Institute) if you use the lifts via PITU you will have a long walk. Lung Function is working with the Hospital to change the instructions in outpatient letters and signage around the Hospital but it could take some time.

Parking for Blue Badge Holders

Park in a blue badge bay and show your blue badge to reception staff along with your vehicle registration number. You have to do this in person. You will then be permitted to park for 4 hours free of charge any additional hours will be chargeable at the standard rate currently £3 per hour. There is no FREE parking in any pay bay. Free parking in a blue badge bay is only permitted for the **blue badge holder** – relatives are not permitted to use your blue badge for visiting when you are an inpatient. Car parking is monitored/managed by ANPR cameras (automatic number plate recognition) for full car parking details you can contact the main reception on 0207 794 0500 ext. 34254

Contact details: 020 7794 0500 ext. 35131. You can email me at kim.fligelstone@nhs.net or kim@mediasolutions.co.uk
Leave a message with Millie 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.



Scleroderma Family Day – Saturday 16 May 2015

It is the 20th anniversary of our Family Day which takes place on Saturday 16 May - the provisional programme is on page 6. The final programme with confirmed speakers will be up on our website in the New Year. I can't quite believe I have been organising the Family Day for twenty years but I do love it! – it is my opportunity to catch up 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

Fundraising

Thank you to all those who made generous donations to our research endeavours in the past year – it really does make a huge difference. I would like to thank to Tom Walker, who ran the Richmond half marathon for Debs his mum, and raised a massive £16,000 to be shared between our unit and Harefield Hospital.

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 we are very grateful to everyone who have bought raffle tickets and continued to support us.

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 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	020 7472 6354
Nurses Scleroderma Nurses Help-line	020 7830 2326



Xmas Newsletter - Scleroderma Unit - Royal Free Hospital

20th Anniversary Scleroderma Family Day – Saturday 16th May 2015

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 the 20 th Annual Scleroderma Family Day	Dame Carol Black Prof Chris Denton Prof David Abraham
10:15 - 10:35	Update from the clinic	Chris Denton
10:35 – 10:55	Laboratory developments	David Abraham
10:55 – 11:15	Foot pain in scleroderma	Begonya Alcacer-Pitarch
11:15 – 11:35	Scleroderma and the kidney – Zebras, birds and genetics	Edward Stern
11:35 – 11:55	Why does scleroderma make you itch?	Sara Zafar
11:55 – 12:15	Emerging therapies for lung fibrosis –	TBC
12:15 – 14:00	Lunch break— discussion groups – see below	
14:00 - 14:45	International Research Collaborations The psycho-social burden of scleroderma	Luc Mouthon
14:45 – 15:30	Progress in a hard disease? Highlights from the last two decades – interactive panel discussion led by Prof Chris Denton	
15:30	Raffle	

Lunchtime Discussions Groups /Demonstrations include

Clinical Trials	Rachel Ochiel and team
Drug information/monitoring	Gillian Murray/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	Louise Parker/Ammalyn Nunag
Thermography	Dr Kevin Howell

